



EFFECT OF ASTHMA ON THE QUALITY OF LIFE AMONG CHILDREN AND THEIR CAREGIVERS IN THE ATLANTA EMPOWERMENT ZONE

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ABSTRACT

Background and Objective. Asthma is the most common chronic pediatric disease and exacts a toll on the health-related quality of life of affected children and their primary caregivers. This investigation describes the relationship between the clinical severity of asthma among inner-city children and their quality of life and that of their primary adult caregivers.

Methods. Telephone interview data were collected from individual adult caregivers of 5–12-year-old children with asthma. Questions addressed the history, diagnosis, and management of the child's asthma, the child's family and social background, the family's socioeconomic status, the caregiver's knowledge and attitude about asthma, and the health-related quality of life of both the child and the caregiver. An asthma severity score was calculated from the caregiver's responses to questions about their child's wheezing frequency, nocturnal and early morning symptoms, and speaking during an asthma attack, as well as the impact of the disease on their child's physical activity and breathing during the prior 4-month period. A clinical asthma triage score was determined from information collected at the emergency department about the child's oxygen saturation, alertness, use of accessory

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respiratory muscles, extent of breathlessness, and peak expiratory flow. Spearman correlation coefficients were used to identify association between quality of life and disease severity, caretaker's asthma knowledge, and functional impact of asthma symptoms.

Results. Data from 240 of 755 eligible children were analyzed. Most children were younger than 11 years, male, black, and non-Hispanic. The children's median duration of asthma diagnosis was 86% of their life (range less than 1 to 11.3 years, median 5.0 years). Of the primary caregivers, 69% had at least completed high school, and 90% reported a total monthly household income of \$1,600 or less. The maximum possible quality-of-life score and the median for caregivers were 91 and 70, respectively; for children, the same scores were 69 and 58, respectively. In addition, there was significant negative correlation of the quality-of-life scores of both the caregivers and children with the number of schooldays the children missed ($r = -0.24$ and $r = -0.26$, respectively, $P < .001$ for both) and the caregivers' and children's asthma severity scores ($r = -0.39$ and $r = 0-.47$, respectively, $P < .001$ for both). The quality-of-life scores of the children and caregivers did not correlate significantly with the asthma triage scores.

Conclusions. The questionnaires captured baseline quality-of-life information about this urban population and will facilitate longitudinal monitoring. The fact that the quality-of-life scores of children with asthma correlated with those of their adult caregivers, but not with their clinical triage scores, highlights the impact of asthma on families and the importance of having a long-term comprehensive management plan that is not based on exacerbations, but that includes both the children and their primary caregivers.

KEY WORDS Asthma, Health-Related Quality of Life, Pediatrics.

INTRODUCTION

Asthma is the most common chronic disease of childhood and has an impact on the quality of life for both the affected children and their primary caregivers.¹ *Health-related quality of life* refers to those aspects of health (physical, emotional, and social) that people personally value, and its assessment has become increasingly important as an outcome measure among people with asthma.^{2,4} Quality of life among children with asthma has been found to be influenced strongly by symptoms and by the extent to which asthma limits their activity and impairs their social and emotional functioning.⁵ Among parents and primary caregivers of children with asthma, quality of life is associated with concerns about the disease, social support, treatment regimens, and the impact the disease has on their daily activities.^{1,3,6} In inner cities, children with asthma and their caregivers have been found to be particularly at risk for poor quality of life because of limited asthma problem-solving skills, multiple asthma managers, problems adjusting to asthma, and a high level of life stress.⁷

ZAP Asthma is a consortium of community, industry, academic, and government institutions with an office based in Georgia in the Atlanta Empowerment Zone (AEZ)—a predominantly black inner-city community in which all of the neighborhoods have a poverty rate that exceeds 35% and in which asthma has

been identified as a health problem.⁸ ZAP Asthma seeks to improve the lives of families in the AEZ who are affected by asthma. One component of ZAP Asthma is an ongoing environmental intervention study assessing the impact of health education delivered by community health workers (CHWs). Enrollment began in January 1998 and was completed in December 1999. This paper investigates, among families enrolled during the first 12 months of the project, the relationship between the clinical severity of the children's asthma at the time of enrollment with the baseline quality of life for the children and their primary adult caregivers.

