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Student perspectives on asthma management in schools: a mixed-methods study examining experiences, facilitators, and barriers to care

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ABSTRACT

Objective: Children spend nearly a third of their day at school, making it a critical point of intervention for those with asthma. This study aimed to illuminate minority students' experiences with asthma at school and perceptions of facilitators and barriers to care. **Methods:** A mixed-methods study was conducted with elementary students with asthma. Participants completed a 24-question survey, drawing exercise to depict experiences caring for their asthma at school, and focus group discussion. Drawings were analyzed for narrative and pictorial themes. Discussions were audio-recorded, transcribed, and independently coded for themes. **Results:** Fifteen children with asthma (8–11 years) participated from two Chicago schools with predominately African-American populations. Most students (79%) indicated they had control of asthma at school, while 85% identified asthma as a problem when exercising. Half (53%) received help with asthma care at school. Drawings depicted cooperative management with adults or peers and the central role of inhalers as part of everyday asthma care in school. Finally, focus groups produced six key themes within the domains of facilitators: 1) support of others; 2) self-efficacy; 3) perception of being normal; and barriers: 4) lack of support from others; 5) difficulty accessing inhaler; 6) perception of being different. **Conclusions:** This study suggests asthma care plays an important role in students' school experiences. Stigma around inhaler use, lack of concern by school staff, and limited access to medications remain as barriers to school-based asthma management. Although facilitators, such as support from teachers and peers, do exist, future interventions must address existing barriers.

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Introduction

Asthma is one of the most common chronic childhood diseases, affecting nearly 7 million US children [1]. Many children face negative consequences including nearly 500,000 emergency department (ED) visits and 14 million missed school days annually [2,3]. Asthma prevalence and its adverse outcomes disproportionately affect minority populations. African-American children are twice as likely to have asthma, four-times more likely to visit an ED for asthma, and seven-times more likely to die from an asthma exacerbation compared to White children [4,5].

Adverse asthma outcomes are largely preventable through regular monitoring, trigger avoidance, and medication use [6]; self-management is fundamental

to these efforts [7]. Though parents play a key role in asthma management for children, this role begins to shift during middle childhood (5–12 years) toward other caregivers and children themselves, as more time is spent away from parents [8]. Children also spend one-third of their day in school. Many do so without asthma plans on file or teachers equipped to manage exacerbations, further emphasizing the importance of self-management [9–11].

Although self-management is critical for school-based asthma care, successful management is also impacted by children's perception of their disease and environment [7]. For example, African-American children (8–17 years) in Atlanta noted poor medication compliance due to skepticism about the benefits of maintenance inhalers and a sense of invincibility

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regardless of medication use [12]. Additionally, Hispanic/Latino elementary school students in Bronx, New York were unwilling to take asthma medications in front of peers due to embarrassment or fear of bullying and teasing [13]; bullying was also identified as a barrier to inhaler use among predominately White elementary and middle school children [14]. Further, these students described limited access to inhalers due to perceived restrictions at school or fear of reprimanding by school staff [13,14]. By focusing on certain aspects of asthma care, these studies shed light on the importance of understanding children's perspectives.

Although many studies explore individuals' experiences with asthma, few studies have examined asthma care from the perspective of elementary school children [12–15]. The literature is particularly sparse as it relates to elementary school children's perspectives about asthma management at school, with existing literature focusing on specific components of school asthma care, such as physical activity or medication use [12–14,16]. No study to date has sought to understand students' experiences and perspectives about asthma management at school as a whole for an age group where children are newly developing personal responsibility for their chronic disease care. This study seeks to fill this gap by exploring elementary school students' experiences with asthma care and perceptions of facilitators and barriers to care at school.

Methods

This cross-sectional study was conducted in spring 2017 within a partnership focused on asthma in two Chicago elementary schools. Both are nonselective public charter schools with predominately African-American (96–97%) and low-income (82% qualify for free/reduced price lunch) student populations; the schools abide by Chicago Public School's Asthma Management Policy [17].

The study included third to fifth grade students based on literature suggesting children can be dependable and valuable reporters of their health starting at 7 years [18]. Using a purposive sampling strategy, participants were recruited through emails, letters, and calls to parents of third to fifth grade children identified to have asthma through school-wide screening [19]. Informed consent and assent were collected. University of Chicago Institutional Review Board approved the study.

