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Asthma Home Management in the Inner-City: What Can the Children Teach Us?

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Abstract

Objective: Knowledge of asthma home management from the perspective of poor minority children with asthma is limited.

Methods: Convenience sampling methods were used to recruit families of low-income children who are frequently in the Emergency Room (ED) for uncontrolled asthma. Thirteen youths participated in focus groups designed to elicit reflections on asthma home management. Data were analyzed using grounded theory coding techniques.

Results: Participants (Mean age=9.2 years) were African-American (100%), enrolled in Medicaid (92.3%), averaged 1.4(SD=0.7) ED visits over the prior three months, and resided in homes with at least one smoker (61.5%). Two themes reflecting multifaceted challenges to the development proper of self-management emerged in the analysis.

Conclusions: Findings reinforce the need to provide a multi-pronged approach to improve asthma control in this high risk population including ongoing child and family education and self-management support, environmental control and housing resources, linkages to smoking cessation programs, and psychosocial support.

Keywords

asthma; children; poverty; self-management; focus groups

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Introduction

Asthma is chronic inflammatory disorder of the airways that causes wheezing, coughing, chest tightness, and shortness of breath (Blakey, Zaidi, & Shaw, 2014). It is a major public health concern with the economic burden of asthma estimated at over \$56 billion annually (Barnett & Nurmagambetov, 2011). Asthma health disparities are well documented, with minority children—particularly those residing in urban poor environments—disproportionately impacted by asthma morbidity and mortality (Loftus & Wise, 2016). Developing proper self-management skills, such as symptom monitoring, medication adherence, and environmental exposure avoidance, is key to preventing uncontrolled asthma (Sleath et al., 2011) and optimizing health, social, and academic outcomes among affected youths (Kaul, 2011). However, African-American and Hispanic children are less likely to have an asthma management plan compared to their non-Hispanic white counterparts (Piper, Glover, Elder, & Baek, 2008). Since asthma morbidity may stem from deficient self-management skills such as poor symptom recognition and/or medication non-adherence (Rhee, Belyea, Ciurzynski & Brasch, 2009), a greater understanding of barriers to effective asthma home management and the process of developing self-management skills in minority youths living in urban poverty is paramount (McClelland & Wenz, 2013).

Qualitative research yields critical insights to everyday life experiences that may inform the development of tailored education and intervention programs for vulnerable populations including individuals with high-risk asthma (Keddem, Barg, Glanz, Jackson, Green, & George, 2015). However, qualitative inquiries into asthma home management from the perspective of poor, inner-city children are limited. One focus group study comprised primarily of non-Hispanic white youths aged 9–15 years identified several consequences of asthma including social limitations, as well as a range of barriers to adherence such as child lack of motivation, distractibility and forgetfulness (Penza-Clyve, Mansell, & McQuaid, 2004). Focus group research that combined low-income minority children aged 8–12 years and their caregivers highlighted a deleterious effect of asthma on child and caregiver quality of life and revealed profound difficulties in home environmental control due to a lack of family financial resources (Laster, Holsey, Shendell, McCarty, & Celano, 2009). Findings from home-based interviews exploring asthma knowledge, perceptions, and autonomy in a sample of racially diverse children with moderate to severe asthma (7–12 years of age) underscored developmental differences in self-management capabilities (Pradel, Hartzema, & Bush, 2001). Younger children were less aware of asthma symptoms and medication roles and tended to identify medications by shape or color only.

Other qualitative research depicts sub-optimal asthma home management in minority families. Interviews with 20 African-American caregivers and children (5–14 years) with asthma suggested that both groups lacked understanding of guideline-based care, with family management activities primarily occurring in response to symptom exacerbation instead of focusing on prevention efforts (McCelland, Wenz, Sood, & Yono, 2013). Concerns about medication side effects resulting in poor medication adherence emerged from focus groups with Hispanic children, adolescents, and parents on asthma self-management beliefs and practices (Martin, Beebe, Lopez, & Faux, 2010). Similarly, a mixed-method study of adherence in a sample of older, primarily African-American

adolescents with asthma indicated that fears of medication side effects and addiction potential to be a significant contributor to non-adherence (Naimi, Freedman, Ginsburg, Bogen, Rand, & Apter, 2009). Housing instability also emerged as a barrier to adherence among the adolescent participants who reported frequent overnight stays away from their primary residence that complicated medication oversight and administration. Further, urban minority adolescents (Mean age=14.25 years) with persistent asthma participating in focus groups described a lack of established routines and competing demands/responsibilities at school and in the broader social environment as additional barriers to proper medication adherence (Blaakman, Cohen, Fagnano, & Halterman, 2014).

