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Quality of life in at—risk school-aged children with asthma

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ABSTRACT

Introduction: Asthma is the most common chronic condition of childhood. Urban, minority children from families of lower socioeconomic status have disproportionately higher rates of asthma and worse outcomes. We investigated the association between the presence of asthma and asthma severity among American, urban, minority children and reported quality of life (QOL) of children and their families.

Methods: We performed a prospective, cross-sectional study comparing QOL of urban, minority elementary school-age children with and without asthma. A convenience sample of children was enrolled from the pediatric emergency department (ED) and a specialized asthma clinic, at a large urban children's hospital. We measured child and parent QOL using the Pediatric Quality of Life Inventory Version 4 (PEDSQL4), and evaluated associations with asthma, parental educational attainment, and frequency of ED visits.

Results: We enrolled 66 children, 76% were African American, and 61% were female. Overall child QOL was higher for those without asthma ($p = 0.017$, $d = 0.59$). Children with asthma also visited the ED almost twice as frequently (t [64] $= -3.505$, $p < 0.001$, $d = 0.8$), and parents of children with asthma reported a lower overall QOL ($p = 0.04$, $d = 0.53$) than those without asthma. Among children with asthma, a higher overall child QOL was associated with decreased asthma severity, more ED visits, and higher parental educational attainment.

Conclusions: Urban, minority elementary school-age children with asthma report a lower QOL than those children without asthma, and decreased asthma severity was associated with higher QOL.

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Introduction

Asthma is the most common chronic condition of childhood (1). Children from families of lower socioeconomic status (SES) (1,2), and minority children have disproportionately higher rates of asthma and worse outcomes (1–3). In 2018, asthma prevalence among U.S. children 18 years and younger was 7.5%. The prevalence of asthma was higher among boys (8.4%) than girls (6.6%) (1), and African-American children had a higher prevalence of asthma (14.0%) than Caucasians (6.1%) (1). Compared to healthy peers, children with asthma experience more stress (4,5), higher hospitalizations rates, increased visits to the emergency department (ED) (6), and increased school absences (7). In 2013 the direct cost of pediatric asthma was $5.92 billion in the U.S. (8).

The World Health Organization-Quality of Life Group (WHOQLG) defines quality of life (QOL) as an "individual's perception of their position in life in the context of the culture and value system in which they live in relation to their goals, expectations, standards, and concerns" (9). The definition of QOL continues to evolve. QOL has also been defined as a multidimensional construct representing a broad range of human experiences (10). It is proposed that QOL includes behavioral competence, perception, environmental dimensions, and psychological well-being that also includes reflection on the past, expectation of the future, and appraisal of the present (11).

Prior studies have assessed the association between asthma, and asthma severity, and QOL among American, urban, minority parents and their children, and contrasting results were found (12,13). Montalto et al. (12) examined QOL in minority school aged children in third and fourth grades in New York City schools, and found that asthma severity did not impact QOL. In contrast, Greenley et al. (13) reported

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a lower QOL as asthma severity increased in school-aged African-American children. A few studies outside of the US found that children without asthma reported a higher QOL than those with asthma (14,15). Systematic reviews report that results are influenced by the criteria used to measure asthma severity, different methodologies, the various instruments used to measure QOL, and diversity in the individuals who assess severity and report on QOL (5,16,17). For example, while parental reporting of a child's asthma is important, it does not capture the child's perspective (18), and parents frequently under-report their child's asthma severity and symptoms (19,20). As asthma and asthma morbidity disproportionately affects American, urban, minority children, an understanding of how asthma affects their QOL may help to inform interventions aimed at reducing these health disparities (21).

We sought to describe the relationship between the presence of asthma and asthma severity among American, urban, minority children and reported QOL of parents and school-aged children. We hypothesized that children without asthma would report a higher QOL than children with asthma, and among children with asthma, reported QOL is higher among those with less severe asthma.

Methods

Study design

This was a prospective, cross-sectional study of a convenience sample of urban, minority, children with and without asthma and their parents. An *a priori* power analysis was conducted using G*Power version 3.01.10 (22). The sample size was determined by calculating minimum meaningful effect sizes, analyzing response rates, and by conducting power analyses of previous studies (12–15,20,21,23–25). According to Cohen a study should have a power of 0.8 (26,27). The power analyses indicated that a sample size of 52 provided sufficient power (0.8) for an independent one tailed *t*-test, $\alpha = 0.05$, and medium-effect size (28). A sample size of 60 with 30 participants in each group met the assumption of normality and provided a power of 0.8 (26,27).

