ORIGINAL PAPERS

Adv Clin Exp Med 2015, **24**, 3, 487–495
DOI: 10.17219/acem/24991

ISSN 1899–5276

Réka Bodnár[1, 2, A–D], László Kádár[3, A, E], László Szabó[4, A, E], Márton Hernádi[1, B], Márió Mikóczi[1, C], Ágnes Mészáros[2, A, D, E]

Health Related Quality of Life of Children with Chronic Respiratory Conditions

[1] Department of Medicine, Heim Pal Children's Hospital, Budapest, Hungary
[2] University Pharmacy Institute of Pharmacy Administration, Semmelweis University, Budapest, Hungary
[3] Department of Pediatrics, Pulmonological Institute, Törökbálint, Hungary
[4] Department of Family Care Methodology, Institute of Health Science, Semmelweis University, Budapest, Hungary

Abstract

Background. In the management of chronic diseases, treatment approaches have changed in recent decades. Not only are clinical outcomes assessed but also the patients' perception of their quality of life has become an important aspect.
Objectives. The aim of our study was to compare the health-related quality of life (HRQoL) of children with cystic fibrosis (CF) to the HRQoL of asthmatic patients, to assess the level of agreement between parent proxy-report and child self-report and to measure the relationship between spirometry and HRQoL.
Material and Methods. 172 children (mean age: 11.61 ± 2.56 years) and their parents completed the questionnaire. The Hungarian version of the Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0) Generic Core Scale was used to assess HRQoL. Lung function was assessed *via* spirometry.
Results. Significantly lower PedsQLTM scores were measured for CF patients on the psychosocial health ($p < 0.05$), emotional functioning ($p < 0.005$) and school functioning ($p < 0.01$) subscales and the total scale ($p < 0.05$) from the children's self-report. The level of child-parent agreement was fair and moderate in both patient populations [intra-class correlation coefficient range (ICC) asthma = 0.29–0.37; ICCCF = 0.39–0.59, $p < 0.001$]. The relationship between forced expiratory volume in 1 second (FEV1) and the physical health subscale ($r = 0.49$, $p < 0.01$) was moderate in young (8–12 years) children and also teenagers (13–18 years), with CF ($r = 0.58$, $p < 0.05$) from self-report. We found weak, non-significant correlations between FEV1 and PedsQLTM subscales in children with asthma (8–12 years) ($r = –0.01–0.18$, ns.).
Conclusions. Children suffering from CF perceive their HRQoL as poorer than children with asthma. In asthmatic patients, it is not sufficient to evaluate clinical outcomes (FEV1); subjective HRQoL should be also estimated in the course of patient care (**Adv Clin Exp Med 2015, 24, 3, 487–495**).

Key words: quality of life, child, asthma, cystic fibrosis, spirometry.

Chronic diseases account for the majority of total disease burden both in adult and pediatric populations due to their mortality and morbidity, hence measuring quality of life is of major importance [1–4]. Traditionally, clinical outcomes such as spirometry are used to assess the progress of respiratory diseases and the effectiveness of treatment but these fail to evaluate the impact the disease has on children's everyday physical, social, emotional and school functioning as well as their perception of their chronic illness. In the last decade, gaining better overall disease control has become more important than measuring the patients' health status according to only objective parameters [5–7].

Nevertheless, disease prevalence, mortality and impact on health related quality of life (HRQoL) are different; consequently, their contribution to overall health burden is not similar [1–4]. In our cross-sectional, multi-center study, two chronic respiratory conditions were chosen, cystic fibrosis (CF) and bronchial asthma, each of which has a considerable

effect on the patient's HRQoL; in contrast to asthma, CF is a rare, genetic disease and CF management (use of antibiotics, dornase alfa inhalation, physiotherapy and lung transplantation) adds up to higher expenditures than the medical treatment of bronchial asthma [8–10]. Monitoring quality of life and incorporating patient reported outcomes (PRO) into daily treatment strategies could ensure optimal disease management and adequate health care utilization by the patient [11–13]. In routine clinical practice there is a need for valid, reliable and easy-to-use methods to evaluate quality of life. A simple way is to use a generic quality of life instrument, such as the PedsQL™ [1, 4]. The other important issue is to what degree is it possible to rely on the child's self assessment and how adequately can caregivers assess their children's quality of life.

Our aim was to assess HRQoL with a general quality of life questionnaire, to evaluate the degree of agreement of child self-report assessment and parent proxy-report and to analyze the relation between PRO and clinical status or opinion of the healthcare professional indicated by spirometry.

