

Assessing proxy reports: agreement between children with asthma and their caregivers on quality of life

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ABSTRACT

Background: Health-related quality of life (HRQOL) questionnaires are important tools to evaluate health status in children with asthma; however, children with asthma and their caregivers have shown only low to moderate agreement in their responses.

Objective: To analyze the agreement between children with asthma and their caregivers on HRQOL, specifically in the domains of activity limitation, emotional function, and overall quality of life (QOL).

Methods: We enrolled 79 pediatric patients (ages 5–17 years) with asthma (53 with acute asthma and 26 with refractory asthma) and their caregivers. Children completed the Pediatric Asthma Quality of Life Questionnaire, and caregivers completed the Pediatric Asthma Caregiver's Quality of Life Questionnaire (potential score, 1–7; higher scores indicate better QOL). We used paired *t* test to examine differences in child and caregiver responses, Pearson correlation to describe patterns of agreement, and multivariate analysis to evaluate the effect of sex, age, and ethnicity on differences in child and caregiver responses.

Results: Children with asthma and their caregivers reported similar scores and demonstrated moderate correlation in emotional function and overall QOL. Children reported a significantly better QOL than their caregivers in response to questions about activity limitation (mean score, 4.62 vs 3.49; *P* < .001). Male children were more likely to differ from their caregivers than females, especially in regard to activity limitation.

Conclusion: Although caregivers of children with asthma can provide useful proxy information about QOL, their responses cannot be substituted for their children's reports regarding activity limitation. Clinicians and researchers should ask both children and their caregivers about asthma-specific QOL.

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Introduction

Asthma is a chronic disease with high morbidity that affects an estimated 7.1 million children in the United States.¹ The disease is a notable health care burden that is associated with an estimated 5.6% of all annual pediatric hospitalizations and 2% of all pediatric physicians' office visits.² Not only are children bothered by the physical symptoms of asthma, including chest tightness, cough, wheeze, and shortness of breath, but their quality of life (QOL) is also

affected. One study found that 45% of adolescents with asthma reported feeling depressed, whereas another noted a significant difference in frequency of participation in physical activities between healthy children and those with asthma.^{3,4} In 2008 alone, 10.5 million missed school days were attributed to asthma.¹ Asthma also affects the QOL of patients' families and primary caregivers, resulting in days missed from work and interference with family activities. In addition, caregivers of children with asthma often worry about their child's well-being.⁵ Despite increasing knowledge of disease pathophysiology and new intervention and management strategies, pediatric asthma continues to be a national problem.²

Asthma is particularly concerning in the pediatric population because the disease prevalence is higher in children than adults.⁶ Investigating the effect of asthma on children is difficult and presents unique challenges. The "4 D's of childhood"—"developmental change, dependence on adults for accessing care and implementing treatments, different disease epidemiology from adults, and demographic characteristics unique to childhood"—are variables that increase the complexity of asthma outcomes research in the

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pediatric population.⁷ Given these challenges, researchers have sought to determine appropriate and valid methods of assessing a child's burden of disease. Health-related quality of life (HRQOL) questionnaires are potential tools to monitor disease status and help guide clinical management.

HRQOL is patient specific and has been defined as “the functional effects of an illness and its consequent therapy on a patient, as perceived by the patient.”⁸ Evaluation of HRQOL in asthma is a vital component of patient assessment because QOL and measurements of clinical asthma control have been found to be only moderately correlated at best.^{5,9–11} Accordingly, most experts agree that QOL instruments and clinical measures of asthma control measure 2 independent aspects of health status, such that each should be assessed individually.^{5,12,13}

Evaluation of health status in pediatric asthma is challenging. In the pediatric population, health care practitioners must rely on the caregiver, the child, or both to gauge symptoms and disease effect on QOL. Although caregivers can provide a proxy report, children as young as 7 years have been found to be dependable reporters of their health status with acceptable reliability and validity.¹⁴ However, previous studies have generally found only low to moderate correlation between caregiver and child responses to various HRQOL questionnaires.^{5,9,15–17} Because there is currently no criterion standard to evaluate QOL in children with asthma, it is important to understand the association between child and caregiver responses on HRQOL questionnaires.

We studied children with asthma and their primary caregivers to assess their overall QOL and disease effect on activity limitation and emotional function. The purposes of this study were to analyze the association between caregiver and child responses and to assess their agreement in each of the domains (activity limitation, emotional function, and overall QOL).