Inclusion criteria were as follows: (a) between 9 and 12 years of age; (b) enrolled in grades 3–5 in the District of Columbia Public Schools (DCPS) during the 2015–2016 school year; (c) have a prior physician diagnosis of asthma for at least 12 months (for the asthma group); (d) have no other chronic medical conditions (e.g. of the neurologic, muscular, respiratory, cardiac, renal, hematologic, or gastrointestinal systems); (e) have a parent whose primary spoken language is English; (f) have a residence in the District of Columbia; (g) have a family member available for a telephone follow-up; and (h) not have a diagnosis of severe persistent asthma (for the asthma group). Children in grades 3–5 were selected because of limited number of studies investigating QOL for this age group; and the Pediatric Quality of Life Inventory Version 4 (PEDSQL4) can be self-administered by children in these grades.

Patients were recruited form the pediatric ED and a specialized ED-based asthma clinic, Improving Pediatric Asthma Care in the District of Columbia (IMPACT DC), at Children's National Hospital (CNH) in Washington, DC between December 2016 and March 2017. CNH is an urban, quaternary care, free-standing children's hospital. Of the ED visits at CNH in 2016, approximately 7000 included a primary discharge diagnosis of asthma among patients aged 12 months to 17 years, and in 2014, 866 children attended the IMPACT DC clinic (29). The study protocol (Pro00005030) was approved by the CNH institutional review board.

Study procedures with data collection

After written informed consent from parents (and assent by children, when age 12 or greater), the corresponding author (SA) used a screening checklist to determine if a child was diagnosed with asthma for more than one year (at risk), and to determine eligibility of children for enrollment in the asthma or non-asthmatic group. The screening checklist and demographic questionnaire were developed in 2002 and are currently in use by the IMPACT DC clinic research team (30). Parents provided information on their income, highest educational attainment, and eligible children's birthdates, gender, race, age, and ethnicity. The appropriate PEDSQL4 form was completed by both the parent and their child. The total number of ED visits made to CNH ED during the past 12 months were abstracted from the electronic medical record, and added to the number of non-CNH ED visits stated by the parents.

Asthma severity

Asthma severity was assigned by the principal investigator (S.I.) using the National Asthma Education Prevention Program (NAEPP) 2007 guidelines (31). According to the NAEPP guidelines, asthma severity is defined by the intensity of the disease prior to the

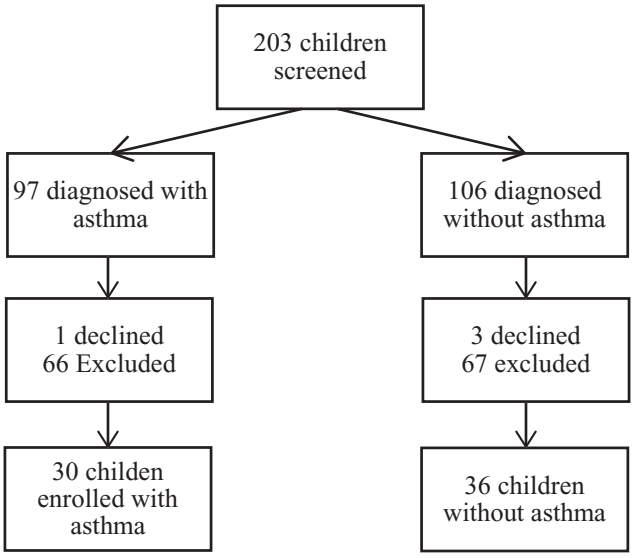


Figure 1. Recruitment of participants.

initiation of treatment incorporating – impairment, risk, and the amount of medication required for control. Asthma severity is divided into four categories: intermittent, mild persistent, moderate persistent, and severe persistent. Impairment is assessed by inquiring about day-time and nighttime symptoms, measuring forced expiratory volume (FEV_1), the volume of air forced out in the first second after taking a deep breath, activity limitation, and frequency of rescue medication use in the past four weeks (31). Risk is assessed by frequency and severity of exacerbations, requiring systemic steroids and hospital admissions in the year prior.

203 families were eligible for screening and 4 families declined to participate. Reasons for ineligibility included, but were not limited to children diagnosed with other exclusionary medical problems, families not living in Washington, DC, and legal guardians not being present. Finally, 30 children with asthma and 36 without asthma were enrolled (Figure 1).