Material and Methods

Participants and Settings

Patients were enrolled at 5 outpatient pediatric units [Department of Pediatrics, Pulmonological Institute (Torokbalint); CF Unit, Heim Pal Children's Hospital, (Budapest); 1st Department of Pediatrics, Semmelweis University, (Budapest); Department of Pediatrics, Kaposi Mor Teaching Hospital, (Mosdos); Department of Pediatrics, Velkey Laszlo Pediatric Health Center, Borsod-Abauj-Zemplen County and University Teaching Hospital, (Miskolc)] in Hungary during the period September 2010 to October 2011.

Inclusion criteria included confirmed diagnosis of asthma or CF, age between 8–18 years, presence of one caregiver during the measurement. Children with acute respiratory infection, co-morbidity and mental retardation or incapacity to complete the questionnaires were excluded from participation. Children and parents completed the questionnaires simultaneously and separately.

One hundred ninety children were asked to participate in our study. Of these 8 (4.21%) had acute respiratory infection during the study, 4 (2.11%) patients suffered from other chronic illnesses (juvenile chronic arthritis, hydronephrosis, hypertonia, disorder of consciousness), 6 (3.16%) parents did not complete the HRQoL questionnaires. A total of 172 (90.53%) children with a confirmed diagnosis of CF or asthma were included for the final analysis.

Spirometry

Forced vital capacity (FVC), forced expiratory volume in 1 s (FEV_1) and forced expiratory flow at 25–75% of forced vital capacity ($FEF_{25–75\%}$) were measured, all expressed as the percentage of the best predicted value based on gender, age and height.

HRQoL

This was assessed with the Hungarian version of the Pediatric Quality of Life Inventory™ v. 4.0 (PedsQL™ 4.0) Generic Core Scale. PedsQL™ Generic Core Scale is a widely used generic HRQoL instrument for a range of children and teenagers from 2 to 18 years of age [1, 14–15].

The PedsQL™ 4.0 Generic Core Scale consists of an overall HRQoL score, the 23-item total scale score; an 8-item physical health subscale and a 15-item psychosocial health subscale. The psychosocial health subscale is composed of a 5-item emotional functioning subscale, a 5-item social functioning subscale and a 5-item school functioning subscale.

The PedsQL™ 4.0 Generic Core Scale is comprised of both a child self-report and parent proxy-report format. We used the child self-report (8–12, 13–18 years) and parent proxy-report (8–12, 13–18 years) versions. The questions refer to the past month [16–18].

The minimal clinically meaningful difference is a 4.4 total score change for child self-report and a 4.5 total score change for parent proxy-report [19].

Consent and Ethics Approval

Written informed consent was obtained from all parents and of patients over 14 years of age who agreed to participate in our study. The study has been approved by the Semmelweis University Regional and Institutional Committee of Science and Research Ethics (118/2010).

Our survey was performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

Statistical Analyses

Descriptive statistics (means, standard deviations and frequencies) were used to characterize the demographic variables, spirometry and scale scores for PedsQL™. Pearson's correlation coefficient (r) was used to observe the strength of the relationships. Differences between the 2 patient

groups were tested using the Pearson chi-square test for categorical variables and the Mann-Whitney *U* test for continuous variables.

The significance level considered was $p \leq 0.05$. Correlation coefficients (r) are defined as weak, if $r < 0.3$, moderate if $r = 0.3–0.7$ and strong if $r > 0.7$ [20].

The agreement between child self- and parent proxy-report on the PedsQL^{TM} 4.0 was assessed using intra-class correlation coefficients (ICC). ICC ≥ 0.80 is usually taken as evidence that a scale is highly reliable between the rates [21]. ICC can be interpreted as follows: ≤ 0.40 indicates poor agreement; 0.41–0.6 indicates moderate agreement; 0.61–0.8 indicates good agreement and ≥ 0.81 indicates excellent agreement [22].

PedsQL^{TM} scores were analyzed across two age groups (children 8–12 years and teenagers 13–18 years) using ANOVA.

Statistical analyses were performed using Statistical Package for the Social Sciences for Windows v. 15.0 (SPSS 15.0).

Results

Sample Characteristics

One hundred seventy two children and their parents joined our study. The mean age of the patients was 11.6 ± 2.56 years (range: 8.0–18.0 years), 54.7 % were male. 78.9% of the parents were mothers, the parents' mean age was 38.9 ± 6.02 years (range: 26.0–62.0 years). The response rate was over 97%.

The characteristics of the children and their parents are summarized in Table 1. Significant differences were found between the two disease groups in gender, FVC, FEV_1 and $FEF_{25–75\%}$ values. A significantly higher proportion of patients (40.5% vs. 18.3%) were hospitalized with cystic fibrosis ($p \leq 0.005$). We observed more frequent passive smoking among asthmatic patients than in the CF patient group (29.2% vs. 10.3%, $p < 0.05$). Parents' educational level was similar in the 2 patient groups (Table 1).