Methods

Study Participants

We used enrollment and first follow-up visit data from a single-center prospective cohort study that assessed the frequency of *Mycoplasma pneumoniae* in pediatric patients with asthma and healthy children.¹⁸ Data were collected between December 2010 and August 2012. We enrolled 79 children with asthma (5–17 years old). All caregivers and children 7 years and older completed QOL assessments; a few children younger than 7 years (3 children 5 years old and 4 children 6 years old) completed the questionnaire.

We enrolled 2 groups of children with asthma: children with a known diagnosis of asthma who were hospitalized for an acute asthma exacerbation (53 children) and children with refractory or difficult to control asthma (moderate to severe persistent asthma) who were recruited during routine outpatient clinic visits (26 children). The refractory asthma group represented children with ongoing asthma symptoms after appropriate medical management, including mitigation of asthma triggers, exclusion of alternative diagnoses, confirmation of treatment adherence, and optimal treatment of other comorbidities.¹⁹ The diagnosis of asthma was based on physician assessment according to national guidelines.²⁰ Exclusion criteria included a diagnosis of pulmonary disease other than asthma (eg, interstitial lung disease, pulmonary hypertension, and bronchopulmonary dysplasia) or other significant medical conditions (eg, cerebral palsy, acute hypertension, active heart failure, cardiac arrhythmias, pregnancy, cancer requiring treatment, and human immunodeficiency virus).

The institutional review board of the University of Texas Health Science Center at San Antonio approved this study. After the study was explained to them, all caregivers of participants signed an institutional review board–approved consent form in English or Spanish, depending on language preference.

QOL Assessment Instruments

Pediatric Asthma Quality of Life Questionnaire with Standardized Activities

The Pediatric Asthma Quality of Life Questionnaire with Standardized Activities (PAQLQ[S]) is a 23-item, self-reported assessment of asthma effect on QOL and is designed for children 7 years and older.¹¹ In general, research assistants read the questions to children, whereas older children were allowed to complete the questionnaire alone. Children and caregivers are interviewed in separate rooms so that respondents do not influence one another. The PAQLQ[S] is divided into 3 domains that contribute to an overall QOL score: activity limitation (5 items), emotional function (8 items), and symptoms (10 items). Seven-point Likert scales are used to assess limitations in normal daily activities, the degree to which the child felt bothered by his disease during the past week, and the frequency of symptoms (eg, 1 indicates all of the time and 7 indicates none of the time). The total score for items in a specific domain and for the entire questionnaire is divided by the number of items to create a domain score or total score, respectively; scores range from 1 to 7, with higher scores indicating better QOL. The minimal clinically important difference in scores (0.5) is defined as “the smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side-effects and excessive cost, a change in the patient's management”.²¹ We calculated scores for each domain and for overall QOL. The PAQLQ[S] is a good evaluative and discriminative instrument with high reliability.^{10,11}

The Pediatric Asthma Caregiver's Quality of Life Questionnaire

The Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) is a 13-item assessment of disease effect on the QOL of caregivers of children ages 7 to 17 years with asthma.²² The PACQLQ is divided into 2 domains that contribute to an overall QOL score: activity limitation (4 items) and emotional function (9 items). Seven-point Likert scales are used to assess the frequency of disruption of family or caregiver activities attributed to the child's asthma during the past week (activity limitation) and the degree to which caregivers believe that their child's asthma has worried or concerned them (emotional function) (eg, 1 indicates all of the time and 7 indicates none of the time). Scores range from 1 to 7, with higher scores indicating better QOL. The minimal clinically important difference in scores is 0.5.²¹ The PACQLQ is a good evaluative and discriminative instrument.^{22,23}

Statistical Analysis

We used SPSS statistical software (version 20.0; SPSS Inc, Chicago, Illinois) to analyze the data. We calculated the PAQLQ[S] and PACQLQ scores at enrollment for each domain (eg, activity limitation and emotional function) and overall QOL for the acute asthma group, the refractory asthma group, and both groups combined (all study participants). We examined data for normality and other specific test assumptions, such as homogeneity of variance. We used χ^2 or Fisher exact tests to analyze frequencies. Two-tailed paired *t* tests were used to examine differences between child and caregiver responses and comparisons between enrollment and follow-up visit. We used Pearson correlation coefficients to examine the pattern of association between child and caregiver responses. We tested for differences in the degree of correlation between child and caregiver responses across QOL domains with the Steiger *z* test.^{24–26}

