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Caregiver perception of asthma management of children in the context of poverty

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Abstract

Objective—Low-income caregivers of young children with high-risk asthma experience social stressors and illness-related demands that may impede effective home asthma management. Knowledge of the caregiving experience in the context of poverty is limited.

Methods—Convenience sampling methods were used to recruit low-income caregivers of children aged 7–12 years, who are frequently in the Emergency Room (ED) for uncontrolled asthma. Thirteen caregivers participated in focus groups that were designed to elicit reflections on asthma home and community management from the caregiver perspective. A grounded theory approach was used in the open coding of transcript data from three focus groups, as well as to revise and reorganize emerging themes and sub-themes.

Results—Participants (Mean age = 33.9 years) were predominantly the biological mother (92.3%), single (84.6%), and impoverished (69.2% reported annual household income ≤ $30,000). Their children (Mean age = 7.8 years) were African-American (100%), enrolled in Medicaid (92.3%), averaged 1.38 (SD = 0.7) ED visits over the prior 3 months, resided in homes with at least one smoker (61.5%), and nearly all (84.6%) experienced activity limitations due to asthma. Five themes emerged in the analysis: intensive caregiving role, complex and shared asthma management responsibility, parental beliefs and structural barriers to guideline-based care, lack of control over environmental triggers, and parent advocacy to improve child asthma care and outcomes.

Conclusions—Caregivers managing a child with high-risk asthma in the context of poverty indicate the need for ongoing asthma education, increased sensitivity to the complexity of home

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The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

asthma management, and family-centered interventions that enhance communication and collaboration between caregivers and providers.

Keywords

Asthma; caregiver; stress; medication use; low-income; focus groups

Introduction

Effective asthma management in the home requires multiple caregiver competencies and behaviors including proper medication administration, avoidance of triggers, implementation of home environmental control protocols, and accurate symptom recognition [1]. In impoverished communities, caregivers of young children with high-risk asthma encounter profound social stressors, in addition to illness-related demands, that collectively impede asthma management, increase morbidity, and impair quality of life [2,3]. When confronted by the profound hardships of poverty such as housing instability, food insecurity, and community violence exposure, a caregiver's capacity to attend to the child's symptom management may be further undermined [4,5], and result in increased ED and urgent care visits [6]. Heightened exposure to asthma triggers in the housing stock of impoverished communities (e.g., rodents, cockroaches, mold, secondhand smoke) is an additional burden for caregivers to address in their efforts to keep their child's asthma controlled [7].

Diverse home and community-based interventions have been developed to reduce inner-city asthma morbidity by strengthening caregiver asthma management competencies and decreasing exposures to environmental triggers [8]. However, asthma health disparities experienced by inner-city, minority children persist. Over 15 years ago, Weil and colleagues [9] cautioned that asthma programs may have reduced efficacy with inner-city families, "if they ignore the psychosocial factors that facilitate or impede the family's ability to carry out medical management plans (p. 1279)." Understanding caregiver experiences with asthma management in the context of inner-city poverty is therefore critical to help inform tailored assessment protocols and family-centered interventions.

A recent qualitative study of inhaled corticosteroids administration in young children with asthma (mean age 5.9 years) highlighted multi-level barriers to guideline-based care [10]. Sub-optimal caregiver problem-solving abilities, Difficulties gauging the child's need for medications, poor parent-provider communication, and concerns about medication side effects were identified as factors undergirding non-adherence. Interviews with low-income Latino caregivers further revealed how barriers may stem from a lack of health insurance, transportation Difficulties, and communication challenges [11].

Findings from focus groups comprised of low-income minority caregivers of children with moderate-to-severe persistent asthma likewise identified individual, family, and systems-level factors undermining effective asthma management including caregiver health beliefs, a lack of school resources and support, inadequate insurance coverage, and poor relationships with healthcare providers [12]. Participants also described substantial psychological burden in their caregiving role and financial constraints that impeded environmental remediation despite awareness of the deleterious effects of triggers on the child's asthma.

Collectively, these qualitative inquiries shed light on the complexity of factors contributing to poor asthma management and child outcomes. However, research with caregivers has generally focused on discrete aspects of asthma management (e.g., barriers to care, treatment adherence) rather than explore the broader lived experience of parents of children with asthma. Because knowledge of how poverty impacts asthma management is especially limited [13], the intent of this study was to examine how low-income, inner-city parents experience asthma caregiving.

