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Stress and Quality of Life in Caregivers of Inner-city Minority Children with Poorly Controlled Asthma

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Abstract

Introduction—Caregiver quality of life (QOL) is known to influence asthma management behaviors. Risk factors for low caregiver QOL in families of inner-city children with asthma remain unclear. This study evaluated the interrelationships of asthma control, stress, and caregiver QOL.

Method—Data were analyzed from a home-based behavioral intervention for children with persistent asthma post asthma emergency department treatment. Caregivers reported on baseline demographics, asthma control, asthma management stress, life stress, and QOL. Hierarchical regression analysis examined the contributions of socio-demographic factors, asthma control, asthma management stress, and life stress in explaining caregiver QOL.

Results—Children (N=300) were primarily African-American (96%) and young (Mean age of 5.5 years). Caregivers were predominantly the biological mother (92%), single (70%), and unemployed (54%). Poor QOL was associated with higher caregiver education and number of children in the home, low asthma control, and increased asthma management stress and life stress. The model accounted for 28% of variance in caregiver QOL.

Discussion—Findings underscore the need for multi-faceted interventions to provide caregivers of children with asthma tools to cope with asthma management demands and contemporary life stressors.

Keywords

asthma; caregiver; stress; quality of life

Introduction

Asthma is the most common childhood chronic health condition, is a leading cause of functional disability (Bai, Hillemeier, & Lengherich, 2007), and is one of the major reasons for pediatric Emergency Department (ED) visits (Boyd et al., 2009). Over the past two decades, asthma prevalence, morbidity, and mortality rates have significantly increased (Diette & Rand, 2007; Lukacs, Francis, Baron, & Crane, 2002), with inner-city minority children and their families disproportionately affected (Persky et al., 2007; Williams, Sternthal, & Wright, 2009). Measuring caregiver *quality of life (QOL)* offers critical insight into the impact of asthma on these vulnerable families (Price, Bratton, & Klinnert, 2002), including the degree to which the health condition interferes with daily life activities and depletes psychosocial and financial resources (Everhart & Fiese, 2009; Patterson & McCubbin, 1983).

A range of clinical and contextual factors increase the risk for low QOL in caregivers of children with asthma. Poor asthma control, for example, is associated with caregiver work absences (Schmier et al., 2007). In a study of children aged 3–7 years with mild persistent to severe persistent asthma, poor asthma control had a negative impact on parental QOL (Haltermann et al., 2004). Asthma management stress, or the perceived burden associated with daily demands of care (Fiese, Winter, Anbar, Howell, & Poltrock, 2008), has also been identified as a risk factor for restricted QOL. Research on family asthma management routines found perceived asthma burden to be inversely related caregiver QOL, even after disease severity was taken into account (Fiese, Wamboldt, & Anbar, 2005). Others similarly observed that a negative association between daily inhaled corticosteroid use and caregiver QOL did not change after controlling for the effects of asthma severity, suggesting that daily management of asthma in a child may be perceived as stressful by some caregivers (Haltermann et al., 2004). Furthermore, even with few asthma symptoms, the association between perceived asthma management stress and decreased caregiver QOL remains (Annett, Bender, DuHamel, & Lapidus, 2003).

Caregivers of inner-city minority children with asthma may be especially vulnerable to poor QOL due to perceived life stressors within families and communities (Clougherty, Kubzansky, Spengler, & Levy, 2009). Life stress is conceptualized as the problems and difficulties experienced in daily life that result in physiological, psychological, and behavioral responses and impact psychosocial functioning (Israel, Farquhar, Schulz, James, & Parker, 2002; Shalowitz, et al., 2006). Several stressors experienced by inner-city families are associated with the public health concept of *neighborhood disadvantage*, including poverty, high crime, lack of access to resources, air pollution, exposure to allergens, substandard housing, and unemployment or underemployment (Attar, Guerra, & Tolan, 1994). Exposure to neighborhood violence, in particular, is linked to poor asthma control in high risk inner-city youths (Swahn, & Bossarte, 2006; Wright et al., 2004). Further, a cumulative risk model inclusive of contextual risks (e.g., neighborhood stresses), cultural risks (e.g., discrimination), and asthma-specific risks (e.g., severity) accounted for more morbidity than poverty or severity alone in a sample of urban children with asthma (Koinis-Mitchell, et al., 2007).

