

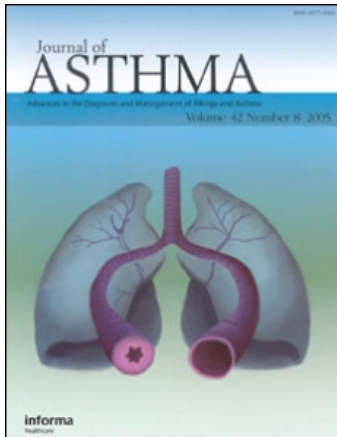
This article was downloaded by: [Holsey, Chanda Nicole]

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Access details: Access Details: [subscription number 914416051]

Publisher Informa Healthcare

Informa Ltd Registered in England and Wales Registered Number: 1072954 Registered office: Mortimer House, 37-41 Mortimer Street, London W1T 3JH, UK



Journal of Asthma

Publication details, including instructions for authors and subscription information:

<http://www.informaworld.com/smpp/title-content=t713597262>

Barriers to Asthma Management Among Urban Families: Caregiver and Child Perspectives

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Online Publication Date: 01 September 2009

To cite this Article Laster, Nastassia, Holsey, Chanda N., Shendell, Derek G., Mccarty, Frances A. and Celano, Marianne(2009)'Barriers to Asthma Management Among Urban Families: Caregiver and Child Perspectives',*Journal of Asthma*,46:7,731 — 739

To link to this Article: DOI: 10.1080/02770900903082571

URL: <http://dx.doi.org/10.1080/02770900903082571>

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REVIEW ARTICLE

Barriers to Asthma Management Among Urban Families: Caregiver and Child Perspectives

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Objective. Asthma is one of the most common chronic diseases of childhood. Those particularly affected are young, poor, African American children. Moreover, rates of emergency department visits, hospitalizations, and mortality are substantially higher for black children. Despite the ample published research on asthma prevalence and asthma management interventions, there is little research available on barriers to asthma care among urban, low-income families as perceived by children with asthma and their caregivers. **Methods.** This qualitative study analyzed data from five focus groups conducted with 28 participants in metropolitan Atlanta. **Results.** This study found caregiver and child health beliefs and perceptions concerning the use of daily controller medications to be a significant barrier to asthma care and proper self-management at home and at school. Barriers to environmental control consisted mostly of financial constraints, which made residential environmental remediation activities difficult to implement. Psychological distress was prevalent among both children and caregivers, which demonstrated the burden associated with managing a chronic illness. **Conclusion.** Families in urban, low-income communities require asthma management interventions tailored to their specific characteristics, barriers, and challenges. Our findings can be used to inform and enhance asthma management interventions for urban families with children with asthma.

Keywords pediatric asthma, focus groups, urban families, barriers, management

INTRODUCTION

The burden of asthma in the United States (U.S.) remains high (1). In 2006, there were approximately 22.9 million physician-diagnosed cases of asthma in the U.S., and about 6.8 million of those cases were children (2). In 2007, 9.1% of children in the U.S., or about 6.7 million, currently had asthma (19). The highest prevalence rates were seen among children 5 to 17 years of age, which constituted 106.3 cases per 1,000 persons in 2006 (2).

The severity of the burden of asthma is most reflected in mortality rates (1, 3) and health care utilization rates. About 3% of hospitalizations, a total of 198,000 hospitalizations, among children in 2004 in the U.S. were due to asthma (1). Asthma emergency room or department (ED) visits accounted for 2.8%, a total of about 720,000 visits, of all ED visits among American children in 2004 (1).

Asthma disproportionately affects young, poor, African American children. Moreover, rates of ED visits, hospitaliza-

tions, and mortality are substantially higher for black children (1, 4). In the state of Georgia, the estimated asthma prevalence among children was reported to be about 12% for black children and about 10% among white children (3). In addition, children who lived in households with an annual income of less than \$20,000 had an estimated asthma prevalence of 17%, the highest among all income groups in Georgia (3).

Although black children have a higher prevalence of asthma, they have a lower rate of ambulatory, or outpatient, care visits. In 2004, black children had 19% fewer ambulatory care visits than white children, a disparity that may have contributed to disparities in ED use, hospitalizations, and mortality (1). Furthermore, also in 2004, in the U.S., compared with white children, black children had a 260% higher ED visit rate, a 250% higher hospitalization rate, and a 500% higher mortality rate for asthma than white children (1).

Despite ample research on various aspects of childhood asthma, the effect of race and ethnicity on asthma prevalence remains uncertain. In fact, many studies have found much of the apparent (perceived) racial differences in asthma prevalence to be confounded by socioeconomic status (SES) and urban residence (5–7). Concentrated neighborhood poverty and other conditions common to urban areas, such as racial segregation, may magnify the effects of poverty and contribute to the deterioration of the physical and social

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environment. Physical environmental factors common to urban areas, such as increased exposure to allergens and irritants (e.g., known environmental asthma triggers like particles from various sources such as diesel exhaust and re-suspended dust, dust mites, pet feces, and cockroach feces), deteriorating housing conditions, and overcrowding, may adversely impact the treatment of asthma (6). Social factors related to urban poverty, such as increased prevalence of mental illness, single parent status, and daily financial stress, may affect the ability to effectively manage a chronic illness such as asthma (5).