Methods

This qualitative 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, as defined by National Asthma Education Prevention Program (NAEPP) guidelines [14] and who are frequently in the ED for uncontrolled asthma [15]. A convenience sampling method was used to recruit caregivers of children aged 7–12 years, who had completed the RCT and agreed to be contacted for future asthma studies. Study staff sent letters inviting 24 eligible caregivers to attend a focus group and share experiences about asthma home management. Interested parents ($N = 20$) contacted the study office, received additional details about the purpose of the study, and agreed to participate. Thirteen (65%) caregivers signed written informed consent 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 produces a richer understanding of caregiver experiences compared with quantitative measures and may enhance self-efficacy and empowerment through sharing similar experiences with peers [12,16]. The focus group script and associated questions were developed by the research team and refined based on prior literature and preliminary data from the RCT. The questions were designed to elicit caregiver reflections on the meaning of asthma home management and to draw out their viewpoints of the range of barriers and facilitators to asthma management in the broader social context (Appendix A). The focus groups lasted an average of 90 minutes, were audio-taped and transcribed verbatim by a trained professional, and produced an average of 30 pages in transcription data per focus group.

Data analysis

Grounded theory coding techniques comprised of the following iterative steps were used to analyze the data. Three research team members, one of whom moderated all focus group sessions, independently performed open coding of the data for initial construct identification and development of tentative themes and sub-themes, a process that was captured through reflexive journaling [17]. The coding scheme and definitions for the themes and sub-themes were synthesized and refined by group consensus in biweekly data analysis meetings over a 5-month period.

The finalized coding scheme was subsequently applied to the three sets of transcripts, with agreement on thematic classification surpassing 90% across raters. Additional techniques to increase the trustworthiness of findings included triangulation across disciplines (e.g., research team members from different professional backgrounds analyzed the data) [18] and the use of an outside reviewer with clinical and research expertise in high-risk pediatric asthma who evaluated the themes and sub-themes against the original transcripts [19]. Furthermore, a third focus group was held to ensure that data saturation was achieved, as indicated by no new themes or sub-themes emerging in the analysis [20].

Results

Focus group caregivers (Mean age = 33.9 years) were predominantly the child's biological mother (92.3%), single (84.6%), employed full- or part-time (69.2%), and reported an annual household income at or less than $30,000 (69.2%). Children were African American (100%), enrolled in Medicaid (92.3%), male (61.5%) and resided in homes with at least one smoker (61.5%). Asthma morbidity and healthcare utilization were high as indicated in Table 1.

The children averaged 7.9 symptoms days over the previous 2 weeks, 7.6 symptom nights over the prior 4 weeks, and had a mean of 1.4 (SD = 0.7) ED visits over the prior 3 months. Nearly all caregivers (84.6%) reported some limitation of child activity due to asthma, yet 46.2% described their child's asthma as well controlled. Comparison of caregivers in the total sample ($n = 113$) and caregivers participating in the focus groups ($N = 13$) indicated no significant differences in socio-demographics or child asthma health characteristics with the exception that children of caregivers participating in the focus group were significantly older than the non-focus-group children [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%; $p = 0.01$).

Five themes encapsulating the caregiver experience of managing asthma in the context of poverty emerged in the analysis (Table 2). 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 I: Intensive caregiving role

Sub-theme 1: Hyper-vigilance: "Sometimes it comes out of nowhere"

Participants described how monitoring their child's asthma symptoms and contexts that raise alarm for an exacerbation is an ever-present and demanding responsibility. Their reflections underscore the unpredictability of asthma exacerbations and highlight how the caregiving role is often a dominant aspect of their everyday life experiences.

> I tend to pay attention to my outer surroundings. And certain surroundings put my antenna up. So, I'm watching her and I'm watching the way she breathes and the way she's coughing. But with us, it has a lot to do with our surroundings, where we're at …you have to watch her, know their every schedule, know certain things, when something's wrong.

Sub-theme 2: Caregiver competencies: “We’re still learning how to take care of kids with asthma”

Caregiver reflections underscore an ongoing process of knowledge building and skill development, with many caregivers evidencing gaps. Learning about the role of controller medications and potential triggers in the home environment emerged as part of the health literacy journey. Caregivers also commented on the challenges of differentiating asthma symptoms from other health concerns.

> When she gets sick …I can’t really tell is it a cold, or is it her asthma kicking in? So it’s like I [am] trying to treat both things. Because it really acts up when she gets sick, and it acts up when the weather changes …and it’s just so much. So it’s like I can’t really tell when it’s her asthma.