These findings offer useful insights to multi-dimensional barriers that may impede the development and implementation of effective self-management skills among minority youths with asthma. Knowledge deficits and inaccurate health beliefs that shape asthma management decisions are evident in adolescents with asthma, and a growing body of research illustrates how non-intentional barriers found in contextual risks such as housing instability and unavoidable exposure to environmental triggers in the home due to family financial constraints may also contribute to poor adherence (Klok, Kaptein, & Brand, 2015). Although assessments of asthma knowledge and management among school-aged youths have long been recommended (Sin, Kang, & Weaver, 2005) and previous research found inner-city children as young as 9 years are self-managing their asthma (Winkelstein, Huss, Butz, Eggleston, Vargas, & Rand, 2000), little is known about how minority children experience asthma management in the home. Our study aims to address this gap by exploring the perspectives of young, urban poor children living with asthma.

Methods

This focus group study is part of a larger, ongoing randomized controlled trial (RCT) testing the effectiveness of an ED and home-based environmental control intervention on children with persistent asthma who have high frequency of ED and urgent care utilization for uncontrolled asthma (Authors, 2015). Families of children aged 7–12 years who had completed the 12-month RCT and agreed to be contacted for future asthma studies were recruited using convenience sampling methods. Letters were sent to 24 eligible families inviting caregivers and their child to attend separate focus groups (caregiver and child) and share experiences about asthma home management. Interested families (N=20) contacted the study office, received additional details about the purpose of the study, and agreed to participate. Thirteen (65%) youths signed written informed consent/assent documents and participated in one of three focus groups that were moderated by two members of the research team July 2015–October 2015. The focus group methodology was selected since it yields a deeper understanding of the lived experience of children with asthma compared with quantitative measures and may normalize asthma challenges through sharing reflections with similar peers (Laster et al., 2009).

The focus group script and associated questions administered to child participants were developed by research team members, informed by preliminary data from the RCT, and vetted by study co-investigators including primary care, specialist and ED providers of young children with poorly controlled asthma. The questions, written to the child

developmental age 7–12 years, were designed to elicit reflections on living with asthma and to draw out child perspectives of the range of barriers and facilitators to asthma management at home and in the broader social context (Appendix A). The focus groups lasted an average of 45 minutes, were audiotaped and transcribed verbatim by a trained professional, and produced an average of 28 pages in transcription data per focus group. Prior to the analysis, research team members who moderated the focus groups read the transcripts to confirm accuracy of presented content.

Data Analysis

Grounded theory coding techniques were used to inductively analyze the data (Oktay, 2012). Two research team members, one of whom moderated all focus group sessions, independently performed line-by-line analysis of the raw data for initial code identification. Reflexive journaling captured immediate impressions of the data and tracked decisions pertaining to the development of codes, and subsequently, themes and sub-themes (Corbin & Strauss, 2008). The coding scheme and tentative definitions for the themes were synthesized and refined in bi-weekly data analysis meetings held over a six-month period. The final coding scheme was applied to the three sets of transcripts, with agreement on thematic classification surpassing ninety percent across raters. Other strategies to enhance confidence in study findings included triangulation across disciplines (e.g., research team members from different professional backgrounds analyzed the data) (Patton, 1999), the use of an outside reviewer who evaluated the themes and sub-themes against the original transcripts, and prolonged engagement in the data analysis process. Additionally, a third child focus group was held to ascertain that data saturation was achieved, as reflected by no new themes or sub-themes emerging in the analysis (Walker, 2012).

