

**An Examination of Life Stressors Experienced by Families of Children with Asthma
in Low-Income Communities of Color**

by

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**To my family for their inspiration and
in memory of my grandparents**

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List of Abbreviations

CAAA	Community Action Against Asthma
CBPR	community-based participatory research
CES	Community Environmental Specialist
CHW	community health worker
ER	emergency room
QOL	quality of life

Abstract

This dissertation identified and explored life stressors impacting families of children with asthma and the characteristics and strategies of community health workers (CHWs) who mitigate these stressors through three separate studies: (i) a qualitative analysis of handwritten notes of CHWs who conducted home visits with families of children with asthma in Detroit, Michigan, during a household intervention study (n=115), (ii) in-depth interviews with CHWs from four asthma programs in diverse geographic regions in the U.S. (n=13), and (iii) a mixed-methods approach, in which the stressors identified in the first study were conceptualized into domains and tested using multivariate regression to determine their association with asthma-related health and quality of life (QOL) outcomes, and social support.

CHWs described families' struggles to obtain basic needs and amenities, including decent housing and employment. Oftentimes, assistive resources were "here today, gone tomorrow". Outside of more tangible stressors, CHWs noted families' interpersonal problems both within and outside the family. Many families were also balancing diverse health issues, which sometimes necessitated prioritizing one family member's health over another's. To address these stressors, CHWs established trust and built rapport with families. CHWs expressed the importance of showing care and compassion, exhibiting good listening skills, and being respectful of families' circumstances. CHWs were dedicated and often assisted by intervening on behalf of families. Yet, some CHWs also recognized the need to move families towards independence.

Regression analyses demonstrated the importance of examining the individual contributions of stressors domains on select asthma-related outcomes. While caregiver-related outcomes (i.e., depressive symptoms, caregiver pediatric asthma-related QOL) were associated with Basic and Work stressors, child outcomes (i.e., asthma symptoms

and severity) were linked to Family Relationships and Family Health. Social support was shown to modify the relationship between Basic stressors and ER visits, as well as caregiver QOL.

This study contributes a better understanding of the larger environmental, social, and psychosocial life stressors that may impede adequate asthma control and management, effective characteristics of CHWs and their strategies for intervening to assist families of children with asthma, and specific stressors important for intervention to improve asthma-related health and QOL.

Chapter 1

Introduction

The prevalence of asthma is at an all-time high among children in the United States (Akinbami, 2006; Bloom, Cohen, & Freeman, 2009), with trends in ambulatory visits, hospitalizations, and emergency department visits showing no real sign of decline (Akinbami, 2006). The disproportionate impact of asthma on racial/ethnic minorities and those of low-income has been well established (Akinbami, 2006; Bloom, et al., 2009; Moorman, et al., 2007). Due to exposure to multiple stressors in urban underserved areas, such as air pollution, poor housing conditions (e.g., substandard housing, residential instability), inadequate access to quality health care and other supportive services, and increased crime and violence (Bryant-Stephens, 2009; Eggleston, 2007; Gold & Wright, 2005; O'Neill, et al., 2003; Sandel & Wright, 2006; Shapiro & Stout, 2002; Weiss, Gergen, & Crain, 1992; Wright, et al., 2004), racially/ethnically diverse residents of low-income urban areas are at greater risk for poor asthma-related health and quality of life (QOL) outcomes.

The documented presence of these and other environmental, social, and psychosocial factors that make demands of an individual (or, collectively, “life stressors”) suggests the importance of understanding the association between perceived stressors and asthma-related health and QOL outcomes, particularly in low-income communities and communities of color. Over the last decade, evidence supporting the association between life stressors and health and QOL indicators for children with asthma and their caregivers has been mounting. Studies have shown that reported life stressors have differentiated children with diagnosed or potential asthma from those without asthma (Shalowitz, et al., 2006). Furthermore, greater number of total life stressors or negative stressors experienced has been associated with poorer asthma morbidity outcomes (Shalowitz,

Berry, Quinn, & Wolf, 2001; Turyk, et al., 2008). In addition to cross sectional studies, a temporal relationship between caregiver reports of life stress(ors) and children's asthma symptoms, such as wheeze, and immune response has been established across a range of children's ages (Marin, Chen, Munch, & Miller, 2009; Milam, et al., 2008; Sandberg, Jarvenpaa, Penttinen, Paton, & McCann, 2004; Sandberg, et al., 2000; Wright, Cohen, Carey, Weiss, & Gold, 2002). Caregiver health and QOL outcomes have also been associated with life stress(ors). Greater caregiver perceived stress has been shown to adversely impact caregiver pediatric asthma-related QOL (Levy, et al., 2004), and number of life stressors and/or total negative stressors has been correlated with caregiver depressive symptoms and poor mental health (Klennert, Price, Liu, & Robinson, 2002; Shalowitz, et al., 2001; Shalowitz, et al., 2006; Weiss, et al., 2009). While life stress(ors) have commonly been assessed as discrete events, either through endorsement of acute or chronic life events or through systematic one-on-one interviews, the relative contribution of any one dimension of stress or individual stressors for families of children with asthma has not been the focus of study findings.

To gain further insight into stressors that may impede adequate asthma care and management, qualitative studies have also been conducted with groups at highest risk (Laster, Holsey, Shendell, McCarty, & Celano, 2009; Mansour, Lanphear, & DeWitt, 2000; Tumiel-Berhalter & Zayas, 2006; Valerio, et al., 2006). While these studies have revealed important issues around medication use, health insurance, communicating with school/health professionals, and environmental remediation, the broader environmental, social, and psychosocial stressors that may have a profound impact on caregiver and child health and QOL have not been identified.

A potential source for more in-depth exploration of life stressors in low-income communities of color is community health workers (CHWs). Also referred to as lay health advisors, outreach workers, and promotoras, CHWs are often members of the communities in which they work and, thus, share the same language, culture, socioeconomic status, and experiences (Eng, Parker, & Harlan, 1997; Eng & Parker, 2002; Giblin, 1989; Lehmann & Sanders, 2007; Rosenthal, et al., 1998; Witmer, Seifer,

Finocchio, Leslie, & O'Neil, 1995). CHWs have been successfully employed in interventions to reduce childhood asthma exacerbation (Bryant-Stephens & Li, 2008; Fisher, et al., 2009; Krieger, Takaro, Song, & Weaver, 2005; Lin, Gomez, Hwang, Franko, & Bobier, 2004; Martin, Hernandez, Naureckas, & Lantos, 2006; Parker, et al., 2008; Postma, Smalley, Ybarra, & Kieckhefer, 2011; Primomo, Johnston, DiBiase, Nodolf, & Noren, 2006; S. G. Williams, et al., 2006). However, in spite of the recognition that CHWs can relate to community members in underserved areas and may often assist families in addressing their life stressors, little is known about the work of the CHWs around stressor reduction, including the types of stressors experienced by families, the impact of these stressors, and the strategies and characteristics of CHWs that can be effective in addressing these concerns with families.

Social support has been shown to reduce the negative impact of stress(ors) on health (Cohen, 1988; Heaney & Israel, 2008; Israel & Schurman, 1990; Thoits, 2010), and has been identified as an important area for future research for reducing asthma disparities (Mangan, Wittich, & Gerald, 2007). Social support may have a role in the relationship between stress and asthma, although there has not been any agreement on whether family or non-family support is more important (Mangan, et al., 2007). Poor asthma-related outcomes for children have been associated with greater family conflict in the family's social environment (Chen, Bloomberg, Fisher, & Strunk, 2003), family dysfunction (Bloomberg & Chen, 2005), and aspects of poor family functioning (Kaugars, Klinnert, & Bender, 2004). An assessment of family resources and asthma-specific demands for parents of children with moderate to severe persistent asthma revealed that compared to their European American counterparts, African American parents had fewer extended family social support resources and found balancing tasks and activities outside of the child's asthma, such as dealing with work- or school-related issues in conjunction with asthma, to be most time-consuming (Lee, Parker, DuBose, Gwinn, & Logan, 2006). Therefore, testing the role of social support in modifying the relationship between life stressors and asthma-related health and QOL may inform the development of effective, sustainable programs to reduce the burden of asthma for families of children with asthma in underserved areas.

Overview of Dissertation

This dissertation examines data from a household environmental childhood asthma intervention study utilizing CHWs in the city of Detroit, and verifies and expands the findings through interviews with CHWs from different asthma programs covering diverse geographic regions across the United States.

This dissertation had three overarching objectives. First, using CHWs' handwritten notes documenting the substance of repeat home visits with caregivers of children with asthma in the city of Detroit—recording both asthma-related issues and those beyond the disease itself—life stressors present in the lives of caregivers during a one-year intensive household intervention study were identified. Additionally, this data allowed for the exploration of strategies that were implemented by CHWs to assist caregivers in resolving or alleviating these life stressors (Chapter 2). Second, to validate and expand the findings in Detroit, qualitative interviews were conducted with CHWs from asthma programs representing diverse geographic regions in the United States. CHWs who had been or were currently involved in household asthma interventions with either repeat home visits or ongoing enrollment of families of children with asthma were invited to participate. The intent of these interviews was to explore commonalities and discrepancies in life stressors experienced by families of children with asthma across sites, and the impact of these stressors on asthma care and management, health, and QOL. These interviews also elicited characteristics and strategies of CHWs to help families achieve “successful” outcomes (Chapter 3). Third, using a mixed-methods approach, an exploratory multivariate regression analysis was undertaken to determine the relationship between stressors domains, derived from the documentation made by CHWs during the intensive first year of the household intervention study, and health services utilization, asthma severity and symptoms, caregiver depressive symptoms, and caregiver pediatric asthma-related QOL, and the role of social support (Chapter 4).

Chapter 5 of this dissertation presents a summary discussion of the findings from these three studies, including implications of the findings for future research and practice.

Chapter 2

Community Health Workers' Documentation of Life Stressors Experienced by Families of Children with Asthma During a Household Environmental Intervention Study in the City of Detroit

ABSTRACT

Objectives: Disparities in childhood asthma are compounded by residence in urban underserved areas, where many of the stressors that contribute to asthma exacerbation are present. Community health workers (CHWs) have been shown to be effective in assisting caregivers of children with asthma in low-income communities of color; yet, studies have not fully investigated the experiences of CHWs to explore life stressors, especially those more tangential to asthma, and how they might impede asthma management and care. Open-ended documentation made by CHWs during a household environmental intervention study provided the basis for exploring life stressors faced by caregivers of children with asthma in Detroit, Michigan, and strategies CHWs used to reduce or mitigate the effect of those stressors.

Methods: Data collected by CHWs as part of an intervention study for childhood asthma was analyzed for this study. Over a two-year period, CHWs conducted repeat home visits to 115 intervention group caregivers of children with asthma. Following each contact, CHWs documented through handwritten notes the content of their discussions, provision of education and supplies, non-asthma related activities (e.g., food referrals), subsequent actions to be taken, and general observations made. Using qualitative data analysis methods, asthma-related and other life stressors experienced by caregivers were identified, as were strategies implemented to assist in addressing these stressors.

Results: CHWs documented important life stressors faced by families of children with asthma, as well as strategies utilized by CHWs to provide assistance. Among the life

stressors experienced were struggles to provide and maintain basic needs and amenities, such as food, clothing, utilities, and transportation, as well as adequate, safe living conditions. Strains or changes in family relationships and structure were also common. Besides asthma, some caregivers were dealing with adverse health conditions in the family, including their own. Academic and behavioral problems among children were also not uncommon, sometimes stemming from learning disabilities or changes in family structure, such as death or incarceration of a loved one. Interpersonal disputes extended to landlords, particularly when needed home repairs were not completed, and employers. Yet, efforts to seek or maintain assistance to alleviate life stressors were sometimes constrained by personal or organizational resources, eligibility, or follow through. In an effort to assist, CHWs allowed caregivers to vent frustrations, provided social support, and connected and ensured families received needed assistance and information. The role of the CHW spanned beyond providing contact information and referrals to include relaying the necessary processes and requirements for assistance, intervening on behalf of the family, tracking down necessary information and resources, and offering assistance to other family members and friends. Importantly, CHWs offered words of encouragement and praised families for their strength and perseverance in dealing with their life stressors.

Implications: This study identified an array of life stressors experienced by families of children with asthma in Detroit, emphasizing the role of CHWs in identifying these life stressors and implementing strategies to assist families in overcoming these stressors. A broader understanding of the types and impact of life stressors on the health and quality of life of children with asthma and their families could enhance the effectiveness and delivery of asthma interventions, particularly for low-income communities of color.

INTRODUCTION

Asthma is one of the leading chronic diseases in children and youth in the United States, with over 10 million children and youth having ever been diagnosed (Bloom, et al., 2009). The disproportionate impact of childhood asthma on racial/ethnic minorities and low-income groups is of growing concern, with non-Hispanic black and Puerto Rican

children and those with a family income below the poverty threshold bearing the burden of disease (Akinbami, 2006; Bloom, et al., 2009). Available data for the past decade or so indicate that children ages 5 to 14 have had the highest prevalence of persons reporting an asthma attack in the previous 12 months compared to all other age groups and, within this age group, blacks have had consistently higher rates of asthma attacks compared to whites (Moorman, et al., 2007). Together, these disparities in asthma are compounded by residence in urban underserved areas, where many of the factors that contribute to asthma exacerbation abound (Bryant-Stephens, 2009; Eggleston, 2007; Gold & Wright, 2005; Weiss, et al., 1992; Wright & Subramanian, 2007). Due to the poor environmental conditions that characterize many urban low-income environments, both inside the home and outside, families of children with asthma who live in these areas are at increased risk of exposure to asthma triggers such as dust mites, cockroaches, mold and mildew, and poor air quality (Bryant-Stephens, 2009; Eggleston, 2007; Gold & Wright, 2005; O'Neill, et al., 2003; Sandel & Wright, 2006; Weiss, et al., 1992). Additionally, these families may have poorer access to regular, quality health care (Bryant-Stephens, 2009; Shapiro & Stout, 2002), and may experience more social and psychosocial problems, including violence, segregation and discrimination, social isolation, and psychological distress, which have implications for asthma control and management (Chen, Fisher, Bacharier, & Strunk, 2003; Gold & Wright, 2005; Koinis Mitchell & Murdock, 2005; Shalowitz, et al., 2006; Wade, et al., 1997; D. R. Williams, Sternthal, & Wright, 2009; Wright, et al., 2004; Wright & Subramanian, 2007).

The documented presence of these and other environmental, social, and psychosocial factors that make demands of an individual (or, collectively, “life stressors”) suggests the importance of understanding the association between caregiver and child experiences of perceived stressors and asthma and other health and quality of life outcomes, particularly in urban underserved areas. For the purposes of this study, life stressors encompass a broad spectrum of events or conditions ranging in their frequency, duration, and impact. These include minor, short-term stressors or daily hassles, major life events such as a death in the family, natural disasters or other cataclysmic events, and more long-term, continuous stressors including chronic strains and ambient stressors (Israel & Schurman,

1990). Over the last decade, evidence supporting the association between life stressors and health and quality of life indicators for children with asthma and their caregivers has been mounting. For families of children with asthma living in racially and ethnically diverse inner-cities, reporting of undesirable life events has been found to be high (Wade, et al., 1997). Studies have shown that the number of life stressors experienced can differentiate children and adolescents by asthma (or potential asthma) and asthma morbidity status. Shalowitz and colleagues (2006) found that caregivers whose children were diagnosed with asthma or had possible asthma reported more total life stressors compared to caregivers of children without asthma. Additionally, a significant dose-response association between odds of asthma and stressful life event reporting has been demonstrated in adolescents, with the odds of asthma increasing with increasing category of events reported (Turyk, et al., 2008).

Studies have also demonstrated the association between greater number of total life stressors or negative stressors experienced and poorer asthma morbidity outcomes, assessed through both self-report and biologic measures (Shalowitz, et al., 2001; Turyk, et al., 2008). Of note, children of low socioeconomic status have been shown to fare worse on measures of immune changes implicated in asthma as well as ratings of chronic life stressors (Chen, et al., 2006). In an attempt to establish a temporal relationship, Sandberg and colleagues (2000) examined the risk of new asthma exacerbations with negative event reporting for a sample of children in Glasgow, Scotland. Children characterized by high chronic stress were found to have an increased risk for new asthma exacerbations within the first two weeks after reporting a severe negative event. No effect was found 2-4 or 4-6 weeks post-event. The small number of participants in the high chronic stress group who satisfied the criteria for the survival analysis methodology limited the ability to test for more immediate effects of negative events on asthma morbidity in this group. However, for children categorized with low-to-moderate chronic stress in the same sample, the timeframe for new asthma attacks was narrowed to 1-2 days following event reporting, with a second peak in risk 5-7 weeks later (Sandberg, et al., 2004). Similarly, results reported in a prospective study revealed that children with asthma who reported high chronic family stress had increased cytokine production in the

presence of an acute stressor. Furthermore, of the children categorized with moderate-to-severe asthma, the ones who experienced the most severe asthma symptoms also reported “double-exposure”, that is, being exposed to both chronic and acute stressors (Marin, et al., 2009).

Given the array of activities that must be learned and performed for effective management and control of childhood asthma (National Asthma Education and Prevention Program, 2007), researchers have also recognized the need to explore the relationship between life stressors and caregiver health and quality of life outcomes. Life stressors and elevated psychological symptoms suggestive of depression have commonly been reported by caregivers of children with asthma in large studies of racially and ethnically diverse inner-city residents (Wade, et al., 1997; Weiss, et al., 2009). In a sample of children with and without asthma, caregivers’ reports of greater symptoms of depression and experiences with life stressors were shown to differentiate those with diagnosed or potential asthma from those without asthma. Furthermore, most of the variation in caregiver depressive symptom reporting was explained by life stressors and social support (Shalowitz, et al., 2006). Degree of asthma morbidity has also been associated with life stressors and depressive symptoms, with caregivers with greater exposure to negative life stressors and more depressive symptoms characterizing children in the high asthma morbidity category (Shalowitz, et al., 2001).

Taken together, these findings suggest the need to address life stressors faced by families of children with asthma in intervention research. However, the ability to address these life stressors may be hampered by limited measurement of and, thus, understanding of life stressors. First, life stressors are often distilled to a summary score or total count, which loses the frequency and specificity of discrete events. Second, the details that underlie the assessment of these life stressors remain unexplored. For example, individuals who report difficulties with moving or changing residences might be experiencing stressors related to problems with a landlord or another family member with whom they reside, not having enough money to move, not being able to find affordable housing, or a combination of these factors. Not knowing the exact nature of the stressor

may hinder the development of effective interventions to reduce these stressors. Third, the validity of stressors reported is subject to recall bias, with assessments made for the past six to 12 months. Fourth, the validity and potential scope of data obtained may be dependent on the acceptance of the individual who collects the data. In general, professional interviewers or graduate students have been employed to collect data on life stressors, which may yield different results than lay workers performing the same task. And, lastly, the absence of provision of support or assistance (i.e., intervention) for families experiencing stressful situations may deter them from fully divulging information about the stressors.

Qualitative studies have also been undertaken to better understand some of the issues impacting racially/ethnically diverse and socioeconomically disadvantaged families of children with asthma. Through focus groups, sources of potential stress that have been identified and include maintaining continuous health care coverage, difficulties with environmental remediation (such as smoking in other people's homes), poor communication with health care providers and school personnel, and limits imposed on social life and work (Laster, et al., 2009; Mansour, et al., 2000; Tumiel-Berhalter & Zayas, 2006; Valerio, et al., 2006). Further qualitative investigation may yield a broader understanding of caregivers' and children's experiences of life stressors, whether related to asthma or not.

One method for additional investigation may be through exploration of the experiences of community health workers (CHWs). CHWs are lay workers with shared demographics, language, culture, and experiences, and are often used to provide education and support to populations of similar socioeconomic status on health issues (Eng, et al., 1997; Eng & Parker, 2002; Giblin, 1989; Lehmann & Sanders, 2007; Rosenthal, et al., 1998; Witmer, et al., 1995). Recognizing the utility of CHWs in childhood asthma, many intervention studies to reduce environmental triggers of asthma in the home have employed CHWs to conduct home visits with families of children with asthma (Bryant-Stephens, Kurian, Guo, & Zhao, 2009; Bryant-Stephens & Li, 2008; Friedman, et al., 2006; Krieger, et al., 2005; Parker, et al., 2008; Postma, et al., 2011; Primomo, et al., 2006; S. G. Williams, et

al., 2006). While these interventions have demonstrated improvements in child and caregiver health and quality of life outcomes, such as reduced asthma symptoms (Bryant-Stephens, et al., 2009; Bryant-Stephens & Li, 2008; Krieger, et al., 2005; Parker, et al., 2008; S. G. Williams, et al., 2006), improved lung function (Parker, et al., 2008), reduced or improved asthma medication use (Bryant-Stephens & Li, 2008; Parker, et al., 2008; Postma, et al., 2011; Primomo, et al., 2006), reduced asthma triggers in the home (Bryant-Stephens, et al., 2009; Bryant-Stephens & Li, 2008; Krieger, et al., 2005; Parker, et al., 2008; Postma, et al., 2011; Primomo, et al., 2006; S. G. Williams, et al., 2006), decreased asthma-related emergent care, hospitalizations, and/or inpatient visits (Bryant-Stephens, et al., 2009; Bryant-Stephens & Li, 2008; Krieger, et al., 2005; Parker, et al., 2008; Postma, et al., 2011; Primomo, et al., 2006), reduced caregiver depressive symptoms (Parker, et al., 2008), and improved caregiver and/or child asthma-related quality of life (Krieger, et al., 2005; Primomo, et al., 2006), little is known about the contribution and role of CHWs in the intervention successes. The level of detail provided on the specific activities prescribed to CHWs is often limited in intervention research. Outside of providing asthma education, delivering and demonstrating the use of asthma-related equipment or supplies, and performing data collection activities, CHWs have been responsible for discussing study-related testing results with families (e.g., skin prick testing) (Parker, et al., 2008), coordinating and/or performing services such as integrated pest management, cleaning, or repairs in the home (Bryant-Stephens & Li, 2008; Krieger, et al., 2005; Parker, et al., 2008; S. G. Williams, et al., 2006), assisting in housing advocacy (Krieger, et al., 2005), and providing referrals to external agencies or organizations for assistance (Krieger, et al., 2005; Parker, et al., 2008; Postma, et al., 2011). Yet, what the CHWs *actually* did and *how* they did it has not been the focus of evaluation. Not knowing this information could potentially mask the important contributions of CHWs to improvements in health and quality of life. In the context of their work with low-income, racially/ethnically diverse families of children with asthma, CHWs may provide an opportunity to explore more fully and better understand the role of life stressors—which have often been overlooked in intervention studies—and effective strategies to assist families in addressing these stressors.

The objectives of this research are to:

1. Identify and explore life stressors experienced by caregivers of children with asthma in the city of Detroit over a two-year period, as documented by CHWs in a household intervention study; and,
2. Explore strategies, such as the provision of social support, that CHWs used to address the life stressors experienced by adult caregivers and their children with asthma.

BACKGROUND

Detroit has been labeled the “epicenter of asthma burden” in Michigan (Wasilevich, Lyon-Callo, Rafferty, & Dombkowski, 2008). Compared to the state as a whole, Detroit has the highest asthma prevalence rate (Wasilevich, et al., 2008). Of particular concern is the impact of asthma on Detroit’s children. The rate of asthma hospitalizations for children in Detroit is among the highest in Michigan, and there is no evidence of a significant reversal of this trend (Wasilevich, et al., 2008). Furthermore, Detroit children on Medicaid have been shown to rely more heavily on emergency room care for asthma compared to Michigan as a whole. Disparities in asthma morbidity and mortality are also evident by race in Michigan. Hospitalizations for asthma are more pronounced in blacks than in whites, both in Detroit and in the state as a whole, as are rates of death from asthma (Wasilevich, et al., 2008).

Community Action Against Asthma (CAAA) is a community-based participatory research (CBPR) partnership that was established to respond to the concerns around childhood asthma in the city of Detroit. The work of the partnership is guided by principles of CBPR (Israel et al., 1998), which at its core encourage active participation of all members in all aspects of the research (Edgren, et al., 2005; Lewis, et al., 2005; Parker, Chung, Israel, Reyes, & Wilkins, 2010; Parker, et al., 2008; Parker, et al., 2003). Members of the CAAA steering committee include community-based organizations, a local health department, health and human service organizations, academic institutions, and a community member at-large. With a focus initially on Eastside and Southwest

Detroit, low-income communities with predominantly African American and Hispanic/Latino residents, respectively, CAAA has engaged the community in household-level intervention and exposure assessment studies, and community organizing and advocacy (Edgren, et al., 2005; Lewis, et al., 2005; Parker, et al., 2010; Parker, et al., 2008). The study described here involves data from CAAA's household intervention study using CHWs to reduce environmental triggers of asthma, with baseline and follow-up measures for the intervention group collected from April 2000 to August 2001 and documented home visits from CESs for the period March 2000 to November 2002 (Lewis, et al., 2005; Parker, et al., 2008).

METHODS

Study Design

The details of the study population and recruitment have been described elsewhere (Lewis, et al., 2005; Lewis, et al., 2004; Parker, et al., 2008). In brief, using a community-based recruitment strategy, almost 10,000 screening questionnaires were distributed by mail and/or in-person to caregivers of children ages 7 to 11 at participating elementary schools in Eastside and Southwest Detroit. Caregivers who reported symptoms consistent with persistent asthma for their children, as assessed by the screening questionnaire, were eligible for enrollment (n=708). Of these, 328 were successfully contacted, enrolled, and randomized to either the intervention (n=162) or control group (n=166), which received the same intervention after a yearlong delay. This study includes the 115 initial intervention group caregivers who completed the study.

Intervention

The purpose of the intervention was to test the efficacy of a standard CHW intervention to assist caregivers in reducing household environmental triggers of asthma. CHWs called Community Environmental Specialists (CESs) conducted visits to participants' homes to deliver asthma-related education and provisions such as a vacuum cleaner, cleaning supplies, and hypoallergenic mattress and pillow covers. In addition, CESs were trained on how to perform integrated pest management (for severe infestation, the CESs worked with a professional extermination service), and on how to provide referrals

to help caregivers with activities such as restoring utilities that had been shut-off, locating affordable housing, securing food, clothing, and furniture, and accessing low-cost medical care. Although the number of home visits throughout the course of the intervention was dependent upon the needs of individual families, each family was scheduled to receive at least nine visits from the CES during the first year of intensive intervention. In the second year, a less intensive intervention was delivered, with the expectation that three follow-up visits would be conducted over the course of the year. Further details of the intervention can be found elsewhere (Parker, et al., 2008).

Data Collection

The primary modes of data collection for the intervention study included a caregiver and child survey, household walk-thru assessment, asthma symptom diary, pulmonary function testing, and environmental monitoring (Parker, et al., 2008). For process evaluation and monitoring purposes, data was also collected by the CESs to document each phone and in-person contact. CESs recorded the date and time of the contact and documented through handwritten notes the individual with whom they spoke, the content of their discussions, any observations, and any follow-up actions or questions. Additionally, CES completed a checklist of items for asthma-related education, supplies given, and activities performed (e.g., integrated pest management) for each visit. Although the CES documentation was largely unstructured, that is, CESs could freely express in writing the important aspects of their visit under the broad heading of “comments/observations”, for the initial two visits the documentation form included a checklist of activities to be covered, as well as designated space to indicate questions and follow-up actions for both the CES and caregiver (see Appendix A). The handwritten comments and observations made by the CESs, hereafter referred to as CES documentation, are the focus of this study. Given the emphasis on evaluating the intervention group (n=115), the control group (which received the intervention after a one-year delay) has not been included in this analysis.

Data Analysis

The CES documentation for the intervention group only was transcribed from handwritten to electronic format, maintaining the date and time the documentation was made and by whom, and residence of the participant (Eastside or Southwest Detroit). Any information that might identify the participant or his/her family was subsequently removed from the transcripts to ensure anonymity. The qualitative documentation was analyzed case-by-case, that is, by reviewing the documentation from all home visits to the same family, using a line-by-line process. Through this process, *in vivo* codes (i.e., using the respondent's words) (Strauss & Corbin, 1998) were assigned to asthma-related and other events or issues perceived to be a source of stress for families, and strategies used by CESs to assist caregivers in resolving or alleviating these stressors. The codes that emerged from the inductive analysis were then organized into focused code categories (Strauss & Corbin, 1998). Using a method of constant comparison, the codes and restatements were reviewed for internal and external homogeneity to ensure that coding categories were meaningful by themselves and differences among them clear (Patton, 2002). The initial findings were reviewed by a three-member team skilled in qualitative methods, which includes two members who were actively involved with the household intervention study. Thematic areas where any divergence in opinion was expressed were further discussed and modified until consensus was reached. Study results were then presented to and discussed among CAAA Steering Committee members, many of whom were involved with the original intervention study, as well as two of the CESs who completed the documentation. The content of these discussions and their implications was noted, discussed further among the data analysis team, and incorporated into the results, as necessary. Basic demographic information for the intervention sample has been summarized using descriptive statistics.

RESULTS

Sample Characteristics

The mean age for adult caregivers was 37.33 years, ranging from age 22 to 74. The majority of intervention participants were racial/ethnic minorities, with 83.19 percent of caregivers self-identifying as African American and 12.39 percent as Hispanic/Latino.

