

Health-related Quality of Life in Children with Chronic Diseases at Thammasat University Hospital

Paskorn Sritipsukho MD*,
Jureebhorn Poomsitong MD*

*Department of Pediatrics, Faculty of Medicine, Thammasat University, Pathumthani, Thailand

Objective: The present study aimed to examine the level of health related quality of life in pediatric patients with common chronic diseases who sought care at Thammasat University Hospital.

Material and Method: Cross sectional study in 134 patients aged 2-18, who visited department of pediatrics at Thammasat University Hospital were performed. Health related quality of life was evaluated using Thai version of Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL™ 4.0). For children aged 2-4 and 5-18, the questionnaire was answered by their guardians and by themselves and their guardians, respectively. The present study evaluated health related quality of life in four aspects: physical, emotional, social and school functioning. Points were then pooled and divided into three categories, namely total, physical health summary and psychosocial health summary scale scores. Each category could have a maximum score of 100.

Results: The mean total scale score from the questionnaire answering by guardians was highest in allergic rhinitis (77.6 ± 12.1). Physical and psychosocial scale scores were 81.7 ± 16.8 and 75.4 ± 12.5 . Total scale scores in asthma, chronic renal diseases, leukemia and lymphoma, and congenital heart defects were 73.8 ± 14.7 , 73.5 ± 18.9 , 64.5 ± 14.0 and 76.2 ± 19.6 , respectively. Cerebral palsy had the lowest total scale score of 27.1 ± 16.7 with physical and psychosocial scale scores of 16.9 ± 7.5 and 33.0 ± 23.2 , respectively. When patients answered the questionnaire by themselves, it was found that allergic rhinitis had the highest total scale score (79.5 ± 13.2). Total scale scores in asthma, chronic renal diseases, leukemia and lymphoma, and heart diseases were 75.2 ± 16.4 , 76.3 ± 16.2 , 70.5 ± 9.4 and 72.4 ± 22.7 , respectively. Cerebral palsy had the lowest scale scores in all categories, with total scale score of 46.1 ± 14.6 , physical scale score of 23.4 ± 6.6 and psychosocial scale score of 58.3 ± 18.8 .

Conclusion: Among chronic diseases, cerebral palsy has the lowest health related quality of life scale scores in all categories, namely total, physical and psychosocial health summary.

Keywords: Quality of life, PedsQL, Chronic disease

J Med Assoc Thai 2012; 95 (Suppl. 1): S8-S12

Full text. e-Journal: <http://jmat.mat.or.th>

Chronic illnesses are those lasting more than three months⁽¹⁾. The illnesses themselves or parent's anxiety affect daily activities of children of different ages and influence their lifestyles. The children need prolonged hospitalization or extensive and longer care than their peers. These directly affect the children, whether because of limitations in their activities, disease conditions, pain, discomfort or the management process. Their emotions and how they express themselves are also affected. Evaluation of health-related quality of life, therefore, is necessary and one

of very important health outcomes⁽²⁾. Current treatment goal has changed from not only focusing on the patients' lifespan or survival, but also improving the remaining health related quality of life in those diseases. Health-related quality of life is the outcome that can neither be observed clinically nor by laboratory tests alone. Evaluation of health outcomes is critical in understanding how diseases and treatments affect patients' lives, particularly when it is from the patients' point of view. This is consistent with holistic care concept, which emphasizes humanized public health.

Health-related quality of life focuses on patients' perspective on diseases and measures losses that affect the patients. To date, tools to evaluate quality of life have been greatly developed, including general questionnaires that assess and compare health-related quality of life in the community and in patients with

Correspondence to:

Sritipsukho P, Department of Pediatrics, Faculty of Medicine, Thammasat University, Pathumthani 12120, Thailand.
Phone: 0-2926-9759
E-mail: paskorn100@yahoo.com

different diseases and specific questionnaires that assess and compare health-related quality of life based on responses to specific diseases⁽³⁾. Health related quality of life evaluation is subjective; so the evaluation in children needs children-specific tools. Thai version of Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales (PedsQL™ 4.0) is a general quality-evaluating tool for children. It is a generic measure used for indicating health related quality of life in both ill and healthy children as well as for health related quality of life comparison among diseases, or between morbid and healthy groups. This questionnaire has good sensitivity and responsiveness and can also demonstrate the impact of diseases on each patient^(4,5). Its validity and reliability (0.83) also are trustworthy⁽⁶⁾. The present study aimed to examine the level of health-related quality of life in various aspects in pediatric patients with common chronic diseases who sought care at Thammasat University Hospital.