Effective asthma management likewise required parents to become knowledgeable of when to seek emergency care for their child. A few participants delineated a clear and detailed plan for managing a child who is experiencing an acute exacerbation. However, as illustrated by the following exchange among three participants, most parents admitted that they waited too long to seek help from providers.

> Parent 1:I’m like, “Look, we can make this work. I’m gonna keep on going …. Then I’m like, “This boy is not going to turn around. And I was finally realizing –
>
> Parent 2:Because I did that one time. You think you can fix it.
>
> Parent 3:So, that’s the thing. And that’s why sometimes we do wait so long to bring them because we think we can turn them around.

Parents also struggled to describe what “well-controlled” asthma means and how it is achieved.

> To me, it’s when you’re giving them the Flovent like they’re supposed to have it, when you know when it’s time for the albuterol, and when you know that it’s time that the albuterol won’t work again, you know that it’s time for the Emergency Room. To me, that’s when it’s well controlled.

Sub-theme 3: “They’re allergic to everything”

Managing the complex allergies experienced by their children was also identified as a significant caregiving responsibility. This sample of children with poorly controlled asthma endorsed a “*laundry list”* of food and environmental allergens that trigger asthma, but are also difficult to completely avoid.

> My brother and I sat and ripped up the carpet. When I bought the house, it had carpet all the way through the house. We ripped up the carpet, when he turned four because I heard then that would help with the dust mites. Like you said, “Bubble.” They live in bubbles.

Interestingly, some parents were aware of the positive allergy but did not link home exposure to their child’s symptoms:

> I have a cat. And so the doctor said she was allergic to the cat. But I've had my cat for almost ten years. So, I know she ain't allergic to mine.

Sub-theme 4: Asthma caregiving: "It can be stressful"

The experience of raising a child with high-risk asthma was also associated with significant psychological stress. Participants reflected feeling "*overwhelmed to have a child that's sick*." The unpredictability of acute exacerbations was particularly worrisome.

> To not be able to see it [flare] coming, that is ridiculously scary …I think I'm gonna lose my mind.

Uncertainty regarding their child's future also weighed heavily on their minds.

> The long term concerns are what can we do, if it's at all possible for him to grow out of it? And if we're close to perfect with it, maybe he will, right? Can he live a normal life while having it?

The financial hardship of raising a child with severe asthma in the context of poverty also contributed to the stress experienced by caregivers. Participants commented that intensive caregiving responsibilities and frequent healthcare utilization left them unable to maintain stable employment.

> Some people are between a rock and a hard place. It ain't because they don't want to. It's because they just can't. Some people have kids come from single parent homes. My husband works two full time jobs for me to stay home with her.

Theme II: Asthma management is a complex and shared responsibility

Sub-theme 1: Skill-building for independence: "I find myself watching"

Participants portrayed a delicate balance of wanting their child to become more autonomous in asthma self-management. Yet, they also acknowledged the need for continued supervision and oversight in asthma care, since in their perspective, their children are not sufficiently attuned to symptoms and "*don't know what's going on*." One mother offered the following reflections regarding her 11-year-old son:

> He'll go outside and I'll be like: [Child Name], take your pump with you because you're outside …And then I'll look out the window, or I'll step outside and I'll see him bent over. I can see him retracting. And he has not pulled that pump out of his pocket, yet ….his mind be like, "Oh, well, I'll just do it later." And later isn't promised to anyone, especially a person with chronic asthma. So it's like you gotta get it together, [Child]. You gotta get it together.

Parents revealed that they check the counters on inhalers to confirm dosages and frequently prompt their children to take medicine when they are preoccupied or forgetful. The following exchange depicts this ongoing involvement.

> Parent 1: Yeah, and you know when they don't [use inhaler] too. There's some time they'll be like, "Oh, I took it, I took it." And I'd be like, "How did you take it when the count's still where it was?

> Parent 2: I'd be like, "I counted the counter so I know."
>
> Parent 1: Clear giveaway.

Strategies to ensure that medications do not unexpectedly run short were also shared:

> Parent 1: Normally, he won't need the one [inhaler] I made him stash for a period of time, so he'll use his up and the school will have one. Then, mine will be the last resort. Even with that, it's "What did you do with it?" "I [child] put it in the washing machine."
>
> Parent 2: I had his doctor prescribe two at a time, so, like you said, I can have one, and he can have one. They never tell you they ran out until they're completely gone.
>
> Parent 3: Until they're completely at zero, and you try to use it, and you spray it and it's nothing.

