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A qualitative study of parent perspectives on barriers, facilitators and expectations for school asthma care among urban, African-American children

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ABSTRACT

Objectives: Minority children experience the disproportionate burden of asthma and its consequences. Studies suggest ethnic groups may experience asthma differently with varied perceptions and expectations among parents of African-American and Latino children. Because parents coordinate asthma care with the school, where children spend a significant amount of their day, this study's goal was to determine parents' perspectives on school asthma management. **Methods:** Focus groups were conducted with parents of children with asthma at four urban schools whose student population is predominantly African-American. A semi-structured guide was utilized focusing on barriers, facilitators and expectations for asthma care at school. Grounded theory principles were applied in this study. **Results:** Twenty-two parents (91% females) representing 13 elementary and 10 middle school children with asthma (61% boys) participated in four focus groups. Most children (87%) had persistent asthma. The identified barriers to effective school-based asthma care included limited awareness of children with asthma by teachers/staff, communication issues (e.g. school/parent, within school), inadequate education and lack of management plans or systems in place. In contrast, the identified facilitators included steps that fostered education, communication and awareness, as supported by management plans and parent initiative. Parents described their expectations for increased communication and education about asthma, better systems for identifying children with asthma, and a trained asthma point person for school-based asthma care. **Conclusions:** Parents of children with asthma identified important barriers, facilitators and expectations that must be considered to advance school asthma management. Improved school-based asthma care could lead to better health and academic outcomes.

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Introduction

Asthma is the most common chronic childhood illness in the United States, affecting 8.4% of children [1]. Asthma and its negative outcomes disproportionately affect urban, minority and underserved youth, including black children in Chicago, who face 2–3 times higher prevalence than white children [1–3]. Even after adjusting for the higher prevalence, black children still have 2–3-fold higher rates of hospitalization and emergency department visits and 4.9-fold higher mortality, as compared to white youth [1,4–6].

In addition to its medical consequences, asthma significantly impacts school attendance and academic performance. Children with asthma miss 1.5 more

school days each year when compared to those unaffected [7] for reasons such as asthma-related symptoms, exacerbations and medical visits [7–9]. Along with lower attendance rates, children who have asthma suffer in school readiness, academic performance, educational achievement and development and behavior [10–14]. Further, more severe asthma correlates with poorer performance [11].

While children in minority groups face the disproportionate burden of asthma morbidity, studies suggest that various ethnic groups may experience asthma differently [15,16]. For example, one study showed more positive attitudes about school were protective from poor asthma outcomes for African-American youth with asthma, whereas higher family

connectedness was protective for Latino children [16]. Another study identified specific differences related to asthma medication concerns among parents of African-American versus Latino children [15]. In fact, culturally tailored programs have been described as an important part of improving asthma outcomes and decreasing disparities [17–19]. Therefore, understanding how these differences among parents of African-American children extend to the school setting is crucial as these perceptions are associated with adherence to asthma care [15].

To minimize asthma's negative consequences, it is critical to ensure effective processes are in place to support asthma management at school. School systems are key partners in asthma care and have a critical role in helping children with asthma succeed academically. National recommendations for school-based asthma include several key elements: identification of students with asthma, use of Asthma Action Plans (AAPs) to provide instructions for managing signs or symptoms, access to medications, plan for emergencies and education about asthma [20,21]. However, research shows school asthma care is not aligned with these guidelines. For instance, students with asthma rarely have access to their quick-relief inhalers (14%) [22] or have the necessary paperwork, including school health management plans (~25%) [23–26]. Importantly, disparities are seen in minority groups, as African-American and Hispanic students have lower odds of having a Section 504 plan on file at school [23].

Therefore, improvements in school-based asthma care are needed. Traditional stakeholders for supporting school-based asthma management include teachers, administrators and nurses. Parents have also been recognized as stakeholders since they create critical connections between home, school and medical care. Thus, it is necessary for parents to understand, trust and participate in the school's asthma care plan [27].

Many prior studies have examined parents' experiences and viewpoints on overall asthma management, including a focus on barriers for low-income minority children in urban and rural settings [28–33]; however, this topic is understudied as it relates to school-based asthma care. In the few studies examining parent perspectives on school asthma care, parents cited barriers including poor coordination, insufficient education and limited school nurse availability [29–31,34,35]. Although these studies together represent various settings and populations (urban/rural, public/private schools, diverse minority groups), each individual study provides insights only about specific aspects of school asthma care, such as chronic disease

identification or AAPs. To date, studies have not examined asthma care using a comprehensive approach.