Roughly one-third of caregivers had a high school diploma, a little over one-third had a GED, and less than 20 percent had 4 years of college or more. Over 96 percent of caregivers were female. Approximately 84 percent of caregivers reported being the mother of the enrolled child, and another almost 10 percent grandmothers. The sample included a large number of families with more than one child (83.48 percent). The average household size was 5.29 total persons. Approximately 90 percent of caregivers reported an annual household income below \$40,000, and almost 57 percent of these families made less than \$15,000. Fewer caregivers owned the home they lived in (34.78 percent) compared to renting (60.87 percent).

The 115 intervention group families were assigned to a total of four CESs as follows: 19, 29, 30, and 37 families per CES. Although four CESs were hired initially to conduct the home visits, one CES departed approximately halfway through the less-intensive second year of intervention group home visits and the other CESs on-staff completed the intervention visits with those families. Based on the caseload numbers, the results presented represent the documentation of CESs in a fairly evenly distributed manner.

Emergent Themes/Codes

LIFE STRESSORS EXPERIENCED BY FAMILIES OF CHILDREN WITH ASTHMA

The list of stressors experienced by families of children with asthma identified through the analysis of the CES documentation is presented in Table 2.1. This is followed by a description of each of these major themes, providing examples of the CESs' exact statements as appropriate.

Lack of basic necessities and amenities

Lack of food, clothing, and utilities. Many families indicated needing help with basic necessities such as food, clothing, and utilities. As noted by one CES following a home visit, it “has been taking everything to feed [the] family”. In some cases, children and adult family members were going without food. Caregivers living with other family members spoke to the difficulties of their living situations “which made for more to feed”. In addition to food, CESs documented the need for clothing for children and/or

Table 2.1. Life stressors experienced by families of children with asthma, as documented by Community Environmental Specialists.

Lack of basic necessities and amenities
Lack of food, clothing and utilities
Lapse or lack of transportation
Lack of furniture and appliances
Trouble maintaining adequate, safe living conditions
Poor or unsafe housing conditions
Concerns about personal safety and neighborhoods
Trouble finding new housing
Housing instability and overcrowding
Issues with employment
Lapse in employment and competing commitments
Working with non-traditional work schedules
Managing multiple physical and mental health issues in the family
Concerns about health insurance
Presence of diverse physical health issues among family members
Problems managing families' physical and mental health issues
Disability of caregivers and children
Substance abuse and gambling
Strains or changes in family relationships and structure
Interpersonal conflicts within the family
Concerns about child's academic performance and behavioral problems
Dealing with the absence or incarceration of other family members
Legal trouble
Emotional and financial toll of legal disputes
Challenges to obtaining or maintaining assistance from individuals, agencies, or organizations
Unresponsive or ineffective agencies or organizations
Funding, resource, and eligibility constraints among agencies and organizations

other adult family members, as well as baby and maternity clothes and supplies. Families also commonly requested assistance with telephone and utilities, such as gas, electricity, and water. While some families were trying to avoid shut offs, others were struggling with how to overcome not having any working service:

“Client[’s] light[s] are turned off. Client state she does not have enough money to pay light bill. Client owes \$450.00... Client state she tried to pay off bill but she doesn’t have that type of money.”

A few caregivers also expressed concern with having their utilities in someone else's name, such as a landlord or ex-boyfriend, or being asked to assume a bill that was not theirs.

Lapse or lack of transportation. The impact of not having dependable transportation was felt broadly by families. Lack of transportation hampered efforts to get to the store, restricted families' abilities to keep doctor's appointments or seek emergency care, and in a few instances contributed to job loss because of "working so far out with no trans[portation]." Obtaining assistance from local agencies and organizations, such as for food and furniture, was also affected by transportation because of having "no way to get to use referral[s]". Some families had to forgo receipt of items that were hard to come by without dependable transportation. By the time one caregiver finally "found trans[portation] to get [a] stove that was offered 3 w[ee]ks ago", it had already been given away.

Lack of furniture and appliances. CESs documented concerns with lack of amenities in the home, such as furniture items and household appliances, and for their children. The majority of requests were for bedroom and living room furniture, with many families in "desperate need of beds", mostly, for their children. Many families also requested assistance with finding working appliances, such as refrigerators and stoves. CESs documented that assistance was limited from most places because, "you must be burnt out or coming from a shelter to get appliance[s]." Families employed short-term solutions such as "using hot plates to cook", a barbeque grill, or someone else's appliances.

Lack of other amenities. Assistance with recreational items and services, particularly for children, was also requested. One CES wrote, "[Caregiver] has been going through some hard times... [is] concerned about the Christmas holiday because her daughters aren't going to have a good Christmas." In addition to assistance for the holidays, some caregivers inquired about after school programs and/or summer camps.

Trouble maintaining adequate, safe living conditions

Poor or unsafe housing conditions. Housing-related issues were frequently cited during home visits. Many caregivers were living with poor housing conditions, ranging from missing plaster and broken windows to major electrical and plumbing issues. One family had “water running everywhere”, and another family’s “kitchen ceiling [was] 3/4 gone from repairs needed on roof and upper flat. The larger concern, however, was that many of these problems posed safety risks in the home. CESs also noted varying severities of pest infestations in the home, strong smells or odors such as from mold and mildew, pet feces, or gas or kerosene, and “cluttery” or unclean home environments. Caregivers who were renting complained of landlords who were unresponsive (or sometimes slow to respond) to needed repairs or remediation. Some landlords who expressed a willingness to do repairs threatened to increase rent to cover the additional repair expenses.

“We also talked about some personal issues, such as her rent actually has been raised from \$185.00 to \$275.00... the landlord said the reason he.... raised the rent [is] so he can start to do repairs on the house.”

When repairs were forthcoming, the timeline for repair efforts was sometimes long. For one family, the CES documentation indicated the landlord was still in the “process of doing repairs needed for home to meet Section 8 guide lines” a full 8 months after the scheduled Section 8 housing inspection. CESs also documented some resistance on the part of tenants to seek assistance with repairs. One caregiver expressed concern that her “landlord would put her out” if she had a Building and Safety representative come inspect her home. Coupled, with few, if any, options for assistance with home repairs, caregivers may have felt as if they could do nothing but wait. A few caregivers, however, discussed seeking legal representation or withholding rent to facilitate home repairs.

Concerns about personal safety and neighborhoods. Caregivers shared their concerns with CESs about personal safety and adverse conditions in their neighborhoods. Perceptions of living in unsafe neighborhoods fueled several caregivers’ desires to move. Problems noted by CESs ranged from illegal dumping to drug activity and shootings. One caregiver noted the impact of a recent shooting, where her front window was shot

out, on her daughter, “When she hears noises, she thinks it’s gun shots”. Several caregivers also told CESs about attempted or actual break-ins to their homes, with one whose “house was left empty.”

Trouble finding new housing. Although a large number of families changed residences during the study period, there were also many families who were interested in moving or finding more adequate, affordable housing—particularly those whose landlords were unresponsive to needed repairs—but the act of finding “better” housing sometimes had its own challenges. Some families who wanted to move could not afford to do so. As documented by one CES, the requirement of a “security deposit and 1st mo[nth’s] rent” was too much. Transportation was also cited as a barrier, hampering one family’s efforts to even inquire about assistance at the housing agency. In addition, eligibility for housing assistance may have precluded families who were not in the most dire of situations. As written by one CES, “[agency] will not be able to help family because family is not having any problems with the court or eviction notice”, which renders caregivers living in the homes of other family members or friends ineligible. Yet, even with an offer of housing assistance, there was some resistance on the part of caregivers to accept the conditions. For example, one caregiver who was living in Southwest Detroit, a predominantly Hispanic/Latino area, indicated to her CES that she did not want to look at housing in East side Detroit, which is mostly African American. The agency providing assistance, however, informed her “that if she does not take any of the choices she will be closed and not be eligible for deposit or first mo[nth’s] rent assistance.” Similarly, another caregiver who was adamant about East side housing decided not to seek help from the agency because they “would not guarantee that she would be getting East side housing” and she needed to “put money into [an] escrow account”.

Housing instability and overcrowding. Caregivers also talked about the instability of their current housing situation. A small number of families had “no choice but to move” because of eviction, yet others lived with the daily fear of being put out of their homes. Identified threats to stable housing included disputes with landlords, potential sale of the

home, inability to pay rent, and foreclosure. Some caregivers had lived for years in dilapidated housing with eviction looming:

“[Caregiver] states she has major problem with housing, has rented home for 20 y[ea]rs at 350.00 a month and [name of real estate agency] went bankrupt. Company lost home and no repairs have been done in several years. [Caregiver] has had 13 eviction notices but has no place to go.”

Over the two-year study period, only a few families experienced a short stay in a homeless shelter during lapses in housing. It was not uncommon for caregivers to report living in the homes of other family members or friends or between homes, that is, living at different homes during the week. Some caregivers discussed moving in with other family members or friends temporarily, while “looking for housing and employment” or in preparation for a move, such as one caregiver who was “stay[ing] with a friend tempor[ar]ily and storing her things over [at her] mom’s house.” Yet, the temporary nature of these arrangements sometimes lasted for months on end: “Caregiver living with sister, will be in her own home within next 2 weeks”, and approximately 7 months later the documentation indicates, “[Caregiver] is currently living with her sister, has not had money to move.” Many caregivers were also providing shelter for other family members, including adult children, grandchildren, nieces, nephews, and cousins. These extended family arrangements sometimes proved stressful for caregivers. CESs reported living situations with many individuals living under the same roof: “15 people living in a two bedroom home”, “5 children, her mother, sister, and nephew who live in the apartment”, “Client has a large family consisting of several grandchildren (age ranging from infant [to] 12 y[ea]rs) and several adult children living in [the] home.” In addition to problems with overcrowding, caregivers spoke candidly to CESs about one-on-one conflicts (e.g., “child did not get along with other children and family was having conflict about situation”) and needing to move because “space is needed” for an ill family member.

Issues with employment

Lapses in employment and competing commitments. Periods of unemployment for many caregivers were noted by the CESs. Although the events precipitating unemployment were not documented in all cases, CESs did note personal issues that affected some

family members' efforts to remain employed as well as to seek employment. For a couple of caregivers, lack of dependable transportation for a job that was not proximate to their home led them to quit their jobs. Dealing with the family's health issues was more often a factor in unemployment. Because of having to take care of another family member or to tend to important matters at home, such as the death of a loved one, a few caregivers could not work or had to quit their jobs. As indicated by the CES of one family, "Reason [caregiver] is unable to work is because of [child's] asthma. This year is the first year that she said 'she has felt peace and [child's] asthma hasn't acted up real bad'". Health issues such as carpal tunnel also led to periods of unemployment for caregivers due to their inability to work. However, not all cases of missed work led to dismissal or leave. Of the caregivers who reported taking time off to tend to their personal issues, only a couple mentioned problems with their employers because of missed work.

Working non-traditional work schedules. According to the CES documentation, many caregivers worked on the weekends or long or odd hours. Work schedules included working double shifts, evening or afternoon shifts, and overtime. Some caregivers complained to CESs of their work schedules interfering with the time they had with their children and the need to change their work hours or find a new job, "[Caregiver] states she does not like working midnite (sic) shift. States she misses children at night." One caregiver cited her work schedule as a barrier to following through with an agency referral made by the CES. Work schedules were further complicated by working more than one job. One caregiver reported working as many as "3 different jobs to help pay for some personal expenses."

Managing multiple physical and mental health issues in the family

Concerns about health insurance. Some families were without health care coverage for adult family members or children. Documented factors contributing to a lapse or lack of insurance included job loss, not having legal custody of child(ren) needing health insurance (e.g., grandparents taking care of grandchildren), and children not being of

dependent age. However, families with insurance also had concerns, such as whether changes in medication or health care providers were still allowable, covered expenses.

Presence of diverse physical health issues among family members. CESs documented the presence of diverse health issues in the family. Among the physical health conditions experienced by caregivers and other adult family members were cancer, high blood pressure, heart and kidney problems, diabetes, auto-immune diseases, muscle, nerve, or joint pain, and pregnancy. There was also a strong family history of asthma among participating families. Not only did many caregivers have asthma themselves, but oftentimes more than one child in the family was also diagnosed. Little mention of other physical health problems afflicting children in the family was made.

Problems managing families' physical and mental health issues. Factors impeding efforts to keep regular health care appointments, attend to emergent health care needs, and maintain appropriate medication for children and other family members were mentioned. Although health maintenance discussions were often focused on the child (or children) with asthma, CESs documented caregivers' troubles with finding a good health care provider, health insurance coverage for children and adults, transportation to maintain regular health visits as well as to seek emergency care, long wait times for appointments, not having childcare options for prolonged health care visits, and work or other activities interfering with making an appointment. In addition, one caregiver spoke about waiting for symptoms to get worse before consulting a health care professional:

“[Caregiver] states child has caught cold and asthma flared up. Had to take treatment on machine several times today. States she will not take child to d[octo]r unless she gets wors[e]. [Caregiver] now has transportation and is able to get around much better.”

Poor adherence to medication regimens was indicated by activities such as sharing of asthma medications in the family, lapses in refilling medications, and medications not being taken as prescribed or at all.

The emotional toll of life stressors left some caregivers feeling “very stressed, overwhelmed with ‘everything and everybody.’” Many caregivers talked about the difficulties of trying to recover from the death of a loved one, dealing with serious health issues in the family, or just being “concerned about ‘living,’” in general. For some caregivers, these episodes were described as “going through a depression stage from time to time”. Yet, few expressed interest in seeking counseling or support services or taking antidepressant medications to help them through these episodes. Descriptions of the mental health issues of other family members were also provided by CESs, most notably, for children in the family. Although caregivers rarely referenced “depression”, CESs noted children having difficulties dealing with a parent’s or another close family member’s death or the physical absence of a parent, going through an “emotional thing” with a child custody battle as reported by the caregiver, or dealing with issues of abuse, neglect, or suicide threats or attempts. Far more interest and participation in mental health counseling or services was documented for children in the family, and not just the child with asthma, than for caregivers themselves.

Many families appeared to be managing their children’s asthma amidst the presence of multiple health issues in the family, and details relayed by CESs indicated some of the hardships experienced by caregivers. First, although families were selected for inclusion in the study based on having *one* child with asthma, many caregivers assumed responsibility for *more than one* child—some for young infants or toddlers—and often more than one child with a physical or mental health condition.

“Member has 6 children. Member’s children with exception of the oldest and her nephew have mental disorder. Her youngest child can’t hear, the other child has a brain tumor. Her nephew, which she also taking care of, has emotional problems. So, she has her plate full.”

At any given time, one child may be doing well while another may be having problems. Second, exacerbation of health conditions sometimes required medical intervention. Those health conditions requiring frequent supervision by a health care professional left caregivers going “back and forth to [the] doctor” for follow-up and/or treatment over a period of months or years, for themselves or others. A large number of families also

reported, and some with great frequency, episodes of asthma exacerbation or breathing problems among children *and* adult family members. Reports ranged from, “asthma... acting up a little” to “as[t]hma attack two week[s] ago and had [to] be rush[ed] to the hospital.” Health events requiring medical intervention were, however, not limited to asthma. Caregivers relayed episodes of outpatient and inpatient surgery, hospitalization for diagnosis of health problems, or aggravation of existing health conditions for themselves and others. The family’s health issues were quite debilitating for some:

“[Caregiver] states she has been very stressed out, mom who has been ill was diagnos[ed] with brain cancer and several other major health issues and has may[be] 3 mo[nths] to live. Recent death at home of her father-in-law 2 days ago and other personal concerns have been overwhelming for [caregiver].”

Lastly, a handful of caregivers spoke of providing short- or long-term care for another adult family member who was “very ill”, including a spouse or parent. Some of these individuals required extensive care, with one CES documenting: “[Caregiver’s] mom very ill, family assisting with routine care, daily 24 h[ou]r care needed.”

Disability of caregivers and children. Disability was another topic mentioned by caregivers during home visits. Although few in number, physical impairments of caregivers included hearing problems, blindness, partial paralysis or weakness, and debilitation from muscle, nerve, and/or joint pain. One caregiver who had suffered a stroke expressed frustration “because she wants to do activity like she use[d] to be able to do” and was in need of home health care. Additionally, CESs documented details regarding caregivers’ concerns about children with a suspected or diagnosed learning disability, hyperactivity, and/or attention deficit disorder. Caregivers relayed problems with “trying to get [children] settled in school”, as some children were performing “below level of [their] grade.” The impact of poor academic performance and behavioral problems for families is discussed in more detail later (see “Concerns about child’s academic performance and behavioral problems”).

Substance abuse and gambling. Substance abuse and gambling, although not often mentioned, afflicted some families. Some caregivers spoke candidly about alcohol and

drug abuse by older children in the family, as well as the parents of children for whom the caregiver was taking care of. A few caregivers were comfortable airing their own problems with drinking, drugs, or gambling. In fact, one caregiver mentioned to the CES “going to [the] casino [and] losing her paycheck”.

Strains or changes in family relationships and structure

Interpersonal conflicts within the family. CESs provided great detail surrounding disputes among family members, as relayed by the caregiver. Caregivers spoke candidly about problems involving individuals such as a spouse, partner, parent of the child, or another family member. The vast majority of caregiver reports of physical, sexual, or emotional abuse or neglect of adults and children in the family were under investigation or legal action, or had transpired in the past. While some family members were struggling with these relationships, others had separated or divorced. According to some caregivers, these relationships had been strained for many years. The CES for one family noted, “[Caregiver] and her husband aren’t on the greatest terms. She says that the only reason they’re together is because of their son.” Those fighting for custody of a child or grandchild also spoke of their lengthy battles with the child’s parent:

“Also [caregiver] is going through a court process because his daughter (child’s mother) is trying to get custody of her son again. [Caregiver] has had his grandson since he was 2 w[ee]ks old.”

And, almost a year and a half later, this same caregiver was determined he “wasn’t going to let that happen.” Caregivers involved in shared custody arrangements also had concerns related to other party’s parenting or caregiving methods. As relayed to the CES of one family, the caregiver had to step-in and provide needed guidance because the “parent has no control of children”. Sometimes these conflicts with family members led to the involvement of social service organizations such as Child Protective Services. Several caregivers were trying to resolve cases involving Protective Services, called in by other family members. Living in extended family households or at different residences during the week appeared to contribute to interpersonal conflicts among family members living under the same roof and discontent with current child custodial arrangements.

Conflicts also involved disputes over money, sometimes from loans not repaid or missed child support payments.

Concerns about child's academic performance and behavioral problems. CESs documented that many caregivers were dealing with children's academic and behavioral problems. Among the issues discussed were poor academic performance and attendance, discontent with schools or classes, and problems with "acting out". Caregivers vented to CESs about bad report cards, falling grades, and children performing below their grade level, which necessitated the need for summer school in select cases. Although many of these caregivers were trying to get help for their children, for some, the issues persisted without resolution. One caregiver whose child was diagnosed with ADD and having "some social problems" enrolled her son in summer school and got him placed in a learning disabilities class for a probationary period of a year. However, after a year and a half of follow-up with the CES, the following was noted:

"States child was put in his right grade and is having problems with lesson. Allowed [caregiver] to ventilate (sic). States she is at a loss for what to do to keep child int[e]rested in school."

Diagnosed or suspected learning or other disabilities and behavioral problems in school were often implicated in poor academic performance or disinterest in school. Several caregivers relayed children's difficulties with being placed in special education and falling behind their peers. Concerns about schools not providing a supportive environment for those with special needs and issues around miscommunication with school officials were also issues of relevance. However, for many families, school attendance was impacted greatly by health events such as exacerbations of asthma, problems with allergies, and colds and viruses. In fact, CESs documented that some episodes of asthma exacerbation necessitated children missing several days to a week of school; yet, the documentation did not suggest any connection between missing school and academic performance. Detailed descriptions were provided for caregivers' concerns with their children, including the child with asthma who was enrolled in the study, getting into trouble and "acting up", which was not limited to the school environment.

Caregivers talked with CESs about their children's problems with gang recruitment or "running with a gang", stealing, fighting or abusive behavior, suicide threats or attempts, disobedience, and suspension or expulsion from school, with some children having more severe problems than others. An additional difficulty was managing these issues when there was more than one child involved or when the behavioral problems of one child affected others in the family. For example, one caregiver's grandson, the child in the study, admitted to stealing her food stamps, which "made her short for food supply." Another caregiver described how her older daughter's behavioral issues sometimes "causes problems" with her younger brothers, alluding to the impact of this stressor on health by stating that her younger son's "asthma is fine if [her] daughter is no[t] around.

Dealing with the absence or incarceration of other family members. Caregivers openly discussed with CESs the difficulties of dealing with intermittent or prolonged absences of family members. It was not uncommon for biological parents to be absent for some children due to death, incarceration, or other issues that led them to be "in and out of [their children's] lives." Some caregivers had assumed or were fighting for permanent or temporary custody, which necessitated the need to apply for additional financial assistance, such as Social Security benefits, for the child in some cases. A couple of caregivers chose to keep the parent's incarceration a secret, providing excuses for their long absences in order to protect the children. These absences sometimes took their toll on the child and caregiver alike.

"States child's mom is still in jail, [will] have court date in Nov[ember]. Child's asthma had been doing very well, had severe asthma attacks on Thurs[day]... Was given several treatment[s] thru her d[octo]r. States she thinks child broke down from stress of not seeing her mom who child thinks is on vacation."

Legal troubles

Emotional and financial toll of legal disputes. CESs documented that quite a few families were seeking assistance from or eliciting help from a lawyer to navigate legal channels for themselves or other family members. While some issues were resolved with expediency, others dragged on, leading some caregivers to feel depressed or "stressed out". One CES noted, "Caregiver] is still going through the custody battle... [caregiver]

gets depressed ab[ou]t it but she knows that she has to keep strong.” Legal representation was also sought for a broad range of other issues including legal guardianship, disputes with landlords, denial of Social Security or other benefits, and juvenile delinquency. For a few caregivers, the financial repercussions of legal matters, including money for bond and attorney fees, were an issue of concern. As documented by the CES of one family, “[caregiver] has no money and can not afford a lawyer that is not free.”

Challenges to obtaining or maintaining assistance from individuals, agencies, or organizations

Unresponsive or ineffective agencies or organizations. Although many families initiated efforts to obtain assistance, not all efforts were met with success, regardless of one’s persistence. Some individuals, agencies, or organizations were reported by caregivers to be unresponsive to their needs or unconstructive. Caregivers complained about both failed efforts to connect for assistance and not having adequate resolution of issues of concern.

“[Caregiver] has been on a rough path, however, is settled now. She has a new place, apartment. Member (i.e., caregiver) s[ai]d, it’s okay, it will do... She had kept tr[y]ing to call the numbers I had given her for the shelters but they only had room for one person. She spent like ab[ou]t \$200.00 on agency to help her find a home. S[ai]d that was a waste of money.”

Funding, resource, and eligibility constraints among agencies and organizations. Some agencies and organizations were simply constrained by the funds or resources they had to offer, and to whom they could offer resources. According to the CES of one family who was in need of beds, “Agency never has items needed when family call[s].” And, sometimes, even when assistance was available, caregivers could not apply or were deemed ineligible. One caregiver who was seeking childcare assistance was not permitted to initiate the application process because she was not her grandchild’s legal guardian. However, her son, the child’s legal guardian, also could not help because he was in jail. Other caregivers were not able to obtain assistance because referral forms or vouchers had expired or deadlines passed. Eligibility for assistance was also an issue for many families. As previously discussed, families who were renting were precluded from

financial assistance with home repairs; furthermore, in order to receive assistance with finding housing, one reputable agency required families have an eviction or court notice. Some families were also disappointed to learn that they did not qualify for items they desperately needed, when they needed them. For example, appliances were often available only to individuals who were “burnt out or coming from a shelter”, and certain referrals, such as for food, could only be used once during a given interval of time, e.g., once a month.

Even with the offer of assistance, certain conditions needed to be met in order to actually receive assistance. While some conditions required minimal effort, others required additional investment of time or other resources. For example, in order to get money to help with storm damage, one caregiver was told that the agency “would not give any money if plumbing repairs have not been made.” Another family was informed their water bill needed to be “paid on” before the agency would provide supplemental financial assistance. Additional activities required to obtain or maintain assistance included renewing paperwork, passing a housing inspection, providing documentation such as a photo identification or a letter stating current housing conditions, and completing a mandatory training program as a part of employment assistance. While CESs could help with some activities, caregivers needed to initiate and follow through with many of these tasks on their own.

“Agency visit by ph[one] to [Gas/electric Company]. Spoke [with] case manager, [agency contact], who state [Gas/electric Company] will not help someone just because they have a medical condition. I explain member (i.e., caregiver) is a recent stroke victim w[ith] a[n] asthmatic child. He explain this was not enough to stop the company from shutting off gas service. However, he did suggest that if she has a d[octo]r written statement explaining member medical condition and the seriousness of her condition they may put a 21 day (sic) hold on account until an assessment is done. Call client back to see if she can get doctor statement to put a hold on gas account.”

Yet, qualifying for and obtaining assistance from agencies and organizations did not guarantee the duration of support. CESs documented that assistance was cut off or reduced for some families during the study period. Although in many cases CESs did not

indicate the specific reasons for loss or reduction in assistance, the documentation alludes to work income rendering individuals ineligible or issues with noncompliance.

STRATEGIES FOR ALLEVIATING OR RESOLVING LIFE STRESSORS

As a part of the intervention, CESs executed a variety of activities to lessen the toll of life stressors experienced by families of children with asthma. The following paragraphs describe some of the strategies documented by CESs, which are summarized in Table 2.2, focusing on strategies directed at stressors other than asthma.

Table 2.2. Strategies used by Community Environmental Specialists to alleviate or resolve life stressors experienced by families of children with asthma.

Connecting families to needed assistance and information

- Providing families with the information necessary to obtain assistance and stressing the immediacy and importance of taking action
- Intervening on behalf of the family to obtain needed assistance and information
- Including family members and friends in the provision of assistance
- Following up on efforts to obtain needed assistance and information

Listening and providing social support

- Listening, and offering comfort and support
 - Being accessible and available
 - Getting to know the family and recognizing accomplishments
 - Offering incentives and tangible assistance
 - Establishing personal boundaries
-

Connecting families to needed assistance and information

Providing families with the information necessary to obtain assistance and stressing the immediacy and importance of taking action. During the course of the intervention, CESs connected and assisted families with obtaining needed assistance or information. This frequently involved referring caregivers to appropriate individuals, agencies, or organizations in response to identified needs, providing an address and phone number and, at times, the name of a point-person for whom families could work directly. To aid requests for items such as food, furniture, and appliances, CESs completed additional forms required by referral agencies and organizations. Assistance, however, was not limited to the mere provision of referrals. In many cases, CESs also relayed what

eligibility (e.g., “must be current with taxes (property)”) and steps were required to obtain assistance so that caregivers could follow through themselves.

“I called the light company... and worked out a payment arrangement for the member (caregiver). Member has a bill \$397.00. [Agency] will take \$120.00 at this time to keep her from [being] disc[onnected]. Member needs to call back [agency] and explain that she thinks that she is being over bill[ed]. Explain all of this to member. Explain that she will have to make payment and she will have to make the phone call.”

CEs also advised families on the immediacy and importance of seeking needed assistance, as well as how best to initiate these efforts. Knowing that delayed action could compromise the availability and distribution of resources and services to needy families, CEs encouraged caregivers to initiate activities such as calling ahead to check on the availability of assistance, scheduling appointments with agency or organization representatives, and completing and returning applications or other materials expeditiously. Additionally, for families experiencing language barriers, CEs recommended asking for a representative who speaks Spanish to assist them. Yet, CEs were careful not to overstate the degree of assistance that might be offered, particularly in the fulfillment of basic needs or housing-related issues, to set realistic expectations for families.

Outside of more formal referral networks, caregivers were encouraged to be their own advocate. This included engaging in activities such as checking the newspaper for housing or employment opportunities, trying local churches or resale shops for appliances (when ineligible for agency assistance), and looking to friend and family networks for assistance, when appropriate. In addition, instead of intervening, CEs often prodded caregivers to initiate conversations with designated individuals, such as landlords, themselves. And, when tangible assistance was not available, some families were encouraged “to keep pushing” and to derive strength and resolve from their higher power.

Intervening on behalf of the family to obtain needed assistance and information. CEs commonly initiated contact with individuals, agencies, or organizations via phone or in-

person on behalf of families, even when many of these families had working phone service. In order to provide accurate information, CESs took it upon themselves to verify availability of assistance or in some situations research and identify potential outlets to meet specific needs expressed by families. The latter sometimes required CESs to consult with physician members of the research team, including a pediatric pulmonologist, or other experts. For example, for one family that was having problems with a gnat infestation, the CES was able to provide some inexpensive, yet effective advice on how to get rid of the pests after consulting with an appropriate professional. Furthermore, CESs helped families to request support or assistance, schedule or reschedule appointments, arrange bill payment options, and avert utility shut offs or get services reconnected. And, in at least one case, the CES also served as the contact person in case the agency needed any other information, since the caregiver did not have a working phone. At times, CESs were able to get done what caregivers could not do on their own.

