

Assessing the quality of life of asthmatic children using the PedQL™

Yulia Wigoeno, Rini Sekartini, Darmawan BS, Sri Rezeki SH

Abstract

Background Asthma is the most common chronic respiratory illness in childhood. Its prevalence in Indonesia is 6.7 - 10%. Asthma influences growth, development and quality of life in affected children. Studies abroad have shown that children with asthma have a decreased quality of life (QoL), yet such data is limited in Indonesia.

Objective To assess quality of life of asthmatic children in Indonesia, the influence of sociodemographic and medical characteristics on QoL, and to compare child self-reporting to their parents' proxy-reporting.

Methods This descriptive analysis, cross-sectional study was conducted from May to July 2010. We assessed the quality of life of asthmatic children aged 2-18 years using the PedsQL™ 4.0 generic scale.

Results A total of 100 asthmatic children and their parents were included, with 43% of the subjects aged 8-12 years and a male to female ratio of 1.7:1. We observed that 26.8% of children who self-reported had impaired QoL, while 35% of children who reported by proxy had impaired QoL. In a multivariate analysis, we found the following characteristics to independently influence QoL: male gender (P 0.018 OR 0.26 95% CI 0.08 to 0.9) based on child self-report, and having partly controlled/uncontrolled asthma based on self-report and proxy-report (P 0.013 OR 6.24 95% CI 1.48 to 26.37 and P 0.018 OR 3.43 95% CI 1.24 to 10.05, respectively). There was good correlation between the self-report and the proxy-report on emotional and social functioning ($r > 0.5$), yet we found physical and school functioning to be weakly correlated ($r < 0.5$).

Conclusions We observed a relatively high (26.8-35%) impaired QoL in asthmatic patients. Parental assessment of their child's QoL was generally lower than the child's self-assessment. Male gender is a protective factor against impaired QoL, but having partly controlled/uncontrolled asthma is a risk factor for lower QoL. [Paediatr Indones. 2011;51:245-51].

Keywords: quality of life, children with asthma, prevalence

Asthma is the most common chronic respiratory illness in childhood. Its prevalence has increased over the last two decades, both in developed and developing countries.¹ Asthma prevalence in children worldwide varies from 2-30%, with the highest prevalences occurring in Australia, New Zealand, and England.² The prevalences of asthma among elementary and high school students in Indonesia are, 10% and 6.7%, respectively.³ Several studies of children with asthma in the USA have indicated that children with asthma and their families experience significant decreases in QoL.^{4,5}

The first widely-accepted definition of QoL was made in 1990 by Schipper and colleagues in Juniper states that QoL is determined by the functional effects of an illness and its consequent therapy, as perceived by the patient.⁶ Quality of life measurement is multidimensional; it is not restricted to physical or psychological effects of treatment. Health-related quality of life (HRQoL) reflects the individual's or family's view about his/her state of health during

From the Department of Child Health, Medical School, University of Indonesia/Cipto Mangunkusumo Hospital, Jakarta, Indonesia.

Reprint requests to: Yulia Wigoeno, MD, Department of Child Health, Medical School, University of Indonesia/Cipto Mangunkusumo Hospital, Jl. Salemba No. 6, Jakarta, Indonesia. E-mail: yulsmid@yahoo.com.ph

and/or after treatment.⁷ Varni JW⁸ developed an instrument to measure quality of life of children and adolescents with chronic illness. The Pediatric Quality of Life Inventory™ (PedsQL™) consists of generic and disease-specific core scales. The PedsQL™ 4.0 Generic Core Scales has been translated into several languages, including Bahasa Indonesia, with internal consistency reliability alpha coefficients of 0.82-0.88. It has been used in several local studies, however, the PedsQL™ 3.0 Asthma Module has not been translated into Bahasa Indonesia.⁹⁻¹¹ Because of this lack of translation and time constraints we used The PedsQL™ 4.0 Generic Scale version Bahasa Indonesia, the main language of Indonesia.