Material and Method

This was a cross sectional study in pediatric patients with chronic diseases, who visited Department of Pediatrics at Thammasat University Hospital during January 2009 to August 2010. Chronic diseases in the present study included cerebral palsy, asthma, allergic rhinitis, congenital heart defects, chronic renal diseases (nephrotic syndrome and lupus nephritis), leukemia and lymphoma. The patients were diagnosed and followed at specialized clinics. Exclusion criteria were critical patients and illiterate or poorly comprehensive guardians. The present study was approved by the human research ethic committee of Thammasat University and obtained the consent from guardians in 2-6-years-old patient cases and from patients and their guardians in 7-18-years-old patient cases.

Data collection and health related quality of life evaluation were performed in patients, who met inclusion criteria, by interviewing using general information questionnaire, the patient's disease questionnaire and Thai version of PedsQL™ 4.0. The questions were closed ones, comprising four core domains: physical, emotional, social and school functioning. For children aged 2-4 and 5-18, the questionnaire was answered by their guardians and by themselves, respectively. There were eight, five, five and five questions in the physical, emotional, social and school domains, respectively. Each question has multiple health related quality of life points to choose from, from 0-4 or the minimal to the maximal health related quality of life interference. The health related quality of

life-related points were then pooled and divided into three categories, namely physical health summary scale, psychosocial health summary scale and total scale scores. The questionnaire had been translated into Thai. The chosen scores were calculated using the PedsQL value with 0 = 100 points, 1 = 75 points, 2 = 50 points, 3 = 25 points, and 4 = 0 point. High mean total scale score indicated good health related quality of life.

The present study recorded data on computer using EpiData version 3.0 and analyzed them using STATA version 9.1, which calculated both total scores and scores of each category in each age range of the patients according to Thai version of the four-domain PedQL™ 4.0. Physical health summary, psychosocial health summary and total scale score are presented as mean ± SD.

Results

The present study was performed in 134 patients; 72 of which were boys, and 62 of which were girls. General patient information is shown in Table 1. The patients with chronic diseases, studied during January 2009 to August 2010, consisted of 21 asthmatics, 25 allergic rhinitis patients, 23 asthmatics with allergic rhinitis, 11 patients with leukemia and lymphoma, 29 patients with heart diseases, 12 patients with cerebral palsy and 13 patients with chronic renal diseases (nephrotic syndrome and lupus nephritis).

As regards the mean health related quality of life score obtained from guardians, it was found that Total scale scores were highest in allergic rhinitis and

Table 1. Patient and parental characteristics

Characteristics	Frequency (n = 134) (%)
Gender: Boy	72 (53.7)
Age in years: Mean ± SD	7.2 ± 3.8
Parental education level	
Primary school	26 (19.5)
Secondary school	67 (50.0)
College and university	41 (48.4)
Patient illness	
Asthma	44 (32.8)
Allergic rhinitis	48 (35.8)
Leukemia and lymphoma	11 (8.2)
Congenital heart disease	29 (21.6)
Cerebral palsy	12 (9.0)
Chronic renal disease	13 (9.7)

allergic rhinitis with asthma (77.6 ± 12 and 77.7 ± 12.7 , respectively). In allergic rhinitis, physical health summary scale score was 81.7 ± 16.8 , and psychosocial health summary scale score was 75.4 ± 12.5 . Cerebral palsy was the disease with the lowest total scale score (27.1 ± 16.7), with physical and psychosocial health summary scale scores of 16.9 ± 7.5 and 33.0 ± 23.2 , respectively. Leukemia had total scale score of 64.5 ± 14.0 , with physical and psychosocial health summary scale scores of 78.9 ± 23.2 and 56.8 ± 12.3 , respectively. Congenital heart defects had total scale score of 76.2 ± 19.6 while the scores in asthma and chronic renal diseases were similar (73.8 ± 14.7 and 73.5 ± 18.9 , respectively) as demonstrated in Table 2.