One model predicting QOL in families of young children with mild to moderate asthma indicates that caregivers who experience several simultaneous life stressors report an especially profound decline in QOL (Everhart, Fiese, & Smyth, 2008). A proposed mechanism for contextual risk factors experienced by inner-city families associated with increased asthma morbidity is that chronic life stress (e.g., poverty, housing instability) (Sandberg et al., 2000) and acute stressors (e.g., community violence) (Sandberg, Javenpaa, Penttinen, Paton, & McCann, 2004) may impede a caregiver's capacity to appropriately

manage their child's asthma, including adherence to the child's complex medication regimens and accessing preventive care (Wright et al., 2004). Because life stressors increase risk for asthma morbidity and contribute to asthma health disparities, greater understanding of the interrelationships of life stress and asthma outcomes is a research priority (Wright & Subramanian, 2007).

In summary, improving caregiver QOL by intervening on associated risk factors has been identified as a primary aim of interventions given its potential impact on the child's disease management (Everhart et al., 2008), caregiver decisions about healthcare utilization (Haltermann et al., 2004), and associations with child QOL (Marsac, Funk, & Nelson, 2006, Williams et al., 2000). However, few studies have examined the influence of both contextual and asthma related risks on caregiver QOL in low-income families of young inner-city children with asthma. In addition, the interaction of risks has not been examined in relationship to QOL except in one study that was primarily comprised of Caucasian caregivers (Everhart et al., 2008). This descriptive study was conducted to address this gap in family science by evaluating the interrelationships of asthma control, asthma management stress, life stress, and QOL in a sample of caregivers of inner-city minority children with poorly controlled asthma. The primary hypothesis tested in this study was that caregiver QOL would be negatively associated with asthma management stress and life stress, after accounting for the effects of asthma control, number of children in the home, and the caregiver's level of education. Exploratory analyses were also conducted to examine the interaction of asthma management stress and daily life stress on caregiver QOL.

Methods

Following study approval by the associated Institutional Review Boards, children with asthma were identified and recruited from daily review of medical records obtained from the pediatric emergency departments (EDs) of the Johns Hopkins Hospital and University of Maryland Medical System. Eligible families were enrolled in an ongoing two-group randomized controlled trial to examine the effectiveness of an asthma communication educational intervention to improve guideline-based preventive asthma care, and to reduce asthma morbidity in high-risk inner-city minority children with asthma (Butz et al., 2011). The inclusion criteria included: (1) physician-diagnosed asthma; (2) 2 ED visits or 1 hospitalization for asthma within past 12 months; (3) mild to severe persistent asthma severity based on National Heart, Lung, and Blood Institute guidelines 2007; and, (4) Age 3 and 10 years. Exclusion criteria included: (1) inability to speak/understand English; (2) other co-morbid respiratory condition (e.g., bronchopulmonary dysplasia); and, (3) children residing in foster care where consent could not be obtained from a legal guardian.

This study presents baseline data collected from 300 families enrolled in the clinical trial. As illustrated in Figure 1, a total of 1630 eligible children were screened for study eligibility. One hundred and twenty-one children were not eligible, and an additional 1209 children were not enrolled due to inability to locate families because of an inaccurate address or phone number listed on child's ED medical record (n=1081) or parent refusal (n=128). Three-hundred families were enrolled into the study over a 26-month period, from November 2008 through January 2011. The trial was registered with clinicaltrials.gov with registration number NCT00860418.

Procedure

Eligible families were contacted via mailed letter of invitation to participate in the study. Follow-up phone calls were made approximately five days after the letter of invitation was sent. Once families passed the screen for inclusion criteria, a home visit was conducted by a research coordinator to obtain informed consent and administer a baseline survey to the

child's primary caregiver. The survey was comprised of questions on background demographics, healthcare utilization, asthma control, asthma management stress, life stress, and caregiver QOL. Families were compensated \$30.00 for their time spent participating in the baseline data collection process.

Measures

Caregiver's Level of Education—Caregivers self-reported on the highest level of education achieved. Responses ranged from 1 (less than 9th grade completed) to 5 (four-year college graduate).

