EMOTIONAL QUALITY-OF-LIFE AND OUTCOMES IN ADOLESCENTS WITH ASTHMA

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Objective  Examine the association between emotional quality-of-life (QOL) and asthma morbidity in adolescents with asthma.

Study design  Cross-sectional survey of 185 adolescents with asthma 11 to 17 years of age cared for in three managed care organizations (MCOs) in the United States. The asthma-specific Pediatric Asthma Quality of Life Questionnaire (PAQLQ) and a short version of the generic Child Health and Illness Profile-Adolescent Edition (CHIP-AE) were used to assess emotional QOL. Asthma morbidity measures were: asthma control, emergency department (ED) visits, hospitalizations, doctor visits for worsening asthma, and missed school because of asthma.

Results  Of the adolescents surveyed, 45% reported feeling depressed, 41% had ED visits, and 30% missed ≥1 day of school because of asthma. Poorer asthma-specific emotional QOL was associated with poorer control of asthma symptoms (P < .0001), missed school (OR 7.1, P < .05), and doctor visits for worsened asthma (OR = 7.0, P < .05).

Conclusions  Emotional symptoms related to asthma are common in adolescents with persistent asthma and asthma-specific QOL is related to increased asthma morbidity, healthcare use, and school absenteeism. Adolescents with high morbidity from asthma exhibit poorer QOL. Therefore, the evaluation of asthma-specific emotional QOL should be included in the assessment of adolescents with asthma. (J Pediatr 2004;145:523-9)

Although regular assessment of quality-of-life (QOL) has been encouraged by national asthma guidelines, there is little evidence of what this means for adolescents with asthma. Measurement of QOL in adults is becoming more common, and increasing evidence suggests this can be useful in determining the impact of asthma therapy on patient perceptions of well-being. Physiologic measures of lung function in asthma, such as forced expiratory volume in one second, have been shown to be poor proxies for functional status and provide limited insight into the impact of disease. Thus, direct assessment of QOL is necessary to understand the impact of the disease on patients’ well-being. There has been less development of measures for adolescents, and it cannot be assumed that similar relationships to emotional QOL seen in adults with asthma will hold true for adolescents with asthma.

National asthma guidelines ask physicians to assess comprehensively patients’ health including evaluations of patients’ perceptions of the impact of asthma and asthma management on their QOL (eg, physical functioning and emotional well-being). Improving patient well-being is recommended as a primary goal of treatment. Therefore, it is important to include QOL as a dimension of outcome measurement.

In asthma, there are several reasons to examine adolescents as a unique group distinct from young children and adults. Evidence on asthma-specific QOL suggests that increased asthma symptoms are related to worse asthma-specific emotional QOL. However, few studies have focused on adolescents. Adolescents are developmentally more mature
than young children, so they may handle the emotional impact of asthma differently from young children. Adolescence is a period of emergence of independent thinking and behavior, which along with various stressors—such as peer pressure—may affect the interpretation of asthma symptoms and even adherence to the prescribed asthma therapy. It is not known if adolescence is also a period when the emotional impact of asthma changes.

The aims of this study are to understand the impact of asthma on the emotional QOL of adolescents with asthma and to examine the association of emotional QOL with functional consequences of asthma (missed school, doctor visits for worsening asthma, emergency department (ED) visits and hospitalizations).

**METHODS**

**Study Design**

Data were collected as part of a study to evaluate asthma and asthma care for 5- to 17-year-olds in three managed care organizations that volunteered to participate in the study. The current report focuses on adolescents 11 to 17 years of age. The study employed a cross-sectional survey of parents of children with asthma. Part of the survey also was completed by the child if he/she was ≥11 years of age. The study was approved by the Committee on Human Research of the Johns Hopkins Bloomberg School of Public Health. Individual informed consent was implied by return of the survey.

**Study Sites**

All participants were enrolled in three large MCOs in the Northeast and Midwest United States during the winter of 1997 to 1998. At least 300 children with asthma 5 to 17 years of age were identified in each MCO. To assure a sufficient number of adolescents, the sample frame was stratified by age (5-10 years and 11-17 years) with at least 150 children to be selected for each stratum.

