

Quality of Life of Children With HIV Infection

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Abstract

Background: Human Immunodeficiency Virus (HIV) infection is an increasing major chronic condition in Indonesia. Children with HIV infection are at risk for low self-esteem, as well as for emotional, behavioral, and social functioning problem. This condition may affect children quality of life (QoL).

Objective: To explore QoL of children with HIV infection and its related factors.

Methods: An analytic descriptive study was carried out in outpatient allergy-immunology clinic of Department of Child Health, Faculty of Medicine, Indonesia University, Dr. Cipto Mangunkusumo Hospital during July 2012-July 2013. Subjects were children with HIV aged 2-18 years old and their caregivers. The QoL was assessed by Indonesian Version of PedsQLTM 4.0.

Results: A hundred children with HIV infection and their caregivers participated in this study. The subject consisted of boys and girls in equal numbers, predominantly 2-4 year old group (40%). The primary caregivers were mostly biological parents (49%). The average age was 69.88 (SD 3.12) months old. Low QoL was found in 41% and 30% subjects based on parent proxy-report and child self-report respectively. QoL of children with HIV infection were 76.76+16.83 and 79.27+9.61 for parent proxy-report and child self-report respectively. Child self-report QoL was associated with age ($r=0.332$, $P=0.010$) and duration of illness ($r=0.294$, $P=0.023$). QoL was not related to sex, child education, economic status, primary caregiver, caregiver education, clinical staging and immunologic classification.

Conclusion: Low QoL of children with HIV infection was found in 41% and 30% subjects based on parent proxy-report and child self-report respectively. Child report QoL was related to age and duration of illness.

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INTRODUCTION

In 2010 worldwide, there are 34 million people living with human immunodeficiency virus (HIV), including 3.4 million children younger than 15 years old. An estimated 390,000 children were newly infected with HIV in 2010, 30% fewer than the peak of 560,000 newly infected children annually in 2002 and 2003. Death among children age less than 15 years old has been declining. There were estimated 250,000 children died from AIDS-related illnesses in 2010. This number was 20% fewer than the estimated death in 2005 from the same causes that reached 320,000 children. This trend reflects the steady expansion of health services to prevent HIV from being transmitted to infants and, to a lesser degree, the slow expansion of access to treatment for children.¹

Since the finding of the first case of HIV infection in Bali in 1987, cases of HIV in Indonesia has increased. HIV infection in Indonesia during 1987-2005 was 859 cases and increased to 21,511 cases in 2012. HIV infection also affecting children aged younger than 15 years old as many as 795 and 749 cases in 2010 and 2012 respectively.²

HIV infection in children is a chronic condition that requires long-term treatment or management, which affect the quality of life of children. One effort to improve the quality of life of children infected with HIV / AIDS is a method of treatment with HAART (Highly Active Antiretroviral Therapy). HAART method was first introduced in 1986,^{3,4} and in Indonesia, this program has been running since 2004.⁵ HAART treatment method is said to be able to lower the viral replication and improve the clinical condition. The success of HAART treatment method is determined by adherence of treatment, clinical and laboratory conditions at the beginning of therapy.

Children with HIV infection/AIDS (Acquired Immune Deficiency Syndrome) are at risk for low self-esteem, as well as for emotional, behavioral, and social functioning problem. These conditions can affect their quality of life.^{6,7} Assessment of quality of life was first introduced for HIV/AIDS research in 1990 to see the effect of antiretroviral treatment to the health status and wellness.⁸ Highly active

antiretroviral therapy has been proven decreasing the number of virus until undetected state and have shown a decrease in morbidity and mortality of HIV infection. Some research results stated that there were only little improvement on quality of life.^{9,10} However, other studies shown that all quality of life were improved by HAART method.¹¹ In general, comparing with the situation before HAART method, the health status of children affected by HIV has shown great improvement with the use of HAART method.

One of the instrument use to assess the quality of life is Pediatric Quality of Live Inventory™ version 4.0 (PedsQL 4.0) Generic Core Scale. Banerjee et al conducted a study¹² in India about quality of life using PedsQL™ 4.0 generic modul amongst HIV children and found that the PedsQL result was 67.7 to 73.6 for the reports of parents and child reports. It shown that their quality of life were lower compared to children that were not infected by HIV. Until today, there is no data available about the quality of life of children with HIV infection in Indonesia.