While poor, black children living in urban areas are disproportionately affected by asthma, their caregivers—parents, legal guardians, family members, relatives—also experience challenges that may impede their ability to successfully manage their child's asthma. In addition to the adverse social and physical factors of the urban environment, urban caregivers of children with asthma may have limited access to medical care due to financial constraints or barriers related to insurance coverage. Black urban caregivers may also have specific health beliefs that conflict with provider recommended treatment guidelines (8, 9). These challenges are important as low-income African American caregivers have identified the caregiver-healthcare provider relationship as a key factor in their ability to manage their child's asthma (10, 11).

Several studies have investigated barriers to clinical and/or environmental asthma management among children with quantitative metrics, e.g., Pediatric Asthma Quality of Life Questionnaire (PAQLQ) for children and the Pediatric Asthma Caregivers Quality of Life Questionnaire (PACQLQ) for adults who care for them (parents, guardians, caregivers including relatives). There are relatively few published studies using qualitative methods to identify barriers related to asthma management and burden of illness as perceived by both children with asthma and their caregivers. Qualitative techniques, such as focus groups, may prove useful in building self-efficacy among caregivers by providing a means of active participation and inquiry. The purpose of this study was to identify and describe potential barriers to effective asthma management among low-income urban families, as perceived by both children with asthma and their caregivers, using focus groups with a semi-structured format of standardized scripts of openended questions to drive discussions. Findings can be used to appropriately tailor asthma interventions for low-income urban African American children with asthma and their families.

METHODS

Focus groups were included as the first specific aim of Project ASPIRE, a community-based participatory research project jointly conducted by the American Lung Association—Southeast Region and the Emory University School of Medicine. The purpose of the focus groups was to inform the curriculum of a proposed home-based family intervention and associated training materials (13) developed in consultation with Project ASPIRE's Community Advisory Board. The second specific aim of Project ASPIRE was to conduct a pilot study of the family intervention, evaluating its initial efficacy, feasibility, and acceptability for up to 25 families receiving the family intervention as compared to up to 25 families receiving enhanced treatment as usual (trigger

control resources and a written asthma action plan). The family intervention integrated individually tailored asthma education with strategies to reduce the impact of caregiver and family stress on asthma management for low-income, urban children with poorly controlled persistent asthma and caregivers under stress. Primary treatment outcomes included measures of asthma self-management (self-reported management, observed MDI/spacer technique, urinary cotinine to assess estimated exposure to environmental tobacco smoke) and morbidity (number of symptom days, school days missed for asthma, and urgent health care utilization for asthma). Secondary outcomes included parent-child relationship quality, family cohesion, and caregiver stress. Project ASPIRE received institutional review board approval from Emory University School of Medicine and Georgia State University before its conduct.

Participants were recruited from three sites: (1) the American Lung Association—Southeast Region (ALA-SE) sponsored Camp Breathe Easy; (2) the Child and Adolescent Psychiatry Outpatient Clinic (CAPOC) of Grady Health System, a large urban hospital; and (3) Project STAR (Support for Treatment of Asthma Research), a longitudinal study examining treatment adherence among low-income children with asthma conducted by Emory University School of Medicine. To participate in the focus group study, adult participants had to be a primary caregiver of a child with physician-diagnosed persistent asthma (moderate or severe) and child participants had to have physician-diagnosed persistent (moderate or severe) asthma. Symptom severity was not assessed by the project; however, asthma severity was verified by medical record review or physician note. Project ASPIRE investigators preferred for participants to be Medicaid-insured; however, they allowed the participation of those who were not.

We chose a qualitative descriptive design using focus group methodology. Purposive sampling was used. The final study population included a targeted convenience sample of children with physician-diagnosed asthma and/or their caregivers who were either affiliated with a local pediatric asthma camp program sponsored by the ALA-SE and/or patients at a local urban children's hospital serving the underserved, Children's Hospital of Atlanta—Hughes Spalding Children's Hospital.

The composition of each focus group varied according to child or caregiver status, child age, and presence of comorbid conditions (Table 1). A total of five focus groups were conducted. Two focus groups were conducted with caregivers of 8- to 13-year-old children with asthma. Another focus group was conducted with adolescents ages 13 to 17 with asthma. A fourth focus group consisted of children ages 8 to 12 with asthma and their caregivers. The fifth focus group was conducted with caregivers of children with asthma and comorbid psychosocial conditions. The caregiver-reported psychosocial conditions for the children included attention deficit hyperactivity disorder and bipolar disorder. A co-investigator, who was also the ALA-SE representative, and a certified asthma educator, acted as the moderator for the five focus groups. However, the principal investigator, who was also the Emory University representative, and a professional psychologist, served as a co-moderator during the fifth focus group. Researchers encouraged equal participation and refocused the interview if necessary, consistent with our semi-structured format (12).