There was a two-stage process to identify patients with asthma. In the first stage, MCOs used administrative data to identify potential asthma patients. Adolescents were identified who had two or more visits ( outpatient or inpatient) for asthma in the last 12 months (International Classification of Diseases, Ninth Revision, Clinical Modification [ICD-9-CM], code 493.x). Two of the MCOs applied the sampling strategy as described earlier. One of the MCOs required at least one encounter with an asthma diagnosis (inpatient or outpatient) or at least one dispensation of a commonly prescribed asthma medication as determined by pharmacy dispensation records. The pharmacy dispensation records were searched by Food and Drug Administration Classification codes for corticosteroids, sympathomimetics, anticholinergics, xanthines, and cromones. Surveys were mailed to parents of sampled adolescents. An advance letter, signed by an MCO official, explained the study to parents and served as an informed consent statement (voluntary nature of participation, procedures to protect confidentiality of information provided, and absence of repercussions in dealings with the MCO and/or medical care provider whether or not they decided to participate). In the second stage, responses from the survey were used to exclude adolescents whose parents indicated their child did not have doctor-diagnosed asthma. Subjects also were excluded if they were not currently enrolled in the MCO.

**Survey Measures**

The survey included questions on general health status, asthma symptoms, impact of asthma on physical function, QOL, family and patient role functioning, health service use, ratings of the quality of care, asthma-related education and participation in care, asthma self-management, and parent and child demographics. One of the MCOs did not include questions on parent education, household size, or parental income in the survey, so findings on these dimensions reflect two of the three participating MCOs. Sources of survey items included the Asthma Therapy Assessment Questionnaire for Children and Adolescents, the New England Medical Center Asthma Outcomes Monitoring System Child Asthma Questionnaire, the Managed Health Care Association Outcomes Management System Asthma Study Questionnaire, the Maryland Medicaid Recipients Study Survey, the Child Health and Illness Profile-Adolescent Edition (CHIP-AE), and the Pediatric Asthma Quality of Life Questionnaire (PAQLQ).

For the current analysis, parents of participating adolescents completed survey questions related to asthma symptoms, health service use, and impact of asthma on physical function. Participating adolescents 11 to 17 years of age completed the short version of the CHIP-AE and the entire version of the PAQLQ, although only the specific domains of these instruments that related to emotional QOL were analyzed for this study. Both instruments have been used in populations of similar age to the adolescents who participated in this study.

The CHIP-AE has been shown to be a valid measure of health-related QOL in adolescents and has been used to study the QOL in adolescents with asthma. The domains of emotional QOL examined in this analysis included self-esteem (3 items, scored 1-4, from CHIP-AE) and emotional discomfort (eight items, scored 1-5, from CHIP-AE). The emotional discomfort domain is designed to measure the emotional distress that impacts on one’s sense of well-being (eg, feeling moody, nervous, or irritable). The self-esteem domain is designed to capture one’s sense of worthiness about self (eg, “I like being the way I am” or “I have a lot of good qualities”). Each individual item was scored according to the degree of agreement with specific statements (eg, “I like being the way I am?” or the frequency of specific feelings (eg, feeling depressed because of asthma). The total score for each of the domains is the mean of the item scores that make up that domain. Higher scores indicate better levels of self-esteem and emotional comfort.

The PAQLQ has been shown to be a valid measure of asthma-specific QOL for adolescents with stable and unstable
asthma, and with different levels of asthma severity.\textsuperscript{7,26,27} The emotional function domain of the PAQLQ (eight items, each scored 1-7) is designed to capture a range of possible feelings that may be present because of asthma, including feeling “frustrated,” “uncomfortable,” “frightened,” “worried,” “angry,” “irritable,” and “different or left out.” The total score for the emotional function domain is the mean of the item scores that make up that domain. Higher scores indicate better levels of emotional function.