The aim of this study is to explore the quality of life of children with HIV infection and its related factors in Department of Child Health, Dr. Cipto Mangunkusumo Hospital, Jakarta.

METHOD

Population

A cross sectional study was carried out in HIV-infected children aged 2-18 years old and their parents or caregivers who were treated in allergy-immunology clinic, Department of Child Health, Faculty of Medicine, University of Indonesia, Dr. Cipto Mangunkusumo Hospital, Jakarta from July 2012 until July 2013. HIV children with mental problem or with other chronic diseases such as heart problem, malignancy, chronic kidney diseases, epilepsy, haemoglobinopathies, asthma or physical disability which might affect their daily activity were excluded.

Minimum sample size was 100 subjects, which was calculated with $\alpha = 0.05$, low quality of life prevalence in children with HIV infection was assumed 50% and target absolute accuracy was 10%.

Human immunodeficiency virus infection in babies

less than 18 months old was established if they have positive clinical symptoms and supported by positive HIV RNA on PCR examination, at least once, due to funding limitation. HIV infection in baby 18 months old or older would be determined with antibody HIV test.¹³

HIV classification was assigned based on clinical category of CDC 1994 would be : N category (asymptomatic), A category (mild symptomatic), B category (moderate symptomatic) and C category (severe symptomatic).¹⁴

HIV classification based on immune category (CD4) on CDC 1994 would be : category 1 (no suppression), category 2 (medium suppression) and category 3 (high suppression).¹⁴

The data about family income was retrieved using interview method with the parents/caregivers. Monthly income was classified into two categories : lower than Rp. 1.529.150,-/ month and Rp. 1.529.150,-/ month or higher. The cut off income was based on regional standard payment in Jakarta during 2012.¹⁵

Primary caregivers were differentiated into three categories : biological parents (father, mother or both), nonbiological caregivers (uncle, aunt, and other family members) or others (taken care by institution or foundation).¹²

The sickness period is determined since HIV infection was established until the subject was included in this research.

This research has been approved by Ethics Committee on Health Research of University of Indonesia, Dr. Cipto Mangunkusumo Hospital, registration number 430/PT02.FK/ETIK/2012, on July 16, 2012.

Research procedure

All children included as research samples were subjected to history taking and physical examinations relevant to HIV infection. The data will be input into the research form. The filling of Pediatric Quality of Life Inventory™ (PedsQL™) version 4.0 form was done by both parents/caregivers and children. For children that were not able to read, the questions was read by researcher to them.

MEASURES

The instrument used to evaluate quality of life was PedsQL™ 4.0 Generic Core Scale. This instrument was developed by Varni JW¹⁶ to measure quality of life of children and teenagers with chronic diseases. Pediatric Quality of Life Inventory™ 4.0 Generic Module has been translated into some languages including Indonesian Language and has been used in some researches with good internal consistent reliability with alpha coefficient between 0.82-0.88.¹⁷

Pediatric Quality of Life Inventory™ was used to evaluate quality of life of children between 2-18 years old. PedsQL™ 4.0 consists of questionnaire that was filled out by both parents and children. The questionnaire consists of 23 questions that are divided into 5 fields; physical function (8 questions), emotional function (5 questions), social functions (5 questions) and school function (5 questions). The questions were related to their activities in the last one month before filling up the questionnaire. The answer for each question was marked with number 0 to 4 (0= no problem, 1= almost has no problem, 2= sometimes has some problems, 3= often has some problems, 4= always has problems) and it will be converted into scale of 0-100 (0=100, 1=75, 2=50, 3=25, 4=0). The total score was counted by adding scores of all questions and divided it with the number of total questions. The higher total score means a better quality of life.¹⁸ Quality of life cutoff value for children with major chronic condition is 77 for age <8 years old and 70 for age >8 years old. If the score fell below the cutoff value then it would be stated as having low quality of life.¹⁹

Statistic analysis

The data was evaluated using SPSS 16.0 version for windows and the relationship between each variable was analyzed using Pearson or Spearman correlation with the level of $P < 0.05$.