The aims of this study were to assess the QoL of asthmatic children, to assess the influence of sociodemographic and medical characteristics on QoL, and to compare QoL scores reported by the children and those reported by their parents.

Methods

We performed a cross-sectional study conducted at the Respiratory Clinic, Department of Child Health, Cipto Mangunkusumo Hospital, Jakarta, Indonesia, from May - July 2010. Participants were pediatric asthma patients who visited the Respiratory Clinic with their parents. Eligible subjects were children with asthma, aged 2-18 years, with literate parents. We excluded those with mental disorders, heart disease, tuberculosis, cancer, kidney problems, and physical limitations. We estimated that at least 96 asthmatic children were needed for this study.

Sociodemographic data including gender, age, parental educational status, socioeconomic status, household density, and family relationships (using FACES III) were collected from parents. Olson et al in Fischer et al developed an instrument to assess family relationship called FACES III (Family Adaptability and Cohesion Evaluation Scale III).¹² FACES III measures 2 main behavioral dimension of family, which are adaptability (10 questions) and cohesion (10 questions). Based on this instrument, there are 2 type of family adaptability (extreme and balanced) and 2 type of family cohesion (extreme and balanced). To determine family relationship, FACES III combines all types of family adaptability

and cohesion into: balanced (both family adaptability and cohesion are balanced), extreme (both family adaptability and cohesion are extreme), and mid-range (either family adaptability or cohesion was balanced and the other was extreme).

Medical data regarding duration of illness was obtained from medical records, while the level of asthma severity and control was determined by the attending physician at the clinic, based on the Global Initiative for Asthma Guidelines (2009) and the National Guidelines of Childhood Asthma (2004).^{13,14} This study was approved by the Medical Ethics Committee of Faculty of Medicine, University of Indonesia. Informed consent was obtained from the parents.

The PedsQL™ 4.0 Generic Core Scales (Generic Scales) is an instrument developed by Varni JW, used over the past 19 years, and published in 1998.⁸ It consists of 23 items categorized into 4 subscales: physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), and school functioning (5 items). It was designed for children and adolescents ages 2-18 years and is available in a self-report version for children/adolescents aged 5-18 years, or a proxy-report version for parents. A 5-point response scale is utilized in both the self-report for children aged 8-18 years and the parent proxy-report (0=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, 4=almost always a problem). To further increase the ease of use, the young child self-report version (ages 5-7 years) has a simplified, 3-point response scale (0=not at all a problem, 2=sometimes a problem, 4=often a problem), with each response choice anchored to happy/sad faces. Items were reverse-scored and linearly transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, 4=0). Therefore, a higher score indicated a better QoL. Scale scores were computed as the sum of the items divided by the number of items answered.

A comparison analysis between sociodemographic and medical characteristics and QoL score were measured by Chi-Square or Fisher test, and then by logistic regression. The correlation between the children's self-reports and the parents' proxy-reports was analyzed using Pearson or Spearman test. The SPSS version 11.5 for Windows was used for data analysis.

Results

A total of 100 children with asthma and their parents were included in our study. **Table 1** shows the characteristics of the subjects and their parents. The male to female ratio was 1.17:1. The age range was 2 - 17.9 years with a mean of 9.7 years, with 43% of the subjects aged 8-12 years. Most parents (mothers) were categorized into mid and high educational status and had a total monthly income above Jakarta's minimum wage. Sixty-eight percent of the subjects lived in crowded houses and 52% were categorized into a mid-range family type relationship. Eighty-seven percent of the subjects had been diagnosed with asthma for more than 1 year, and 82% had infrequent episodes of asthma. Most of the subjects (68%) had partly-controlled asthma, 31% had controlled asthma, and only 1% had uncontrolled asthma.