METHODS

SAMPLING AND ELIGIBILITY CRITERIA

Children with asthma living in the AEZ ZIP code areas were enrolled from the emergency department of the public hospital where most seek their medical care. To be eligible for enrollment in this study, children must have had physician-diagnosed asthma, had been visiting the emergency department for an asthma-related condition, had lived in the same residence in one of the designated AEZ ZIP code areas for at least 6 months, and had been 5–12 years of age at time of visit to the emergency department. Trained CHWs posted in the emergency department approached potential clients and attempted to enroll those who were eligible. CHWs also reviewed emergency department logs to identify potential study clients who visited the emergency department when the enrolling staff was not present; they then telephoned the caregivers of these children and invited them to participate in the study.

The study was approved by a special institutional review board for the protection of human subjects convened at the Centers for Disease Control and Prevention. This special board included AEZ community members. All patients 7 years of age or older and all adult caregivers gave written informed consent prior to the collection of any information.

DATA COLLECTION

Informed consent and demographic information was obtained face to face by the CHW either in the emergency department or during a home visit. Clinical information was extracted from the emergency department record, and telephone interviews were conducted for the remainder of the information. For clients who were enrolled by telephone after their emergency department visit, a home visit was scheduled by the CHWs to secure written consent. After enrollment, the primary adult caregivers were contacted for a telephone interview to collect information on their education level and socioeconomic status, quality of life,

knowledge about asthma, attitude, and actions in response to caring for a child with asthma. For those clients who did not have a telephone, the interview was conducted in person.

SUMMARY SCORING AND INFORMATION COLLECTION INSTRUMENTS

Clinical asthma triage scores. Children's asthma triage scores (Table I) were ascertained using clinical information abstracted from the medical record that had been collected by the emergency department health care providers at the time of study enrollment. This triage is performed routinely at the emergency department among children with asthma. The triage score included oxygen saturation (pulse oximetry), level of alertness (sensorium), use of respiratory accessory muscles, extent of breathlessness (dyspnea), and respiratory rate at the time of the emergency department visit. Emergency department health care providers scored each parameter on a scale of 0–2, with 0 being normal and 2 being the most severe. These data are recorded on a standard asthma flow sheet and used for patient care. The summary clinical asthma triage score was calculated by summing the scores for each item. Higher clinical asthma triage scores indicated a more severe asthma exacerbation in the emergency department. Because a clinical asthma triage score was not always calculated for the least severe cases, records for which all five items were missing were assigned a summary score of 0.5. The imputed score of 0.5 was chosen to reflect an average between scores of 0 and 1, that is, between none and minimal severity.

Telephone survey data and summary measures. A survey company under contract to ZAP Asthma administered, by telephone, several structured questionnaires to the primary adult caregiver (parent/legal guardian). Information was collected on the functional severity of the child's asthma, including symptoms of asthma, quality of life (activity limitation, emotional function, and symptoms), and health care utilization. Other information collected included (1) social and economic impact of asthma, including lost schooldays and workdays; (2) the caregiver's knowledge, practices, and beliefs about asthma; and (3) the effect of the child's asthma on the family's quality of life.

The asthma severity score was based on the caregiver's responses to questions about wheezing frequency, nocturnal and early morning symptoms, speaking during an asthma attack, breathing during the prior 4-month period, and the impact of the disease on the child's physical activity. Higher asthma severity scores indicated more severe disease. The responses were scored and summed for each child to calculate the asthma severity score. Asthma knowledge was

TABLE I Notes on Summary Scores for the Various Measures

Measure	Content (Number of Questions) and Reference	Description of Summary Score
Caregiver's asthma knowledge		Percentage of items answered correctly
Triggers	Agree/disagree statements assessing awareness of things that may worsen asthma (18 items)	
Symptoms and management	Agree/disagree statements assessing awareness of information about the features and treatment of asthma (17 items)	
Caregiver's attitude	Questions assessing importance of asthma among daily problems and the confidence of caregiver taking action to prevent an asthma attack in their child (12 items)	No score is generated, but the percentage of responses for each question is discussed.
Asthma severity score	Questions evaluating child's wheezing frequency, nocturnal and early morning symptoms, and ability to speak during an asthma attack and the impact of the disease on their physical activity and breathing during the prior 4-month period. (7 items)	The responses are scored and summed for each child.
Child's quality of life	Questions categorized according to three domains: emotional function (5 items), activity limitation (4 items), and symptoms (14 items)	The responses are scored and summed.
Caregiver's quality of life	Questions categorized according to two domains: emotional function (9 items) and physical function (4 items)	The responses are scored and summed.
Clinical asthma triage scores	HCP* assessment scores (0-2) assigned to clinical parameters on oxygen saturation, level of alertness, use of respiratory accessory muscles, extent of breathlessness, and respiratory rate for each child in the ED† (5 items)	The overall score is calculated by summing the scores for each item.

