

QUALITY OF LIFE AND OUTCOMES

Level of Parent–Asthmatic Child Agreement on Health-Related Quality of Life

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Background. Direct assessment of health-related quality of life (HRQoL) is necessary to understand the impact of a disease on patients' well-being and to evaluate clinical interventions. There is substantial debate in the literature on pediatric health outcomes concerning who is the most appropriate respondent when assessing children's HRQoL. **Objective.** To evaluate the level of agreement between child self-reports and parent proxy-reports concerning HRQoL in children with asthma. **Methods.** A total of 504 children with asthma and their parents who were referred to outpatient asthma clinic participated in this study. Subjects were divided into two age groups (4–7- and 8–14-year-olds). The DISABKIDS chronic generic measure—long form (DCGM-37), the DISABKIDS smiley measure (DSM), and the DISABKIDS condition-specific modules for asthma were used. The level of agreement between children and parents was evaluated using intra-class correlation coefficients and Bland–Altman analysis. **Results.** A satisfactory level of agreement between younger children and their parents except those with severe asthma with both methods was observed; the level of agreement in the older ones was moderate with the exception of general subscale. Asthmatic children's mean HRQoL scores were significantly lower than their parents for all subscales, except children with severe asthma in the older group, who stated lower HRQoL than their parents in most of the domains except those of Impact and Worry that were in close agreement. Fathers' assessment of HRQoL score was closer to their children's self-assessment in both groups. Families with higher family income showed a greater level of agreement. **Conclusions.** Our study illustrated that parents overestimate HRQoL of their children with asthma even though moderate agreement between child self-reports and parent proxy-reports on HRQoL was noticed. Fathers seem to be better proxy-reporters than mothers. Any evaluation of current approaches to measuring children's HRQoL needs to allow both parent and child to give their own perspective.

Keywords asthma, children, parents, proxy agreement, quality of life

INTRODUCTION

During the last decade there is a broad acceptance that healthcare must focus on patient-related outcomes such as health-related quality of life (HRQoL). This is particularly important in patients with chronic conditions where the treatment is directed toward symptom control rather than cure (1–3). In westernized countries, it is estimated that 5–10% of children have current symptomatic asthma, making this respiratory disorder the most common chronic disease in the pediatric population and one of the major causes of hospitalization among children (4–6).

QoL concerns an individual's satisfaction with all facets of life including physical, social, economic, and psychological well-being. HRQoL is a distinct component of this construct, focusing specifically on the impact of health on an individual's well-being and preferably assessed by self-report (7, 8). As a consequence of this shift in focus from survival to life quality, HRQoL has emerged as an important outcome measure in pediatrics in recent years (8).

The assessment of HRQoL, especially for these chronically ill children, is of importance not only for describing their actual situation and their health-care needs but also for evaluating clinical interventions (9). HRQoL is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment. The degree to which asthma influences HRQoL, however, depends on multiple factors, among which asthma control is likely to play a central role (10).

HRQoL measurement in children deals with special methodological problems, such as the differences in children's ability to understand at different ages and the variation of type of activities with age along with parental influence on child's perceptions (11). Moreover, there is substantial debate in the literature on pediatric health outcomes concerning who is the most appropriate respondent when assessing children's HRQoL (12–14). In general, the preferable source of health status information is the patient (7, 8, 11). In situations where children are unable or unwilling to respond to themselves, measurement of HRQoL is often obtained by parent proxy-report. However, the relationship between child self-reports and

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parent proxy-reports has been shown to be poor in some circumstances (8, 15). A limited number of studies have examined the degree of agreement between parent and child reports and have yielded mixed results. Some studies report high parent-child agreement, whereas others have found low agreement. The degree of agreement may depend on several factors, such as the domain being measured, age, gender, health status, and by a range of social and educational factors (3, 12, 13, 16, 17). The proxy method raises questions concerning which parent to use and whether mother and father reports can be considered equivalent (13, 18, 19).

Another potential problem is the question on how to interpret findings when parents and children's reports diverge. It is difficult to determine whose reports are more accurate because parent's report may be expected to have greater reliability, but child report may have more validity given the subjective nature of HRQoL (13, 18, 19). Consequently, agreement between parent and child reports of HRQoL may vary considerably (13, 18, 19). This study tries to explore the determinants of parent-child agreement concerning HRQoL.

METHODOLOGY

Aim

The primary aim of our study was to evaluate the level of agreement between child self-reports and parent proxy-reports concerning HRQoL in Greek children with asthma.

Participants

A total of 504 children and their parents attending outpatient asthma clinic of Penteli Children's Hospital in Athens participated in the study. They were recruited during a regular follow-up visit over the period from springtime 2005 to autumn 2007. All participating children had to be over 4 years and under 14 years of age. All the eligible children and their parents who attended the outpatient asthma clinic in randomly selected dates throughout the aforementioned time period were interviewed. Subjects were divided into two age groups: aged 4–7 years (group A) and the older ones 8–14 years (group B) matched to the age-appropriate research instruments.

Instruments

The instruments used for the study were the DISABKIDS chronic generic measure—long form (DCGM-37), the DISABKIDS smiley measure (DSM), and the DISABKIDS condition-specific modules for asthma along with a special form for demographic, asthma treatment, asthma symptoms, home environment, school environment, and clinical data (9, 10, 14).