We found 26.8% of the asthmatic children had impaired QoL, based on self-reporting. However, this number increased to 35% in parents' proxy-reports. The mean total score obtained from the children's self-reports was 72.9 (SD 12.6), and that from parents' proxy-reports was 72.2 (SD 12.9). For both types of reports, the highest mean score was in social functioning and the lowest mean score was in school functioning. (**Figure 1**) The authors of the PedsQL™ survey instrument¹⁷ reported that children falling below one standard deviation were "at risk" for impaired QoL. Based on children's self-reports and parents' proxy-reports, there were 18 and 33 children, respectively, who fell below one standard deviation,

and 4 and 2 children, respectively, who fell below two standard deviations (**Figure 2**).

Table 1. Sociodemographic and medical characteristics (n=100)

Characteristic	Total	%
Child's gender		
Male	54	54
Female	46	46
Child's age subgroup (years)		
2 - 4	17	17
5 - 7	15	15
8 - 12	43	43
13 - 18	25	25
Parental education status		
Low	6	6
Mid	49	49
High	45	45
Family socioeconomic status		
Below minimum wage*	29	29
Above minimum wage*	71	71
Household crowding		
Crowded	68	68
Not crowded	32	32
Duration of illness (years)		
< 1	13	13
≥ 1	87	87
Family relationship		
Extreme	52	52
Mid-range	30	30
Balanced	18	18
Level of asthma severity		
Infrequent episodic	82	82
Frequent episodic	18	18
Persistent	0	0
Level of asthma control		
Controlled	31	31
Partly controlled	68	68
Uncontrolled	1	1

* minimum regional wage for Jakarta

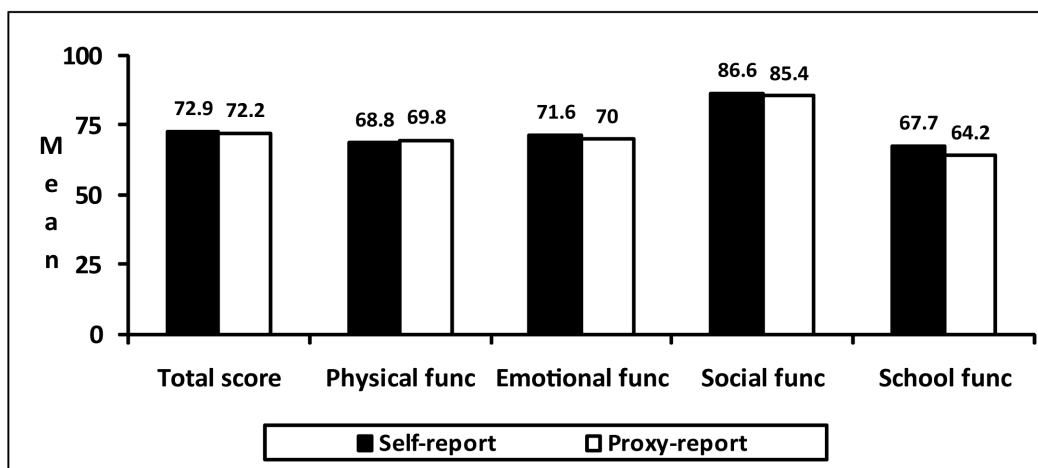


Figure 1. Mean total score and score of QoL domains based on self-report and proxy-report

