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Stress and Quality of Life in Urban Caregivers of Children with Poorly Controlled Asthma: A Longitudinal Analysis

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Abstract

Introduction—The intent of this analysis was to examine the longitudinal effects of risk and protective factors on quality of life (QOL) in caregivers of minority children with asthma.

Method—Caregivers (n=300) reported on demographics, child asthma characteristics, daily asthma caregiving stress, general life stress, social support and QOL. Latent growth curve modeling examined changes in QOL across 12 months as a function of stress, asthma control, and social support.

Results—Caregivers were primarily the biological mother (92%), single (71%), unemployed (55%), and living in poverty. Children were African American (96%), Medicaid eligible (92%), and had poorly controlled asthma (93%). Lower QOL was associated with higher life stress, greater asthma caregiving stress, and lower asthma control over time.

Discussion—Findings underscore the importance of assessing objective and subjective measures of asthma burden and daily life stress in clinical encounters with urban, low-income caregivers of children with poorly controlled asthma.

Keywords

asthma; caregivers; quality of life; stress

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INTRODUCTION

Asthma is one of the most common chronic diseases in children with an estimated 6.8 million youths in the United States affected (Akinbami, 2006; Akinbami, et al., 2012; Bloom, Jones, & Freeman, 2013). Its impact is especially profound among children from low-income and minority families who have a higher prevalence of asthma (Bloom, et al.; Kozyrskyj, Kendall, Jacoby, Sly & Zubrick, 2010; McDaniel, Paxson, & Waldfogel, 2006) and experience greater morbidity compared with non-Hispanic white children (Akinbami, Moorman, & Liu, 2011; Boudreaux, Emond, Clark & Camargo, 2003; Flores, et al. 2009).

Poorly controlled asthma can be very disruptive to the daily life activities for the child through increased school absences, impaired sleep, and restricted social and physical activity (Dean et al., 2010; Wildhaber, Carroll & Brand, 2012), resulting in lower child quality of life (Amaral, Moratelli, Palma, & Leite, 2014). The burden of asthma exacerbations likewise reverberates throughout families who describe substantial psychosocial, caregiving, and financial stresses (Crespo, Carona, Silva, Canavarro, & Dattilio, 2011; Sampson et al., 2013a; Sampson et al., 2013b), beyond the fear of seeing their child struggling to breathe. Not surprising, caregivers of children with poorly controlled asthma report more missed work compared to caregivers of children with controlled asthma (31% vs. 16%) (Dean, et al. 2009), decreased work productivity, with an average of 4.1 hours of productivity loss over a 40 hour work week during their child's asthma episode (Dean, et al., 2010), and higher perceived financial burden than caregivers of children with well controlled asthma (Patel, Brown, & Clark, 2013).

Quality of life (QOL) is regarded as an important marker of the impact of health conditions on patients and their families and is consequently a major outcome measure in research and clinical interventions of chronic disease (Chow, Morrow, Robbins, & Leask, 2013; Indinnimeo, et al., 2014). Identifying risk and protective correlates of QOL in asthma populations is further significant since caregiver QOL is proposed to influence health self-management behaviors such as treatment adherence and decisions about seeking healthcare services (Osman & Silverman, 1996), which may have a significant impact on asthma control. Both objective illness-specific indicators (e.g., frequency of asthma symptoms) and perceptions of caregiving stress have been explored as predictors of QOL in caregivers of children with asthma. Over a decade of evidence indicates higher asthma severity and poor asthma control exert negative effects on QOL in some caregiver populations (Authors 2013a; Cerdan, Alpert, Moonie, Cyrkiel, & Rue, 2012; Levy et al 2004; Okelo et al., 2014; Williams et al., 2000). However, other research suggests caregiver perception of stress due to asthma management demands is a more profound predictor of caregiver QOL compared to the degree of symptoms (Annett, Bender, DuHamel, & Lapidus, 2003; Crespo et al. 2011). Caregiving stress, conceptualized as hardship experienced in relation to managing a child's health condition (Sampson, et al., 2013a), has also been shown to disproportionately impact low-income caregivers (Fiese, Wamboldt, & Anbar, 2005).