The DCGM-37 consists of 37 Likert-scaled items assigned to six dimensions: independence, emotion, social inclusion, social exclusion, limitation, and treatment. They have showed satisfactory internal consistencies of these scales ranging from $\alpha = 0.79$ (social inclusion)

to $\alpha = 0.90$ (emotion). These six dimensions can be combined to produce a general score for HRQoL. DSM assesses general HRQoL in children between 4 and 7 developmental years. A five-point scale of smiley faces response scale was used (9, 14).

The condition-specific asthma questionnaire (DISABKIDS Asthma Module) consists of two domains: the impact domain (six items) concerning limitations and symptoms and the worry domain (five items) concerning fears related to asthma. The internal reliability for the impact domain is $\alpha = 0.83$ and for the worry domain it is $\alpha = 0.84$. Both DISABKIDS self-report versions (child version) and proxy versions (completed by one of their parents) were used (9, 10, 14).

Data Collection

Data were obtained through interviews with children and their parents. After obtaining informed consent from parent and older children, demographic data along with the data concerning home and school environment were collected. Next step was to complete the age appropriate DISABKIDS Instruments. Parents were not present during child's interview and vice versa.

A thorough history concerning asthma symptoms triggers and treatment was also taken and asthma severity assessment was based on symptoms, airflow obstruction, response to treatment, and treatment requirements during the last 6 months before the interview. The level of asthma control was assessed for the 4-week period before the interview. Spirometry and clinical examination were also performed before the interview. Asthma severity was defined according to the updated 2006 GINA guidelines that categorize asthma severity into four categories (intermittent, mild persistent, moderate persistent, severe persistent) and defines asthma control as controlled, partly controlled, and uncontrolled (5).

Data collection was performed after hospital's ethics committee's approval was granted. Parents and older children signed the informed consent for their participation and smaller children gave their oral consent. The study conformed fully with the declaration of Helsinki for biomedical research on human subjects (20).

Statistical Analysis

Intra-class correlation coefficients (ICC) with 95% confidence intervals (CI) and Bland-Altman plots with the corresponding limits of agreement (i.e., $\text{mean}(\text{Difference}) \pm 1.96 \text{ standard deviation}(\text{Difference})$) were used to assess the level of agreement in child's HRQoL scores between children and parents. The percentage of the differences within the aforementioned limits reflects the level of agreement between parents and children's aspect of HRQoL (21, 22). We also calculated ICCs and their 95% CI for categories of children's gender and age, parent's gender, father's and mother's age, place of residence, father's and mother's education, family income, and socioeconomical status, siblings, age at time of diagnosis, duration of the disease, number of visits to doctor per year, asthma severity, and asthma-estimated level

of control. In that case, continuous variables were separate into categories according to the median values. The ICCs were designated as follows: ≤ 0.40 —poor to fair agreement; 0.41–0.60—moderate agreement; 0.61–0.80—good agreement; and 0.81–1.00—excellent agreement.

Shapiro–Wilk test was used to evaluate the normality of all continuous variables. Independent two-sample *t*-test was used to evaluate the association between normally distributed continuous variables, with a categorical variable consisting of two groups. Paired sample *t*-test was used to assess the differences in scores between children and parents. A *p*-value of 5% was considered as statistically significant. All calculations were conducted using SPSS for Windows (v13, SPSS Inc., Chicago, IL, USA).

RESULTS

Group A consisted of 315 children (193 boys) with mean age 5.35 years, whereas Group B 189 (121 boys) with mean age 10.79 years. The majority of parents were mothers (~76% in both groups) and little more than half parents (54.37%) were university or technological institution graduates or had received additional training after high school. Table 1 illustrates descriptive sociodemographic characteristics of participants and their parents for the two age groups, respectively. Reliability as calculated by Cronbach's alpha was high (0.87–0.93) for all subscales.

Younger children (Group A) mean HRQoL score was 67.74 (± 18.44), but their parents showed a higher one (72.54 ± 11.73 , mean difference: -4.8 ; 95% CI: -6.51 to -3.1 ; $p < .001$) (Table 2). Girls rated HRQoL higher than boys (70.29 ± 17.73 vs. 66.13 ± 18.74 ; mean difference: 4.16; 95% CI: 0.03 to 8.29; $p = .048$). Furthermore, mothers rated lower HRQoL score than fathers (71.7 ± 11.71 vs. 75.23 ± 11.47 ; mean difference: -3.5 ; 95% CI: -6.56 –0.46; $p < .001$). Nevertheless, fathers' assessment of HRQoL score was closer to their children self-assessment as the mean ICC was significantly higher than mothers (0.581 and 0.448 respectively, see Table 3). Moreover, the Bland–Altman method showed high agreement of the HRQoL scores between parents and children (94%) (Figure 1).

There was a moderate level of agreement between parents and children in Group B for all subscales, with the exception of the general subscale. It was found that for the DCGM-37 General Score there was a clear difference between parents and their child's assessment (mean difference: -19.2 ; 95% CI: -20.48 to -17.91 ; $p < .001$). In particular, the ICCs range between 0.405 (i.e., inclusion subscale) and 0.720 (i.e., impact) with lower degree of agreement (0.244) for general subscale only. However, Bland–Altman analysis revealed high level of agreement between parents and children in all DCGM-37 Subscales and DCGM Asthma Module Scales (ranged from 96.8% (general score) to 97.9% (impact) (Figure 2). Table 2 illustrates the overall evaluation of all children's HRQoL

subscales as they were reported by the children and their parents and the mean differences between their ratings. The best agreement was found in the emotion, impact, and worry subscales.