Therefore, to develop comprehensive programs to optimally support school asthma management across diverse student populations, it is critical to evaluate the multiple domains of school-based asthma care. Thus, this study aims to determine parent perspectives on barriers, facilitators and expectations for comprehensive school asthma care across an urban network with African-American, low-income children.

Methods

This qualitative study was conducted as part of an academic-community partnership between an academic medical center, school network and community asthma coalition. The nonselective public charter school network includes four schools that serve a primarily African-American, underserved community on Chicago's South Side (1,900 students; 97% African-American; 82% qualify for free or reduced price lunch). Pediatric asthma prevalence was found to be 20–30% in these schools [3,19]. In these public charter schools, asthma care is carried out in alignment with the local public school policy [36].

Focus groups were conducted with parents of children with asthma at each of the four schools. Stratified purposeful sampling was utilized to ensure representation from different schools and grade levels [37]. Parents were recruited to participate through newsletters distributed broadly and letters sent to parents of children with asthma from the research team and school nurses; these children were identified based on a previously described asthma screening process using a validated questionnaire, the Brief Pediatric Asthma Screen [19,38]. Focus groups were stratified by child's grade (elementary/middle school), because parents and school staff may play different roles in care as children become older and self-manage their asthma. The focus groups were conducted at the schools during evening hours. The research team aimed to recruit 5–8 parents per focus group, based on recommendations for conducting focus groups [39]. A facilitator and 1–2 scribes were also present during each group. A minimum of one focus group was planned for each of the four schools. Theme saturation was reached after three focus groups, which aligns with published literature [40]; however, the fourth focus group was completed and analyzed to ensure representation from each school.

Table 1. Interview guide for focus groups with parents of children with asthma.

Domains	Open-ended questions	Follow-up questions
Parent experiences	What arrangements do you have with the school to manage your child's asthma? Who is the point person at the school for you to discuss your child's asthma? Tell us about a time you encountered a challenge with your child's asthma care at school. What do you worry about with regard to your child's asthma when he/she is in school? What do you know about the school's asthma policy? (hand out policy after this question)	How is your child's asthma managed during the school day? Is there anyone else you talk to at the school about your child's asthma? What would need to happen to make it better? What would have been the best solution to this problem? What parts of the policy work for you and your child? What parts of the policy get in the way of your child's care? Why do you think this policy is needed/necessary? Which parts of the policy are happening now at your child's school? Which parts are not happening/have not been implemented? Why do you think this is? What are your feelings about the policy? Do you agree with this policy? What parts of the policy do you agree with? What parts do you disagree with? What additional information would you like about this policy? How? From who? What would need to happen for your child to have a better experience? What should have been available to/done for your child in this situation?
Child experiences	Tell us about a time your child encountered a challenge caring for his/her asthma at school. What happens when your child has trouble breathing or is wheezing at school? Tell us about how your child uses their inhaler at school. How does your child's asthma impact them day-to-day in school?	Does your child carry the quick relief inhaler at school? Why? Where does your child use their inhaler at school? Who, if anyone, helps your child use their inhaler? How is this similar or different at home? How do you decide if you child carries their inhaler or if the inhaler is in the office? What are the reasons that your child does not carry their inhaler? What role does your child's asthma play in their day-to-day life at school? How does your child's asthma affect their attendance/absences from school? How does your child's asthma affect their ability to take part in recess or physical education? Who should the school call when your child has an asthma flare? What would you like to see happen if your child has an asthma flare at school? What do you expect the teachers to know about asthma? How is this different from what you expect the nurses to know about asthma? What type of information would you like to receive? What type of information would you like your child to receive?
Expectations	What do you expect to happen when your child has trouble breathing or is wheezing at school? What role should the teachers and nurses play in caring for your child's asthma? What asthma related programs would you like to see at your child's school? What else can the school do to support your child with asthma?	How is this different from what you expect the nurses to know about asthma? What type of information would you like to receive? What type of information would you like your child to receive?