In some populations, asthma-specific risks are not necessarily the driving force of caregiver QOL outcomes. In an international sample of adolescents with asthma and caregivers,

illness variables including baseline severity, control level, and symptom duration were not associated with child or caregiver QOL (Vila et al, 2003). Instead, socio-demographic and contextual factors may help explain heterogeneity in caregiver QOL. Evidence suggests caregivers who are single (Sampson, et al., 2013b), low-income (Osman, Baxter-Jones, & Helms, 2001), and parenting young children with asthma (Dalheim-Englund, et al., 2004) are at increased risk for impaired QOL. Racial and ethnic differences in QOL outcomes are also noted with minority caregivers reporting lower QOL compared with non-Hispanic white caregivers (Everhart et al., 2012; Everhart, Fedele, Miadich, & Koinis-Mitchell, 2014).

The broader social and environmental context of asthma caregiving, i.e. neighborhood characteristics, is similarly a focus of public health and community nursing science. Interdisciplinary scholars have proposed models for asthma health disparities inclusive of both illness-specific stressors (e.g., asthma severity, control level) and social and contextual stressors associated with residence in disadvantaged communities (e.g., poverty, allergen exposure, housing instability, second hand smoke exposure, food insecurity, violence exposure, access to care) (Authors, 2014a; Murdock, Adams, Pears, & Ellis, 2012; Sampson et al. 2013b; Silvers & Lang, 2012). Our previous cross-sectional study of stress and QOL in inner-city, low-income caregivers of young children with high-risk asthma found that daily life stress explained a significant level of variance in QOL outcomes, even after accounting for the effects of asthma control level and asthma caregiving stress (Authors, 2013a).

Others have argued that asthma outcomes in urban populations may be better explained by the interactive relationship of multiple risks. Everhart, Fiese and Smyth (2008) tested the utility model inclusive of six risk factors (e.g., socioeconomic status, single versus two caregiver households, asthma severity, child QOL, family burden, and family stress) in predicting caregiver QOL and observed a nonlinear relationship between the risk model and QOL in which caregivers who endorsed multiple risks experienced a particularly impaired QOL. Koinis-Mitchell and colleagues (2007) likewise explored the simultaneous effects of cultural, socio-contextual, and asthma-specific risks. Their cumulative risk index more accurately captured rates of Emergency Department (ED) visits and degree of child functional limitation compared with the predictive value of poverty or asthma severity alone. More recently, models inclusive of risk and protective factors have been tested in relation to asthma outcomes. Protective mechanisms found in child self-efficacy and family connectedness mitigated the negative effect of cumulative risks on asthma morbidity in a study of Latino youths with asthma (Koinis-Mitchell, et al. 2012). Although caregiver protective factors such as social support have been shown to reduce experiences of caregiver burden (Scheckner, Arcoleo, & Feldman, 2015) and may optimize child asthma management (Raymond, et al., 2012), asthma family science lacks a risk and resilience model for caregiver QOL in families of young children with poorly controlled asthma.

In summary, there is a range of asthma-specific, sociodemographic, and contextual risk factors linked to caregiver QOL. However, few studies have explored the collective impact of these risks and even less is known about whether protective processes may moderate the effects of these risks. Furthermore, knowledge of how QOL in caregivers of young inner city children with high-risk asthma may evolve over time is limited since the majority of

QOL research has been cross-sectional in nature or comprised of small samples. The intent of this longitudinal analysis is to address these gaps by testing the direct and interaction of effects of asthma caregiving stress, daily life stress, and social support on QOL in a sample of low-income caregivers of minority children with poorly controlled asthma. We hypothesized that both daily life stress and asthma caregiving stress would negatively impact QOL and, secondly, that caregivers who endorsed both risks would experience a particularly compromised QOL. We also expected that caregiver social support would moderate the negative effects of stress on QOL outcomes.

