Quality of Life Among HIV-Infected Children in Thailand

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The aim of the study was to measure quality of life in human immunodeficiency virus-infected children. This is a cross-sectional study among main caregivers of human immunodeficiency virus-infected children. The questionnaire consisted of 5 main domains: general health, physical functioning, symptoms, psychological well being, and social and role functioning. A total of 131 main caregivers (21% males, average age 42.5 years) of human immunodeficiency virus-infected children (28% male, average age 10.1 years) answered the questionnaires. Four out of 5 domains showed that children without immune suppression had a significantly higher quality of life than children with immune suppression.

There was a significant correlation between health care utility and physical functioning, symptoms, and social and role functioning. The instrument had acceptable internal consistency and was a feasible measure of quality of life among human immunodeficiency virus-infected children. The information obtained will enable health care providers to establish comprehensive health care services to serve the needs of these children and their families.

Keywords: quality of life (QOL); HIV/AIDS; HIV-infected children

According to the World Health Organization (WHO) estimates, about 2.2 million children aged less than 15 years were afflicted with HIV at the end of 2004, with about 640 000 newly acquired cases in the same year.1,2 By the year 2003, the WHO estimated that approximately 33 000 Thai children had been infected with HIV since the start of the epidemic, with 21 000 living with HIV/AIDS.2

Because highly active antiretroviral therapy (HAART) considerably prolongs the life of HIV-infected individuals, the improvement of quality of life (QOL) has become an important goal for health care providers.3-5 Quality of life has been defined as a multidimensional interplay between various physical, psychological, and social factors.6 It includes global health perceptions, symptom status, functional status, biologic and physiologic variables, individual and environmental characteristics, and overall QOL.7 This definition of QOL enables us to measure children's functioning in various areas, and because it uses children's and caregiver's perceptions rather than the clinician's view, the assessment should be more accurate.8-10 At present, predictors of QOL in the HIV-infected adult population have been widely researched, but so far few studies have been published that assess QOL in the HIV pediatric population.3,8
The General Health Assessment for Children (GHAC), the standardized tool developed by the Pediatric AIDS Clinical Trials Group (ACTG), has been reported so far as suitable for use with HIV-infected children. It measures specific QOL domains, including health perception, functional status (physical, psychological, and social and role functioning), and HIV symptoms. The authors reported that the tool had very good internal consistency reliability and discriminated between HIV-infected children with AIDS and HIV-infected children without AIDS. They found differences between HIV-infected children with and without AIDS symptom distress, in physical resilience, health perceptions, and social and role limitations. Moreover the GHAC modules appeared to be relatively inexpensive but comprehensive QOL measures which focus on HIV manifestations. However, the authors reported that they found no differences in the measures of physical functioning for children with and without AIDS. This could be the result of the widely fluctuating course of AIDS in children. Storm et al recently used this tool in a report on the QOL among HIV-infected children receiving antiretroviral therapy and found that the tool could show variations in the QOL of children within the groups as well.

Since the year 2000, HAART has been a standard component of care and treatment of HIV-positive individuals in Thailand, as it is in the United States. By 2004, nationwide, about 50,000 HIV-infected people were receiving HAART. At present, HAART is available for all HIV-infected individuals in over 908 health care services in Thailand. However, no studies that assess the QOL among the pediatric HIV/AIDS population in Thailand have yet been published.

Aims

We studied a) the QOL among HIV-infected children in each domain, b) the internal consistency (Cronbach α coefficient) and known group construct validity, and c) the relationship between QOL and health care usage.

Methods

Ethics

The study and survey instrument were approved by the Human Research Ethics Committee of Chiang Mai University. All subjects provided written consent before participation.

Study Design

A cross-sectional study was conducted among the main caregivers of HIV-infected children aged 5 and above, followed up at the HIV clinic of Chiang Mai University Hospital, and Sanpatong District Hospital in northern Thailand. The caregivers were informed about the study, and the study’s nurses asked the caregivers to answer the questionnaire.

