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Orawan Louthrenoo, Peninnah Oberdorfer and Virat Sirisanthana

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What is This?
Psychosocial Functioning in Adolescents with Perinatal HIV Infection Receiving Highly Active Antiretroviral Therapy

Orawan Louthrenoo, MD1, Peninnah Oberdorfer, MD, PhD1, and Virat Sirisanthana, MD2

Abstract
Background: With effective highly active antiretroviral therapy (HAART), perinatally HIV-infected children are living longer through adolescence. Methods: We conducted a cross-sectional study of perinatally HIV-infected adolescents, aged 11 to 18 years. Demographically matched controls were also enrolled. The adolescents completed the Youth Self-Report (YSR), while the caregivers filled out the Child Behavior Checklist (CBCL), to determine emotional and behavioral problems. Results: The sample included 50 HIV-infected adolescents and 56 controls. The internalizing problem scores from the YSR were significantly higher in the HIV-infected group than those in the control group (13.76 versus 9.95, \(P = .02\)). The total competence scores, from both the self-report and the caregiver report in the HIV-infected group, were significantly lower than those of the control group (\(P = .005\) and .001). Conclusion: Although HAART has prolonged the survival of HIV-infected children, they remain at increased risk of psychosocial problems as well as impaired social functioning.

Keywords
psychosocial, HIV infection, adolescents, antiretroviral

Introduction
With the advances in effective highly active antiretroviral therapy (HAART), children who have been infected perinatally with HIV are more likely to survive through adolescence. The health care and needs of these children are changing to resemble those with chronic illnesses, rather than terminal illnesses as in the past. However, despite improvements in medical care, the nature of the disease, with family and social factors, may contribute to the risk of emotional and behavioral problems in HIV-infected adolescents.1-3

HIV infection directly affects the central nervous system, causing neurological damage and encephalopathy. With the introduction of HAART, the prevalence of encephalopathy is decreasing. However, HAART does not completely protect against neurological damage.4 Thus, minor neurological impairments such as developmental delays and cognitive deficits still occur in HIV-infected children.5-7 Disease morbidity, including neurological involvement combined with other environmental factors, has influenced the psychological adjustment of children and adolescents with HIV infection.

Many HIV-infected children live with adults in similar condition, in which case, such parents have to take care of themselves as well as their sick offspring. These families may encounter discrimination, social isolation, or grief because 1 or both parents have died.8-10 As a result, HIV-infected adolescents have experienced losses and changes in their life, thus causing stress and psychological problems. Furthermore, anxiety about their health and uncertain future has great impact on their psychological well-being. Some emerging issues also need to be addressed such as disclosure of the disease11-14 and adherence to medication15 specifically in HIV-infected adolescents, whose care is a complex process that is further complicated by a wide range of psychosocial needs.16 In addition, poor adherence to medication has been also associated with behavioral problems in infected adolescents17 and psychosocial factors, particularly depression and anxiety.18

Some studies have demonstrated no difference in psychological problems between the HIV-infected adolescents and their healthy peers, thus indicating resilience mechanisms among the former. In a study of HIV-infected school-age children and controls, both the caregiver reports and child self-reports showed psychological adjustment scores that did not differ significantly between the HIV-infected and control groups.19 Similarly, a study by Dollfus et al revealed that HIV-infected adolescents, who were followed since birth, had growth and school achievement similar to nationwide norms.20

1 Faculty of Medicine, Chiang Mai University, Chiang Mai, Thailand
2 Research Institute of Health Sciences, Chiang Mai University, Chiang Mai, Thailand

Corresponding Author:
Orawan Louthrenoo, Faculty of Medicine, 110/144 Intawaroros Rd., Chiang Mai University, Chiang Mai, 50200, Thailand.
Email: olouthre@med.cmu.ac.th
However, other findings are inconsistent with these studies. Reviews by Scharko\textsuperscript{21} showed that HIV-infected children had anxiety disorders (24\%), depression (25\%), and attention-deficit hyperactivity disorder (ADHD, 28\%). Similarly, a study by Mellins et al.\textsuperscript{22} found that 47 children with HIV infection had anxiety disorders (40\%) and ADHD (21\%). It was found that HIV-infected adolescents were less likely to complete their academic education than their healthy peers, and those who had lost a parent were more likely to have depression during their lifetime.\textsuperscript{23} Furthermore, Elkington et al.\textsuperscript{24} found that perinatally exposed adolescents using substances were more likely to engage in sexual risk behaviors regardless of their HIV status. A study by Koenig et al suggested that HIV-infected adolescents required multidisciplinary support services including adherence support, reproductive health counseling, and mental health and educational/vocational planning.\textsuperscript{25}

The objective of this study was to assess psychological and behavioral problems in HIV-infected adolescents and compare them with those of healthy controls, in order that appropriate intervention could be provided.