METHODS

This sub-analysis is part of a larger randomized controlled trial that tested the effectiveness of a behavioral/educational intervention in families of children with poorly controlled asthma (Authros, 2012, 2014b). After obtaining institutional review board approval, caregivers of 300 inner-city children with asthma aged 3-10 years were recruited from two major urban hospitals after the child was discharged from a Pediatric ED. A Health Insurance Portability and Accountability Act (HIPAA) waiver was used to abstract contact information during daily review of electronic ED medical records. Caregivers were mailed study information and an opt out letter declining further communication by study staff. Caregivers who did not decline participation were contacted by the study team to screen for study interest and eligibility based on the following parameters: (a) child age 3-10 years, (b) physician diagnosed asthma, (c) > 2 symptom days or rescue medication use/week or 2 > symptom nights/month, (d) controller medication use during the prior 6 months and, (e) two or more ED visits or one hospitalization during the prior 12 months of the index ED visit. Children with other major respiratory conditions were excluded and only one child per family was enrolled.

Study staff screened and enrolled 300 (70%) of the 549 families who were successfully contacted. No differences on key demographics and asthma health status were found between families who enrolled and those who declined participation. Caregivers completed informed consent and were subsequently randomized into a home-based standard asthma education attention control group or a behavioral/education intervention group and prospectively followed for 12 months. Research assistants administered study questionnaires, described below, face-to-face to caregivers at baseline, six-months, and twelve-months post enrollment.

Behavioral/Education Intervention

Caregivers randomized to the intervention group received two home visits by a trained nurse for asthma education, completion of a written asthma action plan, and assistance in arranging a follow-up appointment with the child's primary care provider (PCP). A third intervention visit consisted of the nurse accompanying the caregiver and child to a PCP appointment to advocate for preventive care and guideline-based asthma management.

Standard Asthma Education Attention Control Group

Caregivers assigned to the control group received three home visits by a trained nurse for the same asthma education and a reminder to make a follow-up appointment for the child with their PCP for asthma care.

Measures

Asthma Severity

Child asthma severity was assessed at baseline and included caregiver report of asthma day symptoms over past 14 days and night symptoms over the past 30 days, child activity limitations due to asthma, ED visits, use of controller and rescue medications over the past 6 months, and number primary care practitioner (PCP) visits over past six months. Children were subsequently categorized as having intermittent, mild persistent, moderate persistent, or severe persistent asthma based on national asthma guidelines (USDHHS, 2007).

Asthma Control

Using the National Asthma Education and Prevention Program Guidelines (USDHHS, 2007), an algorithm for child asthma control level was developed based on the frequency of day and night cough, wheeze, and shortness of breath or difficulty breathing symptoms, rescue medication use, activity limitation and number of ED visits and hospitalizations. Based on this algorithm, asthma control was inversely scored as well controlled =1, not well controlled = 2, or poorly controlled = 3).

Asthma Management Stress

Caregivers were asked to quantify the level of asthma management stress over the past month using a visual analog scale (VAS). A score of “0” indicated no stress related to caring for their child with asthma and “10” reflected the highest possible level of asthma caregiving stress. A score of 6-7 suggested moderate asthma-related stress, and a score of 8 or above was regarded as a high level of stress. Evidence suggests the VAS has both discriminative sensitivity as a measure of stress and has construct validity through moderate to high correlations with standardized measures of psychological stress (Lesage, Beriot, & Deschamps, 2012).

Life Stress

Life stress was ascertained using the Perceived Stress Scale-4 Item (PSS4) (Cohen & Williamson, 1988). The validated self-report measure asks respondents to consider the degree of stress over the previous month and includes items “How often have you felt that you were unable to control important things in your life” and “How often have you felt your difficulties were piling up so high that you could not overcome them.” The four items (scaled 0-4), two of which are reverse-coded, are summed to provide a possible range of 0-16 with higher scores reflective of more perceived stress. The PSS4 was previously validated for use in asthma populations (Milam, et al., 2008). Internal consistency in this sample was low but consistent with previously reported psychometrics for the shortened

scale (Cohen & Williamson, 1988), and ranged from a low of α=.63 at Time 1 to a high of α=.68 at Time 2.

Social Support

The emotional/informational support subscale of the Medical Outcomes Study (MOS) was administered to caregivers as a self-report measure of social support (Sherborne & Stewart, 1991). The eight-item Likert scale asks respondents to reflect on how available social support is to them across several scenarios (e.g., "Someone you can count on to listen to you when you need to talk; "Someone to turn to for suggestions about how to deal with a personal *problem"*). Items are scored (1= none of the time; 5= all of the time) and summed with higher scores indicating greater perceived social support. Baseline Cronbach's alpha in this sample was high (α =.95).