Pearson correlation coefficients were calculated to assess the association of child age to differences between child and caregiver responses. Similarly, point-biserial correlations were calculated to analyze the association of dichotomous variables (eg, sex and ethnicity) to these differences. We then used stepwise regression

analysis to determine the effect of child age, sex, and ethnicity on differences in child and caregiver responses. We interpreted correlation coefficients of less than 0.36 as low, 0.36 to 0.67 as moderate, and greater than 0.67 as strong.²⁷ $P \leq .05$ was considered statistically significant.

Results

Baseline Demographics

We enrolled 79 children and their caregivers; 53 had acute asthma and 26 had refractory asthma. In the acute asthma group, 9 children did not complete questionnaires (because of age <7 years), and 2 caregivers failed to complete questionnaires, resulting in 42 pairs. In the refractory asthma group, 1 child did not complete a questionnaire (age <7 years), resulting in 25 pairs. Twenty-nine child-caregiver pairs (11 in the acute asthma group and 18 in the refractory asthma group) completed at least 1 follow-up visit 2 to 13 months after enrollment.

Fifty-eight children (73%) enrolled were males, 39 children (49%) were white, and 59 (75%) identified themselves as Hispanic (predominantly Mexican American). Seventy-six caregivers (96%) were female and 78 (99%) were English speaking. All continuous variables, including age, body mass index (BMI), and QOL scores, were distributed normally. Baseline demographic information was analyzed, and no significant difference in child sex, mean age, race, or ethnicity was found between the asthma groups. A significantly higher BMI percentile was noted in the refractory asthma group (mean [SD], 79.14 [28.4]) when compared with patients in the acute asthma group (mean [SD], 62.81 [36.8]) ($P = .047$) (Table 1).

Child-Caregiver Response Agreement

Children and their caregivers had similar scores for overall QOL in both the acute asthma group and the combined groups. Children reported a slightly higher mean score than their caregivers, but the difference was not statistically significant (3.91 vs 3.80, $P = .62$, for the acute asthma group and 4.23 vs 3.91, $P = .07$, for the combined groups). Results for the emotional function domain were similar (4.16 vs 4.00, $P = .48$, for the acute asthma group and 4.41 vs 4.09, $P = .08$, for the combined groups). In contrast, for the activity limitation domain, children and their caregivers differed significantly in their responses. Children reported a significantly higher mean score, indicating better QOL, for activity limitation compared with their caregivers. This was true in the acute and refractory asthma groups and the combined group (4.35 vs 3.36, $P = .001$, 5.07 vs 3.71, $P = .002$, and 4.62 vs 3.49, $P < .001$, respectively). In addition to this observed difference in child and caregiver scores for activity limitation, the refractory asthma group also demonstrated significant child and

caregiver differences for overall QOL and emotional function (Table 2 and Fig 1).

Eleven child-caregiver pairs in the acute asthma group and 18 child-caregiver pairs in the refractory asthma group completed QOL questionnaires at both enrollment and follow-up visits. The difference between child and caregiver scores within pairs at the follow-up visit was not statistically different from enrollment. This was true in all 3 domains for both the acute asthma group (mean child-caregiver difference at enrollment vs follow-up, 1.65 vs 1.79, $P = .73$, for activity limitation; 1.16 vs 1.80, $P = .09$, for emotional function; 0.93 vs 1.30, $P = .46$, for overall QOL) and the refractory asthma group (mean child-caregiver difference at enrollment vs follow-up, 1.39 vs 1.33, $P = .90$, for activity limitation; 0.74 vs 0.55, $P = .62$, for emotional function; and 0.81 vs 0.72, $P = .81$, for overall QOL).

The difference in child and caregiver scores was calculated for each pair of respondents in each domain. We calculated how often this difference in scores was clinically important (a difference of ≥ 0.5). In the combined asthma group, 44 (66%) of the child-caregiver pairs differed by 0.5 or more; this was true in all domains. The frequency of clinically important differences in child and caregiver scores was highest in the activity limitation domain and lowest in overall QOL (60 pairs [89.6%] vs 45 pairs [67.2%], respectively, $P = .009$). The acute and refractory asthma groups were similar in the frequency of minimal clinically important difference between child and caregiver scores.

