

# Quality of life in asthmatics – concordance among children, adolescents, and their parents

*Qualidade de vida na asma brônquica – a concordância das percepções das crianças, adolescentes e seus pais*

*Calidad de vida en el asma brônquico – la concordancia de las percepciones de los niños, adolescentes y sus padres*

Laura Janne L. Aragão<sup>1</sup>, Maria Wanderleya L. Coriolano-Marinus<sup>2</sup>, Gabriela Cunha S. Sette<sup>3</sup>, Maria Cristina F. Raposo<sup>4</sup>, Murilo Carlos A. de Britto<sup>5</sup>, Luciane Soares de Lima<sup>6</sup>

## ABSTRACT

**Objective:** To evaluate the perception of the quality of life of asthmatic children and adolescents and their parents, investigating the agreement rates in each domain using the Pediatric Asthma Quality of Life Questionnaire - Adapted (PAQLQ-A).

**Methods:** Cross-sectional study conducted at two outpatient clinics of a university reference center for asthmatic children and adolescents in Recife, Brazil. After meeting the ethical requirements, health-related quality of life data were collected using the version of the PAQLQ adapted and translated into Portuguese. The questionnaire was answered by 126 patients (70 children and 56 adolescents) and their parents. Agreement was analyzed by the Kappa statistic test using the computer program SPSS, version 13.0, software.

**Results:** Agreement between children and parents' answers varied from "unsatisfactory" to "poor". The worst agreement rate was found in the domain symptoms, especially regarding the item "wheezing", and in the domain emotions, regarding the item "feel bothered". Agreement between adolescents and their parents' answers varied from "unsatisfactory" to "fair",

with the worst agreement rate in the domain activities, especially in the item "feel bothered by not being able to be with other people", and the best agreement rate was found in the domain emotions, in the item "feel uncomfortable."

**Conclusions:** The PAQLQ-A was not well understood by the studied population and agreement regarding the perception of the quality of life of asthmatic children and adolescents between patients and their parents was poor. Appropriate instruments adapted to regional characteristics or even revalidation of international instruments considering regional diversity should be developed.

**Key-words:** quality of life; child; adolescent; asthma; parents.

## RESUMO

**Objetivo:** Avaliar a percepção da qualidade de vida, com relação à asma, pelas crianças, adolescentes e seus pais, verificando as concordâncias existentes em cada domínio do questionário *Pediatric Asthma Quality of Life Questionnaire* Adaptado (PAQLQ-A).

Instituição: Programa de Pós-graduação em Saúde da Criança e do Adolescente da Universidade Federal de Pernambuco (UFPE), Recife, PE, Brasil

<sup>1</sup>Mestre em Saúde da Criança e do Adolescente pela UFPE; Professora Assistente 2 do Departamento de Medicina da Universidade Estadual do Rio Grande do Norte (UERJ), Mossoró, RN, Brasil

<sup>2</sup>Doutoranda em Saúde da Criança e do Adolescente pela UFPE; Professora Substituta do Departamento de Enfermagem da UFPE, Recife, PE, Brasil

<sup>3</sup>Doutoranda em Saúde da Criança e do Adolescente pela UFPE; Professora Assistente do Departamento de Enfermagem da UFPE, Recife, PE, Brasil

<sup>4</sup>Doutora em Economia pela UFPE; Professora Adjunta do Departamento de Estatística da UFPE, Recife, PE, Brasil

<sup>5</sup>Doutor em Saúde Pública pela Fundação Oswaldo Cruz (Fiocruz); Professor do Departamento de Pós-graduação em Saúde Materno-Infantil do Instituto de Medicina Integral (IMIP), Recife, PE, Brasil

<sup>6</sup>Doutora em Ciências Pneumológicas pela Universidade Federal de São Paulo (Unifesp); Professora Titular do Departamento de Enfermagem da UFPE, Recife, PE, Brasil

Endereço para correspondência:  
Luciane Soares de Lima  
Rua do Futuro, 77, apto 1.101 – Graças  
CEP 52050-010 – Recife/PE  
E-mail: luciane.lima@globo.com

