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Insights from parents can guide asthma care for urban, minority children

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To the Editor

Misalignment in the perceptions of asthma and asthma management between parents and physicians likely contribute to disparities in asthma outcomes.^{1, 2} While parental concerns were identified as important barriers to care in studies conducted about a decade ago,^{2–5} we chose to investigate again to see if findings hold after a period of rapid healthcare change after the enactment of the Affordable care Act.

We conducted seven focus groups among 48 parents and caregivers from the urban, primarily African-American population in St. Louis, Missouri (3–13 per group). Participants were recruited from community sites. Most were female (mother 83.3%, grandmother

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DECLARATION OF INTEREST

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10.5%, father 4.2%, missing 2.1%), African American (85.4%), and lived in urban ZIP codes in which 20% of residents lived below the federal poverty line (70%). Their children had a physician diagnosis of asthma for a median of 6.0 years (interquartile range, 3.5 to 8.0 years). Washington University Human Research Protection Office approved the study: all participants provided written consent and received \$40.

Meetings were conducted by two racially concordant, specially trained facilitators using an interview guide structured for the study. The guide comprised open-ended questions to address beliefs about asthma, asthma management, provider relationships, and ideas for improvement, while allowing members leeway in discussing their child's asthma. Each meeting lasted 90 minutes and was audiotaped and professionally transcribed. The transcripts were reviewed independently by two investigators to identify themes and develop codes. Discrepancies were discussed until consensus was reached. All transcripts were coded and themes were identified using a grounded theory approach. Five major themes, which we found to correspond to areas of concern were identified: (Table I).

Theme 1: Impact of asthma on the child and family

Caregivers consistently found providing asthma care to be stressful and overwhelming. Commonly reported stressors included needing to avoid triggers and keeping up with complex treatment regimens. The financial impact of asthma was a major setback, including recurring bills, missed work, and transportation costs. Many caregivers reported their child had experienced significant asthma morbidity that limited their activities and caused them to miss school, but considered these symptoms normal and not requiring medical attention.

Theme 2: Asthma management

Caregivers voiced significant concerns about asthma medications, worrying that their child might become immune to or dependent on them. To minimize use they adjusted treatment based on symptoms and discontinued altogether when their child seemed well. In every group, participants eagerly shared information about natural and home remedies including a steamy shower, cold air, honey, eucalyptus oil, coffee, and Vicks. They constantly expressed concern about trigger exposure and some restricted visits to relatives and friends to avoid triggers.

Theme 3: Responsibility for asthma care

Caregivers almost universally assumed full responsibility for providing asthma care, even when others were available to help, and many expressed feelings of isolation. They often reported being afraid, especially early in the diagnosis. Their fear stopped them from retaining information, preventing effective care. They felt responsible for educating themselves and others about asthma.

Theme 4: Relationship with physician

All caregivers reported access to a physician who was valued if they were accessible, genuinely concerned, took the time to listen, and provided asthma education when the child was well. They mistrusted those who prescribed too many medications, based treatment on trial and error, and excluded the parent from treatment planning. Few said that they

discussed changes in home management with their doctors. The few who had experienced specialist care preferred it and felt the specialist provided more education and support.

Theme 5: Inadequate asthma education

A universal theme was that insufficient time was spent on education and it was provided at times when the caregivers were stressed, making it difficult for them to understand and retain the information. Caregivers felt guilty that their ignorance had caused preventable office and emergency department visits and worried about teaching asthma care to their children.

We found that caregivers from this high-risk primarily African-American sample want and need help from their physicians to care for their child's asthma. However, they identified issues with the medical approach to asthma management that impacted effective partnerships. A particular concern was inadequate asthma education. Low expectation for asthma functioning and concern about asthma medications are consistent with earlier studies in other urban, African American populations.²⁻⁵ Knowledge of common parental concerns together with ideas for improvement offered by caregivers in this study that are based on their lived experience, suggest a number of recommendations to improve collaborative care for physicians to consider. A meaningful partnership could be established at diagnosis by encouraging the caregiver to attend regularly scheduled office visits for ongoing education, skill training and support. The relationship could be sustained by providing wanted information such as advice regarding the developmentally appropriate involvement of their child in asthma management. Physicians might explore the emotional toll of asthma and help parents to identify pragmatic solutions that fit with their social context. Concerns about asthma medications could be addressed directly by simplifying treatment regimens. Shared decision making could be encouraged by discussing the pros and cons of treatment choices, including natural remedies. Allergy testing to identify avoidable triggers could inform environmental control strategies and reduce unnecessary work. Over time, the provider and parent could together develop a long-term management plan tailored to the child and family's specific needs, context, and routines. This approach to asthma care is promoted in national guidelines and has been shown to improve children's asthma outcomes and patient satisfaction without prolonging office visits.^{6, 7}

Strengths of this study are the rich data from this sample about parents' lived experiences with asthma and their suggestions for collaborative care. However, we cannot generalize our findings to other populations, although similar concerns have been reported in other urban African American and Hispanic populations.^{2-5, 8} Also, our qualitative methods do not allow quantifying the proportion of participants with any given concern.