“Family is stressed for oldest child trying to commit suicide 2 days ago. States she has not been able to seek counseling for her. Info[rmation] given for mental health app[ointment]t given for 3-9-01... [Caregiver] did receive a letter w[ith] app[ointment]t date for [Housing Agency], app[ointment]t date and time is same as app[ointment]t for her daughter’s mental health app[ointment]t. [Caregiver] contacted [Housing Agency] who would not change app[ointment]t. CES contacted [name of contact at agency] who was able to change app[ointment]t to 3-14-01, 12:00.”

CESs also scheduled and attended more than a few joint visits with social service agency representatives that occurred either in the home or office. For one caregiver who had no way of getting to her agency appointment and was noted to be “crying and very depressed”, the CES took it upon herself to accompany the caregiver to her appointment.

Additionally, CESs obtained forms, applications, and other requested items and delivered them to families. Among these were applications for Toys for Tots or food stamp programs, agency referral forms, and infant and maternity clothing and supplies. One CES noted helping a caregiver to complete a housing application and then taking the completed form back to the agency. Some caregivers also asked CESs for letters of

support for the child with asthma, such as for Social Security benefits. This included letters stating that the child was participating in CAAA, the severity of the child's asthma, and/or the harm of triggers of asthma for the child with asthma.

Including family members and friends in the provision of assistance. Although the primary focus of the intervention was on the caregiver and child with asthma, at the request of caregivers, CESs connected and helped other family members and friends to obtain assistance and information. While the vast majority of extra assistance was requested for family members, one caregiver asked for a furniture referral for a friend who was willing to provide transportation "if she can also use a referral". In many cases, help was not limited to providing contact information for individuals, agencies, or organizations. CESs sometimes requested needed resources, such as infant clothing and supplies, for other family members and followed up by delivering the items to the caregiver.

Following up on efforts to obtain needed assistance and information. CESs followed up by inquiring about the acquisition of items such as food, clothing, and appliances, as well as eliciting whether contact was made with the individuals, agencies, or organizations to which families had been referred and if their issues were adequately resolved. Even with the time elapsed between home visits, CESs were often vigilant in assessing the outcome of efforts to obtain assistance and information. One caregiver's pursuit of assistance with major housing repairs was documented to have been resolved approximately 4 months later when the caregiver, "did get application [with agency] filled out over the phone". Some inquiries were supplemented with direct observations of individuals or conditions in the home, such as documenting the presence or absence of furniture or the general physical, mental, or emotional state of the caregiver. If warranted, CESs would help families to readdress issues that had not been adequately resolved.

However, not all offers of assistance were welcomed. Several families were documented as either being resistant to seeking or accepting the conditions of assistance from agencies or organizations. In these situations, CESs encouraged, but did not insist, that

caregivers reconsider their decision. Alluding to the importance of and potential difficulties in locating new housing, CESs strongly urged a couple of caregivers to accept the housing assistance offered from a local agency. For one family, the CES cited the negative impact of current housing conditions on the family's health; for another, the CES emphasized that assistance was contingent upon the caregiver not being "choosy to which side of town she moved" and to reconsider the offer of assistance.

Listening and providing social support

Listening, and offering comfort and support. The documentation spoke to the depth of relationships CESs had established with families. One CES noted that, "[Caregiver] was very grateful to have me to talk to because she feel she can trust me and look upon me as a friend". An overwhelming number of narratives documented the CES's role as listener, allowing caregivers to vent their emotions and often with the most personal of information. The home visit was characterized by one CES as "a stress reducer", allowing caregivers to talk about any (and all) issues of concern in their lives. In some cases, caregivers initiated these contacts, whether for the company or for someone to talk to:

"Went to see client and she was depressed. She called me and asked if I can come to see her because she wanted to talk to me, she was feeling down. [Caregiver] had lost her job."

It was not uncommon for CESs to note that the caregiver was "unable to discuss [asthma] because [s/he] was feeling stress about other concerns". Therefore, many home visits were not rich in asthma education but rather dense in describing issues outside of asthma; yet, sometimes after discussing other issues, CESs were able to get to asthma, making listening a necessary precursor to delivering asthma education.

The CES's role also included comforting and expressing concern for the family's well-being. CESs provided emotional support and understanding, and acknowledged the family's personal concerns, from expressing their condolences for deaths in the family to offering congratulatory praise for marriages. In addition, on more than a few occasions,

CESs initiated visits or phone calls to follow-up on issues of potential concern from prior home visits. For example, one CES went back to the home later in the day to check on the caregiver because she appeared to be “heavily medicated”, from an earlier sickness, and “not functioning” during the initial home visit. However, when CESs found themselves limited in their ability to act, sometimes their presence and comfort was all they could provide: “I honestly couldn’t give [caregiver] any advice because the little I did have she has already done. So, I informed her [that if] I can loan you my ear, I will.”

Being accessible and available. Because of the time allotted between home visits, with 9 visits in year one and 3 visits in year two, CESs often made themselves accessible and available to families between visits by providing the study’s toll-free number and, in some cases, their personal cell phone numbers. Cell phones were not issued to CESs as a part of the intervention study due to University policy.

“Adv[ised] member that there are three more visits that he is going to get from me. Explained that they will be scattered but if need to me to come out between time all he would need to do is call.”

CESs encouraged caregivers to call with any questions or concerns, and also if they needed referrals to agencies or organizations, which was comforting to some families.

“Also, let [caregiver] know if she needed assistance w[ith] anything or need a referral that she can call me. When I s[ai]d that to her, she seemed a little more [re]laxed and s[ai]d we’ll talk ab[ou]t that soon.”

One CES also left her cell phone number for the caregiver, who was the child’s grandparent, to share with the child’s mother.

Getting to know the family and recognizing accomplishments. Although the intervention was focused on managing childhood asthma, CESs took it upon themselves to become familiar with the individuals and activities of the family as a whole. Concurrent with eliciting personal problems requiring advisement, support, and assistance, CESs also inquired about the family’s social activities. The documentation relayed conversations about family reunions and trips, choir performances, and just

talking about “men, relationships, life.” Some caregiver’s also shared their personal accomplishments with CESs, who were quick to praise their hard work and dedication. While one caregiver had started a summer lunch program in her community, another had completed classes at a local university.

Additionally, families’ efforts towards resolving or alleviating their stressors did not go unnoticed. CESs lauded caregivers for following through with referrals made to agencies or organizations, as well as for taking the initiative to address issues of concern in the absence of referral. CESs praised caregivers for their fortitude and perseverance amidst “real stressor[s]”, and particularly for taking care of their families. They acknowledged the obstacles overcome by some caregivers in keeping their families together and healthy, and maintaining employment and shelter.

Offering incentives and tangible assistance. To supplement the standard incentives provided to study participants, CESs sometimes offered incentives themselves. Some children were offered a “treat” or “goodie” to motivate them to improve their behavioral or academic performance, which included activities related to the intervention (e.g., having children keep their room clean) as well as those more external (e.g., improving their grades in school). The documentation also revealed that occasionally CESs provided monetary or tangible assistance to families.

“States she will not have any money until Fri[day]. Has no one to help with receiving any food. Family at dinner last night very upset that child will not have anything to eat when she gets home. \$10.00 given to [caregiver] to buy a little food.”

Assistance was also provided in the form of a ride to a job interview that same day and use of a personal cell phone to address an emergent health situation.

Establishing personal boundaries. Although CESs nurtured their relationship with families over a period of two years, they sometimes had to establish personal boundaries or limits to the type of assistance they could and would provide. Sometimes, if assistance was offered beyond the scope of intervention study activities, it would be provided with

the caveat of “don’t depend on me all the time.” CESs were also clear to explain what activities could not be guaranteed by the study as well as by the CES herself, suggesting that CESs would do the best they could to assist.

DISCUSSION

The results from this study are derived from a unique set of data from CHWs (or CESs) documenting the details of home visits and other contacts made with families of children with asthma in Detroit, Michigan, during a two-year asthma intervention study. The data capture the source and impact of potential life stressors from the perspective of CESs who had established rapport with families over time. Although the home-based intervention was focused on helping families manage and control their child’s asthma, the CES documentation indicated the presence of other life stressors that may have precedence to concerns about asthma. CESs, therefore, also had to implement strategies to resolve or alleviate these other stressors to bring the focus back to asthma.

CESs noted the difficulties of caregivers in providing basic needs and amenities for their families, which is likely contributed by the low average household income of participants in this study. While stressors such as involuntary shut-off of utilities (Quinn, Kaufman, Siddiqi, & Yeatts, 2010; Shalowitz, et al., 2001), inadequate furniture and appliances (Quinn, et al., 2010), and issues around transportation (Mansour, et al., 2000; Shalowitz, et al., 2001) have been cited in other asthma studies, lack of food and clothing, for example, have not been reported previously for families of children with asthma. Of grave concern is the documented recurrent and prolonged nature of many fundamental stressors, and the limited (or nonexistent) resources or services in the community to assist families. And, sometimes in order to obtain assistance, families had to satisfy strict eligibility requirements, which often favored only those in dire need. Understandably, for many families, securing basic needs and amenities may have taken the focus off of asthma preventive care, to the detriment of the child or other family member(s) with asthma. An episode of acute asthma distress may have been the trigger required to bring the focus back to asthma.

The findings from this study highlight important issues confronting low-income caregivers living with other family members or friends, whether moving in with others themselves or hosting others in their own homes. Though these arrangements were often intended to be temporary, some turned long-term. With already limited provisions for their own families and few, if any, options for decent housing, which was often a precipitating factor for these moves, caregivers may have had to stretch their meager resources to cover the needs of the collective household, particularly if that household was also of low-income. While living with extended family could afford certain advantages, such as childcare and shared transportation, the upset to routines and exacerbation of existing stressors (or creation of additional stressors) may be more concerning. For example, caregivers may assume responsibility for others in the home which may worsen their own self-care practices, children with a chronic health condition may have another adult or child who does not understand how to care for them, families may have to deal with issues around overcrowding, the home may suffer additional wear and tear, and interpersonal conflicts may escalate in extended living arrangements. From the perspective of asthma, living with others in temporary situations could also challenge maintaining and adhering to an asthma management plan and advocating for reduction of triggers in and around the home, especially with frequent relocation.

The impact of life stressors on grandparent caregivers has not been adequately addressed in the area of asthma. An analysis of U.S. Census data by the Pew Research Center showed a steady increase in children living with grandparents, with recent estimates at one in 10 children. Among these children, approximately four in 10 lived with a grandparent who was their primary caregiver. Furthermore, the majority of grandparents raising children were doing so with single parents (49 percent) or no parents (43 percent) in the household, and approximately 18 percent of grandparent caregivers were living below the poverty line (Livingston & Parker, 2010). In comparison to their non-caregiving peers, Minkler and Fuller-Thomson (2005) found that African American grandparent caregivers aged 45 and over were more likely to be living in poverty or drawing public assistance. The findings from this study help to identify some of the important issues for grandparent caregivers of children with asthma in low-income

communities of color. In addition to the child with asthma, some grandparents were caring for other children or adults, and managing a host of different health problems. With limited financial resources, grandparents may have had to make some difficult decisions about how to allocate their resources, perhaps putting the needs of the family above their own. Exhaustion, depression, limitations in activities of daily living, and poor self-care and other health behaviors are common experiences of grandparent caregivers (Blustein, Chan, & Guanais, 2004; Kolomer, 2008; Minkler & Fuller-Thomson, 1999). Symptoms of psychological distress have been reported with frequency by caregivers of children with asthma (Wade, et al., 1997; Weiss, et al., 2009), though not limited to grandparent caregivers, and a positive association between caregiver depressive symptoms and the child's asthma morbidity (Martinez, Perez, Ramirez, Canino, & Rand, 2009; Shalowitz, et al., 2001) has been demonstrated. With the rise in grandparents taking care of children, it will be critical to build a better understanding of the unique stressors facing grandparents and how to assure better health and quality of life outcomes for grandparent caregivers and children with asthma alike.

Many of the academic and behavioral problems identified by caregivers in this study have been reported by others. The results from a study conducted with a large sample of Catholic school students in Chicago showed that 43 percent of adolescents had experienced a stressful school event, including suspension, changing schools, and failing a class, though there was no difference in reporting between adolescents with and without asthma. However, adolescents with asthma were significantly more likely to report events such as a physical fight, encounters with the police, and gang-related problems compared to those without asthma (Turyk, et al., 2008). Behavioral problems were also found to be elevated in a large study of children with asthma recruited from inner-cities across the U.S. (Wade, et al., 1997). The CES documentation extends these findings by identifying some of the root causes of academic and behavioral problems, including diagnosed or suspected learning or other disabilities, changes or difficulties with child custody arrangements, and absence of a parent (e.g., by death or incarceration), which were not restricted to children with asthma. The protracted nature of some of these

stressors and the strain put on caregiver-child and other familial relationships may present as competing priorities for adequate management and warrant early intervention.

With the economic downturn and steady decrease in state and public funding, the availability and accessibility of resources and support in the city of Detroit will likely continue to be a problem for needy families. As a result, many families may have prolonged or more frequent bouts of forgoing basic needs and amenities. Being overwhelmed by their stressors may also deter families from initiating efforts to find or maintain assistance, particularly when an additional investment of time or money is required. A study of parents of children with asthma who were receiving Medicaid indicated the difficulty and time required to complete monthly paperwork to maintain coverage, especially when balancing other household and childcare responsibilities (Valerio, et al., 2006). The challenges with obtaining government benefits such as Supplemental Security Income have also been noted by others (Mansour, et al., 2000). Therefore, until the processes for obtaining assistance from agencies and organizations are simplified, families may be forced to either forgo basic needs or to prioritize what they deem to be the most pressing first, which may not be asthma.

Intervention studies often lack specificity in the performance of activities prescribed to CHWs, thus, over simplifying how families are connected to needed assistance and information. The array of activities undertaken by CESs in this study extended well beyond that of providing contact information for individuals, agencies, and organizations. CESs intervened when appropriate, relayed information from third parties, and followed up with families on the status of efforts to obtain assistance and information. The extent of assistance offered by CESs, particularly for issues outside of asthma, speaks to the difficulties families experienced in advocating for themselves in a resource poor environment. Whether not knowing what resources were available or not knowing how to obtain them, assistance from CESs may have been essential to resolving stressors and opening communication around asthma. However, in the absence of “intervention”, will families have the knowledge and fortitude to overcome their stressors?

The role of CHWs in listening and providing social support has been well documented in the literature (Eng & Parker, 2002; Rosenthal, et al., 1998). Although anecdotal evidence from asthma intervention studies suggests that the personal attributes of CHWs may, in part, contribute to intervention successes (Bryant-Stephens & Li, 2008; Friedman, et al., 2006; Krieger, Philby, & Brooks, 2011; Parker, et al., 2008), these contributions have gone largely unmeasured. The CES documentation noted the importance of building trust with families, which was facilitated by having the same outreach workers visit the same families over time. In a climate of limited community resources and services, sometimes all CESs could do was listen and offer social support. The role of CESs in offering assistance with issues outside of asthma may have encouraged families to contact CESs for *any* problems they may be experiencing, simply because they had no where else to turn. Although the focus of the intervention was on asthma, congruent with other studies, CESs sometimes had to suspend conversations about asthma to address issues that were more pressing for families at that moment (Fisher, et al., 2009; Friedman, et al., 2006; Krieger, et al., 2011). Friedman and colleagues (2006) estimated that CHWs in affiliated Allies Against Asthma programs spent 25 percent of their time addressing issues outside of asthma. However, being privy to families' personal information and being looked upon as a friend of the family may have compelled CESs to offer assistance from their own pockets or make themselves available to families outside of formal study-related activities. Although these gestures likely had a positive impact on retention and fidelity of the intervention, the replicability of the intervention may be the ultimate compromise.

LIMITATIONS

Although access to the detailed documentation of asthma outreach workers provides a snapshot into the lives of families of children with asthma over a two-year period, some important limitations in the data source and method of data collection deserve mention. First, the timeline of the intervention precluded CESs from making visits at regular intervals for all families. In order to complete nine visits in the first year and three in the second, some CESs had to schedule home visits in shorter intervals, thus, perhaps not capturing the long-term impact of some life stressors. Furthermore, some families

required (or requested) more home visits and support than others. The CES documentation, therefore, may actually under represent some of the issues that families who had less visits experienced. Second, the quality and completeness of the documentation may also have been influenced by the pace with which CESs conducted their home visits and other contacts. With the need to schedule multiple families on the same day, information from these contacts may have been mis-documented or not documented at all, especially for CESs with heavier caseloads. Third, although the CESs had standard visit protocols and contact forms, only general guidelines were provided on how their comments and observations should be noted. As a result, the length and detail of documentation varied by CES. Some CESs focused more on documenting asthma-related activities and problems, which may have included “pet” topics that were discussed more frequently and more in-depth, while others included details of life stressors outside of asthma. However, the presence of a checklist for asthma education and supplies on each form may actually have encouraged CESs to document and expand on activities outside of asthma that could not be checked on the form. Fourth, how forthcoming some families were about their personal problems may have varied by CES, given the CESs’ individual characteristics and personalities. Some CESs may have been more skilled at putting families at ease or connecting with families. Thus, the documentation may not have adequately captured each family’s stressor experience wholly, perhaps underestimating the impact of certain stressors on families of children with asthma. Yet, sharing the same culture and being from the same communities in which they worked, CESs may have been better able to build rapport and trust with families over time. And, lastly, unlike traditional measures of stress, the CES documentation is limited in its ability to speak to the breadth and severity of life stressors experienced by families. Yet, what the data source does offer is a more comprehensive and intricate view of families’ experiences with life stressors over time, and ways to successfully intervene to improve these conditions for families.

IMPLICATIONS FOR RESEARCH

Families of children with asthma in low-income communities, particularly those from diverse racial/ethnic backgrounds, face immense challenges in managing asthma and

other stressors in their lives. In order to get families thinking about asthma, it is often necessary to address other needs that may take the forefront, such as making sure families have access to basic needs and amenities. At the very least, asthma programs working with low-income populations should provide community resource lists that are comprehensive, detailed, and current, using the knowledge of CHWs and others in the community. Although a lot of time and effort may be required to connect families with needed resources, not being equipped to respond to expressed concerns could jeopardize trust and ultimately render the intervention less effective (or ineffective). Arming families with the knowledge and skills to function independently can benefit families long after the completion of the intervention study.

Interventions should recognize and be flexible and accommodating of changes in living arrangements and diverse family structures. By not acknowledging the potential for instability in low-income populations, studies are in essence not generalizable. With frequent relocation and the propensity for families to live in multi-generational households—and the prolonged nature of some of these arrangements—interventions should consider portability and other nuisance factors (e.g., noise, size) of equipment and supplies, simplicity and cost effectiveness in more permanent features of the intervention (e.g., weatherization, removal of carpet), and teaching families how to manage and control asthma in these changing environments. Not only might fewer families be lost to follow-up or ineligible, but the investment in recruitment and retention of families, not to mention asthma-related equipment and supplies, would not be wasted. Researchers should explore the unique issues facing grandparent caregivers, especially those who might be caring for other children (or adults) in addition to the child with asthma. For example, grandparents may need assistance with applying for aid for children under their care, learning how to manage different health issues in the family, not just asthma, and prioritizing their own health amidst other stressors that may be overwhelming the family.

Although this study identifies some of the important life stressors that may compete with asthma-related priorities, the current study cannot delineate the life stressors most strongly associated with poor caregiver and child health and quality of life outcomes.

Including measures of life stressors, which have generally been absent from asthma intervention studies, may assist in the identification of common stressors and their perceived severity and provide areas to target in intervention research. Additionally, the impact of life stressors on vulnerable subgroups, such as grandparent caregivers, should be explored further. By incorporating this information, asthma programs may be more effective in helping families of children with asthma from low-income communities of color to alleviate or overcome issues in their lives that prove stressful, while simultaneously improving long-term asthma (and other) health and quality of life outcomes.

IMPLICATIONS FOR PRACTICE

Childhood asthma intervention researchers have recognized the value and utility of CHWs in improving child and caregiver health and quality of life outcomes, yet relatively unexplored are the specific strategies implemented by CHWs to achieve these outcomes. The role of CHWs in home-based intervention research with families of children with asthma has primarily been to provide asthma education and supplies, conduct surveys or other data collection activities, and provide asthma-related or other referrals. However, to date, no studies have examined how and to what degree CHWs have adhered to the fidelity of these prescribed activities. The success of interventions may be contingent upon supplying more than just a contact number. Intervention programs should more clearly outline what strategies were undertaken by CHWs and evaluate the success of these efforts in both implementation and follow through by the family and CHW alike. Not being able to fully describe the specific activities undertaken by CHWs, especially those associated with the achievement of successful health and quality of life outcomes, leaves little in the way of being able to establish best practices for workers in the field.

Chapter 3

A Multi-Site Examination of Characteristics of and Strategies Used by Community Health Workers to Address Life Stressors Experienced by Families of Children with Asthma in Low-income Communities of Color

ABSTRACT

Objectives: Community health workers (CHWs) have been instrumental in helping families to cope with the environmental, social, and psychosocial factors that may contribute to asthma exacerbation or hamper efforts to manage and control asthma. Yet, the stressors facing families and specific ways in which CHWs can intervene to assist families have not been well delineated. Drawing from the experiences of CHWs working with families of children with asthma from multiple geographic regions in the United States, this study identified and explored the stressors present in low-income communities of color and strategies utilized by workers to assist families with these stressors.

Methods: A total of 13 CHWs involved in household asthma interventions participated in this study. The sample included CHWs from four geographically distinct asthma programs in the United States serving urban, low-income, racially and ethnically diverse populations. Through qualitative semi-structured in-depth interviews, CHWs were asked to describe common life stressors experienced by families of children with asthma—whether related to asthma or not—and strategies they have used to assist families in achieving “successful” outcomes for resolving or alleviating their life stressors. While the focus of this inquiry is on CHW strategies, a brief overview of life stressors is provided for appropriate context.

Results: The stressors experienced by families of children with asthma included both asthma-related and other more general life stressors. With regards to asthma, CHWs

detailed families' difficulties with repeat episodes of asthma exacerbation and adverse environmental conditions that required remediation in the home. Some of the contributing factors included families' difficulties with maintaining asthma medication and up-to-date equipment, and affording co-pays for adequate asthma health maintenance. Difficulties communicating around asthma, whether to health professionals or other family members in the home, was also noted, along with disruptions or limitations placed on family members' usual activities as a result of asthma, such as older siblings who may have to assume care responsibilities when a younger sibling with asthma is sick. To counter these stressors, CHWs engaged families in asthma education, assessed, demonstrated, and assisted families with asthma-related activities, and gave families the confidence and skills to better manage asthma.

CHWs relayed families' difficulties with affording basic needs and amenities such as food, utilities, transportation, and decent housing, which was often exacerbated by the "here today, gone tomorrow" nature of assistive resources and services. Prioritizing the family's health-related concerns was also complicated in an environment of limited resources, with caregivers sometimes setting aside their own health needs to care for others. CHWs highlighted the impact of these and other stressors on custodial grandparents, because of the additional responsibility and monetary expense of taking care of a young child. Some CHWs also spoke of the issues impacting another important subgroup of the population, those with illegal immigration status. Their ineligibility for many forms of assistance and more limited English proficiency hampered their ability to communicate and bring stressors to resolution. Problems with familial and other relationships, and children's academic and behavioral issues were also described. In order to begin to address these broad stressors, offers of assistance from CHWs necessitated establishing trust and building rapport with families. CHWs described the importance of strategies and characteristics such as showing care and compassion, exhibiting good listening skills, and being respectful of the circumstances facing families. Many CHWs exhibited a strong dedication to families, and assisted by connecting families to needed information and resources, sometimes by intervening on their behalf.

Yet, some CHWs also recognized the importance of moving families towards independence, given their finite amount of time with families.

Implications: This study contributes a better understanding of the larger environmental, social, and psychosocial life stressors impacting families of children with asthma from low-income communities of color. It also includes recommendations and best practices for mitigating these stressors from CHWs who work (or have worked) with asthma programs from different geographic regions in the United States. The experiences of these CHWs, though focused on asthma, could help to inform the standardization of CHW training and competencies, not only for asthma but also for other chronic health conditions.

INTRODUCTION

Childhood asthma has risen steadily over the past three decades and, although currently stable, asthma rates remain at high levels. Not surprisingly, trends for asthma-associated ambulatory visits, hospitalizations, and emergency department visits also show no sign of decline (Akinbami, 2006). Especially worrisome is the continued disproportionate impact of childhood asthma on urban populations who are low-income and/or of racial/ethnic minority status, particularly non-Hispanic blacks and Puerto Ricans (Akinbami, 2006; Bloom, et al., 2009; Moorman, et al., 2007). Children with asthma who live in low-income urban areas are at greater risk for asthma exacerbation based on their increased exposure to adverse environmental conditions (Bryant-Stephens, 2009; Eggleston, 2007; Gold & Wright, 2005; Weiss, et al., 1992; Wright & Subramanian, 2007). Among these conditions are indoor triggers such as cockroaches and mold, associated with dilapidated, older housing (Bryant-Stephens, 2009; Sandel & Wright, 2006), and poor air quality (Eggleston, 2007; O'Neill, et al., 2003). In addition to physical and environmental triggers of asthma, many researchers have recognized the contribution of psychosocial stressors to poor asthma-related outcomes, including crime and community violence, (Bryant-Stephens, 2009; Gold & Wright, 2005; D. R. Williams, et al., 2009; Wright, et al., 2004), segregation and discrimination (D. R. Williams, et al.,

2009), and neighborhood disadvantage (Gold & Wright, 2005; Koinis Mitchell & Murdock, 2005).

These “psychosocial-environmental conditions conducive to stress” (Israel & Schurman, 1990, p. 195) (or life stressors) may present formidable challenges to families of children with asthma, particularly in urban, low-income communities of color. Elevated reporting of undesirable events has been found in a large sample of racially, ethnically diverse children with asthma in inner-cities across the United States (Wade, et al., 1997).

Though this study did not include a reference group, researchers have shown that children with physician-diagnosed asthma reported more stressors than children without asthma (Shalowitz, et al., 2006). Increased morbidity related to asthma has also been positively associated with total (or negative) life stressors (Shalowitz, et al., 2001; Turyk, et al., 2008). Finally, a temporal relationship between stressful events and asthma exacerbation, with stressful events preceding episodes of asthma exacerbation, has been found for families of children with asthma (Marin, et al., 2009; Sandberg, et al., 2004; Sandberg, et al., 2000). Gaining a better understanding of the stressors that families have to weather and intervening to reduce these stressors could, therefore, have a positive impact on the health and quality of life of children with asthma and their caregivers.

In the face of rising health care costs and provider shortages in underserved communities, interventions utilizing community health workers (CHWs) have proven valuable for reaching members of these populations (Rosenthal, et al., 1998; Smedley, Stith, & Nelson, 2003; U.S. Department of Health and Human Services, 2007). Oftentimes, as members of the same community and racial/ethnic group, CHWs are in a unique position to assist individuals and groups in communities that have traditionally not had access to quality health care (Eng, et al., 1997; Eng & Parker, 2002; Giblin, 1989; Lehmann & Sanders, 2007; Rosenthal, et al., 1998; Witmer, et al., 1995). CHWs have gained recognition in bridging the gap between members of these communities and health care services (Smedley, et al., 2003; U.S. Department of Health and Human Services, 2007; Witmer, et al., 1995).

For childhood asthma, interventions utilizing CHWs have demonstrated improvements in health and quality of life outcomes such as child asthma symptoms (Bryant-Stephens & Li, 2008; Eggleston, et al., 2005; Fox, et al., 2007; Parker, et al., 2008; Thyne, Rising, Legion, & Love, 2006), child asthma-related hospitalizations (Bryant-Stephens & Li, 2008; Fisher, et al., 2009; Krieger, et al., 2005; Lin, et al., 2004; Parker, et al., 2008; Primomo, et al., 2006), caregiver depressive symptoms (Parker, et al., 2008), caregiver asthma-related quality of life (Clougherty, Kubzansky, Spengler, & Levy, 2009; Krieger, et al., 2005; Primomo, et al., 2006), and asthma trigger reduction in the home (e.g., cockroaches, dust mites) (Bryant-Stephens & Li, 2008; Eggleston, et al., 2005; Krieger, et al., 2005; Lin, et al., 2004; Martin, et al., 2006; Parker, et al., 2008; Primomo, et al., 2006; Takaro, Krieger, & Song, 2004; S. G. Williams, et al., 2006). Common activities prescribed to CHWs who conduct home visits with families of children with asthma have included providing asthma education, delivering and demonstrating the use of asthma-related equipment and supplies, reviewing the results of asthma-related testing (conducted as a part of the study), coordinating or performing activities around asthma trigger reduction, collecting data through home assessments or interviews, and making referrals to needed resources or services (Bryant-Stephens & Li, 2008; Krieger, et al., 2005; Parker, et al., 2008; Postma, et al., 2011; Primomo, et al., 2006; Thyne, et al., 2006; S. G. Williams, et al., 2006).