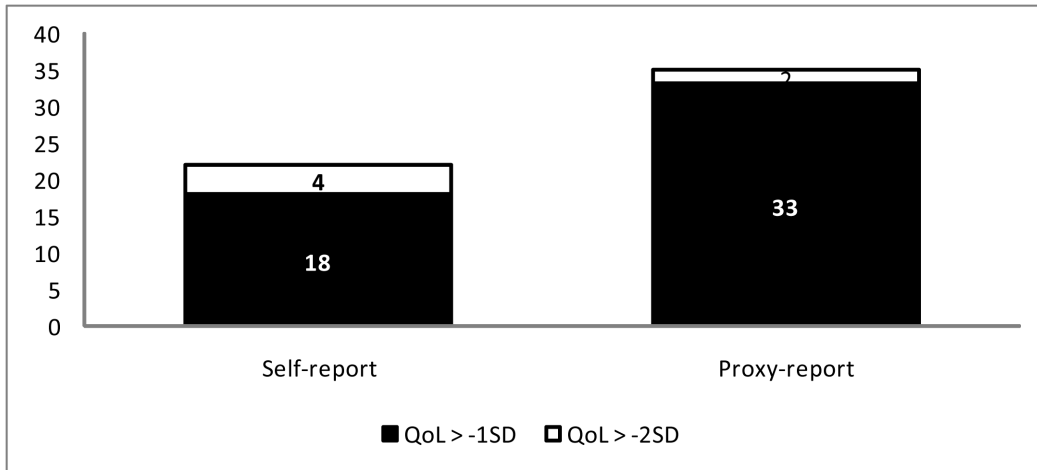


Figure 2. Level of disruption of quality of life based on self-report and proxy-report

Table 2. Correlation of self-report and proxy-report

Score of QoL	Mean	SD	p	R
Total score			<0.001	0.57
• Child	72.9	12.6		
• Parent	72.2	12.9		
Physical functioning			<0.001	0.49
• Child	68.8	14.8		
• Parent	69.8	16.1		
Emotional functioning			<0.001	0.63
• Child	71.6	19.2		
• Parent	70.0	20.0		
Social functioning			<0.001	0.50
• Child	86.6	14.1		
• Parent	85.4	14.4		
School functioning			<0.001	0.48
• Child	67.7	19.5		
• Parent	64.2	20.0		

Bivariate analysis on children’s self-reports showed a significant relationship between male gender and higher QoL ($P=0.022$, OR 0.27; 95% CI 0.08 to 0.85), whereas parents’ proxy-reports showed a significant relationship between the level of asthma control and QoL ($P=0.049$, OR 3.02; 95% CI 1.01 to 9.46). In multivariable regression analysis on children’s self-reports, the male gender ($P=0.018$, OR 0.26; 95% CI 0.08 to 0.9) and level of asthma control showed significant relationships with QoL, whereas parents’ proxy-reports showed no significant relationship with any characteristics except for the level of asthma control. Poor asthma control (uncontrolled/partly controlled), according to

children’s self-reports, increased the risk of impaired QoL by 6.2 times (OR 6.24, 95% CI 1.48 to 26.37). However, according to parents’ proxy-reports, this risk increased by 3.53 times (OR 3.53, 95% CI 1.24 to 10.05).

Parental proxy-reporting showed a lower total mean score of QoL than child self-reporting on almost all functions except physical functioning (Table 2). There was a good correlation between children’s self-reports and parental proxy-reports on total, emotional and social functioning scores ($r > 0.5$), yet physical and school functioning were weakly correlated ($r < 0.5$).

Discussion

Children aged 8-12 years old represented 43% of the subjects in our study. This data is in agreement with a report by the Indonesian Pediatric Association, stating that the peak asthma population is in elementary school children, accounting for 10% of asthmatics.³ We observed more males than females with asthma, with a male: female ratio of 1.17:1. A survey conducted in 16 European countries showed that girls have lower risk of developing asthma during childhood, but the risk becomes equal to that of males during puberty, and will increase by 1.4 - 5.9-fold after puberty. The age-related increased risk in developing asthma is caused by hormonal differences and airway diameter differences between the two genders.¹⁵

Most of the patients' mothers had medium or high education levels, which may have contributed to their actively seeking treatment for their children. Most of the subjects had infrequent episodes of asthma, but we found the majority (68%) of the subjects were partly controlled asthmatics. This contrast may be caused by the application of two different guidelines to classify the disease and disease control, the PNAAL 2004 and GINA 2009.^{13,14}

Our results showed that the mean QoL score of asthmatic children, according to self-reports, was 72.9 (SD 12.6), and that from parents' reports was 72.2 (SD 12.9). Mean total score in this study was similar to the report of Varni *et al.*^{16,17} Yet in their study, lower scores were found in all domains; in this study, the social functioning score was higher than theirs. Our higher social function score may be caused by the fact that most of the subjects (68%) lived in homes with a population density of less than 7 m². More family members who live in the same home with the child provide better social stimulation.