Deciding when asthma exacerbations warranted emergency services also surfaced as a complex and evolving process in the caregiver-child dyad. In most cases, parents unilaterally chose to take the child in to the hospital. A sub-set of participants, particularly those with older children, described a shared decision-making approach.

> When we get to a hospital is because he's like mom, I need to go to the hospital. He's been having asthma since he was a baby so he is well aware of when he feels like he can manage through it or when he's like no, I need to go ….I'm like at the first, I'm like let's go, you know, because that's how I was but now I'm learning to allow him– it's because I want him to start being more independent and responsible when it comes to his asthma.

Sub-theme 2: Social support and asthma management: "They know the drill"

Participant reflections depicted a multi-layered web of family and friends who are likewise engaged in monitoring and managing their child's asthma. This group of caregivers, primarily single mothers, crafted a network of social relationships to rely on in their child's care.

> My sister had it [asthma] when she was younger really bad. So, she had a whole lot of hospital stays and things like that. So, we, my mother and we know how serious it is. So, my whole family, they be on it.

In some instances, caregivers purposively limited the child's social outings to contexts where adults have knowledge of asthma management.

> Their children have asthma too so they know the drill. They got the EpiPens. …. And I feel actually, sadly enough, I feel more comfortable with someone who do have it and know the drill rather than someone that don't.

Sub-theme 3: School engagement in asthma: "You're playing with my daughter's life"

School involvement in asthma management is essential for this high-risk population, but our participants generally described frustrations related to a perceived lack of adequately trained staff who are cognizant of their child’s asthma symptoms and the need for emergency relief medication. Concerns were also raised regarding a perception of teachers labeling and stigmatizing their children as kids who “*just wanna get out of class”* to use medications, or who have behavior and attention Difficulties when the steroid use is the contributing factor. A perception of school policy that created access barriers to asthma medications emerged as a particularly significant source of frustration among parents as illustrated by the following exchange among three parents:

> Parent 1: The one thing I didn’t like, even though he doesn’t have to carry one around in his pocket, was that they [school administration] told me he couldn’t carry one around in his pocket ….You gotta take it to them and they gotta hold it in the office.
>
> Parent 2: What if he’s in the gym and he’s having an asthma attack and he needs it right now?
>
> Parent 3: Or the nurse is out to lunch
>
> Parent 2: Right
>
> Parent 3: [or] is not in the building?

Theme III: Parental beliefs and structural barriers to guideline-based care

Sub-theme 1: Caregiver beliefs: “Do I worry about giving it [asthma medication] to him every day? Yes, I do”

Personal health beliefs often guided caregiver decisions around managing the child’s asthma. Some participants refused to administer daily medications due to concerns about potential side effects experienced by the child, yet others commented on the possibility of the medications losing potency if used on a regular basis.

> I even admitted this to the doctors at the Emergency Room. One of them was looking at me like I was nuts, and the other one was like “I understand mom.” Because I just told him that I don’t give him Flovent every day. I’m like, “I think that a medicine on a person everyday has effects on them.

Caregiver self-efficacy beliefs also influenced medication administration decisions, especially when a child experienced an acute exacerbation. Some participants reported feeling more comfortable having health professionals manage the acute care of asthma exacerbations, rather than administering albuterol doses at home, out of concern for their child’s health and safety.

> See how they do it in the Emergency Room …how they do it back to back-to-back? The reason why I don’t do it like that because it raises his heart [rate]. When they’re in the Emergency Room, they’re right on top of it. So, it scares me to give it to him the way they do it.

Sub-Theme 2: Structural barriers: “It’s not that we really want more”

The participants’ experiences shed light on access to care barriers that impacted asthma management and heightened their frustration with providers. Some described challenges related to receipt of specialty care for asthma. Difficulties fulfilling prescriptions when inhalers are empty or lost was particularly prevalent. Parents revealed that the ED is used as a resource to obtain these medicines when other avenues are not accessible. The following exchange among study participants poignantly captures this dynamic:

> Parent 1: Even if you talk to the pharmacist, “He lost it [inhaler].”
>
> Parent 2: And you can’t get another one.
>
> Parent 1: But he lost it. “Do you understand what I’m saying to you?”
>
> Parent 1: It’s not that we really want more [asthma medications] …Sometimes I will literally have to bring him to the emergency room just to get another script. [prescription]
>
> Parent 2: That’s me.
>
> Parent 3: Me too.

