ARTICLE

Improving Care of Inner-City Children with Poorly Controlled Asthma: What Mothers Want You to Know

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ABSTRACT

Introduction: Low-income caregiver perspectives on asthma management are understudied but may illuminate strategies to improve care delivery and child outcomes.

Method: Purposive sampling methods were used to recruit 15 caregivers of children with frequent asthma emergency department visits. Interviews explored how poverty and stress affect asthma management. Grounded theory coding techniques were used to analyze the data.

Results: Participants were the biological mother (100%) and were poor (75% had mean annual income ≤ $30,000). Their children (mean age = 6.9 years) were African American (100%), enrolled in Medicaid (100%), and averaged 1.5 emergency department visits over the prior 3 months. Four themes emerged: (a) *Deplorable Housing Conditions,* (b) *Allies and Adversaries in School-Based Asthma Management,* (c) *Satisfaction With Asthma Health Care Delivery,* and (d) *Prevalent Psychological Distress*.

Discussion: Impoverished caregivers of children with frequent asthma emergency department visits describe stress that is multifaceted, overwhelming, and difficult to eradicate. Their experiences underscore the need for improved school-based asthma management and family-centered approaches to health care delivery. J Pediatr Health Care. (2018) ■■, ■■-■■.

KEY WORDS

Asthma management, caregiver, poverty, provider relationships, stress

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INTRODUCTION

Poorly controlled asthma is a major cause of morbidity and mortality in children (Normansell, Kew, & Stovold, 2017; O'Byrne et al., 2013). Although nearly 50% of youths with asthma experience an acute exacerbation annually (Akinbami, Moorman, Garbe, & Sondik, 2009), low-income, minority youths are disproportionately at higher risk for uncontrolled asthma and asthma-related emergency department (ED) visits (Zhang, Lamichhane, & Diggs, 2016). The causes of poorly controlled asthma are multifactorial and include environmental exposures to triggers in the home and community (e.g., second hand smoke, rodents, mold, dust mites), poor condition knowledge and self-management skills, access to care barriers including difficulties with medication administration in the school, and hardships associated with poverty (Bellin et al., 2014, 2017; Borowsky, Little, & Cataletto, 2013; Bruzzese et al., 2012; Camacho-Rivera, Kawachi, Bennett, & Subramanian, 2014; Lang et al., 2013; Ungar, Cope, Kozyrskyj, & Paterson, 2010). Caregiver psychosocial factors such as life stress and depressive symptoms further heighten risk for child asthma morbidity (Bellin et al., 2015; Clawson, Borrelli, McQuaid, & Dunsiger, 2016; Feldman et al., 2011, 2013; Lim, Wood, Miller, & Simmens, 2011; Martin et al., 2013; Tibosch, Verhaak, & Merkus, 2011). To improve asthma control and reduce asthma health disparities, a range of home-, community-, and ED-based interventions have been developed (Pinnock et al, 2017; Welsh, 2014), but the suboptimal outcomes for low-income, minority children persist.

Designing and implementing effective interventions for this population requires greater understanding of how social inequities stemming from family poverty and caregiver stress affect asthma management (Clouteir, 2008). Qualitative methodologies may be particularly fruitful in shedding light on caregiver experiences and, in turn, informing responsive asthma programs (Searle, Jago, Henderson, & Turner, 2017). For example, a mixed-methods investigation of daily life stress in a sample of 40 urban poor caregivers of children with asthma found that semistructured interviews offered deeper insights into family-, finance-, and caregiving-related stressors compared with quantitative measures (Sampson et al., 2013). Qualitative research with urban low-income families likewise showed important findings related to barriers to asthma management such as financial constraints impeding effective home environmental control, concerns about asthma medication adverse effects resulting in nonadherence to guideline-based care, and profound psychological distress in caregivers (Bellin et al., 2017; Laster, Holsey, Shendell, McCarty, & Celano, 2009; Waters et al., 2017). Other qualitative interviews and focus group research with caregivers of children with asthma highlighted the need for increased sharing of asthma information in clinical encounters (Kieckhefer & Ratcliffe, 2000) and, more specifically, improved provider sensitivity to the sociocultural context of minority families (Riera et al., 2015; Tumiel-Berhalter & Zayas, 2006). In-depth interviews with parents further identified strained family relationships and roles because of the intensive nature of asthma caregiving and asthma knowledge deficits as other potential sources of stress (Archibald, Caine, Ali, Hartling, & Scott, 2015; Rydström, Dalheim-Englund, Segesten, & Rasmussen, 2004).

In summary, a growing body of research offers some insight into the magnitude of stress experienced by caregivers of children with asthma and the need for enhanced caregiver–provider relationships in the shared management of childhood asthma. However, the experience of impoverished caregivers of minority children with poorly controlled asthma remains understudied but is critical to understand in light of persistent asthma health disparities. This study aims to build on these previous studies by examining caregiver perspectives on how stress and poverty affect asthma home management and exploring how asthma management in the community may be improved from the unique caregiver lens.

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METHODS

This qualitative study was part of a larger, institutional review board–approved, randomized controlled trial (RCT) testing the efficacy of an ED- and home-based environmental control intervention for young children with frequent asthma ED visits (Butz et al., 2017). Inclusion criteria for the RCT included (a) physician-diagnosed persistent and uncontrolled child asthma based on current national asthma guidelines (U.S. Department of Health and Human Services, 2007), (b) two or more child ED asthma visits or one or more hospitalizations over the past 12 months, and (c) residence in the Baltimore metropolitan area. Children were excluded if they had significant other non-asthma respiratory conditions (i.e., cystic fibrosis). Purposive sampling methods were used to recruit caregivers who had completed the RCT and agreed to be contacted for future asthma studies. Because maternal depression and life stress are associated with greater risk for child asthma morbidity and impaired caregiver quality of life (Bellin et al., 2015; Clawson et al., 2016; Martin et al., 2013; Otsuki et al., 2010; Pak & Allen, 2012; Shalowitz, Berry, Quinn, & Wolf, 2001), study staff sent letters inviting 37 caregivers who reported clinically significant depressive symptoms (Center for Epidemiologic