Another way to analyze child and caregiver responses is to look at the pattern of correlation between their responses, regardless of the score. Child and caregiver responses demonstrated low to moderate positive and statistically significant correlation in overall QOL ($r = 0.33$, $P = .03$, and $r = 0.51$, $P = .009$, in acute and refractory subgroups, respectively). Similarly, child and caregiver responses were moderately correlated in the emotional function domain. This pattern was seen in both asthma groups, and the correlation was highest in the refractory asthma group ($r = 0.40$, $P = .009$, and $r = 0.60$, $P = .001$ for acute and refractory asthma, respectively).

Child and caregiver responses were not significantly correlated for activity limitation; this was true in both asthma groups. The degree of correlation was significantly lower in the activity limitation domain compared with the emotional function and overall QOL domains ($z = -2.31$, $P = .02$; $z = -2.26$, $P = .02$, respectively, for pairwise differences). The degree of correlation in child and caregiver responses was similar in the emotional function and overall QOL domains ($z = -1.27$, $P = .20$) (Fig 2).

Table 2
PAQLQ and PACQLQ scores at enrollment

	Child mean score	Caregiver mean score	Two-tailed paired <i>t</i> test <i>P</i> value ^a	Pearson correlation (<i>r</i>) ^b
Acute asthma group				
Activity limitation (n = 42)	4.35	3.36	.001	0.20 ($P = .20$)
Emotional function (n = 42)	4.16	4.00	.48	0.40 ($P = .009$)
Symptoms (n = 44)	3.48			
Overall quality of life (n = 42)	3.91	3.80	.62	0.33 ($P = .03$)
Refractory asthma group				
Activity limitation (n = 25)	5.07	3.71	.002	0.24 ($P = .25$)
Emotional function (n = 25)	4.82	4.24	.046	0.60 ($P = .001$)
Symptoms (n = 25)	4.53			
Overall quality of life (n = 25)	4.75	4.07	.03	0.51 ($P = .009$)
Combined groups				
Activity limitation (n = 67)	4.62	3.49	<.001	0.24 ($P = 0.06$)
Emotional function (n = 67)	4.41	4.09	.08	0.50 ($P < .001$)
Symptoms (n = 69)	3.86			
Overall quality of life (n = 67)	4.23	3.91	.07	0.43 ($P < .001$)

Abbreviations: PACQLQ, Pediatric Asthma Caregiver's Quality of Life Questionnaire; PAQLQ, Pediatric Asthma Quality of Life Questionnaire.

^aDifference between child and caregiver score.

^bCorrelation between child and caregiver score.

Table 1
Baseline characteristics of the study population^a

Characteristics	Acute asthma (n = 53)	Refractory asthma (n = 26)	<i>P</i> value ^b
Age, y	9.5 (3.0)	10.6 (2.6)	.13
Male, No. (%)	38 (71.7)	20 (76.9)	.62
Race			.33
White	29 (54.7)	10 (38.5)	
Black	10 (18.9)	6 (23.1)	
American Indian	1 (1.9)	0 (0)	
Asian	2 (3.8)	0 (0)	
Other	11 (20.8)	10 (38.5)	
Hispanic, No. (%)	40 (75.5)	19 (73.1)	.82
BMI percentile	62.8 (36.8)	79.1 (28.4)	.047
Spanish-speaking caregiver	1 (1.9)	0	>.99

Abbreviation: BMI, body mass index (calculated for age and sex).

^aData are presented as mean (SD) unless otherwise indicated.

^b*P* value for difference between groups.

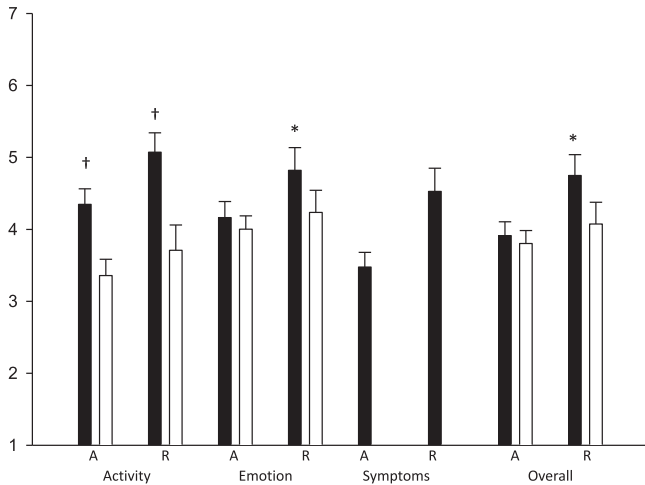


Figure 1. Quality-of-life child and caregiver responses by group. Mean child (dark bars) and caregiver (light bars) responses in acute (A) and refractory (R) asthma groups by domain (activity, emotional, symptoms, and overall). * $P \leq .05$ and † $P \leq .01$ for child-caregiver difference.