Verbal informed consent was obtained from each parent. All participants completed a brief questionnaire, including demographics, background about their child's asthma and current management and viewpoints about school asthma care. Then, a semi-structured format was used to elicit parent perspectives about facilitators, barriers and expectations for

asthma management at school. A pre-determined set of open-ended questions was asked to prompt discussion and specific follow-up questions helped elicit detailed information (Table 1). Probing questions were utilized throughout the focus group to clarify responses and explore themes; these questions differed based on the discussion at each group and were

impacted by the information learned at prior sessions. The facilitator, scribes and principal investigator debriefed after each focus group to discuss and refine concepts and questions. Each focus group lasted 60 min. Parents received a \$20 gift card for participation; dinner and childcare were provided.

Focus groups were audio-recorded and transcribed verbatim. All identifying information was removed before analysis. Qualitative analysis software (ATLAS.ti 5.2, Berlin, Germany) was used to code and organize data. Data was analyzed using grounded theory methods of qualitative research, applying inductive reasoning to use the information collected to better understand asthma care in the school [41,42]. Study team members (N.A., M.D., V.P., A.V., M.V.) individually read and openly coded one transcript. The team met to compare codes, resolve discrepancies and agree upon a coding framework through an iterative process. Two members (N.A., M.D.) then coded all transcripts using this framework. New codes and discrepancies were resolved through discussion. The codes were grouped into themes and subthemes as part of the thematic analysis. Several approaches were applied to maximize trustworthiness and validity of the results [37,43,44]. Triangulation was utilized with our findings corroborated through review and feedback from school personnel (including nurses), community asthma leaders and asthma health professionals (pediatricians, pulmonologists and asthma health services researchers). The lead investigator (A.V.) reviewed all transcripts to ensure the themes and subthemes accounted for the main points described by parents. The focus group facilitator also reviewed the final themes and did not identify additional ideas. The study was exempt by the University of Chicago Institutional Review Board.

Results

Twenty-two parents representing 23 children (13 elementary, 10 middle school) participated in four focus groups between February and April 2015 (Table 2). Each focus group had 4–7 parent participants, of whom 91% ($n=20$) were female. Most of the children represented were male (61%, $n=14$) and in elementary school (57%, $n=13$); this aligns with the grade distribution of student population.

The majority of children had persistent asthma, as evidenced by controller medication use (87%, $n=20$) (Table 2). Approximately half (52%, $n=12$) of children experienced daytime symptoms and three-quarters (74%, $n=17$) had nighttime symptoms over the

Table 2. Demographics of focus group participants and current asthma care for their children.

	N	%
Total parents/guardians ^a	22	–
Total children represented ^a	23	–
Gender of parents/guardians		
Female	20	91%
Male	2	9%
No response	2	9%
Race/ethnicity of parents/guardians		
Black or African-American	18	82%
Multiracial	2	9%
No response	2	9%
Child's sex		
Male	14	61%
Female	8	35%
No response	1	4.3%
Child's grade		
Elementary	13	57%
Middle	10	43%
Child's controller medication use		
Yes	20	87%
No	2	8.7%
No response/unknown	1	4.3%
Inhaler location at school (check all that apply)^b		
Child carries his/her quick relief inhaler ("self-carries")	16	70%
Child keeps his/her quick relief inhaler in school/nurse's office	7	30%
Child keeps his/her quick relief inhaler at home	7	30%
Child does not have a quick relief inhaler	1	4.3%
No response	2	8.7%
Updated AAP plan at school (within last year)		
Yes	13	57%
No	10	43%
504 plan on file at school		
Yes	5	22%
No	10	43%
Don't know what a 504 plan is	8	35%

^aFocus group participants included: one mother/father pair representing one child and another mother/father pair representing their two children with asthma. In addition, one female parent represented three children with asthma.

^bFor six children, parents indicated that their child kept his/her quick relief inhaler in more than one location: 2 carry and keep in office; 4 carry inhaler with them as well as keep in school office and at home.

past week. For current school asthma care, participants reported 70% ($n=16$) of their children carry his/her own quick-relief inhaler at school and 30% ($n=7$) keep it in the school/nurse's office; six children keep a quick-relief inhaler in more than one location. More than half of participants (57%, $n=13$) indicated their child has an updated AAP on file at school, defined as within the last year. Also, 22% ($n=5$) of participants reported their child has a health management (Section 504) plan on file at school, 43% ($n=10$) reported they do not, and 35% ($n=8$) stated they did not know about 504 plans.