Baseline Asthma Control—Consistent with the National Asthma Education and Prevention Program Guidelines (2007), asthma control was based on day and night frequency of cough, wheeze, and shortness of breath or difficulty breathing symptoms experienced over the last two weeks (0–14 days).

Asthma Management Stress—Asthma management stress over the past month was ascertained using an 11-point visual analog scale (VAS). Caregivers were asked to select the number between 0 and 10 on the VAS that indicated their level of asthma stress, which was defined as the level of stress related to caring for their child with asthma. Anchors included “0,” defined as no stress, and “10,” reflecting the highest possible level of stress. A score of 6–7 reflects moderate asthma-related stress, and a score of 8 or above was assigned a high level of stress. The validity of the VAS has been previously established through moderate correlations with objective measures of pain ($r=0.88$ to $r=.98$) (Price, Bush, Long, & Harkins, 1994).

Life Stress—The Crisis in Family Systems (CRISYS) was administered to caregivers as a self-reported measure of contemporary life stressors (Shalowitz, Berry, Rasinski, & Dannhausen-Brun, 1998). The CRISYS was developed to measure a range of community stressors experienced by individuals living in poverty. Study participants completed the following CRISYS subscales: financial (11 items), legal (3 items), career (4 items), relationships (6 items), safety in the home (3 items), safety in the community (8 items), medical issues pertaining to self (6 items), medical issues pertaining to others (4 items), and home issues (7 items). The dichotomized CRISYS items (0 = no, 1 = yes) are scored using the total count of life stressors experienced in the previous six months, with higher scores reflecting higher levels of life stress. The two-week test-retest reliability in a sample of low-income African American women was high ($r=.88$, $p<.001$) (Shalowitz et al., 1998). Convergent construct validity of the CRISYS is supported by a moderate correlation with the Center for Epidemiological Studies-Depression scale ($r=.44$, $p<.001$) (Berry, Shalowitz, Quinn, & Wolf, 2001). Cronbach's alpha in the current study sample was 0.70.

Caregiver Quality of Life—Caregivers completed the Activity Limitation scale of the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) as a self-report index of QOL in the context of caregiver daily life experiences (Juniper et al., 1996). The Activity Limitation scale is comprised of four items that reflect how the child's asthma may impact the caregiver's sleep, work, and family experiences (e.g., “*Were you awakened at night because of your child's asthma?*”; “*Did your family need to change plans because of your child's asthma?*”). Responses are given on a 7-point scale, where “1” represents severe impairment and “7” represents non-impairment. A total score is derived from the mean of all items, with higher scores reflecting a more favorable QOL. The intraclass correlation coefficient (ICC) was 0.84 for the Activity Limitation scale (Juniper et al., 1996). The construct validity of the measure is indicated by inverse relationships with symptom days

($r=-.48$, $p<.001$) and nights ($r=-.43$, $p<.05$) (Haltermann et al., 2004). Cronbach's alpha for the Activity Limitation scale in the current study sample was 0.83.

Data Analysis

Pearson correlation coefficients were initially conducted to test the strength of the relationship between the primary outcome, caregiver QOL, and the independent variables of asthma control, the caregiver's level of education, number of children in the home, asthma management stress, and life stress. Next, hierarchical multiple regression analysis was performed to examine the unique contributions of asthma management stress and life stress in explaining variance in caregiver QOL. The covariates (caregiver education level, number of children in home, asthma control) were entered on step one of the model, asthma management stress factor on step two, and life stress factor on step three. A second hierarchical regression model was run to test a moderating influence of life stress on the relationship between asthma management stress and caregiver QOL. The covariates were again entered on step one, the centered asthma management stress and life stress factors on step two, and the interaction term of asthma management stress and life stress on step three. The total variance accounted for by the factors (adjusted R^2) and the changes in explained variance associated with each step of the model (R^2 -change) were examined. The strength of the relationship between each stress factor and caregiver QOL was computed using F -square (Cohen, 1988). All data analyses were performed using PASW/SPSS v.18. Two-sided tests were used and p values <0.05 were considered significant.