Table 1. Participant characteristics (n = 172)

	Asthma (n = 133)	**Cystic fibrosis (n = 39)**	**p-value**
Patient Age in years, mean ± SD[a]	11.5 ± 2.5	11.8 ± 2.8	0.71[1]
Gender, n (%) male	83 (62.4%)	11 (28.2%)	**0.001**[2]
FVC[b](%), mean (range)	109.3 (78.0–162.0)	92.1 (33.0–136.0)	**0.001**[1]
FEV_1[c](%), predicted, mean (range)	100.7 (65.0–139.0)	80.6 (24.0–121.0)	**0.001**[1]
$FEF_{25–75\%}$[d](%), mean (range)	85.8 (37.0–166.0)	64.6 (7.0–124.0)	**0.001**[1]
MMAS-8[e] score, mean (range)	6.4 (3.0–8.0)	6.0 (1.0–8.0)	0.69[1]
Hospitalization Yes, n (%)	24 (18.3)	15 (40.5)	**0.005**[2]
Parent Mother n (%)	104 (78.8)	31 (79.5)	0.93[2]
Education Primary school n (%) High school n (%) College degree or beyond n (%)	 36 (27.5) 62 (47.3) 33 (25.2)	 10 (25.6) 17 (43.6) 11 (28.2)	0.31[2]
Chronic diseases Yes, n (%)	30 (23.1)	6 (15.4)	0.30[2]
Smoking Yes, n (%)	38 (29.2)	4 (10.3)	**0.02**[2]

[a] SD – standard deviation.
[b] FVC – forced vital capacity.
[c] FEV_1 – forced expiratory volume in 1 s.
[d] $FEF_{25–75\%}$ – forced expiratory flow at 25–75% of forced vital capacity.
[e] MMAS-8 – morisky medication adherence scale 8-Item.
[1] Mann-Whitney U test.
[2] Pearson χ^2 test.

Comparison of PedsQL™ Scores of the Different Patient Groups

Table 2 presents mean PedsQL™ scores. We found significantly lower total PedsQL™ scores in all domains except physical and social functioning in CF children compared to asthma with the child self-report perspective and the measured difference was clinically significant. In the case of the parent proxy-report, we could not detect any significant differences between the two patient groups.

Internal consistency coefficients for each domain were calculated using the Cronbach α. The reliability coefficients ranged from r = 0.88 to 0.93 (Table 2).

Comparing the HRQoL of asthmatic and CF patients in age groups with child self-report, as shown in Table 3; in our young (8–12 years) patients we observed a significantly lower score only on the school functioning subscale among CF patients ($p < 0.01$). In teenagers (13–18 years), significant differences were detected between PedsQL™ psychosocial health ($p < 0.05$), emotional functioning ($p < 0.05$) and total scale did not ($p < 0.05$). The results presented in Table 3 did not show any signifcant differences for the parent proxy-report in both age groups across disease groups.

Parent-Child Agreement

Intra-class correlation coefficients (ICC) between the child self-report and parent proxy-report are presented in Table 4. A significant agreement between dyads (proxy and child self-report) was observed across all scales ($p < 0.001$). The level of agreement between child self- and proxy-report was poor in the case of asthma (ICCasthma = 0.29–0.37) and was moderate in CF patient (ICCCF = 0.39–0.59).

Correlation Between PedsQL™ Child Self-Report and Spirometry

To evaluate the clinical utility of the PedsQL™, correlations were calculated between the scores of the PedsQL™ and spirometry parameters (FVC, FEV_1 and FEF 25–75%), correlation rates are summarized in Table 5. In the case of CF, we found mainly moderate correlations between the HRQoL data and spirometry. In the case of asthma, interestingly, we found negative weak correlations in our younger patients between FEF 25–75% and the psychosocial health subscale ($r = -0.26$, $p < 0.05$), the emotional functioning subscale ($r = -0.23$, $p < 0.05$), the school functioning ($r = -0.32$, $p < 0.01$), the total scale score ($r = -0.23$, $p < 0.05$); between the school functioning subscale and FEV_1 ($r = -0.26$, $p < 0.05$). In the case of the parent proxy-report, significant correlations were found only between the CF patients' physical score and FVC ($r = 0.58$), FEV_1 ($r = 0.54$) and $FEF_{25–75\%}$

Table 2. Comparison of mean PedsQL™ Generic Core Scale scores of children with asthma to those of children with cystic fibrosis

