

Level of Agreement between Children with Asthma and their Parents on Quality of Life

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What's Known

- Child-parent agreement is a controversial issue in children with asthma.
- The PedsQL™ 3.0 Asthma Module is a reliable and valid instrument to measure children's HRQoL.

What's New

- Iranian children and their parents perceive children's HRQoL differently.
- Child-parent agreement can be affected by the child's age and gender. It can also vary from culture to culture, or one instrument to another.

Abstract

Background: Child-parent agreement is a controversial aspect of measuring health-related quality of life (HRQoL) in children and adolescents. The aim of this study was to assess the agreement between the child self-reports and parent proxy reports of the PedsQL 3.0 Asthma Module in Iranian children with asthma to evaluate HRQoL. Moreover, the psychometric properties of the child and parent reports of the PedsQL 3.0 Asthma Module were assessed in the present study.

Methods: Participants were 112 children with asthma and their parents, who completed the Farsi version of the PedsQL 3.0 Asthma Module. The multitrait-multimethod correlation matrix and factor analysis were used to test whether the child self-reports and the parent proxy reports measured the same construct. Additionally, convergent and discriminant validity and internal consistency were assessed using the Pearson correlation.

Results: The correlation between the child and parent HRQoL perceptions ranged between 0.13 and 0.36 across the same domains. Our factor analysis revealed that the child self-reports and the parent proxy reports measured 2 different constructs of HRQoL. Furthermore, our findings showed that both the child self-reports and the parent proxy reports of the PedsQL 3.0 Asthma Module had excellent internal consistency and acceptable convergent and discriminant validity.

Conclusion: Although the child self-reports and the parent proxy reports of the Farsi version of PedsQL 3.0 Asthma Module showed good psychometric properties, they were not interchangeable. Our children with asthma and their parents evaluated child HRQoL from their own viewpoints.

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Introduction

Asthma is the most prevalent chronic disease in the pediatric age group.¹ Globally, the prevalence of allergic diseases is increasing, particularly in countries with middle or low income. Also, the complexity and severity of allergic diseases such as asthma continue to increase, especially in children and adolescents, who are bearing the greatest burden of these diseases. The World Health Organization reports that the number patients having asthma in the world is about 300,000,000 and that it is expected to increase to 400,000,000 by the year 2025.² These patients have more clinical visits, although clinical and physical parameters such as hospital admissions result in more physical

and emotional disturbance. Asthma symptoms and the pulmonary function test are important, but health-related quality of life (HRQoL) can introduce a more comprehensive description of the impact of asthma on the life of children.³

According to previous research, asthma affects different aspects of child HRQoL, including physical, emotional, social, and school functioning. In recent years, focus has shifted from survival to quality of life, so HRQoL has emerged as an important outcome measure in pediatrics.⁴ Nowadays, there are several specific instruments to assess the HRQoL of children and adolescents diagnosed with asthma through child self-reports and parent proxy reports.⁵ The PedsQL 4.0 Generic Core Scales and the PedsQL 3.0 Asthma Module are 2 pediatric HRQoL instruments which have been widely used in different cultures and languages, and they have shown good reliability and validity between children and their parents.^{6,7} Although child self-reports are considered to be the more accurate method for measuring HRQoL, parent proxy reports provide complementary information concerning child HRQoL, not least when children lack skills such as cognition and linguistic ability necessary for the self-completion of HRQoL measures or when they are too ill or fatigued to complete an HRQoL instrument.⁸

However, an essential question is to what extent parent proxy reports provide a good substitute for child self-reports. According to Eiser and Morse,⁹ agreement with parent is higher among children with chronic disease than that among healthy children irrespective of age or gender, although it may depend on the specific measure of the HRQoL employed. Moreover, it has been shown that children report their HRQoL lower than do their parents, depending on gender, age, and temporary illness.¹⁰

Child-parent agreement has been previously assessed in children with asthma.^{11,12} Nevertheless, except for 2 studies in the United States and China,^{13,14} no other investigations have been undertaken to evaluate this agreement on the basis of the PedsQL 3.0 Asthma Module. Given the controversy surrounding this issue in the literature on quality of life,^{4,15,16} we sought to assess whether parent proxy reports could be used as a substitute for child self-reports in the PedsQL 3.0 Asthma Module.