Some authors have indicated that in order to even begin to address asthma, CHWs often needed to help with issues outside of asthma first (Friedman, et al., 2006; Krieger, et al., 2011). To date, assessments of the experiences of CHWs working in asthma have been rare and have yielded little in the way of the strategies and characteristics of CHWs that help to support families through the broad stressors they may experience. Strategies mentioned include offering assistance and support by making referrals to appropriate resources or services (not limited to asthma) (Krieger, et al., 2005; Parker, et al., 2008; Postma, et al., 2011), accompanying participants to clinic appointments (Friedman, et al., 2006), and having a flexible schedule and being available between scheduled visits (Brown, Hennings, Caress, & Partridge, 2007; Friedman, et al., 2006; Krieger, et al., 2011). Additional strategies identified from written logs documenting the content and

logistics of CHWs' telephone and face-to-face contacts with patients with diabetes included instilling confidence in families and offers of tangible assistance through helping with transportation and completion of forms. The most common type of assistance logged by CHWs, however, was encouragement and motivation, which occurred during approximately three quarters of contacts with patients (Davis, O'Toole, Brownson, Llanos, & Fisher, 2007). In addition to strategies, a national study identified qualities or characteristics of community health advisors (or CHWs) that support and strengthen their role, including being empathetic, persistent, resourceful, and respectful (Rosenthal, et al., 1998).

While CHWs have proven effective in asthma management and control programs, the interactions between CHWs and families of children with asthma, and thus, how and why they are effective, have not been studied. The roles and responsibilities of CHWs have often been described with brevity and little is known about how workers adhered to and implemented asthma protocols and consequent training needs (Viswanathan, et al., 2009). Given their acceptance in the community, in intervention studies, and their knowledge of factors affecting families in underserved communities and resources available to assist, CHWs may provide an intimate and comprehensive view of how to intervene and engage families of children with asthma to reduce the impact of stressors in their lives. Yet, in order to even begin to look at the role and activities of CHWs in the area of asthma, it is necessary to first understand the circumstances facing families of children with asthma above and beyond the disease itself. Through semi-structured in-depth interviews with CHWs representing asthma programs in diverse geographic regions in the United States, this study seeks to:

1. Identify common life stressors experienced by families of children with asthma living in low-income communities of color, whether related to asthma or not, as perceived by CHWs who conducted home visits with these families; and,
2. Identify and explore effective characteristics of and strategies used by CHWs to resolve or alleviate life stressors experienced by families of children with asthma.

METHODS

Sample

Using a qualitative methodology, semi-structured in-depth interviews were conducted with a convenience sample of 13 CHWs from asthma home visiting programs. The majority of programs were identified based on a review of the literature, but one program approached the principal investigator to inquire about inclusion in the study. Contact with CHWs was initiated only if the site's director or primary contact was open to participating. In order to be included, sites had to employ outreach workers who: (i) were lay individuals with at least a high school education who were members of the communities in which they worked; (ii) worked in low-income communities of color in the U.S.; (iii) implemented asthma home-based "interventions" with families of children with asthma, including providing asthma education, asthma-related supplies/services, and general and asthma-related advocacy, support, and counseling; and (iv) conducted repeat home visits to the same families over the period of at least 12 months or conducted repeat home visits to families in a rolling, on-going effort. Sites where CHWs conducted home visits in partnership with certified health professionals, such as nurses, were not eligible for inclusion. Participating sites represented diverse geographic regions in the United States including the West, Midwest, Southeast, and Northeast.

Procedures

The study protocol, interview guide, and informed consent document were approved by the Institutional Review Board at the University of Michigan. The directors of eligible sites were contacted via phone and/or email to introduce the study and request their participation. The recruitment flyer, informed consent, interview guide, and demographic questionnaire were available upon request to these directors. Sites that were interested in participating designated a staff member to assist with the initial contact of CHWs. Only CHWs who had worked with (or were currently working) with families of children with asthma, and had been working in this capacity for at least one year, were provided with a study flyer and invited to participate. CHWs were told to expect an introductory email and a follow-up phone call from a member of the research team at the University of

Michigan to discuss the details of the study and to answer any questions. The follow-up activities occurred within 1-2 weeks of the initial contact. During the phone call, the purpose of the study and expectations were explained. CHWs who were interested in participating were asked for their availability during a pre-determined time period so that all of the interviews from a single site could be scheduled during the same 1-3 day period, since interviews were to be conducted on-site. A formal date, time, and location for the interview was determined during a subsequent call, with details reiterated via email. Approximately 3-4 days before the scheduled interview, a reminder email was sent to each participant. Each site's contact person was also asked to gather any materials providing more detail about their asthma program or CHWs (e.g., training manual) for review at the time of the site visit.

One-on-one interviews were conducted in-person, on-site at a location convenient and comfortable for the participant. Two copies of the informed consent document were available so that participants could follow along while the interviewer read the document aloud. Participants were asked if they had any questions or concerns before signing the consent form. The consent document indicated the expected time commitment for the interview was 1 to 1.5 hours and requested permission for digital recording and transcription. CHWs were informed that every precaution would be taken to keep confidential any information that might identify them, their affiliates, or the families with whom they work(ed). During the interview, participants were encouraged to ask clarification questions and to indicate when statements should be "off the record". Participants maintained the right to decline to answer any questions or end the interview at any time. Upon completion of the interview, a short demographic questionnaire was self-administered by the participant. A \$45 cash incentive was offered in appreciation of the participant's time and effort. Within one week of completing the interview, all sites received a thank you email. The email indicated that a summary of the findings would be available in written format at a future date.

Interviews

For the qualitative in-depth interview, an interview guide was developed by the principal investigator, reviewed by the research team, and shared with the director and/or contact person at each participating site upon request. The approximate time per interview was 1 to 1.5 hours. Substantive areas included in the interview guide were: (i) background and role of CHWs, specific to their work with families of children with asthma; (ii) life stressors faced by families of children with asthma; (iii) an assessment of the impact of life stressors on asthma care and management, health, and quality of life; and (iv) strategies CHWs used to help families to resolve and alleviate life stressors. (See Appendix B for a copy of the interview guide.)

A basic demographic questionnaire was self-administered upon completion of the in-depth interview. In addition to age, gender, race/ethnicity, and education, CHWs were asked to indicate what type(s) of organizations they had worked for (e.g., health department, community-based organization, university) and topical areas of their work (e.g., HIV/AIDS, maternal-child health). (See Appendix C for a copy of the demographic questionnaire.)

In addition to the interviews, the principal investigator reviewed relevant documents such as CHW training manuals, detailed descriptions of intervention or asthma programs, and educational materials provided to program participants to provide contextual information for each site. This document review was not formally coded but instead was used by the investigator to inform herself of the details and context of the various CHW programs.

Data Analysis

Data for this study was analyzed as follows. For the qualitative in-depth interview data, digitally recorded interviews were transcribed verbatim and any information that might identify participants or their sites was subsequently removed from the transcripts.

Transcripts were reviewed for accuracy with the digital recording and supplemented with notes taken during the scheduled interviews. *In vivo* codes were assigned through a line-by-line review of each transcript, with the resulting codes further organized into focused

code categories. This inductive process involved constant comparison of coding categories to ensure that they were clear and distinct (Patton, 2002; Strauss & Corbin, 1998). Thematic areas that emerged from this process were reviewed and refined by a three-member research team with qualitative expertise. The team met to discuss their findings and any discrepancies in themes were discussed until the group achieved consensus on the themes. (An example of how the interview data was coded qualitatively is shown in Table 3.1.)

Table 3.1. Example of qualitative data analysis demonstrating development of focused code categories linking *in-vivo* codes to excerpts from interview transcripts.

Focused Code Category	<i>In-vivo</i> Code	Excerpt from Interview^a
Showing care, compassion, and understanding	Trying to be understanding and putting myself in their shoes	[I: So, as a community health worker, what have you done to overcome some of these challenges that you've mentioned?] R: Um, what have I done? Just being patient. (laughs) Being very understanding of people, why it's happened to them, uh, why they feel that way, um, put me-- myself into their shoes. (R1, Site A)
	Showing you care is important	[I: And then we talked about some of the challenges that you face, but what would you say is the most challenging about your work?] R: So, for me, if somebody's depressed, I'm not gonna sit on my hind, you know, legs and just say-- it's true she has to do the work and you have to help motivate her to do the work. So, not doing the work for her is very important. I do, I am very clear on that. But sometimes showing you care and then showing them that they can do that is just as important. (R2, Site B)

I, Interviewer
R, Respondent

^aText from interviews may also be found under different *in-vivo* codes or focused code categories

Data from the demographic questionnaire was summarized using descriptive statistics. For the presentation of the data, whenever possible, quotations exist in their unaltered format. However, in cases where the participant or site's confidentiality may be violated if presented in its original format, the language has been edited accordingly. The edits in no way alter the meaning or content of what was said or intended by the CHWs who were interviewed. At a future date, the results from this study will be shared in written format with participating sites and CHWs to validate the findings and synthesize their implications for practice.

RESULTS

Sample Characteristics

All thirteen of the CHWs interviewed were female. The sample was evenly distributed among three age categories, with one-third of CHWs in each of the following age groups: 31-40 years, 41-50 years, and 51 years and older. Three primary racial ethnic groups were identified by study participants. Five CHWs self-identified as Hispanic, seven as African American, and one as Asian. All of the CHWs indicated having at least one year of college. Approximately 30 percent (4/13) had four or more years of college. While none of the CHWs had asthma themselves, eight CHWs cared for a child with asthma and five cared for someone else with asthma. Five CHWs did not have asthma themselves or care for someone with asthma.

On average, participants reported 9.19 years of experience as a CHW, although the range of experience was 2 to 30 years. When asked specifically about the length of time as a CHW in asthma, the mean was approximately 7 years (ranging from 1.5 to 13.5 years). For the majority of participants (11/13), the site with which they were affiliated was their first experience as a CHW working in the area of asthma.

Site and Asthma Program Characteristics

To protect the identities of CHWs participating in this study, site affiliations are described in broad strokes. Sites with asthma programs represented regions in the West, Midwest, Southeast, and Northeast United States. Table 3.2 lists the site affiliations of

the CHWs interviewed. Three of the four sites administered an asthma program that enrolled families for a period of 12 to 24 months, with multiple visits, while one site had rolling, ongoing recruitment and generally conducted one home visit per family, though some families received more than one visit when necessary. CHWs described working with both boys and girls with asthma under the age of 18, and as young as infants at one site. CHWs noted that adult caregivers were mostly female, ranging in age from young parents to grandparents. The racial/ethnic make-up of families varied across sites. Although families were mostly African American and/or Hispanic, at two sites Vietnamese families were also involved in their programs. CHWs indicated that families were primarily of low-income. Family size and structure also varied at each site. While some CHWs indicated a caseload of mostly married couples or partners, other workers within the same site described visiting mostly single parent (and female-headed) households, perhaps reflecting the differences in the composition of their individual caseloads. Furthermore, average household size per site ranged from an average total family size of 2 to 5 members to as many as 9 to 13 family members living in the same home. The CHWs at all sites, however, described different sets of family members and/or friends living together in the same home.

Table 3.2. Affiliation of participating sites and number of community health workers (CHWs) interviewed at each site (N=13).

Site	Site Affiliation	# of CHWs
1	County Health Department	2
2	State Health Department	4
3	Non-profit	4
4	University	3

Briefly, CHWs performed similar functions across sites. In addition to delivering asthma-related education and supplies, CHWs conducted assessments of the home environment. At some sites CHWs also provided non-asthma related supplies (e.g., smoke detectors) or conducted testing themselves (e.g., lead). Likewise, the CHW's role often extended beyond asthma to address families' needs more broadly, usually by connecting families with other information and resources.

Emergent Themes/Codes

BROAD AND ASTHMA-RELATED LIFE STRESSORS EXPERIENCED BY FAMILIES OF CHILDREN WITH ASTHMA

To provide context for the discussion of strategies utilized by CHWs while working with families of children with asthma, Table 3.3 presents the array of life stressors experienced by families, which includes asthma-related stressors as well as life stressors more broadly. In the paragraphs that follow, selected descriptions of these stressors are highlighted. Care was taken to try to ensure that the included quotations and examples are fairly evenly distributed across participating sites and CHWs.

Table 3.3. Broad and asthma-related life stressors experienced by families of children with asthma living in low-income communities of color, as reported by community health workers.

Broad Life Stressors

- Not being able to afford basic needs and amenities
- Trouble obtaining or maintaining health insurance
- Presence and impact of diverse physical or mental health issues or disabilities of caregiver and other family members
- Problems related to work
- Not being proficient in spoken or written English
- Illegal immigration status
- Inadequate living conditions and housing instability
- Relationship problems and troubles communicating with one another
- Children not doing well academically or behaviorally
- Legal problems
- Concerns about personal safety and neighborhood of residence
- Difficulties obtaining and maintaining assistance/resources

Asthma-related Life Stressors

- Exacerbation of asthma
- Exposure to asthma triggers in and around the home
- Trouble maintaining asthma medication regimens or equipment
- Trouble maintaining regular health maintenance or seeking emergent care for asthma
- Difficulties advocating or communicating around asthma and asthma trigger reduction
- Disruptions or limitations placed on the family's usual activities because of issues around asthma control and management

Lacking basic needs and amenities and poor living conditions were common stressors mentioned by CHWs in this study. Among some of the most challenging stressors facing

families was not having enough money for food, utilities, health insurance, and transportation. For many families it was “figuring out where they’re gonna come up with the money every month to pay their [bills].” The issues faced by custodial grandparents in providing for the child with asthma deserve mention, given that many CHWs worked with caregivers who were grandparents:

“Okay, I (grandmother) was just taking care of me first. And now, here I got four kids dropped in my lap that I love and I care deeply about.’ If love paid the bills, it wouldn’t be no problem, but you don’t have the money or the resources or nor the places to go to. Because if you find them a place to go to take care of the housing, it’s got to be registered with the city, your taxes got to be paid, can’t be a water bill... You’re talking about a \$1,000 or whatever I need just to get things paid up to start this process.”

Limited monetary resources and inadequate insurance also made it difficult for families to maintain asthma medications and to update asthma-related equipment. Children in active distress from asthma were sometimes taken to emergent appointments “to get an inhaler, just to get the [asthma] medication in them. Additionally, needing to come up with the money for an office visit co-pay deterred families from regular health maintenance. “So, they don’t even make their next child’s appointment for asthma because they know that they’re supposed to come in with \$20 or \$40 that they don’t have.” Pursuing scheduled or unscheduled health care visits was further complicated by not being able to afford to miss work and not having access to transportation. “I can’t imagine five or six children going into a cab, going to the ER (emergency room) with one child.” To compound the situation, many families were exposed to triggers of asthma, including dust, mold and mildew, and pests, via dilapidated housing. With landlords who were unresponsive to repair requests and limited options for decent housing, CHWs stated that many of their families either could not afford to move or had to move in with other family members. As a result of these extended family or multi-generational households, CHWs fielded concerns about advocating for the child with asthma when living in someone else’s home, as well as troubles policing the activities of other family members living in their own home (e.g., no smoking inside).

Many families were contending with other physical and mental health issues in addition to the child's asthma. CHWs spoke about caregivers who had assumed caretaking responsibilities for another family member who was elderly or had other health problems, or for more than one child with diverse medical needs. On top of caring for other family members, many caregivers had physical or mental health issues themselves. In an environment of limited resources, CHWs recalled situations where families were not able to focus on preventive care. Instead, the focus shifted to the health issue that was most pressing at that moment in time.

“And if you're a diabetic and you have to have insulin every day, and you have a child with asthma that you feel like as long as they're not aflare, you're gonna be more concerned with getting that diabetic medication.”

In some cases, caregivers felt so obliged to care for everybody else that they set aside their own health needs. According to a number of CHWs, this was a detriment to the child with asthma because if caregivers were not at their “optimal best”, they could not adequately address the needs of their children. Older children also played a role in caregiving for younger children, including the child with asthma, due to exorbitant childcare costs and the work obligations of adult caregivers, sometimes missing school as a result. Consequently, CHWs stated that some of these children “didn't even know how to be a child”.

The CHWs in several regions mentioned difficulties with illegal immigration status, particularly in the West. In addition to limited economic opportunities, not having legal status made families ineligible for certain types of assistance. For example, one CHW explained that children usually have access to some kind of medical insurance, regardless of their immigration status, but that it's much harder for adults without legal status to get insurance and, thus, adequate health care. CHWs also talked about some of the factors that deterred families from advocating for themselves. Among these were fears around deportation and eviction if they complained to landlords about poor housing conditions.

“I had one family, mold and mildew. I went in there, me and the translator went to this visit in [name of area of city], and got into the home. We sat down, trying

to do the visit. The house had just flooded... They had ripped all the carpet out. But the-- I guess it had seeped within the walls. And me and the translator got sick... I could not catch my breath. My eyes started watering. My nose just.... I mean, I had never experienced that... The next step is code enforcement. We can recommend it, but if the parent doesn't call, the code enforcement won't come out. She was a[n] illegal... couldn't call because she knew she was illegal. And if she got thrown out of that apartment, she had nowhere to go."

Though some families were “waiting on hope” that their immigration status would change, the reality was that deportation could happen at any time. And, “when a deportation like that happens... if mom really or dad really goes... who’s the next leader?” Who will take charge of the child’s asthma?

Advocacy efforts were also hampered by lack of proficiency in spoken and written English. Families encountered problems communicating with and/or deciphering written correspondence from schools, clinics, and agency or organization representatives. Specific to asthma, CHWs described that families did not feel understood by their doctors and did not know how to bring up questions because of language barriers, which had an eventual impact on medication use and adherence. However, poor doctor-patient communication was not limited to the non-English speaking. Many families shared with CHWs their difficulties in understanding what was discussed during the office visit or knowing that they had a right to ask questions of their provider.

Resources and services to assist families were often limited within the communities. One CHW found the situation in her community to be laughable, “There’s not any resources that we could provide that are actually out there. Like, anything that we would want to supply [families] with, it’s not there.” Many CHWs blamed the economy for the cutbacks in resources and services, with the caveat that they are “kind of here today, gone tomorrow” and “you never know how long they’re going to last”. Several CHWs also mentioned that families were being cut-off from benefits such as Medicaid. However, even in the presence of available assistance, the CHWs at several sites stated that some families just did not know where to go get the help they needed. In addition, the time required to obtain assistance was clearly a challenge for some families because of all the

“red tape to [get] to the resources”. On the one hand, there was sometimes “a little bit other than what meets the eye, that they don’t say until you go and try to get the help. Then it’s not for you, it’s for somebody else.” At the same time, repeated efforts to obtain assistance were sometimes met with failure time and again:

“... you go to the free clinic, you got to be there at 6:00[am], and they only take so many people a day. And you got to start the whole process over again the next morning just to try to see the doctor.”

Access to transportation further complicated some families’ efforts to follow through on referral information.

EFFECTIVE CHARACTERISTICS OF AND STRATEGIES USED BY COMMUNITY HEALTH WORKERS TO ASSIST FAMILIES OF CHILDREN WITH ASTHMA WITH LIFE STRESSORS

Even with the cumulative array of life stressors facing families of children with asthma, CHWs were able to implement strategies to help families to alleviate and sometimes overcome their stressors. Table 3.4 lists some of the effective characteristics of and strategies utilized by CHWs to assist families in low-income, racially and ethnically diverse communities. Again, the quotations selected for inclusion are fairly evenly distributed across sites and CHWs.

PERSONAL CHARACTERISTICS AND BROAD STRATEGIES

Establishing trust and building rapport with families

Showing care, compassion, and understanding, and being a good listener. CHWs were empathetic and “very understanding of people, why it’s happened to them, why they feel that way... put myself into their shoes.” By showing families care and compassion, CHWs found that families would open up to them. The act of visiting the home itself let families know that somebody cares. At least one CHW from each site also noted the importance of calling or stopping by to see how families were doing or to follow-up on asthma or other concerns that might have been touched on in previous home visits. Engaging families in this way also aided retention efforts by allowing CHWs to assess if phone numbers or addresses had changed.

Table 3.4. Effective characteristics of and strategies utilized by community health workers to assist families of children with asthma living in low-income communities of color to overcome or alleviate their life stressors, as reported by community health workers.

Personal Characteristics and Broad Strategies

Establishing trust and building rapport with families

Showing care, compassion, and understanding, and being a good listener

Fostering friendships, being honest and truthful

Being respectful and not passing judgment

Exhibiting dedication and being prepared

Being accessible and available

Helping instill confidence in families

Giving families hope and letting them know they have rights

Encouraging and moving families towards independence

Ensuring families are connected to appropriate information/resources/services

Identifying and verifying resources and services available in the community,
and giving this referral information to families

Intervening on behalf of families or providing tangible assistance oneself

Following up on referrals to obtain needed assistance

Asthma-specific Strategies

Engaging families in asthma education and encouraging uptake of information

Normalizing asthma and asthma triggers

Assessing, demonstrating, and assisting with asthma-related activities

Giving families the confidence and skills to better manage asthma

Listening to families, regardless of whether the conversation was geared towards asthma, was a common among CHWs. Sometimes families just needed someone to vent to and wanted to be heard. Being a “stranger”, that is, somebody outside of the family, also helped for those who wanted to share things that were “private” and needed to know it would not get back to anyone else, particularly another family member. One CHW remarked on how much families appreciated her listening, “you’ll be surprised how much that helps someone.”

CHWs noted that to be a good listener and to show care and compassion at all times, often required patience on the part of the CHW. Noted one CHW:

“I have had home visits when I’m talking to a parent and she’s on the phone... And she says [over the phone], like, ‘Oh, no, I’m not doing anything. So, what’s going...?’ And then, she says [to me], ‘Oh, keep talking... I’m listening. I’m listening.’ And she’s talking to somebody (laughter) and I’m like. But, you know,

you have to have patience... So, you have to be persistent and, and be very patient..."

Fostering friendships, being honest and truthful. Regardless of how long the follow-up period for individual asthma programs, representatives from each site emphasized the importance of developing a relationship or, in some cases, a friendship with families. This made families feel comfortable to ask questions and share what was going on, and receptive to allowing CHWs to get them the help they needed. Some CHWs had become so accepted in the family that they were invited to “barbecues and baby showers and Sunday dinner”. A variety of strategies were undertaken to establish and nurture relationships with families. First, it was sometimes necessary for CHWs to establish the legitimacy of their affiliated program. The CHWs at two sites that recruited program participants through referrals from their doctors or clinics were able to reassure families that “they (doctors) would not give us (asthma program) referrals if they didn’t know us.” One CHW capitalized on her organization’s non-profit status to counter the general distrust of social service agencies, emphasizing that her organization was not affiliated with state programs. Second, CHWs tried to emphasize to families, “I’m just a regular person like them” by being very informal in their dress and demeanor. “I talk to them like they are a next-door neighbor, a friend.” Third, CHWs made a point to remember family members by name or “something specific about them” to try to build trust with families. Fourth, although the purpose of the home visits was for asthma control and management, CHWs spent time talking to families about their lives outside of asthma. This included conversations about “family stuff”, children’s events at school, and hobbies, to name a few. Lastly, CHWs reciprocated by sharing personal experiences and lessons learned from their own lives, whether it was comparing notes about what has worked for their children with regards to asthma or relating to some of the challenges of raising children themselves (e.g., “I don’t like picking up behind mine”).

CHWs emphasized the importance of being honest and telling the truth in their work. Although some workers had access to some kind of list or booklet of resources, they were realistic and upfront about what they could do to help. This included not making empty promises as well as admitting, when appropriate, “I don’t have all the answers, and I

can't solve all the problems, but I can check it out for you." And, if they do not know the answer or efforts to find the answer are unsuccessful, they are very honest: "If you don't know it, you don't know it. (laughs) Tell them right off the bat, 'Well, I can't help you with that, but what else is going on?' (laughs)." Lying to families was not an option for one CHW, and she expected the same courtesy from the families that she worked with:

"'Oh, now, you know this house is a mess.'" And they usually be like, '[Name of CHW], no.' Uh, 'Yes, it is. You really need to take out-- oh, what's going on?' Or, I look at the medication and be like, 'Oh, you've been taking it all fourteen days?... Oh my goodness, Miss [client's name], I know you're not... getting ready to lie to me.' She's like, '[Name of CHW], I'm saying maybe he (child) only took it seven days.' I was like, 'Now, that sounds a lot better... You don't have to lie to me.' They're like, 'Okay.'"

Another aspect important to establishing relationships with clients was the guarantee of privacy. CHWs were aware of the potential repercussions of sharing some types of information, e.g., caregiver's drug addiction, with others and clearly communicated how families' privacy would be respected, with regards to the content of their conversations.

Being respectful and not passing judgment. The majority of those interviewed mentioned the importance of being respectful and nonjudgmental towards families, because "being judgmental... immediately shuts the door". One of the ways in which CHWs accomplished this was by being upfront about the purpose of their home visit: "I'm not here to judge you on how you live, just to point out some of the things that may help manage the asthma." CHWs understood the circumstances that families were facing and spoke of the importance of being open-minded and non-offensive, particularly when observing the conditions within the home, their lifestyle. "I accept their situation for what it is." Several CHWs also explained that they were respectful of cultural norms. This included not being critical of the use of alternative therapies or home remedies for asthma, and in one case being amenable to meeting the head of a Hispanic household at a neutral location outside of the home prior to conducting any home visits.

Exhibiting dedication and being prepared. It was clear from the interviews that CHWs viewed their role as helping families to improve their situation and, in particular, their

child's asthma. More than a few CHWs indicated working a lot of overtime, and sometimes providing assistance on their own time, outside of regular work hours. Although many CHWs were accommodating of families' schedules by conducting visits on the weekends and during evening hours, one CHW did mention not wanting to make a practice of visiting families during odd hours "because nobody wants to work six, seven days a week". The dedication of some CHWs to their work was also evident from their attention to preparatory activities: "I review... I prepare... people don't trust you, if you don't know the answer". Being prepared for the visit was also a way in which one CHW gained self-confidence in her ability to help her families, by being able to respond to questions that may come up during the visit.

Being accessible and available. An important component of building trust was making sure that families knew that CHWs were available for assistance, even outside of regular business hours. Although cellular phones were not issued to CHWs in three of the four sites, they felt compelled to provide a way for families to contact them. "We're not supposed to give them our personal phone number, but I sometimes overstep that when I see I need to..." In part, CHWs' providing of their contact number(s) was also a strategy that aided retention efforts because some families would call their CHW if they had changed residences just to let them know.

Helping instill confidence in families

Giving families hope and letting them know they have rights. CHWs provided hope as a way to get some families through difficult times. As remarked by one respondent, getting the caregiver "on a level of feeling that there is hope for them... that she can take care of that family" trickles down to the child with asthma so that the child is "also able to have a better life". Furthermore, reminding families "that there's help out there" was a confidence booster, particularly when families were feeling overwhelmed. In some cases, CHWs informed families that they had a right to a service and could do something about their situation instead of sitting idle. For example, some families were told by their CHW, "If you're paying rent, you're entitled to live in a healthy home." Since the workers at one site started doing home visits at a particular apartment complex, the city's

housing compliance office noted taking an entire month at a time to help the complainants because “they’ve gotten so many reports now”.

Encouraging and moving families towards independence. The temporary nature of asthma programs encouraged the implementation of strategies to enable families to become self-sufficient, independent. CHWs were sometimes deliberate in how they offered assistance, “That is what we can do together... I don’t tell them, this is what I can do for you”. By utilizing a team approach, CHWs were able to show their support for families while letting families know that they, too, had a responsibility to action. In addition, at least one CHW from each site discussed the importance of imparting to families that they could complete tasks on their own, because “I’m not going to be there all the time”. One of the primary ways in which CHWs fostered independence was through linking families with needed services and assistance but leaving the follow through to families, which will be discussed in more detail in the paragraphs that follow. In some situations, CHWs were able to advise families on the steps needed to resolve issues of concern. Other times, they would encourage families to initiate conversations with individuals such as their doctor or landlord for resolution. Bringing caregivers together for a “family night” event at one site encouraged caregivers get to know each other so that they could help each other out:

“Because this parent might have a car; and this parent, she might have a car, but she don’t have money to get there. This parent might have the money. So, [parents] working together as a team.”

Ensuring families are connected to appropriate information/resources/services

Identifying and verifying resources and services available in the community, and

giving this referral information to families. A major role for CHWs was to connect families to a broad array of resources and services. In fact, helping families to resolve their stressors was often a way to gain entry or to stay in touch with families over time. “You might have a hard time getting into the home until they have an issue that came up and you help them with it. And, then you can get back in the house”. CHWs made referrals based on need, affordability, and geographic proximity. To facilitate these

linkages, each site utilized a list or booklet of resources and services in the community. However, with the “here today, gone tomorrow” nature of assistance from agencies and organizations, many CHWs indicated the need to verify contact information and availability. “So, if you don’t check it, if I just give them a number, it’s not valuable. And things change.” For some, it was “a job in itself” to stay current. In addition to having a tangible reference, many CHWs had intimate knowledge of the resources and services available in their communities, and sometimes in their own building or through an affiliate, and were very resourceful themselves. One CHW shared how she acquired this knowledge:

“As far as me, personally, myself, I’m always looking for resources, new things. I go to health fairs, and I go to meetings in the community and find out what’s going on. You know? And I get all that information. Like I said, if I know somebody who can benefit from it, I let them know.”