Theme IV: Lack of control over environmental triggers: Impact of poverty

Sub-theme 1: Frustration: “I feel like everything that I’m doing is not working”

Parents described uncertainty about the sources of triggers in the child’s life, as well as a feeling of helplessness in their efforts to reduce child exposure to allergens. Participants expressed frustrations about the failure of intensive home remediation work, “*no carpet, no dust mites, no pets*,” in improving their child’s health status.

> I have done everything that I feel like I possibly can …I clean so much because I feel like if I clean, I’ll keep everything out, keep everything away. But I still feel like it’s not enough. If I see some dust, I’m gonna go crazy, and I drive my landlord crazy. ‘I want my vents cleaned. I want everything to be cleaned.’ ….I don’t know what else to do.

Other participants drew attention to how family poverty and housing instability left their child vulnerable to allergen exposures that were out of their control.

> You don’t know where they’re going to sleep. My son has the pillow [allergy proof pillow cover] that they gave him that keeps the dust mites away. He has that on his mattress. So, I don’t know where he’s gonna go with someone else and if they’re gonna have dust mites.

Sub-theme 2: Pervasive child secondhand smoke exposure: “You’re sending me to the Emergency Room”

A major source of concern shared by participants was the myriad ways their children encountered secondhand smoke, even when smoking bans were in place for the home. Indirect smoke exposure was commonplace and occurred through clothing, furniture and car upholstery, and hair.

> She [sister] smokes like a chain smoker and she's always embracing and hugging. I have to say to her, "Girl, you can't do that." She'll wash her hands …but it's in her clothes. It's in her skin. And she would wear wigs. It's in her wig. And she's always hugging ….I have to explain, "You cannot do that. You're sending me to the Emergency Room."

A sub-set of caregivers smoked themselves and lacked insight to how smoke permeates the home dwelling, or they used ineffective strategies (e.g., spraying Lysol) to remove smoke from the home environment.

> I smoke in the house. I don't smoke in the same room with him. And I don't smoke in my car at all. And I don't allow anybody else to smoke in my house. I know that's crazy because I smoke in there, but …he already knows don't come in my room. And usually if I smoke, I try to smoke in my room. Don't come in here. Or you know, just stay upstairs or something.

Theme V: Parent advocacy

Sub-theme 1: Advocacy to reduce triggers: "We can cut some of that asthma down"

Participants generally recognized the importance of reducing child exposure to triggers, smoking in particular, and were empowered to advocate for their child's health in encounters with family, friends, and even interactions with neighbors.

> One time he [adult friend] was about to [smoke], I said no, I'm not trying to go to the hospital, I'm not trying to be in there for 12 maybe 24 hours. Can you take it all across the street?

Part of the advocacy role entailed setting limits and curbing social interaction with family members and friends who smoked.

> My brother smokes heavily and you know, he's like oh, someone, if you can't promise me that you're not gonna smoke while he's [son] there then he can't come over and so now his visits are limited to maybe once every six months but I'm fine with that because if that's [smoking] more important to you than you seeing your nephew, so be it.

Sub-theme 2: Advocacy to improve interactions with providers: "Listen to the Parents"

Caregivers also underscored the importance of self-advocacy in encounters with providers in the school and healthcare systems. Their experiences suggest that some providers do not value parents as experts on their child's life.

> Lately, I've been feeling like they aren't as understanding when it comes to him. I don't know if they're just trying to get you in and get you out or what it is. It's kind of rushed and they are dismissing what I'm saying as a parent …I just feel like they don't listen as much as they used to when he was younger.

Parents raising children with severe asthma have also had to advocate for themselves when faced with accusations of child abuse and neglect:

> Parent 1: My child has extreme eczema, and this is the way that his arms and his legs look. They're [health professionals] questioning me, "What's this?" You think I'm beating on him."
>
> Parent 2: They sent the social worker in my room because it was one of our flare-ups. The lady was, 'You were beating on her because she came in here crying." "No, she was crying because I had to call my father to come get his truck. I'm sorry. I left it out there [in ED lot]. I hope it doesn't get towed.'
>
> Parent 1: Or they're in the [child welfare] system became they miss so many [school] days because they're in the hospital or they're sick. The school system will come after you. "Why is your child missing so many days?"