Five major themes emerged: awareness of asthma status, communication about asthma, education about asthma and care, school asthma management and parent initiative. Within each theme, barriers, facilitators and expectations for asthma care were described (Table 3).

Table 3. Summary of parent-described barriers, facilitators and expectations to school asthma care.

Barriers	Facilitators	Expectations
• Teachers not aware of child's asthma status • Limited knowledge about asthma among teachers, staff and students • Poor communication between teachers, office staff and nurses	• Parent initiative to educate child and teachers about asthma • Child being able to recognize own symptoms and respond appropriately • Presence of school asthma management plans	• Education programs about asthma for teachers, staff and all students • Better communication within school (nurse/office staff to teachers) and from school to home • Creation of an asthma point person to respond to flares

Awareness of asthma status

Parents identified that awareness of children with asthma among teachers and staff is needed to provide care and peer awareness is important for supporting care.

Barriers

Parents noted that school staff may be unaware of their child's asthma diagnosis, describing, *"The hardest part is just making everybody aware that she has it."* (middle school female). Parents perceived there is no system in place to make teachers aware of the children with asthma, explaining *"I bet if I go to my son [sic] classroom, each class, [the teachers] wouldn't know he's asthmatic. I bet you all on that."* (middle school male). Awareness by the primary teacher was insufficient as parents expressed concern that ancillary teachers, such as physical education teachers or recess staff, may not be aware of their child's asthma. The lack of awareness was particularly concerning for parents who said their child tends not to speak up. Parents noted this barrier had educational impact, because when parents perceived that teachers and staff did not know their child had asthma, parents preferred to keep their child at home in the case of asthma symptoms or exacerbations.

Facilitators

Some parents described a tight-knit school community that fosters asthma awareness. Parents stated they frequently saw and connected with families who have children with asthma, therefore becoming aware of other affected children. Some parents of upper elementary and middle school students also described that their children share their asthma status with close friends who can help in case of an emergency. One middle school parent explained: *"[My daughter] let her close friends know so if something happened then they know to go in her purse and get [the inhaler] out."*

Expectations

Parents described strategies for increasing awareness of asthma status, including documentation in each

classroom about children's asthma status and a system for notifying ancillary and substitute teachers. One parent of an elementary school girl stated: *"In each one of those classrooms [where] there's a child who has asthma, the teacher [should be] informed."* Parents also preferred that their child's peers were aware about who has asthma to be able to assist in an emergency, particularly among upper elementary and middle school students.

Communication

To support care in school, parents discussed the need for communication about asthma between several different parties within the school and between home and school, including parent-teacher, teacher-student, parent-office staff/school nurse, office staff/school nurse-teacher and parent-student.

Barriers

Parents described limited cross-communication about asthma within the school as a significant barrier to optimal care. One parent of a middle school girl explained: *"...it becomes an issue when [the school staff is] not all working together... they need to all work together and whatever it is that that child needs, they need to make sure that child has it."* Parents explained that they did not know if or how the school shared health forms or updated asthma information between the school nurse, teachers and staff. The parent of a middle school boy stated: *"I don't trust like, you know, the nurse telling [the teachers]."* Parents also expressed that it appeared there was no communication between their children's primary teacher and other teachers (i.e. physical education) regarding asthma.

Facilitators

Parents frequently explained that direct parent-teacher communication was a major facilitator to asthma care at school. Most often, parents initiated this communication to inform their child's teacher of the asthma diagnosis or update them about treatment plan changes. One elementary school parent explained: *"I tell his teacher, I need him to go down at 10 and 2*

and he uses [the inhaler] in the office and they make sure, like everybody's kind of on the same page. If he's not down there, they're calling for him."

Expectations

Parents desired improved communication between all parties. They suggested various approaches to enhance communication from the school to parents, including via email, in person, through newsletters and at school registration. Parents also offered suggestions about how to enhance communication about asthma within the school, including emails to teachers and staff, announcements at all-staff events and posted information in each classroom. One parent of a middle school female explained: "If you already submitted all your documentation, the school is responsible for letting all the teachers know." In addition, some parents expressed that "the [asthma point] person should be the school nurse." (elementary school male). Others desired a full-time, trained asthma point person with whom they could communicate and facilitate care in addition to the nurse, because nurses are not present at each Chicago school full-time.