Caregiver Quality of Life

Caregivers completed the Activity Limitations scale of the Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) as a measure of QOL (Juniper, et al., 1996). The Activity Limitations scale is comprised of four items that explore the extent to which the child's asthma negatively impacts the caregiver's sleep, work, and family experiences (e.g., "Did your child's asthma interfere with your job or work around the house;"; "Did your family need to change plans because of your child's asthma"). Responses are given on a 7-point Likert-type scale, where "1" represents severely impaired QOL and "7" indicates no impairment. The items are summed with higher scores suggesting a more positive QOL. The measure has established psychometric properties and has been administered as a measure of QOL across diverse caregiver populations in the US and internationally (Al-Akour & Khader, 2009; Okelo et al, 2014; Riera et al., 2015). Construct validity was previously shown through inverse relationships with asthma symptom days (r=-.48, p<.001) and symptom nights (r=-.43, p<.05) (Halterman et al., 2004). Baseline Cronbach's alpha for the Activity Limitation scale in this sample of caregivers was .83.

Data Analysis

Latent growth curve modeling (LGCM) using Mplus version 6 (Muthén & Muthén, 2011) was performed to examine changes in quality of life (QOL) over time. Data in LGCM are described by latent change factors (i.e., *means* and *slopes*) that estimate both group-level change and individual-level change. Intercept values were estimated by fixing factor loadings at each time point to one. Slope values were then estimated by assigning fixed factor loading representing time (baseline, six-months, twelve-months). Maximum-likelihood estimation with robust standard errors (MLR) was used to address missing data that never exceeded 9% for any single variable. Based on α=.05 and β=.80 a priori power analysis indicated a minimum sample of 217 for testing the structure of the LGCM (RMSEA<.10), and a minimum sample of 152 for testing individual parameters (b>0) (Preacher & Coffman, 2006; Soper, 2013). QOL was measured at all three time points. Control variables measured at baseline only were treatment group assignment, child's age, mother's education level, employment, and asthma severity. Time-varying covariates in the

model were measured at baseline, six-months, and twelve-months, and included social support, life stress, asthma caregiving stress, and asthma control level.

Three nested LGC models were analyzed. Model 1 was an unconditional model comprised of longitudinal QOL scores only. Model 2 added covariates including both baseline control variables and time-varying covariates. Model 3 incorporated moderating effects between asthma caregiving stress, life stress, and social support (e.g., *Social Support* X *Life Stress*, *Social Support* X *Asthma Caregiving Stress*, and *Life Stress* X *Asthma Caregiving Stress*). The fit of the models to the data was estimated using both sample and population-based indices (Kline, 2005). Sample-based indices estimate how well the proposed model actually fits the observed relationship among study variables and included the chi-square test of goodness of fit, which is the relative chi-square statistic that accounts for sample size, and the Akaike Information Criteria (AIC); ratios of 3:1 for the relative chi-square are indicative of good fit (Carmines & McIver, 1981) and lower AIC values indicate improved fit between nested models (Kline, 2005). Population-based indices estimate discrepancies between the observed data and population values. The mean square error of approximation (RMSEA), with values <.06 preferred (Hu & Bentler, 1999), and the comparative fit index (CFI) and the Tucker-Lewis index (TLI) with preferred values over 0.90 (Kline, 2005; Hu & Bentler, 1999) were included in this analysis.

RESULTS

As previously reported, caregivers were primarily the biological mother (n=276, 92.3%) and single (n=210, 70.7%) (Authors, 2014b). A majority had completed high-school education/ received their GED (n=117, 39.1%) or attended some college or trade school (n=81, 27.1%) (Table 1). More than half of the sample was unemployed (n=161, 54.6%), and of those who were employed, a third reported only part-time work (n=46, 34.3%). Annual family income was low in this sample of inner city caregivers, with nearly three-fourths reporting less than $20,000 (n=187, 71.9%). The children were young (*M*=5.65, *SD*=2.19), African-American (n=286, 95.7%), and Medicaid eligible (n=275, 91.7%).