QOL instrument

The PEDSQL4 is a validated instrument used to compare QOL between healthy children and those with acute and chronic health conditions (32). It is a two-part brief survey with 23 questions. The first part is completed by the parent(s) where they assess their child's QOL, and the second part is completed by the child. Four domains of QOL are assessed: (a) physical functioning (eight items assessed e.g.: do you have problems running); (b) emotional functioning (five items assessed e.g.: do you feel angry or scared); (c) social functioning (five items assessed e.g.: do you get along with other children); and (d) school functioning (five items assessed e.g.: do you have problems paying attention in class). The respondents are asked to indicate how much of a problem each item had been during the past month, using a 5-point Likert-type scale, with 0 = never a problem to 4 = almost always a problem. All items are reverse scored and linearly transformed to a 0–100 scale ("0"=100, "1"=75, "2"=50, "3"=25, and "4"=0). Scaled scores are computed as the sum of the items, and a higher score indicates a better QOL. Answers to questions in the four domains are combined to produce three QOL scores, (1) psychosocial QOL, (2) physical QOL, and (3) overall QOL. The psychosocial QOL score is composed of school functioning, social functioning, and emotional functioning. The physical QOL score consists of items about physical functioning, and the overall QOL score is comprised of both the psychosocial and physical scores. A total of six QOL scores were calculated, three by the child (psychological, physical, and overall), and three by the parent (psychological, physical, and overall). The range of measurement of the PEDSQL4 is based on the percentage of scores from the maximum possible score (ceiling) to the minimum possible score (floor). The PEDSQL4 has been shown to have excellent internal consistency and reliability (32).

Data analysis

All analyses were performed using the Statistical Package for the Social Sciences (SPSS) version 24 (I.B.M., Armonk, NY). The data was screened for duplicate cases, missing values, and outliers. Duplicate cases were checked by matching a child's initials, gender, and age with a log that was kept for all participants. There were no duplicate or missing values, and no outliers were found on examining standardized *z* scores, box plots and bar graphs. We calculated means and proportions. Independent *t*-tests, analysis of covariance (ANCOVA), analysis of variance (ANOVA), and a series of hierarchical regression were conducted.

We compared demographic information using: (1) independent *t*-tests for continuous variables: age, and total number of ED visits (*number of non-CNH ED and CNH ED visits for the past 12 months from the point of enrollment)*, and (2) Pearson chi-square tests for categorical variables: parental education attainment (*grades 1–11, 12th grade, some college, and college graduate.),* and asthma severity *(intermittent, mild persistent, and moderate persistent).* The assumptions of

random sampling, normality, the homogeneity of variances or homoscedasticity, and linearity between the dependent variables and the covariates were met. The significance for all models were set at $p < 0.05$, with the exception of the child physical and total (overall) domains which were set at $p < 0.025$.

The scatterplots did not demonstrate significant linearity, but the assumption was met. The homogeneity of regression slopes indicated interaction was not significant and the assumption was met. To make the case for multivariate normality, no outliers were found using the test of Mahalanobis distance. Correlations were run to examine if multicollinearity was met and if Tolerance was greater than 0.10 and the variance inflation factor (VIF) was less than 10.0 for the independent variables in the regression models. Diagnostics revealed that "age" and "grade" exhibited multicollinearity. Hence "grade" was removed because it exhibited the larger inflation factor and less correlation with the dependent variables.

Results

Descriptive analyses

The participants included 66 children and their parents, 30 children with asthma, and 36 without asthma: 39% were male, 76% were African American, mean age was 10.13 years (SD = 1.00) for those with asthma, and 9.94 years (SD =1.12) for those without asthma (Table 1). Incomes were highly variable; however, 63% of the families with children diagnosed with asthma and 75% of the families with children without asthma earned less than $50 000 per year. For those with asthma, 70% were classified as intermittent asthma, 17% with mild persistent asthma, and 13% with moderate persistent asthma by the PI per the NAEPP 2007 guidelines (31). The mean number of visits to the ED was 3.37 ($SD = 2.25$) for children with asthma and 1.78 ($SD = 1.39$) for those without asthma, (t [64] = −3.505, $p = 0.001$, $d = 0.8$).