When the patients answered the questionnaire by themselves, it was found that Total scale score was highest in allergic rhinitis (79.5 ± 13.2) with physical and psychosocial health summary scale scores of 83.8 ± 13.1 and 74.1 ± 14.6 , respectively. Asthma with allergic rhinitis had total scale score of 79.2 ± 9.6 whereas patients with asthma only had less total scale score

(75.2 ± 16.4). Chronic renal diseases and heart diseases had total scale scores of 76.3 ± 16.2 and 72.4 ± 22.7 , respectively. That in leukemia and lymphoma was 70.5 ± 9.4 . The disease with the lowest total quality of life was cerebral palsy with total, physical health summary and psychosocial health summary scale scores of 46.1 ± 14.6 , 23.4 ± 6.6 and 58.3 ± 18.8 , respectively, as shown in Table 3.

Discussion

The results have shown that the health-related quality of life in children varies in different chronic diseases. The disease with the lowest total scale score has been cerebral palsy. Category-wise, the lowest physical health summary scale scores have been 16.9 ± 7.59 and 23.4 ± 6.6 as evaluated by the guardians and the patients, respectively. Total scale scores given by the patients themselves in asthma, congenital heart defects, renal diseases and allergic rhinitis have been 75.2 ± 16.4 , 72.4 ± 22.7 , 76.3 ± 16.2 and 79.5 ± 13.2 , respectively. These are rather low when compared with

Table 2. PedsQL scale scores of proxy reports among patients with chronic diseases

Diseases	Frequency (n = 134)	Health related quality of life Mean \pm SD		
		Physical Health	Psychosocial Health	Total Score Scale
Asthma only	21	78.1 ± 18.8	71.5 ± 14.7	73.8 ± 14.7
Allergic rhinitis only	25	81.7 ± 16.8	75.4 ± 12.5	77.6 ± 12.1
Asthma and allergic rhinitis	23	75.5 ± 19.8	78.8 ± 13.0	77.7 ± 12.7
Leukemia and lymphoma	11	78.9 ± 23.2	58.8 ± 12.3	64.5 ± 14.0
Congenital heart diseases	29	76.4 ± 23.3	76.4 ± 17.9	76.2 ± 19.6
Cerebral palsy	12	16.9 ± 7.5	33.0 ± 23.2	27.1 ± 16.7
Chronic renal diseases	13	77.6 ± 24.2	71.9 ± 17.3	73.5 ± 18.9

Table 3. PedsQL scale scores by self reports among pediatric patients with chronic diseases

Diseases	Frequency (n = 90)	Health related quality of life Mean \pm SD		
		Physical Health	Psychosocial Health	Total Score Scale
Asthma only	12	74.2 ± 20.3	78.5 ± 15.6	75.2 ± 16.4
Allergic rhinitis only	22	83.8 ± 13.1	74.1 ± 14.6	79.5 ± 13.2
Asthma and allergic rhinitis	18	79.8 ± 9.1	78.8 ± 11.4	79.2 ± 9.6
Leukemia and lymphoma	9	88.8 ± 15.1	57.5 ± 29.4	70.5 ± 9.4
Congenital heart diseases	15	70.6 ± 24.7	73.3 ± 22.9	72.4 ± 22.7
Cerebral palsy	2	23.4 ± 6.6	58.3 ± 18.8	46.1 ± 14.6
Chronic renal diseases	12	80.4 ± 22.5	74.9 ± 15.9	76.3 ± 16.2

those reported in normal students in other countries by Varni JW and colleagues⁽⁷⁾, who studied the health related quality of life in 2,437 students with total scale score of 80.64. Another study by Gkoltsiou K and colleagues⁽⁸⁾ in 567 students found total quality of life score of 81.10. Pongwilairat K et al⁽⁹⁾ evaluated health-related quality of life in children of school age with attention deficit disorder at pediatric psychiatric clinic, Maharaj Nakorn Chiang Mai Hospital with PedsQLTM questionnaire in children aged 8-12. The results found that children with attention deficit had significantly poorer health related quality of life than normal children ($p < 0.001$). It is clear that chronic diseases have impact on overall health related quality of life in pediatric patients.