Conflito de interesse: nada a declarar

Recebido em: 14/12/2010

Aprovado em: 15/7/2011

**Métodos:** Estudo transversal realizado em dois ambulatórios universitários de referência para seguimento de crianças e adolescentes asmáticos em Recife (PE). Após o cumprimento das exigências éticas, os dados sobre a qualidade de vida foram obtidos por aplicação do PAQLQ, em sua versão traduzida adaptada e validada para a língua portuguesa. O questionário foi respondido por 126 pacientes (70 crianças e 56 adolescentes) e seus respectivos pais. Um banco de dados criado no programa SPSS, versão 13.0, foi analisado com o teste de concordância *Kappa*.

**Resultados:** A concordância das respostas entre crianças e pais variou de ruim a sofrível, observando-se as piores concordâncias no domínio sintomas para o item “chiado no peito” e, no domínio emoções, para o item “sentiu-se irritado”. As respostas dos adolescentes e seus pais tiveram a concordância avaliada entre ruim e regular; sendo a pior concordância observada no domínio atividades, no item “incomodado por não poder estar com os outros” e a melhor concordância notada no domínio emoções, no item “desconfortável”.

**Conclusões:** O PALQ-A não foi bem compreendido pela população estudada e não houve concordância na percepção sobre qualidade de vida das crianças e adolescentes asmáticos e seus pais. Recomenda-se a elaboração de instrumentos adequados às especificidades regionais ou ainda a revalidação de instrumentos internacionais, de forma que atendam à diversidade regional.

**Palavras-chave:** qualidade de vida; criança; adolescente; asma; pais.

## RESUMEN

**Objetivo:** Evaluar la percepción de la calidad de vida, respecto al asma, por los niños, adolescentes y sus padres, verificando las concordancias existentes en cada dominio cuando aplicado el cuestionario *Pediatric Asthma Quality of Life Questionnaire* Adaptado (PAQLQ-A).

**Métodos:** Estudio transversal realizado en dos ambulatorios universitarios de referencia para seguimiento de niños y adolescentes pediátricos asmáticos en Recife (PE, Brasil). Después del cumplimiento de las exigencias éticas, los datos sobre la calidad de vida fueron obtenidos mediante la aplicación del PAQLQ, en su versión traducida adaptada y validada para la lengua portuguesa. El cuestionario fue contestado por 126 pacientes (70 niños y 56 adolescentes) y sus respectivos padres. Una base de datos creada en el programa SPSS, versión 13.0, fue analizada estadísticamente con la prueba de concordancia de *Kappa*.

**Resultados:** La concordancia de las respuestas entre niños y padres varió de mala a aceptable, observándose las peores concordancias en el dominio síntomas para el ítem «sibilancias en el pecho» y en el dominio emociones para el ítem «se sintió irritado». Las respuestas de los adolescentes y sus padres tuvieron la concordancia evaluada entre mala y regular; siendo la peor concordancia observada en el dominio actividades, en el ítem «incomodado por no poder estar con otros» y la menor concordancia notada en el dominio emociones, en el ítem «incómodo».

**Conclusiones:** El PAQLQ-A no fue bien comprendido por la población estudiada y no hubo concordancia en la percepción sobre calidad de vida de los niños y adolescentes asmáticos y sus padres. Se recomienda la elaboración de instrumentos adecuados a las especificidades regionales o, además, mediante la revalidación de instrumentos internacionales, de modo a que atiendan a la diversidad regional.

**Palabras clave:** calidad de vida; niño; adolescente; asma; padres.

## Introduction

Asthma is a chronic inflammatory disease characterized by hyperresponsiveness of the lower airways and variable airflow limitation. This disease can spontaneously remit or improve with treatment. Its clinical manifestations include recurrent episodes of wheezing, dyspnea, chest tightness, and cough, particularly at night and in the morning upon awakening<sup>(1)</sup>.

Treatment, according to asthma classification, should address aspects such as inhaled or systemic anti-inflammatory drug therapy, bronchodilators, short or long term  $\beta_2$ -agonists, and use of anti-leukotrienes associated with control of environmental triggering factors. Immunotherapy is indicated for atopic asthma, when diagnosed by specific increased immunoglobulin E (IgE) and positive immediate hypersensitivity skin test<sup>(1)</sup>.