There is no precise measurement tool for asthma severity included in the 1997 National Asthma Education and Prevention Program (NAEPP) guidelines that can be applied to research, so to provide an estimate of asthma severity, a measure was constructed to approximate the scheme outlined in the guide lines\textsuperscript{12} by ordinally categorizing parental responses to questions about asthma symptom frequency over the prior 4-week period: wheezing, chest tightness, cough, shortness of breath, flares, and the degree of symptoms between attacks. Symptom severity was categorized as mild intermittent, mild persistent, moderate persistent, and severe persistent in accordance with the 1997 NAEPP guidelines.\textsuperscript{12}

### Outcome Variables (Asthma Morbidity)

Outcomes assessed for the prior 12-month period included parent reports of: (1) ED visits for asthma; (2) hospitalizations for asthma; (3) doctor visits for worsening asthma; and (4) the number of days of missed school because of asthma in the prior 4-week period. The Pediatric Asthma Control Score (PACS)\textsuperscript{17,20,21} also was used as an outcome for this analysis. The PACS is composed of items that assess asthma symptoms, impact of asthma on planned activities, and asthma medication use, and it is scored as a count of seven dichotomously scored items, with higher scores indicating worse control of asthma symptoms. It is part of the Asthma Therapy Assessment Questionnaire.\textsuperscript{21}

### Independent Variables

Parents completed survey items about the child's demographics (age, gender, race, household size) and parent characteristics, including race and education. Adolescents completed questions on both generic and asthma-specific aspects of emotional QOL.

### Analysis

Descriptive statistics were generated using proportions and means. Scores for self-esteem, emotional comfort, and emotional function domains were examined as continuous variables then divided into quartiles of low (worst) to high (best) scores, with approximately equal numbers of patients in each quartile. For bivariate analyses, most outcomes were dichotomized (none vs any), and the percentages of adolescents with each outcome were examined by quartiles of emotional QOL, with statistical significance determined by the $\chi^2$ test for trend. The PACS was treated as a continuous variable with differences in quartiles of emotional QOL scores tested by the Kruskal-Wallis test. To examine the contribution of certain potential confounding factors, multivariable linear, logistic, and ordinal logistic regression models (as appropriate) were used to adjust for the child’s age, race, gender, and asthma severity. A two-tailed $P < .05$ denoted statistical significance for all analyses. The Statistical Analysis Systems, version 6.0 was used for all computations (SAS Institute, Cary, NC).

### RESULTS

#### Demographics and Asthma Morbidity (Table I)

Of 464 eligible adolescents identified by the MCOs, 185 completed the survey (40%; parent completion rate was 41.3%). At the two MCOs that provided such information, parent participation was higher among those with male children than among those with female children (50.8% vs 40.2% and 64.1% vs 56.2%). At the one MCO that provided information on types of plans offered, those enrolled in point-of-service plans were less likely to participate in the study than those in health maintenance organization plans (28.6% vs 50.8%).

Among the 185 adolescent participants, 77% were White and 57% were male. For asthma-related events in the prior 12 months, 10% of the adolescents had been hospitalized, 41% had had ED visits, and 77% had had doctor visits for worsening asthma. Thirty percent missed at least 1 day of school over the prior 4 weeks. Using definitions established by the 1997 NAEPP guidelines, 53% of the adolescents had

### Table I. Characteristics of adolescents with asthma (n = 185)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>76.5</td>
</tr>
<tr>
<td>Black</td>
<td>16.3</td>
</tr>
<tr>
<td>Other</td>
<td>7.2</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>57.1</td>
</tr>
<tr>
<td>Female</td>
<td>42.9</td>
</tr>
<tr>
<td>Asthma severity</td>
<td></td>
</tr>
<tr>
<td>Mild intermittent</td>
<td>16.0</td>
</tr>
<tr>
<td>Mild persistent</td>
<td>30.8</td>
</tr>
<tr>
<td>Moderate persistent</td>
<td>32.5</td>
</tr>
<tr>
<td>Severe persistent</td>
<td>20.7</td>
</tr>
<tr>
<td>Parent level of education completed</td>
<td></td>
</tr>
<tr>
<td>Less than high school</td>
<td>4.0</td>
</tr>
<tr>
<td>High school</td>
<td>18.6</td>
</tr>
<tr>
<td>Some college or other training after high school</td>
<td>48.5</td>
</tr>
<tr>
<td>College graduate</td>
<td>15.5</td>
</tr>
<tr>
<td>Postcollege graduate or degree</td>
<td>13.4</td>
</tr>
<tr>
<td>Number of other members living with child</td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td>28.6</td>
</tr>
<tr>
<td>3</td>
<td>50.0</td>
</tr>
<tr>
<td>$\geq$4</td>
<td>21.4</td>
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symptoms consistent with either moderate or severe persistent asthma. Most parents had attended some college or received additional training after high school.