Results

Children participating in the focus groups ($n=13$) were African American (100%), enrolled in Medicaid (92.3%), male (61.5%), averaged 9.2 years at the time of focus group (range 6–14 years), resided in homes with at least one smoker (61.5%) and were poor with over two-thirds (69.2%) of the families reporting an annual income of less than \$30,000. As depicted in Table 1, asthma morbidity and healthcare utilization for asthma were high. Per caregiver report at enrollment into the RCT, the children averaged 7.9 symptoms days over the previous two weeks, 7.6 symptom nights over the prior four weeks, and had a mean of 1.4 ($SD=0.7$) ED visits over the prior three months indicating poor asthma control. A majority of caregivers (84.6%) described some limitation of child activity due to asthma, yet nearly half (46.2%) described their child's asthma as well controlled. The children were sensitized to a range of indoor and outdoor allergens based on allergen specific anti-IgE serology for ten common allergens conducted upon enrollment in the RCT (Table 2). Comparison of children from the larger sample ($n=113$) and those participating in the focus groups ($N=13$) revealed no statistically significant differences in socio-demographic data, child asthma morbidity, or healthcare utilization, with the exception that children who subsequently participated in the focus group were older than the non-focus group children at baseline [7.8 years ($SD=2.6$) vs. 6.1 years ($SD=2.6$); $p=0.03$] and were more likely to have had a prior ICU admission (61.5% vs. 27.1%; $p=0.01$).

Two themes and six sub-themes capturing the lived experience of poor urban children with asthma emerged in the analysis (Table 3). No differences in thematic results were observed between participants who completed the control arm of the RCT (n=7) or those in the intervention group (n=6).

Theme 1: Barriers to Asthma Management

Sub-Theme 1: Housing instability.—Consistency in asthma management routines is, in part, a function of stable home environments. However the participating children revealed significant turmoil in their living situations, with frequent family moves or alternate sleeping locations on a regular basis. This transition between households created an extra burden in asthma management, as the children and caregivers had to remember to bring medications and devices to each location. When specifically asked about the number of places they had slept in the previous month, the children responded:

Two - my house and sleep over.

(ID#011)

I go to my mom's friend house, and my house and my family houses.

(ID#085)

Sometimes I sleep at my godmother...I stayed the night at my daddy's house....my godmother's house, twice.

(ID#001)

Changes in living situations added complexity to asthma management, especially medication administration. Some participants described keeping medications in the homes of relatives where they occasionally stayed:

At my aunt's house, my uncle's...I go over there for the weekends. I don't have to take pumps or clothes because I've been there last year, and last year before that, and last year before that.

(ID#082)

The frequent moves also had an emotional impact on the children. One 9-year-old male shared the following reflections about his experiences: *"Sometimes I feel sad because I'm usually in culture shock because we move a lot."*(ID#100)

Sub-Theme 2: Pervasive trigger exposure.—Avoidance of triggers in the home and community is essential for well-controlled asthma. Study participants were very atopic with 91.7% of those tested sensitized to at least one allergen (Table 2). Yet, the children described ongoing exposure to triggers, even when an allergy had been identified. Contact with pet dander (cat and dog) was common, as captured by the following exchange among three participants:

I'm allergic to cats and dogs, and I got a dog.

(I #001: + Cat Allergy)

And I have a cat.

(ID#023: + Cat, + Dog)

I have a cat. I have a dog.

(ID#039: untested)

Second-hand smoke was particularly prevalent in the lives of the children. Nearly two-thirds (8/13, 61.5%) identified one family member who smoked, and most had several immediate and extended family members who smoked in the homes, even when the health hazards of smoke exposure were acknowledged. Further, nearly half of the children had a positive cotinine (43%) level reflecting smoke exposure in the previous 24 hours:

She [mom] tries her best not to smoke around me. She'll try to her best to go to another room and stuff.

(ID#050)

My father did [smoke] and my grandfather did. I just go to my mother's room and watch TV with my baby brother. When I always go downstairs, they always smoke while at the refrigerator getting something to drink.

(ID#056)

My grandmother smokes but she said, "Go away from the cigarette smoke."

(ID#001)

A few children reflected that their families had established home smoking bans, but in some cases, enforcement of these bans was inconsistent:

My grandma, she won't let my brother or my sister smoke inside her house. She tells them to go outside. And my mama, she doesn't care if my brother and my sister smoke upstairs because it's their room.