There is evidence that the clinical and laboratory parameters have a weak correlation with what the child is experiencing on a daily basis and with parents' perception of their children's quality of life (QoL). QoL varies among individuals according to their expectations about disease and life, which may change over time and according to life experiences<sup>(2)</sup>. For a long period of time, QoL measurement in children was based on the conventional measure of asthma severity, measure of lung function, presence and intensity of symptoms, medication requirements, and parents' reports<sup>(3)</sup>.

It is important to keep in mind that information on QoL has been considered as indicators of evaluation of effectiveness, efficiency, and impact of certain treatments for groups of patients with various diseases when control procedures for specific health problems are compared<sup>(4)</sup>. Currently, QoL is an essential research topic, because its results contribute to define and approve treatments, as well as evaluate costs and benefits of medical care<sup>(5,6)</sup>.

Juniper *et al*<sup>(7,8)</sup> developed the Pediatric Asthma Quality of Life Questionnaire (PAQLQ), validated and published in English in 1996 and subsequently in 20 other languages. The PAQLQ consists of 23 questions divided into three domains: activity limitation (five questions), symptoms (10 questions), and emotional function (eight questions). In the domain activity limitation, three questions were individualized, enabling the patient to choose the most difficult activity. The responses are measured using a seven-point scale, where "one" means maximum loss and "seven" means no loss. The questionnaire was tested and adapted to be used in Brazil. The original format was maintained, but five activities that are not part of local culture (ball hockey, football, skiing, baseball and ice skating) were excluded. The remaining items were maintained in accordance with the translation, but they were reordered to make administration easier. The new translated and adapted questionnaire was called the Pediatric Asthma Quality of Life Questionnaire - Adapted (PAQLQ-A) and the same rating scale (one to seven) was used<sup>(9)</sup>.

With regard to the QoL of children and adolescents with asthma, there are many speculations and diverse viewpoints. Therefore, only the results of methodologically well conducted research can overcome such speculations and perhaps offer suggestions for programs and welfare policies based on the findings and on the search for integration of these children with their families. These considerations motivated the present study, whose objective was to evaluate children, adolescents and their parents' perception of QoL in relation to asthma, investigating the agreement rates in each domain using the PAQLQ-A<sup>(8)</sup>.

## Method

Cross-sectional study conducted at the outpatient clinic of pediatric allergy and immunology, Hospital das Clínicas, Universidade Federal of Pernambuco (UFPE), and at the outpatient clinic of pediatric pulmonology, Instituto de Medicina Integral Professor Fernando Figueira. The hospitals included in the study are public institutions,

accredited by the Ministry of Education, being university reference centers in Recife (PE) for the treatment of allergic and lung diseases, respectively. The project was approved by the Research Ethics Committee at the UFPE, number CAAE 1427.0.172.000-05.

Children aged 7 to 9 years and 11 months of age and adolescents aged 10 to 19 years were included<sup>(10)</sup>. According to the classification of asthma severity, we included children and adolescents with intermittent bronchial asthma, as well as mild, moderate and severe persistent asthma<sup>(1)</sup>. We excluded those diagnosed with chronic respiratory and immune disorders such as bronchiolitis, bronchiectasis, and interstitial pneumonia. Thus, the study population consisted of 70 children, 56 adolescents and their parents. The interviews were conducted in a single meeting between April and August 2006.

Data collection was conducted by the principal researcher and two students trained in the administration of the PAQLQ-A, which was translated and validated in 2004 by La Scala, Naspitz and Solé<sup>(9)</sup>. The PAQLQ-A comprises 23 questions divided into three domains: symptoms, emotions, and activities. A response card with a score of one to seven (one=maximum loss and seven=no loss) was shown for each question. The questions were related to the past week and divided according to the question in green card (quantifying the frequency) and blue card (quantifying the intensity of the symptoms).