**Emotional Quality-of-Life**

Seventy-five percent of parents reported having worried about their child’s emotional health during the prior 4 weeks. In the same preceding 4-week period, adolescents commonly reported emotional symptoms, with 45% reporting that they had felt depressed or “blue” 24% had had episodes of crying a lot, and 48% had felt nervous or “uptight.”

In bivariate analyses, worse asthma-specific emotional QOL scores (PAQLQ) were significantly related to worse asthma control (Figure), more days of missed school, and doctor visits for worsening asthma (Table II). In particular, adolescents with the lowest levels of PAQLQ scores were 40% more likely to have had a doctor visit for worsening asthma and were three times more likely to have missed school from asthma when compared with those with the best levels of asthma-specific emotional QOL (Table II). Similar trends were apparent for ED visits and hospitalizations for asthma, but these did not reach statistical significance.

Among measures of asthma morbidity, the asthma control score showed the strongest and most consistent relationship with measures of emotional QOL. There were significantly fewer asthma control problems for adolescents with the best versus worst levels of emotional function and emotional discomfort (Figure).

We performed additional bivariate analyses to examine the relationships of patient race, gender, parent education, and household size to asthma morbidity. Interestingly, no adolescents from households with only one or two other people living with them had been hospitalized, compared with 24% of adolescents from households with four or more others in the house. There were twice as many asthma control problems for adolescents whose parents did not complete high school compared with adolescents of parents who had a postcollege graduate education. Blacks were more likely than Whites to be seen in the ED (74.1% vs 33.3%; \( P = .001 \)) and to be hospitalized (14.8% vs 9.5%; \( P = .04 \)) and were less likely to have a doctor visit for worsening asthma (74.1% vs 80.2%; \( P = .09 \)). There was an overall racial difference in frequency of those who missed school because of asthma, but this was not statistically significant (44.4% vs 28.6%; \( P = .1 \)). There was no difference between Black and White adolescents in mean pediatric asthma control score or in parental education. There was no relationship of patient gender to morbidity.

**Multivariable Results**

There were strong positive relationships between indices of asthma health and the asthma-specific emotional QOL (PAQLQ) after controlling for age, race, gender, and asthma severity (Table III). Teens with the lowest levels of asthma-specific emotional QOL had poorer control of asthma (\( P < .0001 \)) (data not shown) and were more likely to have...
missed school (P < .01) or to have had doctor visits for worsening asthma (P < .01; Table III). A similar, but nonsignificant trend was seen for hospitalizations. There was no clear association between ED visits for asthma and any measure of emotional QOL. For the generic measures of emotional QOL, we observed weakly positive, nonsignificant relationships with other measures of asthma health (data not shown).

### CONCLUSIONS

In this study of adolescents enrolled in MCOs and mostly with persistent asthma, poor emotional QOL (such as feelings of worry or anger because of asthma) was common. This study shows how emotional QOL relates to hospitalizations, ED visits, missed school, or doctor visits for worsening asthma in adolescents with asthma. Adolescents reporting worse asthma-specific emotional QOL reported more frequent school absence and doctor visits for asthma. Also, poorer asthma-specific emotional QOL was strongly related to worse asthma control.