(ID#039)

Even when home smoking bans were in place--"*I have a sign that says...don't smoke in our house*" (ID#056)--complete smoke avoidance was difficult due to the children's living situations in multi-family dwellings or row homes where "*all my neighbors smoke*" (ID#023). The row houses are typically characterized by open and connected porches, which allows smoke to flow between and permeate multiple residences. The following exchange among three participants captures the challenge of avoiding neighbors' smoke:

Go in my room and put the upstairs window open, so I could get off the scent and not inhale those [neighbor's] cigarettes.

(ID#001)

If the [neighbor's] door opens, I would just put a pillow on my head, so I won't smell the smoke—or close the door and the window.

(ID#085)

In my old house my neighbors did [smoke] and I could smell it. It like traveled over to where I live. And if I'm playing outside, I try not to go over there because it's

traveling in the air. I don't want to inhale that. So I just try to stay away from where they are smoking. So I don't trigger my asthma.

(ID#011)

Moreover, some neighbors are smoking directly on the property of the children's home:

When I go outside, I see somebody that lives across the street on my porch smoking

(ID#023).

The strategies used by the child and family to protect against second-hand smoke (SHS) exposure for the children were largely ineffective. Moving the child or smoker to a different room, child breath-holding, and using fabric barriers or air fresheners suggest that families lack understanding of how smoke permeates the home environment and underscores the need for behavioral and motivational interventions for families to institute a total home smoking ban for children with asthma because the home is the primary point of SHS exposure.

I have to hold my breath when they start smoking.

(ID#023)

My mother and my brother and sister—they smoke in their room, and whenever they're smoking, they tell me not to come in and to come back later. My mama... she just goes there in her room, and smokes a cigarette. And if I'm down there [in mother's room], she like tells me to go under the covers so that no smoke will get in my face.

(ID#111)

I would just spray some air freshener in the house.

(ID#085).

Sub-Theme 3: Psychological burden of poorly controlled asthma.—Most children described activity and social restrictions due to poorly controlled asthma. When asked about how asthma impacts their lives, participants reflected that avoiding situations that were detrimental to their health at times engendered feelings of loss, frustration, and sadness. One 11-year-old girl described her experiences as follows:

I can't stand it because it's like if I'm too active, my asthma triggers. Basketball in school – can't do that much. Like my gym teacher sits me out sometimes if he thinks that it's too much for me to handle. And also playing outside because my little cousin and their friends always want to go outside. I'm like, "I can't go on the grass." So having to stay outside, play tag, and not go on the grass and stuff.

(ID#011)

Other children reflected on how time with family members or friends, including those who they had strong attachments with, was purposively curtailed because of concerns about second-hand smoke:

Out of all my uncles, we have the most in common...but I can't go there that often because he smokes.

(ID#097)

I wanted to go to my cousin's house but his dad smokes.

(ID#085)

The children's emotional reactions to second-hand smoke exposure were especially poignant. Their candid comments illustrate deep distress about having smokers in their lives, as encapsulated in the following exchange among participants:

It [adults smoking] makes me angry because I hate it.

(ID #023)

It makes me be sad and angry. When they [family members] always smoke, I get irritated and then I just go upstairs and watch TV and close my door.

(ID#056)

It stinks. I don't understand the concept of smoking. What's the whole point?

(ID#097)

Theme 2: Developing Asthma Self-Management

Sub-Theme 1: Building asthma knowledge base.—Understanding what asthma is, the role of medications and devices in managing it, and triggers for exacerbations sets the foundation for asthma self-management. When asked who taught them about asthma, the majority of children responded that family members were the primary sources of their information, many of whom were described as having asthma themselves:

My father taught me how to use it [inhaler] because he had asthma too. Everybody on my father's side got asthma.

(ID#045)

My momma [taught me] because she had asthma, too.