We found 18 (self-reports) and 33 (proxy reports) asthmatic children who required strict observation and frequent control. For these subjects, if there is no future improvement or a decrease in QoL, consideration should be made to change the management of their asthma. There were also 4 and 2 patients, according to children's and parents' reports, respectively, who required immediate changes in their asthma management. As a standard in determining QoL impairment for asthmatics, we used the assessment method of Varni *et al.*¹⁷ This standard also used by Susanto⁹ and Suharto¹⁸ in their studies because there is no standard QoL scores for healthy children in Indonesia.

A comparison analysis found that gender (self-reports) and level of asthma control (self and proxy-reports) significantly correlated with the QoL. Male gender was a protective factor (P 0.018 OR 0.26 95% CI 0.08 to 0.9), while poor asthma control (uncontrolled/partly controlled) was a risk factor for QoL impairment in asthmatic children. It is unclear why the male gender was a protective factor. Boys may be less bothered by their asthma. Children with good asthma control, regardless of the level of asthma severity, had good quality of life. Further study is required to determine the length of good asthma control that will improve quality of life.

Most of the subjects in our study (43%) were aged 8-12 years old. We found that age had no significant correlation with QoL. In contrast, Simon *et al.*¹⁹ reported a significant association between low QoL and the teen years. Their study reported that QoL starts to decrease by the age of 6-7 years in both genders, and will reach its lowest score by the age of 11-12 years for girls and 13-15 years for boys. By the age of 16-17 years, both girls and boys reported a slight increase.

The parental level of education, especially that of mothers, influences the rearing of children and the children's ability to interact. However, our study showed that there was no significant correlation between a mother's level of education and the QoL of her asthmatic child. Annett *et al.*²⁰ conducted a survey of 339 pairs of parents-children and concluded that the level of parents' education and the children's QoL also had no significant correlation ($p > 0.05$). Perhaps the mothers' level of formal education did not reflect their rearing practices or their knowledge of a disease. Mothers with low level of formal education, but who educated themselves with health information from our audiovisual media, may gain sufficient knowledge in dealing with asthma.

Some studies conducted locally and abroad stated that a higher socio-economic level significantly correlated with quality of life.^{18,19,21} A higher socio-economic level of the family may indicate better parental attention to children's health, as well as the ability to afford medication. In our study, we reported a different result; there was no significant correlation between socio-economic level and quality of life. This difference in our study may be because the majority of the subjects (71%) came from families with a total monthly income higher than the minimum wage of metropolitan Jakarta.

Suharto¹⁸ reported a significant positive correlation between the density of residents in the house and quality of life. They explained this result by arguing that a larger number of residents in a home created better socialization and child rearing, thus increasing the social functioning quality of life. Nonetheless, our study found that the density of residents in the home did not significantly correlate with quality of life, despite the high mean social functioning score.

The length of illness did not have a significant correlation with the quality of life in our study. Vila *et al*²² and Warschburger *et al*²³ stated that the length of illness in asthmatic children did not have a significant correlation with their quality of life. If the asthma was diagnosed early and the patient received optimal treatment, the frequency of attacks would decrease and lung function would increase, thus increasing the quality of life.²⁴

Children's ability to face problems is influenced by their surrounding environment. Supportive parents, harmonic families, and a conducive environment will help a child adapt to his health condition. Our study found that the type of family relations did not have a significant correlation with quality of life. Subjects with impaired quality of life in our study mostly came from an extreme type of family relation. It was caused by too strong or too weak adaptation ability and family emotional relations.