Results

The children ($N=300$) were primarily male (59%), African American (96%), young, with a mean age of 5.5 years ($SD=2.2$), and enrolled in Medicaid (92%). Caregivers were predominantly the child's biological mother (92%), had achieved a high school degree or more education (70%), were single (70%), unemployed (54%), and reported a household income less than \$10,000 (50%). Caregivers reported an average of 4.63 ($SD=1.97$) household members, including a mean of 2.4 ($SD=1.36$) children in the home.

Asthma morbidity was high, as expected by study design, with over half (59%) reporting five or more symptom days ($M=7.24$, $SD=5.31$), 45% endorsing five or more symptom nights ($M=6.61$, $SD=5.61$), and 45% indicating daily rescue medication use, all over the past two weeks. Mean ED visits reported during the prior six months were high ($M=3.23$, $SD=3.19$; range 0–20 visits), yet over half of caregivers (52%) considered their child's asthma to be well controlled. Forty-one caregivers (14%) endorsed a moderate level of asthma management stress (score 6–7), and a third (34%) reported high asthma management stress (score 8) ($M=5.16$, $SD=3.72$).

Based on items endorsed on the CRISYS scale, caregivers reported experiencing an average of 10.55 ($SD=5.84$) life stressors in the past six months. The most frequently endorsed CRISYS items included, *Did your child(ren) become ill or did your child(ren) have a flare-up of a chronic illness?* (87.8%), *Did you look for a job?* (54.0%), *Did the utility or phone company threaten to cut off your service because you couldn't pay bills?* (51.3%), *Did rats, mice, or insects bother you in your home?* (49.0%), *Did you see drug dealing in your building or neighborhood?* (38.7%), and, *Did you hear violence outside your home?* (37.7%).

Caregiver QOL Activity Limitation scale scores ranged from 4 – 20 out of a possible range of 4 – 20 ($M=17.87$, $SD=7.50$), and were significantly and negatively associated with two-week daytime symptoms ($r=-.32$, $p<.001$), two-week nighttime symptoms ($r=-.33$, $p<.001$), asthma management stress ($r=-.38$, $p<.001$), and life stress ($r=-.24$, $p<.001$) (Table

1). Child age ($r = .07$, $p = .07$) and caregiver employment status ($r = .09$, $p = .09$) were non-significant. However, QOL was related to the caregiver's level of education ($r = -.14$, $p = .02$) and the number of children in the home ($r = -.12$, $p = .04$), with greater education and increased number of children associated with lower caregiver QOL (Table 1).

Caregiver Quality of Life Model

As shown in Table 2, the overall model inclusive of the socio-demographic variables, asthma control indicators, asthma management stress, and life stress, explained a significant amount of variance in caregiver QOL (Adjusted $R^2 = .28$, $F(6, 266) = 17.78$, $p < .001$). The change in explained variance associated with the addition of the socio-demographic variables (caregiver's level of education, number of children in home) and the asthma control indicators (symptom days and nights during the past two weeks) on step one of the model was significant ($R^2\Delta = .18$, $F(4, 262) = 14.26$, $p < .001$). As predicted, the addition of asthma management, stress to the model on step two ($R^2\Delta = .09$, $F(1, 261) = 33.69$, $p < .001$; $f^2 = .10$) and life stress on step three ($R^2\Delta = .02$, $F(1, 260) = 6.71$, $p = .01$; $f^2 = .02$) were supported and within the range of a medium and small effect size, respectively, based on the benchmarks established by Cohen (1988). In the final model, a main effect was observed for the caregiver's level of education level ($\beta = -.13$, $p = .01$), number of children in the home ($\beta = -.16$, $p = .003$), asthma symptom nights ($\beta = -.21$, $p = .005$), asthma management stress ($\beta = -.28$, $p < .001$), and life stress ($\beta = -.14$, $p = .01$). Low caregiver QOL was associated with increased education, a higher number of children in the home, more asthma symptom nights, a greater perceived burden of asthma management, and higher daily life stresses.

A second hierarchical regression model was run to explore whether the caregiver's self-report of contemporary life stressors exacerbated the negative influence of asthma management stress on caregiver QOL. The covariates (caregiver's level of education, number of children in the home, asthma control) were entered on step one, the centered asthma management stress and life stress variables on step two, and the interaction term of asthma management stress and life stress on step three. However, the change in explained variance associated with the interaction term was non-significant ($p > .05$).