TABLE 1.—Summary of information about five focus groups in PROJECT ASPIRE.

Date Conducted	Transcription	No. of Participants	Group type	Black	White	M/F Or Gender ratio	Medicaid/ Peachcare	Private Insurance	Uninsured
12/18/06	1/8/07	5	Caregivers	3	2	1/4	2	3	0
1/17/07	1/24/07	4	Caregivers	4	0	0/4	3	1	0
2/13/07	2/21/07	6	Adolescents (13–17 yr)	6	0	4/2	6	0	0
2/27/07	3/6/07	9	Caregivers & Children (8–13 yr)	9	0	4/5	7	0	2
3/29/07	4/5/07	4	Caregivers (Children w/ Comorbid Conditions)	4	0	0/4	4	0	0
Total		28		26	2	9/19	22	4	2

Focus groups were conducted using a standardized script of open-ended questions (see Appendix A) in a semi-structured format. The standardized script was used to guide and facilitate discussion. Not all questions were asked in every group. For example, certain questions asked during the first two groups were not necessarily posed to the teenager-only group. In appreciation for their participation, focus group participants were given a \$20 cash incentive. Focus groups were audiotaped and transcribed by a professional transcription company. Each focus group session lasted for about one hour and was conducted at a community facility in varied locations accessible to the public in metropolitan Atlanta.

The total number of participants was 28, with 4 to 9 participants in each of the 5 focus groups (Table 1). Focus groups involved both caregivers over age 18 and children 8 to 17 years of age. The majority of participants (26 [92.9%]), were African American. In addition, a total of 22 participants (78.6%), both caregivers and children, received Medicaid or the State Children’s Health Insurance Program (SCHIP; see Tables 1 and 2).

Three team members independently reviewed and coded each transcript into themes. Once responses were independently coded, investigators met to consolidate findings. Instances of theme discrepancy were discussed until a majority consensus was reached. As a result, four overarching, mutually exclusive themes encompassing participant responses to the list of questions (see Appendix A) were identified. The four themes were (1) barriers to asthma management, (2) psychological distress, (3) barriers to environmental control, and (4) social support.

RESULTS

A total of 28 individuals participated in 5 focus groups, with 4 to 9 participants in each group. Focus groups involved both caregivers of children with asthma and children 8 to 17 years of age with current documented physician-diagnosed asthma. Of the five focus groups, the majority of participants were African American (92.9%) and female (67.9%) (Table 2). In addition, 78.6% of the participants, both caregivers and

children, were Medicaid-insured or SCHIP-insured; 7.1% were uninsured.

To facilitate comparison by group type, the two groups conducted with caregivers only were combined in subsequent analyses as group A (Table 2). This group consisted primarily of African American females; 44% received private medical insurance for the target child. Group B was conducted solely with black Medicaid-insured adolescents. Both caregivers and children comprised group C, which was 22.2% uninsured. Group D, caregivers of children with comorbid psychosocial disorders, consisted solely of black female Medicaid-insured caregivers.

Responses of the focus group participants were organized into the four identified overarching themes: (1) barriers to asthma management, (2) psychological distress, (3) barriers to environmental control, and (4) social support. Barriers to asthma management and psychological distress were further organized into sub-themes. Sub-themes were defined as distinct categories or ideas within the subset of the overall theme. Aggregate results are presented in Table 3 and then discussed by sub-theme with a few key examples presented.

Barriers to Asthma Management

Sub-Theme 1: Child Health Beliefs/non-Adherence. Focus group participants identified child nonadherence to asthma treatment as an asthma management barrier. Many children admitted to not adhering to treatment regimens, expressing a general lack of concern with taking daily controller medications. Some children felt that taking daily medications was pointless and that the risk of having an asthma episode was the same whether they took the medications. For example, one child responded, “There could be some instances where you’re fine but you still take your medicine anyway, but if you’re not that active—if you’re not that active, then taking your medicine every day, it just—after a while it just seems to become pointless. There’s no point in taking it.”

The idea of feeling ‘invincible’ was cited many times by caregivers in response to child non-adherence. Caregivers believed that their children felt as though nothing bad could happen to them and, thus, they did not see the importance of

TABLE 2.—Demographic data (as percentages) on each of five focus groups in PROJECT ASPIRE.

	Group A (Caregivers only)	Group B (Adolescents)	Group C (Caregivers & Children)	Group D (Caregivers /comorbid)	Total
Black	77.8%	100%	100%	100%	92.9%
White	22.2%	0%	0%	0%	7.1%
Female	88.9%	33.3%	55.6%	100%	67.9%
Medicaid-insured	55.6%	100%	77.8%	100%	78.6%
Private Insurance	44.4%	0%	0%	0%	14.3%
Uninsured	0%	0%	22.2%	0%	7.1%

TABLE 3.—Summary of theme and sub-theme data from five focus groups in PROJECT ASPIRE.