A moderate agreement between younger children and their parents was observed (mean ICCs range: 0.359–0.393), with a marginal significance in children with severe asthma (mean ICC: 0.252; 95% CI: -0.122 –0.630; $p = .046$). Similarly, older ones with severe asthma showed lower HRQoL scores than their parents in most of the domains (mean ICCs range: -0.043 to 0.197) except the medication, impact, and worry that were in moderate agreement with their parents (Table 3).

Correlation between parents and children scores showed lower values in children with uncontrolled asthma in both groups; this was more pronounced in Group B in all subscales and general score (their ICCs ranged from -0.063 (medication) to 0.354 (worry)). Families with higher family income performed greater level of agreement (Table 4). The degree of agreement between parents and children regarding the children's HRQoL scores in association with different demographic or disease characteristics in both of the groups are presented in Tables 3 and 4.

Figure 3 illustrates DSM score (DSM-S) score in Group A ($n = 315$) as was stated by both parents and their children. Figure 4 illustrates DCGM-37 subscales score in Group B ($n = 189$) as was stated by both parents and their children. The black line indicates mean score in both figures.

DISCUSSION

We studied the degree of agreement between parents and their asthmatic children on HRQoL. In general, parents tend to overestimate their child's HRQoL but their overall agreement was satisfactory suggesting that children could be considered as a reliable reporter. Nevertheless, fathers were found to be better proxy reporters than mothers.

Poor agreement between carers and children ratings of HRQoL has been noted in several studies (2, 3, 9, 11, 15, 17). Children are often regarded as unreliable respondents and early attempts to rate their HRQoL were based on data provided by mothers. However, children and parents do not necessarily share similar views about the impact of illness, and therefore there are calls to involve children more directly in decisions about their own care and treatment (23).

In a systematic review about the relationship between children's HRQoL rating made by parents and children, authors concluded that parents and children agree upon more observable phenomenon such as level of physical activity, functioning and symptoms; conversely, poor agreement was observed in more subjective areas, such as social or emotional domains (19). In our study the best agreement was noticed in the emotion, impact and worry subscales indicating that even in subjective areas there was high agreement. This may be partly explained from the chronicity of illness since children with better asthma

TABLE 1.—Descriptive socio-demographic characteristics of children and their parents*.

	Overall (n = 504)	Group A, 4–7 year-old (n = 315)		Group B, 8–14 year-old (n = 189)	
		Boys n (%)	Girls n (%)	Boys n (%)	Girls n (%)
Number of Participants					
Age* (years)		193 (61.27)	122 (38.73)	121 (64.02)	68 (35.98)
BMI (kg/m ²)*	18.8 (3.4)	5.73 (1)	5.30 (1)	10.83 (2.05)	10.03 (1.97)
Age at time of Diagnosis* (years)	3.4 (2.5)	17.61 (3.02)	17.28 (3.08)	19.44 (4.14)	19.19 (3.17)
Duration of Treatment* (years)	3.8 (2.7)	2.35 (1.51)	2.49 (1.51)	4.80 (3.16)	5.22 (2.75)
Nationality		3.06 (1.32)	2.84 (1.58)	5.52 (3.57)	4.87 (3.28)
Greek	469 (93.05)	182 (94.3)	112 (91.8)	112 (92.6)	63 (92.6)
Other	35 (6.95)	11 (5.7)	10 (8.2)	9 (7.4)	5 (7.4)
Place of residence					
Urban	378 (75.00)	146 (75.6)	89 (73.0)	95 (78.5)	48 (70.6)
Rural	126 (25.00)	47 (24.3)	33 (27.0)	26 (21.5)	20 (29.4)
Siblings					
No	163 (32.34)	62 (32.1)	45 (36.9)	38 (31.4)	18 (26.5)
Yes	341 (67.66)	131 (67.9)	77 (53.1)	83 (58.6)	50 (73.5)
Doctor's visits per year					
<3	201 (39.88)	43 (38.2)	78 (61.8)	57 (47.1)	23 (33.8)
≥3	303 (60.12)	150 (61.8)	44 (38.2)	64 (52.9)	45 (66.2)
Asthma Severity					
Mild intermittent	52 (10.32)	15 (7.8)	19 (15.6)	14 (11.6)	4 (5.9)
Mild persistent	227 (45.04)	90 (46.6)	57 (46.7)	47 (38.8)	33 (48.5)
Moderate	201 (39.88)	79 (40.9)	40 (32.8)	52 (43.0)	30 (44.1)
Severe	24 (4.76)	9 (4.7)	6 (4.9)	8 (6.6)	1 (1.5)
Asthma Control	277 (54.96)				
Controlled	168 (33.33)	94 (48.7)	74 (60.7)	63 (52.1)	46 (67.6)
Partly controlled	59 (11.71)	73 (37.8)	36 (29.5)	40 (33.1)	19 (27.9)
Uncontrolled		26 (13.5)	12 (9.8)	18 (14.9)	3 (4.4)
		Fathers	Mothers	Fathers	Mothers
Number of Participants		74 (23.49)	241 (76.51)	46 (24.34)	143 (75.66)
Age* (years)		36.02 (5.27)	33.10 (5.01)	41.13 (5.18)	38.43 (4.77)
Educational status (years)					
Low-Basic (≤12 years)	274 (54.37)	46 (62.16)	131 (53.94)	29 (63.04)	68 (47.55)
High (>12 years)	230 (45.63)	28 (37.84)	110 (46.06)	17 (36.96)	75 (52.45)
Family income (€ per month)					
0–2000	181 (34.5)	135 (42.86)		46 (24.34)	
2001–4000	289 (57.4)	162 (51.43)		127 (67.20)	
>4000	34 (6.7)	18 (5.71)		16 (8.46)	
Family Socio-economical Status					
Low	53 (10.4)	21 (6.67%)		32 (16.93)	
Medium	349 (69.2)	217 (68.89%)		132 (69.84)	
High	102 (20.2)	77 (24.44%)		25 (13.23)	

Data are presented as n (%), except otherwise stated.