Effect of Sex on Child-Caregiver Agreement

We found differences in child-caregiver agreement based on sex. In general, male children were more likely to differ from their caregivers than female children. Male children reported higher scores than their caregivers in all domains, indicating better QOL. This difference was significant in the activity limitation domain ($P < .001$) and emotional function and overall QOL in the combined groups ($P = .02$ and $P = .009$, respectively). In contrast, female children did not differ significantly from their caregivers in reported activity limitation. In addition, female children reported lower scores than their caregivers in all domains in the acute asthma group and in the emotional function and overall QOL domains in both groups combined, although most differences were not statistically significant (Fig 3).

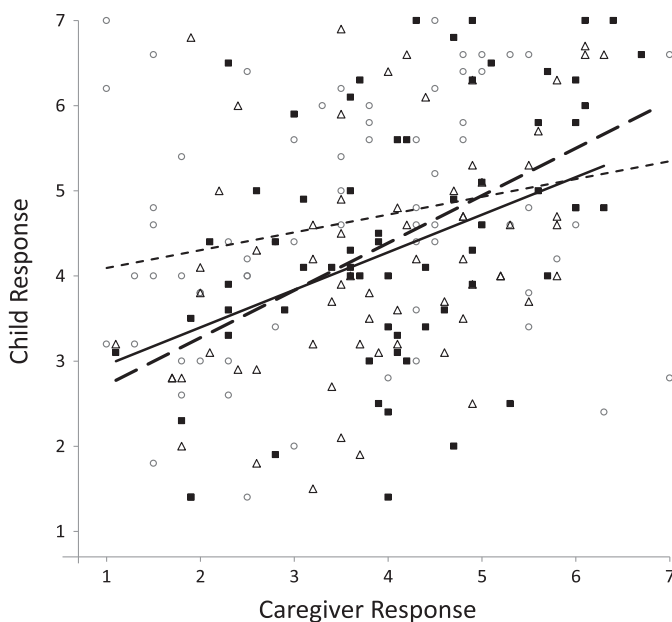


Figure 2. Child and caregiver quality-of-life responses by domain. Child-caregiver pairs and fitted line by domain: activity (solid circles, dotted line, $r = 0.23^*$), emotional (open squares, dashed line, $r = 0.50^\dagger$), overall (solid triangles, solid line, $r = 0.43^\dagger$). $P = .02$ for * vs †.

Although more likely to significantly differ from their caregivers in their responses, male respondents were also more likely to correlate with their caregivers in their response patterns. For combined groups, male children and their caregivers had moderate correlation in overall QOL and emotional function ($r = 0.466$, $P = .001$, and $r = .54$, $P < .001$, respectively). Lower correlation was seen in the activity limitation domain ($r = 0.365$, $P = .01$). In contrast to the male children, female child and caregiver responses did not correlate significantly in any of the domains.

Multivariate Analysis of Differences in Child and Caregiver Responses

We initially performed the Pearson correlation and point biserial correlations to examine the effect of child age, sex, and ethnicity on the difference in child and caregiver responses. As expected, only sex correlated significantly with the difference in responses in that male children were more likely than females to differ from their caregivers. This was true for the activity limitation domain and overall QOL ($r = 0.360$, $P = .003$, and $r = 0.283$, $P = .02$, respectively). Subsequently, we used stepwise regression to further characterize the effect of sex, child age, and ethnicity (independent variables) on the difference in child and caregiver responses (dependent variable). Male children were more likely than female children to differ from their caregiver in activity limitation and overall QOL ($\beta = 0.360$, $t_{3,113}$, $P = .003$, and $\beta = 0.283$, $t_{2,377}$, $P = .02$, respectively). Sex explained a significant proportion of variance in child and caregiver differences in activity limitation and overall QOL ($R^2 = 0.130$, $F_{1,65} = 9.69$, $P = .003$, and $R^2 = 0.080$, $F_{1,65} = 5.651$, $P = .02$, respectively).