Differences in quality of life between children with asthma and those without asthma

We found differences between children with and without asthma in reported physical child QOL ($p = 0.001$, $d = 0.97$), overall child QOL ($p = 0.017$, $d = 0.59$), and overall parent QOL ($p = 0.04$, $d = 0.53$) (Table 2). Using ANCOVA, QOL was compared between groups after controlling for age, gender, and the total number of ED visits. Significant differences were found only in the physical child QOL and overall child QOL. The physical child QOL was significantly lower in children with asthma compared to those without asthma, F (1,61) = 14.69, $p = 0.001$, η_p^2 =0.19, and asthma explained 19% of the variance. In addition, overall child QOL was significantly lower in children with asthma compared to those without asthma, F (1,61) = 7.65, $p = 0.007$, η_p^2 = 0.11, and asthma explained 11% of the variance.

Table 1. Demographics of children and parents enrolled in the study.

	Children with asthma *n* (%)	Children without asthma *n* (%)
Gender		
Male	14 (46.7%)	12 (33.3%)
Female	16 (53.3%)	24 (66.7%)
Age		
9	10 (33.3%)	18 (50.0%)
10	9 (30.0%)	7 (19.4%)
11	8 (26.7%)	6 (16.7%)
12	3 (10.0%)	5 (13.9%)
Race		
Black/African-American	23 (76.6%)	26 (72.2%)
White/Caucasian	0 (0.0%)	2 (5.6%)
Asian	0	1 (2.8%)
Other	7 (23.3%)	7 (19.4%)
Grade		
Third	11 (36.7%)	22 (61.1%)
Fourth	11 (36.7%)	6 (16.7%)
Fifth	8 (26.7%)	8 (22.2%)
Severity of asthma (*n*)		
Intermittent	21 (70%)	
Mild persistent	5 (17%)	
Moderate persistent	4 (13%)	
Parental education attainment		
1–11th Grade	4 (13.3%)	4 (11.1%)
12th Grade	12 (40.0%)	17(47.2%)
Some college	7 (23.3%)	7 (19.4%)
College graduate	7 (23.3%)	8 (22.2%)
Income		
$5000 or less	3 (10.0%)	13 (36.1%)
$5001–$50,000	16 (53.3%)	14 (38.9%)
$50,001–$100,000	6 (20.0%)	7 (19.4%)
Above $100,000	5 (16.7%)	2 (5.5%)

Differences in the quality of life among children with asthma

We used ANOVA to compare QOL among children with asthma, differences were found in two domains. First in the physical parent QOL F (2,27) = 6.25, $p = 0.006$. The effect size was large (η^2 = 0.317) and asthma severity accounted for 31.7% of the change. Second, in the overall parent QOL F (2,27) = 4.33, $p = 0.023$, η^2 = 0.243. The effect size was large (η^2 = 0.243) and 24.3% of the change was accounted for by asthma severity. Using the pairwise Bonferroni procedure, we determined that significantly higher overall parent QOL scores were reported for those with intermittent asthma compared to those with moderate persistent asthma ($p = 0.023$).

Table 2. Means, standard deviations, and effect sizes for child and parent QOL using the pediatric quality of life inventory comparing children with and without asthma.

Instrument	Mean QOL score (SD)[a]	*p*	*d*	95% CI (LL, UL)
Child psychosocial QOL[b]				
Asthma	1090.75 (302.47)			
Without asthma	1193.75 (272.97)	0.151	0.36	(−38.68, 244.51)
Child physical QOL[c]				
Asthma	600.83 (156.26)			
Without asthma	722.22 (81.46)	0.001	0.97	(61.53, −181.25)
Child overall QOL[d]				
Asthma	1692.33 (48.43)			
Without asthma	1915.97 (324.71)	0.017	0.59	(91.49, 223.64)
Parent psychosocial QOL[b]				
Asthma	1045.83 (336.25)			
Without asthma	1186.81 (277.26)	0.07	0.45	(−9.85, 291.79)
Parent physical QOL[c]				
Asthma	603.33 (167.74)			
Without asthma	684.72 (173.13)	0.05	0.47	(−2.91, 165.69)
Parent overall QOL[d]				
Asthma	1649.17 (457.67)			
Without asthma	1876.39 (402.00)	0.04	0.53	(15.79, 438.65)

Notes: The effect size (d) for *t*-tests were defined by Cohen (27) as small $d = 0.2$, medium $d = 0.5$, large $d = 0.8$.
[a]Higher scores indicate better quality of life.
[b]The physical function consisted questions related to activity.
[c]The psychosocial summary score was composed of school functioning, social functioning, and emotional functioning.
[d]The overall score was comprised of the psychosocial and physical scores.