Patients and Methods

Participants

Recommendations for the minimum number of subjects for testing the construct validity of a quality-of-life questionnaire have ranged from

100 or 400 or more.¹⁷ Participants in this study were both children with asthma (n, 112) and their parents (mostly their mothers). The average age of the pediatric patients was 9.94 years, with a range of 8 to 18 years. Regarding gender, 59 patients were boys, 46 were girls, and 7 children's gender was not reported. Based on the guidelines for the diagnosis and management of asthma (Expert Panel Report 3),¹⁸ 71% of the patients suffered from mild persistent asthma, 25% from mild intermittent asthma, 3% from mild persistent asthma, and 1% from severe persistent asthma. Children were eligible for participation if they were diagnosed as having asthma (according to the National Institute of Health's guidelines) previously or for the first time. Only children 8 years or older were eligible for participation in the study because younger children cannot complete questionnaires. Recruitment strategies comprised patients referring to the Dr Kashef allergy clinic affiliated to Shiraz University of Medical Sciences, Shiraz, Iran, for their first visit or follow-up. The children and their parents signed informed consent forms, and they were also meticulously instructed as to how to fill the PedsQL 3.0 Asthma Module. Moreover, 2 of the authors (third and fourth authors) were responsible to fill in the instrument for children via face-to-face interviews, and they were also available to respond to the parents' possible queries about the items in the parent proxy report.

Measures

The PedsQL 3.0 Asthma Module is a 28-item questionnaire with child and parent report versions. This instrument assesses HRQoL in 4 different subscales: Asthma Symptoms (11 items), Treatment Problems (11 items), Worry (3 items), and Communication (3 items). The parent proxy reports of the PedsQL 3.0 Asthma Module is designed for 4 age groups: Toddlers (age, 2–4 years), Young Children (age, 5–7 years), Children (age, 8–12 years), and Teens (age, 13–18 years). However, the child self-reports of the instrument are available for Young Children (age, 5–7 years), Children (age, 8–12 years), and Teens (age, 13–18 years). In the present study, we used only the Children (age, 8–12 years) and Teens (age, 13–18 years) versions of the PedsQL 3.0 for both child and parent reports. Responses were given on a 5-point Likert scale (0=Never, 1=Almost never, 2=Sometimes, 3=Often, and 4=Almost always). According to the PedsQL 3.0 Asthma Module scoring manual, all the rating scale categories of the negatively worded items were transformed to 100, 75, 50, 25, and 0, respectively.

Accordingly, the responses were transformed to a 0-to-100 scale, such that higher scores denoted a better HRQoL. The English version of the PedsQL 3.0 Asthma Module was translated into the Farsi language (with permission from the copyright holder) using standard guidelines, including independent forward and backward translation.

Statistical Analysis

The construct validity of the child self-reports and the parent proxy reports of the PedsQL 3.0 Asthma Module was assessed via the exploratory factor analysis with a varimax rotation. The convergent and discriminant validity of the child self-reports and parent proxy reports was evaluated using the Spearman correlation. Convergent validity was supported if an item correlated moderately ($r \geq 0.4$) with the scale to which it was hypothesized to belong. Discriminant validity was supported whenever a correlation between an item and its hypothesized subscale was significantly higher than that with the other subscales. The multitrait-multimethod correlation matrix and the factor analysis were employed to test whether the child self-reports and the parent proxy reports measured the same construct. If similar domains from the child self-reports and the parent proxy reports showed a high correlation (e.g., above 0.7), it suggested that both the self and proxy reports might be measuring the same construct. The mean values of the child and parent reports of the PedsQL 3.0 Asthma Module subscale scores were compared between sex and age groups using the independent *t* test. All the statistical analyses were performed with Statistical Package for the Social Sciences (SPSS), version 16.