Our findings suggest that, in this high-risk population, previously identified barriers to care persist and need to be addressed, and that input from families can guide the way forward.

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Abbreviations

IQR Interquartile-range

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Clinical Implications Box

Our interview data suggest that barriers to care in this high-risk primarily African-American population identified 10 years ago persist today and that parents and caregivers may have pragmatic ideas about how to address these barriers and implement patient-centered care.

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Table I

Parent's quotes to illustrate their concerns.

<p>Theme 1: The Impact Of Asthma On The Child And Family <i>"There's a lot of coughing, a lot of coughing."</i> <i>"I think it's very exhausting for kids. Emotionally, mentally, and physically."</i> <i>"I'm so tired of this asthma. It's really sumpin'."</i> <i>"Some of us are overwhelmed. We're nervous. We're upset so we miss a lot of things."</i> <i>"It's a financial burden too cause what if you don't have bus fare [to get to school]? I call my neighbor and get some bus fare, but I have to get bus fare for the child to come back to wherever I'm goin', too."</i></p>
<p>Theme 2: Asthma Management <i>"It jus' seems like it takes so much paraphernalia. You got the machine sitting by his mom's bed, we've got the ... inhalers, n', the medicine, an syringes, and the Prednisone in the fridgerator..."</i> <i>"I try to prevent steroids. I try to use uh remedy like the steamy shower, cold, use to open up the freezer door, put his face in the freezer, a cold pack. Do those things and it helps."</i> <i>"I feel if he don't need it every day, I don't give it to him because it makes 'em immune."</i> <i>"And it's like, I don't want her to go over to her friend's house, she thinks I'm being mean and evil. But, I don't know what kinda carpet they have. I don't know if they clean.... I don't wanna be overprotective,.... but it's really kinda scary."</i> <i>"I like dust all the time and I'm constantly sweeping and vacuuming everything....I change his bed sheets constantly it seems."</i></p>
<p>Theme 3: Responsibility For Asthma Care <i>"I don't even have a job, but it feel like I have one."</i> <i>"I have to. Learn about it, and stay up on everything, because my knowledge can..help save my kids."</i> <i>"My mama tell me bring him here....but I feel like no-one can take care of him like I can when he's sick..."</i> <i>"My mom took care of me and she won't even keep him.... Nobody wants to even watch him because he is hyper and they are scared. His dad's.....gonna probably let my baby pass out somewhere. I'm scared to leave him with him...."</i></p>
<p>Theme 4: Relationship with Physician <i>"It's a trial and error process." "They experiment so much."</i> <i>"The doctor has not explained, she just gives us a new prescription."</i> <i>"We have a local pediatrician....he doesn't seem real tuned into it."</i> <i>"I do like our pediatrician. He will take the time to talk with us, and really listen."</i> <i>"He always explains this is what's gonna happen...and he's just really thorough."</i> <i>"She remembers. So it's like a personal relationship."</i></p>
<p>Theme 5: Inadequate Asthma Education <i>"I think there's a lot of information to be given about asthma, it's not a ...1, 2, 3, 4 visit conversation. And like you say, when you're there, it's usually when your child is sick, and I think for years I didn't hear half of what my pediatrician maybe was saying."</i> <i>"I feel like I know what to do a lot more now than I used to, but when mine was diagnosed at about three, uh, I felt, well, completely clueless, and even my pediatrician and uh, the specialist, I, I felt like they were talking to me but yet, I didn't understand, really; I didn't understand much."</i> <i>"Early on I felt like I was coming in quite a bit and it could have been avoided if they had educated me more. And if they couldn't educate me, if they could have referred me to some other specialist um I think that would have saved the emergency room visit that would have saved me call in every time cause I just, I was never around asthma so I didn't know what the treatment was or what the signs were of him having, you know, an issue of breathing and all those things so they could have done a better job of that."</i> <i>"He's allergic to trees, grass, so he has things that triggers, so it's all tied together, but I guess when we first were finding out, I didn't realize, you know, the importance between the two. I just thought you could have allergies, and I never realized that in most cases the allergies somewhat trigger the asthma attack."</i> <i>"After a while you figure it out." "Practice makes perfect."</i></p>