QOL Instrument

The QOL instrument was adopted and modified from the GHAC tool for QOL that was used in the ACTG 219 study. After permission to translate was granted, 2 investigators separately translated the GHAC tool for QOL into Thai. The translation was checked and edited by another member of the research team. When difficult questions about the translation or editing process arose, they were solved through discussion among the members of the research team and an outside expert from the Department of Psychology, Chiang Mai University. The tool was tested among 20 caregivers of children admitted to the hospitals and then modified to suit Thai cultural norms and peculiarities.

We kept the number of the items asked as the GHAC, except in the health utility domain in which we added 1 question. The number of questions in each domain as compared to the original GHAC is shown in Table 1. The tool has been modified as follows.

In the physical functioning domain, we changed the phrase ‘walking one block’ to ‘walking from one electric pole to another’, and ‘active sports, like bowling’ to ‘football’. In the health care utility domain, we added the questions, how many times in the past 4 weeks the parents a) bought medication for the child from a pharmacy without a prescription from the doctors and b) administered home medication to the child because these are common practices in Thailand. Moreover, we deleted the question about how many times the child had been visited by a nurse or health care provider in the past 4 weeks as home visits by health care personnel are not common. Furthermore, in a question regarding alternative treatments that caregivers provide for the child, we added the example ‘consultation of magicians and mediums’ because this is a common practice in Thailand.
In the study, a trained pediatric nurse used the tool to obtain information on QOL and to interview the parents and caregivers in the same method it was done in the previous study from the United States. The questionnaire for children consisted of 5 main domains (Table 1). Regarding the use of health services, we asked how many times in the past 4 weeks the child a) was admitted to the hospital, b) had to see a physician in addition to regular appointments and how many times caregivers a) bought medication for the child from a pharmacy without a prescription, b) administered home medication to the child, and c) called nurses for advice about their sickness.

### Data Collection

The trained nurses interviewed parents and caregivers of HIV-infected children enrolled in the study. The data were first recorded on paper and then transferred into a computer program.

### Data Analysis

The Thai translated version of GHAC was administered to 131 caregivers of HIV-infected children. The results were reported based on the children’s immunological classification—whether their CD4 counts were <25% (immunosuppressive group) or ≥25% (normal group). Demographic and clinical variables including age, sex, social status, treatment regimen, questionnaire respondent, maternal education, and diagnosis of AIDS were reported as proportions. Student t test was used to compare mean results and χ² test to compare proportional results. Reliability was determined from Cronbach α (reliability coefficient). The construct validity was studied between HIV-infected children with impaired immunity and those without impaired immunity. All P values are 2-tailed at a significance of .05.

### Results

#### Demographic Characteristics

A hundred and thirty-one main caregivers (average age 42.5; standard deviation [SD] 12.7; range 16-71 years) of HIV-infected children (average age 10.1; SD 2.7; range 6-17 years) receiving HAART at the HIV clinics answered the questionnaire. Table 2 shows the characteristics of the children and caregivers. Twenty-one percent of the respondents were the biological parents, 62.6% were other relatives, and 16.0% were foster parents or institutional caregivers. More than half of the caregivers (61.1%) reported that they had completed primary school as their highest level of education. Almost all children acquired their HIV infection perinatally (98.5%; n = 129). Two children received the HIV infection from blood transfusions. Most of them (78.6%) were females. The average duration of receiving HAART was 76.3 weeks (SD 32.4; range 1-186). Their average CD4
count was 20% (SD 8.1; range 2-40). About 43% of the children were reported to be aware of their HIV diagnosis. Most of the children (97%) were attending schools.

QOL Measurement

The mean scores for each QOL domain among all children are shown in Table 3. Higher scores indicate a better QOL. General health perception ratings for most children were at the upper end of the scales, and 38.3% of children ranged over the lower 70% of possible scores. When we asked caregivers about their ratings on each subitem, 35.3%, 39.8%, and 49.6% of children were ranked in the lower 70% of possible scores for physical well being, emotional functioning, and daily activities, respectively. About one-fourth (26.3%) of the children had at least some limitation in physical functioning, with more frequent limitations in vigorous activities (22.6%) than in basic activities of daily living (8.3%). Almost all (97%) children had at least 1 psychological problem. Psychological problems commonly reported by caregivers were that the child had sudden changes in mood and feelings (55.6%), the child was disobedient at home (55.6%), and the child argued too much (54.9%). One or more limitations in social and school functioning were reported for 37.6% of children. Individual limitations included health limitations in activities (12%) and school attendance (37.6%).