Consistent with study design, at baseline most children had moderate persistent (n=52, 17.4%) or severe persistent asthma (n=117, 39.3%), and almost all were categorized as having poorly controlled asthma (n=280, 93.3%) based on the frequency of symptoms, rescue medication usage, and asthma-related emergency services (Table 1). At baseline, the children averaged 3.23 ED visits (*SD*=3.2) and 1.32 urgent care visits (*SD*=3.37) during the previous six month period and 29% had at least one hospitalization. A third of caregivers (n=102, 34.6%) rated asthma caregiving stress at 8 or above, suggestive of a high degree of burden, and 61 caregivers (21.7%) endorsed the highest possible level of asthma stress (score of 10) at baseline. Mean daily life stress over the previous month was 5.69 (SD=3.56; range 0 - 16), with a third of caregivers reporting a score of 8 or higher on the PSS4 (n=99, 33%). At baseline, most caregivers reported access to emotional/instrumental support, with 218 (72.7%) scoring at 30 or above on the MOS social support scale (range 8-40).

On average, the QOL composite scores reflected a moderate impact of asthma on caregivers, with participants indicating greatest effect on sleep. At baseline, nearly half of the sample

reported being awakened during the night on a regular basis in the previous week because of their child's asthma (n=147, 49.2%), and over a third experienced sleepless nights all or most of the time in the previous week (n=113, 37.3%). However, QOL scores improved over time from mean of 17.98 (*SD*=7.49) at baseline to 22.75 (*SD*=5.79) at six-months to 22.87 (*SD*=6.24) at twelve-months, with statistically significant differences between baseline and six-months ($p<.001$) and between baseline and 12-months ($p<.001$).

Asthma caregiving stress decreased over time with a baseline mean of 5.16 (*SD*=3.72), a six-month mean of 3.63 (*SD*=3.46) and a 12-month mean of 3.61 (*SD*=3.53); significant decreases in mean scores were observed between baseline and six-month as well as baseline and 12-month ($p<.001$). A similar trend was observed for life stress with statistically significant ($p<.001$) decreases in mean scores observed between baseline (*M*=5.70, *SD*=3.56) and six-month (*M*=4.99, *SD*=3.53), as well as baseline and 12-month (*M*=4.99, *SD*=3.68). Statistically significant increases in mean Social Support scores were observed between baseline (*M*=32.90, *SD*=8.75) and six-month (*M*=33.62, *SD*=8.31) as well as between six-month and 12-month (*M*=34.33, *SD*=8.18). Lastly, asthma control level improved somewhat over time, with a significant decrease in the number of children categorized as poorly controlled from baseline (93.3%, *n*=280) to six-month and twelve-month (61.5% at both time points, *n*=30 and 39, respectively). The number of children categorized as having well controlled asthma increased from 0% at baseline to 14.3% (*n*=39) at twelve-months.

Latent Growth Curve Model Results

LGC model analyses were used to assess changes in quality of life over time as a function of life stress, asthma caregiving stress, asthma control, and social support. Fit statistics for the nested models are presented in Table 2. Results indicate acceptable fit between the data and all three models. Unstandardized parameter estimates, standard errors, and *p*-values are provided in text; parameter estimates and 95% CIs are provided in Table 3. An unconditional model using QOL over time was tested first. Results for the intercept and slope were 19.27 (*se*=.40,$p<.001$) and 2.12 (*se*=.25,$p<.001$), respectively. The statistically significant and positive intercept indicates that the average QOL score was greater than zero over time; the statistically significant positive average slope indicates a significant increase in QOL scores over time.

Results for the second LGC model indicate good fit as evidenced by a RMSEA of .06 and high values for CFI (.83) and TFI (.78). The only significant parameter estimate for the control variables was a negative difference in intercept by asthma severity level (b=-.91, *se*=.37,$p=.01$), indicating that higher asthma severity is associated with lower overall QOL scores. The absence of significant relationships between slope and intercept with treatment group assignment, child age, income, or education suggests changes in QOL over time are not impacted by these control variables in our sample of low-income, inner-city caregivers.