Theme	Sub-Theme	Group A (Caregivers only)	Group B (Adolescents)	Group C (Caregivers & children)	Group D (Caregivers/ co-morbid)	Total
Barriers to Asthma Management	Child Health Beliefs	13 ^a	60	6	2	81
	Caregiver Health Beliefs	14	1	0	7	22
	Lack of School/Daycare Support	6	1	3	1	11
	Inadequate Insurance coverage	4	0	7	0	11
	Health Care Provider Issues	8	1	12	1	22
	Total Identified	45 ^c	63	28	11	147 ^b
Barriers to Environmental Control		12	5	9	17	43
Psychological Distress	Child Quality of Life (QoL)	2	28	11	1	43
	Caregiver QoL	40	1	22	48	111
	Health Care Provider	4	1	4	0	8
	Total Identified	46	30	37	49	162
Social Support		44	10	22	12	88

^aFrequencies or number of responses in each sub-theme.

^bTotal number of responses in each overall theme.

^cTotal number of responses for each overall theme by group type.

taking daily medications. In addition to non-adherence, caregivers also reported that their children did not pay attention to their asthma signs, symptoms, and triggers.

Sub-Theme 2: Caregiver Health Beliefs/non-Adherence. Many caregivers modified the asthma treatment regimens recommended by their provider based on personal health beliefs. Some caregivers reported that they administered daily controller medications only when they felt it was appropriate, for example during the allergy season or when their child was coming down with a cold. A few caregivers refused to administer daily medications entirely, choosing to rely solely on a nebulizer and the rescue inhaler. Some caregivers modified treatment guidelines based on fears that their child would become addicted to the medications while others worried their child would become immune to the medications over time. An example of a response was, “I don’t like the meds themselves because to me it’s an addiction. It’s a control. Okay, let me explain why I said that it’s an addiction, because their bodies get used to taking this medicine at this precise time. . . .”

Overall, most caregivers reported adequate asthma management knowledge, with some expressing that they had participated in an asthma management class through their health care provider. However, some caregivers expressed a lack of asthma knowledge, such as not being able to accurately remember which medications were prescribed for their children and not knowing the purpose of and/or proper technique to use a peak flow meter. In addition, some caregivers felt as though their child would some day outgrow asthma.

Sub-Theme 3: Lack of School/Daycare Support. Most caregivers believed that the schools were not equipped to handle a child with asthma. Both caregivers and children felt that school personnel did not have adequate asthma knowledge and that the availability of school nurses was limited. According to some caregivers, children were not allowed to carry or self-administer rescue inhalers in their school district. For example, one response was, “Because I had one teacher, she’s like she [the child] can’t keep that in her bag. She can’t do this. I’m like I got a note from a doctor, the school nurse who know[s].” These reports suggested a lack of school personnel knowledge of recent Georgia state laws that allow children to carry rescue inhalers with them at

school. A few caregivers reported encouraging their child to violate school policy by carrying their rescue inhaler. In addition, caregivers repeatedly identified finding daycare to be an obstacle due to some daycare centers not accepting children with asthma or other comorbid conditions, such as ADHD.

Sub-Theme 4: Inadequate/Inconsistent Insurance Coverage. While most caregivers and children were Medicaid-insured or SCHIP-insured, a few caregivers described periods of time during which the child was uninsured. Failure to meet eligibility criteria for Medicaid or SCHIP, while still unable to afford private insurance, was cited as a barrier to receiving care for their child’s asthma. Caregivers with private insurance also identified high co-payments and premiums as barriers to care, especially high co-payments for medications. In addition, changes in health care plans and the medications that are covered by that plan were also perceived to create barriers to care. For example, “. . . my children are on Medicaid which is a state health program. And it is so hard to get their medicines. Every time the formulary changes, it says if my children’s health condition is suddenly changed—And medicines that we know already don’t work for them, suddenly they want us to get those instead of the ones that we’ve already isolated as the ones that work, and, you know, in terms of dealing with the insurance companies, because they moved to another plan where you have to select an insurance plan, but they don’t tell you up front which medications they’re going to cover, which ones they’re not, and then when you try to get some—they say there’s always a way to get the medication if your child absolutely needs it.”

Sub-Theme 5: Health Care Provider Issues. A positive relationship with a health care provider was cited as an instrumental factor in receiving quality care according to caregivers. Caregivers expressed that being able to effectively communicate with their provider increased self-efficacy about managing their child’s asthma. Some caregivers also expressed comfort in knowing how to contact their child’s primary care provider in emergencies.

There were also several health care issues that caused caregivers to feel frustrated and dissatisfied, such as limited availability of providers and the inability to obtain a nebulizer. Children agreed with caregivers, expressing that they

rarely see their primary care provider. Caregivers also voiced concerns that providers did not want to diagnose their child with asthma, often times diagnosing their children with bronchitis or the common cold. An example response was, "But I kind of later got the impression that they didn't want to just automatically diagnose you with asthma or bronchitis. They were trying to kind of wait and see, you know, what it was going to [was] or wasn't going to develop into. But as a first time parent, that was nerve racking to me."