*HCP: health care provider.

†ED: emergency department.

measured by two sets of scores, one based on the caregivers' responses to questions about asthma triggers and the other based on their responses to questions about symptoms and treatment. Two questions were used to assess the attitude of caregivers to the management of the disease: One addressed the importance of the disease relative to other daily problems, and the other addressed the confidence that the caregivers felt in taking action to prevent their children from having an asthma attack.

The survey instruments used to address quality of life were modified versions of the Pediatric Asthma Quality of Life Questionnaire and the Pediatric Asthma Caregiver Quality of Life Questionnaire. These questionnaires were developed originally by Elizabeth Juniper and colleagues at McMaster University (Hamilton, Ontario, Canada) and, in the case of Pediatric Asthma Quality of Life Questionnaire, revised subsequently for caregiver administration.⁹⁻¹¹ We modified these questionnaires by removing items that were not appropriate for a warmer climate and an urban inner-city population and, in the case of the caregiver questionnaire, formatted it for telephone administration. For the modified Pediatric Asthma Quality of Life Questionnaire, responses were scored and summed. The questions on this questionnaire were grouped into three domains: emotional function, activity limitation, and symptoms. The modified Pediatric Asthma Caregiver Quality of Life Questionnaire was scored similarly, and questions were grouped into two domains: emotional function and physical function. Higher scores on either of the quality-of-life questionnaires indicate better quality of life. Both questionnaires were administered to the primary caregiver of the child with asthma.

STATISTICAL ANALYSIS

For this report, we calculated the range, median, and quartiles for continuous variables and frequency distributions for categorical variables. We also calculated Spearman rank correlations between scores for caregivers' and children's quality of life with each other and with caregivers' asthma knowledge, education, income, employment, and days of work missed; children's days of school missed; percentage of children's life with asthma; asthma severity and clinical asthma triage scores. We tested for Spearman rank correlations significantly different from zero at $\alpha = .05$. The Statistical Analysis System (SAS) was used for all analyses.¹² Adjustments were not made for multiple comparisons.

RESULTS

A total of 755 eligible children was seen in the emergency department during the first year, of which 301 (40%) along with their caregivers were enrolled; 240 (80%) had complete survey information, of which 178 (74%) also had emergency department information available for analysis. Reasons for not enrolling in the study included refusal to participate (44%), inability to contact during follow-up (24%), inability to complete follow-up (16%), failure to meet ZIP code area residence requirement (10%), and involvement in another study or other (6%).

Of the 240 children, 87% were less than 11 years of age, 61% were male, all but 1 were black, and 97% were non-Hispanic. All the children were seen for

regular medical care, 82% by a pediatrician or family practitioner. Half of the children had asthma for at least 86% of their life (median time since diagnosis 5.0 years, range less than 1 to 11.3 years) (Table II). Of the primary adult caregivers, 69% had completed high school or gone to college, 56% were employed at the time of the interview, and 90% reported a total monthly household income of \$1600 or less (Table III).

More than 75% of primary caregivers correctly answered at least half the questions concerning their knowledge of asthma triggers, symptoms, and treatment (Figure 1). Except for birds and cockroaches (identified correctly by 40% and 49%, respectively), more than half (54–93%) of the caregivers knew the

TABLE II Demographic and Asthma Disease Characteristics of the Children (N = 240)

	n	%
Child age, years		
5–6	84	35
7–8	63	26.3
9–10	63	26.2
11–12	30	12.5
Gender		
Male	146	60.8
Female	94	39.2
Race		
Black	239	99.6
White	1	0.4
Ethnicity		
Hispanic	7	2.9
Non-Hispanic	233	97.1
HCP* seen for regular medical care		
Pediatrician	171	71.3
Family practitioner	25	10.4
Allergist	19	7.9
Other specialist	2	0.8
Other, don't know	23	9.6
Percentage of life with asthma diagnosis, %	Range 0–99	
	25th percentile 50	
	Median 86	
	75th percentile 930	
Average time since diagnosis, years	Range 0–11.3	
	25th percentile 4.0	
	Median 5.0	
	75th percentile 7.3	

*HCP: Health Care Provider.