Annet *et al*²⁰ reported that quality of life was not affected by severity of the disease, but by the level of anxiousness. Some researchers emphasized the influence of asthma control on quality of life, the risk of exacerbations, and lifestyle improvement.²⁵⁻²⁸ Similarly, our study found that the severity of asthma did not significantly correlate with quality of life. Subjects with frequent or infrequent episodic asthma, with the same level of asthma control had a similar quality of life.

The quality of life of asthmatic children in our study was assessed from two different sources of information: patients and their parents. The parents tended to give lower marks than the patients themselves. Parson *et al*²⁹ reported that parents with children suffering from chronic conditions tend to give lower marks when asked about their child's quality of life compared to children themselves. Moreover, Eiser *et al*³⁰ found that parents who scored their own quality of life as low, tended to give lower marks to their child's quality of life. These findings suggest that parents project their feelings onto their view of their child's quality of life. Our study shows a fairly good correlation between the children's and the parents' reports, in accordance with other studies that compared parents' and children's reports.^{9,31}

In conclusion, the prevalence of impaired quality of life in asthmatic children based on self-reports was 26.8%, while that based on proxy-reports was 35%. The level of asthma control and male gender showed

a significant correlation to improved quality of life in asthmatic children. Children can be a trusted source of information in assessing their own quality of life when using an assessment test appropriate to their age and development.

References

1. Koenig JQ. Air pollution and asthma. *J Allergy Clin Immunol*. 1999;104:717-22.
2. O'Byrne P. GINA Workshop report update. c2004 [cited 2010 Jan 21]. Available from: <http://www.ginaasthma.org>
3. Epidemiologi asma. In: Rahajoe N, Supriyatno B, Setyanto DB, editors. Pedoman nasional asma anak. Jakarta: Pulmonologi Workgroup, Indonesian Pediatrician Association; 2004. p. 1-4.
4. Moonie SA, Sterling DA, Figgs L, Castro M. Asthma status and severity affect missed school days. *J School Health*. 2006;76:18-24.
5. Glazebrook C, McPherson AC, Mac-Donald IA, Swift JA, Ramsay C, Newbould R, et al. Asthma as a barrier to children's physical activity: implications for body mass index and mental health. *Pediatrics*. 2006;118:2443-9.
6. Juniper EF. How important is quality of life in pediatric asthma? *Pediatr Pulmonol Suppl*. 1997;15:17-21.
7. Eiser C. Children's quality of life measures. *Arch Dis Child*. 1997;77:350-4.
8. Seid M, Varni JW, Jacobs JR. Pediatric health-related quality-of-life measurement technology: intersections between science, managed care, and clinical care. *J Clin Psychol Med Settings*. 2000;7:17-27.
9. Susanto Y. Penilaian kualitas hidup anak yang menderita kanker dengan metoda PedsQL [dissertation]. [Jakarta]: University of Indonesia, Medical school; 2009.
10. Sitaresmi MN, Mostert S, Gundy CM, Sutaryo, Vermaan AJP. Health-related quality of life assessment in Indonesian childhood acute lymphoblastic leukemia. *Health Qual Life Outcomes*. 2008;6:1-8.
11. MAPI Research TRUST. Pediatric quality of life inventory. [cited Jan 21 2010]. available from: <http://www.mapi-trust.org>
12. Diagnosis dan klasifikasi. In: Rahajoe N, Supriyatno B, Setyanto DB, editors. Pedoman nasional asma anak. Jakarta: Pulmonologi Workgroup, Indonesian Pediatrician Association; 2004. p. 12-5.
13. Fischer J, Corcoran K. Instrument for families. In: Fischer J, Corcoran K, editors. Measures for Clinical Practice and Research. 4th ed. New York: Oxford University Press; 2007.