Hierarchical multiple regression analyses for children with asthma

Two hierarchical multiple regression models were performed to examine the relationship between age, total number of ED visits, parental education attainment, and asthma severity with each child and parent QOL variable. Model 1 included age, total number of ED visits, and parental education attainment, and a statistically significant proportion of the variance was not explained in any of the measured outcomes. Asthma severity was added in the second model, and children were compared against those with moderate persistent asthma.

Association with asthma severity – model 2

Asthma severity explained 37.2% of the variance in psychosocial child QOL, F (7,22) = 3.45, $p = 0.012$, adjusted $R^2 = 0.372$, 30.6% of the variance in physical child QOL F (7,22) = 2.82, $p = 0.029$, adjusted $R^2 = 0.306$, and 44.7% of the variance in overall child QOL F (7,22) = 4.34, $p = 0.004$, adjusted $R^2 = 0.447$.

Independent predictors – total number of ED visits

There were positive correlations between ED visits and QOL. The total number of ED visits explained 29% of the variance in psychosocial child QOL t (22) = 3.71, p=.001, $sr^2 = 0.298$, 11% of the variance in physical child QOL t (22) = 2.14, $p = 0.044$, sr^2= 0.109, and 27% of the variance in overall child QOL t (22) = 3.76, $p = 0.001$, $sr^2 = 0.270$. Among those children with asthma, a higher number of ED visits was associated with higher overall child QOL.

Independent predictors – parental education attainment

We compared children whose parents achieved a 12th grade or some college education against those who graduated from college, and there were negative correlations. Those who completed a 12th grade [t (22) = −2.83, $p = 0.01$, $sr^2 = 0.174$] or some college education [t (22) = −2.53, $p = 0.02$, $sr^2 = 0.138$] explained 17% and 14% of the variance in psychosocial child QOL, respectively. For physical child QOL, 14% [t (22) = −2.42, $p = 0.024$, $sr^2 = 0.140$] and 11.5% [t (22) = −2.20, $p = 0.038$, $sr^2 = 0.115$], respectively, of the variance was explained. In overall child QOL 20% [t (22) = −3.20, $p = 0.004$, $sr^2 = 0.195$] and 15% [t (22) = −2.86, $p = 0.009$, $sr^2 = 0.156$], respectively, of the variance was explained. Children whose parents were college graduates reported higher QOL scores.

Independent predictors – asthma severity

We made comparisons between children diagnosed with intermittent and mild persistent asthma against those diagnosed with moderate persistent asthma. Those with intermittent and mild persistent asthma explained: [t (22) = −1.76, $p = 0.023$, $sr^2 = 0.129$] 13% and [t (22) = −3.38, $p = 0.003$, $sr^2 = 0.248$] 25% of the variance in psychosocial child QOL, respectively. For physical child QOL the variance was [t (22) = 3.28, p=.003, sr^2= 0.258] 26% and [t (22) = 3.70,

p=.001, sr^2= 0.329] 33%, respectively. For overall child QOL, the variance was 20% [t (22) = 3.26, p=.004, sr^2= 0.202] and 33% [t (22) = 4.16, p=.000, sr^2= 0.329], respectively. Children with less severe asthma reported higher QOL scores.

Lastly, asthma severity explained 29.4% of the variance in physical parent QOL, F (7,22) = 2.724, p = 0.034, adjusted R^2 = 0.294. In physical parent QOL, intermittent asthma explained 40% of the variance [t(22) = 4.07, p = 0.001, sr^2 = 0.403], and mild persistent asthma explained 24% of the variance [t (22) = 3.12, p = 0.005, sr^2 = 0.237], respectively. Compared with parents of children diagnosed with moderate persistent asthma, physical parent QOL was higher for parents of children with less severe asthma.

Discussion

We demonstrated an association between asthma and asthma severity and child and parent reported QOL. We found that children with asthma and their parents reported a lower QOL than those without asthma. This result supported our hypothesis, and is aligned with findings from other studies (17,33,34). Greenley et al. (13) also reported a lower QOL for school-aged African-American children with severe asthma. This finding was also supported by Montalto et al. (12) who reported QOL was lower in minority children compared with Caucasian children. However, the QOL between groups were not significantly different, and this might be attributed to children being grouped according to the number of hospitalizations and their functional ability.