**Methods**

**Study Population and Design**

A cross-sectional study was performed in the Pediatric Infectious Diseases Clinic at Chiang Mai University Hospital, a tertiary care hospital in northern Thailand. Eligible HIV-infected adolescents were enrolled consecutively between June and September 2011. The inclusion criteria comprised age of 11 to 18 years, perinatal HIV infection, under HAART at the time of analysis, and having caregivers who could provide information and accompaniment. Those with neurological impairment, living in an orphanage, or unable to understand the Thai language were excluded from the study. A demographically matched group, including healthy controls of a similar age without chronic infection, was selected randomly for comparison from a local public school.

Demographic data were obtained from caregivers of both groups. Regarding the HIV-infected adolescents, clinical data were reviewed from medical charts. The adolescents, HIV-infected and uninfected, were asked to complete the Youth Self-Report (YSR) form and caregivers filled out the Child Behavior Checklist (CBCL). The CBCL is a parent-report questionnaire, in which the child is rated on various behavioral and emotional problems. The YSR is a self-administered survey that is derived from the CBCL. Both the YSR and CBCL are available in many languages, and they have been used widely to assess emotional and behavioral problems that have occurred within the past 6 months.\textsuperscript{26,27} They assess internalizing (ie, anxiety, depression, and somatic complaints) and externalizing (ie, aggression and noncompliance) behaviors. The scale of YSR and CBCL comprises internalizing, externalizing, and total behavioral problem scores. It is divided into 8 subsets including anxiety/depression, social withdrawal, somatic complaints, social problems, thought problems, attention problems, delinquent behaviors, and aggressive behaviors; the higher the scores, the more the problems. Abilities in social activities such as sports, and school performance were also assessed within the total social competence scale. Higher competence scales indicate better performance. Correlation between self-report from the YSR and caregiver-report from the CBCL was also assessed. Written informed consent from parents/caregivers and assent from adolescents were obtained from all study participants. The study was approved by the ethics committee of the Faculty of Medicine, Chiang Mai University.

**Data Analysis**

Data were analyzed using SPSS software version 17.0. Descriptive variables were reported as mean, standard deviation (SD), and frequency or percentage, as appropriate. Categorical variables were compared by the chi-square test. For continuous variables, the student t test was used to compare the 2 variables. Spearman correlation was used to assess the association between self-report and caregiver report scores. A P value of less than .05 was considered statistically significant.

**Results**

A total of 106 adolescents were enrolled into the study, including 50 cases in the HIV-infected group and 56 healthy participants in the control group. The overall mean age was 14.21 ± 1.51 years (Table 1). Approximately half of the adolescents in the HIV-infected group lived with their biological mother or father, while nearly 90\% of healthy controls lived with both of their biological parents. The HIV-infected adolescents had a mean CD4 count of 690 cells/mm\(^3\) (range 10-1465, interquartile range [IQR] 542) and most of them were virally suppressed. Complete suppression of viral load (<50 copies/mL) was achieved in 84\%. The mean duration of receiving HAART was 6.9 ± 2.3 years. Eighty percent of HIV-infected adolescents belonged to the World Health Organization (WHO) clinical statuses 1 and 2. Demographic and immunological characteristics of the adolescents in both groups are shown in Table 1.

Adolescents with HIV infection reported themselves as having significantly more internalizing problem scores than healthy controls (Table 2). The somatic complaints and social problem subsets were significantly higher in infected adolescents than those in the controls. When using a binomial test for clinical problems in subscales, only the social problem’s score was significantly higher in the HIV-infected group. The competence scores of infected adolescents were lower than those of healthy controls in all areas, suggesting that these infected adolescents had impaired social competence abilities. Results from the self-report are shown in Table 2.

From the CBCL, the internalizing and total problem scores as rated by the caregivers were also higher in the infected adolescents than that in the controls but the differences were not statistically significant (Table 3). Similar findings were found when using a binomial test for clinical
problems between the 2 groups. Only the withdrawn problem subset in HIV-infected youth was significantly higher than that of healthy controls. Adolescents with HIV infection showed lower total competence scores in 3 areas including activity, sociability, and school, as reported by caregivers, thus indicating impaired social competence abilities. CBCL results are shown in Table 3.