In contrast, the model generally supported relationships between the time-varying covariates and QOL. Greater life stress predicted lower QOL at baseline (b=-.26, *se*=.12,$p=.03$), six-month (b=-.19, *se*=.09,$p=.03$), and 12-month data points (b=-.21, *se*=.10,$p=.03$). Higher scores for asthma stress predicted lower scores for QOL at baseline (b=-.65, *se*=.12,$p<.001$),

six-months (b=-.73, *se*=.10,*p*<.001), and twelve-months (b=-.71, *se*=.11,*p*<.001). Poorer asthma control was likewise associated with lower QOL scores at all three time points; at baseline b=-2.75(*se*=1.02,*p*=.007), at six-month b=-1.82 (*se*=.40,*p*<.001), and at twelve-month b=-2.05 (*se*=.35,*p*<.001). However, no statistically significant relationships were found between social support and QOL at any time point (p>.10). Moderate to large effect sizes for explained variance were observed over time in the covariates model with R^2= 15.3% at baseline, 43.8% at six-months, and 57.6% at twelve-months.

The third nested model incorporated interaction effects between life stress, daily asthma stress, and social support at each time point. The interaction terms for life stress and social support and for asthma caregiving stress and social support were not significant at any time point (p>.10). The same results were obtained for the interaction between life stress and asthma caregiving stress (p>.10). Although Model 3 had slightly better fit statistics, in the absence of significant interactions it does not account for more variance in the model (R^2= 15.6% at baseline, 43.6% at six-months, and 56.2% at twelve-months). Consequently, Model 2, the covariates model, is the more parsimonious model and is chosen as the final model in these analyses.

DISCUSSION

To our knowledge, this longitudinal analysis is the first to explore protracted influences of asthma caregiving stress and daily life stress on QOL while also testing a moderating effect of social support on the relationship between caregiver stress experiences and QOL. The study hypotheses were partially supported as higher perceptions of asthma caregiving stress and daily life stress were associated with lower QOL. Caregiver QOL scores improved over the course of the study, with a significant increase occurring from baseline to the six-month follow-up and maintained through the 12-month period. We did not detect QOL differences between caregivers randomized to the intervention or control group, but this may be due to the intensive nature of the attention control protocol in which caregivers in both the intervention and control groups received three home visits for asthma education and management guidance by a community nurse. This level of support may have been sufficient to neutralize differences in change in QOL between the two groups.

We found both objective and subjective dimensions of asthma burden to be associated with lower QOL. Across all time points, poorer asthma control, as measured by rescue medication use, symptom frequency, and use of urgent care services (ED visit and hospitalizations), was a significant predictor of lower caregiver QOL. Likewise, caregiver perception of higher asthma caregiving demands was related to more impaired QOL over the 12-month follow-up. These results are consistent with previous studies that observed QOL to negatively correlate with symptom severity (Cerdan, et al., 2012; Levy, et al. 2004; Okelo, et al., 2014) and caregiving burden (e.g., Fiese et al., 2005) and build from those investigations by also showing clinical severity and perception of asthma burden may independently explain heterogeneity of QOL outcomes in inner-city, low-income caregiver populations.

Specifically, the baseline correlation between asthma control level and asthma caregiving stress was statistically significant but low (r=0.15, $p < .05$). This suggests that exclusively inquiring about frequency and severity of child symptoms and use of emergency services for asthma care may not necessarily reflect the impact of asthma on caregivers. Exploring the caregiver's perception of asthma burden may yield additional information that is not otherwise captured. Since caregivers experiencing high levels of stress may lack the emotional and physical availability to carefully monitor their child's treatment adherence and engage in primary prevention activities (Crespo, et al., 2011), our data highlight the importance of screening for both objective and subjective experiences of asthma caregiving stress during clinical encounters with this population.

Self-reported life stress was more modestly related to QOL when compared with asthma control level and asthma caregiving stress, as indicated by the standardized coefficients reported in Table 3. However, higher life stress was related to lower QOL scores at each time point, so assessing and discussing diverse experiences of stress in clinical encounters with this population seems prudent. Sources of life stress identified in research with low-income inner-city caregivers suggest that they reside in homes with high rates of rodent infestation and utilities instability (Authors, 2013a; Matsui, 2014), have concerns about neighborhood safety including community violence exposure (Authors, 2014a; Coutinho, McQuaid, & Koinis-Mitchell, 2013), and experience additional hardships such as unemployment (IOM, 2000). Research with Latino families previously emphasized the need for considering asthma management in the context of ongoing life stress (Everhart, et al. 2012), and our findings similarly underscore this message for low-income, inner-city caregivers of minority children.