RESULT

A total of 102 subjects met the inclusion criteria for this study. Two subjects were excluded because of incomplete data. Only 100 subjects were eligible

for data analysis. The subject consisted of boys and girls in equal numbers. The average age was 69.88 (SD 3.12) months old; 40 children (40%) were in 2-4 year old group and 65 children (65%) did not go to school. The complete characteristic of subjects is described in table 1.

The internal consistency reliability alpha

coefficient for the PedsQL™ 4.0 is described in Table 2. It can be seen that internal consistency reliability alpha coefficients for children 5-12 years old were higher for parent proxy-report (0.81) than for child self-report (0.33).

Low quality of life among children with HIV infection based on child self-report were found in

Table 1. Children with HIV infection based on sociodemography and medical characteristic

Characteristic	N (%)
Gender, n boys (%)	50 (50)
Age	
2- 4 years old	40 (40)
5-7 years old	35 (35)
8-12 years old	25 (25)
Child Educational Background	
Did not go to school	65 (65)
Elementary school	35 (35)
Primary Caregiver	
Biological parents	49 (49)
Non-biological parents	43 (43)
Others/ foundation	8 (8)
Primary Caregiver Educational Background	
Uneducated	2 (2)
Elementary school	10 (10)
Junior high school	15 (15)
Senior high school	61 (61)
Diploma/other college degree	12 (12)
Family Income	
< Regional standard payment	56 (56)
≥ Regional standard payment	44 (44)
Sickness period (months), mean (SD)	37.15 (25.67)
HIV Clinical Categories	
N (asymptomatic)	5 (5)
A (mild symptomatic)	30 (30)
B (moderate symptomatic)	40 (40)
C (severe symptomatic)	25 (25)
HIV Immune Categories	
1 (without suppression/ CD4 ≥ 25%)	51 (51)
2 (medium suppression/ CD4 15-25%)	20 (20)
3 (high suppression/ CD4 < 15%)	29 (29)

Table 2. Cronbach's α coefficients for PedsQL™ 4.0 Generic core scale child self-report and parent proxy-report for children with HIV Infection

Scale	2-4 years old	5-12 years old
Child self-report		
Physical function	-	0.39
Emotional function	-	0.11
Social function	-	-0.02
School function	-	0.41
Total score	-	0.33
Parent proxy-report		
Physical function	0.85	0.59
Emotional function	0.84	0.65
Social function	0.76	0.73
School function	-	0.71
Total score	0.92	0.81

Table 3. Subscore and total score of PedsQL™

PedsQL™	Child self-report Mean (SD)	Parent proxy-report Mean (SD)
Physical function	82.28 (14.85)	78.02 (20.81)
Emotional function	78.25 (16.31)	72.40 (19.89)
Social function	86.00 (13.24)	85.05 (19.66)
School function	70.60 (17.72)	64.72 (18.28)
Total score	79.27 (9.61)	75.76 (16.83)

Table 4. The relationship between total score of PedsQL™ based on child and parent reports and sociodemography and clinical factors

Sociodemography and clinical factors	PedsQL™ child self-report, r (P value)	PedsQL™ parent proxy-report, r (P value)
Gender	-0.197 (0.132)	-0.020 (0.841)
Child age	0.332 (0.010)	0.022 (0.829)
Child educational	0.184 (0.518)	0.058 (0.570)
Main caregiver	0.163 (0.212)	0.134 (0.183)
Main caregiver educational	0.000 (1.000)	-0.114 (0.260)
Family income	0.059 (0.656)	-0.080 (0.427)
Sickness period	0.294 (0.023)	-0.131 (0.193)
HIV clinical category	-0.008 (0.949)	-0.147 (0.146)
HIV immune category	-0.232 (0.075)	-0.047 (0.640)

30 subjects (30%) and the value became higher when based on parent proxy-report which was 41 subjects (41%). The average of PedsQL™ total score in children with HIV infection was 79.27 (SD 9.61)

based on child self-report and 75.76 (SD 16.83) when based on parent proxy-report. Subscore for physical, emotional, social and school function for child and parent report were described in table 3.