Several recommendations to improve care delivery and parent-provider interactions were offered by participants, including developing more trust in parent decision-making. Parents also emphasized the need for greater sensitivity to the plight of raising children with high-risk asthma in the context of poverty.

> I had a car, but I don't have a car anymore. I was told by a [medical] resident, "Maybe you need to get a new car." How am I gonna get a new car if I can't keep hours on the job, if I'm here coming to see you guys?
>
> They say inconsiderate things like that. I'm here. Do you understand that I'm here? I'm an hourly person, and I'm screwed.

Finally, the experience of sharing reflections and frustrations in the context of the focus group generated a sense of cohesion and pooled advocacy among participants. The following exchange is one example of how the caregivers advocated for each other.

> Parent 1: I'd like to see her son get a nebulizer machine at home.
>
> Parent 2: That's what I want you all to tell the doctors.
>
> Parent 3: Yes, [child] needs a nebulizer.

Discussion

Asthma scholars previously called for a greater understanding of child asthma management in low-income racial/ethnic minority families [21], and our findings extend the evidence of several risk factors related to caregiver knowledge deficits and structural barriers to asthma management, as well as caregiver strengths found in their advocacy efforts for improved child asthma care and outcomes. An enhanced appreciation of the complexity of medication administration and symptom control in the home and broader social environment emerged as a particularly critical contribution of this research. This sample of low-income, inner-city caregivers of minority children with high-risk asthma generally lacked understanding of role of controller medications and struggled to define "well-controlled" asthma. Consistent with previous qualitative inquiries, parent concerns about long-term efficacy and health impacts of medication usage were also associated with suboptimal asthma management [12,22].

One new finding from our research was that the parental decision-making process to seek emergency care for a child with asthma is challenging for caregivers. Parents may attempt to "turn things around" with rescue medication administration at home and often wait too long until the symptoms are so severe that emergency services are needed. Healthcare providers may not appreciate the complexity of this decision-making process because parents are not routinely educated to assess for respiratory distress or poor color.

Wood and colleagues [23] previously emphasized the importance of assessing caregiver asthma health literacy in African American families, and our findings suggest targeted education regarding asthma medication administration and information support related to tiered care is an ongoing need. Encouraging caregivers to voice their concerns and beliefs about home asthma care with their child's provider, followed by the development of a shared decision-making plan, may build rapport-building between providers and caregivers, illuminate ineffective or inaccurate home management of acute exacerbations, and enhance caregiver quality-of-life [24,25].

Another salient finding emerging in our research highlights multiple structural barriers to child asthma medication administration that catalyzed caregiver advocacy. Participants in the focus group affirmed and validated each other's frustration related to accessing providers who may prescribe and refill medications, which in turn left them relying on the ED for prescriptions. This increased healthcare utilization contributes to the significant expenditures on asthma and inadequate guideline-based asthma care [26] and is reflective of barriers to timely telephone or office visit access to providers.

Inconsistent access to medication administration was also encountered in the school system, which raised safety concerns among parents, reduced their trust in the school system, and empowered them to seek change. Although nearly every state has passed legislation allowing children with asthma to "self-carry" inhalers, local enforcement often varies with requirements that schools should follow to allow "self-carry" [27]. Engaging the school system in either access to a school system-wide asthma manager or to a telemedicine asthma care clinic are proposed strategies to possibly allay the distrust between caregivers and the school system and enhance child asthma management.

The profound financial constraints experienced by this group of caregivers living in poverty also left them struggling to adhere to guideline-based care, which for some, resulted in stigmatizing encounters with healthcare professional. These caregivers, others in low-income residences, lacked the resources to consistently implement environmental control recommendations such as air filters, dehumidifiers, mattress covers, carpet removal, mold remediation, and regular washing of sheets in hot water [28].

Housing instability and residence in sub-standard rental properties exacerbated feelings of helplessness and frustration as parents endeavored to protect their children from allergen exposures that are common in inner-city housing and difficult to eradicate. This theme of a "lack of control" likewise surfaced in research with families in shelter homes [29] and underscores the need for providers to be more thoughtful about the hardships of caring for high-risk children in the context of poverty, holistically assess caregiver burden and stress in clinical encounters, and facilitate linkages to community resources to ameliorate these stressors. Since participation in the focus group seemed to generate a sense of cohesion among the low-income caregivers as they reflected on similar life challenges, directing parents to support groups for more long-term relationships may help reduce feelings of helplessness and isolation.