(ID#056)

Heterogeneity in understanding asthma medications and devices surfaced in the children's responses yet participants described self-administering medications as young as 6 (ID#100) and 7 years of age (ID#039, ID#111). Not surprising, younger participants generally described their inhalers by color only "*clear and yellow*" (ID #001) and were not able to identify the names of their medications, "*I don't know [the name] because I don't look at it. It's a liquid*" (ID#082). However, some of the older children also struggled to identify their asthma medications, as illustrated by the following quote from an 11-year-old participant:

"This is the pump I got, and I got another one. A green one."

(ID#039).

Learning about asthma triggers was likewise a core element in moving towards effective asthma self-management. Participating children displayed, in general, an extensive

awareness of how exposures in the home and community may exacerbate their asthma. The identified causes of asthma triggers were diverse and ubiquitous in nature (tree and grass pollen, tobacco smoke, pets, exercise). One 13-year-old male commented that “*everything*” (ID#097) flared his asthma, and another responded, “*Yeah, everything, the grass, trees, mice, cats*” (ID#045). The participants were especially attuned to the deleterious impact of smoke exposure on asthma:

Well, I definitely can't be near cigarette smoke. Because like say I walk into a store, and somebody's smoking right outside the door, or walks past and I inhale the smoke, I'm immediately going to start coughing, and feel like my breath is getting – like I'm shortening of breath. So I have to take my inhaler everywhere I go. Because if I don't, that's like I could be rushing into the emergency room, if I inhaled that.

(ID#011)

Sub-Theme 2: Establishing medication management and storage routines.—

Creating regular schedules and habits for medication administration and storage emerged as another critical pillar of building asthma self-management. Older children tended to exhibit a deeper awareness of how routines are crucial to well controlled asthma, as illustrated by the following exchange among two participants aged 13 and 14 years regarding medication use:

I'm used to it, I just know when I take it.

(ID#045)

It's a routine.

(ID#097)

Yeah, it's just a routine.

(ID#045)

Over and over again.

(ID#097)

The children's reflections portray a complex array of parents, extended family members, and friends, who are involved in medication oversight. This web of support was essential for the sub-set of children who admitted that they were forgetful or distracted in their medication management, or simply lacked the knowledge base.

I forget, too, because I just be playing on my games, and playing my Xbox and stuff, and playing with my friends.

(ID#085)

My momma has to remind me [to] take my pump...I'm really sleepy, coming back from school and coming back from my uncle's house...she had to [wake child up] when I'm about to doze off. She'll tell me to take my medicine.

(ID#082)

In some cases, a step-wise progression of transferring asthma management from caregiver to child was delineated in the participants' stories. Not surprising, caregivers were most involved in medication administration and storage for younger children. Over time, however, some children assumed more responsibility in managing their asthma, with symptom awareness identified as a critical step in the process.

I [11 year old] just take it by myself. If I feel like out of breath, and make sure I have my pump near me at all times because I never know what could trigger my asthma. So most of the time, I just take it myself. Like when I was younger, she had to give it to me.

(ID#011)

I usually take mine before I start running around because that's more safe because you don't know if something will happen.

(ID#100)

The children also identified specific strategies for medication storage to help them adhere to treatment and be proactive in anticipating acute exacerbations. A 14-year-old participant shared, "*I keep my medicine in a cabinet in a bathroom so when I wake up and brush my teeth I get to take it*" (ID#045). However, a sub-set appeared to lack understanding of why consistency in medication storage is important. One 13-year-old commented, "*It'll be somewhere around my room-- on top of the game or on the dresser*" (ID#097). A younger participant likewise seemed uncertain of where his medications were stored, "*I think I keep mine on the shelf*" (ID#001). Another concerning dimension of asthma management was the sharing of asthma medications. A majority of children had family members living with asthma, and as they moved between homes, some relied on medicines in the homes of their extended family members. The following comment by an 8-year-old male reflects one example of family sharing of asthma medications:

"I got a grandmother who got really bad asthma just like me, and she got a bunch of medicine and pumps. That's why I go over to her house because she got everything that I really need...she shares some of my medicine."

(ID#082)

Sub-Theme 3: Empowerment and self-efficacy.—The experience of sharing reflections in the context of a group setting seemed to validate the children's experiences, strengthened their confidence in asthma management, and empowered them to share "words of wisdom" for others who are diagnosed with asthma. These young participants emphasized the importance of medication adherence, avoidance of environmental exposures, and management of an acute asthma episode at home as some final messages to other children about their asthma:

Use their medicine....and don't get around people that smoke

(ID#085)

Don't mess with your asthma.