Contrary to expectations, the risk and resilience model tested in this study was not supported. In particular, we were surprised by the lack of a relationship between social support and QOL over time. Although the bivariate association was significant (r=.14, p=.02), in the latent growth curve model, access to emotional and instrumental support was neither directly related to caregiver QOL, nor did social support weaken the observed relationships between asthma burden, life stress and QOL. However, a ceiling effect in the MOS social support scale may have contributed to the lack of association in this study. At baseline, over a third of the caregivers (N=115, 38.3%) reported a score of 40 on the scale, which is the highest possible score, and 70% of caregivers had scores at or above 30, which substantially reduced variability in the sample. Alternatively, these findings perhaps indicate that emotional and informational resources specific to reducing asthma burden may instead be of greater benefit to caregivers of children with high-risk asthma. It is possible that once the child's symptoms and asthma management routine are stabilized, social support for more general problems of daily life increases in importance for caregiver well-being. We were also intrigued by the non-significant interaction between asthma caregiving stress and daily life stress on QOL. Although it was anticipated that caregivers who endorsed both asthma burden and life stress would report a more robust decline in QOL, study findings failed to support the cumulative risk relationship. Instead, results indicate that experiencing just one stressor (asthma caregiving stress, life stress) heightens vulnerability to lower QOL among inner-city caregivers of minority children with high-risk asthma.

Limitations and Future Directions

Including healthcare and family-level variables, such as access to and collaboration with asthma specialists and supportive family interactions to manage daily asthma stress, may further improve the model. National guidelines emphasize the importance of patient- and family-centered approaches to healthcare delivery across chronic health groups, and a growing body of empirical evidence highlights the clinical value of this practice for asthma populations. A recent study by Carpenter and colleagues (2013) found the quality of interactions with healthcare providers during asthma visits to be directly associated with more optimal caregiver outcomes. Specifically, a greater number of provider questions during asthma related clinical encounters with children aged 8 – 16 predicted higher caregiver QOL during a one-month follow-up. Family functioning variables may also contribute to both child and caregiver outcomes. Previous research has shown that parenting style may prospectively predict child asthma symptoms (Nagano, et al., 2010), and in a study of 255 caregivers of young children aged 2 -10 years with asthma, more dysfunctional parenting style (e.g., laxness or over-reactivity) was associated with greater difficulty in managing the child's asthma behavior (Morawska, Stelzer, & Burgess, 2008). Alternatively, evidence suggests positive perceptions of family cohesion and expressiveness may enhance quality of life for both the child and caregiver (Crespo, et al. 2011).

It is possible that using an alternative measure of caregiver QOL may likewise improve the model through stronger associations between life stress and QOL. The Activity Limitations scale administered in this study is a condition-specific measure of how a child's asthma symptoms may disrupt functioning and impair caregiver QOL. A generic index of QOL may offer a more comprehensive picture of the degree to which daily life stress negatively affects a caregiver's physical health, psychological health, and social relationships. Additionally, our study sample composition was unique in that we purposively recruited children with high-risk asthma. Consequently, our model may not be generalized to broader caregiver population, including those who reside in rural areas, are high-income, or have children with well-controlled asthma. Finally, the potential interdependence of caregiver functioning and child asthma control warrants further attention. It is possible that greater perceived asthma stress leads to impaired caregiver QOL and erodes the caregiver's capacity to adhere to demanding asthma management routines. In turn, this may heighten risk for poorer child asthma control and greater asthma burden. Research with larger caregiver samples and more data points may help disentangle the nature of these associations.

In summary, our study contributes to the asthma family science literature by testing a model of risk and resilience in a large sample of low-income, inner-city caregivers of young children with high-risk asthma. Findings underscore the importance of capturing objective and subjective measures of asthma burden. Integrating questions about daily life stress in clinical assessments with this population is likewise indicated. The study further highlights vulnerability to lower QOL among inner-city caregivers of young children with high-risk asthma when just one stressor is present (asthma caregiving stress, life stress). Multifaceted assessment processes and tailored supports are needed to bolster QOL in urban caregivers of young minority children with poorly controlled asthma.