[a]PedsQL™ subscales	Asthma			Cystic fibrosis			p-value*
	number	mean ± SD[b]	Cronbach α	number	mean ± SD	Cronbach α	
Child self-report							
Physical health	133	79.14 ± 14.95	0.88	39	72.92+17.42	0.93	0.061
Psychosocial health	133	80.58 ± 13.58	0.88	39	75.34 ± 13.96	0.92	**0.028**
Emotional function	133	78.59 ± 17.59	0.89	39	70.38 ± 17.30	0.92	**0.005**
Social functioning	133	84.96 ± 18.40	0.89	39	85.00 ± 16.58	0.93	0.778
School functioning	133	78.30 ± 15.33	0.88	39	70.51 ± 14.63	0.93	**0.002**
Total score	133	80.22 ± 13.04	0.88	39	74.70 ± 13.89	0.92	0.023
Parent proxy-report							
Physical health	129	71.12 ± 16.48	0.89	39	70.03 ± 22.53	0.92	0.859
Psychosocial health	129	72.22 ± 14.80	0.88	38	73.89 ± 15.24	0.92	0.728
Emotional function	129	67.26 ± 19.61	0.89	38	69.87 ± 21.54	0.93	0.461
Social functioning	129	80.11 ± 19.75	0.89	39	81.83 ± 16.19	0.93	0.844
School functioning	129	68.89 ± 18.75	0.89	39	69.20 ± 16.87	0.92	0.989
Total score	129	71.74 ± 13.90	0.88	39	73.47 ± 15.79	0.92	0.580

[a] PedsQL™ – Pediatric Quality of Life Inventory ™4.0 Generic Core Scales.
[b] SD – standard deviation.
* Mann-Whitney *U* test.

Table 3. Comparison of mean PedsQL™ Generic Core Scale scores of children with previous healthy control data of Berkes et al. [23]

[a]PedsQL™ subscales	Asthma		α[c]	Cystic fibrosis		α	P-value[d] (between asthma and CF)	Controls	
	number	mean ± SD[b]		number	mean ± SD			number	mean ± SD
Child self-report (8–12 years)									
Physical health	84	79.38 ± 15.03	0.86	27	73.84 ± 18.12**	0.93	0.22	157	82.32 ± 14.83
Psychosocial health	84	79.65 ± 14.75	0.86	27	76.17 ± 14.25	0.93	0.19	157	77.94 ± 14.66
Emotional functioning	84	78.42 ± 18.91*	0.87	27	71.67 ± 18.29	0.93	0.07	157	72.23 ± 17.74
Social functioning	84	82.44 ± 20.96	0.87	27	87.04 ± 14.95	0.93	0.48	157	84.39 ± 16.51
School functioning	84	78.08 ± 16.21	0.87	27	69.63 ± 15.93*	0.93	**0.009**	157	77.20 ± 17.28
Total score	84	79.60 ± 13.81	0.86	27	75.45 ± 14.02	0.93	0.16	157	79.47 ± 13.49
Parent proxy-report									
Physical health	83	71.15 ± 16.56*	0.88	27	73.73 ± 23.06*	0.93	0.29	159	81.44 ± 14.66
Psychosocial health	83	73.51 ± 13.77*	0.86	26	76.88 ± 15.94	0.93	0.30	159	76.61 ± 13.23
Emotional functioning	83	68.55 ± 18.65	0.88	26	74.04 ± 20.15	0.93	0.15	159	71.19 ± 16.72
Social functioning	83	79.53 ± 19.15*	0.87	27	84.07 ± 17.49	0.94	0.22	159	83.72 ± 14.85
School functioning	83	71.22 ± 17.96	0.88	27	71.25 ± 17.40	0.93	0.96	158	74.84 ± 16.92
Total score	83	72.42 ± 13.01***	0.86	27	76.47 ± 16.19	0.93	0.15	159	78.30 ± 12.23
Teen self-report (13–18 years)									
Physical health	49	78.73 ± 14.95*	0.91	12	70.84 ± 16.28***	0.90	0.12	100	83.15 ± 14.62
Psychosocial health	49	82.18 ± 11.24**	0.91	12	73.47 ± 13.72	0.89	**0.04**	100	77.14 ± 12.31
Emotional functioning	49	78.88 ± 15.25***	0.92	12	67.50 ± 15.15	0.89	**0.02**	100	67.95 ± 17.31
Social functioning	49	89.29 ± 11.86	0.92	12	80.42 ± 19.71***	0.91	0.15	100	88.85 ± 14.82
School functioning	49	78.67 ± 13.86*	0.92	12	72.50 ± 11.58	0.89	0.13	99	74.42 ± 15.53
Total score	49	81.30 ± 11.64	0.91	12	73.02 ± 14.03**	0.89	0.04	100	79.23 ± 11.82
Parent proxy-report									
Physical health	46	71.06 ± 16.52***	0.92	12	61.72 ± 19.68***	0.89	0.17	100	82.45 ± 15.22
Psychosocial health	46	70.26 ± 16.47***	0.91	12	67.40 ± 11.69***	0.90	0.48	100	78.71 ± 12.47
Emotional functioning	46	64.92 ± 21.23*	0.92	12	60.83 ± 22.55**	0.92	0.39	100	71.30 ± 17.04
Social functioning	46	81.17 ± 20.96***	0.91	12	76.77 ± 11.92***	0.91	0.20	100	89.30 ± 14.69
School functioning	46	64.70 ± 19.60***	0.92	12	64.58 ± 15.29***	0.90	0.89	99	75.43 ± 16.06
Total score	46	70.49 ± 15.45***	0.91	12	66.71 ± 13.01***	0.89	0.31	100	79.99±11.80