The research was explained to parents or guardians, children and adolescents, including its objectives, importance and implementation. After guardians, children, and adolescents agreed to participate in the study, they signed a written consent form. Participants included in the study underwent anamnesis and clinical examination. They were also evaluated considering their classification of asthma severity<sup>(1)</sup>. Next, an interviewer administered the PAQLQ-A to the children and adolescents. And the same questionnaire was administered to parents without the presence of the child/adolescent with the purpose of comparing the answers provided by children/adolescents and their parents.

To calculate the sample size for each age group, we used a sequential procedure, starting with a pilot sample of 20 children and 20 adolescents. Next, we randomly selected a new sample of the same size and performed tests of mean differences or proportions according to the variable of interest. We repeated this procedure until reaching stable measures, which occurred with a sample of 70 children and 56 adolescents.

Data were processed using the computer program SPSS version 13.0, and the Kappa coefficient was used to measure the degree of agreement. This is an index of adjusted agreement that ranges from -1 to +1 and minimizes the chance factor. As suggested by Andrade and Zicker<sup>(11)</sup>, these values can vary from <0.00 (unsatisfactory or no agreement); 0.00 to 0.20 (weak); 0.21 to 0.40 (poor); 0.41 to 0.60 (fair); 0.61 to 0.80 (good); 0.81 to 0.99 (excellent); and 1.00 (perfect). In cases where the data is presented using non-parametric statistics, we used Spearman's rank correlation coefficient. In all cases, the level of confidence was set at 95%.

## Results

Our sample consisted of 126 children and adolescents and their parents (126). Children and adolescents' median age was 9 and 13 years, respectively. Among children, mild persistent asthma (25/36%) was the most prevalent type of asthma, whereas among adolescents there was predominance of intermittent asthma (22/39%). Allergic rhinitis was the most common associated disease – in 64 children (91%) and 49 adolescents (87%). Demographic characteristics are shown in Table 1.

Table 2 shows the frequency of questions answered by children, adolescents and their parents regarding the several domains of the instrument. In some items of the questionnaire, the sample was significantly reduced because both parents and children did not understand the question. It is worth noting, for example, that

43% of children did not provide information combined with their parents in the variable "Feel left out." In the domain emotions, we also found lack of understanding of the terms "uncomfortable" and "feel frustrated", which led to the exclusion of 15 and 13 pairs of children/parents and adolescents/parents, respectively, from the agreement analysis for the answers in these items of the questionnaire.

Table 3 show that the agreement between the children and their parents' answers in the domains symptoms, emotions, and activities of the PAQLQ-A ranged from unsatisfactory to poor. As for the items showing the worst agreement, we found that in the domain symptoms, the worst item was "wheezing"; in the domain emotions, the worst items were "feel left out" and "feel angry"; and in domain activities, the worst agreement rate was in the item "feel bothered while performing activities in the past week." Items with the highest level of agreement (poor) were: symptoms ("trouble sleeping"), emotions ("feel frustrated" and "feel worried") and activities ("bothered for being unable to be with other people").

Regarding the agreement between adolescents and their parents, the results are shown in Table 4. In the domain symptoms, the item showing the worst agreement was "feel breathless." As for the item "trouble sleeping," there was perfect agreement between parents and adolescents. In the domain emotions, the item that had the worst agreement was "feel frustrated" and "feel angry" and, in the domain activities, the item with the worst agreement was "feel bothered for being unable to be with other people."

**Table 1** - Distribution of demographic and clinical variables of children and adolescents with asthma

	Children		Adolescents	
	n=70	%	n=56	%
Sex				
Male	40	57.1	32	57.1
Female	30	42.9	24	42.9
Classification of asthma severity				
Intermittent	15	21.4	22	39.3
Mild persistent	25	35.7	12	21.4
Moderate persistent	22	31.4	18	32.1
Severe persistent	8	11.4	4	7.1
Associated diseases				
Allergic rhinitis	64	91.4	49	87.5
Atopic dermatitis	9	12.9	6	10.7
Conjunctivitis	10	14.3	-	-
Food allergy	10	14.3	3	5.4

**Table 2** - Frequency distribution of agreement between asthmatic children/adolescents and their parents according to the three domains of the Pediatric Asthma Quality of Life Questionnaire - Adapted