It is also noteworthy that in this sample of low-income families of children with high-risk asthma, the majority of households had at least one smoker, and nearly one quarter of the caregivers were smokers. Moreover, some parents lacked understanding of the pervasive nature of smoke exposure and considered that restricting smoking to certain rooms or floors of the home would shield their child from secondhand smoke (SHS) exposure. Providers of high-risk, inner-city children with asthma consequently need to ask specific questions about parental perception and understanding of SHS reduction efforts in the home. Since smoking may be used as stress management [30], it is perhaps unrealistic to expect immediate goals for a smoke free environment in families coping with the array of psychosocial hardships linked to extreme poverty.

Alternatively, building rapport over time with caregivers who smoke and facilitating connections to community resources that address stressors (e.g., depression, trauma, housing) in tandem with conversations on smoking cessation may be a more fruitful approach to sustained behavioral change [31]. This strategy is consistent with the participants' recommendations that providers listen to parents and be more sensitive to their caregiving role, particularly as it relates to managing a child with high-risk asthma in impoverished communities.

Limitations and future directions

Our findings are preliminary given the use of convenience sampling methods, the modest number of caregivers who participated in the focus groups, and sample composition. Although data saturation was achieved in the analysis, it is possible that other salient aspects of the caregiving experience were not captured. Caregivers who are especially impacted by poverty may not have had the financial, physical or emotional availability to participate in the qualitative study. Additionally, since our sample was exclusively comprised of parents of African-American children, the caregiving experience depicted in this study may not be reflective of other racial/ethnic minority populations.

Finally, in future research, it would be fruitful to pair focus group methodology with in-depth interviews to draw out the experiences of caregivers who feel more comfortable reflecting on hardships individually with research staff. Despite these limitations, insights into the caregiving experience in the context of poverty suggest the need for ongoing asthma education, enhanced provider sensitivity to parental asthma care needs, and interventions to improve access to and communication with providers in the school and healthcare systems.

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Appendix A: Parent focus group questions

Asthma Control

1. Please describe what a healthy environment should be for your child with asthma.
2. What challenges are involved with keeping a healthy environment for your child? Prompt: cigarette smoke exposure, housing problems, other animals.
3. What does it mean to have well controlled asthma?
4. Do you feel it is of any value to your child to keep regular clinic or pediatric appointments when there is no current asthma problems?

Basic Asthma Knowledge

1. What are the symptoms that let you know your child is having an asthma attack? (Prompt: cough, see chest retractions, less active … …)
2. What does asthma do to your child's lungs?
3. Do you think children with asthma also have increased eczema or allergic rhinitis (Runny nose due to allergies?

Child's Medication Use

1. Do you have any concerns or worries about asthma medications that were prescribed for your child?
2. Sometimes parents are ambivalent about asthma medications. What has your experience been? What are your thoughts about asthma medications?
3. How do you remember which asthma medicine to give to your child when they have breathing problems or wheezing?
4. Is there anything you would like your doctor to know about asthma medicines that your child takes for asthma
5. How do you think steroid medication such as Prelone, Decadron, help your child's asthma?
6. What triggers you to know when it is time to refill your child's asthma medicines? (Prompt: do you ever run out of medicine? Who monitors to refills?)
7. Do you supervise your child taking their asthma medicines or do you give the medicines yourself?
8. At what age do you think your child can take their asthma medicines by themselves? (PROBE: oral, inhaled and nebulized medicines)
9. If your child self-administers their medication, what Difficulties do you think they have?

Secondhand Smoke Exposure

1. Smoking can be a challenge for many people and families. Has smoking been an issue in your lives –either for yourself or your families? We know that some children with asthma are exposed to cigarette smoke.
2. Do you think your child is exposed to cigarette smoke now? If not, why not?
3. What are some of the challenges to prevent cigarette exposure for your child (Prompt: grandmother smokes and we live in her house, neighbors smoke on porch outside …..)
4. What suggestions do you have for us to help families avoid cigarette smoke?
5. Are you able to ask someone to stop smoking around your child?

6. Are you comfortable in asking someone to stop smoking around your child? (Prompt: significant other, grandmother, best friend, neighbor, teacher ….)

Family/Parent Stress

1. Tell me about the stress involved with taking care of your child with asthma?
2. When ranking stresses in your life right now, how do you rank the stress of taking care of your child with asthma as compared to other stressors in your life?