Discussion

This study extends understanding of the range of socio-demographic risk factors and stress experiences that are related to low caregiver QOL in inner-city families of minority children with asthma. A higher caregiver level of education and number of children in the home, poor asthma control, and increased asthma management stress and life stress were all associated with reduced caregiver QOL. In the final model, the combined effects of these socio-demographic, asthma control, and stress factors accounted for a significant amount of variance in caregiver QOL (R^2 Adjusted = 0.28).

Consistent with prior research with this population, poorly controlled asthma, specifically the number of symptom nights over a two-week period, was strongly associated with low caregiver QOL (Halterman et al., 2004; Dean, Calimlim, Kindermann, Khandker, & Tinkelman, 2009). A particularly intriguing finding relates to the observed significant relationship between the caregiver's level of education and QOL. In this sample of inner-city families, a higher education level was associated with poorer QOL. It is possible that caregivers with a higher level of education are more likely to be employed and thus have their work schedules disrupted because of poor asthma control in their children. Dean and colleagues previously found that caregivers of children with uncontrolled asthma reported significantly higher work absenteeism than their counterparts (Dean et al., 2009). A greater number of children in the home was also associated with low caregiver QOL. This finding

may reflect that increased childcare responsibilities limit the caregiver's ability to successfully manage a child with asthma, which may subsequently result in a negative impact on caregiver sleep, work, and family experiences as measured in QOL.

Asthma management stress was commonly reported in these caregivers, with over one-third endorsing a very high level of perceived burden of care. Given the disease specific measure of QOL used in this study, it was not surprising to find that asthma management stress was more strongly related to caregiver QOL compared to daily life stress. In fact, based on the standardized coefficients in the final regression model, asthma management stress had the strongest association with caregiver QOL.

The caregiver's experience of stress beyond what is associated with the child's asthma is also notable. Study participants commonly reported daily life stresses related to looking for a job, utilities insecurity, rodent and cockroach infestation, and residence in high crime neighborhoods where they witnessed drug use and were exposed to violence. These complex psychosocial stressors may decrease a caregiver's capacity to appropriately manage their child's asthma, but remain understudied in past asthma intervention programs (Williams et al., 2009). One recent interdisciplinary intervention used an asthma risk profile, which was based on a review of biopsychosocial barriers to asthma management, to tailor a cognitive-behavioral problem-solving session for families of inner-city youths with asthma (Walders et al., 2006). Intervention youths had fewer ED visits and inpatient services, but no differences in asthma symptoms or QOL were found between the intervention and comparison families. Walders and colleagues (2006) acknowledged that the single family session offered in their intervention was likely not sufficient to address the complex stresses experienced by high-risk inner-city families. Others have similarly explored the effectiveness of a culturally tailored family intervention delivered by an asthma counselor over the course of two home visits (Canino et al., 2008). Educational content included identifying and overcoming barriers to care, appropriate medication use, caregiver psychological health, and environmental triggers. Caregivers randomized to the educational group reported less frustration and more confidence in their ability to successfully manage their child's asthma than the non-intervention group, but no differences in caregiver QOL were observed between the two groups.

These prior psychosocial asthma interventions and key findings from the present study provide underscore the utility of home-based multi-faceted interventions to address caregiver stress related to asthma management and daily life stress experienced by inner-city families. However, the level of engagement between the interventionist nurses/health educators and families, and the degree of tailored services provided to families in the intervention studies, were restricted in scope and perhaps contributed to the limited reported findings. A recent review of educational and behavioral asthma interventions found the following eight common elements in effective programs: (1) recognizing the multiple factors that influence childhood asthma and its control, (2) carefully assessing the participants' risk factors and needs in achieving asthma control, (3) tailoring program elements to the caregiver to the greatest extent possible, (4) basing interventions on sound principles of learning and change, (5) considering both the physical and social environments, (6) involving significant family members in intervention activities to enhance caregiver support, (7) focusing on children with the most serious disease, and (8) selecting a venue where learning can be optimized (Clark, Mitchell, & Rand, 2009, p. S190). Collectively, these findings indicate that successful psychosocial interventions in underserved inner-city minority children with asthma and their families require targeted and comprehensive interdisciplinary strategies to provide the caregiver with tools to cope with asthma management demands, as well as the contemporary life stressors experienced by this population.