* Mean Values (standard deviations)

TABLE 2.—Evaluation of the degree of agreement between parents and children as concerns the scores of children's QoL.

	Children (mean ± SD)	Parents (mean ± SD)	Mean difference (95% CI)	ICC (95% CI)	P-value
Group A, 4–7 year-old (<i>n</i> = 315)					
Smiley's score	67.7 ± 18.4	72.5 ± 11.7	–4.8 (–6.51 to –3.1)	0.480 (0.371 – 0.573)	<.001
Group B, 8–14 year-old (<i>n</i> = 189)					
Independence	78.2 ± 16.5	83.9 ± 11.4	–5.75 (–7.75 to –3.75)	0.479 (0.318 – 0.604)	<.001
Physical limitation	53.3 ± 10.2	60.9 ± 12.7	–2.54 (–4.34 to –0.75)	0.405 (0.278 – 0.517)	<.001
Emotion	74.9 ± 21.5	75.1 ± 16.9	–0.17 (–2.43 to 2.09)	0.668 (0.581 – 0.740)	.890
Exclusion	86.4 ± 16.9	90.2 ± 11.8	–3.77 (–5.57 to –1.96)	0.607 (0.493 – 0.698)	<.001
Inclusion	67.8 ± 12.0	69.2 ± 9.1	–1.43 (–3.09 to 0.22)	0.405 (0.280 – 0.517)	<.001
Medication	67.1 ± 21.5	73.3 ± 20.5	–6.15 (–8.82 to –3.38)	0.586 (0.462 – 0.684)	<.001
General	57.9 ± 9.85	77.1 ± 11.3	–19.2 (–20.48 to –17.91)	0.244 (–0.077 to 0.574)	<.001
Impact	72.6 ± 21.4	71.6 ± 19.4	0.92 (–1.26 to 3.11)	0.720 (0.644 – 0.782)	<.001
Worry	67.6 ± 19.9	68.5 ± 19.1	–0.90 (–3.42 to 1.16)	0.596 (0.496 – 0.681)	<.001

Notes: ICC ≤ 0.40 poor to fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80 good agreement, and 0.81–1.00 excellent agreement. ICC, intraclass correlation coefficient; SD, standard deviation.

TABLE 3.—Evaluation of the degree of agreement between parents and children as concerns the scores of children's quality of life by different demographic or disease characteristics (group B (children aged between 8 and 14 years old ($n = 189$)))

Mean values ^a	N	Independence				Physical limitation				Emotion				Exclusion				Inclusion				Medication				Impact				Worry				General			
		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		ICC ^u		ICC ^a		95% CI	
Children's gender																																					
Female	68	0.503		0.370		0.637		0.730		0.637		0.733		0.320		0.566		0.735		0.601		0.239		0.566		0.735		0.601		0.239		0.566		0.735		−0.084 to 0.571	
Male	121	0.465		0.423		0.686		0.554		0.686		0.554		0.447		0.592		0.703		0.593		0.244		0.592		0.703		0.593		0.244		0.592		0.703		0.073–0.581	
Father's age																																					
<41	86	0.550		0.355		0.576		0.574		0.576		0.574		0.440		0.582		0.659		0.550		0.215		0.582		0.659		0.550		0.215		0.582		0.659		−0.076 to 0.539	
≥41	103	0.410		0.447		0.728		0.635		0.728		0.635		0.375		0.577		0.767		0.632		0.261		0.577		0.767		0.632		0.261		0.577		0.767		−0.078 to 0.601	
Mother's age																																					
<38	75	0.531		0.346		0.542		0.544		0.542		0.544		0.435		0.548		0.648		0.532		0.214		0.548		0.648		0.532		0.214		0.548		0.648		−0.083 to 0.533	
≥38	114	0.424		0.427		0.732		0.651		0.732		0.651		0.384		0.607		0.763		0.630		0.259		0.607		0.763		0.630		0.259		0.607		0.763		−0.072 to 0.602	
Parent's gender																																					
Female	143	0.446		0.365		0.647		0.609		0.647		0.609		0.373		0.549		0.683		0.544		0.233		0.549		0.683		0.544		0.233		0.549		0.683		−0.079 to 0.559	
Male	46	0.582		0.506		0.738		0.606		0.738		0.606		0.539		0.716		0.831		0.747		0.282		0.716		0.831		0.747		0.282		0.716		0.831		−0.072 to 0.644	
Place of residence																																					
Urban area	143	0.476		0.405		0.675		0.629		0.675		0.629		0.391		0.563		0.744		0.598		0.243		0.563		0.744		0.598		0.243		0.563		0.744		−0.077 to 0.574	
Rural area	46	0.502		0.406		0.647		0.545		0.647		0.545		0.444		0.665		0.623		0.593		0.250		0.665		0.623		0.593		0.250		0.665		0.623		−0.076 to 0.601	
Asthma severity																																					
Mild	18	0.186		0.023		0.269		0.389		0.269		0.389		0.306		0.246		0.273		0.167		−0.061		0.246		0.273		0.167		−0.061		0.246		0.273		−0.148 to 0.171	
intermittent																																					
Mild	80	0.466		0.325		0.667		0.577		0.667		0.577		0.318		0.623		0.695		0.515		0.216		0.623		0.695		0.515		0.216		0.623		0.695		−0.064 to 0.553	
persistent																																					
Moderate	82	0.450		0.446		0.680		0.588		0.680		0.588		0.516		0.469		0.724		0.606		0.222		0.469		0.724		0.606		0.222		0.469		0.724		−0.082 to 0.545	
Severe	9	0.194		0.197		0.096		0.132		0.096		0.132		−0.043		0.386		0.475		0.662		0.096		0.386		0.475		0.662		0.096		0.386		0.475		−0.050 to 0.459	
Level of asthma control																																					
Controlled	109	0.456		0.277		0.568		0.522		0.568		0.522		0.380		0.604		0.665		0.434		0.163		0.604		0.665		0.434		0.163		0.604		0.665		−0.055 to 0.466	
Partly controlled	59	0.238		0.221		0.667		0.534		0.667		0.534		0.237		0.399		0.661		0.604		0.215		0.399		0.661		0.604		0.215		0.399		0.661		−0.089 to 0.531	
Uncontrolled	21	0.330		0.191		0.224		0.245		0.224		0.245		0.295		−0.063		0.360		0.354		0.029		−0.063		0.360		0.354		0.029		−0.063		0.360		−0.086 to 0.230	
Mother's education																																					
Lower	75	0.477		0.320		0.625		0.549		0.625		0.549		0.430		0.607		0.646		0.539		0.222		0.607		0.646		0.539		0.222		0.607		0.646		−0.080 to 0.545	

