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.
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KEY WORDS

Asthma, caregivers, quality of life, stress

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., 2013; 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 (QOL) (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, 2013b), beyond the fear of seeing their child struggling to breathe. Not surprisingly, caregivers of children with poorly controlled asthma report more missed work compared with caregivers of children with controlled asthma (31% vs. 16%) (Dean, Calimlim, Kindermann, Khander, & Tinkelman, 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).

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., 2013). Identifying risk and protective correlates of QOL in asthma populations is further significant because caregiver QOL is proposed to influence health self-management behaviors such as treatment adherence and decisions about seeking health care 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. More than a decade of evidence indicates that higher asthma severity and poor asthma control exert negative effects on QOL in some caregiver populations (Bellin et al., 2013; Cerdan, Alpert, Moonie, Cyrkiel, & Rue, 2012; Levy et al., 2004; Okelo et al., 2014; Williams et al., 2000). However, other research suggests that caregiver perception of stress due to asthma management demands is a more profound predictor of caregiver QOL compared with 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 affect 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, sociodemographic and contextual factors may help explain heterogeneity in caregiver QOL. Evidence suggests that caregivers who are single (Sampson et al., 2013b), have a low income (Osman, Baxter-Jones, & Helms, 2001), and are parenting young children with asthma (Dalheim-Englund, Rydström, Rasmussen, Möller, & Sandman, 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, that is, 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 and control level) and social and contextual stressors associated with residence in disadvantaged communities (e.g., poverty, allergen exposure, housing instability, secondhand smoke exposure, food insecurity, violence exposure, and access to care) (Bellin et al., 2014; 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 (Bellin et al., 2013).

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 (i.e., 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, sociocontextual, 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