[a] PedsQL™ – Pediatric Quality of Life Inventory ™4.0 Generic Core Scales.
[b] SD – standard deviation.
[c] Cronbach α.
[d] Mann-Whitney *U* test.

* significance level at $p < 0.05$ compared to healthy controls.
** significance level at $p < 0.01$ compared to healthy controls.
*** significance level at $p < 0.001$ compared to healthy controls.

Table 4. Intra-class correlation coefficients between PedsQL™ 4.0 Generic Core Scales for parent proxy-report and child self-report in different patient groups

Patient groups	Physical health	Psychosocial health	Emotional functioning	Social functioning	School functioning	Total score
Asthma (n = 133)	0.35	0.34	0.29	0.31	0.33	0.37
Cystic fibrosis (n = 39)	0.59	0.47	0.39	0.39	0.42	0.47

All correlations are significant at the $p < 0.001$ level.

Table 5. Pearson correlation coefficients between parameters of spirometry and PedsQL™ 4.0 Generic Core Scales in different diagnostic groups

[a]PedsQL™ subscales	Asthma			Cystic fibrosis		
	FVC[b]	FEV_1[c]	$FEF_{25-75\%}$[d]	FVC	FEV_1	$FEF_{25-75\%}$
Child self-report (8–12 years)						
Physical health	0.01	–0.01	–0.08	0.46*	0.49**	0.43*
Psychosocial health	–0.59	–0.18	**–0.26***	0.34	0.31	**0.40***
Emotional functioning	–0.05	–0.18	**–0.23***	0.17	0.15	0.26
Social functioning	0.03	–0.03	–0.10	0.37	0.31	0.30
School functioning	–0.14	**–0.26***	**–0.32****	0.29	0.30	**0.43***
Total score	–0.05	–0.15	–0.23*	0.35	0.31	0.36
Parent proxy-report (8–12 years)						
Physical health	–0.03	0.14	0.15	0.58**	0.54**	0.43*
Psychosocial health	–0.04	0.06	0.034	0.30	0.30	0.29
Emotional functioning	–0.12	–0.04	–0.03	0.38	0.37	0.34
Social functioning	0.08	0.13	0.07	0.19	0.22	0.21
School functioning	–0.05	0.08	0.06	0.11	0.12	0.17
Total score	–0.02	0.14	0.12	0.41*	0.41*	0.37
Child self-report (13–18 years)						
Physical health	0.18	0.04	–0.12	0.29	0.58*	0.70*
Psychosocial health	0.06	–0.13	–0.22	0.14	0.36	0.34
Emotional functioning	0.09	–0.09	–0.18	–0.14	0.12	0.29
Social functioning	0.08	–0.09	–0.15	0.28	0.43	0.28
School functioning	–0.04	–0.16	–0.22	0.20	0.40	0.33
Total score	0.11	–0.08	–0.20	0.17	0.43	0.46
Parent proxy-report (13–18 years)						
Physical health	0.11	–0.03	–0.13	0.43	0.43	0.20
Psychosocial health	–0.05	–0.10	–0.10	0.24	0.04	–0.29
Emotional functioning	0.02	–0.11	–0.20	0.14	–0.08	–0.30
Social functioning	0.05	0.04	0.02	0.26	0.06	–0.34
School functioning	–0.20	–0.17	–0.06	0.14	0.16	0.04
Total score	–0.01	–0.09	–0.12	0.27	0.17	–0.08

* $p < 0.05$ (2-tailed).
** $p < 0.01$ (2-tailed).
[a] PedsQL™-Pediatric Quality of Life Inventory™ 4.0 Generic Core Scales.
[b] FVC –Forced Vital Capacity.
[c] FEV_1 – Forced Expiratory Volume in 1 s.
[d] $FEF_{25-75\%}$ – Forced Expiratory Flow at 25–75% of forced vital capacity.