Results

Table 1 shows the results of the convergent and discriminant validity of the child self-reports and the parent proxy reports of the Farsi version of the PedsQL 3.0 Asthma Module. According to Table 1, the scaling success rates for convergent validity were 100% in all the subscales, except for Treatment Problems and Asthma Symptoms in the parent proxy reports and the child self-reports, correspondingly. Moreover, the results showed that the scaling success rates for discriminant validity were above 80% in all the domains of the child self-reports and the parent proxy reports. According to Table 1, the Cronbach's α coefficients (internal consistency) in all the domains of the child and parent reports were >0.7 . The findings also demonstrated that the HRQoL subscale scores across the

children with asthma and their parents were not statistically significant. The results of the exploratory factor analysis to assess the construct validity of the child and parent reports of the PedsQL 3.0 Asthma Module are presented in Table 2. In the child self-reports and the parent proxy reports, all the items that should be in the Asthma Symptoms, Treatment Problems, Worry, and Communication subscales were clearly loaded on these domains, except for Items 1 and 2 in the treatment problems of the parent proxy reports and Item 4 in the Asthma and Treatment subscales of the child self-reports.

Table 3 depicts the correlations between the child self-report domains and the parent proxy report domains for the PedsQL 3.0 Asthma Module domains in the multitrait-multimethod correlation matrix. The 4 bold-faced numbers show the correlations between the scores when the child and parent reports were utilized to assess the same trait. These correlations ranged between 0.13 and 0.36 and were <0.70 . The exploratory factor analysis with a varimax rotation was drawn upon to determine whether the child self-reports and the parent proxy reports measured the same construct, and the results are depicted in Table 4. The findings indicated that the first factor encompassed all the domains of the parent proxy reports and that the second factor extracted comprised all the domains of the child self-reports, except the Asthma Symptoms subscale, which had greater loading in the parent proxy reports. Moreover, significant differences between the sex (boy and girl) and age (8–12 and 13–18 years) groups were not found for all the subscale scores of the child self-reports and the parent proxy reports of the PedsQL 3.0 Asthma Module, with the exception of the Communication subscale, which was significant between the boys and girls in the child self-reports (Table 5). Our findings showed that the boys rated themselves significantly higher than did the girls on the Communication subscale (69.91 ± 32.53 vs. 56.52 ± 31.22 ; $P=0.03$).

Discussion

The current study presents the psychometric properties for the Farsi version of the PedsQL 3.0 Asthma Module across children with asthma and their parents. Consistent with the Cronbach's α coefficients reported in studies in China and the United States,^{13,14} all the coefficients in the child self-reports and the parent proxy reports were >0.75 , indicating the high internal consistency of the Farsi version of the PedsQL 3.0 Asthma Module. Furthermore, the good convergent and discriminant validity of the instrument confirmed

Table 1: Item scaling tests: Cronbach's α and convergent and discriminant validity for the PedsQL 3.0 Asthma Module subscales

	Items	Mean \pm SD	Cronbach's α	Convergent validity ^a		Discriminant validity ^b	
				Range of correlation	Scaling success (percent)	Range of correlation	Scaling success (percent)
Parent proxy report							
Asthma symptoms	11	69.71 \pm 16.80	0.80	0.42–0.70	11/11 (100)	0.037–0.4	30/33 (91)
Treatment problems	11	77.49 \pm 18.14	0.79	0.30–0.79	10/11 (91)	0.07–0.45	26/33 (80)
Worry	3	67.48 \pm 26.59	0.81	0.82–0.86	3/3 (100)	0.16–0.33	9/9 (100)
Communication	3	70.76 \pm 26.68	0.76	0.77–0.80	3/3 (100)	0.11–0.42	9/9 (100)
Child self-report							
Asthma symptoms	11	69.26 \pm 15.87	0.75	0.35–0.66	10/11 (91)	0.01–0.23	30/33 (91)
Treatment problems	11	75.89 \pm 17.29	0.78	0.40–0.70	11/11 (100)	0.01–0.34	29/33 (88)
Worry	3	68.67 \pm 27.38	0.79	0.81–0.86	3/3 (100)	0.10–0.22	9/9 (100)
Communication	3	64.28 \pm 32.96	0.79	0.77–0.85	3/3 (100)	-0.02–0.25	9/9 (100)