Barriers to Environmental Control

While both caregivers and children were knowledgeable about environmental asthma triggers, they had limited access to environmental remediation. Many caregivers cited financial constraints as barriers to environmental control. Homeowners were faced with the sole responsibility of expenditures such as buying multiple air conditioners with particle and pollen filtration, removal of carpet, and home improvements due to water damage. These expenditures were in some cases too high for caregivers to outlay and maintain and, thus, made environmental remediation difficult if not impossible. For example, "... with owning your house and not having unlimited income, sometimes you notice things that might be a trigger, but you just can't afford to change them, and my house is—brick and it's about 60 years old as are most of the houses in the community, and what we've all noticed is that we get moisture on the wall in the wintertime and if you—if a tile [ph] falls behind the bed it's going to mold and mildew if you don't find it and get it off the wall."

Caregivers that lived in rental properties discussed the lack of support from property managers and landlords. They expressed difficulties in convincing property managers to make the needed repairs and changes in their homes. In addition, a few caregiver responses reflected overcrowded living conditions, describing instances where new neighbors move in and create new cockroach infestations. These residential environmental challenges may present challenges to effective asthma management.

Caregivers also expressed concerns about their child's school environment. A few caregivers described conditions in the school environment likely to exacerbate the child's asthma-related symptom prevalence and severity. For example, "I'm having a problem. My kids are at—school is new, the premises are not, and 2 weeks ago they tiled the roof and from the moment you entered the door you smelled tar, and this went on for a whole week and another week they came at—my older sons they came to this classroom and so he got to class and started wheezing and so they called me and wanted to know what should they do."

Psychological Distress

Sub-Theme 1: Child Quality of Life. Most children felt some psychological burden due to their illness, expressing feelings of fear and panic during asthma episodes. Some children felt as though their school coaches and physical education (P.E.) teachers expected too much of them and felt nervous during times when they could not have their rescue inhaler with them, for example during P.E. or football practice. For example, "I was just trying to run [during] practice because I really wanted to make the team, and then

I had to stop. I had to put my—I tried to put my—tried to stop it, but nothing really worked, so I—I didn't know what to do and the coach had to run over to me and give me my asthma [inhaler] because I didn't have any pockets and I could barely take my medicine because I was so scared." Conversely, some children felt as though adults treated them as if they were handicapped or had a disability. Children also expressed that having asthma made them feel embarrassed, and caregivers were aware of this as well.

Children also felt that their activity level was restricted by their illness. Most children believed that if they didn't have asthma they would be able to participate in more physical activities. For example, when asked what having asthma prevented them from doing, one child responded, "Activity—if I'm doing sports. I can't go as hard as you know the next person can." Some caregivers admitted they had restricted their child's activity; for example, they had kept them indoors during allergy season.

Sub-Theme 2: Caregiver Quality of Life. Caregivers felt a significant psychological burden due to having a child with a chronic illness. Most caregivers constantly worried and feared for their child's safety, especially during asthma episodes, hospitalizations, and emergency department (ED) visits. Caregivers voiced concerns of rarely being able to rest due to the constant state of worry despite having the support of family members and relatives. For example, "... when we were back there she was a baby then, and she couldn't breathe. I'm like—I panicked. I actually panicked. I think I called everybody after I called the ambulance". A few caregivers also reported that the persistent stress was taking a toll on their own health as well.

Caregivers also felt that their activity was limited by their child's illness. Some caregivers felt that their ability to work was adversely affected by their child's asthma. An example response was, "A lot time employers say that they understand your situation, when you have to leave whenever. You just feel a little uncomfortable. . . ." The ability to have a social life and maintain family plans was also negatively affected by their child's asthma.

Sub-Theme 3: Frustrations with Health Care Providers. Some caregivers expressed frustrations with judgmental attitudes and discrimination from health care providers. An example response was, "I'd say bedside manner. They're just so cavalier; they don't look you in the eye, you know, okay, here comes another kid". Caregivers felt as though providers did not take their child's disease seriously and did not take the time to follow up. A few caregivers also reported that their child's primary healthcare provider did not take the time to get to know them or their child better.

Social Support

Caregivers and children identified sources of asthma management support including positive relationships with health care providers as well as school nurses. They also identified support from family, friends, and community resources such as the ALA-SE sponsored Camp Breathe Easy. Caregivers reported feeling more at ease leaving their children in the care of people whom they trusted, such as their church community. For example, "... it helps me out a lot [of] our nights

we go to church because they might be downstairs in the daycare or doing something with their friends . . . when they're running around the church with their friends and I have adult conversation, I'm at peace, I'm relaxed".