(r = 0.43) and between the total score and spirometry parameters.

In our teenagers (13–18 years), we found significant relationships only in CF, which was moderate between the physical health subscale and FEV_1 (r = 0.58, $p < 0.05$) and $FEF_{25–75\%}$ (r = 0.70, $p < 0.05$) by the child self-report.

Hungarian healthy controls' general PedsQL™ data was previously assessed by Berkes et al. The data is summarized in Table 3 [23].

Discussion

HRQoL deterioration compared to the general population of the two chronic diseases was evaluated, both with child self-assessment and parent proxy-report. In pediatric conditions it is widely discussed whether to ask the patient him- or herself or rather the caregiver, in order to be able to evaluate disease progress and HRQoL [24–26].

Our results demonstrate that both asthma and CF have a substantial impact on the child's HRQoL. As expected, patients with CF perceive their HRQoL as poorer on psychosocial health, and expressively on the emotional functioning and school functioning subscales and on the total scale score, than children with asthma assessed with the child self-report.

In the 8–12 year-old age group, HRQoL is deteriorated mainly on the school functioning subscale in patients with CF. In the older age group, teenagers (13–18 years) suffering from CF, life with significantly poorer HRQoL regarding all psychosocial subscales (except school functioning and social functioning) and the total scale of the PedsQL™ than teenagers with asthma measured by child self-report. This could be explained by the phenomenon that younger children do not completely understand their illness yet, but teenagers do realize the essence of their disease. Teenagers with CF favor their healthy friends, so they would like to live a sterling life but they need to recognize that they have limitations on account of their physical condition, their lung function, and they also have to care about their daily obligatory inhalation therapy. None of these impact on asthmatic teenagers; it is well documented in the literature that children with CF usually spend more time on their treatment [27–28]. Children suffering from asthma can live roughly normal lives if their asthma is well controlled. They could only face some limitations on physical functioning, and with physical education. Their HRQoL may deteriorate if they have an exacerbation but not permanently on a day to day basis, in contrast to CF, which is a progressive disease with a continually decreasing lung function and physical condition.

Measuring HRQoL with parent proxy-report in both age groups (8–12 and 13–18 years), we could not find any statistically or clinically significant differences. In a previous publication, the age of the child was identified as a factor affecting the level of parent-child agreement, healthy children of an older age have the ambition to declare autonomy and so cause higher disagreement between parents and children [24, 29]. Nevertheless, parents, who are outsiders, have just some impressions of how is it to live with a chronic respiratory disease in childhood. From an external viewpoint, an exacerbation in asthma could be frightening and parents might consequently underestimate their child's HRQoL. Caregivers of CF patients, who know better the progress of their child's illness, have a better understanding of their child's limitations and they are used to this condition; hence they are more likely to overestimate their child's HRQoL. This might be the reason why parents of asthmatic children perceive their child's HRQoL similarly to the way CF patients' parents do. Previous publications have highlighted the importance of regular communication directly to the children and adolescents about their illness and the fact that caregivers cannot completely reflect the self-estimation of their child's HRQoL [2, 24–26]. On the other hand, if parents are self-confident regarding the management of their children's disease, besides leading to improved QoL of the child, at the same time it could result in more rational health care utilization as well.

Concerning the agreement of the patient reported outcomes and the clinical outcomes, our results suggest a generally weak correlation between spirometry and HRQoL in children with asthma.

The weak, negative correlations observed between spirometry and PedsQL™ scores in asthmatic children are interesting since clinicians assess their patients' health status mainly according to spirometry in routine care. Our survey highlighted that decreased lung function could bring on poorer HRQoL of CF patients; a non-linear relationship was found between asthma patient's HRQoL and spirometry. Clinicians could not estimate which domain of HRQoL is deteriorated in patients with asthma on the basis of the spirometry.

In contrast to asthma, in CF we measured moderate correlations between physical health and spirometry parameters in both age groups from the child self-report. Therefore in the course of asthma care it is difficult to conclude how the patient is feeling only based on spirometry. As our results show, a child having good lung function could live

with a poor HRQoL or vice versa. Hence clinicians should assess both lung function and quality of life, estimating their patients' objective and subjective parameters together.