^aNumber of correlations between the items and the hypothesized scale corrected for overlap ≥ 0.4 /total number of the convergent validity tests. ^bNumber of the convergent correlations significantly higher than the discriminant correlations/total number of the correlations

Table 2: Factor loadings (rotated)^a of the 4-factor solution of the PedsQL 3.0 Asthma Module subscales

	Parent proxy report				Child self-report			
	AS	TP	W	C	AS	TP	W	C
Asthma symptoms (AS)								
Pain or tightness in his or her chest	0.423	-0.042	0.191	0.184	0.504	0.028	0.105	-0.120
Feeling wheezy	0.468	0.187	0.115	-0.004	0.607	0.076	0.187	-0.141
Having asthma attacks	0.501	0.179	0.016	0.022	0.597	0.111	-0.070	0.034
Getting scared while having asthma attacks	0.488	-0.040	0.175	-0.025	0.283	0.357	0.115	0.017
Getting out of breath	0.754	-0.035	-0.046	-0.033	0.608	-0.021	-0.044	-0.090
Coughing	0.408	0.163	0.018	0.112	0.307	0.133	0.015	0.100
Taking a deep breath	0.599	0.157	0.131	0.259	0.464	-0.009	-0.085	-0.011
Having a stuffy or runny nose	0.372	0.178	0.071	0.152	0.447	0.101	0.112	0.012
Waking up at night with trouble breathing	0.715	0.117	-0.065	0.034	0.466	0.047	-0.038	0.005
Playing with pets	0.358	0.091	0.212	0.039	0.289	0.213	0.147	0.075
Playing outside	0.483	0.170	0.127	0.048	0.395	0.198	0.116	0.075
Treatment problems (TP)								
Medicines making him or her feel sick	0.281	0.130	0.265	0.060	0.208	0.340	0.010	-0.046
Trouble sleeping because of medicines	0.331	0.111	0.124	0.129	0.280	0.350	0.136	0.037
Trouble using his or her inhaler	0.222	0.310	0.238	0.163	0.016	0.426	0.270	0.023
Disliking carrying his or her inhaler	0.253	0.361	0.191	0.156	-0.012	0.057	0.296	0.133
Being responsible for his or her medicines	0.198	0.732	0.033	0.150	0.002	0.386	-0.049	0.098
Controlling his or her asthma	0.403	0.535	0.012	0.069	0.050	0.468	-0.111	0.311
Refusing to take medicines	0.036	0.612	0.059	0.183	0.105	0.356	0.119	0.053
Forgetting to take medicines	0.101	0.730	-0.032	-0.005	0.099	0.370	0.026	-0.042
Getting anxious when he or she has to have medical treatments	0.112	0.396	0.166	0.005	0.119	0.741	0.074	0.058
Getting anxious about going to the doctor	0.140	0.355	0.226	0.109	0.115	0.796	0.171	0.037
Getting anxious about going to the hospital	0.014	0.485	0.152	0.126	0.014	0.764	0.051	0.159
Worry (W)								
Worrying about the side effects of medical treatments	0.057	0.163	0.747	0.174	0.072	0.103	0.699	-0.056
Worrying about whether or not medical treatments are working	0.191	0.114	0.814	-0.011	0.089	0.038	0.910	0.030
Worrying about his or her asthma	0.101	0.110	0.670	0.021	0.080	0.086	0.618	0.081
Communication (C)								
Telling the doctors and nurses how he or she feels	0.128	0.069	0.100	0.705	-0.035	0.039	0.064	0.800
Asking the doctors or nurses questions	0.083	0.256	-0.079	0.893	-0.006	0.042	0.100	0.965
Explaining his or her illness to other people	0.125	0.198	0.160	0.490	-0.022	0.199	0.108	0.473