DISCUSSION

Caregiver and child responses to focus group questions were organized into four overarching themes: (1) barriers to asthma management, (2) barriers to environmental control, (3) psychological distress, and, (4) social support. These themes, which emerged from content analysis following the conduct of our focus groups, are relevant to asthma outcomes among low-income urban families. Clearly, the barriers to asthma management among urban families with children with asthma are substantial given the disproportionate rate of hospitalizations, ED visits, and mortalities among black low-income children (1). Barriers to environmental control are also relevant to urban families owing to the unique characteristics of urban settings associated with adverse asthma outcomes, such as increased allergen exposure, overcrowding, and concentrated poverty (5, 6). The third theme, psychological distress, was formed to capture quality of life issues as well as mental health concerns related to asthma management. Caregiver emotional distress may also play a significant role in successful pediatric asthma management (11).

Within barriers to asthma management, children expressed many contradictory health beliefs and practices. While some children felt they could perform at a level equal to children without asthma if they took their prescribed daily controller medications, others felt that taking daily controller medications was unnecessary. Children voiced concerns that even if they took asthma medications daily, they were still at the same risk of having an asthma episode as if they were not taking daily medications. More concerning, many children openly admitted to lying to their caregivers about taking their daily asthma medications. Caregivers also commented on child non-adherence, stating that their children felt "invincible," as if nothing bad could happen to them.

What is particularly noteworthy is that parents of younger children and teenagers allowed inappropriate delegation of asthma self-management to children too young, too poorly trained, or too unmotivated to assume the role of managing their condition. Some parents in our study allowed children to take on the responsibility of adjusting medication per their leisure or to not take it at all. This is different from what has been found in prior research. In studies by Wade et al. (13) and McQuaid et al. (14), parents encouraged responsible asthma self-management in children but remained actively involved in asthma care as appropriate. However, in the current study, parents may have allowed children too much responsibility for asthma care because of other social challenges associated with living in low-income urban settings (15). Many competing issues may interfere with the ability to appropriately identify a child's level of responsibility of treatment (self-management) in these settings: single parenting, multiple children with asthma or other co-morbid health and psychosocial conditions, lack of time to properly train/oversee asthma management due to working outside of the home, and so on. Thus, this is an area to focus on in future studies and interventions.

Despite the many misconceptions shared by caregivers, they expressed high self-efficacy in managing their child's asthma. Even among those who did not administer daily controller medications to their children, they were confident in their abilities to manage exacerbations using a nebulizer and rescue inhaler. Interestingly, many discussed the ability to manage their child's asthma by making dietary modifications. As discussed earlier, black urban caregivers sometimes possess health beliefs that are in conflict with provider recommended treatment guidelines (8, 9). This may include alternative medicine, home remedies, or as explored here, dietary changes. It is important to note that some families reported use of alternative therapies in asthma treatment such as massage, relaxation exercises, diet therapy, and vitamins. Studies have shown no statistically significant differences in asthma severity or length of time between exacerbations (16, 17) among families who use alternative therapies. Nevertheless, given the results of the present study, healthcare professionals should be prepared to explore and validate (if appropriate) the caregiver's use of alternative treatment and to discuss how alternative therapies can be integrated with routine medical treatment to maximize adherence to protocols specified in written asthma action plans. It is also important for health care providers to be culturally sensitive to the family's desire to incorporate alternative practices to facilitate more open physician-patient relationships and better management of children's asthma (17). Since it was found that some caregivers felt stress and frustration with their relationship with health care providers, better healthcare provider/caregiver communication efforts may help to mediate the barrier of provider stress in pediatric asthma care.

Many of the limitations of this study are inherent to qualitative focus group studies. First, it was not possible to generalize these findings beyond the scope of the study population because participants were self-selected and, therefore, both nonrandom and non-representative, i.e., a targeted convenience sample. Also, in a focus group setting the same individual may repeat statements, or some individuals may participate little. As a result, it is difficult to assimilate, code, and quantify these qualitative data across focus groups. We attempted to overcome this limitation by utilizing experienced moderators who encouraged equal participation and refocused the interview when necessary, in addition to professional transcription and coding comments.

Conclusion and Recommendation

Despite the ample published research on asthma prevalence and asthma management interventions, limited information exists about barriers to asthma care among urban low-income families as perceived by children with asthma and their caregivers. This qualitative study used focus group methodology, with a semi-structured format of standardized scripts of open-ended questions to drive discussions to investigate the perspectives of both children and adults in the management of asthma. Caregiver and child health beliefs and perceptions concerning the usage of daily controller medications were reported to be a major barrier to asthma care. Barriers to environmental control consisted mostly of financial constraints that made identified and/or desired environmental trigger remediation activities difficult to achieve.

Psychological distress was prevalent among both children and caregivers, which demonstrated the burden endured from managing a chronic illness.