It is known that children with asthma might live with poor HRQoL even if they have good lung function. Since they are stigmatized or because they are afraid of exacerbations, using reliever medications in public could be a sticky affair. Our discrepant associations were similar to the observations of Juniper et al. in pediatric asthma [3]. Another study identified the impact of asthma on daily life as a stressor, which could increase emotional problems for children with asthma [30]. CF patients experience severe limitations day by day. If they have a better period without exacerbations, their lung function improves, having a direct positive impact on their HRQoL.

We found significant differences between healthy children's quality of life and the HRQoL of our patients. An interesting discrepancy was found between the HRQoL scores of children with asthma and the PedsQL^{TM} scores of healthy children. In the 8–12-year old age group, asthmatics perceived their HRQoL better than healthy children in the emotional functioning domain assessed with the child self-report in contrast to the parent proxy-report. In the 13–18-year old age group, according to child self-report, almost every aspect of the psychosocial domain was assessed with higher scores by children with asthma than healthy children. In CF we could not find this kind of difference. These aspects reflect that measuring HRQoL could be quite complex and different in childhood than in adulthood. Another explanation could be that children with asthma were excluded from our study if they had an exacerbation in the period of measuring. Therefore patients whose asthma was well-controlled took part in our survey and their HRQoL was quite better than healthy children's because they could compare their life with exacerbation or without. Healthy children could not imagine how much worse their life might be if they had to live with a chronic disease.

It is also important to determine who is adequate to perceive the child's HRQoL in the different chronic diseases with different characteristics. As our results suggest, not only the chronological age and the domain type of the questionnaire have an effect on the agreement between children's and parents' reports, but it also depends on the type of the disease.

Our study had some limitations. This was not a nationwide study, only a multicenter one. Our results from this cross-sectional study were not sufficient to highlight the importance of longitudinal, follow up measures.

In conclusion, PedsQL^{TM} is a useful instrument, it provides a better understanding of the aspects of the HRQoL of both asthma and CF and so it may help in treatment optimization collectively with the clinical parameters. In CF caregivers and the children assessed, the child's HRQoL was very similar, independently from the age, so clinicians could ask either the child or the caregivers, whereas in asthma it is not enough to assess HRQoL only from the child's perspective, since children could not perceive their HRQoL realistically in contrast to the caregivers'. Irrespective of the age group, in the course of holistic asthma care, not only respect of the clinical status is essential but also the HRQoL by parent proxy-report.

Acknowledgements. We would like to thank the children, the parents and the clinical staff of the Heim Pal Children's Hospital CF Unit, Pulmonological Institute of the Torokbalint Department of Pediatrics, Semmelweis University First Department of Pediatrics, Department of Pediatrics of the Kaposi Mor Teaching Hospital (Mosdos), Velkey Laszlo Pediatric Health Center of Borsod-Abauj-Zemplen County and the University Teaching Hospital Department of Pediatrics and to Mesko Attilane for her assistance with the statistical analysis. We are grateful to Dr. Andrea Berkes PhD who gave us free access to the mean HRQoL scores of the healthy Hungarian pediatric population. We are thankful for the support and valuable comments on English language and proof-reading of Chris Eberhardie, Honorary Principal Lecturer, Kingston University and St George's University, London. The quality of life questionnaire (PedsQL^{TM}) was developed by Dr. James W. Varni.

References

[1] **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, 800–812.

[2] **Quittner AL, Modi A, Cruz I:** Systematic review of health-related quality of life measures for children with respiratory conditions. Paediatr Respir Rev 2008, 9, 220–232.

[3] **Juniper EF:** How important is quality of life in pediatric asthma? Pediatr Pulmonol Suppl 1997, 15, 17–21.

[4] **Kuźniar T, Ślusarz R, Patkowski J:** Quality of life in patients with asthma. Adv Clin Exp Med 1999, 8, 2.

[5] **O'Byrne PM, Reddel HK, Eriksson G, Ostlund O, Peterson S, Sears MR, Jenkins C, Humbert M, Buhl R, Harrison TW, Quirce S, Bateman ED:** Measuring asthma control: a comparison of three classification systems. Eur Respir J 2010, 36, 269–276.

[6] **Bateman ED, Boushey HA, Bousquet J, Busse WW, Clark TJ, Pauwels RA, Pedersen SE:** Can guideline-defined asthma control be achieved? The Gaining Optimal Asthma ControL study. Am J Respir Crit Care Med 2004,170, 836–844.