To personalize the process of obtaining assistance, some CHWs were able to create alliances with agencies and organizations, thus, linking families with a contact person so that “folks will be attended to, and it’s not just a number”. CHWs also referred families to networks of individuals whom they knew personally (e.g., people who were looking to hire workers), reputable volunteers services, and events going on in the community, whether related to asthma or not.

Intervening on behalf of families and providing tangible assistance oneself. Assistance from CHWs was not limited to identifying resources and services. CHWs made phone calls, obtained forms and other paperwork, faxed requests for information, and met in-person with agency and organization representatives to initiate and follow-up on needed assistance for families. When appropriate, calls were made with family members present so that questions could be readily answered and the behavior modeled, particularly when language barriers were experienced. One CHW explained:

“So, you have to make the call while you’re there to make sure it works... And then I show them how I do it. They listen to me doing it in English. If they (agency or organization representative) have questions, I say, ‘Okay, so this is

what I said.’ And I repeat to them what I said in Spanish... the families get confused because people are so fast with giving them information.”

Doing the calls together, and sometimes offering the use of their cellular phones, was strategic in some cases to make sure families did not put off seeking assistance. In addition to providing agency- and organization-level support, CHWs intervened in other ways to support families. Several workers from different sites mentioned speaking directly with landlords to resolve issues of concern to the family. While some CHWs exercised caution when talking to landlords, particularly when the landlord was aware of the family’s legal status, others demanded that adversities be rectified, reminding landlords “that there are laws”. To lend further support, CHWs accompanied caregivers to doctor’s appointments and other events, secured letters of support for asthma- and non-asthma related stressors, provided assistance with translation of oral and written correspondence, and helped caregivers to complete forms and other paperwork. Some CHWs also mentioned using the Internet to assist families. This included downloading needed forms, working alongside those with Internet access to get online assistance, or emailing helpful information to families. With the difficulties in securing needed resources and services, sometimes workers provided tangible support themselves. CHWs mentioned contributing money to help families to pay for basic needs or for bill pay, helping by taking food to families, providing transportation to help families get groceries or go to doctor’s appointments, and collecting items like winter clothing and furniture for distribution to needy families.

Following up on referrals to obtain needed assistance. Providing referrals did not complete the assistive process for many CHWs. Oftentimes, workers would follow-up with families on the status of efforts to obtain assistance and readdress issues of concern: “Have you gotten in contact with anybody?” “Did it help? Was it successful?” One CHW explained the benefit of checking in with families on their pursuit of assistance to correct misinformation or misinterpretations:

“... so, one family had heard that [referral agency] doesn’t have any utility resource program. Well, they do, and it is a permanent discount program. They just probably didn’t have funding in September. But they’re going to get new

funding in October. But they (caregiver) didn't know that. And the [agency representative] didn't tell them that or they told them and they didn't-- misunderstood that. So, getting really clear information to them is really important. And being able to check the information they have and not assume that what they have is accurate. So, always doing the back tracking."

Furthermore, following up with families on the status of assistance allowed CHWs to help families to address any concerns or grievances. The following describes how discourteous agency or organization representatives were handled:

"... I've had clients (caregivers) with referrals that we have made, [where the agency representative] wasn't so nice, and when they (caregiver) let me know, then I went up the chain of command, you know, to (knocking on table) their supervisors. Because when a person is in need, they don't need to be talked to, you know, any kind of way. They already experienced enough problem[s], so they need to be treated with respect. So, I have went down that road, and don't have a problem with going that road either... and have gotten results, too."

For families who were hesitant to seek assistance, CHWs provided motivation to help families to achieve the desired outcome. Sometimes this required helping the caregiver to see the impact of their stressors on the child with asthma. For one caregiver who had put off seeking mental health counseling, the CHW remarked, “Do you know that it will actually help you take care of your children if you take care of yourself?”

ASTHMA-SPECIFIC STRATEGIES

Engaging families in asthma education and encouraging uptake of information

While provision of information and education about asthma was a required component of all of the CHWs interviewed, they acknowledged the need to first ensure families were receptive to hearing the information on asthma. Among the strategies described by CHWs to encourage receptivity to asthma education was to make families feel comfortable and competent in the care of the child with asthma. One CHW told her families that “it’s impossible for us to know everything about asthma”, and simply asked them “to be open to the idea of learning”. Emphasizing that the child’s asthma can be controlled if they understand it better was another way to encourage uptake of asthma information. However, there was a fine line between reminding families what they

needed to do to improve their child's asthma and being "too pushy", and thus CHWs were reminded not to overwhelm families with education or do too much at the same time.

In addition to encouraging receptivity to asthma education, strategies were directed towards making sure families understood the information. Some CHWs were astute in their ability to get a feel for a person's comprehension by reading their body language, "You can kind of tell from their gestures or... their first initial reaction if they understand it or not". Noted another CHW, when engaging families "you cannot always use the same technique" to the same end, so "you have to learn how to talk to the person in order to be effective". A couple of CHWs mentioned adjusting their teaching strategies to be commensurate with the family's level of education and literacy, which entailed reviewing the materials distributed to families one-by-one and making sure the information was grasped. CHWs were accommodating of different learning styles and provided age-appropriate education through the use of visual aids, such as videos, flash cards, and diagrams.

To increase receptivity to the education and behavioral change messages, CHWs also emphasized the importance and benefits of asthma trigger reduction for the whole family. By adopting behavioral changes in support of the child with asthma, families were, in essence, creating a better, healthier home environment. Many CHWs spoke of the presence of other children or adults in the home with asthma. Thus, activities such as having a clean home and quitting smoking would not only help individuals with asthma but also be healthier for other family members. CHWs also emphasized how the caregiver him/herself could benefit from getting asthma under control: "... the changes that [caregivers] do is gonna impact their life. It's going to make their lives easier. It's gonna [be] less time, you know, wasted on the ER (emergency room) doctor's and everything." Some CHWs reinforced with families the "small steps" necessary to keep their children well to encourage behavior change. Furthermore, by getting a good management plan in place and learning to recognize symptoms before they worsen, families could get their child's asthma under control.

Normalizing asthma and asthma triggers

CHWs educated families about asthma and asthma triggers to help them to better control and manage the disease. One education strategy was to “normalize” asthma by assuring caregivers that having a child with asthma was no cause for shame. For some, this involved telling caregivers and their children with asthma that a lot of people have asthma and that they are not alone. This was a useful strategy for one CHW to counter families’ denials of asthma. CHWs also emphasized that families could live a “normal life” and overcome asthma, citing that there are athletes who have asthma and can still play football, dance, and run. In addition, the ubiquitous nature of asthma triggers such as dust in the home was pointed out to some families in hopes of discouraging clutter and dust accumulation: “I say, ‘Dust is something we can’t stop from coming in.’”

Assessing, demonstrating, and assisting with asthma-related activities

The CHWs at all participating sites were responsible for administering survey instruments with families and, hence, played a large role in assessment activities to address potential contributors to asthma exacerbation. In addition to the data that was collected, CHWs asked about the use (or misuse) of asthma medications and reasons for non-adherence, and then used that information to correct misinformation and help families to rectify issues of concern. An assessment of the equipment and technique used to deliver medication was also conducted, and any technical problems were addressed. CHWs also inquired about health maintenance visits for asthma, including whether families had a doctor or medical insurance, and tried to connect them with appropriate assistive resources so that the child had a “medical home”. In some instances, doctor’s appointments were scheduled with assistance or urging from CHWs. To help families to control and manage asthma, all of the asthma programs included provision with accompanying education of some equipment, supplies, and services, such as pillow and mattress covers, cleaning supplies, vacuum cleaners, peak flow meters and spacers, medication storage containers, and integrated pest management services and supplies. In addition to these services, equipment, and supplies, while in the family’s home, CHWs tried to bring attention to the environmental triggers creating an unhealthy environment

for the child with asthma: "... we would do a[n] eye-browse, which we would browse around the home to see what it was that we saw that would cause the possible asthma triggers." Several workers also assisted in reducing asthma triggers in the home themselves:

"... what I do also is I actually go in there, help vacuum the floor of the child's room. And, uh, straighten his room out to make it look really nice and clean and get rid of clutter in there, get it out."

Giving families the confidence and skills to better manage asthma

Of the asthma-specific strategies mentioned by CHWs, many involved giving families (including caregivers and the child with asthma) confidence and skills to better manage the child's asthma and encouraging advocacy activities. This skill-building consisted of the activities and strategies described previously. However, in addition to the activities targeted towards the caregiver, CHWs also sought to teach skills and instill confidence among other family members, including the child with asthma. Many CHWs noted that asthma education should be inclusive of children because "... they can flip the script... they can feel like they're taking charge of their health."

"The child needs to know that the medication, it's took at 7:00[am], then when they get to school and the school nurse call them, you know, and she don't come at 10:00[am] and, say-- or 8:00[am], 'It's time for your medication.' So, you know, just working with each other."

In addition to being aware of when medication should be taken, CHWs also encouraged children to let an adult know when their medication needs to be refilled.

"... I tell my kids, even my little first graders, if you feel like you got that canister, and you giving yourself that treatment, and you feel no medicine is in there, you need to go let mama know, 'Mama, I need more medicine.'"

CHWs also tried to provide children with ways to "have a little say-so in their health". For example, when it comes to smoking, children could be their own best advocates by engaging in activities such as actively avoidance of smoke, particularly when in another person's home, and sharing pamphlets about secondhand smoke with those who smoke in

the home. One CHW suggested that children should be versed in how to properly clean, not only to reduce triggers of asthma in the home, but to teach responsibility; after all, “you’re raising adults”. Education was inclusive of all persons involved in the care of the child with asthma, including other adult caregivers such as family members, older siblings, and daycare and school personnel. CHWs would sometimes deliver that education themselves either one-on-one or through group asthma trainings and workshops. Families were encouraged to provide a copy of the child’s asthma action plan to all individuals who care for the child so that everyone knows what to do in case of an asthma-related event.

In addition to these activities, CHWs sought to increase the skills and confidence of families in dealing with the health care system. They educated families on how to communicate within the healthcare system and advocate on behalf of the child with asthma. As stated previously, some families needed to know that they had the right to see a doctor even if they did not have the money for the office visit co-pay. Furthermore, the CHWs at a couple of sites stressed that it was okay to ask questions of the doctor. “Yeah, [caregivers] don’t ask because they just don’t think it’s important or they shouldn’t ask or they don’t have the right.” To keep track of asthma concerns, several CHWs suggested writing down whatever the problems and taking them to the doctor’s visit and keeping a diary of the child’s asthma symptoms. Furthermore, families were encouraged to share with doctors any other medications the child was taking, to ask about procedures such as allergy testing, and to determine what extracurricular activities were safe for the child with asthma. CHWs also suggested that caregivers discuss an asthma action plan with their child’s doctor so that everyone is aware of what to do, when appropriate.

CHWs also targeted individuals from the broader community for education on asthma control and management. For example, CHWs educated landlords on products they could use for integrated pest management, involved health personnel such as school nurses in asthma training sessions, and encouraged being proactive and sharing asthma information with employers so that they can better understand “what’s going on in your household”.

DISCUSSION

Interventions utilizing CHWs have had a positive impact on families of children with asthma in low-income communities and with persons of color. The participants for this study included CHWs who conducted asthma-related home visits in metropolitan cities across different geographic regions in the United States. Drawing from their diverse background and experiences, CHWs were asked to identify common life stressors faced by families they worked with as well as effective characteristics or strategies used to engage families and assist them in addressing these stressors, whether related to asthma or not. The results here detailed how CHWs effectively offered support and assistance to families to reduce adversities and improve asthma management and control.

CHWs are often from the same communities and share the same demographic profile as the populations with which they work (Eng, et al., 1997; Eng & Parker, 2002; Giblin, 1989; Lehmann & Sanders, 2007; Rosenthal, et al., 1998; Witmer, et al., 1995), but the contribution of personal attributes of CHWs is vital to their effectiveness (Rosenthal, et al., 1998; Zuvekas, Nolan, Tumaylle, & Griffin, 1999). In this study, characteristics such as compassion, warmth, open-mindedness, and dedication were cited by CHWs as helpful in building trust and establishing rapport with families, which have also been identified by others in studies of asthma (Friedman, et al., 2006; Krieger, et al., 2011) and more broadly (Rosenthal, et al., 1998; Zuvekas, et al., 1999). When implementing asthma programs with a home visiting component, the importance of personal characteristics should not be underestimated. Not only do CHWs have to gain entree to the home (and sometimes over an extended period of time), but, by the nature of asthma work, they also need to access and assess certain areas of the home. Therefore, CHWs who are accepting of families' circumstances and sincerely committed to helping them to reduce asthma-related and other stressors in their lives may, by virtue, aid retention of families and facilitate the desired behavior change. Postma et al. (2011) hypothesized that the high retention rate at one of their study sites may have been related to the empathy of that particular CHW because of having a child with asthma him/herself. If the effectiveness of asthma programs is, in part, contingent upon the personal attributes of the individuals

employed, then investing time and resources into the hiring and training of CHWs could aid in the success of future programs.

In addition to strong interpersonal skills, the CHWs interviewed for this study had a broad knowledge of the resources and services available in their communities. As demonstrated by others, in order to even begin to address asthma, it was sometimes necessary for CHWs to help with other stressors first (Friedman, et al., 2006; Krieger, et al., 2011). Therefore, CHWs needed to be equipped to respond appropriately to the diverse needs of families. If CHWs are not prepared to address stressors at the forefront of people's minds, they may have a hard time engaging families in asthma education. Furthermore, if they do not appear knowledgeable about the resources in their communities or do not provide resources that are appropriate to the family's circumstances, they might be perceived as being incompetent and undependable, which could jeopardize future opportunities to follow-up with the family. While resource lists and booklets can assist CHWs in providing referrals, the "here today, gone tomorrow" nature of resources in low-income communities emphasizes the need to be up-to-date on what is available right now. CHWs with more experience in the field are at an advantage because they may be better able to match families with resources and services because of the depth of their working knowledge. Furthermore, CHWs who are housed in buildings with programs serving similar populations or who have access to affiliated programs may have additional resources (and a contact name) to offer families.

CHWs were sensitive and responsive to families' needs. However, the circumstances surrounding the degree to which CHWs intervened to connect families to needed resources and services deserve further exploration. CHWs working in the area of asthma may prioritize helping families to initiate and follow through on asthma-related tasks, such as helping families to schedule health care appointments for the child with asthma or getting landlords to make needed repairs to reduce triggers of asthma in the home. Likewise, expediting the resolution of non-asthma related stressors may be a tactic to increase receptivity to program-related activities, such as asthma education. How much CHWs intervene may also be contingent upon the individual worker as well as his or her

assessment of how overwhelmed families are by their life stressors. Furthermore, certain subgroups of the populations, such as those with illegal immigration status or poor English proficiency, may require more commitment on the part of CHWs to initiate and follow-up on assistance. The array of activities that CHWs engaged in to connect families to needed assistance (e.g., making phone calls or in-person visits to organizations, accompanying family members to appointments, picking up forms, writing letters), speaks to the complexity of their role, one that has not been fully described in the literature. The descriptions provided by the CHWs of the extent to which they attempted to help families suggests the level of families' difficulties in navigating the system alone, particularly in the face of scarce community resources. Limits to the extent to which CHWs could connect families to resources may have necessitated a reliance on existing social networks, which may have further strained some families' already tenuous relationships.

At odds with efforts to make sure families could obtain assistance was the desire to encourage self-sufficiency based on the finite amount of time CHWs had with families. This suggests a tension in the CHW approach that might inadvertently lead to a dependence on CHW assistance among families. Few studies have examined this issue and whether it is indeed an issue of concern for programs employing CHWs.

Although many of the strategies mentioned in this study are essential to the success of asthma programs utilizing CHWs in low-income communities and communities of color, their implementation may take time and energy on the part of CHWs. The asthma programs for which the CHWs worked all recognized that asthma does not exist in a vacuum and, therefore, there was a need to include the provision of referrals for asthma and non-asthma related issues. However, initiating and following up on referrals may be a time consuming task (Friedman, et al., 2006), taking time away from asthma education and sometimes requiring the scheduling of additional visits. Getting to know families and gaining their trust may also require a commitment of time. When home visits are infrequent, CHWs may have to continually secure the buy-in of families at each contact. Although relationships may be easier to maintain when home visits occur with greater

frequency, CHWs who have been welcomed into the family fold may be called on more often to provide social support, for someone to listen. Coupled with the protocols required for asthma education, the collective activities undertaken by CHWs can overwhelm a 40-hour work week, especially when caseloads are high.

LIMITATIONS

Although this study includes a small sample of CHWs, the opinions expressed represent a relatively experienced group of racially, ethnically diverse CHWs working around asthma in low-income communities of color. CHWs are in a unique position to acquire personal information from families based on their shared background and experiences, yet the data collected may be subject to bias. For example, CHWs may have honed in on issues that they themselves perceived to be difficult rather than stressors of salience to the families they worked with. Furthermore, the circumstances of families who were seen more recently may have been brought to the forefront, thus, diminishing or omitting the experiences of those seen less recently. Yet, the one-on-one, open-ended format of the interviews and inclusion of more than one CHW at each site may have helped to counter any potential bias. Furthermore, the correspondence across sites and CHWs suggests some commonality among the experiences of CHWs. Based on the exploratory nature of this study, the impact of stressors and strategies for notable subgroups of the population, such as African American and Latino families, could not be made. Nonetheless, inquiring about the experiences and role of CHWs employed by asthma programs administered by different types of organizations from geographically distinct regions in the United States lends credence and significance to the findings. While the case studies or examples provided by CHWs helped to illustrate important points, ascertaining if these case studies represent unique or more commonplace events was a methodological challenge. Differentiating which stressors were most challenging or strategies most effective was also difficult. CHWs, however, provided detailed descriptions of the manifestation and impact of stressors on families and how they provided assistance, which is essential to developing effective interventions to reduce the impact of stressors on families of children with asthma and improve asthma-related outcomes.

IMPLICATIONS FOR RESEARCH

The findings from this study emphasize the need to explore more fully the life stressors experienced by families, and their resultant impact on asthma-related and other health and quality of life outcomes. This includes identifying stressors that are most salient to families as well as those that may impede adequate asthma control and management. The life stressors experiences of special subgroups of the population, such as racial/ethnic minorities as well as custodial grandparents and families without legal immigration status, and effective strategies for working with these groups should also be further explored. In addition, this study emphasizes that merely describing the activities prescribed to CHWs working in the area of asthma has been demonstrated to be insufficient, limiting the interpretation of findings as well as the replicability of research. More specificity around the strategies actually undertaken by CHWs, the impact of these strategies on asthma-related and other health and quality of life outcomes, as well as the feasibility of implementing these program-related tasks and activities is warranted. Similarly, more research is needed to understand the contribution of CHW characteristics or attributes, whether innate or learned, in asthma intervention programs. This could be accomplished by identifying CHWs with these desired characteristics or attributes, through soliciting assistance from community partners with an established and strong presence, such as through community-based participatory research partnerships (Israel, Eng, Schulz, & Parker, 2005; Israel, Schulz, Parker, & Becker, 1998).

The potential for dependency on programmatic resources, services, and staff, whether tangible or emotional, should be considered and addressed by researchers who employ CHWs. If self-sufficiency is the long-term goal, at what point do the activities of CHWs actually hinder families' abilities to address stressors on their own? One could argue that relying on CHWs for support and assistance—regardless of whether it is lending a listening ear, providing agency contact information, or resolving issues on behalf of families—may render families unable to resolve issues on their own because of their inexperience in navigating through existing networks or developing their own networks. For example, when working with families with illegal immigration status, CHWs cannot be there to help indefinitely, accompanying them to appointments, making phone calls on

their behalf, or translating correspondence. Therefore, it is absolutely essential that programs incorporate and prioritize strategies to prepare individuals to function independently and encourage self-reliance.

IMPLICATIONS FOR PRACTICE

The effectiveness of interventions targeting families of children with asthma in low-income communities of color may be limited by the diverse and sometimes dire circumstances facing families. With dwindling options for assistance in communities due to widespread budget cuts, a guide with relevant and up-to-date assistive resources is clearly indicated for families. Not only can these resources enable CHWs to address issues with families as they arise, but they can also prepare families to function in the absence of a CHW. Efforts to build capacity through sustainable community- and policy-level initiatives are also needed. Organizations serving low-income populations and populations of racial/ethnic minorities often have resource constraints of their own, necessitating the expansion of policies and funding to create and sustain opportunities for special programs. For example, funds could be allocated towards simplifying the paperwork and processes for applying for assistance, including using language that is appropriate for the target audience, and making translators available for individuals in need of those services. Integrating CHWs into public assistance or related programs to effectively counsel and reach individuals and streamline the application process may also have utility, if appropriate reimbursement mechanisms are in place.

An understanding and awareness of the impact of families' life stressors on CHWs themselves is also needed. Assisting families through a multitude of life stressors may take a toll on CHWs, especially in an environment of limited resources. Not having many (or any) options to offer families to help them through their difficult times may place CHWs in an awkward and uncomfortable position, since their job is to assist families. Moreover, motivating families who may be overwhelmed with their life stressors and reluctant to keep appointments with CHWs can lead to frustration and feelings of rejection (Brown, et al., 2007). Recognizing these issues, supportive services

should be in place to validate and assist CHWs with the difficult aspects of their jobs, and to help them to avoid burnout.

With more specificity of the characteristics of and strategies used by CHWs that have been shown to be effective in asthma research, best practices can be synthesized and integrated into existing CHW training programs and certification processes as benchmarks for key competencies in asthma control and management. The relevance of these characteristics and strategies to individuals in low-income communities who are diagnosed with other chronic diseases should also be explored. If there is overlap, preparing a curriculum that emphasizes applicable cross-disciplinary learning lends flexibility to employment of CHWs in the workforce. Furthermore, making this information more broadly accessible through peer-reviewed articles and web-based resources can maximize the reach of this knowledge.

Chapter 4

Examining the Association Between Life Stressors, Asthma-related Health and Quality of Life, and Social Support: Findings From a Community Health Worker, Home-based Intervention for Families of Children with Asthma

ABSTRACT

Objectives: Caregiver life stressors have been associated with adverse caregiver and child asthma-related health and quality of life (QOL) outcomes. Knowledge of whether some life stressors (or domains of life stress) are more highly associated with health and QOL outcomes than others, however, has been limited because findings for life stressors have typically been reported in totality and not by specific domain. Although social support has been shown to reduce the negative impact of life stress(ors) on asthma, the contribution of social support to asthma-related outcomes has not been an area of focus. This study used a mixed-methods research approach, employing qualitative and quantitative data collection and analysis, to explore the relationship between conceptually distinct domains of life stressors and standard measures of caregiver and child asthma-related health and QOL, and the role of social support.

Methods: Using qualitative methods, asthma-related and other life stressors were coded from the handwritten documentation made by CHWs during home visits with caregivers of children with asthma in the intensive first year of a household environmental intervention study (n=115). Focusing on the broad stressors (i.e., lack of food, trouble with landlords, child's behavioral problems, caregiver health issues), conceptually distinct domains of life stressors were identified. These stressors domains included: lack of basic needs and amenities (Basic), lapse of or dissatisfaction with employment (Work), physical and/or mental health problems in the family (outside of the participating child's asthma) (Family Health), and problems with interpersonal relationships (Family Relationships). Each domain was scored based on the number of unique stressors

experienced by families in that domain, as documented by CHWs, and the sum of these domains was calculated. Using health and QOL outcomes from an annual survey administered to caregivers of children with asthma in the same intervention study, multivariate regression analysis was then used to model the association between stressors domains and health services utilization, asthma severity, asthma symptoms, depressive symptoms, and caregiver pediatric asthma-related QOL, testing for the role of social support in modifying these relationships.

Results: Multivariate analyses testing the role of baseline social support in modifying the relationship between stressors domains and asthma-related health and QOL outcomes support the hypothesis that social support may buffer the impact of certain life stressors. Caregivers with documented Basic stressors were more likely to report 1 or more ER visits in the past 12 months (OR: 3.975, 95% CI: 1.070, 14.764, $p=0.039$). Social support was shown to modify the relationship between Basic stressors and ER visits, with a decrease in the odds of reporting 1 or more ER visits for those experiencing Basic stressors in the presence of higher levels of perceived social support (OR: 0.548, 95% CI: 0.298, 1.007, $p=0.053$). Social support also played an important role in modifying the impact of Basic and Total stressors on caregiver pediatric asthma-related QOL, with caregiver ratings of their QOL due to the child's asthma being worse for families with more documented stressors in these domains. However, in the presence of social support, the negative impact of Basic (Estimate: 0.149, 95% CI: -0.002, 0.300, $p=0.052$) and Total stressors (Estimate: 0.078, 95% CI: -0.006, 0.161, $p=0.068$) on asthma-related QOL was significantly reduced.

When social support and stressors were modeled separately, Total stressors was found to be an important predictor of asthma severity, with caregivers with more documented stressors being more likely to have children characterized with persistent asthma (relative to non-persistent asthma) (OR: 1.311, 95% CI: 1.069, 1.606, $p=0.009$). Those who reported problems with Family Relationships also had a greater odds of having a child categorized with persistent asthma (OR: 2.041, 95% CI: 1.049, 3.970, $p=0.036$). In addition, worse asthma symptomatology was associated with more documented Family

Health, Family Relationships, and Total stressors, independent of social support. Lastly, for caregiver depressive symptoms, Work was the only stressors domain that was predictive of caregiver depressive symptoms. Caregivers indicating more work-related stressors also reported more symptoms of depression (Estimate: 0.092, 95% CI: -0.005, 0.188, $p=0.063$). Social support did not exhibit an independent effect on any of the outcomes.

Implications: These data provide a unique opportunity to use a mixed-methods approach to investigate alternative ways to conceptualize and operationalize caregiver life stressors for childhood asthma. The results from this study suggest that looking at life stressors in their totality may actually mask the individual contributions of stressors domains on asthma-related outcomes. Furthermore, social support may play a differential role in modifying these relationships. Identifying individual stressors domains and their contributions to health and QOL outcomes, therefore, may inform the development of effective interventions to reduce the burden of childhood asthma among low-income populations and populations of color.

INTRODUCTION

Researchers have recognized the importance of environmental, social, and psychosocial factors (or life stressors) on asthma-related health and quality of life (QOL). Whether measured through specific events or situations, or more broadly, life stressors refer to a broad spectrum of events or conditions including daily hassles, chronic strains, major life events, ambient stressors, and natural disasters and cataclysmic events (Israel & Schurman, 1990). Evidence of life stressors in urban, low-income, and racially and ethnically diverse communities and their impact on families of children with asthma—where the burden of asthma is greatest—is mounting, which has broad implications for all children (Bloomberg & Chen, 2005; Bryant-Stephens, 2009; Eggleston, 2007; Gold & Wright, 2005; Weiss, et al., 1992; D. R. Williams, et al., 2009). Residence in urban underserved areas exposes families to stressors that can affect asthma care and management through poor indoor and outdoor air quality, poor housing conditions (e.g., substandard housing, residential instability), inadequate access to quality health care and

other supportive services, and problems such as crime and violence (Bryant-Stephens, 2009; Eggleston, 2007; Gold & Wright, 2005; O'Neill, et al., 2003; Sandel & Wright, 2006; Shapiro & Stout, 2002; D. R. Williams, et al., 2009; Wright, et al., 2004). In addition, neighborhood stressors such as low collective efficacy and physical/social disorder, have also been linked to negative asthma outcomes such as waking at night, exercise intolerance, and perceived controllability of the child's asthma (Quinn, et al., 2010).

In the asthma literature, caregivers have commonly been asked to identify and/or rate life stress(ors) through experiences of stressful life events or chronic stressors. Studies on childhood asthma have demonstrated an association between caregivers' reports of life stress(ors) and children's asthma symptoms, such as wheeze, prospectively across a range of children's ages (Milam, et al., 2008; Sandberg, et al., 2004; Sandberg, et al., 2000; Wright, et al., 2002), though Milam and colleagues (2008) found a significant association only for boys and those whose parents did not have asthma. The risk and/or immediacy of a new asthma attack was also shown to be significantly increased for children of caregivers who reported any severe event(s), regardless of whether accompanied by chronic stressors (Sandberg, et al., 2000). Among a subset of children reporting low to moderate chronic stress in the same sample, the risk for a new asthma attack increased 1-2 days following severe negative life event reporting (Sandberg, et al., 2004). Outside of measures of the child's asthma, caregiver perceived stress was shown to be associated with poor caregiver asthma-related QOL (Levy, et al., 2004). Number of life stressors and/or total negative stressors has also been correlated with caregiver depressive symptoms and mental health (Klennert, et al., 2002; Shalowitz, et al., 2001; Shalowitz, et al., 2006; Weiss, et al., 2009). Not only have life stressors and depressive symptoms been shown to distinguish mothers of children with asthma or probable asthma from mothers of children without asthma in a low-income, racially/ethnically diverse sample (Shalowitz, et al., 2006), but the combination of higher scores for depressive symptoms and more negative life stressors for caregivers of girls with asthma predicted poorer asthma morbidity in a sample of mixed socioeconomic status (Shalowitz, et al., 2001). Martin and colleagues (2007) also found the odds of having a child with diagnosed

asthma or potential asthma was greater for Mexican American caregivers reporting more life stressors. While life stress(ors) have often been assessed in the form of discrete events, either through endorsement of acute or chronic life events or through systematic one-on-one interviews, the relative contribution of any one domain on asthma-related outcomes for caregivers and their children with asthma has not been the focus of these analyses.