Among the infected adolescents, all the behavioral problems scale scores reported by caregivers were similar between adolescents with complete suppression of viral load (n = 42) and those without (n = 8). Three self-rated subscale scores, namely withdrawn problems, aggressive behavioral problems, and thought problems, were significantly higher in the adolescents with a viral load of more than 50 copies/mL.

Psychosocial problems reported by caregivers were correlated moderately with those from self-reports, especially the internalizing problem score and total competency score (P = .05), as shown in Table 4.

### Discussion

The findings from both the self and caregivers’ reports in this study revealed that adolescents with HIV infection had more psychological problems than healthy controls. It was found that infected adolescents reported more somatic complaints without medical explanation, and their caregivers reported more significant social withdrawal in them. We also found from both self-reports and caregivers’ reports that the competence scores, including sport, social, and school activities, were significantly lower in infected adolescents than in those of healthy individuals, thus indicating poorer performance. This means that although these adolescents have had better physical health from HAART and less hospitalization, they might experience other stressors such as family and environmental factors that contribute to their psychological health.

Unlike others with chronic illnesses, children and adolescents with HIV infection are more likely to experience parental...
Table 3. Child Behavior Checklist Results in HIV-Infected and Noninfected Adolescents.

<table>
<thead>
<tr>
<th>Problems scale, mean (SD)</th>
<th>HIV-Infected Adolescents, N = 50</th>
<th>Healthy Controls N = 56</th>
<th>Mean difference, (95% CI)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internalizing problems</td>
<td>11.32 (7.14)</td>
<td>9.32 (8.18)</td>
<td>2.00 (−0.98–4.97)</td>
<td>.19</td>
</tr>
<tr>
<td>Anxious/ depressed</td>
<td>3.84 (3.38)</td>
<td>3.88 (3.84)</td>
<td>−0.04 (−1.44–1.37)</td>
<td>.96</td>
</tr>
<tr>
<td>Withdrawn</td>
<td>3.12 (1.99)</td>
<td>2.14 (2.04)</td>
<td>0.98 (−0.20–1.75)</td>
<td>.01</td>
</tr>
<tr>
<td>Somatic complaints</td>
<td>4.36 (3.26)</td>
<td>3.30 (3.30)</td>
<td>1.06 (−0.21–2.32)</td>
<td>.10</td>
</tr>
<tr>
<td>Externalizing problems</td>
<td>7.44 (4.84)</td>
<td>8.57 (7.39)</td>
<td>−1.13 (−3.52–1.15)</td>
<td>.35</td>
</tr>
<tr>
<td>Delinquent behavior</td>
<td>1.96 (1.94)</td>
<td>2.16 (2.40)</td>
<td>−0.20 (−1.05–0.65)</td>
<td>.64</td>
</tr>
<tr>
<td>Aggressive behavior</td>
<td>5.46 (3.58)</td>
<td>6.41 (5.34)</td>
<td>−0.95 (−2.69–0.79)</td>
<td>.28</td>
</tr>
<tr>
<td>Other problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social problems</td>
<td>3.44 (2.59)</td>
<td>2.68 (2.53)</td>
<td>0.76 (0.23–1.75)</td>
<td>.13</td>
</tr>
<tr>
<td>Thought problems</td>
<td>2.18 (2.53)</td>
<td>2.41 (2.39)</td>
<td>−0.23 (−1.18–0.72)</td>
<td>.63</td>
</tr>
<tr>
<td>Attention problems</td>
<td>3.60 (2.98)</td>
<td>3.57 (3.13)</td>
<td>0.03 (−1.15–1.21)</td>
<td>.96</td>
</tr>
<tr>
<td>Total problem score</td>
<td>31.96 (19.17)</td>
<td>30.27 (23.02)</td>
<td>1.69 (−6.52–9.91)</td>
<td>.68</td>
</tr>
<tr>
<td>Competence scale, mean (SD)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities</td>
<td>7.73 (3.01)</td>
<td>9.26 (2.74)</td>
<td>−1.53 (−2.64 to −0.42)</td>
<td>.007</td>
</tr>
<tr>
<td>Sociability</td>
<td>7.94 (2.28)</td>
<td>9.13 (2.06)</td>
<td>−1.19 (−2.02–0.35)</td>
<td>.006</td>
</tr>
<tr>
<td>School</td>
<td>4.56 (1.11)</td>
<td>5.11 (0.43)</td>
<td>−0.55 (−0.88 to −0.21)</td>
<td>.002</td>
</tr>
<tr>
<td>Total competence score</td>
<td>20.14 (5.24)</td>
<td>23.19 (3.87)</td>
<td>−3.04 (−4.80 to −1.28)</td>
<td>.001</td>
</tr>
</tbody>
</table>

Abbreviations: CBCL, Child Behavior Checklist; CI, confidence interval; SD, standard deviation.