Education about asthma and asthma care

Parents emphasized that education about asthma for children and staff impacted care in school. Knowledge about signs, symptoms and management of asthma was seen as critical for affected students and caregivers during the school day.

Barriers

Parents identified inadequate knowledge about the causes, signs, symptoms and management of asthma among their child, peers, teachers and school staff as a major barrier. For children and peers, parents stated that the lack of education resulted in their children choosing not to tell peers or teachers about symptoms, delaying treatment initiation and/or continuing physical activity despite symptoms. For teachers/staff, parents perceived that "the school didn't have anything in place to sit down and educate the staff" (more than one child with asthma). Parents also described that limited asthma knowledge among teachers and staff may lead to delays in recognition of symptoms and in treatment, expressing worry about "staff being uninformed about what signs and symptoms to look for in children that have asthma...and take it lightly." (elementary school girl).

Facilitators

Parents who reported their children had adequate asthma education saw this as major facilitator to care at school. Some parents felt confident in their children's ability to recognize symptoms, share information with others and administer the quick-relief inhaler independently. An elementary school parent explained: "[My daughter is] very educated on when she needs it, how much she needs it, how to take it, and she always let everyone know, I'm a asthmatic[sic]." Parents also perceived that education for teachers and staff empowered them to act in case of symptoms among students. Parents described actions they took to increase knowledge about asthma, taking it upon themselves to educate their children about asthma to ensure s/he can recognize symptoms and respond appropriately at school. For example, one parent described a conversation with their elementary school son:

And then I go, "Do you feel better?"

"Yeah."

I'm like, "Okay, when you start feeling like this, you need to ... take this [inhaler]."

Parents also described their efforts to educate their children's teachers about asthma. One parent shared: "I made it my business to go to [the teachers] and say look, this is a medical condition that my baby has, these are things that I need you to pay attention to and take preventative precautions." (more than one child with asthma).

Expectations

Parents desired mandatory school-based education about asthma for children with asthma, peers, teachers and staff. Parents expected yearly education for teachers to include information about signs, symptoms and management of exacerbations. One parent of a middle school boy explained: "[Teachers] should know the severity of it and know that there are different signs for different kids and that if they see any of the signs, be proactive instead of reactive." Additionally, parents wanted education for students with asthma and their peers to occur in a setting such as gym or health class. A parent of a middle school male described: "On TV they portray having asthma as a sign of being a nerd or a wimp or a weakling, but if the kids know that you could literally die from an asthma attack, they won't [think that]." Parents viewed asthma education as a way to empower peers with the knowledge and skills to respond to an emergency and as a mechanism to reduce stigma associated with asthma. A parent of a

middle school boy suggested *“having like a health education day... or pamphlets to show the kids why it’s important to watch out for certain things or what to do if your friend passes out.”*

School asthma management

Parents described various arrangements they made with the school to manage their child’s asthma. These arrangements included both informal approaches and also formal plans, such as AAPs and 504 Plans, in accordance with school policies.

Barriers

Among children without an asthma management plan on file at school, parents felt the lack of a formal plan was a major barrier to care and a source of worry. Some parents indicated they were not aware that AAPs could be shared with school or 504 plans could be created for asthma. An elementary school parent explained: *“He has an action plan for at home, but I never ever knew that the school had a 504. I know what to do if he’s red, what to do if he’s yellow, but I didn’t know that the school had this plan.”* In addition, parents described informal mechanisms in place at the school that impacted their child’s asthma management, including office clerks with limited health training who provide care when nurses were not present, poor organization of quick-relief inhalers in the school office and attendance policies penalizing students for missed school days due to asthma exacerbations. For example, one middle school parent described: *“So [my son] felt like he couldn’t say anything because it was not a nurse there. And they were going to just going to tell him, you know, wait until the nurse gets there.”*

Facilitators

Parents whose children had an AAP or 504 plan on file with the school felt this plan facilitated care at school. One parent of a middle school female described their utilization of management plans: *“I’ve got a 504 plan. Then I always give an asthma plan of action so [school staff and teachers] all know – [my child] knows what it is too.”* Another parent explained that the plans supported care for their elementary school son: *“I had the whole action plan with the school and he would go to the school nurse and he would do a breathing treatment during the day with the nurses as well as he had his inhaler with him as well.”* Parents also described the significant role of the school nurse in supporting school-based asthma care

and the associated trust in this person held by the parents and their children with asthma.