Child and Caregiver Response Styles

We evaluated the frequency of Likert scale response choices of child and caregiver respondents for each specific question to determine selection patterns. We used these data to evaluate whether children and their caregivers displayed a tendency to select extreme responses, such as “none of the time” or “all of the time,” rather than using the full range of options available on the Likert scale. Approximately 30% to 50% of children and caregivers responded to specific questions with either a 1 or 7 (extremes of the scale), and the remainder rated their QOL somewhere between these extremes (ie, they selected a response between 2 and 6). Children and caregivers in both asthma groups demonstrated this response pattern. Thus, we

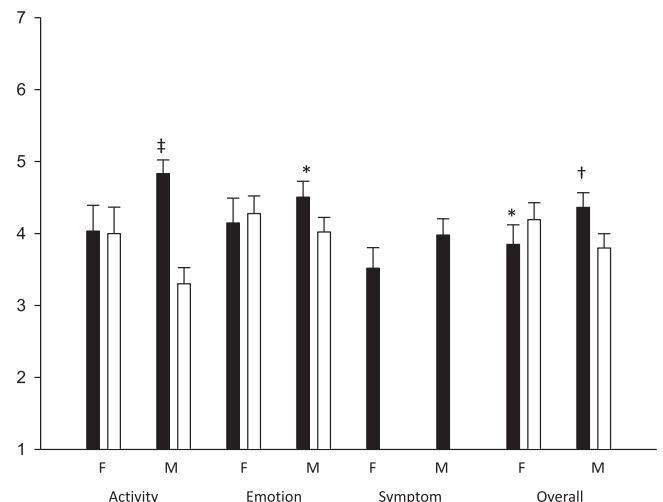


Figure 3. Quality-of-life child and caregiver responses by sex. Mean child (dark bars) and caregiver (light bars) responses by domain. * $P \leq .05$, † $P \leq .01$, and ‡ $P \leq .001$ for child-caregiver difference.

did not find a tendency for either children or their caregivers to favor selection of extreme responses in either direction.

Discussion

This study demonstrates that physicians should ask both children and their caregivers about the effects of asthma on a child's QOL, especially with regard to disease effect on activity limitation. Our data further contribute to increasing evidence that caregiver reports cannot be used in place of a child's report about disease-specific QOL.^{5,16,28,29} We found that children and their caregivers were most likely to differ significantly on the activity limitation subscale. Child-caregiver pairs had less difference in scores and higher levels of correlation for emotional function and overall QOL. Thus, our data agree with previous literature that the degree of child-caregiver agreement on HRQOL questionnaires depends on the specific domain studied.^{17,28} Our study is unique in that we enrolled children with an acute asthma exacerbation and children with chronic asthma and found similar patterns of child-caregiver responses in these 2 groups.

In the activity limitation domain, we found that children generally felt less limited and reported higher scores than did their caregivers. However, caregivers were asked to report on the effect of asthma on family activities rather than on the child's physical activities. Thus, the 2 questionnaires provide information on related but not identical constructs. A previous study by Erikson et al,³⁰ using the PAQLQ and PACQLQ in children 9 to 17 years of age, found that children rated their activity limitation lower than did their caregivers. These opposite results could be attributed to differences in study population. Our study included a higher proportion of young children and males than did the study by Erikson et al. Asthma in young children may have a greater effect on the activities of the family, whereas older children may function more independently, and thus, caregivers may be less aware of their child's limitations. Our study included a high proportion of male children, who were more likely to report higher scores in activity limitation than female respondents. Our cohort may represent a group of less active children, given the high BMI percentiles noted in our enrolled study participants. These children might report less activity limitation because they are sedentary, whereas their caregivers' ratings are based on the disease effect on family activities. Erikson et al³⁰ found that caregivers had higher scores in the activity limitation domain (indicating better QOL) when household income was higher, the child had longer enrollment in a specialty clinic, and when the caregiver thought that seeing the child's physician was convenient. It is possible that our cohort includes families with little access to asthma care, especially within the acute asthma group, such that caregiver scores in the activity domain are lower than those reported in previous studies. Without an independent criterion standard for assessment, it is difficult to know whether children or their caregivers are more accurate in assessing QOL.