Higher	68	0.479	0.472	0.706	0.669	0.383	0.567	0.775	0.641	0.267	−0.074 to 0.613
Father's education											
Lower	17	0.469	0.337	0.653	0.520	0.398	0.655	0.706	0.657	0.251	−0.073 to 0.595
Higher	29	0.487	0.449	0.681	0.688	0.413	0.536	0.726	0.551	0.240	−0.080 to 0.569
Siblings											
No	56	0.517	0.370	0.616	0.602	0.351	0.646	0.649	0.619	0.217	−0.065 to 0.559
Yes	133	0.464	0.421	0.686	0.610	0.425	0.559	0.755	0.586	0.258	−0.082 to 0.591
Children's age											
<10 (group B) <5 (group A)	85	0.460	0.350	0.654	0.557	0.412	0.588	0.735	0.631	0.247	−0.083 to 0.580
≥10 (group B) ≥5 (group A)	104	0.499	0.449	0.682	0.651	0.402	0.585	0.712	0.571	0.243	−0.073 to 0.581
Age at diagnosis											
<5 (group B) <2 (group A)	97	0.448	0.399	0.672	0.660	0.339	0.601	0.726	0.562	0.244	−0.086 to 0.570
≥5 (group B) ≥2 (group A)	92	0.517	0.413	0.666	0.550	0.479	0.568	0.714	0.631	0.246	−0.066 to 0.592
Duration of disease											
<1	20	0.455	0.384	0.635	0.571	0.639	0.531	0.665	0.413	0.259	−0.106 to 0.624
≥1	169	0.482	0.407	0.668	0.609	0.363	0.596	0.721	0.616	0.242	−0.073 to 0.576
Doctor's visits (per year)											
<3	80	0.413	0.357	0.708	0.588	0.391	0.513	0.730	0.687	0.229	−0.081 to 0.556
≥3	109	0.486	0.379	0.586	0.570	0.389	0.591	0.680	0.502	0.214	−0.073 to 0.538
Family income											
0–2000	46	0.507	0.443	0.600	0.496	0.276	0.554	0.702	0.595	0.240	−0.094 to 0.569
2001–4000	127	0.473	0.343	0.671	0.634	0.464	0.620	0.707	0.577	0.237	−0.071 to 0.572
>4000	16	0.484	0.693	0.825	0.787	0.303	0.472	0.833	0.729	0.301	−0.058 to 0.710
Socio-economical status											
High	32	0.455	0.190	0.595	0.644	0.224	0.496	0.765	0.644	0.141	−0.049 to 0.453
Medium	132	0.455	0.442	0.676	0.575	0.425	0.601	0.686	0.548	0.272	−0.081 to 0.610
Low	25	0.543	0.511	0.639	0.734	0.418	0.581	0.851	0.754	0.217	−0.090 to 0.568

^aICC ≤ 0.40 poor to fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80 good agreement, and 0.81–1.00 excellent agreement.