- p. 239-40.
14. Bateman ED. Pocket guide for asthma management and prevention in children 5 years and younger. [updated 2009, cited Jan 21 2010]. Available from: <http://www.ginaasthma.org>
 15. De Marco R, Locatelli F, Sunyer J, Burney P. Differences in incidence of reported asthma related to age in men and women: A retrospective analysis of the data of the European respiratory health survey. *Am J Respir Crit Care Med*. 2000;162:68-74.
 16. Varni JW, Burwinkle TM, Rapoff MA, Kamps JI, Olson N. The PedsQL™ in pediatric asthma: reliability and validity of the Pediatric Quality of Life Inventory™ generic core scales and asthma module. *J Behav Med*. 2004;27:297-318.
 17. Varni JW, Seid M, Skarr D, Burwinkle TM. Health Assessment Project—First Year Results, Data Insights Report No. 10 (Sacramento: Children's Health Assessment Project). October 2000 [cited 2010 August 18]. Available from: <http://www.mrmib.ca.gov/MRMIB/HFP/PedsQLYr2CHHS.pdf>
 18. Suharto S. Faktor-faktor yang berhubungan dengan kualitas hidup anak asma [dissertation]. [Semarang]: Diponegoro University, Medical School; 2005.
 19. Simon AE, Chan KS, Forrest CB. Assessment of children's health-related quality of life in the United States with a multidimensional index. *Pediatrics*. 2008;121:e118-26.
 20. Annet RD, Bender BG, DuHamel TR, Lapidus J. Factors influencing parent reports on quality of life for children with asthma. *J Asthma*. 2003;40:577-87.
 21. Apter AJ, Reisine ST, Affleck G, Barrows E, ZuWallack RL. The influence of demographic and socioeconomic factors on health-related quality of life in asthma. *J Allergy Clin Immunol*. 1999;103:72-8.
 22. Vila G, Hayder R, Bertrand C, Falissard B, Blic J, Simeoni MCM, et al. Psychopathology and quality of life for adolescents with asthma and their parents. *Psychosomatics*. 2003;44:319-28.
 23. Warschburger P, Busch S, Bauer CP, Kiosz D, Stachow R, Petermann F. Health-related quality of life in children and adolescents with asthma: results from the ESTAR study. *J Asthma*. 2004;41:463-70.
 24. Singh M, Mathew JL, Malhi P, Srinivas BR, Kumar L. Comparison of improvement in quality of life score with objective parameters of pulmonary function in Indian asthmatic children receiving inhaled corticosteroid therapy. *Indian J Pediatr*. 2004;41:1143-7.
 25. Chen H, Gould MK, Blanc PD, Miller DP, Kamath TV, Lee JH, et al. Asthma control, severity, and quality of life: quantifying the effect of uncontrolled disease. *J Allergy Clin Immunol*. 2007;120:396-402.
 26. Moy ML, Israel E, Weiss ST, Juniper EF, Dube L, Drazen JM, et al. Clinical predictors of health-related quality of life depend on asthma severity. *Am J Respir Crit Care Med*. 2001;163:924-9.
 27. Sullivan SD, Wenzel SE, Bresnahan BW, Zheng B, Lee JH, Pritchard M, et al. Association of control and risk of severe asthma-related events in severe or difficult-to-treat asthma patients. *Allergy*. 2007;62:655-6.
 28. Vollmer WM, Markson LE, O'Connor E, Frezier EA, Berger M, Buist AS. Association of asthma control with health care utilization: a prospective evaluation. *Am J Respir Crit Care Med*. 2002;165:195-9.
 29. Parson SK, Barlow SE, Levy SL, Supran SE, Kaplan SH. Health related quality of life in pediatric bone marrow transplant survivors: according to whom? *Int J Cancer Suppl*. 1999;12:46-55.
 30. Eiser C, Eiser JR, Stride CB. Quality of life in children newly diagnosed with cancer and their mothers. *Health Qual Life Outcomes*. 2005;3:29.
 31. Herjanic B, Reich W. Development of a structured psychiatric interview for children: agreement between child and parent on individual symptoms. *J Abnorm Child Psychol*. 1982;10:307-24.