Consistent with our hypothesis, we also demonstrated that among children with asthma, lower asthma severity was associated with a higher overall child QOL. An inverse relationship between asthma severity and child and caregiver QOL is well documented (5,35–38). We also found an association between higher number of total ED visits and higher overall child QOL. The association between ED utilization and QOL in the literature focuses on asthma related ED utilization. Several studies in similar populations as ours have documented an association between higher asthma related ED and lower caregiver QOL (5,37,39). Fewer studies have documented an association between child QOL and asthma related ED-utilization. Carey et al. (39) documented child physical QOL was lower among African American children in Georgia with high numbers of asthma related ED visits. Garro (35) demonstrated a similar association, however, among a small sample (n = 26) of Latinx children. To our knowledge, the relationship between child QOL and *frequent* overall ED use, among children with asthma, has not been published. This association needs further investigation.

Children with asthma visited the ED twice as frequently as those without asthma which may indicate a higher frequency of acute, serious illness. Urban, minority families with children diagnosed with asthma often view the ED as the primary source of care (40). Routine asthma care for children can reduce unscheduled ED visits (41,42). Unfortunately, families who are seen in the ED for asthma care do not follow-up with their primary care providers for a variety of reasons, including transportation barriers and language issues (41,42). Further research is warranted to understand these barriers and how purposeful interventions can be developed.

Higher levels of parental education attainment are associated with reductions in adverse health comes in children (43). We found children with asthma whose parents were college graduates reported a higher QOL compared with parents who were not college graduates. A lower level of parental education attainment is associated with lower health literacy (44), and this can alter a child's asthma outcome (45). Parental understanding of their child's asthma management through shared decision making improves asthma outcomes (46). Future research in the use of less technical language, slowing down rate of speech, and user of shorter phrases in the ED to improve a parent's understanding of their child's asthma is warranted.

Asthma education for families provided in hospitals and schools reduces ED visits (47). This is important because academic outcomes are not impeded in children with well-controlled asthma (48,49), and school attendance does not differ significantly when compared with their healthy peers (50,51). However, crafting policies that provide asthma education for school personnel, and families requires co-operation among many stakeholders (52). Continued research is needed to understand the gaps in knowledge, perspectives, and barriers to asthma education, particularly in schools.

We noted no differences in psychosocial parent and child QOL (all were uniformly low) between those with and without asthma. This might be attributed to the stress that families experience in the ED where the survey was conducted (53), or may reflect the shared background of living in an urban environment. Although our study did not evaluate the impact of stress in the management of asthma, the interplay of environmental factors that support well-being

(salutogenesis) are important to understand (54). For example, characteristics such as resiliency, or the ability to overcome adversity may develop through the interaction of parenting style and child traits (55,56). It is plausible that factors that promote resiliency alter a child's ability to cope with stressful situations such as an asthma excerbation (56–58). However, this question warrants further investigation.

Bhagat et al. (59) reported that asthma severity negatively impacted the socio-emotional well-being and physical activity of a child, and this finding has been reported by other researchers (33). In concordance, we found children with asthma reported a lower child physical QOL score than those without asthma. Further studies are required using a longitudinal design to investigate the potentially beneficial role of physical activity on QOL and asthma (60).

Limitations

Our study has several limitations. First, the sample size was small and a cross-sectional design was utilized. However, the reported findings are statistically significant and suggestive of observed changes. Second, the participants were recruited from a single site, limited to English speaking families, and one school district. Third, parents who were not as involved in their child's health may have decided not to participate. Fourth, QOL measurement is influenced by the individual who completes the QOL instrument, how the child is identified with asthma, the length of time for symptom recall, and the method used to determine asthma severity (5). Prior research has used parent-determined asthma severity (16,17), the 1997 NAEPP guidelines and spirometry, and the Global Initiatives for Asthma (GINA) guidelines (61,62). Although, parental reporting is important it is not always objective, and spirometry measures can be difficult to complete in the ED due to a lack of resources and personnel. Last, the responses may have been affected by factors that include, but, are not limited to being present in the ED, and a desire to please the researcher (16).

Conclusions

This study determined that urban, minority children with asthma and their parents reported a lower QOL, and visit the ED more frequently than those without asthma. Among children with asthma, QOL was highest when parents were college graduates, asthma severity was low, and with frequent ED visits. Urban, minority families are disproportionately affected with higher asthma prevalence and asthma morbidity. An understanding of the child's and parent's perspectives about the relationship between QOL and asthma could help to inform effective interventions.

Declaration of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Human subjects approval

This study protocol (Pro00005030) was approved by the Children's National Health Systems Institutional Review Board.

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