Expectations

Parents described several expectations for implementing school asthma plans to support their child’s care, including a trained asthma point person, better tracking system for inhalers and revised attendance system. Because the nurse is not present full-time, parents desired *“a full time person [that] is there at all times, whether it be a gym teacher or somebody like that”* (middle school female). Further, parent expectations about attendance included: *“If you have a child that’s missing a lot of days of school, there should be options. There should not be a penalty if a child is sick.”* (elementary school female).

Parent initiative

Parents viewed themselves as advocates for their children and frequently employed strategies to ensure their children receive appropriate care at school.

Barriers

When parents perceived that systems were not in place to support their child in school, parent initiative resulted in alternate plans, termed “workarounds.” These “workaround” strategies were employed by parents to ensure adequate asthma care at school for their child, often resulting in loss of time, productivity and wages. For example, parents described how they or family members came to school to administer treatments every four hours to keep their children at school when ill. An elementary school parent explained: *“Times when I don’t want him to miss that many days I will bring his nebulizer to the school myself and at lunchtime I sit in the office and give him a treatment.”* Alternatively, parents would keep their child home from school when sick to provide care, described by one elementary school parent: *“I don’t want the school to have to worry about stopping their instruction because I have to give [my child] a breathing treatment.”* Another elementary school parent stated: *“I just keep her at home because I think that’s my only option.”*

Facilitators

Parents also described their initiative to file AAPs and 504 plans at school and their efforts to identify and impact the level of awareness, communication and education about asthma at school. One example of parent initiative included: *“I had to teach [my child],*

you know, to recognize when her chest feels tight.” (elementary school). Another parent of an elementary school female described their initiative: *“On parent-teacher conference days I sat down with [the teachers] and explained my child’s condition to them as well as made it my business to meet any other teachers they interact with...to just make them aware of my baby’s condition and let them know what things to look for and just to not blow it off.”*

Expectations

Parents explained that they were the advocates for their child. One parent of a middle school male stated: *“With the parents especially if your child has asthma you are, you know, the spokesperson for your kid.”* Parents also described an expectation to be available at all times in case of symptoms or questions, as explained by one elementary school parent: *“Like I tell them, she even look like she’s breathing wrong, please call me.”*

Modifying factors and outcomes

Parents delineated several modifying factors that influence school asthma care, including child’s age, self-efficacy and asthma severity. Parents reported increased age and perceived self-efficacy allowed their children to better manage their own asthma. One parent described that the creation of a 504 plan would have been helpful earlier but now was no longer necessary, because her middle school son was able to manage his asthma independently. Asthma severity also correlated with increased parent initiative and development of asthma management plans. One middle school parent described the impetus for a 504 plan: *“[My daughter’s asthma] was really bad at that point. I wanted to make sure something was in place. I sat down with a social worker and everybody [at school] and then we put the plan together.”* Finally, throughout the discussions, parents shared that all five themes impacted their child’s attendance, participation and performance in school, as well as healthcare utilization.

Discussion

This study offers important insights about school asthma care for inner-city, African-American, low-income children. It adds depth and breadth to the existing literature by describing parent perspectives about barriers, facilitators and expectations for school asthma management for this population.

Asthma disparities in prevalence, care and medical outcomes are well-described. For children, these disparities extend to school setting, with recent literature showing minority and low-income children with asthma are less likely to have 504 plans at school [23]. Thus, studies like this one allow for examination of barriers and facilitators in this urban, African-American population, while also taking a comprehensive approach to examine multiple domains of asthma care at school.