	Combined information Children and parents (n=70)		Combined information Adolescents and parents (n = 56)	
	n	No response (%)	n	No response (%)
Domain symptoms				
1. Cough	70	0	56	0
2. Asthma attack	69	1.0 (1.4)	56	0
3. Wheezing	70	0	56	0
4. Chest tightness	65	5.0 (7.1)	54	2.0 (3.6)
5. Shortness of breath	70	0	56	0
6. Fatigue	70	0	55	1.0 (1.8)
7. Night awakening	70	0	56	0
8. Feel breathless	69	1.0 (1.4)	56	0
9. Trouble sleeping	70	0	56	0
10. Trouble breathing deeply	70	0	56	0
Domain emotions				
1. Feel frustrated	57	13.0 (18.6)	55	1.0 (1.8)
2. Feel worried	69	1.0 (1.4)	56	0
3. Feel angry	70	0	56	0
4. Feel left out	40	30.0 (42.9)	47	9.0 (16.1)
5. Frustrated by not being able to be with other people	57	13.0 (18.6)	55	1.0 (1.8)
6. Uncomfortable	55	15.0 (21.4)	56	0
7. Terrified by asthma attack	69	1.0 (1.4)	56	0
8. Feel annoyed	69	1.0 (1.4)	56	0
Domain activities				
1. Feel bothered by not being able to be with other people	66	4.0 (5.7)	54	2.0 (3.6)
2. Feel bothered while performing activities in the past week	66	4.0 (5.7)	54	2.0 (3.6)

## Discussion

The assessment of QoL in asthmatic children and adolescents and their parents did not show good agreement in our sample. We believe that this result may have been influenced by the difficulty in understanding the terms used in the questionnaire both by children/adolescents and their parents. The best agreement found between the answers provided by adolescents and their parents must have occurred because of better understanding of the terms in the questionnaire. While we assume that adolescents can verbalize their emotions and symptoms in a more effective manner, studies have shown that agreement with the parents' answers would be impaired, since parents tend to underestimate the impact of the disease on the lives of adolescents<sup>(12-14)</sup>.

The assessment of QoL is recognized by health professionals as a "link" that tries to fill the gap between

diagnosis and management of clinical treatment. Bronchial asthma management in children and adolescents should not focus only on patients' survival, but also on the improvement of QoL, covering fundamental and important aspects involved in the family dynamics and perception of children and their parents' experiences<sup>(2,5,6)</sup>. Such assessments are conducted using generic or specific instruments. The instrument used to assess QoL – the PAQLQ-A – is specific and was chosen because it aims to understand fundamental aspects for the proper assessment of QoL. In addition, it was translated and validated into Portuguese, having good applicability because it can be answered by the patient or administered by a trained interviewer<sup>(5)</sup>. However, in the present study, participants experienced difficulties to understand the instrument, possibly due to cultural issues related to language comprehension and children' literacy.

**Table 3** - Agreement between children and their parents' answers in the administration of the questionnaire Pediatric Asthma Quality of Life Questionnaire - Adapted

	Kappa coefficient	Agreement	p-value
Domain symptoms			
1. Cough	0.159	Weak	<0.001
2. Asthma attack	0.058	Weak	0.490
3. Wheezing	0.014	Weak	0.860
4. Chest tightness	0.028	Poor	0.750
5. Shortness of breath	0.139	Poor	0.090
6. Fatigue	0.133	Poor	0.130
7. Night awakening	0.066	Weak	0.450
8. Feel breathless	0.210	Poor	0.010
9. Trouble sleeping	0.288	Poor	0.001
10. Trouble breathing deeply	0.245	Poor	<0.001
Domain emotions			
1. Feel frustrated	0.371	Poor	<0.001
2. Feel worried	0.361	Poor	<0.001
3. Feel angry	0.253	Poor	<0.001
4. Feel left out	-0.011	Unsatisfactory	0.920
5. Feel bothered by not being able to be with other people	0.198	Weak	0.050
6. Uncomfortable	0.053	Weak	0.600
7. Terrified by asthma attack	0.244	Poor	<0.001
8. Feel annoyed	0.008	Weak	0.920
Domain activities			
1. Feel bothered by not being able to be with other people	0.235	Poor	<0.001
2. Feel bothered while performing the activities of past week	0.102	Weak	0.240