Our data suggested a number of recommendations for development and implementation of home-based asthma management interventions targeting low-income urban minority families. First, asthma education efforts must identify and address caregiver and child attitudes and beliefs about asthma treatment in a culturally competent manner, as these attitudes and beliefs are likely to affect asthma management practices and asthma morbidity. In addition to education, asthma management interventions with low-income pediatric patients should include a psychological component to address the caregiver stress and family processes (20) affecting asthma outcomes. Identification and treatment of underlying issues, such as caregiver stress or poor caregiver-child communication, may have a positive impact on the family's ability to perform prescribed asthma management strategies. Furthermore, interventions should be individually tailored with multiple components (21), including discussion of age-appropriate strategies for managing asthma exacerbations as well as advice about how to coordinate with school personnel and health care providers via proper communication strategies. Finally, to target other unique barriers identified by urban families in the present study, interventions should also provide referrals to community resources for social, legal, economic, and psychological issues. Addressing these underlying family-specific issues may have a positive impact on asthma management outcomes.

Some promising interventions that integrate psychological interventions with asthma education include an asthma psychoeducational program that incorporates family therapy (18) and a joint consultation model in which a pediatrician and a child psychiatrist act as co-therapists (22). In addition, a randomized clinical trial is underway of the Project ASPIRE home-based family intervention, which includes modules addressing caregiver stress, caregiver-child communication, child stress, and communication between caregivers.

In conclusion, families in urban low-income settings require asthma management interventions tailored to their specific needs given their unique characteristics, which may render a standard asthma management intervention ineffective or only marginally effective. Findings from this study provide further insight about the barriers and challenges faced by these susceptible, vulnerable sub-population groups and can be used to inform and enhance asthma management interventions for low-income urban families with children with asthma.

ACKNOWLEDGMENT

Project ASPIRE was funded 2006 to 2009 by the National Heart, Lung and Blood Institute of the National Institutes of Health (NIH/NHLBI; R21). The authors are grateful to the participants, without which this work would not have been possible. They thank the in-kind support provided by the Emory University School of Medicine; American Lung Association of the Southeast; the Institute of Public Health at Georgia State University; and, the University of Medicine and Dentistry of New Jersey, School of Public Health.

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APPENDIX: FOCUS GROUP QUESTIONS FOR PROJECT ASPIRE FOCUS GROUP PARTICIPANTS.

I. INTRODUCTORY

Thanks for taking the time to be here. I am Dr. Chanda Mobley and this is: _____. I (we) will be your

facilitator for the evening. The purpose of this focus group is to give parents of children with asthma an opportunity to share their thoughts about asthma care in Atlanta; the strengths and weaknesses of metro Atlanta; and ways that that asthma care in the Atlanta community can be improved or enhanced. We are not here to push any particular agenda or points, but rather to hear your frank and honest opinions about your experiences. There are no right or wrong answers, no current habits or behaviors to be ashamed of. We all have our own likes and dislikes and our own thoughts and feelings about asthma. This focus group will also give you an opportunity to inform Project ASPIRE staff of your thoughts and suggestions on what things to include in our home-based asthma education program, and to also allow us to identify and understand important issues that you are facing when you make decisions about your child's health and medical treatment, particularly as it related to asthma.

I want to remind everyone that the discussion here is confidential. We will not report your comments by name, and we ask that you respect one another's privacy in the same way. We don't expect you to tell us anything that you would be uncomfortable sharing with the group. But we do hope that you will be honest with your responses to the questions I ask.

[Refreshments will be provided after the completion of the interview. Thank you.]

[Before we begin, I am handing out the informed consent form. I will go over it with you and then ask you to sign it. We want to make sure that you understand that your participation in this focus group is completely voluntary.]

Review and Collect Informed Consent Forms

[I'm going to ask a series of questions, but mainly we want to hear from you. My role is to guide the discussion. Sometimes we may really get going on one question, and I'll have to move you on to the next question so that we cover everything. Please don't take that personally! We just need to hear from you about several topics. We want to hear from all of you, so don't hesitate to speak up.]

[I'd like to also remind you that we will be audio-taping the conversation so that we can have an accurate record of what was said. No one will be identified or reported by name. Please try to speak clearly and one at a time, if possible.]

Do we have any questions before we get started?

I want to take a few minutes to give everyone a chance to introduce themselves.

Let's go around the room and introduce ourselves. Tell us. . . (see below)]

- a. Tell us your name and the name of your child/children with asthma.
- b. Tell us one thing you enjoy doing [with your child?]
- c. Has your child ever been to Camp Breathe Easy or Hughes Spalding Children's Hospital? If so, what did you or he/she enjoy best about Camp or the care received at HSCH?

[We are going to switch gears just a little and talk about the Atlanta community (specifically, Fulton and DeKalb Counties) in general and its ability to meet the needs of children with asthma.]

II. Community Capacity Perspective

- a. What are some of the strengths of your community (where do you live—county, general area, etc)?
- b. Name some resources in your community.
- c. What is bad about our health care system in Atlanta?
- d. What would you change about the way you get health care from your doctors and/or hospital?
- e. Renters only: what is difficult about renting regarding your child's asthma?
- f. Owners only: what is difficult about owning your home as it relates to your child's asthma.
- g. What do we need more of to take care of children with asthma in Atlanta? (What are some things that would help you/people in Atlanta take care of children with asthma in Atlanta?)