Study Limitations and Implications for Future Research

Study findings are restricted by several methodological considerations. Common-method variance (e.g., variance attributed to measurement method) cannot be ruled out as an explanation for the significant relationships because of the use of self-report measures. However, objective measures of caregiver stress were cost prohibitive in this study. Future research on stress in this population may benefit from including both subjective (e.g., self-report) and objective (e.g., salivary cortisol) measures of stress. Also, longitudinal data are needed to clarify the directionality of observed relationships. Although asthma management stress and life stress were treated as predictors of caregiver QOL, it is possible that compromised caregiver QOL drives the level of perceived stress, and not vice versa. Other methodological limitations relate to the purposeful selection of low-income inner-city caregivers of minority children with poorly controlled asthma. Study findings may not be generalized to other caregiver populations, including caregivers in rural settings, caregivers of children with well-controlled asthma, or caregivers with higher incomes. Lastly, the model may be improved by including other factors that have been identified as correlates of poor QOL in inner-city families of youths with asthma. Exposure to second hand smoke has been previously found to predict low QOL, even after controlling for asthma severity (Halterman et al., 2004). Also, since self-report of QOL may be influenced by the caregiver's affect (Price et al., 2002), it would be important to control for depressive and anxiety symptoms.

Despite these limitations, this study advances an understanding of the multiple factors associated with reduced caregiver QOL in families of inner-city minority children with poorly controlled asthma and indicates some considerations for clinical management of inner-city children with asthma. The impact of uncontrolled pediatric asthma, especially night symptoms, affects not only the children but extends to their caregivers who have the burden of care. Successful clinical interventions to improve caregiver QOL must attend to the specific aspects of asthma management as well as the as the contemporary daily life stressors experienced by low-income inner-city caregivers. Pediatric health care providers working with this population should systematically assess caregiver stress levels, especially for caregivers of high risk children with asthma. Caregivers who endorse high stress levels should be provided counseling and appropriate referrals to obtain resources to modify stressors that are often associated with poverty, including emergency utility assistance and home environmental control to address infestations or other indoor exposures. It has been suggested that interventions targeting even one area may be effective in improving caregiver QOL, and this in turn has implications for better management of asthma (Everhart et al, 2008). In conclusion, targeted services that attend to the asthma management education needs and psychosocial stressors are paramount to enhance caregiver QOL in inner-city minority families.

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Figure 1.
Participant Recruitment and Retention Flow

Table 1

Significant Bivariate Associations with Caregiver Quality of Life (N=300)

Variable	1	2	3	4	5	6	7
1. Number of Children	---	-0.11**	-0.02	0.01	-0.02	-0.05	-0.12*
2. Caregiver Education		---	-0.06	-0.04	0.04	0.11	-0.14*
3. Day Symptoms			---	0.70**	0.21**	0.11	-0.32**
4. Night Symptoms				---	0.26**	0.08	-0.33**
5. Asthma Management Stress					---	-0.25**	-0.38**
6. Caregiver Life Stress						---	-0.24**
7. Caregiver Quality of Life							---

Note.

**
 $p < .001$,*
 $p < .05$

Table 2

Hierarchical Multiple Regression Results for Caregiver Quality of Life Model (N=300)

	Predictor	Total R^2 Adjusted	ΔR^2	F	ΔF	df	B	SE	β
Step 1	Caregiver's Level of Education	0.17	0.18	14.26**	14.26**	4,266	-1.03	0.41	-0.13*
	Number of Children in Home						-0.85	0.28	-0.16*
	Asthma Symptom Days						-0.16	0.10	-0.11
	Asthma Symptom Nights						-0.27	0.10	-0.21*
Step 2	Asthma Management Stress	0.26	0.09	19.56**	33.69**	1,261	-0.57	0.11	-0.28**
Step 3	Life Stress	0.29	0.02	17.78**	6.72*	1,260	-0.18	0.07	-0.14*

Note. The reported unstandardized and standardized coefficients are from the final regression model.

* $p < .05$ ** $p < .001$