To improve school care, it is critical to understand where parents see potential breakdowns in processes. Our study identified several barriers to asthma care at school. Some of these barriers have been described in other populations, including limited awareness [30], poor communication within the school [35] and insufficient education about asthma [30]. Our finding of similar barriers as those described in other populations suggests that school processes may be more the same than different, even if the setting, structure or population differs. This suggests that, while disparities exist, lessons can be learned from and translatable to various school environments and populations. Notably, parents in our study described limited communication from the school overall, as previously described in Chicago [34]. However, most parents in our study did not perceive parent-teacher communication to be a major barrier primarily due to the high level of parent initiative taken to engage teachers one-on-one about their child’s asthma care. Parents described that their initiative enabled appropriate utilization of formal systems for school asthma care, such as establishing care plans with the school. At the same time, parents also described how their initiative led to the creation of workarounds to ensure appropriate awareness, communication and education, such as parents educating teachers about their child’s asthma or coming to school mid-day to give medications. This type of initiative represents an empowerment on the part of the parents to control and positively impact their child’s asthma care, aligned with prior studies where empowerment has been linked to asthma self-management practices [45,46].

Parent-reported facilitators to effective asthma care and expectations for care should inform the development plans for school asthma programs. This study identified key facilitators to asthma care, including: increasing awareness about who has asthma within the school; maintaining close communication between parents, teachers and staff and increasing asthma education for children, teachers and staff. School officials and asthma health professionals must consider what

can be done to enhance or change current systems to support each of these facilitators. While some may require leveraging significant resources, simple processes may be sufficient – for example, ensuring teachers and staff in the classroom (i.e. substitute teachers, recess monitors) have readily available access to a list of students with asthma; importantly, consideration must be given to ensure privacy. An additional simple approach may include schools raising asthma awareness among all students by incorporating developmentally appropriate activities in a science or health class, such as role play about helping a peer with asthma.

Further, parents described that AAP plans and 504 plans helped facilitate care when in place. Prior studies show completion rates are low, thus efforts should be directed toward these management plans [23–25]. Communication about management plans can occur annually during school registration, disseminating information to parents about the processes for developing such plans. Additionally, although parents in these focus groups did not explicitly discuss it, health-care professionals are well-poised to reinforce the importance of management plans in schools. Lastly, parent-described expectations for school-based asthma care augment prior studies that outline expectations for improved collaboration and education about asthma to improve care; the detailed ideas can be used to inform discussions with school administrators and nurses [30]. Feasibility must be considered in these discussions in light of schools' limited resources in terms of personnel, time, and finances. For example, hiring a full-time asthma point person may not be feasible, however full-time school staff members can be designated as the asthma point person(s), with additional training for this staff member and clear communication to families to build trust.

One limitation of this study is the small number of participants who represent children across a wide age distribution. Although this broad age distribution may have limited the description of children's unique needs across different grade levels, this broader approach made it possible to examine parents' perspectives about multiple domains of asthma care across a school network. Participants were residents of a primarily African-American community in Chicago with high pediatric asthma prevalence. Further, the four schools in this study are part of a public nonselective charter school network in Chicago, which have more flexibility in educational regulations; however, the schools' health practices align with the local public schools. The generalizability of the results may be limited with regard to public schools, given potential

differences of families enrolled, sense of community created and resources available between charter and noncharter public schools. Thus, this study adds important information about multiple domains of school asthma care for inner-city, African-American, low-income children; however, findings may not represent the opinions of parents throughout Chicago or in African-American communities nationally. Additionally, parents who are frustrated with school asthma care or interested in improving care in the school may have self-selected to participate in the study. These findings reflect only one perspective, that of parents. Due to the qualitative nature of the study, it was not feasible to verify parent responses about whether the child had an AAP or inhaler in the school. Future studies should examine the perspectives of other stakeholder groups, such as teachers and administrators, and validate findings with available objective data to provide a full perspective on school asthma care. Finally, participants may have responded in socially desirable ways; this response bias may have played a role, although less likely because of stories that emerged through the focus group process.

Conclusions

This study adds crucial data about the current processes of asthma care at school and identifies parent perceived barriers, facilitators and expectations about multiple domains of school-based asthma care for inner-city, African-American, low-income children. By understanding what parents identify as the major barriers to school care, their voices can be incorporated in the development of future school asthma programs and policies. Further, school programs that recognize parents as key stakeholders in asthma care of students should promote the major facilitators to care and incorporate their expectations for good care, thereby increasing the likelihood of success and ensuring children are receiving optimal asthma care at school. Ultimately, programs that foster awareness, communication and education about asthma within the school may help reduce absenteeism, improve academic performance and reduce healthcare utilization among children with asthma.

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