[Now, I would like to talk a little bit about what you know about asthma and seek your thoughts on good asthma control.]

III. Asthma Knowledge/Asthma Control

- a. What do you know about asthma?
- b. What are some things that would help you take care of you/your child's asthma? What can be done to help take better care of asthma?
- c. Do you believe your child will "outgrow" asthma and or what types of other therapies have they used (like the chihuahua, steam in the shower, etc.

IV. Feelings/Thoughts about having asthma (Parents)

- a. How does your child's asthma affect your life? Probes: Does it affect your work schedule? Does it take away from time you have to spend with your other children? Does it affect your social life?
- b. Does your child having asthma make you afraid? Probe: How?
- c. What is the worse part about your child having asthma? Probe: Do you worry about him/her getting really sick?
- d. How do you think your life would be different if you didn't have a child with asthma? Probes: Would you be able to get more things done? Would it be easier on you if your child did not have asthma?

V. Feelings/Thoughts about having asthma (Children/Teens)

- a. Do you believe that you actually have asthma? Probe: Does your friends know that you have asthma? Do you worry about having asthma? (Do you know other kids with asthma?)
- b. Does having asthma make you afraid? Probe: How does having asthma make you feel afraid?

- c. What is the worst part about having asthma? Probe: Do you worry about getting really sick?
- d. How do you think your life would be different if you didn't have asthma? Probes: Do you think your friends or family would treat you differently if you did not have asthma? Would you be able to participate in more activities if you did not have asthma? Would it be easier on your mom if you did not have asthma?
- e. What type of activities would you like to do but can't because of your asthma?

VI. Asthma Control Barriers (Parents)

- a. Many people do not take their daily controller medicine (e.g. Flovent) as prescribed, sometimes for good reasons. Tell me about a time your child did not take his/her controller medicine. Probe: How did this affect them?
- b. How do you feel about your child having to take medicines every day? Probes: Do you feel afraid? Do you worry about side effects of the medicine? Do you feel it is a waste of time?
- c. Are there things about asthma treatment that you do not understand? What would help you to understand asthma treatment better?
- d. Many people do not tell their doctor or caregiver that they do not take their medicine. How does a person know when it is safe to tell their doctor? Probes: Tell me how someone can gain your trust to share this information. Have you ever been confused by something your doctor told you about an asthma treatment? Do you think your child is getting good care from the doctor? How do you tell a doctor if you are not pleased with your child's asthma care? What would make you more comfortable with talking to your doctor?
- e. Families and friends are very important. Tell me how a family member or a friend might help you with helping to manage your child's asthma. Probes: Do you have family members or friends that help you? Tell me ways they assist. (If not, what are some of the reasons they don't help. Probe: Are they afraid of your child's asthma? Do they have the necessary knowledge about your child's asthma to assist you? Are you afraid to let them assist you?)
- f. Do you find it hard to balance all the things in your life? What are some of your stressors? How do you manage the stress in your life?
- g. What are things that get in way of taking care of your child's asthma? Probes: Transportation? Money? Do you know how to get resources? Would learning about available resources be helpful to you?
- h. How does your child's school work with you to take care of your child's asthma? Probes: Do you think the school is helping? Do you think the staff could do anything better or differently to help? What are they doing well to help?

VII. Asthma Control Barriers (Children/Teens)

- a. Many people do not take their daily controller medicine as prescribed. Tell me about a time you did not take your control medicine. Probe: Was there anything you could have done to get out of that situation? [see comments for parents above]
- b. How do you feel about taking medicines every day? Probes: Do you feel afraid? Do you feel it is a waste of time? Side effects?
- c. Are there things about asthma treatment that you do not understand? What would help you to understand asthma treatment better?
- d. Many people do not tell their doctor or caregiver that they do not take their medicine. How does a person know when it is safe to tell their doctor? Probes: Tell me how someone can gain your trust to share this information. Have you ever been confused by something your doctor told you about an asthma treatment?
- e. Families and friends are very important. Tell me how a family member or a friend might help you take care of your asthma. Tell me how a family member or a friend might keep you from taking care of your asthma. Probes: Do you know how they feel about you taking medicine and staying away from triggers?

VIII. Suggestions for Home-Based Asthma Education Programs

- a. Have you ever participated in an asthma education program? Probes: If so, what do you think you needed to learn that was not taught? What is it that you really wanted that was missing?
- b. Do you have any advice for how the ALA – SE and Emory Univ. can develop Project ASPIRE to make it a successful program?
- c. What do you think a new program such as Project ASPIRE can do to help families of children with asthma?

IX. Summarize

- a. Let's summarize the key points of our discussion.
- b. [The assistant moderator will give a brief 2-minute summary of the responses to questions 2–8 (if applicable).]

X. Conclusion

- a. Have we missed anything?
- b. Thank everyone for their time and open responses.
- c. Tell about future enrollment opportunities for Project ASPIRE.
- d. Eat refreshments
- e. Adjourn