Table 4. Correlation of Psychosocial Functioning between the Caregiver Report and Youth Self-Report.

<table>
<thead>
<tr>
<th>Youth Self-Report</th>
<th>Internalizing Problems</th>
<th>Externalizing Problems</th>
<th>Total Problem Score</th>
<th>Total Competency Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver report</td>
<td>.47&lt;sup&gt;b&lt;/sup&gt;</td>
<td>.27</td>
<td>.39&lt;sup&gt;b&lt;/sup&gt;</td>
<td>−.04</td>
</tr>
<tr>
<td></td>
<td>Externalizing problems</td>
<td>.18</td>
<td>.35&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.27</td>
</tr>
<tr>
<td></td>
<td>Total problem score</td>
<td>.37&lt;sup&gt;b&lt;/sup&gt;</td>
<td>.35&lt;sup&gt;a&lt;/sup&gt;</td>
<td>.39&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td></td>
<td>Total competency score</td>
<td>−.07</td>
<td>−.19</td>
<td>−.19</td>
</tr>
</tbody>
</table>
<sup>a</sup> P = .01;  
<sup>b</sup> P = .05.

illnesses and possible death. This study found that only half of the infected adolescents lived with their biological mother or father, while others, whose parents were dead, lived with their grandparents who were old and earned a low income. Furthermore, their physical health and required medication adherence may interfere with their social activities, thus affecting peer relationships, as suggested by lower competence scores. Increased self awareness of their differences from adolescent peers also put them at risk of emotional and behavioral problems.

According to caregivers, HIV-infected adolescents, who lived with relatives or in foster care (27 out of 50 cases), had difficulties, including total, internalizing, and externalizing problems, more frequently than those who lived with at least one biological parent (P = .02, .01, and .01, respectively). This is possibly because those adolescents who have lived with relatives or in foster care were exposed to the loss of both parents and changes to another home, which meant a major life adjustment.

The findings in this study were similar to those of Bomba et al<sup>23</sup> which found that HIV-infected children and adolescents aged 5.6 to 18 years had lower social competence and lower quality of life than healthy controls. Furthermore, it was found that substance-using children of HIV-infected parents, whether infected or affected, were more likely to engage in sexual risk behaviors. This means that other factors influence the behavior of children other than HIV itself. Contrary to our findings, Bachanas et al<sup>19</sup> revealed that psychological adjustment scores from both caregiver report and child self-report did not differ significantly between the HIV and the control groups. Their study included children and adolescents aged from 6 to 16 years, and some of them had not been told about their diagnosis. Our participants were older, and all of them had been informed about their HIV status. Therefore, findings might vary in different settings.

The strength of this study is the inclusion of emotional and behavior problem assessments from both the adolescents themselves and their caregivers in order to obtain more accurate information. Also, there was a correlation between psychosocial functioning from the caregiver reports and the self-report (r range .35-.47). The correlations between the YSR and the CBCL for the Diagnostic and Statistical Manual of Mental Disorders–oriented scales were similar to those reported by Achenbach et al<sup>26</sup> (r = .44, range .39-.48). However, there were some limitations in this study. First, as the participants were from 1 tertiary care center, the results may not be generalized. Second, the timing for access to HAART varied in each case although the mean duration of HAART administration
was approximately 7 years. Third, since this was a cross-sectional study, the results represented the information from a short period of time and may not represent status in the long time. Furthermore, information from the school that provided the participants would project an alternative view of the children and adolescents in this study.

In conclusion, the findings of this study show that adolescents with HIV infection had more emotional problems than do healthy controls. Scores from these adolescents on sociability and activity performance of these adolescents also are lower than those of the healthy controls. These findings might apply to adolescents with other chronic medical conditions as well. Therefore, despite the fact that HAART improves health care, HIV-infected adolescents are still at risk of psychological problems and impaired social functioning from family and environmental factors. Appropriate psychosocial intervention should be integrated into the comprehensive health care of adolescents with HIV infection in order to meet their needs for a better quality of life.

Declaration of Conflicting Interests
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