The study responsible for the adaptation and validation of the questionnaire in Brazil showed difficulties in administering the instrument to the ages between 7 and 8 years old and to some children with low socioeconomic status, evidencing children's difficulties to understand the meanings of words like "frustrated," "moderately" or "uncomfortable"<sup>(9)</sup>. In our study, we found similar results regarding difficult words and terms, such as the term "feel left out." This may have been one of the reasons for poor agreement between adolescents and their parents and unsatisfactory agreement between children and their parents, since the sample was reduced in this particular item.

With respect to the agreement between children and their parents' answers, we found that parents did not show good understanding of the impact of asthma on their children's lives. Perhaps because their perception is supported by the observation of the clinical manifestations of the disease, such as cough, dyspnea, night awakening, use of bronchodilators, number of visits to emergency rooms in the past month, among others. This finding suggests that in children aged 7 to 12 years, clinicians cannot totally rely on parents' report to control children's QoL. Whenever children provide reliable and valid information about their experiences related to the disease, such

data should be taken into consideration. Parents' perception should be used as supplementary information<sup>(6,15)</sup>.

With regard to adolescents and their parents, the results showed that parents can obtain information with the report of experiences of their children's daily lives considering that children have moderate understanding of the disease. Clinicians should generally rely on adolescents reports because their parents tend to report only what they observe and not what adolescents actually experience<sup>(13,14)</sup>.

There are differences in the administration of the questionnaire to children and adolescents regarding the understanding of the "concept" of what is real and what is subjective, i.e., the younger age groups may provide empirically reliable reports on the concept of health, such as pain and use of medications, but they do not understand the concept associated with the emotional impact of the disease, which is well reported by the older age groups and adolescents<sup>(9,16,17)</sup>. The level of understanding of written language and the reading ability can also restrict the age-appropriateness of the questionnaire<sup>(9,16,17)</sup>. While assessing the QoL of children, it is important to bear in mind that children participate in multiple social contexts, including the relationship with parents and family functioning,

**Table 4** - Agreement between adolescents and their parents' answers in the administration of the questionnaire Pediatric Asthma Quality of Life Questionnaire - Adapted

	Kappa coefficient	Agreement	p-value
Domain symptoms			
1. Cough	0.168	Weak	0.050
2. Asthma attack	0.322	Poor	<0.001
3. Wheezing	0.235	Poor	0.010
4. Chest tightness	0.300	Poor	<0.001
5. Shortness of breath	0.152	Weak	0.100
6. Fatigue	0.354	Poor	<0.001
7. Night awakening	0.170	Weak	0.070
8. Feel breathless	0.032	Weak	0.750
9. Trouble sleeping	-	Perfect	0.530
10. Trouble breathing deeply	0.097	Weak	0.340
Domain emotions			
1. Feel frustrated	0.156	Weak	0.120
2. Feel worried	0.397	Poor	<0.001
3. Feel angry	0.361	Poor	<0.001
4. Feel left out	0.212	Poor	0.050
5. Feel bothered by not being able to be with other people	0.268	Poor	0.010
6. Uncomfortable	0.425	Fair	<0.001
7. Terrified by asthma attack	0.253	Poor	0.010*
8. Feel angry	0.156	Weak	0.120
Domain activities			
1. Feel bothered by not being able to be with other people	-0.051	Unsatisfactory	0.620
2. Feel bothered while performing activities in the past week	0.231	Poor	0.030*

\*Due to the impossibility of calculating the Kappa coefficient (data matrix was not symmetric), we calculated the Spearman's correlation coefficient

their peers, the school, and the community. Each of these contexts contributes to the impact of the disease and its treatment, being qualitatively different for children and adults.