Hallstrand TS et al⁽¹⁰⁾ studied quality of life in adolescents with mild asthma in three suburban western Washington schools, using PedsQLTM for patients with mild asthma and comparing with those with allergic rhinitis or exercise-induced bronchoconstriction. The present study found that the asthmatics had significantly lower overall quality of life as well as physical, emotional and academic scores than the other patients. However, the present study has found that the quality of life scores in the four domains have not been significantly different between asthma and allergic rhinitis patients. The present study result discrepancy could have come from different disease severity in selected patient groups. Leukemia and lymphoma have had total scale scores, evaluated by the guardians and the children, of 64.5 ± 14.0 and 60.8 ± 15.3 , respectively. Psychosocial domain has been the most affected with the scores of 58.8 ± 12.3 and 57.5 ± 29.4 by the guardians and the children, respectively. The most striking affected domain has been school functioning. Requiring chemotherapy and infection prophylaxis affected patients to take days off during the treatment.

Conclusion

Disease with the poorest health related quality of life is cerebral palsy; of which total, physical health summary and psychosocial health summary scale scores are all lower than those in the other chronic diseases. Leukemia and lymphoma have low school-functioning quality of life scores.

Acknowledgement

The present study was granted by the Faculty of Medicine, Thammasat University.

Potential conflicts of interest

None.

References

1. Wise PH. Developmental disabilities and chronic illness. In: Kliegman RM, Behrman RE, Jenson HB, Stanton BF, editors. Nelson textbook of pediatrics. 18th ed. Philadelphia: Saunders Elsevier; 2007: 187-97.
2. Bowling A. Concepts of functioning, health, well-being and quality of life. In: Bowling A, editor. Measuring health: a review of life measurement scales. 3rd ed. New York: Open University Press; 2005: 1-8.
3. Meltzer EO. Quality of life in adults and children with allergic rhinitis. *J Allergy Clin Immunol* 2001; 108 (1 Suppl): S45-53.
4. Varni JW, Burwinkle TM. The PedsQL as a patient-reported outcome in children and adolescents with Attention-Deficit/Hyperactivity Disorder: a population-based study. *Health Qual Life Outcomes* 2006; 4: 26.
5. Varni JW, Seid M, Knight TS, Uzark K, Szer IS. The PedsQL 4.0 Generic Core Scales: sensitivity, responsiveness, and impact on clinical decision-making. *J Behav Med* 2002; 25: 175-93.
6. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001; 39: 800-12.
7. Varni JW, Burwinkle TM, Seid M. The PedsQL 4.0 as a school population health measure: feasibility, reliability, and validity. *Qual Life Res* 2006; 15: 203-15.
8. Gkoltsiou K, Dimitrakaki C, Tzavara C, Papaevangelou V, Varni JW, Tountas Y. Measuring health-related quality of life in Greek children: psychometric properties of the Greek version of the Pediatric Quality of Life Inventory(TM) 4.0 Generic Core Scales. *Qual Life Res* 2008; 17: 299-305.
9. Pongwilairat K, Louthrenoo O, Charnsil C, Witoonchart C. Quality of life of children with attention-deficit/hyper activity disorder. *J Med Assoc Thai* 2005; 88: 1062-6.
10. Hallstrand TS, Curtis JR, Aitken ML, Sullivan SD. Quality of life in adolescents with mild asthma. *Pediatr Pulmonol* 2003; 36: 536-43.