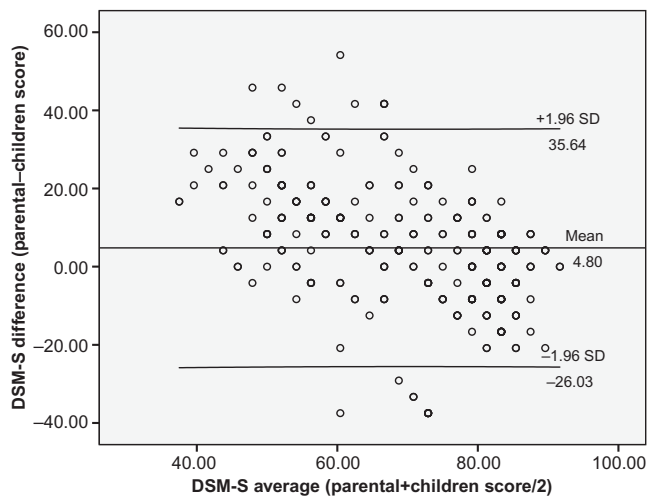


FIGURE 1.—Bland-Altman plot analysis for the HRQoL scores between asthmatic children in the group A (4–7 years old) and their parents with the corresponding 95% limits of agreement for DISABKIDS Smiley Measure (DSM-S).

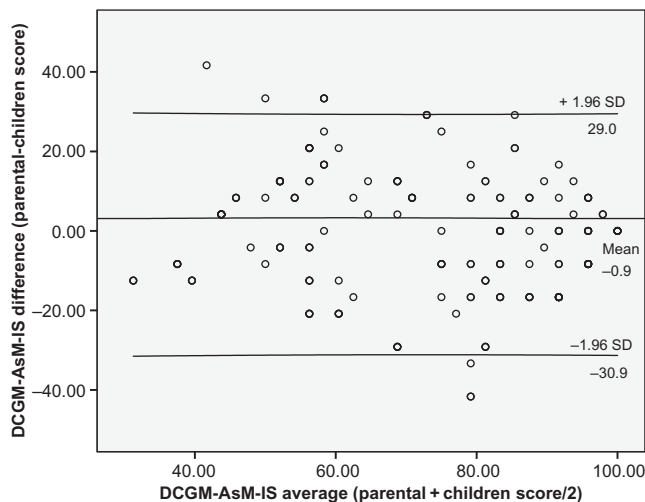
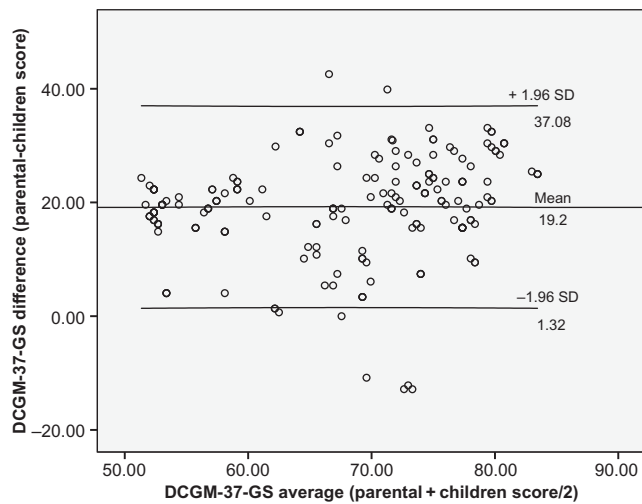


FIGURE 2.—Bland-Altman plot analysis for the HRQoL scores between asthmatic children in the group B (8–14 years old) and their parents with the corresponding 95% limits of agreement for DISABKIDS Chronic Generic Measure General Score (DCGM-37-GS) and Impact Score of DCGM Asthma Module Scale (DCGM-AsM-IS).

control and longer duration of the disease stated better HRQoL and their mean ICCs were higher indicating better agreement with their parents.

In a multicenter study, HRQoL of 500 children, aged 8–12 years with cerebral palsy living in seven European countries was assessed using the Kidscreen questionnaire (10 domains) through self-reports and parent proxy reports (24). The mean child-reported scores of QoL were higher than the parent proxy reports in eight domains, lower for the finances domain, and similar for the emotions domain concluding that factors associated with disagreement were different according to the direction of disagreement. In our study children rated lower HRQoL scores in all domains in both age groups and the disagreement was higher for the general score in older ones. Therefore, parents may overestimate their children's HRQoL. Taking into account the subjective nature of HRQoL, our findings suggest that the child's self-reported assessment on his/her HRQoL, possibly could be the first-choice source of information.

Some parents may have limited knowledge about their children's HRQoL, particularly the impact on social and emotional well-being. Barbosa and Gaviao in their systematic review focused on the pattern of agreement/disagreement between parent and child reports about child's HRQoL, concluded that children and parents do not necessarily share similar views about HRQoL (25). We found that children from families with higher socio-economical status and parents with higher education showed better agreement. Although the parents' reports may be incomplete due to lack of knowledge about certain experiences, they still provide useful information. Moreover, proxy reports are likely the most appropriate source of information about HRQoL in some groups of children who are unable reliably to report about their own experience.

Parents' reports might become less accurate as the child gets older and becomes more independent. At that point children's own reports tend to be more accurate (11). Our findings concerning the mean scores along with the ICC in children aged between 4 and 7 years revealed a moderate agreement between parental and children reports. But on the contrary, in both groups, the mean ICCs of older children were higher or equal, indicating better agreement of older children with their parents. However, in the literature there are studies that have reported opposite or no significant age effects (13, 15, 19). A study by Annett, Bender, DuHamel, and Lapidus with children with asthma reported parent-child agreement increased with child age (26). Ronen, Streiner, and Rosenbaum reached similar conclusions, with younger age predicting greater differences between parents and children with epilepsy (27). These results may be dependent on the specific measure of HRQoL employed, the type of information being requested from a proxy reporter or the use of appropriate questionnaire techniques (19, 28, 29).