To implement the assessment of health-related QoL in children, researchers need to assess whether the instrument is appropriate for the age group, considering instructions, vocabulary, sentence structure, content, answer options, contextual factors, and cognitive and cultural differences<sup>(8,18)</sup>. Another important aspect is that due to the greater variability of answers expected from children belonging to younger age groups, a larger sample is needed to determine the effect of treatment on the QoL.

Thus, the determinant of QoL assessment in children and adolescents is complex and efforts should be focused on traditional clinical and laboratory assessments, as well as on QoL assessments. Whenever children are able to provide valid and reliable information, their report is the ideal strategy, because it is consistent with the definition of health-related QoL that emphasizes the patient's subjective perspective<sup>(9,11,13,19)</sup>. Some researchers suggest collecting information from children and their parents. This perspective can provide the impact of the

disease and treatment, and influence in the lives of children and adolescents and their families<sup>(8,20,21)</sup>. Studies have examined this issue by assessing the degree of agreement between parents and children's reports. The assumption is that a high level of agreement would indicate that both the child/adolescent and the parents could answer questionnaires assessing the QoL of children and adolescents<sup>(4,16,17,22,23)</sup>. However, this satisfactory agreement was not found in the present study, suggesting that, especially among children, the parents' perception of the QoL of asthmatic children is very different from that perceived by children. With respect to adolescents, there was a better agreement, although it was perfect in only one item related to sleeping difficulty. Nevertheless, the worst agreement was found between adolescents and their parents' answers in the domain activities.

In case of disagreement, researchers and health professionals need to determine which report is more reliable or appropriate for the studies. The degree of agreement may depend on several factors, such as domains of the questionnaire, children and adolescent's age, and parents and caregivers' perception of the children's health and disease. For example, agreement has been shown to be higher for the domain activities compared to the domain

emotions. With regard to age, older age is associated with greater agreement<sup>(16,24)</sup>, which is in agreement with our study.

Another relevant issue, which has not been well defined, is whether parents are the most appropriate adult respondents. Some children may spend more time with the teacher, nanny or another family member than with parents, and these caregivers may have a more accurate view of the child's physiological and social aspects<sup>(8,21,25)</sup>. In Brazil, there is shortage of data regarding the reliability of the information provided by caregivers.

Therefore, QoL is considered a measure of clinical outcome that prioritizes the patient's own subjective assessment of the effects of a disease or its treatment on daily life and their level of satisfaction and well-being<sup>(5,26)</sup>.

The present study highlights aspects to be considered in the administration of instruments developed and validated to assess QoL among children and adolescents. The first aspect is related to the generic and specific instruments used, which are originally designed in other countries and validated in Brazil. We need to consider the huge inter-regional

differences in Brazil, what makes some questions confusing and difficult to be understood in different places. Another aspect to consider is the cognitive development of children and adolescents, which needs to be respected when assessing the QoL of asthmatic children and adolescents, considering that patients' self-report needs to be analyzed and complemented with information provided by parents.

The PAQLQ-A was not well understood by our sample. The agreement rate between parents and children/adolescents' answers was not satisfactory, and the lowest degree of agreement was found between children and parents. To minimize problems related to the administration of validated international instruments, we recommend the development of instruments adapted to the regional characteristics or even international revalidation in order to meet the regional needs. Additionally, we suggest the development of communication strategies between health professionals, children, and parents with the purpose of achieving better assessment of the impact of asthma on the several life dimensions of children, adolescents, and their families.