TABLE III Characteristics of Primary Adult Caregivers (N = 240)

	n	%
Caregiver education		
Elementary	2	0.8
Some high school	72	30.1
Completed high school	144	60.3
College	21	8.8
Currently employed		
Yes	133	55.6
No	106	44.4
Monthly household income (\$)		
<500	75	35.7
500-1,200	87	41.4
1,201-1,600	28	13.3
1,601-2,500	16	7.6
2,501-4,200	4	1.9

triggers that worsened asthma symptoms, but they were correct less often (32–47%) about those exposures not known to worsen symptoms (e.g., mosquitoes and eggs). Most of the children's caregivers incorrectly believed asthma episodes occurred without warning (87%), that the children can become addicted to their medicines (63%), and that people with asthma have no way to know how well their lungs are working (59%).

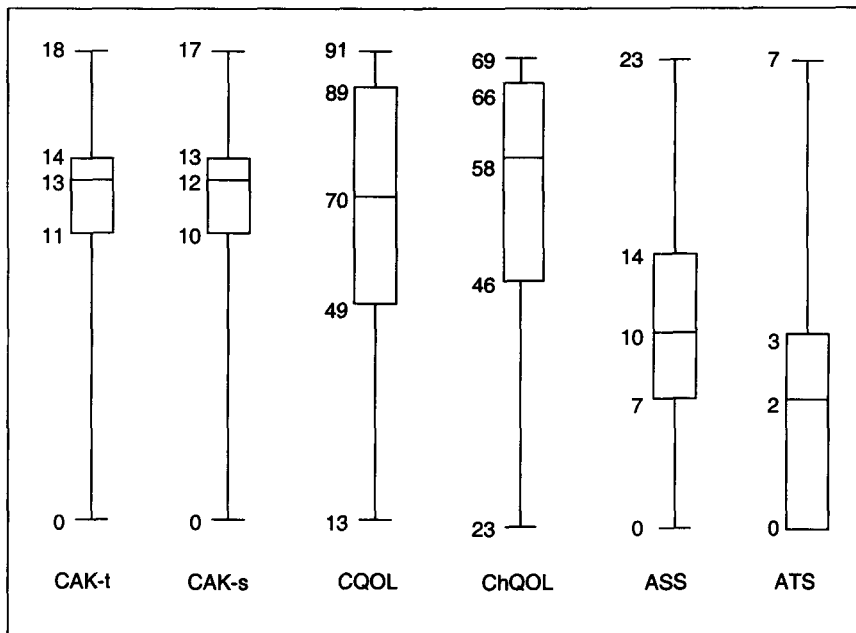
Of all caregivers, 95% considered their children's asthma to be among the top third of their daily problems, and 77% of caregivers were very confident that they knew what actions to take to help prevent their child from getting an asthma attack.

Higher quality-of-life scores among adult caregivers correlated with higher quality-of-life scores among children ($r = 0.64$, $P < .001$) (Table IV). In addition, quality-of-life scores for both the caregivers and children correlated negatively with the number of days the children missed school ($r = -0.24$ and $r = -0.26$, respectively, $P < .001$ for both) and with children's asthma severity scores ($r = -0.39$ and $r = -0.47$, respectively, $P < .001$ for both). Children's quality-of-life scores correlated positively with the caregivers' knowledge of symptoms ($r = 0.21$, $P < .01$) and their own age at asthma onset ($r = 0.20$, $P < .01$) and negatively with the percentage of their life with asthma ($r = -0.18$, $P < .01$) (Table IV). Correlations between scores for the individual domains of the children's quality-of-life survey (emotional function, activity limitation, and symptoms) and those of the caregiv-

ers' quality-of-life survey (emotional and physical) were similar to the correlations between the overall quality-of-life scores and measures of knowledge and other variables. The quality of life scores for children and caregivers did not correlate significantly with the clinical asthma triage score (Table IV).

DISCUSSION

Several findings of this study are noteworthy. Quality-of-life scores for both children with asthma and their primary caregivers correlated significantly with fewer days of school missed and a lower asthma severity score. Higher quality-of-life scores for children correlated positively with their age at asthma onset and negatively with the percentage of their lives with asthma. Higher quality-



Legend

- CAK-t denotes caregivers' knowledge of asthma triggers
- CAK-s denotes caregivers' knowledge of asthma symptoms
- CQOL denotes caregivers' quality of life
- ChQOL denotes caregivers' report of children's quality of life
- ASS denotes asthma severity score
- ATS denotes asthma triage score

Values

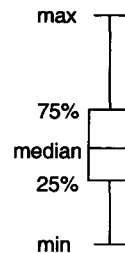


FIGURE 1 Summary Statistics for Knowledge of Triggers and Symptoms, Caregivers' Quality of Life, Caregivers' Report of Children's Quality of Life, Asthma Severity Score, and Asthma Triage.