^aVarimax rotation with maximum likelihood extraction methods

Table 3: Multitrait-multimethod correlation matrix: Correlations between the child self-report domains and the parent-proxy-report domains for the PedsQL 3.0 Asthma Module

Parent proxy reports	Child self-reports			
	Asthma symptoms	Treatment problems	Worry	Communication
Asthma symptoms	0.30	0.15	0.23	0.08
Treatment problems	0.07	0.36	0.06	0.13
Worry	0.08	0.16	0.31	0.13
Communication	0.06	0.24	0.04	0.13

Table 4: Factor loadings^a of the 2-construct solution

	Factor 1	Factor 2
Parent proxy report		
Asthma symptoms	0.79	0.47
Treatment problems	0.61	0.46
Worry	0.65	0.05
Communication	0.48	0.24
Child self-report		
Asthma symptoms	0.57	0.06
Treatment problems	0.09	0.75
Worry	0.29	0.40
Communication	0.50	0.74

^aExtraction method, principal component with a varimax rotation

that all the items belonged to their own subscales. Also similar to the Chinese version,¹³ our exploratory factor analysis revealed that the Farsi version of the PedsQL 3.0 Asthma Module encompassed 4 underlying factors.

Nonetheless, our findings did not exactly chime in with the Chinese version¹³ insofar as items such as “medicines making him or her feel sick” and “trouble sleeping because of medicines” in the parent proxy reports had higher correlations with the Asthma Symptoms subscale rather than with the Treatment Problems subscale. These findings reveal that phrases such as “feel sick” and “trouble sleeping” do not convey similar meaning across Iranian and Chinese parents. This problem can be attributed to cross-cultural differences between Iranian and Chinese children. However, all the items in the Asthma Symptoms, Worry, and Communication subscales had a clear factor loading for the parent proxy reports. Also, only “getting scared while having asthma attacks” in the Asthma Symptoms subscale and “disliking carrying his or her inhaler” in the Treatment Problems subscale for the child self-reports were not associated with their own subscale.

The results of the exploratory factor analysis (Table 2) and convergent and discriminant validity indicated that the Farsi version of the PedsQL 3.0 Asthma Module measured the construct that it was intended to measure. In comparison with the Chinese children with asthma in the above-mentioned investigation,¹³ our Iranian children

with asthma had significantly low quality-of-life scores in all the domains. Additionally, the parents of the Iranian children with asthma in our study rated their children’s HRQoL lower than did the parents of the Chinese children. Nevertheless, by comparison with the American children in the aforementioned investigation,¹⁴ our Iranian children with asthma reported low HRQoL scores in all the domains except the Asthma Symptom subscale, according to the self- and proxy reports using the PedsQL 3.0 Asthma Module. Moreover, in line with previous findings in the studies conducted in the United States and China, there were no statistically significant differences in the HRQoL scores between the child self-reports and the parent proxy reports in our Iranian subjects.

While moderate and high correlations were observed between the children and their parents in the United States and China studies, we found a low correlation between the child self-reports and the parent proxy reports in all the domains of the Farsi version of the PedsQL 3.0 Asthma Module. The discrepancy between our findings and those of the United States and China studies confirms a previous report, which showed that in the PedsQL 3.0 Asthma Module, child-parent agreement could be affected by cross-cultural differences.¹⁹ However, our results were similar to those in a previous research, which reported moderate to poor parent-child agreement using the KIDSCREEN.²⁰ For example, while the American parents tended to underestimate their child’s quality of life, the parents from Iceland overestimated it. Furthermore, our exploratory factor analysis (Table 4) extracted 2 different quality-of-life domains: one comprised all of the subscales of the parent proxy reports, while the other one contained all of the subscales of the child self-reports except for Asthma Symptoms, indicating that the child self-reports and the parent proxy reports of the Farsi version of the PedsQL 3.0 Asthma Module measure 2 different constructs. It should be noted that the level of agreement across children and their parents can vary from measure to measure and from sample to sample. Still, our findings were concordant with those in previous studies on