Our results are consistent with a study by Vollmer et al, who examined asthma-specific QOL in adults with asthma and found a significant relationship between healthcare use for asthma and poorer asthma-specific QOL. Our findings are also consistent with studies by Juniper and others who have found that the PAQLQ is responsive to changes in asthma status within and between individual adolescents with varying severity of asthma. The mean scores of emotional QOL in the adolescents who participated in our study are similar to those published by Juniper and others. These studies, however, included few adolescents and did not report on how poorer asthma-specific emotional QOL relates to school attendance or healthcare use for asthma.

One advantage of our study is that we examined the relationship of two different types of QOL instruments—one...
asthma-specific, the other generic—to different measures of asthma health. There are few studies on adolescents with asthma that have used the CHIP-AE, so comparisons with other results are limited. Forrest et al examined emotional asthma that have used the CHIP-AE. Compared with those without asthma, they found a lower sense of well-being, health satisfaction and self-esteem, as well as greater emotional symptoms in those adolescents with reports of recent episodes of wheezing. We, too, found a significant relationship between emotional discomfort and asthma symptoms (as measured by PACS) but not for healthcare use. In addition, our findings suggest that self-esteem does not differ among adolescents with asthma. This difference in findings of relationships between asthma, self-esteem, and emotional comfort may be a result of the way in which asthma was examined, as we did inquire into a number of different aspects of asthma health, rather than solely on the presence or absence of a single symptom. The relationship of CHIP-AE measures to healthcare use for asthma has not been previously published.

There are potential limitations to this study. Though items used in this study to measure QOL in adolescents with asthma have been previously validated, we recognize that self-reported data about asthma morbidity are subject to limitations of recall, recall bias, and selection bias. Our sample of adolescents was enriched by those with recent healthcare encounters—many times for worsening asthma that required a doctor visit or an ED evaluation. Therefore, our findings are likely to be more generalizable to adolescents with worse asthma control. In addition, this study examined adolescents who were patients within the setting of a MCO, so our findings may not be reflective of adolescents who have no health insurance or who receive their healthcare in other settings. The response rates to our survey were modest, although, this may in part a result of the older age group of children who were sampled for this study. Nevertheless, it is possible that we mis-estimated the prevalence of poor emotional QOL because of our inability to assess non-responders. In addition, our findings may not be reflective of adolescents with asthma who were not participating MCOs who did not participate in the study. Further studies on adolescents with asthma will be needed to clarify the relationship of emotional QOL and asthma. Lastly, this was a cross-sectional study, so inferences of causality cannot be made from the associations we observed. Our study showed that worse emotional QOL in adolescents with asthma is strongly related to measures of greater asthma health burden. Whether emotional QOL is a result of or cause of greater asthma morbidity cannot be addressed by this study. It is possible that adolescents with poorer emotional QOL represent a subgroup of adolescents with asthma who are at greater risk for healthcare use because they are unable to adequately manage their asthma. The converse may also be true, in that worse asthma control can be detrimental to emotional QOL. Longitudinal studies in adolescents are needed to determine whether improvements in asthma health result in improvements in emotional QOL, and whether those adolescents who feel worse about their asthma subsequently require more healthcare use in the future.

National asthma guidelines recommend periodic assessment of asthma health, including its impact on QOL. A thorough assessment of QOL includes both physical manifestations and the emotional impact of asthma. Screening for emotional QOL may allow detection of adolescents at risk for missing school and higher healthcare use because of asthma, and more importantly, those who are experiencing poor QOL. There is evidence that individuals vary in how they interpret their asthma symptoms, even for a given level of airway obstruction, and that their perception of symptoms relates to their emotional state. Although there is growing evidence supporting the need to incorporate the patient’s burden of asthma into the overall patient assessment, both generic QOL and asthma-specific QOL instruments remain as research tools and have not been incorporated into standard clinical practice. With further evidence of the importance of assessing health-related QOL in adolescents with asthma, QOL instruments may become part of a more comprehensive clinical assessment. Parents and clinicians should inquire about emotional symptoms because of asthma, as there may be significant functional emotional symptoms that are not readily captured by exploring asthma symptoms, medication requirements, or by spirometry.

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