The diverse research team included asthma educators, community coalition leaders, school nurses, physicians, and researchers; each brought 1–3 decades

of experience with children in clinical, school, and/or community settings. To maximally engage elementary school children, a mixed-methods approach was utilized with surveys, drawings, and focus groups [20,21]. The team iteratively designed the questionnaire, drawing prompt, and focus group guide based on study aims and existing literature. Drawings were utilized because they can help depict thoughts that are difficult to communicate verbally, especially for children [20,22]. Drawings have also been used as a research method to offer a unique look into patients' perceptions of illness by allowing for introspection, nonverbal expression of emotions, and more in-depth follow-up discussions [23–25]. While studies in adults have utilized drawings and analyzed these separately from interviews or focus groups, only two prior studies with children (5–12 years) included drawings related to asthma; however, drawings were used to prompt discussion and only transcripts were analyzed [15,26]. A mixed-methods study incorporated and analyzed drawings in combination with interviews to describe children's experiences with anaphylaxis; however this approach has not been previously applied for asthma [25].

Based on recommendations for research with children, the study was carried out in school libraries or activity rooms to create an informal, relaxed environment and limit pressure to provide "right" answers [20]. Sessions were held after-school, lasted 60 min, and included 3–7 participants. Only the research team was present; parents, teachers, staff, and non-asthmatic children were not in the room. In the session, each child first completed a questionnaire focused on current asthma care practices, perceptions toward school asthma management, and demographics. Participants then completed a drawing exercise with the prompt: "Draw about taking care of your asthma at school". Participants also wrote a caption and verbally described their drawings. Next, the focus group was led by a research team member (A.H.) with prior experience in conducting focus groups and interviews. This 30–40 min discussion focused on asthma care at school, including policy and rules, support, emotional and social environment, and desired improvements (Table 1). To promote engagement of children, age-appropriate activities were incorporated throughout the session [20]. For example, a beach ball was passed student-to-student as they responded to question prompts. Also, students passed around a "magic wand" and shared one wish to improve asthma care at school. At the conclusion, participants received a \$15 gift card. Each child's parent completed a

Table 1. Question guide for focus groups with elementary school students with asthma, divided by topics.**Policy and rules**

1. What are your school's rules about taking care of your asthma?
2. Who do you think makes up the rules? Do you know?
3. What about rules thinking about when you can use your inhaler? Are there rules about when you're allowed to use the inhaler or do you have to ask someone first before you can use it?
4. Are you allowed to carry your inhaler yourself?
5. Do you know of any rules the school has for asthma management?
6. Is there a difference between if you have trouble breathing in your regular class or in gym class or recess on how you would respond? Are there different rules for those different classes?

Support

1. When you're at school, what do you do when you have asthma symptoms, like trouble breathing or wheezing?
2. Does anyone help you take care of asthma at school and, if so, who is that person?
3. How is it going to get your inhaler when you're feeling like you're having a real attack?
4. Do you feel comfortable using your inhaler in front of your friends or classmates?
5. Have any of your peers or your friends helped you take care of your asthma at school?
6. Do you think you could care for your asthma without the school nurse? Why or why not?
7. What do your teachers know about your asthma? How do they know you have asthma?
8. Does anyone else in school help you with your asthma? Anyone other than your teachers help you and your nurse help you with that?
9. How does your doctor help you take care of your asthma at school?
10. Does your principal help you take care of your asthma at school?
11. Do the security personnel or the security guards here help you with your asthma?
12. Sometimes do you feel like you're not sure if you should take your inhaler or not? What do you do in those situations?

Emotional and social environment

1. Do you feel that your asthma keeps you away from certain activities at school, or not?
2. What happens if you have trouble breathing or if you start using your inhaler in front of your classmates or your friends?
3. What do you tell your friends about having asthma?
4. How does it feel to ask your teacher for help when your asthma's bothering you?
5. Have you ever been treated at school differently because of your asthma?
6. What worries or fears do you have about your asthma when you're at school?
7. Does it ever feel different taking care of your asthma here at school versus at home?
8. How do you feel about having asthma when you're at school?

Desired improvements

1. If you could wish for anything using this magic wand, what change would you make in your school regarding your asthma?
2. Are there any other ways that your teachers or other people at your school can help support you and help you take care of your asthma better?

questionnaire about asthma severity and control, including Childhood Asthma Control Test (cACT) [27].

Quantitative data was analyzed using descriptive statistics (means, standard deviations, proportions). For drawings, inductive analysis was completed using a design framework called AEIOU–Activities, Environments, Interactions, Objects, Users [28]. This framework is typically applied to behavioral data captured through direct or indirect observation, such as