(ID#001)

I would tell them to make sure they know when they feel out of breathe, and make sure to tell someone. Because if you don't tell someone, you could just straight out faint. You could fall out. So make sure – I would tell them, “Tell your mom, closest adult, if you're feeling out of breath because you never know what could happen”

(ID#011)

Discussion

This focus group study exploring asthma home management from the unique lens of young, urban children with poorly controlled asthma found multifaceted challenges to the development proper of self-management. Asthma knowledge, inclusive of symptom monitoring, trigger awareness, and proper medication usage, has long been regarded as a prerequisite for effective home self-management (USDHHS, 2007). Significant knowledge gaps related to symptom awareness and medication management were observed in our participants, but these findings are consistent with previous research in minority youths and underscore the need for continued education related to self-management in low-income minority families. For example, nearly half (41%) of African-American adolescents with asthma in one study reported that it was not possible to prevent an acute exacerbation (Sin, Kang, & Weaver, 2005). Other research found minority youths to be more likely to have inaccurate asthma control perception, which may result in delay or failure to seek treatment (Rhee, Belyea, & Elward, 2008). Children participating in our study were generally able to describe an association between trigger exposure and onset of asthma, but a disconnect between recognizing asthma triggers and the behaviors required to reduce their triggers in the home or broader community was evident. Perhaps this discordance is due to the child following the parent's inaccurate asthma self-management activities in the home. Alternatively, the children were developmentally unable to comprehend prevention of asthma symptoms.

Consistent family routines and structured home environments are viewed as central to promoting adherence, especially during the developmental shift from childhood to adolescence when autonomy in asthma self-management increases (Bruzzese, Carcone, Lam, Ellis, & Naar-King, 2014; Fiese, Wamboldt, & Anbar, 2005). Housing instability, specifically the transient nature of sleeping arrangements described by children participating in our research, adds complexity to the development of proper asthma self-management skills. Asthma medications need to be accessible in every residence, triggers may change across locations—which is especially problematic in children such as those in our sample who have multiple sensitizations—and adult oversight and management of the child's asthma may vary with some guardians lacking understanding of guideline-based care. Without consistent access to proper caregiver supervision and training, skill development in asthma self-management is comprised resulting in increased risk for poorly controlled asthma (Beachman & Deatrack, 2013), as observed in these children.

Findings of children regularly spending time away from their primary residence were similarly noted in a sample of 40 older adolescents (15–18 years) with high-risk asthma (Naimi, Freedman, Ginsburg, Bogen, Rand, & Apter, 2009) and underscore the need to assess whether the child sleeps in one location or has multiple dwellings. Determining the

amount and type of asthma supervision including environmental control practices across the residences may lead to an individualized child self-management plan. However, as these topics are raised with caregivers in clinical encounters, it is important to be mindful of building rapport, framing questions in a non-stigmatizing fashion, and being sensitive to how financial hardships may negatively impact asthma management (Authors, 2016; Ungar, MacDonald, & Cousins, 2005).

Child forgetfulness about medication administration and over-reliance on short-acting beta agonists among the children who self-administered their medication before exercise or trigger exposures were additional indicators of self-management deficits or the premature transfer of the responsibility to manage their asthma. Notably, the young age of child self-administering asthma medications was previously observed in a comparable group of inner-city youths (Winkelstein et al., 2000). This is concerning since successful autonomy in medication management requires cognitive, physical, and psychosocial abilities that school-age children may lack (Beacham, & Deatrick, 2013). A recent study of self-management in minority youths in early adolescence found children who reported having more asthma responsibility were less likely to engage in asthma management steps, which raised questions about whether asthma responsibility was occurring too early (Bruzese et al., 2012). Poor adherence to asthma management behaviors are regularly noted in asthma research with children and adolescents (Jonsson, Egmar, Hallner, & Kull, 2014; Koster, Philbert, de Vries, van Dijk, & Bouvy, 2015) and suggest the need for targeted questions probing child and caregiver perceptions of adherence and capacity for autonomy in asthma management (Klok et al., 2015).