Pediatric Quality of Life Inventory™ 4.0 child self-report was related with age ($r = 0.332$, $P = 0.01$) and sickness period ($r = 0.294$, $P = 0.023$) while gender, child educational, primary caregiver, primary caregiver educational background, HIV clinical category and HIV immune category did not have any relationship. Pediatric Quality of Life Inventory™ 4.0 parent proxy-report had no relationship with each factor (table 4).

DISCUSSION

Quality of life is defined as individual subjective perception of the effect of health condition including diseases and treatment to various aspect of life including physical, psychological and social function.²⁰ Quality of life affects individual or family point of view on his health status during or after treatment.²¹

In this study, quality of life of children with HIV infection for both parent and child report are better than that of from study conducted by Banerjee et al¹⁷ in India with the total score was 67.7 for parent report and 73.6 for child report. The QOL in this study was also higher compared to the study result by Punpanich et al² in Thailand showed 76.11 for child report. This result might be related to 1) massive attempt in spreading information about HIV infection and government support in Indonesia to prevent the spreading of HIV infection, 2) the implementation of HAART method in HIV infection, 3) free medical supply for people suffered from HIV infection. This condition could change the family and subject perspectives towards HIV infection which could provide better social live and better engaged in their daily activities without any financial problem due to affordable treatment. However, Gupta et al²² in India got a higher total score of QOL than that of in our study, in which the child PedsQL total score report and parent report were 89.31 and 87.05 respectively.

Internal consistency reliability alpha coefficient PedsQL™ 4.0 Indonesian language version was good with cronbach's alpha coefficient that was 0.81 for parent proxy-report. This result was similar to other researches that showed good internal consistent reability with alpha coefficient between 0.82-0.88.¹⁷

The Cronbach's alpha coefficient child self-report was 0.33 (reliable enough). This may be related to the level of literacy and cognitive child 5-12 year age group with HIV infection that was still low.

Quality of life in child self-report for physical and psychosocial function had higher results than Banerjee et al¹² in India. The reason of this result might be due to the sample bias in which, the children included in this study were outpatient setting, so children with more severe major infection might not included as subject of this research. Most of the sample (three-quarters) were children aged of 2-7 years old which means their sickness period were relatively shorter than the usual and the appearance of severe symptoms of HIV infection were rare. During the age period of 2-7 years old the psychosocial development has not reach the mature stage, children have not understood about HIV infection and how it will affect their social and health life.

Quality of life of children was related to their age and sickness period. The older the children the lower their quality of life. It also has the similar results with sickness period, the longer their sickness period the lower their quality of life. Older children have longer sickness period and this condition exposed them to lower quality of life. The older children have better understanding about HIV infection and how it affects their social life.

In our research, there was no relationship between the quality of life among children and clinical and immune category which corresponded with previous research by Punpanich et al⁷ in Thailand and Gupta et al.²² This was probably caused by the similarity of the sample that Punpanich and this research used, where the samples were from outpatient setting who relatively had better health status compare to inpatient samples. For instance, a child that was classified with C category had good clinical condition because he got potent antiretroviral and antimicroba treatment. Some previous researches shown that antiretroviral treatment had relationship with increased quality of of life of children with HIV infection.^{12,23,24}

There are some limitations in this research. First, this is a cross sectional study that could not evaluate if

there were any differences between the pre and post quality of life. Second, each child showed different response to the questionnaire, older children were able to fill up the questionnaire by themselves and children younger than 8 years old or had poor literacy level filled up the questionnaire using interview method. With two different approaches it might resulted in two different answers.

CONCLUSION

This research shown that there were 30% of children with HIV infection that had low quality of life based on child self-report and 41% based on parent proxy-report. The quality of life of children with HIV infection based on child self-report had relationship with their age and sickness period.

This research was conducted only for children with HIV infection that already have had HAART treatment so this research could not be generalized to other population. So, it requires further research if we want to explore quality of life in children with HIV infection with other than above conditions.

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