TABLE IV Correlation Coefficients and P-values for Children's and Caregivers' Quality-of-Life (QOL) Scores

Variables	QOL Correlations	
	Caregiver n = 213–227	Child n = 216–231
Caregivers' quality of life scores	—	0.64†
Children's quality of life scores	0.64†	—
Knowledge of trigger	-0.11	-0.11
Knowledge of symptoms/treatment	0.11	0.21†
Asthma severity score	-0.39†	-0.47†
Days missed—work	-0.10	-0.03
Days missed—school	-0.24†	-0.26†
Age of asthma onset	0.08	0.20*
Percentage of life with asthma	-0.06	-0.18*
Clinical asthma triage score	-0.08‡	-0.15§

* $P < 0.01$ † $P < .001$

‡n = 169

§n = 171

of-life scores for children also correlated positively with higher knowledge about asthma among caregivers. For the quality-of-life measure, we found a statistically significant positive correlation between the quality of life of children with asthma and the quality of life of their primary adult caregivers. In addition, the clinical asthma triage score computed from emergency department data did not correlate with any of the quality-of-life measures.

These findings are consistent with previous results from other studies and further quantify the impact of asthma on the quality of life of children and their primary caregivers.^{2,3,7-9} We have highlighted quality-of-life evaluations because the National Asthma Education and Prevention Program recommends that any program to monitor asthma periodically assess any missed work or school, any reduction in usual activities, any disturbance in sleep, or any change in caregiver activities resulting from a child's asthma.¹³

Previous studies have found that correlations are only weak to moderate between acute clinical measures and how patients feel and are able to function.² This is corroborated partly in our study by the lack of significant correlation between quality-of-life scores for children and caregivers and the acute clinical asthma triage scores. This finding accents the significant variability of asthma, suggesting that first-line health care providers should not focus too much on individual severe asthma episodes as a marker of poor quality of life. While the

treatment of acute asthma is crucial, the successful management of asthma requires a long-term proactive comprehensive plan that addresses children and their families.

There are several key limitations of this study. The first is that the children's quality of life was reported by their caregiver; this may have increased the likelihood of a positive correlation between the factors for the child and the caregiver. In the initial study design, children older than 7 years were to be permitted to complete their own quality-of-life surveys, while those 5–7 years old would have their primary caregiver complete the questions. However, for logistical and ethical reasons and because we wanted the data collection to be uniform, especially given that the survey was to be done by telephone, we chose the primary caregiver as the respondent for all children. There is evidence indicating that caregivers of children with asthma often have poor awareness of the issues and feelings troubling those children, especially for children over 11 years of age, and that children as young as 6 years can respond successfully to the Pediatric Asthma Quality of Life Questionnaire.^{14,15} Nevertheless, we consider that the results of our study were not influenced severely by this issue given that most of the children we surveyed were less than 11 years of age. Although similar quality-of-life instruments for adults have been validated in inner-city populations, the pediatric questionnaire has not been validated similarly.¹⁶

The second limitation is that the results of a survey of children with asthma who are treated in a hospital emergency department may not be generalizable to the general population of children in the AEZ who have asthma. These children's asthma may be more severe than that of other children who receive care in the regular clinic at this public hospital or other facilities. This would increase the likelihood of poor quality-of-life scores. Sampling children in other, less acute health care settings would address this limitation.

The third limitation affecting a portion of this analysis is that quality-of-life surveys usually are designed for repeated measurements, especially during pharmacologic, behavioral, and educational interventions. This analysis is part of an environmental intervention study, and longitudinal follow-up data on survey participants' quality of life are now being assessed. Over time, the correlations that we found in this initial analysis of the data may change. Another related limitation is that the univariate correlation coefficients, while statistically significant, are relatively small, implying that other factors not measured in this study may be influencing quality of life and asthma.

Our findings underscore the significance of quality of life as an issue for children with asthma and their primary caregivers and the need for comprehen-

sive management plans that address asthma within the family context. Interestingly, asthma health education in these families may also need to address the things that do not exacerbate asthma, as well as the things that are known to trigger an asthma attack. The results of our study also provide a good baseline from which to monitor longitudinally the quality of life of children with asthma and their primary caregivers. In our future work in inner-city populations, we may use focus group methodology to refine quality-of-life instruments so that they are appropriate for the racial, ethnic, and socioeconomic makeup of particular populations.¹⁷

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