The pervasive and emotionally impactful presence of second-hand smoke (SHS) in the lives of the young children with poorly controlled asthma emerged as a particularly alarming finding in our study. A majority of children resided with at least one family member who smoked. Further, indirect smoke exposure occurred through extended family members, as well as neighbors due to the porous nature of their row homes characterized by shared walls and porches. While high rates of SHS have been previously documented in low-income youth with asthma (McCarville, et al., 2013), our study offers insights to the ineffective strategies used by the caregiver and child to minimize SHS exposure. Moving the child or smoker to a different room, covering the child's face with blankets, and child breath-holding activities suggest poor understanding how smoke permeates the home, an inability to implement total home smoking ban, or a lack of motivation to eliminate SHS exposure.

Another notable contribution of our study sheds light on the negative psychological impact of having family members who smoke. The child participants described sadness, frustration, and anger about ongoing exposure to second-hand smoke as well as social restrictions that limited time with family members who smoked. It is clear that children understand dangers of inhaling second hand smoke but, given their age, they are lacking social or behavioral skills or political capital to have smokers removed from their daily environment. In light of the intensive emotions expressed by children in our study, it may be worthwhile to refer youth with high-risk asthma to therapeutic groups where they may share reflections with similar peers. The experience of talking about asthma home management seemed to engender confidence and enhance self-efficacy in some of the participants. Others have also

noted the value of normalizing experiences within the pediatric asthma population (Protudjer, Kozyrskyj, Becker, & Marchessault, 2009), especially since a poor attitude toward asthma is barrier to self-management in adolescents (Rhee, Belyea, Ciurzynski, & Brasch, 2009).

Limitations

Since the focus groups were comprised of children across a broad age range (6–14 years), it is possible that younger participants may have been reticent to join the conversation and share experiences. Future research would benefit from collapsing the youths into more developmentally similar groups. It would also be intriguing to include caregivers in the focus groups to ascertain similarities and differences in perceptions of home asthma management. Previous research with international adolescents (Mean age=14.9 years) with asthma and their mothers identified divergent perspectives on asthma impact and responsibility (Heyduck, Bengel, Farin-Glattacker, & Glattcker, 2015). Despite these limitations, the findings from this study contribute to the pediatric asthma literature by advancing understanding of the experience of asthma home management from the perspective of young, urban poor children. The comments and feelings about how asthma affects their lives are particularly enlightening and demonstrate the importance of including children in the discussion and plan during healthcare visits. Home management of asthma for these youths is challenging and complicated by a range of modifiable barriers, such as knowledge deficits, as well as contextual risks linked to poverty that are difficult to ameliorate such as housing instability. Findings reinforce the need to provide a multi-pronged approach to improve asthma control in this high risk population including ongoing child and family education and self-management support, environmental control and housing resources, linkages to smoking cessation programs, and psychosocial support.

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Appendix A.: Child focus group questions

Home Stability/Instability

1. How many different places have you slept in the past 4 weeks?
2. Where do you live today? Who do you live with today?
3. Do you have a favorite toy you take with you when you sleep in different places? (It they take toy do they take asthma medicines?).
4. How do you feel when you move to different places?

Medication Use

1. What medicines do you take to help your asthma?
2. Who taught you how to take your asthma medicines?
3. Does anyone help you take your medicines? How do they help you? (place on the counter, actually give you the medicine, watch you take the medicine?)
4. Where do you usually keep your asthma medicines?
5. When you move to a different place, who is responsible for making sure your medicines come with you? Do you have a routine for packing your medications and unpacking medication in your different or new home?
6. Do you ever forget to take your asthma medicines? If you forget, who usually reminds you to take the medicines? Why do you think you forget your asthma medicines? Does moving to a new place cause any difficulties with taking your medications on a regular basis?
7. How do you know when you need to use your inhaler or nebulizer for your asthma? What signs does your body give you when you need to use your asthma medicine?
8. Are there any activities you enjoy doing but you cannot do because of your asthma. Tell us some of them. How does this make you feel?