School

1. How does the school handle your child’s asthma? Is there a school nurse that you work with? Can you describe how you do work with the school nurse? Is she/he helpful? How? Is your child allowed to take their medicine in school? Carry their medicine?
2. Has your child ever had any problems getting help for asthma at school?
3. Do you think your child is exposed to anything that triggers your child’s asthma in school? (Prompt: any smokers in school, any animals in school, fumes from buses’or other fumes in school?)

Table 1

Characteristics of parent focus group participants (*N* = 13).

Caregiver Characteristics	*N* (%)
Age (Mean, SD)	33.9 (9.2)
Relation to child participant	
Birthmother	12 (92.3)
Father	1 (7.7)
Highest Educational Level	
Some High school	3 (23.c)
High school grad or GED	4 (30.8)
Some college+	6 (46.2)
Employed	
Yes	9 (69.2)
No	4 (30.8)
Marital Status	
Single	11 (84.6)
Married	2 (15.4)
Divorced/Widowed/Other	0 (0.0)
Household Income	
< $10,000	4 (30.8)
$10,000–$30,000	3 (23.1)
$20,000– $29,000	2 (15.4)
> $40,000	3 (23.1)
Refused	1 (7.7)
Child Characteristics	
Age (Mean, SD)	7.8 (2.5)
Gender	
Male	8 (61.5)
Female	5 (38.5)
Race/Ethnicity	
African AmericanWhite/Hispanic or Other	13 (100)
Insurance	
Medicaid	12 (92.3)
Private/other	1 (7.7)
Child Health Characteristics	
Symptom days past 2 weeks (Mean, SD)	7.9 (5.7)
Symptom nights past 4 weeks (Mean, SD)	7.6 (8.1)
Number PCP visits for routine asthma care (Mean, SD)	0.62 (0.8)
Number ED visits for asthma past 3 months (Mean, SD)	1.4 (0.7)
Limitation of Activity due to asthma	
Not at all	2 (15.4)
Slightly/Very slightly	7 (53.8)

Caregiver Characteristics	***N* (%)**
Moderate	1 (7.7)
Very/Extremely/Total	3 (23.1)
Well-Controlled Asthma Over Past 4 weeks (Caregiver Perception)	
Yes	6 (46.2)
No	7 (53.8)
Unsure	0 (0.0)
Asthma Specialty Care in Past 2 Years	
Yes	2 (15.4)
No	11 (84.6)
Asthma medication fills past 12 months	
ICS fills (Mean, SD)	2.92 (2.9)
Controller fills (Mean, SD)	5.9 (5.6)
Short acting beta-agonist fills (Mean, SD) ≥ 4 fills over past 12 months= 29.8%	4.6 (3.2)
HEDIS ratio (Mean, SD)	0.42 (0.23)
Smoking Characteristics of Household	
Number of smokers in the home	
None	5 (38.5)
1	5(38.5)
2	2(15.3)
3 or more	1 (7.7)
Caregiver is a smoker	3 (23.1)

Table 2

List of themes and sub-themes.

THEME I: INTENSIVE CAREGIVING ROLE

Sub-theme 1: Hyper-vigilance: “Sometimes it comes out of nowhere.”
Sub-theme 2: Caregiver competencies: “We’re still learning how to take care of kids with asthma.”
Sub-theme 3: “They’re allergic to everything.”
Sub-theme 4: Asthma caregiving: “It can be stressful.”

THEME II: ASTHMA MANAGEMENT IS A COMPLEX AND SHARED RESPONSIBILITY

Sub-theme 1: Skill-building for independence: “I find myself watching.”
Sub-theme 2: Social support and asthma management: “They know the drill.”
Sub-theme 3: School engagement in asthma: “You’re playing with my daughter’s life.”

THEME III: PARENTAL BELIEFS AND STRUCTURAL BARRIERS TO GUIDELINE-BASED CARE

Sub-theme 1: Caregiver beliefs: “Do I worry about giving it to him every day? Yes, I do.”
Sub-Theme 2: Structural barriers: “It’s not that we really want more”

THEME IV: LACK OF CONTROL OVER ENVIRONMENTAL TRIGGERS: IMPACT OF POVERTY

Subtheme 1: Frustration: “I feel like everything that I’m doing is not working.”
Sub-theme 2: Pervasive child smoke exposure: “You’re sending me to the Emergency Room.”

THEME V: PARENT ADVOCACY

Sub-theme 1: Advocacy to reduce triggers: “We can cut some of that asthma down.”
Sub-theme 2: Advocacy to improve interactions with providers”“Listen to the Parents.”