Qualitative studies have been undertaken to expand the collective understanding of the barriers faced by caregivers and their children with asthma, particularly, with racial/ethnic minorities of low-income. While these studies have identified important stressors related to direct asthma care and management (e.g., lapses in health insurance coverage, difficulties communicating with school personnel/health professionals, troubles executing environmental remediation), broader environmental, social, and psychosocial stressors do not appear to have been explored (Laster, et al., 2009; Mansour, et al., 2000; Tumiel-Berhalter & Zayas, 2006; Valerio, et al., 2006). Furthermore, the heavy reliance on focus groups methodology limits inquiries to a smaller number of individuals at one point in time.

Social support has been shown to reduce the negative impact of stress(ors) on health (Cohen, 1988; Heaney & Israel, 2008; Israel & Schurman, 1990; Thoits, 2010), and has been identified as an important area for future research for reducing asthma disparities (Mangan, et al., 2007). The presence of multiple caregivers for children with asthma (Wade, et al., 1997) and array of tasks that must be performed to effectively control asthma (National Asthma Education and Prevention Program, 2007) indicates that social support may have a role in the relationship between stress and asthma, although there has not been any consensus as to whether family or non-family support is more important (Mangan, et al., 2007). In a sample of mostly Caucasian adults with physician-diagnosed asthma, asthma-related social support was associated with lower emergency room usage for those with more severe disease (Janson-Bjerklie, Ferketich, & Benner, 1993). A similar relationship was found in a low-income, more racially/ethnically diverse sample of children with asthma, where lifetime hospitalizations for asthma was associated with

greater reported conflict in the family's social environment (Chen, Bloomberg, et al., 2003). Additionally, family dysfunction has been linked to poor asthma-related outcomes for children (Bloomberg & Chen, 2005). An assessment of family resources and asthma-specific demands for parents of children with moderate to severe persistent asthma revealed that African American parents had fewer and inadequate resources in the area of extended family social support compared to European Americans, although the difference was not statistically significant. For demands, African American parents cited that balancing tasks and activities outside of the child's asthma was most time-consuming (e.g., dealing with work- or school-related issues while at the same time organizing asthma treatments, managing the financials and paperwork related to the child's asthma, and providing emotional support for other children in the family), while Caucasian families cited that tasks more directly related to care of the child with asthma (e.g., emotional support for the child with asthma, dealing with episodes of asthma exacerbation) were most time-consuming (Lee, et al., 2006). Together these results suggest that social support may play an important role in modifying the relationship between life stressors and asthma-related health and QOL.

Although a relationship between life stressors and asthma-related health and QOL outcomes has been documented, the interpretation and applicability of these findings is limited by methods to date for measuring life stressors among caregivers of children with asthma. To explore and challenge current trends in conceptualizing and operationalizing life stressors for caregivers of children with asthma, and to test the role of social support, this study uses a mixed-methods approach. Using qualitative methods, longitudinal data collected by community health workers (CHWs) during repeat home visits over a one-year period was analyzed to identify life stressors of relevance to participating families. This approach has the potential to allow for a broader scope of stressors to emerge because: (1) the nature of the inquiry was open-ended so that stressors could be coded by domain; (2) the data was collected by a CHW who was a member of the community and able to establish trust and rapport with families; and (3) visits were conducted with regular frequency (i.e., a planned 9 visits in the first year of the intervention). Upon coding of the stressors by domains, quantitative analyses were conducted to explore the

association between the life stressors domains and asthma-related health and QOL outcomes. This study attempts to address the shortcomings of current methodologies to assist in the development of effective, sustainable programs for reducing the burden of asthma for families of children with asthma in underserved areas.

Using data from an intensive one-year CHW intervention study to improve household environmental triggers for asthma among families of children with asthma, this study seeks to examine the association between life stressor domains and self-reported child's asthma symptoms, child's asthma severity, caregiver depressive symptoms, and caregiver pediatric asthma-related QOL, above and beyond perceived social support.

BACKGROUND

Source of Data: Community Action Against Asthma (CAAA)

This study analyzed data collected by Community Action Against Asthma (CAAA), a community-based participatory research (CBPR) partnership, as a part of a CHW-delivered household intervention study for families of children with asthma. CAAA has combined epidemiological and intervention research on environmental causes of asthma exacerbation in children. CAAA has focused its efforts primarily in Eastside and Southwest Detroit, which are low-income communities of color with a high proportion of African American and Latino/a residents, respectively. The steering committee is composed of representatives from community-based organizations, health and human service organizations, a local health department, academic institutions, and a community member at large. Guided by a set of CBPR principles (Israel, et al., 1998), CAAA involves and encourages active participation of steering committee members in all aspects of the research, from proposal development to dissemination of study findings (Edgren, et al., 2005; Lewis, et al., 2005; Parker, et al., 2010; Parker, et al., 2008; Parker, et al., 2003).

CAAA Household Intervention Study Design

The CAAA household intervention study employed a randomized controlled staggered design. To identify and recruit children with asthma, CAAA distributed 9,627 screening

questionnaires by mail and/or in-person to the caregivers of school-aged children at 44 elementary schools in Eastside and Southwest Detroit (Lewis, et al., 2004). Eligible caregivers had a child aged 7 to 11 with mild intermittent to severe persistent asthma, were Spanish- and/or English-speaking, could complete an interview and had a child who could do the same, and lived in one of the defined geographic areas. Asthma severity was assessed using screening questions derived from the American Thoracic Society's respiratory questionnaire for adults (Hopp, Townley, Biven, Bewtra, & Nair, 1990), which had been previously validated in a sample of children with asthma in the city of Detroit (Clark, et al., 2002).

Three hundred and twenty eight caregivers provided informed consent and agreed to participate in the study. Randomization was accomplished using a random number generator and the study enrollment was as follows: 162 caregivers/children in the intervention group (Wave 1) and 166 in the delayed intervention or control group (Wave 2). Of the 298 caregivers who began the household intervention study, approximately 95% were females, with most identifying themselves as the mother (84.7%) or grandmother (8.16%) of the child with asthma. The mean age for caregivers was 36.9 years. The racial/ethnic make-up of caregivers was approximately 81% African American and 11% Hispanic or Latino/a. With regards to education and income, approximately 37% of caregivers had less than a high school degree and the majority reported an annual family income below \$40,000, with almost 75% reporting an income below \$20,000. Approximately 70 percent of those enrolled were retained, leaving 115 intervention and 111 control group caregivers/children who completed a post-intervention caregiver survey. For more information on the study population and recruitment, please see Parker et al. (2008). The sample for this study includes the 115 caregivers/children in the intervention group.

CAAA Intervention Description

CAAA's household-level intervention, adapted from the Seattle-King County Healthy Homes Project (Krieger, et al., 2002), was a two-year intervention consisting of an intensive first year where participants received a minimum of 9 home visits from a CHW

called a Community Environmental Specialist (CES), and a less intensive second year where 3 follow-up visits were conducted. During the home visits, CESs educated caregivers and their families about asthma and environmental triggers of asthma such as dust, cockroaches and rodents, pets, environmental tobacco smoke, mold and mildew, and other strong odors; assisted caregivers with developing an asthma action plan; reviewed results of dust and allergy skin testing; provided hypoallergenic mattress cover(s) for the child's bed, a vacuum cleaner with a HEPA filter, and cleaning supplies; and responded to caregivers needs for referrals and other assistance as required. For details on the intervention and CES training, please consult Parker et al. (2008). Given the staggered study design, the "control group" received the intervention one year after the intervention group, thus serving as the control during the first intensive year of the intervention.

CAAA Data Collection

Data collected from participants in the CAAA household intervention included survey data, lung function measurement data, and an initial household assessment. The surveys were administered to caregivers by trained community interviewers. These community interviewers scheduled home visits with caregivers in the intervention group to administer an annual survey at baseline, 12 months, and 24 months. The caregiver survey assessed caregiver knowledge, attitudes, and beliefs about asthma, child asthma severity, asthma health service utilization, caregiver health and asthma-related QOL, behavior change to reduce environmental triggers to asthma, social support, neighborhood cohesion and concerns, and neighborhood environmental conditions. The household assessment included a walkthrough to identify potential asthma triggers in the home. In addition to these annual measures, respiratory symptom data were collected in a diary format daily for a two-week period seasonally (i.e., four times a year) for a total of 11 seasons for both study groups. A community staff member who had undergone extensive training worked with caregivers and children on the correct technique for spirometry and reinforced the technique on subsequent visits.

An additional source of data was the CES documentation form. Following each home visit, CESs completed a form noting the date, time, and duration of the visit, if over 30 minutes, and a checklist of education discussed (e.g., dust mites), supplies provided (e.g., cleaning supplies), and activities performed (e.g., counseling/referrals). The forms also included space for CESs to document through handwritten notes the content of their discussions, observations made, and necessary follow-up activities (hereafter referred to as “CES documentation”) (see Appendix A). Four CESs covered the study’s caseload of families. Though one CES departed mid-way through the second year of the intervention study, her caseload was picked up by the other CESs on staff.

METHODS

Using data from the original CAAA household intervention, this study investigates the relationship between life stressors and asthma-related health and QOL outcomes, and the role of social support in modifying these relationships. Given the majority of home visits were conducted during the first year of intensive intervention, all analyses will be restricted to year one. Thus, this study uses survey data collected at baseline and 12 months, and the corresponding CES documentation specific to the intervention group. The current study is, therefore, a longitudinal evaluation of the group that received the intervention at the onset of the study. Unless otherwise specified, these variables were collected as a part of the CAAA Annual Caregiver Survey.

Outcome Variables

Child asthma symptoms and severity. A series of questions was asked to assess the child’s asthma symptoms and severity. Caregivers were asked to indicate the frequency of their child’s asthma symptoms such as cough, wheezing, shortness of breath, and chest tightness or heaviness and their association with colds, exercise or running and playing hard, and sleep disturbance over the past 12 months. The response categories were: 1 = never, 2 = 1 or 2 times in the whole year, 3 = 3 to 12 times in the whole year, 4 = more than 1 time per month, 5 = more than 2 times per week, 6 = every day (Clark, et al., 2004). Most of the questions for asthma severity were derived from the American Thoracic Society’s respiratory questionnaire for adults (Hopp, et al., 1990) and adapted to

incorporate National Asthma Education and Prevention Program 2 severity categorization and information about asthma medication use. Children were classified as having probable asthma with the presence of at least three of the six non-exercise related symptoms, experiencing exercise symptoms at least three times or more in the past year, and having doctor or health care provider diagnosed asthma or using asthma-related medications prescribed by a doctor. Children with probable asthma were then further classified as having probable moderate to severe asthma, probable mild persistent asthma, or probable mild intermittent asthma. Those with moderate to severe asthma reported daily daytime symptoms, sleep disturbance more than two times per week, and daily use of doctor-prescribed medications for asthma. For probable mild persistent asthma, daytime symptoms were reported at least two times per week, sleep disturbance more than one time per month, and doctor-prescribed medications for asthma daily. All other children were classified as having probable mild intermittent asthma.

Health services utilization. Questions were derived to assess the number of scheduled and unscheduled medical visits to a doctor's office, emergency room, and hospital for breathing problems and/or asthma. Caregivers indicated the number of times in the past 12 months these visits were necessitated, as well as the time frame since the last visit (i.e., in the past 2 weeks, in the past 3 months, or in the past 12 months).

Caregiver depressive symptoms. Caregiver depressive symptoms were measured using a shortened version of the Center for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977). The 11-item scale (Kohout, Berkman, Evans, & Cornoni-Huntley, 1993) has been shown to perform well in diverse samples while decreasing the amount of time for administration (Carpenter, et al., 1998; Kohout, et al., 1993). Respondents were asked to rate statements such as feeling lonely or having a poor appetite based on how much the statement has applied to them in the past week on a scale from 1 to 3, where 1= hardly ever, 2= some of the time, and 3= most of the time. The scores were summed and divided to arrive at a mean score.

Caregiver asthma-related quality of life. The Paediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) includes 13 items to examine caregivers' experiences with activity limitations and concerns with emotional functioning as a result of their child's asthma (Juniper, et al., 1996). To assess concerns with activity limitations, caregivers were asked to rate four questions based on their level of worry or concern in the past week on a scale from 1 to 5, where 1 is very, very worried or concerned and 5 is not worried or concerned. The eight questions on emotional functioning assessed how often caregivers experienced events such as needing to change plans, feeling frustrated or impatient, and sleepless nights in the past week because of their child's asthma on a scale from 1 to 7, where 1 is all of the time and 7 is none of the time. The measure resulted in an overall mean score for QOL, and a mean score for each of the domains.

Independent Variables

Stressors domains. Four stressors domains were derived from the CES documentation (methodology described in "Data Analysis"): Basic, Work, Family Health, and Family Relationships. The domain score represents the number of unique stressors experienced in that domain during the year-long intervention. In addition, the stressors across the four domains were summed to create a total stressors score.

Caregiver social support. Two dimensions of social support were measured using questions from a validated scale (Strogatz, et al., 1997). Emotional support was assessed by asking respondents about the availability of somebody to love and care for them, and to confide in. For instrumental support, participants were asked how often they feel they would be able to get help from somebody without having to pay them for activities such as cleaning or small repairs around the house, care if they were sick, help with solving personal problems, watching their children, moving furniture, and transportation. The sum of each dimension of social support was calculated using the following scores derived from the response categories, 1=always, 2=most of the time, 3=sometimes, 4=never. In this study, social support was reverse coded.

Caregiver basic demographics. Basic demographic variables included caregiver gender, race/ethnicity, education, and household income.

Data Analysis

Qualitative Methodology and Derivation of Stressors Domains from the CES

Documentation

The handwritten CES documentation was transcribed noting the date, time, duration, and type of visit, the CES who conducted the visit, and the participant's locale (i.e., Eastside or Southwest Detroit). Information that might identify individuals was removed from the transcripts to maintain confidentiality. Following a line-by-line review of the documentation for each home visit, caregivers' life stressors were identified and coded using *in vivo* codes (i.e., the words of the respondent) whenever possible (Strauss & Corbin, 1998). A comparative analysis was undertaken to ensure that the codes were clear and distinct, and the codes were then organized into higher level, focused code categories (Patton, 2002; Strauss & Corbin, 1998). A team of three researchers skilled in qualitative methods, two of whom were involved with the initial data collection, discussed and refined the preliminary coding and categorization. This study uses the subset of broad life stressors experienced by families of children with asthma (see Table 2.1, Chapter 2).

After consensus on the qualitative coding and categorization was reached, the resulting broad life stressors were further combined and organized into larger stressors domains. To accomplish this, the principal investigator reviewed the content of each broad stressor to determine which of these could be combined to form a meaningful, yet conceptually distinct domain. Stressors for which objective measures existed, such as poor housing conditions and lack of health insurance, were excluded. This process resulted in a series of 15 domains. An examination of each stressors domain was then undertaken to determine the feasibility of inclusion for meaningful analysis. A total of 4 domains were excluded due to low numbers of individuals experiencing the stressor (ranging from 4 to 11 participants), which included stressors such as legal problems and issues around home and neighborhood safety. The remaining 11 domains were then examined and reviewed

by members of the research team for their salience and ability to stand alone. Upon further examination it was determined that of these 11, two domains (changes in family structure and other caregiving responsibilities) were not be conceptually distinct from problems with families' interpersonal relationships and physical and/or mental health problems in the family, respectively, and were excluded. The remaining nine stressors domains were reviewed by the research team and further combined into the following six domains: (1) lack of basic needs and amenities; (2) trouble with living arrangements and wanting/needing to move; (3) physical and mental health problems experienced by the family (which does not include the participating child's experiences with asthma); (4) lapse or dissatisfaction with employment; (5) problems with interpersonal relationships; and (6) trouble obtaining or maintaining assistance from individuals, agencies, or organizations. Upon further correlational analysis, four broad stressors domains were included in this analysis, for which the methodology is described in the Results section.

Quantitative Methodology

Descriptive statistics were used to summarize caregiver baseline demographic, housing, health, and QOL characteristics and social support, and child's baseline asthma medication use, asthma symptoms and severity, and health services utilization for the intervention group. Data from the CES documentation, including number of home visits, CES caseload, and stressors domains, were also summarized.

An example of how the stressors domains were coded and scored can be found in Table 4.1. Briefly, each qualitatively coded stressor from the CES documentation was assigned an appropriate string variable in SAS. To arrive at a conservative estimate, stressors domains accounted only for unique stressors experienced in the first year of the intervention. Therefore, if a specific stressor (i.e., variable) was experienced by the same caregiver more than once during the first year of the intervention, the stressor was only counted once in the domain score. A Total stressors score was calculated as the sum of the scores for the four primary domains.

Table 4.1. Domain scoring from Community Environmental Specialist (CES) qualitative data: An example of how qualitative data around basic needs and amenities was coded and then a score calculated.

Domain	Qualitative Code (Variable)	Excerpt from CES Documentation ^a
Basic	Caregiver needs food (FOOD)	Family in need of food, referral given. (ID#123, 07-30-2000)
Basic	Caregiver in need of clothing for child and/or other family members (CLOTH)	Also, just have been getting ready for school. Needed for me to write a referral for uniforms, pants, and shirts for the boys... (ID#123, 08-08-2000)
Basic	Caregiver needs baby clothes and/or other baby supplies for self and/or other family member (CLOTH)	Also was telling me about her other daughter who is pregnant and is due on Saturday. [Caregiver] wanted to know if I can help her get some baby clothes, baby seat, and other baby supplies. Adv[ised] that I will see on what I can do to get her some help for her new grandson. (ID#123, 09-06-2000)
Basic	Caregiver needs assistance with getting gas bill paid and/or getting or keeping gas on (UTILS)	[Q: Comments/Observations that you want to note.] Member said she needs help with payments for her gas bill. (ID#123, 03-30-2000)
Basic	Caregiver needs assistance with getting electric/light bill paid and/or getting or keeping electricity on (UTILS)	[Caregiver's] electricity was shut off. (ID#123, 05-24-2000)

Basic Domain Score = 3

Q, Question noted on documentation form

^a In the interest of clarifying how domains were scored, the excerpts from the CES documentation though representative of participants' experiences, are not stressors experienced by a single participant in this study

Although models considered in this analysis may appear to be cross-sectional, the inclusion of the outcome at baseline as a predictor is allowing for the assessment of change over time of the outcome while adjusting for stressors. Generalized estimating equations (GEE) were used to adjust for the correlations inherent in repeated observations of the same individuals over time to arrive at valid inferences (Diggle, Liang, & Zeger, 1994; Zeger & Liang, 1992). Notable advantages of GEE are the ability to maximize power and allowing for each individual to serve as his/her own control (Zeger & Liang, 1992, p. 1826). In these analyses, GEE accounted for the clustering of observations of

the same individual over time. GEE with normal distribution and identity link was used in models with continuous outcomes, i.e., wheeze with cold, wheeze without cold, social support, and depressive symptoms. GEE with binary distribution and the log link was used for binary outcomes for emergency room visits and persistent asthma. All statistical analyses were conducted using SAS Version 9.3 (SAS Institute Inc., Cary, North Carolina).

After the stressors domains derived from the qualitative analysis were reviewed for their theoretical salience and scored, they were subsequently modeled using multivariate regression. The effect of each stressors domain (ST) on caregiver and child health and QOL outcomes collected at year one (Y_{T1}) was modeled, where ε is the error term. The six outcomes for these models were emergency room visits, persistent asthma, wheeze with cold, wheeze without cold, caregiver depressive symptoms, and caregiver pediatric asthma-related QOL. Model 1 tested the association between each of the four stressors domains (D) (i.e., Basic, Work, Family Health, and Family Relationships) on the outcomes, while controlling for the baseline value of the outcome of interest (Y_{T0}), baseline caregiver demographic characteristics (D_{T0}), and baseline social support (SS_{T0}). In addition, this model included a two-way interaction term, ($ST_{T1} * SS_{T0}$), to assess if baseline social support modified the association between stressors and the outcomes of interest. Models with emergency room visits or persistent asthma as the outcome did not include the baseline value of the outcome variable because approximately three-quarters of the sample, for each outcome, did not change their status from baseline to year one.

$$Y_{T1} = \beta_0 + \beta_1(D)_{T0} + \beta_2(Y)_{T0} + \beta_3(ST)_{T1} + \beta_4(SS_{T0}) + \beta_5(ST_{T1} * SS_{T0}) + \varepsilon \quad \text{Model 1}$$

If the interaction between social support and the stressors domains in Model 1 was not significant ($p\text{-value} > 0.10$), then Model 2 tested if social support confounded the relationship between stressors and the outcome of interest.

$$Y_{T1} = \beta_0 + \beta_1(D)_{T0} + \beta_2(Y)_{T0} + \beta_3(ST)_{T1} + \beta_4(SS_{T0}) + \varepsilon \quad \text{Model 2}$$

Lastly, if social support was not significant in Model 2 (p-value > 0.10), then Model 3 tested if the stressors domain had an independent effect on the outcome of interest.

$$Y_{T1} = \beta_0 + \beta_1(D)_{T0} + \beta_2(Y)_{T0} + \beta_3(ST)_{T1} + \varepsilon \quad \text{Model 3}$$

RESULTS

Characteristics of Caregivers and Children with Asthma

Table 4.2 shows the demographic, housing, health, and QOL characteristics of caregivers in the intervention group. The vast majority of caregivers were female and identified as the mother of the child with asthma. Non-Hispanic African Americans and Hispanics made up almost 96 percent of the sample, with African Americans accounting for 83.2 percent. Over one-third of caregivers had less than a high school education, and over two-thirds reported a household income of \$20,000 or less. More caregivers were renters (60.9 percent) than homeowners, and the average household size was 5.3 persons. Over 90 percent of the sample had health insurance. Only about one-third of caregivers reported “poor” or “fair” health, and the mean pediatric asthma-related QOL score was high at 5.5, indicating better QOL. On a scale from 1 to 3, the mean depressive symptom score was 1.6. The mean level of social support in the sample was 2.9, which showed that on average caregiver perceived high levels of social support.

The asthma-related characteristics of children in the intervention group are shown in Table 4.3. The majority of children were classified with persistent asthma (78.2 percent). Although approximately one-third indicated not taking any asthma medication at all, almost half of the children were on a short acting bronchodilator only. Approximately one-third of children had one or more visits to the emergency room for an asthma-related event in the past 12 months.

Table 4.2. Baseline demographic, housing, health, and quality of life characteristics for caregivers of children with asthma in the intervention group (n=115).

Characteristic	n (%)	Characteristic	n (%)
<u>Caregiver Demographics</u>		<u>Housing</u>	
Mean age, years (SD)	37.3 (10.9)	Home ownership	
Gender		Rent	70 (60.9)
Female	111 (96.5)	Own	40 (34.8)
Male	4 (3.5)	Neither	5 (4.4)
Relation to child with asthma		Mean household size, persons (SD)	5.3 (2.4)
Mother	94 (83.9)		
Grandmother	11 (9.8)		
Other	7 (6.3)		
Race/ethnicity		<u>Caregiver Health and Quality of Life</u>	
African American, non-Hisp	94 (83.2)	<u>Health insurance</u>	
Hispanic/Latino/Spanish	14 (12.4)	Yes	105 (92.9)
Caucasian, non-Hisp	3 (2.7)	No	8 (7.1)
Other	2 (1.8)	<u>Self-rated overall health</u>	
Education		Excellent	20 (17.4)
Grades 1-8	4 (3.5)	Very good	23 (20.0)
Grades 9-11	38 (33.6)	Good	29 (25.2)
High school diploma, GED	45 (39.8)	Fair	30 (26.1)
Some college, technical school, or associates degree	26 (23.0)	Poor	12 (10.4)
Household income		Mean CES-D score (SD) ^a	1.6 (0.5)
< \$10,000	42 (37.8)	Mean social support (SD) ^b	2.9 (0.9)
\$10,001-\$20,000	35 (31.5)	Mean PACQLQ score (SD) ^c	5.5 (1.6)
> \$20,000	26 (23.4)		

SD, standard deviation

non-Hisp, non-Hispanic

CES-D, Center for Epidemiologic Studies Depression Scale

PACQLQ, Paediatric Asthma Caregiver's Quality of Life Questionnaire

^a scale scored from 1 to 3, where higher scores indicate more depressive symptoms

^b scale scored from 1 to 4, where higher scores indicate more social support

^c scale scored from 1 to 7, where higher scores indicate better asthma-related quality of life

Table 4.3. Baseline asthma-related characteristics for children with asthma in the intervention group (n=115).

Characteristic	n (%)
Child's asthma severity	
Mild intermittent	25 (21.7)
Mild persistent	29 (25.2)
Moderate-severe persistent	61 (53.0)
Child's medication level	
No asthma medication	39 (33.9)
Short acting bronchodilator only	53 (46.1)
Controller medication without corticosteroid	10 (8.7)
Inhaled corticosteroid or oral corticosteroid	13 (11.3)
Child's asthma-related emergency room visits in the past 12 months	
None	65 (63.7)
≥ 1 visit	37 (36.3)

Summary of Stressors Domains

Using the six stressors domains derived from the CES documentation (and described previously in the Data Analysis section), Pearson's correlations were computed to assess for multicollinearity. Two domains (trouble with living arrangements and wanting/needing to move and trouble obtaining or maintaining assistance from individuals, agencies, or organizations) had moderately high correlation coefficients, 0.58753 and 0.5542, respectively, when paired with the lack of basic needs and amenities domain. Given the mean household size was 5.3 persons and it was not uncommon for family members to move in together, families experiencing difficulties with acquiring basic needs for their families may also have been those with more tension in their living arrangements. Likewise, trouble with obtaining and maintaining assistance may be more relevant to those who were experiencing problems with securing basic needs and amenities, as resources in the community to support such needs may have been sorely lacking. With the potential overlap with basic needs and amenities, the aforementioned two domains were excluded from this analysis. The correlation coefficients for the remaining four stressors domains are shown in Table 4.4, and a summary of the types of stressors defining each domain can be found in Tables 4.5 and the frequency of stressors mentioned within each domain can be found in Table 4.6.

Table 4.4. Pearson correlation matrix of stressors domains.

Stressors Domain	Work	Family Health	Family Relationships
Basic	0.25770	0.20067	0.21555
Work		0.15590	0.17273
Family Health			0.40155

Basic, Lack of basic needs and amenities

Work, Lapse or dissatisfaction with employment

Family Health, Physical and/or mental health problems of family members

Family Relationships, Problems with interpersonal relationships

Table 4.5. Types of life stressors experienced by families of children with asthma by qualitative domain, as relayed through handwritten documentation made by CHWs during home visits.

Abbreviation	Domain Defined	Types of Life Stressors
Basic	Lack of basic needs and amenities	<ul style="list-style-type: none"> - Lack of food - Lack of clothing - Cannot pay utilities - Needs furniture - Needs appliances - Interrupted phone service - Problems with transportation
Work	Lapse or dissatisfaction with employment	<ul style="list-style-type: none"> - Experiencing a lapse in employment - Wanting a change of employment or hours, more work - Not having a traditional work schedule - Missing work for personal reasons
Family Health	Physical and/or mental health problems of family members	<ul style="list-style-type: none"> - Health problems for caregiver of child with asthma - Health problems for adult family member other than caregiver of child with asthma - Health problems for children in the family^a
Family Relationships	Problems with interpersonal relationships	<ul style="list-style-type: none"> - Relationship problems for caregiver of child with asthma - Academic and behavioral problems for children in the family

^a does not include asthma-related problems for participating child with asthma

Table 4.6. Frequency of documented stressors in Basic, Work, Family Health, and Family Relationships domains for the intervention group (n=115).