Table 5: Subscale scores of the child self-reports and the parent proxy reports of the PedsQL 3.0 Asthma Module for the age and sex groups

	Mean±SD		P value	Mean±SD		P value
	Male (n, 59)	Female (n, 46)		8-12 years (n, 92)	13-18 years (n, 20)	
Parent proxy report						
Asthma symptoms	68.72±19.62	71.49±13.18	0.41	69.98±17.47	68.41±13.53	0.71
Treatment problems	76.31±19.74	78.90±16.53	0.47	76.58±18.57	81.70±15.75	0.25
Worry	65.53±27.78	69.38±25.88	0.47	70.65±25.98	62.91±24.96	0.31
Communication	71.75±26.26	71.73±25.61	0.99	70.92±26.68	70.00±27.35	0.88
Child self-report						
Asthma symptoms	67.18±16.65	70.89±14.79	0.24	69.73±16.17	67.04±14.55	0.49
Treatment problems	76.15±19.50	75.44±14.35	0.83	74.80±17.04	80.09±17.94	0.15
Worry	67.51±27.84	70.83±26.51	0.53	71.01±26.59	57.91±29.05	0.06
Communication	69.91±32.53	56.52±31.22	0.03	61.59±34.03	76.66±24.57	0.07

healthy Iranian school children, which reported that parent proxy reports could not be used as a substitute for child self-reports in the 3 well-known pediatric HRQoL instruments, namely the Farsi version of the KINDL,²¹ KIDSCREENN-27,²² and PedsQL 4.0.²³ Therefore, in the present study, the imperfect agreement between the ratings of child HRQoL made by the parents and the children may have been due to their different understanding of asthma risk factors and their effect on child HRQoL.²⁴ Moreover, a previous investigation measuring HRQoL in children and adolescents (>12 years old) with asthma showed that the parents of the adolescents in the study could not provide information beyond that obtained from the adolescents' reports. However, in our study, 82% (90 out of 112) of the participants were children aged between 8 and 12 years. Hence, the low agreement between the child self-reports and the parent proxy reports could be attributed to the age of the children, who were mostly under 12 years old and naturally had less cognitive ability and linguistic skill than did their parents for the completion of the instrument.

Our study had some limitations. All the patients in our study were selected from an outpatient clinic, which means that patients admitted with severe persistent asthma were not included in the study. Thus, these findings cannot be generalized to children with very severe disease. Moreover, we do not know to what extent the child-parent agreement can be affected by child and parent age, child and parent gender, severity of impairment, and socioeconomic factors. Another limitation is that the study sample was collected from one clinical setting, which can reduce the generalizability of the findings. Although a previous research has shown that fathers and mothers have different interpretation from their child HRQoL,²⁵ this issue could not be assessed in the present study. This

is because more than 93% of the parents who participated in our study were mothers. Such issues should, therefore, be considered in future studies with larger sample sizes.

Conclusion

In summary, our findings revealed that parent proxy reports cannot be used as a substitute for a child self-report in the Farsi version of the PedsQL 3.0 Asthma Module. Hence, measuring the HRQoL of a child with asthma necessitates that both parent and child be allowed to give their own perspective. Moreover, we found excellent convergent and discriminant validity for the instrument, which indicates that both the child self-reports and the parent proxy reports measured the intended construct. Finally, for a valid comparison of pediatric quality of life rated by children and parents, future studies should focus on assessing the differential item functioning of the PedsQL 3.0 Asthma Module to test whether children and their parents respond consistently to the items of the measure.

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