video or photography, and allows all elements of a scene to be itemized, categorized, and then examined for recurring patterns of interplay between them. In this study, the AEIOU framework was applied to analyze drawings, which are similar to scenes captured through camera. This represents a novel application of the AEIOU framework, which is typically used to systematically deconstruct and interpret complex, real-world settings, rather than constructed settings. One researcher (K.E.), with extensive experience in healthcare delivery design, examined the drawings alongside captions to categorize and analyze for major themes. Two researchers (J.N. and A.V.) independently reviewed this analysis. Focus groups were audio-recorded, transcribed verbatim, and de-identified before analysis. Field notes written during focus groups were also reviewed during analysis. Analysis was completed iteratively based on principles of grounded theory, an inductive analytic approach without pre-determined frameworks or hypotheses [29]. Two researchers (J.N. and D.V.) independently read transcripts to identify key points and recurring concepts. Through an iterative process of reading, coding, and discussion by the research team, codes were developed and a master codebook was built. These codes were further organized into overarching domains, themes, and sub-themes. The codebook was utilized to code all focus group transcripts. To establish inter-coder reliability, two researchers (J.N. and D.V.) independently coded the same excerpts of text and compared results; discrepancies were resolved through discussion. NVivo software (Version 11.4.1, QSR International) was used for qualitative analysis.

Results**Participants**

From 44 parents contacted for study recruitment, 15 students with asthma participated in one of three sessions; parent questionnaires were completed for 13 children (Table 2). Participants were 8–11 years [mean = 9.5; standard deviation (SD) = 1.1]; 60% were male. Though race/ethnicity was not collected, participants reflected the schools' population. Nearly 40% of participants ($n = 5/13$) had uncontrolled asthma (cACT score ≤ 19). Parents reported 46% ($n = 6/13$) of participants had school absences and 54% ($n = 7/13$) had ED visits for asthma in the past 12 months, similar to local and national data [30,31].

Experiences with asthma management in school: questionnaires

The majority of students reported they can control their asthma at school (79%, $n = 11/14$) (Table 3). For nearly three-fourths of students ($n = 11/15$), nothing keeps them from taking care of their asthma. Still, over a third ($n = 5/14$) worry about caring for their asthma at school and two-thirds ($n = 9/14$) are unaware of school rules about asthma care. Though most students feel capable of asthma self-management at school, over half do so with support ($n = 8/15$),

primarily from teachers and friends. When experiencing asthma symptoms at school, students tell a teacher, get their inhaler, and/or act like nothing is wrong. For most students (85%, $n = 11/13$), asthma is somewhat of a problem while running, exercising or playing sports. Further, 43% of students say asthma interrupts their ability to keep up with peers ($n = 6/14$). All students said they use a quick-relief inhaler at school and three-quarters carry it with them in a bookbag, pocket, or purse ($n = 10/13$).

Table 2. Participants' demographics, asthma severity and outcomes.

Demographics of children ($n = 15$), n (%)	
Male gender	9 (60%)
Age, years, mean (SD)	9.5 (1.06)
School grade	
3 rd	5 (33%)
4 th	7 (47%)
5 th	3 (20%)
Asthma control and morbidity in past 12 months, parent reported ($n = 13$)	
Uncontrolled based on Childhood Asthma Control Test (score ≤ 19)	5 (38.5%)
Exacerbations (≥ 1 times)	13 (100%)
Oral steroid courses (≥ 1 times)	9 (69.2%)
Emergency department visits (≥ 1 times)	7 (53.8%)
Hospitalizations (≥ 1 times)	3 (23.1%)
Missed school (≥ 1 days)	6 (46.1%)
Parent missed work (≥ 1 days)	6 (46.1%)

Experiences with asthma management in school: drawings

Fourteen participants completed drawings to describe asthma experiences at school. Two content categories were identified in the drawings: cooperative management and inhaler usage (Figures 1 and 2; Supplementary material).

For the collection on cooperative management, drawings depicted children engaging with each other or adults in different scenarios for asthma care. Many of these images depict a particular situation or drama; for example, a child noticing another child is coughing and asking if they are okay; a child pulling out an inhaler so they can play with another child, culminating in a shared

Table 3. Elementary school student experiences and attitudes about asthma care in school.