Number of Stressors by Domain	Number and % of Persons Reporting Specified Range of Stressors
Basic (max: 5)	
0	71 (61.7)
1	20 (17.4)
2 or more	24 (20.9)
Work (max: 4)	
0	72 (62.6)
1	35 (30.4)
2 or more	8 (7.0)
Family Health (max: 7)	
0	46 (40.0)
1	27 (23.5)
2 or more	42 (36.5)
Family Relationship (max: 4)	
0	80 (69.6)
1	16 (13.9)
2 or more	19 (16.5)
Total (max: 15)	
0	25 (21.7)
1	13 (11.3)
2	22 (19.1)
3	18 (15.7)
4 or more	37 (32.2)

max, maximum number of stressors reported by domain

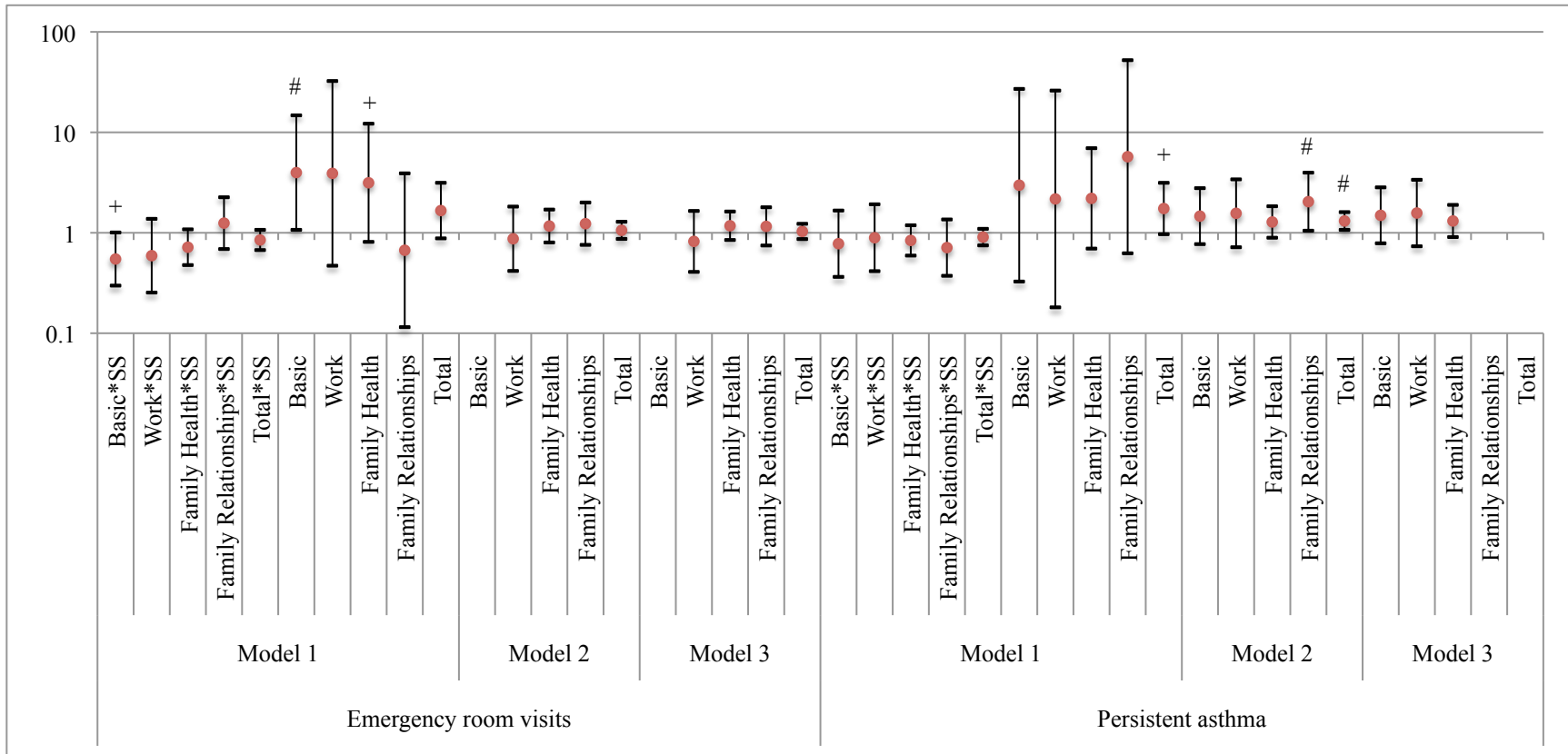
To provide a context for the stressors documented by CESs during the first year of intensive intervention, the mean (SD) number of home visits received by families in the intervention group was 9.7 (3.0) in year one, ranging from 0 to 19. The 115 intervention families were distributed in the following manner across CESs: 25 percent (29/115), 26 percent (37/115), 32 percent (30/115) and 17 percent (19/115). The CES with the smallest caseload departed the study in year two of the intervention, and the remaining outreach workers on staff picked up and completed the home visits with that CES's families.

Multivariate Analyses

Figure 4.1 depicts the odds ratios for each life stressors domain and social support in models predicting emergency room (ER) visits and persistent asthma. The findings suggest that social support may buffer the impact of life stressors on ER visits, although not for all stressors domains. Basic and Family Health stressors were found to be predictive of ER visits at the $p < 0.10$ level. Caregivers with documented Basic stressors were more likely to report 1 or more ER visits (relative to none) in the past 12 months (OR: 3.975, 95% CI: 1.070, 14.764, $p=0.039$). There is evidence that social support modifies the relationship between Basic stressors and ER visits, with a decrease in the odds of reporting 1 or more ER visits for those experiencing Basic stressors in the presence of higher levels of perceived social support (OR: 0.548, 95% CI: 0.298, 1.007, $p=0.053$). Of note, caregivers who had less than a high school education were significantly less likely to report 1 or more ER visits compared to those who had schooling beyond a high school diploma or GED (OR: 0.209, CI: 0.047, 0.924, $p=0.039$). The Family Health domain was also a significant predictor of reporting 1 or more ER visits (OR: 3.147, 95% CI: 0.812, 12.194, $p=0.097$), although the interaction coefficient for Family Health and social support in Model 1 did not reach statistical significance (OR: 0.718, 95% CI: 0.477, 1.082, $p=0.114$). When social support and Family Health were modeled independently (Model 2), the Family Health domain did not remain significant (OR: 1.167, 95% CI: 0.801, 1.703, $p=0.421$) (see Appendix D, Tables 4.7a-b for model estimates).

No evidence was found that social support modifies the relationship between the stressors domains and persistent asthma (Model 1). Although none of the interaction coefficients in Figure 4.1 were significant, they suggest that social support may protect against the risk of being characterized with persistent asthma. The Total stressors experienced by families may be an important predictor of asthma severity, with caregivers with more documented stressors being more likely to have children characterized with persistent asthma (relative to non-persistent asthma). While the results suggest that social support modifies the effect of Total stressors (Model 1) (OR: 1.744, 95% CI: 0.968, 3.144, $p=0.064$), the strength of the association between Total stressors and persistent asthma

Figure 4.1. Odds ratios and 95% confidence intervals for life stressors domains and social support in predicting emergency room visits (1 or more relative to none) and persistent asthma (relative to non-persistent asthma).



*SS, interaction with social support

+ significant at $p < 0.100$

significant at $p < 0.050$

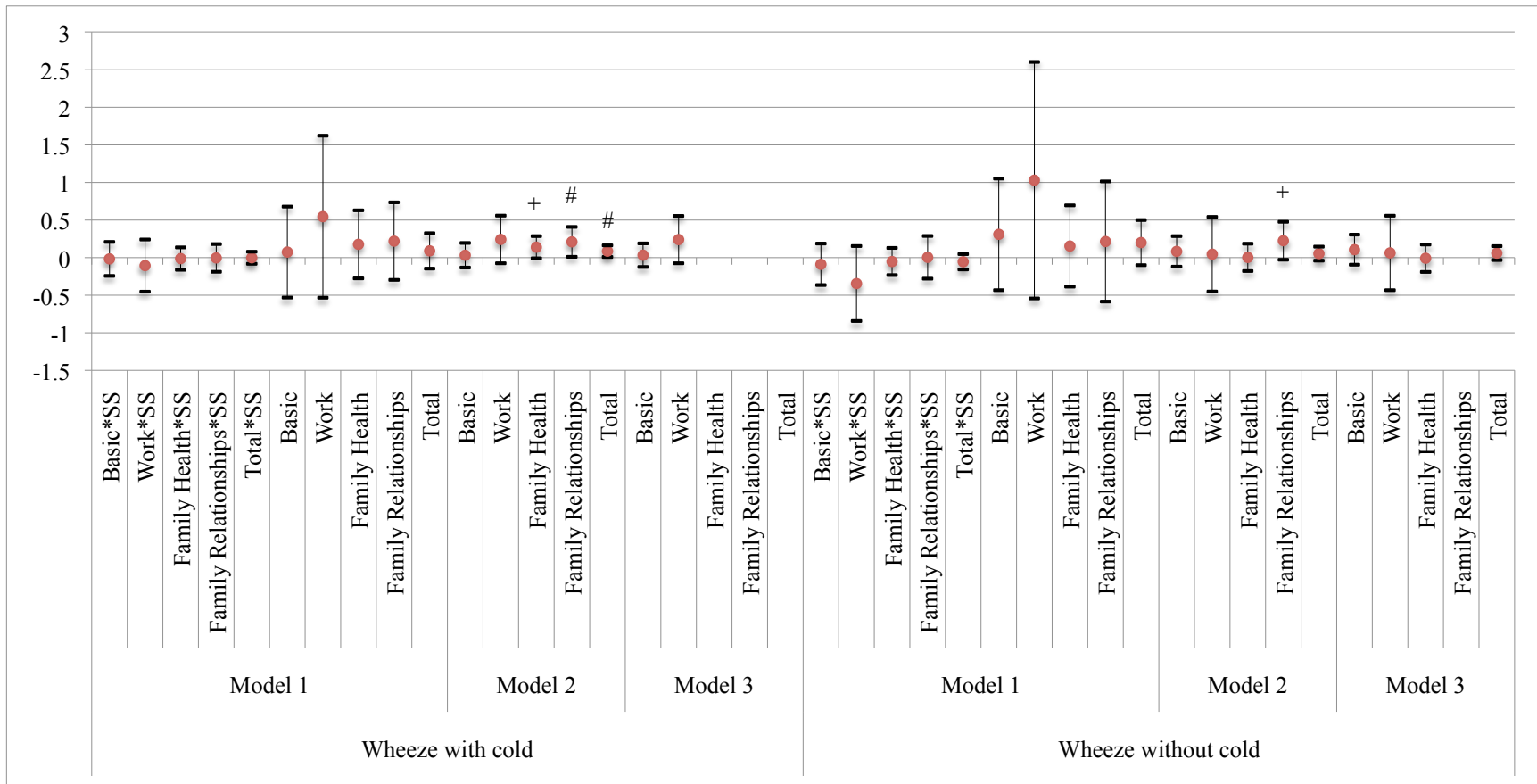
Bars, 95% confidence interval

NOTE: Model 3 is adjusted for caregiver basic demographics (age, gender, race/ethnicity, education, and household income) and the stressors domain. Model 2 is adjusted for Model 3 and social support. Model 1 is adjusted for Model 2 and social support, stressors domain interaction.

increased when the interaction term was removed from the model (Model 2) (OR: 1.311, 95% CI: 1.069, 1.606, $p=0.009$). Social support, however, was not shown to be an important predictor in models with Total stressors (OR: 0.692, 95% CI: 0.368, 1.299, $p=0.252$). The Family Relationships domain also reached statistical significance when it was modeled independent of social support in predicting persistent asthma (Model 2). Those who reported problems with Family Relationships had a greater odds of having a child categorized with persistent asthma compared to non-persistent asthma (OR: 2.041, 95% CI: 1.049, 3.970, $p=0.036$). Again, social support had no independent effect (OR: 0.678, 95% CI: 0.380, 1.210, $p=0.188$). None of the caregiver demographic variables were significantly associated with persistent asthma when Total stressors or Family Relationships were included in the models (see Appendix D, Tables 4.8a-b for model estimates).

Figure 4.2 presents the results from linear regression models predicting wheeze with and without cold. The effect of the stressors domains on wheeze appears to be tempered by social support. Several stressors domains were positively associated with worse asthma symptomatology in children with asthma when social support and stressors were modeled separately (Model 2). Reports of wheeze with cold were associated with Family Health (Estimate: 0.139, 95% CI: -0.009, 0.286, $p=0.065$), Family Relationships (Estimate: 0.210, 95% CI: 0.011, 0.409, $p=0.039$), and Total stressors (Estimate: 0.086, 95% CI: 0.009, 0.163, $p=0.030$), with more episodes of wheezing with cold for children whose families had more documented stressors in these domains. A significant relationship between wheeze without cold and the Family Relationships domain was also found (Estimate: 0.225, 95% CI: -0.028, 0.477, $p=0.081$). For all of these models, social support had no relationship to wheezing outcomes. However, non-Hispanic blacks reported significantly fewer episodes of wheeze with and without cold than their non-black counterparts in each of the aforementioned symptom-stressor models (see Appendix D, Table 4.8c-e for model estimates).

Figure 4.2. Point estimates and 95% confidence intervals for life stressors domains and social support in predicting wheeze with cold and wheeze without cold.



*SS, interaction with social support

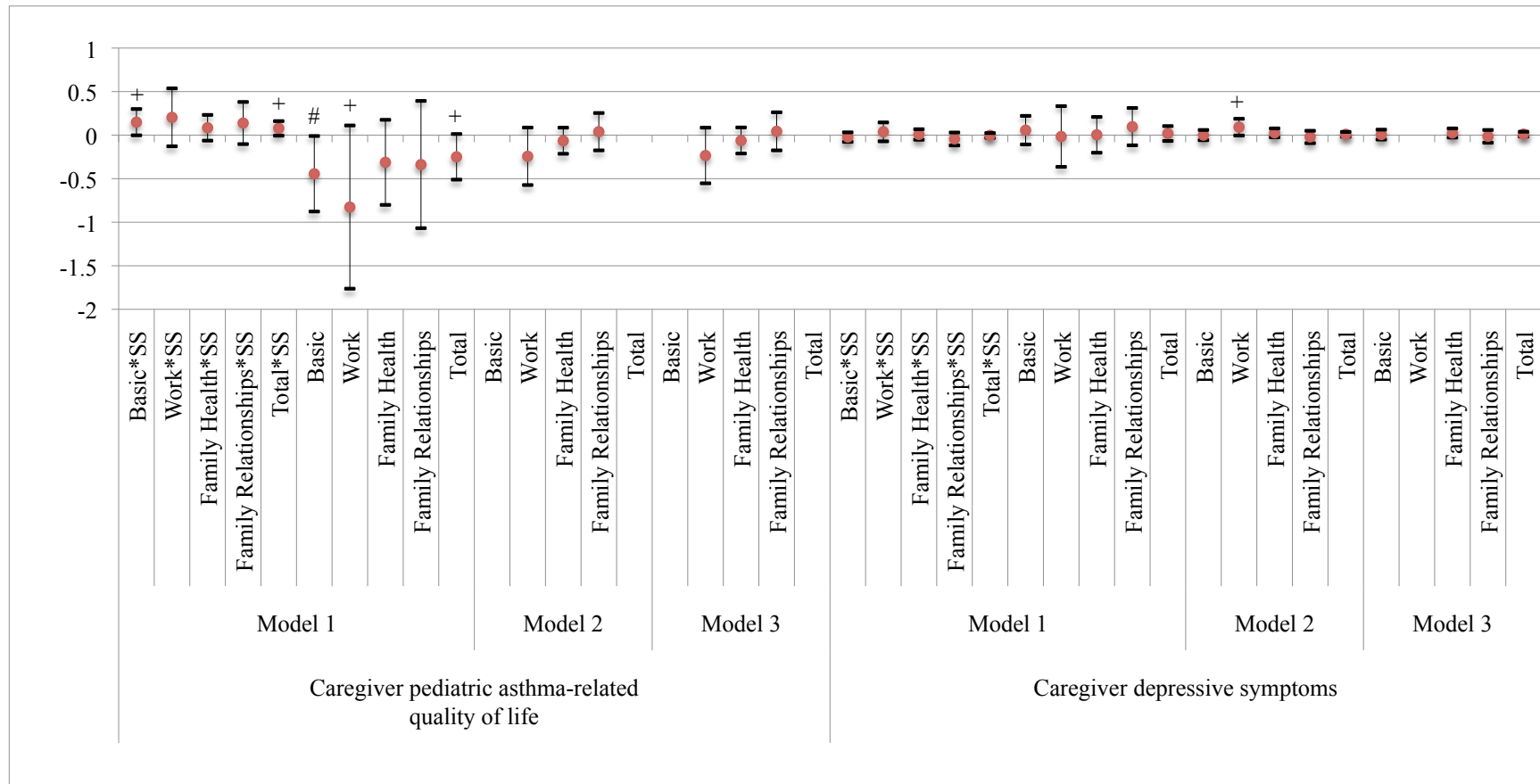
+ significant at $p < 0.100$; # significant at $p < 0.050$; Bars, 95% confidence interval

NOTE: Model 3 is adjusted for caregiver basic demographics (age, gender, race/ethnicity, education, and household income), the baseline value of the outcome, and the stressors domain. Model 2 is adjusted for Model 3 and social support. Model 1 is adjusted for Model 2 and social support, stressors domain interaction.

Figure 4.3 depicts the general trend of worse caregiver pediatric asthma-related QOL with more documented stressors, and that social support may buffer the impact of stressors on asthma-related QOL. Basic and Total stressors were each negatively associated with caregiver pediatric asthma-related QOL. Therefore, caregiver ratings of their QOL due to the child's asthma were worse for families with more documented Basic stressors (Estimate: -0.444, 95% CI: -0.877, -0.010, $p=0.045$). However, in the presence of social support, the negative impact of Basic stressors on asthma-related QOL was reduced (Estimate: 0.149, 95% CI: -0.002, 0.300, $p=0.052$). Caregiver age and female gender were positively associated with asthma-related QOL in models with Basic stressors. Total stressors was also significantly associated with worse asthma-related QOL (Estimate: -0.249, 95% CI: -0.511, 0.013, $p=0.062$), and social support was shown to buffer the effect (Estimate: 0.078, 95% CI: -0.006, 0.161, $p=0.068$). In models with Total stressors, older and female caregivers also demonstrated better asthma-related QOL. Although the interaction coefficient between the Work domain and social support was not statistically significant (Estimate: 0.204, 95% CI: -0.128, 0.537, $p=0.229$) in Model 1, the Work coefficient was significant (Estimate: -0.826, 95% CI: -1.763, 0.111, $p=0.084$). However, when modeled independently (Model 2), neither social support (Estimate: 0.067, 95% CI: -0.193, 0.327, $p=0.613$) nor the Work domain (Estimate: -0.243, 95% CI: -0.573, 0.087, $p=0.148$) explained the variance in asthma-related QOL (see Appendix D, Table 4.7c-d for model estimates).

As shown in Figure 4.3, Work was the only stressors domain that was predictive of caregiver depressive symptoms (Model 2). Caregivers indicating more work-related stressors also reported more symptoms of depression (Estimate: 0.092, 95% CI: -0.005, 0.188, $p=0.063$). Social support did not exhibit an independent effect on depressive symptoms (Estimate: -0.050, 95% CI: -0.136, 0.035, $p=0.251$). None of the demographic variables were associated with depressive symptoms. Incidentally, outside of depressive symptoms, the only other outcome with a statistically significant relationship to Work stressors was caregiver pediatric asthma-related QOL, though the interaction coefficient in Model 1 and the coefficient for the Work domain in Model 2 were not significant, and nor was social support (see Appendix D, Table 4.8f for model estimates).

Figure 4.3. Point estimates and 95% confidence intervals for life stressors domains and social support in predicting caregiver pediatric asthma-related quality of life and caregiver depressive symptoms.



*SS, interaction with social support

+ significant at $p < 0.100$; # significant at $p < 0.050$; Bars, 95% confidence interval

NOTE: Model 3 is adjusted for caregiver basic demographics (age, gender, race/ethnicity, education, and household income), the baseline value of the outcome, and the stressors domain. Model 2 is adjusted for Model 3 and social support. Model 1 is adjusted for Model 2 and social support, stressors domain interaction.

DISCUSSION

This study employs a novel approach of using the handwritten documentation made by CHWs during home visits with families of children with asthma to examine the impact of life stressors, on asthma-related health and QOL outcomes in a predominantly low-income, racially and ethnically diverse sample. To date, few studies have examined the impact of individual life stressor domains on health and QOL, instead relying on summative scores or biologic indicators of stressful life experiences for these inferences. The results from this study suggest that social support may have a differential role in modifying the impact of stressors on asthma-related outcomes, and that looking at stressors in their totality may actually mask important individual contributions of stressors domains on asthma-related health and QOL.

The Basic stressors domain was the only individual domain where social support had a significant and positive influence on asthma-related outcomes, specifically, ER visits and caregiver pediatric asthma-related QOL. When basics like food, clothing, and utilities are being met, caregivers may be better able to focus on the child with asthma and asthma trigger reduction, thus, averting episodes of asthma exacerbation that might land the child in the ER and resulting in more positive perceptions of asthma-related QOL. However, troubles securing basic needs and amenities can impact the well being of the entire family, particularly when the family is without food, heat, or beds/mattresses. Understandably, preventive health maintenance may not be a priority for caregivers in these dire circumstances. With non-existent or difficult to acquire resources and services common to low-income communities and communities of color, overcoming deficiencies in basic needs and amenities may present a formidable challenge without supportive networks in place. Thus, being able to garner instrumental, emotional, or affective social support to resolve or temporarily stave off Basic stressors may allow caregivers to focus their attention on activities to assist in the health of the child with asthma.

Although much of the research examining the impact of life stressors on asthma-related outcomes has measured stressors using quantitative and qualitative methods, findings have typically been reported by total life stressors or number of negative life stressors

(Sandberg, et al., 2004; Sandberg, et al., 2000; Shalowitz, et al., 2001; Shalowitz, et al., 2006). The unique contributions of many of the individual stressors domains in this study, therefore, would have been missed. A relationship between stressors domain and type of asthma-related outcome was demonstrated by the findings. For outcome measures associated with caregiver psychological functioning and QOL, Basic and Work stressors emerged as important predictors. Stressors in the Basic and Work domains may adversely impact caregivers' mental health because they reflect fundamental resources needed for survival. Furthermore, managing work- and school-related activities in conjunction with asthma has also been found to be among the most time-consuming demands for African American caregivers of children with asthma (Lee, et al., 2006). To compound these issues, resources in the community to assist caregivers in overcoming the stressors in these particular domains are limited because of high unemployment rates or few organizations with viable resources, which may elevate reports of depressive symptoms. With caregiver depressive symptoms potentially differentiating caregivers with children with diagnosed or potential asthma from those without asthma (Shalowitz, et al., 2006), interventions to reduce adverse outcomes for caregivers of children with asthma may hinge upon addressing factors that challenge their role as a family provider.

Outcomes related to the child's asthma severity and symptomatology tended to be associated with the Family Health and Family Relationships domains. The presence of competing health problems in the family may complicate the management and control of the child's asthma. Caregivers who are experiencing health problems themselves or are managing the health issues of other adults and children, in addition to one child with asthma, may be distracted from administering asthma medications on the correct schedule or not recognize or intervene before symptoms of asthma worsen. Although characteristics of poor family functioning have been associated with adverse asthma-related outcomes (Kaugars, et al., 2004), the association between persistent asthma and the Family Relationships domain—which includes problems with dealing with personal relationships and children's academic and behavioral problems—warrants further investigation. In a prospective study of children with asthma, family stress (or problems with interpersonal relationships among family members) was found to be associated with

cytokine production, with those who reported high chronic family stress having increased cytokine production, a mediator for immune response to foreign antigens, in the presence of an acute stressor (Marin, et al., 2009). It also may be that caregivers with children who are experiencing stressors around academic and behavioral problems may have a more difficult time getting their children to comply with behaviors to improve asthma control and management. As a result, these children may be more likely to be classified as having more severe asthma. An alternative explanation may be that the severity of the child's asthma may be influenced by his/her exposure to other family members' relationships, with more relationship stressors being associated with more severe asthma.

LIMITATIONS

While capitalizing on the strengths of a unique combination of data sources, this study has some notable limitations. First, the lack of standardization of CES documentation and elicitation likely created differences in reporting of stressors by CES. Some CESs may have reported more detail than others, thus, underestimating the stressors experienced by families. However, the documentation of life stressors during a planned nine (or more) repeat visits to the home over a one-year period allowed CESs not only to build a relationship with families but to capture these stressors experiences at regular intervals. Second, CES characteristics may have contributed to the quality and breadth of the data collected. For example, CESs who were better able to engage families may have encouraged more discussion around stressors than those who created more professional distance with families. Third, given the programmatic roles and responsibilities of CESs, the quality and accuracy of the documentation may have been subject to recall as caseloads were ramping up. Some stressors may not have been noted while others may have been noted incorrectly. The frequency of contacts and follow-up suggests that CESs got to know families and the details of their life stressors. Fourth, the documentation did not allow for assignation of severity to the stressors. The number of times an individual stressor was noted, for example, did not necessarily mean it was more severe in nature. Yet, CESs were able to elicit an incredible breadth of stressors that may not have been accessible otherwise. And, lastly, the correspondence between stressors and survey data may vary across families. Not knowing exactly when each stressor was experienced, the

date of the home visit was the best estimate to establish a temporal relationship to each stressor and, thus, the survey data.

IMPLICATIONS FOR RESEARCH

This study contributes preliminary evidence on the importance of examining the relationship of individual domains of life stressors, compared to a global assessment of life stress, and the role of social support in predicting asthma-related health and QOL outcomes. The differential impact of individual domains of life stress on the outcomes in this study underscores the need to better understand these and other stressors in order to intervene with low-income populations and populations of color to improve asthma-related outcomes. To determine the strength of these associations, next steps should include adding other covariates, in a step-wise fashion, to test their explanatory role. Among these are: the relationship of the caregiver to the child with asthma (i.e., mother, grandmother), home ownership status household size including the number of children and adults in the family, medication level, and caregiver self-rated health. In addition, because different outreach workers documented the stressors in this study, models should test if there is a significant CHW effect or if the number of home visits received impacts the associations.

Future research should explore if there are any notable similarities or differences in the life stressors experiences of important subsets of the population that may not have been well represented in the sample for this study. For example, the life stressors experienced by Hispanics, those without legal immigration status, grandparent caregivers, and male caregivers could reveal if perhaps different approaches to intervening to reduce life stressors, and improve asthma-related outcomes and social support, may be warranted. In addition, life stressors research should be extended to include caregivers of children with other chronic diseases, such as diabetes, to determine if the stressors experiences of racial/ethnic minority caregivers in low-income communities are similar regardless of the chronic disease experienced. Based on these findings, current measures of life stressors should be examined to see if they are representative of the experiences of low-income, racially/ethnically diverse populations.

More research on the role of social support is critical to understanding why social support modifies the relationship between some life stressors domains and asthma-related health and QOL outcomes but not others. Perhaps there are certain types of social support (i.e., emotional, instrumental, informational, or appraisal) that may be more effective in buffering the negative impact of, for example, not having basic needs and amenities on emergency room visits. Knowing this information could help in the development of interventions, particularly those utilizing CHWs, to provide needed support to families and, thus, improve the health of children with asthma and their caregivers. While CHW interventions have demonstrated improvements in asthma-related health and QOL outcomes, the provision of social support by CHWs has not been a focal point (Postma, Karr, & Kieckhefer, 2009). With a better understanding of the types of social support that are effective in helping low-income families to address their life stressors, the adverse impact of these stressors on asthma-related outcomes may be effectively tempered.

IMPLICATIONS FOR PRACTICE

A more detailed look at the stressors impacting families of children with asthma in low-income communities of color can inform the development of and support for appropriate community- and policy-level initiatives to reduce life stressors that adversely impact asthma, as well as other chronic diseases. For example, this might include establishing mentoring programs through community-based organizations to provide role models for young children who may be struggling with academic and behavioral problems. Furthermore, asthma control and management should be inclusion of helping families to resolve important stressors outside of asthma, such that health care professionals and school personnel view the discussion of the broad stressors experienced by families as standard practice.

While social support may be an effective strategy for modifying the impact of certain stressors on asthma-related health and QOL, the provision of social support should emphasize skills building so that families can effectively navigate the system in

environments where resources are absent or limited. One way to accomplish this is by integrating CHWs into more permanent supportive roles, based on their shared experiences and ability to establish rapport with families, so that they are accessible to those families in greatest need. As a part of their role, CHWs could educate families on what resources/services are available in their communities and how to access them to address current and future life stressors.

Chapter 5

Conclusion

This dissertation identified and explored life stressors impacting families of children with asthma and the characteristics and strategies of community health workers (CHWs) who mitigate these stressors through three separate studies : (i) a qualitative analysis of handwritten notes of CHWs who conducted home visits with caregivers of children with asthma in Detroit, Michigan, during an intensive household intervention study (n=115), (ii) qualitative in-depth interviews with CHWs from four asthma programs in diverse geographic regions in the U.S. (n=13), and (iii) a mixed-methods approach, in which the stressors identified in the first study were conceptualized into stressors domains and tested using multivariate regression to determine their association with asthma severity and symptoms, health services utilization, caregiver depressive symptoms, and caregiver pediatric asthma-related quality of life (QOL).

The findings from this dissertation highlight the life stressors facing families of children with asthma in low-income communities of color, effective characteristics and strategies of CHWs to intervene to address them, and their association with asthma-related health and QOL outcomes. Some of the lessons learned from this research are described in the paragraphs that follow.

Measurement of Life Stressors and Social Support

CHWs described a broad array of life stressors, in both their home visit documentation (Chapter 2) and their in-depth interviews (Chapter 3), as impacting families of children with asthma. As demonstrated in the mixed-methods study (Chapter 4), different domains of life stressors appear to be associated with different aspects of asthma management, suggesting the need for more specificity in life stressors measurement. Yet,

validation from families that these stressors are indeed important to their lived experience should also be sought. Data from these inquiries suggest that developing a new measure of life stress may be needed to adequately capture the breadth of stressors experienced by families. Including a measure of specific life stressors domains, which has generally been absent in asthma intervention study, may provide a more objective way to look at the stressors in larger low-income populations and populations of color and inform the development of appropriate asthma interventions.