คุณภาพชีวิตด้านสุขภาพของผู้ป่วยเด็กโรคเรื้อรังที่โรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติ

ภาสกร ศรีทิพย์สุโข, จุรีภรณ์ พุ่มศรีทอง

วัตถุประสงค์: เพื่อศึกษาระดับคุณภาพชีวิตด้านสุขภาพของผู้ป่วยเด็กโรคเรื้อรังที่พบบ่อยที่รับการรักษาที่โรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติ

วัสดุและวิธีการ: เป็นงานวิจัยสำรวจแบบตัดขวางในผู้ป่วยเด็กอายุ 2-18 ปี จำนวน 134 ราย ที่มารับการรักษาที่แผนกกุมารเวชกรรมโรงพยาบาลธรรมศาสตร์เฉลิมพระเกียรติ ประเมินคุณภาพชีวิตด้านสุขภาพโดยใช้แบบสอบถาม Pediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL™ 4.0) ฉบับภาษาไทย โดยให้ผู้ปกครองเป็นผู้ตอบแบบสอบถามสำหรับเด็กอายุ 2-4 ปี ให้ผู้ป่วยและผู้ปกครองเป็นผู้ตอบแบบสอบถามสำหรับเด็กอายุ 5-18 ปี เป็นการประเมินคุณภาพชีวิตใน 4 ด้านคือ ด้านกายภาพ ด้านอารมณ์ ด้านสังคม และด้านโรงเรียน และทำการรวมคะแนนคุณภาพชีวิตโดยแบ่งเป็น 3 กลุ่มคือคะแนนคุณภาพชีวิตโดยรวม คะแนนคุณภาพชีวิตด้านร่างกาย และคะแนนคุณภาพชีวิตด้านจิตสังคม มีคะแนนเต็มในแต่ละด้านคือ 100 คะแนน

ผลการศึกษา: พบว่าค่าเฉลี่ยของคะแนนคุณภาพชีวิตโดยที่ผู้ปกครองเป็นผู้ตอบแบบสอบถาม ในโรคภูมิแพ้จมูก มีคะแนนคุณภาพชีวิตโดยรวมมากที่สุดคือ 77.6 ± 12.1 คะแนนคุณภาพชีวิตด้านร่างกาย และคะแนนคุณภาพชีวิตด้านจิตสังคมคือ 81.7 ± 16.8 และ 75.4 ± 12.5 คะแนนคุณภาพชีวิตโดยรวมของโรคหอบหืด โรคไตเรื้อรัง โรคมะเร็งเม็ดเลือดขาวและมะเร็งต่อมน้ำเหลือง และโรคหัวใจพิการแต่กำเนิดเป็น 73.8 ± 14.7 , 73.5 ± 18.9 , 64.5 ± 14.0 และ 76.2 ± 19.6 ตามลำดับ โรคสมองพิการมีคะแนนคุณภาพชีวิตโดยรวมน้อยที่สุดคือ 27.1 ± 16.7 คะแนนคุณภาพชีวิตด้านร่างกายและคะแนนคุณภาพชีวิตด้านจิตสังคมเป็น 16.9 ± 7.5 และ 33.0 ± 23.2 ในส่วนของผู้ป่วยเป็นผู้ตอบแบบสอบถามประเมินคุณภาพชีวิตด้วยตนเองพบว่า โรคภูมิแพ้จมูกมีคะแนนคุณภาพชีวิตโดยรวมมากที่สุดคือ 79.5 ± 13.2 คะแนนคุณภาพชีวิตโดยรวมของโรคหอบหืด โรคไตเรื้อรัง โรคมะเร็งเม็ดเลือดขาว และโรคมะเร็งต่อมน้ำเหลือง และโรคหัวใจมีคะแนนคุณภาพชีวิตโดยรวมคือ 75.2 ± 16.4 , 76.3 ± 16.2 , 70.5 ± 9.4 และ 72.4 ± 22.7 ตามลำดับ ส่วนโรคสมองพิการมีคะแนนคุณภาพชีวิตต่ำสุดในทุกด้าน โดยคะแนนคุณภาพชีวิตโดยรวมเป็น 46.1 ± 14.6 คะแนนคุณภาพชีวิตด้านร่างกาย 23.4 ± 6.6 และด้านจิตสังคม 58.3 ± 18.8

สรุป: โรคสมองพิการเป็นโรคที่ผู้ป่วยเด็กมีคะแนนคุณภาพชีวิตด้านสุขภาพต่ำสุดคือ ซึ่งมีคะแนนคุณภาพชีวิตโดยรวมคุณภาพชีวิตด้านร่างกาย และด้านจิตสังคมต่ำกว่าโรคเรื้อรังอื่นในทุกๆ ด้าน