Up to 84.2% of the children experienced at least 1 symptom related to HIV infection during the past month, and 6.8% of them felt at least moderate overall discomfort. Commonly reported symptoms were skin problems such as rash (33%), respiratory symptoms (33%), headache (30.8%), runny nose and sinus trouble (21.8%), and gastrointestinal symptoms (19.5%). Concerning health care utility in the past month, 33.8% of caregivers reported that they self-administered medication to the child at home at least once. One-fifth (22.6%) of caregivers reported having taken the child to a private clinic, 19.5% reported having bought medication from drug stores without a prescription, and 10% reported having called health care personnel for advice. Seven percent of children were reported to have been admitted to the hospital in the past month.

Reliability

Cronbach α coefficient was the following: average 0.84, general health 0.76, physical functioning 0.95, psychological well being 0.85, HIV-related symptoms 0.92, and social and role functioning 0.71.

Construct Validity (Known Group)

To assess known group construct validity, we examined scale differences among children who had a normal immunity (CD4 count ≥ 25%) and those who had impaired immunity (CD4 count < 25%). We hypothesized that children with a CD4 count of less than 25% would show lower physical functioning, more symptoms, more psychological problems, and more social and role limitations than children who had a normal level of CD4 cells. As shown in Table 4, the results indicated significant differences for physical functioning (P = .001), psychological well being (P = .02), symptoms related to HIV infection (P = .008), and social and role functioning (P = .002). There were no significant differences in general health between the 2 groups (P = .25).

Relationship Between QOL and Use of Health Care

We also examined the relationship between the 5 QOL modules and use of health care. We hypothesized that HIV-infected children with impaired immunity levels have greater access to health care than those who had normal immunity levels. As shown in Table 5, the negative outcome measures were associated with a
higher use of health care services. Poor physical functioning, more symptoms, and low social functioning were significantly related to the higher use of health care services ($P < .05$). There was no association between use of health care and general health or psychological functioning ($P > .05$).

**Discussion**

The results showed that the Thai version of the GHAC, a measure of QOL for use in HIV-infected children, showed a fairly good internal reliability (mean $= 0.84$) and discriminated between HIV-infected children with normal and suppressed levels of CD4 cells. The study indicated significant differences of QOL between HIV-infected children who had a normal level of CD4 cells and those who had a suppressed level of CD4 cells in physical functioning, psychological well-being, symptoms related to HIV infection, and social and role functioning. Moreover, the study shows that the QOL in the main domains of physical functioning, symptoms, and social and role functions related to HIV infection significantly correlated with use of health care among all children. The mean score for general health among all children was reported to be 30 (out of 40). Up to 84.2% of those children had some degree of symptoms related to HIV infection. A total of 33.8% of caregivers reported that they self-administered medication to the child at home at least once in the past month.

In comparison to the GHAC modules used in the ACTG 219 study, our QOL tool showed similar results concerning the high internal consistency reliability of physical functioning (identical Cronbach $\alpha = 0.95$) and HIV-related symptom domains (previous study: Cronbach $\alpha = 0.89$ vs our study: Cronbach $\alpha = 0.93$). Our study showed lower reliability values in the domains of general health (Cronbach $\alpha = 0.86$ vs 0.76) and psychological well-being (Cronbach $\alpha = 0.90$ vs 0.85). For the social and role functioning domain, both studies indicated a similar lower internal consistency reliability (previous study Cronbach $\alpha = 0.72$ vs our study Cronbach $\alpha = 0.71$).

Concerning the construct validity of the tool, in agreement with our hypothesis, the QOL among those who had a normal immunity (CD4 count $\geq 25\%$) had statistically significant higher total mean scores than those who were immunosuppressive (CD4 count $< 25\%$) for 4 out of 5 main domains. These results agree with those reported by Gortmaker et al when categorized into 2 groups (children who had AIDS and those without AIDS).