## References

1. Autoria não referida. IV Brazilian Guidelines for the management of asthma. *J Bras Pneumol* 2006;32 (Suppl 7):S447-74.
2. Carr AJ, Gibson B, Robinson PG. Measuring quality of life: is quality of life determined by expectations or experience? *BMJ* 2001;322:1240-3.
3. Juniper EF. How important is quality of life in pediatric asthma? *Pediatr Pulmonol* 1997;15 (Suppl):17-21.
4. Guyatt GH, Juniper EF, Griffith LE, Feeny DH, Ferrie PJ. Children and adult perceptions of childhood asthma. *Pediatrics* 1997;99:165-8.
5. Wilke RJ, Burke LB, Erickson P. Measuring treatment impact: a review of patient-reported outcomes and other efficacy endpoints in approved product labels. *Control Clin Trials* 2004;25:535-52.
6. Segre M, Ferraz FC. The concept of health. *Rev Saude Publica* 1997;31:538-42.
7. Juniper EF, Guyatt GH, Epstein RS, Ferrie PJ, Jaeschke R, Hiller TK. Evaluation of impairment of health related quality of life in asthma: development of questionnaire for use in clinical trials. *Thorax* 1992;47:76-83.
8. Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in the parents of children with asthma. *Qual Life Res* 1996;5:27-34.
9. La Scala CS, Naspitz CK, Solé D. Adaptation and validation of the Pediatric Asthma Quality of Life Questionnaire (PAQLQ) in Brazilian asthmatic children and adolescents. *J Pediatr (Rio J)* 2005;81:54-60.
10. Brasil - Secretaria de Atenção à Saúde - Departamento de Ações Programáticas Estratégicas. Marco teórico e referencial: saúde sexual e saúde reprodutiva de adolescentes e jovens. Brasília: Ministério da Saúde; 2006.
11. Andrade AL, Zicker F. Estudos de prevalência. In: Organização Pan-americana da Saúde. Fundação Nacional de Saúde. Métodos de investigação epidemiológica em doenças transmissíveis: manual do instrutor. Brasília: Funasa; 1997. p. 33-42.
12. Cassol VE, Solé D, Menna-Barreto SS, Teche SP, Rizzato TM, Maldonado M *et al*. Prevalence of asthma among adolescents in the city of Santa Maria, in the state of Rio Grande do Sul, Brazil. *International Study of Asthma and Allergies in Childhood (ISAAC) Project. J Bras Pneumol* 2005;31:191-6.
13. Wright JG, Young NL. A comparison of different indices of responsiveness. *J Clin Epidemiol* 1997;50:239-46.
14. Katz JN, Larson MG, Phillips CB, Fossel AH, Liang MH. Comparative measurement sensitivity of short and longer health status instruments. *Med Care* 1992;30:917-25.
15. Fernandes AL, Oliveira MA. Avaliação da qualidade de vida na asma. *J Pneumol* 1997;23:148-52.
16. Theunissen NC, Volges TG, Koopman HM, Verrips GH, Zwiderman KA, Verloove-Vanhorick SP *et al*. The proxy problem: child report versus parent report in health-related quality of life research. *Qual Life Res* 1998;7:387-97.
17. Rebok G, Riley A, Forrest C, Starfield B, Green B, Robertson J *et al*. Elementary school-aged children's reports of their health: a cognitive interviewing study. *Qual Life Res* 2001;10:59-70.
18. Reichenberg K, Broberg AG. Quality of life in childhood asthma: use of the Paediatric Asthma Quality of Life Questionnaire in a Swedish sample of children 7 to 9 years old. *Acta Paediatr* 2000;89:989-95.
19. Kirkwood BR. *Essentials of medical statistics*. Oxford: Blackwell Science; 1988.
20. Burbach DJ, Peterson L. Children's concepts of physical illness: a review and critique of the cognitive-developmental literature. *Health Psychol* 1986;5:307-25.
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;10:347-57.
22. Clarke SA, Eiser C. The measurement of health-related quality of life (QOL) in paediatric clinical trials: a systematic review. *Health Qual Life Outcomes* 2004;2:66.
23. Annett RD. Assessment of health status and quality of life outcomes for children with asthma. *J Allergy Clin Immunol* 2001;107 (Suppl 5):S473-81.
24. April KT, Feldman DE, Platt RW, Duffy CM. Comparison between children with Juvenile Idiopathic Arthritis (JIA) and their parents concerning perceived Quality of Life. *Qual Life Res* 2006;15:655-61.
25. Osman LM, Baxter-Jones AD, Helms PJ; EASE Study Group. Parents' quality of life and respiratory symptoms in young children with mild wheeze. *Eur Respir J* 2001;17:254-8.
26. Christakis DA, Johnston BD, Connell FA. Methodologic issues in pediatric outcomes research. *Ambul Pediatr* 2001;1:59-62.