In our study, caregiver and child emotional function responses tended to be moderately correlated. Correlation was generally highest in the emotional function domain in the refractory asthma group. Children with chronic asthma symptoms and their caregivers have had the opportunity to share the day-to-day experience of asthma over time and thus may exhibit stronger agreement in their assessment of the effect of asthma on emotional function. A previous systematic review reported different findings, with generally low correlations ($r < 0.3$) for domains that were non-observable (ie, social or emotional).²⁸ This previous review, however, included children with a number of different chronic diseases, not just asthma. Accordingly, our results demonstrate that children with the specific diagnosis of asthma may communicate better with their caregivers and are thus more in sync in recognizing the disease's effect on the child's QOL.

We found that child-caregiver agreement was similar at enrollment and follow-up in both asthma groups across all domains. It is not surprising that there was no difference in agreement over time in the refractory group because these children and their caregivers had likely become accustomed to the chronic effect of the disease on the child's QOL, such that their pattern of agreement remained similar. However, child-caregiver agreement in the acute asthma group was also similar over time, despite enrollment during an acute exacerbation and follow-up when their asthma was more stable. These findings bear further exploration in future studies with a larger sample.

Although one previous study found no effect of sex on PAQLQ scores,³⁰ our study results indicate that sex had a significant effect on child-caregiver response agreement. Female respondents typically reported lower scores than their caregivers (although not statistically different), and their responses did not correlate significantly with caregiver responses. Male respondents, on the other hand, differed significantly from their caregivers in all domains, especially in the activity limitation domain where male child scores were higher than their caregivers. In our study, lower female respondent scores on the symptoms subscale likely lowered the overall QOL scores reported by female children. It is also possible that male children were downplaying the effect of their illness so as not to seem weak or vulnerable, especially with regard to physical activity.

Our study did not find a significant effect of age on child-caregiver agreement across any of the domains studied. In contrast, a previous study reported that child-caregiver agreement improved with increasing age of the child.²³ Similarly, another study demonstrated that children 11 years and older were good reporters of asthma health status and QOL, whereas caregiver reports provided additional information for younger children.³¹ Our study may have lacked sufficient statistical power to demonstrate the effect of age on child-caregiver agreement.

The differences we found between child and caregiver responses were not explained by a tendency of either group to respond more frequently on the extremes of the Likert scale (1 or 7). Both child and caregiver respondents generally used the full scale across almost all questions on the PAQLQ and PACQLQ, respectively. Previous studies have found conflicting results regarding response patterns. Davis et al³² found that children were more likely to give extreme scores than their caregivers, whereas Theunissen et al³³ found that child scores tended to be less extreme than caregiver scores. In contrast to the 2 previous studies cited, our study was limited to children with asthma and included children older than 12 years. It is possible that older children used the full scale, and children with asthma were more accustomed to rating their health status than healthy children or children with other illnesses.

Our study had a few limitations. The PAQLQ is validated for children 7 years and older; however, we administered the questionnaire to a total of 7 children who were 5 or 6 years old based on the research assistant's subjective evaluation of the child's capability. This could have affected our outcomes if these young children actually were not able to comprehend the questions. In addition, the caregivers enrolled in our study were overwhelmingly female. This may have skewed our data on caregiver responses and our interpretation of the agreement between children with asthma and their caregivers. One prior study reported that fathers and children had greater agreement than mothers and their children.¹⁶ Because our study population included few female participants (a reflection of the male predominance in pediatric asthma), we were unable to fully assess the effect of sex on child-caregiver agreement. Similarly, few African American children were enrolled in our study, so we were unable to fully examine child-caregiver patterns in this group of children, who have a higher prevalence, hospitalization rate, number of emergency department visits, and mortality rate compared with

other races.³⁴ Finally, although the PAQLQ and PACQLQ are designed to address the most common concerns of children with asthma and their caregivers, these instruments may not necessarily measure all of the problems that every individual would find to be important.³⁵

Caregivers of children with asthma can provide useful proxy information about asthma-related QOL. However, children and their caregivers do not always agree, particularly in their assessment of activity limitation due to asthma. Thus, it is critical to obtain information from both parties in the evaluation of children with asthma. Future research is needed to determine the role of language, caregiver sex, and disease severity on differences between child and caregiver responses to QOL questionnaires.

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