Especially for teenagers, we found that children with mild intermittent asthma and children with severe asthma showed lower agreement with their parents in comparison

TABLE 4.—Evaluation of the degree of agreement between parents and children as concerns the scores of children's QoL by different demographic or disease characteristics (group A ($n = 315$)).

Mean values ^a	N	Smileys score	
		ICC ^a	95% CI
Children's gender			
Female	122	0.555	0.417–0.668
Male	193	0.431	0.288–0.551
Father's age			
<41	149	0.484	0.350–0.598
≥41	166	0.480	0.322–0.606
Mother's age			
<38	152	0.552	0.427–0.656
≥38	163	0.421	0.267–0.550
Parent's gender			
Female	241	0.448	0.335–0.548
Male	74	0.581	0.341–0.736
Place of residence			
Urban area	263	0.503	0.374–0.606
Rural area	52	0.388	0.132–0.596
Asthma severity			
Mild intermittent	34	0.359	0.025–0.620
Mild persistent	147	0.363	0.215–0.495
Moderate	119	0.393	0.164–0.568
Severe	15	0.252	–0.122 to 0.630
Level of Asthma control			
Controlled	21	0.503	0.124–0.759
Partly controlled	100	0.525	0.320–0.673
Uncontrolled	154	0.465	0.293–0.557
Mother's education			
Lower	110	0.463	0.323–0.532
Higher	131	0.482	0.331–0.604
Father's education			
Lower	28	0.449	0.308–0.572
Higher	46	0.502	0.473–0.781
Siblings			
No	107	0.440	0.270–0.582
Yes	208	0.504	0.378–0.609
Children's age			
<10 (group B) <5 (group A)	128	0.544	0.405–0.657
≥10 (group B) ≥5 (group A)	187	0.436	0.294–0.556
Age at diagnosis			
<5 (group B) <2 (group A)	134	0.605	0.468–0.710
≥5 (group B) ≥2 (group A)	181	0.401	0.263–0.521
Duration of disease			
<1	26	0.330	–0.023–0.622
≥1	289	0.496	0.392–0.586
Doctor's visits (per year)			
<3	121	0.519	0.327–0.660
≥3	194	0.433	0.309–0.541
Family income			
0–2000	135	0.507	0.355–0.631
2001–4000	162	0.433	0.288–0.557
>4000	18	0.796	0.540–0.918
Socio-economical status			
High	21	0.654	0.323–0.843
Medium	217	0.432	0.310–0.538
Low	77	0.562	0.362–0.708

^aICC ≤ 0.40 poor to fair agreement, 0.41–0.60 moderate agreement, 0.61–0.80 good agreement, and 0.81–1.00 excellent agreement.

to the ones with mild or moderate persistent asthma. It appears that teen-caregiver agreement on asthma depends on the type of information being sought. In a similar study on the agreement between 63 urban African-American teen and caregiver pairs to questions about teenager's asthma, responses were not significantly different for estimates of symptom-days, activity limitations, or nights

awakened nor for report of emergency department visits or hospitalizations. Agreement was weak for perceived asthma control and severity (30).

In a previous study in Greece, with 800 schoolchildren and their parents poor to moderate agreement between self and proxy report was observed, especially for the younger ones. Impact of gender was detected as girls

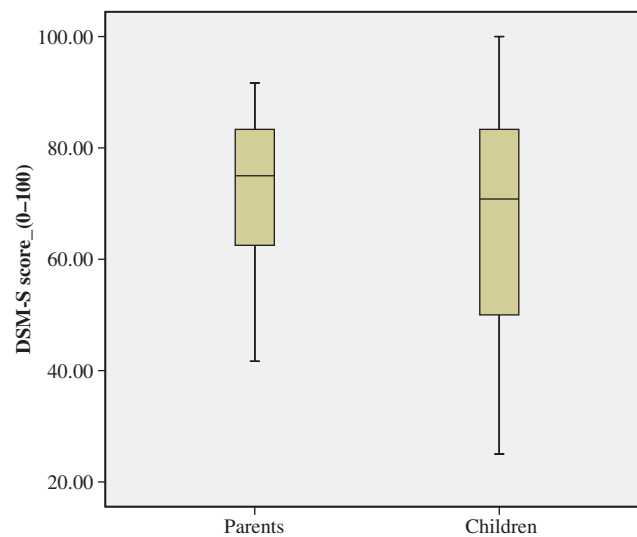


FIGURE 3.—DISABKIDS Smiley Measure (DSM-S) score in group A ($n = 315$) as was stated by both parents and their children. The black line indicates mean score.