[7] **Juniper EF, Bousquet J, Abetz L, Bateman ED:** Identifying 'well-controlled' and 'not well-controlled' asthma using the Asthma Control Questionnaire. Respir Med 2006, 100, 616–621.
[8] **Bedouch P, Marra CA, Fitzgerald JM, Lynd LD, Sadatsafavi M:** Trends in asthma-related direct medical costs from 2002 to 2007 in British Columbia, Canada: a population based-cohort study. PLoS One 7 (12):e50949.
[9] **Bahadori K, Doyle-Waters MM, Marra C, Lynd L, Alasaly K, Swiston J, FitzGerald JM:** Economic burden of asthma: a systematic review. BMC Pulm Med 2009, 9, 24.
[10] **Lieu TA, Ray GT, Farmer G, Shay GF:** The cost of medical care for patients with cystic fibrosis in a health maintenance organization. Pediatrics 1999, 103, e72.
[11] **Quittner AL:** Measurement of quality of life in cystic fibrosis. Curr Opin Pulm Med 1998, 4, 326–331.
[12] **Abbott J, Webb K, Dodd M:** Quality of life in cystic fibrosis. J R Soc Med 1997, Suppl 31, 37–42.
[13] **Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M:** Measuring quality of life in children with asthma. Qual Life Res 1996, 5, 35–46.
[14] **Varni JW, Seid M, Rode CA:** The PedsQL: measurement model for the pediatric quality of life inventory. Med Care 1999, 37, 126–139.
[15] **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, 175–193.
[16] **Chan KS, Mangione-Smith R, Burwinkle TM, Rosen M, Varni JW:** The PedsQL: reliability and validity of the short-form generic core scales and Asthma Module. Med Care 2005, 43, 256–265.
[17] **Varni JW, Limbers CA:** The PedsQL 4.0 Generic Core Scales Young Adult Version: feasibility, reliability and validity in a university student population. J Health Psychol 2009, 14, 611–622.
[18] **Varni JW, Burwinkle TM, Rapoff MA, Kamps JL, 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.
[19] **Varni JW, Burwinkle TM, Seid M, Skarr D:** The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr 2003, 3, 329–341.
[20] **Polgar S, Thomas S:** Correlation. In: Introduction to research in the health sciences. Eds: Polgar S, Thomas S, Churchill Livingstone, Melbourne 1995, 1st ed., 237–253.
[21] **Eiser C, Morse R:** Can parents rate their child's health-related quality of life? Results of a systematic review. Qual Life Res 2001, 10, 347–357.
[22] **Landis JR, Koch GG:** The measurement of observer agreement for categorical data. Biometrics 1977, 33, 159–174.
[23] **Berkes A, Varni JW, Pataki I, Kardos L, Kemeny C, Mogyorosy G:** Measuring health-related quality of life in Hungarian children attending a cardiology clinic with the Pediatric Quality of Life Inventory. Eur J Pediatr 2010, 169, 333–347.
[24] **Davis KJ, Disantostefano R, Peden DB:** Is Johnny wheezing? Parent-child agreement in the Childhood Asthma in America survey. Pediatr Allergy Immunol 2011, 22, 31–35.
[25] **Britto MT, Kotagal UR, Chenier T, Tsevat J, Atherton HD, Wilmott RW:** Differences between adolescents' and parents' reports of health-related quality of life in cystic fibrosis. Pediatr Pulmonol 2004, 37, 165–171.
[26] **Riley AW:** Evidence that school-age children can self-report on their health. Ambul Pediatr 2004, 4 371–376.
[27] **Ziaian T, Sawyer MG, Reynolds KE, Carbone JA, Clark JJ, Baghurst PA, Couper JJ, Kennedy D, Martin AJ, Staugas RE, French DJ:** Treatment burden and health-related quality of life of children with diabetes, cystic fibrosis and asthma. J Paediatr Child Health 2006, 42, 596–600.
[28] **Abbott J, Gee L:** Quality of life in children and adolescents with cystic fibrosis: implications for optimizing treatments and clinical trial design. Paediatr Drugs 2003, 5, 41–56.
[29] **Cremeens J, Eiser C, Blades M:** Factors influencing agreement between child self-report and parent proxy-reports on the Pediatric Quality of Life Inventory 4.0 (PedsQL) generic core scales. Health Qual Life Outcomes 2006, 4, 58.
[30] **Vila G, Hayder R, Bertrand C, Falissard B, De Blic J, Mouren-Simeoni MC, Scheinmann P:** Psychopathology and quality of life for adolescents with asthma and their parents. Psychosomatics 2003, 44, 319–328.

Address for correspondence:

Réka Bodnár
Department of Medicine
Heim Pal Children's Hospital
Budapest
Hungary
E-mail: rekabodnar@ymail.com

Conflict of interest: None declared

Received: 3.04.2014
Revised: 22.07.2014
Accepted: 4.09.2014