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Table 1

Descriptive Statistics for Model Variables

	Baseline	6-month	12-month
Quality of Life[a]	17.87 (7.50)	22.75 (5.79)	22.87 (6.24)
Treatment Group[b]			
• Control	49.3% (148)		
• Intervention	50.7% (152)		
Child's Age[a]	5.56 (2.19)		
Education[b]			
• <12th grade	29.8% (91)		
• HS grad/GED	39.1% (117)		
• College/Trade Sch	27.1% (81)		
• College grad	4.0% (12)		
Employment[b]			
• Yes	45.4% (134)		
• No	54.6% (161)		
Asthma Severity[b]			
• Intermittent	5.0% (15)		
• Mild	38.3% (114)		
• Moderate	17.4% (52)		
• Severe	39.3% (117)		
Life Stress[a]	5.70 (3.56)	4.99 (3.53)	4.99 (3.68)
Asthma Stress[a]	5.16 (3.72)	3.36 (3.46)	3.61 (3.53)
Asthma Control[b]			
• Well	0.0% (0)	10.5% (30)	14.3% (39)
• Not well	6.7% (20)	28.0% (80)	24.2% (66)
• Poorly	93.3% (280)	61.5% (176)	61.5% (168)
Social Support[a]	32.90 (8.75)	33.62 (8.31)	34.33 (8.18)

[a] Mean(SD)

[b] Percentage(*n*)

Table 2

LGM Fit Statistics

Outcome	Model	X^2	X^2/df	RMSEA	CFI	TLI	AIC
QOL	Unconditional	29.38***	29.38	0.31	0.08	−1.74	5642.83
	Covariates	124.32***	1.91	0.06	0.83	0.78	5713.58
	Interactions	145.49***	2.24	0.05	0.84	0.79	5723.28

RMSEA = Root Mean Square Error of Approximation

CFI = Comparative Fit Index

TLI=Tucker-Lewis Fit Index

AIC=Akaike Information Criteria

*** $p<.001$

Table 3

Latent Growth Curve Model Coefficients over 12 Months

Covariates	Intercept	Slope	Baseline	6-month	12-month
Unstandardized Coefficients					
Treatment Group	.76 (−.38, 1.91)	−.59 (−1.39, .20)			
Child Age	.20 (−.05, .45)	.04 (−.13, .21)			
Education	−.10 (−.77, .56)	−.21 (−.65, .24)			
Employment	.32 (−.87, 1.50)	.37 (−.49, 1.22)			
Asthma Severity	−.91* (−1.53, −.30)	.34 (−.08, .77)			
Life Stress			−.26* (−.45, −.06)	−.19* (−.33, −.04)	−.21* (−.37, −.05)
Asthma Stress			−.65*** (−.84, −.45)	−.73*** (−.89, −.57)	−.71*** (−.88, −.53)
Asthma Control			−2.75*** (−4.43, −1.07)	−1.82*** (−2.48, −1.18)	−2.05*** (−2.63, −1.47
Social Support			−.05 (−.14, .03)	−.04 (−.10, .01)	−.01*** (−.08, .06)
Standardized Coefficients					
Treatment Group	---	−.44 (−1.15, .28)			
Child Age	---	.03 (−.10, .16)			
Education	---	−.15 (−.49, .19)			
Employment	---	.27 (−.42, .96)			
Asthma Severity	---	.25 (−.17, .68)			
Life Stress			−.04* (−.06, .01)	−.03* (−.06, −.007)	−.04* (−.06, −.008)
Asthma Stress			−.09*** (−.11, −.06)	−.13*** (−.15, −.10)	−.12*** (−.14, −.09)
Asthma Control			−.38*** (−.61, −.15)	−.32*** (−.43, −.25)	−34*** (−.43, −.25)
Social Support			−.007 (−.02, .005)	−.007 (−.02, .002)	−.002 (−.01, .009)

Note. 95% Confidence Intervals provided in parentheses

* $p<.05$

*** $p<.001$