Second Hand Smoke Exposure

1. Are you around anyone that smokes cigarettes every day? If so, where do they live? How often are you around the person who smokes cigarettes?
2. Who smokes cigarettes in your home and where do they smoke?
3. If they smoke outside, can you smell the cigarette smoke on their clothes when they hug you?
4. How do you feel after being around cigarette smoke? How does it affect your asthma?
5. Are there rules in your home about cigarette smoking? If yes, what are the rules, who has to follow the rules and who enforces the rules?
6. Where are you when you are around the most cigarette smoke? (PROBE: Bus stop, car, house, mother's bedroom...)
7. Do any of your neighbors smoke? If yes, do they smoke around you?

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Table 1.

Characteristics of Child Focus Group Participants¹ (N=13)

ID	Baseline age/Age at time of focus group	SEX	Asthma Severity	ED Visits/3 Months	Hospitalizations/12 months	Symptom Days/2 Weeks	Symptom Nights/4 Weeks	Number of Smokers in Home
001	6/8	M	Persistent-mild	1	0	2	2	2
011	9/11	F	Persistent-moderate	1	0	6	6	2
023	5/7	F	Persistent-moderate	1	0	3	6	0
039	9/11	M	Persistent-moderate	3	2	14	7	1
045	12/14	M	Persistent-moderate	1	0	14	7	1
050	11/12	F	Persistent-moderate	2	0	14	21	1
056	5/6	F	Persistent-moderate	2	1	8	7	0
072	5/6	F	Persistent-mild	1	0	1	1	0
082	7/8	M	Persistent-mild	1	0	1	0	1
085	6/7	M	Persistent-moderate	1	0	14	28	0
097	12/13	M	Persistent-moderate	1	0	4	8	1
100	8/9	M	Persistent-moderate	1	0	8	6	0
111	7/8	M	Persistent-moderate	2	0	14	0	3

¹ Presented demographics and asthma characteristics are from baseline data collected upon enrollment in the RCT.

Table 2.

Characterization of Allergen Sensitization² and Cotinine Level³ by Child Participant (N=13)

Subject ID #	Cat +	Dog +	Mouse +	Cockroach +	House Dust Mite +	Mold +	Oak Tree +	Ragweed +	Timothy Grass +	Cotinine P=Positive (>1.0) N= Negative
001	X						X	X	X	2.59 (P)
011	X	X	X	X	X	X	X	X	X	Missing
023	X	X	X			X				0.85 (N)
039										2.18 (P)
045		X	X	X		X				0.57 (N)
050	X	X	X	X	X	X	X	X	X	2.52 (P)
056										1.94 (P)
072	X	X								0.57 (N)
082	X	X	X	X	X	X	X	X	X	2.3 (P)
085	X	X		X	X	X	X	X	X	0.37 (N)
097	X	X	X	X	X	X	X	X	X	0.49 (N)
100	X	X			X	X				0.47(N)
111	X	X		X			X	X	X	9.69 (P)

²Established by Allergen specific IgE serology by radioallergosorbent (RAST) testing to ten common indoor and outdoor allergens (mouse, cockroach, cat, dog, aspergillus, alternaria, timothy grass, oak, ragweed and dustmite).

³Child saliva samples were collected during the index ED asthma visit using a 3-cm cotton swab (Salimetrics, State College, PA) that was placed under the child's tongue for 1 minute to absorb a minimum of 1 ml of saliva. The cotinine analysis serves as a biomarker of nicotine exposure over the prior 24 hours. A cotinine cutoff level of 1.0 ng/ml was used to define positive SHS exposure based on comparable samples of inner-city children with asthma (McCarville, Sohn, Oh, Weiss, & Gupta, 2013).

Table 3.

List of Themes and Sub-Themes

Theme 1: Barriers to Asthma Management	
Sub-Theme 1:	Housing Instability
Sub-Theme 2:	Pervasive Trigger Exposure
Sub-Theme 3:	Psychological Burden of Poorly Controlled Asthma
Theme 2: Developing Asthma Self-Management	
Sub-Theme 1:	Building Asthma Knowledge Base
Sub-Theme 2:	Establishing Medication Administration and Management Routines
Sub-Theme 3:	Empowerment and Self-Efficacy

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