Knowing specifically what types of social support are most effective in reducing the impact of life stressors on families of children with asthma can also have immense benefit. The measurement of social support, therefore, should be broadened to include an assessment of different types of non-disease specific support, i.e., emotional, instrumental, informational, and appraisal, in addition to family characteristics and family support. With the diverse life stressors that compete with efforts to manage and control asthma, asthma-specific social support may not adequately capture resources in the family's social environment that can be effective in modifying the negative impact of stressors on asthma-related health and QOL.

Community Health Worker Interventions

The effectiveness of interventions targeting families of children with asthma in low-income communities of color may be limited by the diverse and sometimes dire circumstances facing families. In order to begin to educate families on asthma, these other issues need to be addressed and/or resolved first. This can be accomplished by providing families with up-to-date resource lists and/or employing CHWs to assist families directly. As such, programs utilizing CHWs should be aware of the time required to assist families in low-income communities and communities of color. Not only may families in these areas be experiencing more life stressors, but CHWs' effectiveness in building trust and establishing rapport with families may encourage families to rely upon CHWs for any problems that may arise. Therefore, the time required to do their job may be increased exponentially.

Asthma programs should be aware of the potential for dependency on programmatic resources, services, and staff. At what point should CHWs stop offering assistance? CHWs from the multi-site study (Chapter 3) mentioned the need to encourage families' self-sufficiency, given that their involvement with the families would be time limited. Yet, they also expressed wanting to do everything they could to assist families. This suggests a tension in the CHW approach that might inadvertently lead to a dependence on CHW assistance among families. Few studies have examined this issue and whether it is indeed an issue of concern for programs utilizing CHWs.

Researchers should also recognize that families of children with asthma may be highly mobile, with frequent changes in their living arrangements, and have diverse family structures. Therefore, interventions should be flexible and accommodating of these changes. Portability of asthma-related equipment and supplies and issues around cost-effectiveness need to be balanced with the value of the science.

Community Health Workers as a Workforce

More research is needed to understand the contribution of CHW characteristics and strategies, whether innate or learned, to asthma intervention programs. With more specificity on the strategies and characteristics of CHWs that have been shown to be effective in asthma, best practices can be synthesized and integrated into CHW training and certification. The broad application of these characteristics and strategies to other chronic disease categories should also be explored. If there is overlap, preparing a curriculum that emphasizes applicable cross-disciplinary learning lends flexibility to employment of CHWs in the workforce. Furthermore, making this information more broadly accessible via web-based resources can maximize the reach of this information.

Assisting families with life stressors that can be prolonged in nature or experienced on repeat occasions can have an adverse impact on the emotional health and well being of CHWs. With few assistive resources available in low-income communities and communities of color, CHWs may feel somewhat powerless in their role to provide tangible assistance or helpful information to families. In addition, showing care and

compassion and providing a listening ear may be taxing, particularly when caregivers may not have anyone else to turn to. As a result, organizations or groups that employ CHWs should be cognizant of the need to provide counseling or supportive services for CHWs as a part of their job, which may have the added benefit of reducing worker burnout. Furthermore, teaching CHWs effective stress reduction techniques and opportunities for stress reduction may also be warranted.

Future Directions for Research on Life Stressors and Social Support

The findings from this dissertation indicate that individual stressors domains may make a unique contribution, above and beyond the sum of these stressors domains. Therefore, examining the association between specific stressors domains and asthma-related and other health and QOL outcomes, including the contribution of other covariates, may be a pivotal next step. The contribution of life stressors to the asthma-related health and QOL of other important subgroups of the population, which were not well represented in this study, is also warranted. This includes Hispanics, those without legal immigration status, grandparents caregivers, and caregivers who are male. Disparate life stressors experiences among these groups could lead to very different intervention approaches to improve asthma-related and other outcomes. Furthermore, expanding this research to include caregivers of children with other chronic diseases, such as diabetes, could answer if there are similarities in stressors experiences regardless of the chronic disease experienced.

The duties and responsibilities prescribed to CHWs in intervention research may underestimate the array of activities actually undertaken by CHWs. As a result, CHW activities should be documented and reviewed to ascertain if specific characteristics of or strategies used by CHWs are associated with positive outcomes related to asthma. Research on the role of social support should be expanded to understand not only what aspects of social support are common to families of children living in areas of disadvantage but also what aspects of social support have the potential to reduce the impact of life stressors and improve asthma-related outcomes.

Efforts to build capacity through sustainable community- and policy-level initiatives are sorely needed in low-income communities of color. While a lofty goal, advocating for funding and policies to improve access to basic needs and amenities has the potential to reduce poor asthma-related health and QOL outcomes and improve social support. Another potential area to develop includes integrating CHWs into public assistance or related programs to effectively counsel and reach individuals in greatest need, and ensure appropriate reimbursement from these programs. Lastly, health care professionals should be required to attend continuing medical education courses to discuss the impact of broad stressors on the health and QOL of caregivers and their children with asthma, so that assessing and addressing life stressors is standard practice for asthma control and management.

Appendices

Appendix A

Community Action Against Asthma Visit 1 Documentation Form

CES name _____

ID # of child _____

Address/telephone change _____

Date of visit _____

Time visit started _____

Time visit ended _____

Were the following topics covered? (Check in box if topic covered; if not, please provide an explanation of why you were unable to cover the topic in the "Comments/Observations section" on the next page

- Overview of project
- Key features of asthma
- Explanation of what are asthma triggers, what they do, and how you can control them
- How you can control asthma and the things a child can do if their asthma is controlled
- Medications

Supplies Given

- Asthma education pamphlets

Actions

- Check furnace filter for name, type so you can bring new filter next time
- Check bed where child sleeps to see if it is single or double bed so you can bring mattress cover. Ask if there are other children with asthma (to see how many covers you will need)

Questions from caregiver and how you responded?
(Please list any questions the caregiver asked about the project and/or asthma and briefly tell how you responded).

Questions from caregiver for which you need more information to answer.

Comments/observations that you want to note.

Follow-up actions by CES.

Action steps for caregiver, if any (please attach).

Appendix B

Community Health Worker Interview Guide (HUM00040640)

INTRODUCTION

Thank you for speaking with me today. With your help, we would like to identify situations or events that may be difficult for families of children with asthma to deal with and may cause stress (which we will refer to as “stressors” throughout this interview). In particular, we are interested in learning about the stressors experienced by families of children with asthma who live in low-income communities of color, that is, issues that may cause stress in their every day lives, whether related to asthma or not. These could include stressors in the home or in the neighborhood, things that might have happened to family members or friends that may be stressful, or issues impacting families’ abilities to care for a child (or children) with asthma. In addition, we would like to explore ways that community health workers, such as yourself, help families to address these stressors and to improve their health and quality of life. By sharing your knowledge and experiences as a community health worker, the information you provide will help us to design more effective interventions so that we may better assist families of children with asthma, and particularly those who live in low-income communities of color.

[READ DEFINITION IF RESPONDENT NEEDS MORE CLARITY]

[DEFINITION – STRESSOR: An event or situation that is difficult to deal with and may cause stress in a person’s life. For example, stressors could include non-asthma related issues such as death of a loved one and worries about paying bills, or asthma-related issues such as difficulties with pest control in the home and trouble with frequent asthma attacks]

Do you have any questions before we get started?

EXPERIENCE AS A COMMUNITY HEALTH WORKER

I'd like to start off by asking you about your experience as a community health worker working with families of children with asthma.

1. Specifically, how long have you worked with families of children with asthma as a community health worker?
2. What type(s) of organizations have you been employed by as a community health worker, specifically, working with families of children with asthma?

[PROBE: community-based organization/agency, health department, university]

3. In general, what are the characteristics of the families of children with asthma you have worked with as a community health worker, in terms of, for example, their age, gender, race/ethnicity, income?

[PROBE: family size, marital status, employment status, single/multi-family home]

4. Briefly, please describe your role as a community health worker specific to your work with families of children with asthma, that is, what do you do?

[PROBE: make referrals, provide emotional/social support, provide education, provide equipment/supplies]

FAMILY LIFE STRESSORS

I'd now like to focus our discussion on identifying situations or events that may be difficult for families of children with asthma to deal with and may cause stress for families. Again, these stressors could include things that affect families' day-to-day living, specific events or situations experienced by caregivers or children that may be stressful, or ongoing strains or issues that families face. I'd like to encourage you to think broadly about the stressors that families you work with experience, and not limit yourself only to those stressors that are related to the child's asthma.

5. Thinking about some of the specific challenges faced by the families of children with asthma that you work with—such as those brought about by our current economic situation—I'd like to ask you to complete the following phrase: The families of children with asthma that I work with have difficulties dealing with [and may experience stress in their lives when]...

[LIST STRESSORS – VERBATIM WHENEVER POSSIBLE]

[ENCOURAGE RESPONDENT TO THINK BROADLY – BOTH STRESSORS RELATED TO ASTHMA AND THOSE BEYOND THE DISEASE ITSELF]

[READ DEFINITIONS IF RESPONDENT DOES NOT COVER RANGE OF POSSIBLE STRESSORS]

- [DEFINITION / EXAMPLES – DAILY HASSLES (ANNOYANCES) – common or minor experiences that might be frustrating or bothersome on a day-to-day basis – e.g., unreliable transportation, job dissatisfaction]**
- [DEFINITION / EXAMPLES – STRESSFUL LIFE EVENTS – major events or situations that disrupt or threaten to disrupt normal activities; events or situations associated with changes or transitions in life stages – e.g., death of a loved one, being the victim of a crime, getting married, birth of a child]**
- [DEFINITION / EXAMPLES – CHRONIC/ONGOING STRAINS – challenges, hardships, and problems that people experience over time in their daily lives; events or situations that cause people to make life adjustments continuously – e.g., not having enough food for the family, chronic disease]**

[PROBE: To help you in thinking about the types of stressors faced by the families you work with, what kinds of referrals do you make for families?]

6. Of all the stressors you have mentioned, which ones do you think are most difficult or challenging for the families you work with to overcome? [STRESSOR]

[ASK – “Why do you think [STRESSOR] is so difficult or challenging for the families you work with?” as each one is mentioned]

7. We have talked about stressors that are difficult or challenging for families to overcome, now I'd like you to think about which stressors—whether related to asthma or not—have the greatest negative impact on families' abilities to care for a child (or children) with asthma?
[STRESSOR]

[PROBE: stressors that place the greatest demand on caregiver(s), stressors that require the most effort or energy to resolve, stressors that might get in the way of taking care of a child with asthma]

[ASK – “In what way does [STRESSOR] impact families' abilities to care for a child with asthma?” as each one is mentioned]

8. What impact, if any, have the stressors that families of children with asthma experience had on the health and quality of life of caregivers of children with asthma?

[PROBE: caregiver's physical and mental health, caregiver's quality of life or general emotional, social, and physical well-being]

9. What impact, if any, have the stressors that families of children with asthma experience had on the health and quality of life of the child with asthma?

[PROBE: child's physical and mental health, breathing problems/asthma symptoms, and quality of life or general emotional, social, and physical well-being]

10. What impact, if any, have the stressors that families of children with asthma experience had on the health and quality of life of other family members, adults and children alike?

[PROBE: other family members' physical and mental health, other family members' quality of life or general emotional, social, and physical well-being]

COMMUNITY HEALTH WORKER STRATEGIES AND CHALLENGES

Now that we have talked about the various situations or events that may cause stress for families of children with asthma, I would like to switch gears and have you think about things that you have done to help these families to overcome these stressors.

11. As a community health worker, what kinds of things have you done to help families to resolve or lessen the impact of their stressors? For example, thinking about the stressors that you have mentioned, what kinds of things have you done to help families with these issues?

[LIST CHW STRATEGIES – VERBATIM WHENEVER POSSIBLE]

[ASK – “You also mentioned [STRESSOR], what have you done to help families resolve this issue?” for those not mentioned]

12. Of the things that you have done to help these families, what do you believe have been most effective in helping these families resolve or lessen the impact of the stressors that affect their ability to care for a child or children with asthma? That is, what kinds of assistance are most critical for families of children with asthma? [STRATEGY]

[ASK – “Why is [STRATEGY] so critical?” as each one is mentioned]

13. What are some of the challenges you have faced while assisting families of children with asthma in addressing some of the things that may cause stress for them?

[LIST CHALLENGES – VERBATIM WHENEVER POSSIBLE]

[PROBE: receptivity of families to information/assistance, availability of resources (both in the community and for CHWs), scheduling follow-up visits with families]

14. As a community health worker, what have you done to overcome some of the challenges you have identified?

[ASK – “For example, what have you done to overcome [CHALLENGE]?” for each one mentioned]

Now, I would like to ask you about the ways that you, as a community health worker, establish trust, build relationships, and engage with the families you work with.

15. In your role as a community health worker, you make multiple visits to the same individuals or families over time. I would like to hear about some of the things you have done to build relationships and establish trust.

[PROBE: how do you communicate with the family, how do you establish your/project's legitimacy, how do you make families feel comfortable]

16. When you first visit a family, what are some of the strategies you have used to get families interested in participating in [STUDY/PROGRAM]?

[PROBE: how do you present yourself and [STUDY/PROGRAM], how do you get your foot in the door]

17. Given the lapse in time between home visits, please describe some of the strategies you have used to keep families interested and engaged in [STUDY/PROGRAM]?

[PROBE: how do you communicate with families, how do you encourage families to stay involved with the [STUDY/PROGRAM], how do you motivate families]

18. Sometimes there are things that make it difficult for families to continue their participation in projects or research. In your experience with families of children with asthma, what kinds of things have made it difficult for the families you work with to continue their participation?

[LIST LOSS TO FOLLOW-UP – VERBATIM WHENEVER POSSIBLE]

[ASK – “What kinds of things have you done to encourage families’ continued participation with [LOSS TO FOLLOW-UP]?” as each one is mentioned]

PERSONAL REFLECTION

19. As we've discussed, there are some things that limit what community health workers can do within the confines of time, money, and other resources. Given our discussion today, if you were to design a one-year community health worker home visiting program for families of children with asthma, what are absolutely essential elements to include?

[PROBE: what services should CHWs perform, what supplies should families receive, what resources should be available to families, what resources should be available to CHWs]

20. Specific to your work with families of children with asthma, as a community health worker, what do you find most rewarding about your work?

21. We have talked about some of the challenges you have faced while working with families of children with asthma, but what would you say is most challenging about your work?

22. Is there anything else that we haven't talked about today that you would like to tell me about?

Thank you for taking the time to talk with me today. The findings from this project will be shared with participating sites, programs, and interviewees from diverse geographic locales across the United States. The information that you have provided me with today will be useful in helping us to determine how to more effectively design future asthma intervention projects in low-income communities of color, particularly those utilizing community health workers. I look forward to sharing a summary of the findings with you in written format in the near future. Thank you again for your willingness to help with this important project.

Appendix C

Community Health Worker Demographic Questionnaire (HUM00040640)

Experiences and Roles as a Community Health Worker

1. In your role as a community health worker, not just for asthma, which of the following type(s) of organizations have you been employed by? **[CHECK ALL THAT APPLY]**

- ₁ State or Local Health Department
- ₂ Community-based Organization/Agency
- ₃ Health Clinic
- ₄ Hospital
- ₅ University/College
- ₆ National Organization
- ₇ Other (specify _____)

2. In your role as a community health worker, which of the following type(s) of health conditions have you worked to address? **[CHECK ALL THAT APPLY]**

- ₁ Asthma
- ₂ Diabetes
- ₃ Heart/Cardiovascular disease
- ₄ HIV/AIDS
- ₅ Maternal-child health
- ₆ Other (specify _____)

3. Including all of your experiences, not just for asthma, how long have you worked as a community health worker?

_____ year(s)

Basic Demographics

4. Are you: ₁ Male
₂ Female
5. Which of the following categories best represents your current age?
₁ 21-30 years
₂ 31-40 years
₃ 41-50 years
₄ 51-60 years
₅ Over 60
6. Are you Hispanic or Latino? ₁ Yes
₂ No
7. Which of the following best represents your race? **[PLEASE CHECK ONE ONLY]**
₁ African American/Black
₂ American Indian/Alaska Native
₃ Arab/Middle Eastern/Chaldean
₄ Asian
₅ Caucasian/White
₆ Native Hawaiian or Other Pacific Islander
₇ Multi-Racial (specify _____)
₈ Other (specify _____)
8. What is the highest grade or year of school you have completed?
₁ Grades 1 through 8
₂ Grades 9 through 11 (some high school)
₃ Grade 12 (high school graduate)
₄ GED
₅ College 1 year to 3 years (some college or technical school or associates degree)
₆ College 4 years or more (college graduate)

9. Outside of your role as a community health worker, do you, personally, care for a child with asthma?

₁ Yes

₂ No

10. Do you care for someone else with asthma?

₁ Yes

₂ No

11. Do you, yourself, have asthma?

₁ Yes

₂ No

Appendix D

Results from Logistic and Linear Regression Models Exploring the Association Between Life Stressors Domains and Asthma-related Health and Quality of Life, and Social Support

Table 4.7a-b. Odds ratios of emergency room visits (1 or more relative to none) associated with caregiver demographic characteristics, baseline social support, and the Basic (4.7a) or Family Health stressors domain (4.7b).

a	Model 1			b	Model 1		
	OR	95% CI	p-value		OR	95% CI	p-value
Age	1.007	0.961, 1.054	0.785	Age	1.008	0.959, 1.059	0.760
Gender female	0.369	0.028, 4.879	0.449	Gender female	0.603	0.063, 5.758 0.583,	0.660
Race/ethnicity non-Hispanic Black	7.087	0.719, 69.882	0.094	Race/ethnicity non-Hispanic Black	4.161	+ 29.681	0.155
Education Less than high school	0.209	0.047, 0.924	0.039	Education Less than high school	0.211	0.048, 0.927	0.039
High school graduate	1.227	0.370, 4.069	0.738	High school graduate	1.364	0.401, 4.636	0.619
Post high school				Post high school			
Household income < \$10,000	1.233	0.391, 3.887	0.721	Household income < \$10,000	1.339	0.425, 4.220	0.618
\$10,001 - \$20,000	0.465	0.138, 1.571	0.218	\$10,001 - \$20,000	0.504	0.137, 1.852	0.302
> \$20,000				> \$20,000			
Domain: Basic	3.975	1.070, 14.764	0.039	Domain: Family Health	3.147	0.812, 12.194	0.097
Social Support (SS)	1.617	0.778, 3.363	0.198	Social Support (SS)	2.032	0.644, 6.414	0.227
Basic*SS	0.548	0.298, 1.007	0.053	Family Health*SS	0.718	0.477, 1.082	0.114

Table 4.7c. Caregiver Paediatric Asthma-related Quality of Life (PACQLQ) at year one regressed on caregiver demographic characteristics, baseline PACQLQ, the Basic stressors domain, and baseline social support.

	Coeff	Model 1		p-value
		95% CI		
Intercept	0.678	-2.255, 3.610		0.651
Age	0.021	0.000, 0.042		0.048
Gender				
female	1.036	-0.164, 2.235		0.091
Race/ethnicity				
non-Hispanic Black	0.108	-0.476, 0.692		0.716
Education				
Less than high school	0.094	-0.557, 0.745		0.777
High school graduate	0.108	-0.524, 0.739		0.738
Post high school				
Household income				
< \$10,000	-0.097	-0.733, 0.540		0.766
\$10,001 - \$20,000	0.179	-0.294, 0.652		0.459
> \$20,000				
PACQLQ at baseline	0.408	0.222, 0.594		<.0001
Domain: Basic	-0.444	-0.877, -0.010		0.045
Social Support (SS)	-0.045	-0.352, 0.263		0.777
Basic*SS	0.149	-0.002, 0.300		0.052

Table 4.7d. Caregiver Paediatric Asthma-related Quality of Life (PACQLQ) at year one regressed on caregiver demographic characteristics, baseline PACQLQ, Total stressors, and baseline social support.

	Coeff	Model 1		p-value
		95% CI		
Intercept	1.310	-1.786, 4.406		0.407
Age	0.021	0.001, 0.042		0.041
Gender				
female	0.915	-0.174, 2.004		0.100
Race/ethnicity				
non-Hispanic Black	0.199	-0.415, 0.813		0.526
Education				
Less than high school	0.096	-0.533, 0.725		0.765
High school graduate	0.039	-0.597, 0.674		0.905
Post high school				
Household income				
< \$10,000	-0.083	-0.715, 0.550		0.797
\$10,001 - \$20,000	0.228	-0.263, 0.720		0.363
> \$20,000				
PACQLQ at baseline	0.407	0.222, 0.591		<.0001
Domain: Total	-0.249	-0.511, 0.013		0.062
Social Support	-0.179	-0.559, 0.200		0.355
Total*SS	0.078	-0.006, 0.161		0.068

Table 4.8a-b. Odds ratios of persistent asthma (relative to intermittent) associated with caregiver demographic characteristics, baseline social support, and the Family Relationships stressors domain (4.8a) or Total stressors (4.8b).

a	Model 1			Model 2		
	OR	95% CI	p-value	OR	95% CI	p-value
Age	0.975	0.931, 1.022	0.293	0.975	0.931, 1.022	0.291
Gender						
female	4.671	0.137, 159.734	0.392	3.716	0.153, 90.091	0.420
Race/ethnicity						
non-Hispanic Black	0.398	0.107, 1.482	0.170	0.394	0.106, 1.467	0.165
Education						
Less than high school	0.349	0.078, 1.566	0.170	0.370	0.085, 1.621	0.187
High school graduate	0.897	0.259, 3.106	0.864	0.842	0.247, 2.871	0.783
Post high school						
Household income						
< \$10,000	2.997	0.687, 13.072	0.144	2.897	0.702, 11.967	0.142
\$10,001 - \$20,000	0.420	0.123, 1.433	0.166	0.436	0.130, 1.460	0.178
> \$20,000						
Domain: Family Relat	5.718	0.625, 52.290	0.123	2.041	1.049, 3.970	0.036
Social Support (SS)	0.750	0.408, 1.377	0.353	0.678	0.380, 1.210	0.188
Family Relat*SS	0.712	0.373, 1.357	0.301			
Relat, Relationship						

b	Model 1			Model 2		
	OR	95% CI	p-value	OR	95% CI	p-value
Age	0.992	0.950, 1.035	0.698	0.990	0.949, 1.034	0.661
Gender						
female	9.658	0.936, 99.629	0.057	7.376	0.789, 68.952	0.080
Race/ethnicity						
non-Hispanic Black	0.330	0.085, 1.285	0.110	0.305	0.079, 1.184	0.086
Education						
Less than high school	0.293	0.057, 1.514	0.143	0.299	0.060, 1.493	0.141
High school graduate	0.991	0.272, 3.618	0.989	0.928	0.261, 3.303	0.909
Post high school						
Household income						
< \$10,000	3.341	0.739, 15.117	0.117	3.241	0.733, 14.336	0.121
\$10,001 - \$20,000	0.389	0.115, 1.313	0.128	0.418	0.128, 1.361	0.148
> \$20,000						
Domain: Total	1.744	0.968, 3.144	0.064	1.311	1.069, 1.606	0.009
Social Support (SS)	0.886	0.410, 1.915	0.759	0.692	0.368, 1.299	0.252
Total*SS	0.906	0.749, 1.095	0.305			

Table 4.8c-d. Wheeze with cold at year one regressed on caregiver demographic characteristics, baseline wheeze with cold, baseline social support, and the Family Health stressors domain (4.8c) or Total stressors (4.8d).

c	Model 1			Model 2		
	Coeff	95% CI	p-value	Coeff	95% CI	p-value
Intercept	2.036	-0.412, 4.484	0.103	2.123	-0.061, 4.307	0.057
Age	0.006	-0.019, 0.031	0.642	0.006	-0.019, 0.030	0.644
Gender						
female	-0.131	-0.994, 0.732	0.766	-0.146	-1.003, 0.711	0.738
Race/ethnicity						
non-Hispanic Black	-0.740	-1.444, -0.036	0.040	-0.740	-1.442, -0.037	0.039
Education						
Less than high school	-0.234	-0.789, 0.321	0.409	-0.237	-0.797, 0.324	0.408
High school graduate	0.076	-0.453, 0.605	0.778	0.071	-0.451, 0.592	0.791
Post high school						
Household income						
< \$10,000	0.383	-0.243, 1.009	0.230	0.387	-0.242, 1.016	0.228
\$10,001 - \$20,000	-0.335	-0.966, 0.297	0.299	-0.329	-0.953, 0.297	0.303
> \$20,000						
Wheeze with cold	0.453	0.267, 0.640	<.0001	0.452	0.265, 0.640	<.0001
Domain: Family Health	0.177	-0.276, 0.629	0.445	0.139	-0.009, 0.286	0.065
Social Support (SS)	0.011	-0.371, 0.393	0.954	-0.006	-0.294, 0.281	0.966
Family Health*SS	-0.013	-0.162, 0.136	0.865			

d	Model 1			Model 2		
	Coeff	95% CI	p-value	Coeff	95% CI	p-value
Intercept	1.815	-0.442, 4.072	0.115	1.835	-0.222, 3.892	0.080
Age	0.009	-0.014, 0.032	0.430	0.009	-0.014, 0.032	0.430
Gender						
female	-0.099	-0.931, 0.733	0.815	-0.101	-0.928, 0.726	0.810
Race/ethnicity						
non-Hispanic Black	-0.811	-1.528, -0.095	0.026	-0.812	-1.532, -0.092	0.027
Education						
Less than high school	-0.335	-0.885, 0.215	0.233	-0.336	-0.886, 0.214	0.232
High school graduate	0.040	-0.497, 0.576	0.885	0.038	-0.493, 0.569	0.888
Post high school						
Household income						
< \$10,000	0.406	-0.200, 1.011	0.189	0.406	-0.201, 1.014	0.190
\$10,001 - \$20,000	-0.296	-0.907, 0.315	0.343	-0.294	-0.896, 0.308	0.338
> \$20,000						
Wheeze with cold	0.445	0.252, 0.638	<.0001	0.444	0.249, 0.640	<.0001
Domain: Total	0.090	-0.146, 0.325	0.454	0.086	0.009, 0.163	0.030
Social Support (SS)	0.030	-0.362, 0.421	0.882	0.025	-0.261, 0.310	0.865
Total*SS	-0.002	-0.082, 0.079	0.970			

Table 4.8e. Wheeze without cold at year one regressed on caregiver demographic characteristics, baseline wheeze without cold, the Family Relationships stressors domain, and baseline social support.

	Model 1			Model 2		
	Coeff	95% CI	p-value	Coeff	95% CI	p-value
Intercept	2.584	-0.860, 6.028	0.141	2.576	-0.816, 5.969	0.137
Age	0.011	-0.016, 0.038	0.437	0.011	-0.016, 0.038	0.436
Gender						
female	-0.110	-1.562, 1.343	0.883	-0.109	-1.557, 1.340	0.883
Race/ethnicity						
non-Hispanic Black	-0.870	-1.662, -0.078	0.031	-0.870	-1.662, -0.078	0.031
Education						
Less than high school	-0.405	-1.154, 0.343	0.289	-0.405	-1.142, 0.333	0.282
High school graduate	0.330	-0.307, 0.968	0.310	0.331	-0.297, 0.959	0.301
Post high school						
Household income						
< \$10,000	0.382	-0.383, 1.147	0.327	0.381	-0.370, 1.133	0.320
\$10,001 - \$20,000	-0.301	-1.028, 0.426	0.417	-0.303	-1.009, 0.404	0.401
> \$20,000						
Wheeze without cold	0.396	0.228, 0.565	<.0001	0.397	0.229, 0.564	<.0001
Domain: Family Relat	0.214	-0.585, 1.014	0.599	0.225	-0.028, 0.477	0.081
Social Support (SS)	-0.113	-0.467, 0.242	0.533	-0.111	-0.438, 0.216	0.507
Family Relat*SS	0.004	-0.280, 0.288	0.979			

Table 4.8f. Depressive symptoms at year one regressed on caregiver demographic characteristics, baseline depressive symptoms, the Work stressors domain, and social support.

	Model 1			Model 2		
	Coeff	95% CI	p-value	Coeff	95% CI	p-value
Intercept	1.788	0.658, 2.918	0.002	1.760	0.625, 2.895	0.002
Age	-0.001	-0.008, 0.005	0.737	-0.001	-0.008, 0.005	0.705
Gender						
female	-0.387	-0.865, 0.090	0.112	-0.382	-0.864, 0.100	0.120
Race/ethnicity						
non-Hisp Black	0.050	-0.146, 0.246	0.618	0.041	-0.159, 0.241	0.689
Education						
Less than high school	0.129	-0.070, 0.327	0.204	0.125	-0.074, 0.324	0.218
High school graduate	0.076	-0.104, 0.257	0.407	0.082	-0.098, 0.262	0.369
Post high school						
Household income						
< \$10,000	0.098	-0.091, 0.287	0.307	0.107	-0.082, 0.297	0.267
\$10,001 - \$20,000	-0.060	-0.229, 0.109	0.487	-0.062	-0.231, 0.108	0.476
> \$20,000						
CES-D at baseline	0.360	0.196, 0.523	<.0001	0.347	0.186, 0.508	<.0001
Domain: Work	-0.016	-0.364, 0.333	0.930	0.092	-0.005, 0.188	0.063
Social Support (SS)	-0.066	-0.158, 0.026	0.159	-0.050	-0.136, 0.035	0.251
Work*SS	0.038	-0.071, 0.146	0.495			
Relat, Relationships						

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