Compared with the previous study concerning the QOL among HIV-infected children receiving HAART in the United States using similar modules of measurement, Storm et al reported a lower proportion of children having general health ratings of below 70% than our study (25% vs 38.3%). However, in our study, we found that a lower proportion of children had a limitation of physical functioning in vigorous activities (22.6% vs 46%). We found higher individual limitations on school attendance than in

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<thead>
<tr>
<th>Table 4. Relationship of Quality of Life Scales to the Level of Immunology (CD4 count $&lt; 25%$ vs $\geq 25%$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>1. General health</td>
</tr>
<tr>
<td>2. Physical functioning</td>
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<tr>
<td>3. Psychological well being</td>
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<tr>
<td>4. Symptoms</td>
</tr>
<tr>
<td>5. Social and role functioning</td>
</tr>
</tbody>
</table>

**Abbreviation:** SD, standard deviation.

$^{a}$Equal variances assumed.

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<thead>
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<th>Table 5. Estimated Correlation of Health-Related Quality of Life Modules With Health Care Usage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlation With Health Care Usage (Correlation Coefficient)</td>
</tr>
<tr>
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</tr>
<tr>
<td>1. General health</td>
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<tr>
<td>2. Physical functioning</td>
</tr>
<tr>
<td>3. Psychological well being</td>
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<tr>
<td>4. Symptoms</td>
</tr>
<tr>
<td>5. Social and role functioning</td>
</tr>
</tbody>
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the children in the United States’ study (37.6% vs 17%). The common HIV-related symptoms reported in both studies were respiratory symptoms (18% in previous study vs 33% in our study) and gastrointestinal symptoms (14% in previous study vs 19.5% in our study). One of the most common symptoms concerning caregivers in our study was rash. This could be an adverse reaction to drugs, especially at the beginning of HAART, but in this study, we did not determine the cause of that rash.13

Because the average duration of children receiving HAART was 76 weeks, we found that most mean scores across the main domains were at the upper end of the scales. However, some children still experienced limitations in vigorous activities, HIV-related symptoms, and social and role functioning. There appeared to be a correlation between the CD4 counts and these domains because the mean scores of QOL domain showed significant differences between those who had a normal level of CD4 cells and those who were immunosuppressed.

We found no correlation between use of health care and general health. We can theorize that because the questions about general health focus on a 3-month period and contain 4 items, the tool might not be sensitive enough to detect the general health of children. The questions relating to symptoms, in contrast, focus on the most recent month and contain 20 items.

Certain limitations should be considered when interpreting the findings. First, because the study was a cross-sectional study, we did not have information on test-retest reliability. Follow-up of those subjects and consecutively measuring their QOL would provide us with a better understanding of potential changes. Second, the time spent to complete each questionnaire was about 30 minutes, which may be too long to be of practical use in other studies. Finally, we have not yet reported on other factors affecting QOL in this study (such as disclosure status, depression, anxiety, and risk taking behavior) besides the CD4 T-cell level because those studies are still underway. Further studies may include long-term evaluations of QOL among these children and the development of a short version of the measurement (through the exclusion of items that show a low sensitivity to QOL) that can be administered more frequently.

To the best of our knowledge, this is the first study that has attempted to establish an appropriate tool for measuring QOL among HIV-infected children in Thailand. The findings provided us with a feasible and reliable tool that can be used with other HIV-infected children receiving HAART in the country. They may also help us to better understand how to care more holistically for HIV-infected children receiving HAART. Even though a previous study conducted by our team found that most children who receive HAART achieve reduced viral loads and an increase in their CD4 counts,13 this present study shows that these children remain at health and psychosocial risk because of the chronic nature of their illness. Many children still have some limitations in their physical functioning, symptoms related to HIV infection, and school attendance. The information obtained will enable health care providers to establish comprehensive health care services to serve the needs of these children and families. The authors are presently using the tool to measure QOL in children who are long-term adherents to HAART at the HIV Clinic of Chiang Mai University Hospital. Moreover, they are planning to assess other factors that are associated with QOL, such as disclosure and adherence.

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