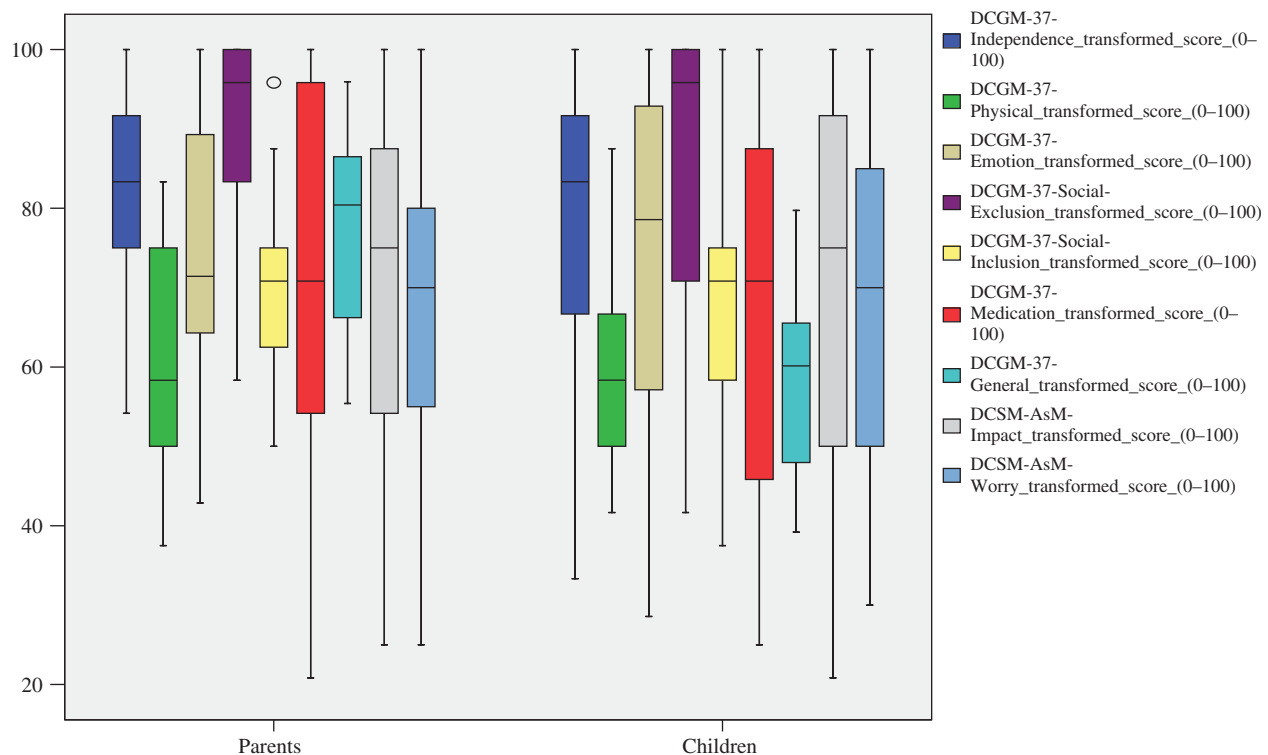


FIGURE 4.—DISABKIDS Chronic Generic Measure—long form (DCGM-37) subscales score in group B ($n = 189$) as was stated by both parents and their children. The black line indicates mean score.

reported lower HRQoL than boys on the Emotional Functioning subscale (31). In our study girls reported lower mean HRQoL scores in both age-groups performing better agreement than boys with their parents. An explanation for this could be different parent reasoning and the socially constructed gender differences. Moreover, sons and daughters differ in their relationships with each parent and in the extent of their closeness to parents during adolescence, suggesting a possible interaction effect of age and gender in parent-child agreement on HRQoL ratings (9). Additionally, a recent qualitative study suggested that

the reasons for such child-parent discordance are mainly due to differences between reasoning and differences between response styles (32).

The proxy method raises questions concerning which parent is more reliable and whether mother and father reports can be considered equivalent (13, 19). In a study comparing children's and parents' responses on the TNO-AZL Questionnaires for Children's HRQoL (TACQOL) children reported significantly lower HRQoL than their parents on most scales and were less extreme than their parents (17). The results of this exploratory study indicate

that parents' reports cannot be substituted for the child's response (17). In addition, it has been found that agreement among raters may differ as a result of factors such as child sex, age, and condition (12). In our study the stratified analysis by the parent filling the questionnaire showed that the degree of agreement of fathers with children was higher compared to that observed between mothers and children. This can be partly explained by cultural effect (paternalistic family functioning), quality of father-child interaction, maternal overprotection and increasing fathers' involvement in child development. There is some evidence that fathers have different perspectives on child health and behavior compared to mothers. Hay et al. found signs that parents were reporting different sorts of problems linked to different influences. The father's rating was primarily associated with the child's cognitive ability (33). Disagreement between parents and children's reports of HRQoL is a consequence of each individual's beliefs about the child's health and well-being. Furthermore, parents vary in their awareness, sensitivity and tolerance of children's health concerns (8).

Because neither the child's self-report nor the parent's proxy report is without risk, some researchers have suggested obtaining information from both, the child and a parent. This approach may provide the most complete picture of how a disease or treatment impacts the lives of children and their families (34). Matza et al. in their review concluded that the decision of whether to use child-report, parent-report, or both, requires consideration of numerous factors including the child's age, the domains of HRQoL that may be addressed, the disease area, the study design, and the intended use of the data (13). Agreement between parent and child report of HRQoL varies considerably, and further research is needed to clarify the factors that may influence this level of agreement.

CONCLUSIONS

This study suggests that parents overestimate HRQoL of their children with asthma even though satisfactory agreement between child self-report and parent proxy-report on HRQoL was found. Fathers seem to be better proxy reporters than mothers. Any evaluation of current approaches to measuring children's HRQoL therefore, needs to consider the provision made for children to rate their own HRQoL. Parents still are appropriate source of information about HRQoL, even more in cases that children are unable reliably to report about their own experience.

ACKNOWLEDGEMENTS

The DISABKIDS project was supported by the European Commission (QLG5-CT-2000-00716) within the Fifth Framework Program "QoL and Management of Living Resources." The European Union has granted this project for the development of a modular questionnaire to assess

HRQoL in children and adolescents with chronic health conditions. *****

DECLARATION OF INTEREST

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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