Influences at school, n (%)			
Someone at school knows I have asthma ($n = 15$) ^a			11 (73.3%)
Teacher/staff			11 (73.3%)
Nurse			1 (6.7%)
Friends/classmates			6 (40%)
Not specified			2 (13.3%)
Someone helps me take care of asthma at school ($n = 15$)			8 (53.3%)
Teacher/staff			4 (26.7%)
Nurse			1 (6.7%)
Friends/classmates			3 (20%)
Something keeps me from taking care of asthma at school ($n = 15$)			4 (26.7%)
I have been bullied or teased about asthma at school ($n = 14$)			1 (7.1%)
Managing asthma at school n (%)			
Use quick relief asthma medicine at school ($n = 14$)			14 (100%)
Type of quick relief medicine used by child ($n = 14$) ^a			
Inhaler			14 (100%)
Nebulizer			4 (28.6%)
Location medicine kept ($n = 13$) ^a			
Book bag/purse			9 (69.2%)
Office			2 (16.6%)
Pocket			1 (8.3%)
Everywhere			1 (8.3%)
Attitudes toward asthma ($n = 14$)			
	Strongly disagree/ disagree	Agree/ strongly agree	I don't know
I understand my asthma and how to take care of it.	0 (0%)	13 (92.9%)	1 (7.1%)
There are rules at my school that make it easier for me to take care of my asthma.	2 (14.3%)	5 (35.7%)	7 (50.0%)
I ask for help with taking care of my asthma at school when I need it.	6 (42.9%)	8 (57.1%)	0 (0.0%)
The teachers and other adults at school help me take care of my asthma when I need it.	4 (28.6%)	7 (50.0%)	3 (21.4%)
I worry about taking care of my asthma at school.	8 (57.2%)	5 (35.7%)	1 (7.1%)
I can control my asthma at school to allow me to participate and learn in class.	2 (3.4%)	11 (78.6%)	1 (7.1%)
I cannot keep up with my classmates and friends due to my asthma.	7 (50.0%)	6 (42.9%)	1 (7.1%)

^aStudents were able to choose more than one answer.



Figure 1. In number one, my mom tells me every morning ‘Do not forget your asma’ but I never do. In number 2, I am walking trough my class room door with my bag and my inhaler. – 10 year old male.



Figure 2. I am holding my inhaler. – 11 year old male.

“yay”; a mother prompting her child at home to bring the inhaler to school and that child again at school proudly with the inhaler (Figure 1). In another example, a 10-year-old boy depicts an interaction with a teacher and describes in the caption: “A boy who is having [an] asthma attack and

need to tell his teacher and his teacher says take his asthma pump so he took his asthma pump and now he [feels] better.” (Child 2). These illustrations depict asthma management as intertwined into everyday life and interactions with others. Illustration elements include speech bubbles, multiple people figures, emotions, and drawn contextual elements that situate activities at home and school.

A second collection of drawings focused on inhaler usage and was twice as large as the first collection. All illustrations feature a single individual engaging with an inhaler, without other people and without an activity context to connect this to a story. Illustration elements include inhalers, labels, and numbers. Notably, no outcome is depicted, just usage. Labels, rather than speech bubbles, are the narrative elements; for example, counting to 10, using a spacer, or taking three puffs (Figure 2). These illustrations suggest a focus on achieving competency and personal responsibility: I know how to use my inhaler all by myself. These drawings also suggest mastery over technology; the inhaler, and sometimes spacer, is the focal point with numbers and other elements of precision depicting a process.

Facilitators and barriers to asthma management in school: focus groups

Within focus groups, six major themes emerged and were grouped into two overarching domains: facilitators and barriers to asthma management (Table 4).

Table 4. Representative quotations of elementary school-age students about asthma care at school, by domain and theme.

Theme	Subtheme	Representative quotations
Domain: Facilitators		
Support of others	Teacher and school staff support	"Every time when I try to ask [my teacher] if I can take my asthma pump, she will – she will, like, watch me take my asthma pump or [tell me to] make sure I do it right." Child 10 "Really, I get treated a little bit differently, by like the teachers who know that I have asthma. If I need to take a break, they'll let me take a break because ... they know I have asthma." Child 13 "[The teachers] have a workshop so they can find out about it. Whenever a child comes up to them and says they need their inhaler and their spacer, they will be able to know what to do." Child 9
	Parental support	"The first picture that I drew was about my mom. She's always keeping in check and making sure that I always have my asthma pump in my bag, but I normally don't really take it out unless I need it." Child 13
	Peer support	"My friends actually help me – like, when I was having my asthma attack. They don't make fun of me ... they will understand that I need to take it." Child 4 "When I was in gym and we were doing – I think it was a game. I forgot what it was called, but it had a lot of running. Then, I started to get slower and started to cough and then my friends went to go and get the teacher and help so I could get my inhaler. So I used my medicine." Child 9
Self-efficacy	Confidence	"I can mostly control [my asthma] myself ... I know when I need to take [my inhaler] and when I don't." Child 13 " ... they would say, do you want help, and I say no because I already know how to do it." Child 5
	Behaviors	"Like, every time I have trouble breathing or if my asthma's getting worse, I'll probably take my asthma pump and won't go outside until my asthma – until I feel better." Child 11 "I tell my friend – when they hit me in my chest, I say I have asthma, you can't do that." Child 4 "I would like to change the school for my asthma, kind of make it cleaner because sometimes it happens because of the dust. Sometimes there's a little dust around and stuff." Child 15
Perception of being normal		"It's not really that much of a deal to my friends ... It's okay [to take my inhaler] in front of my friends. They won't laugh or anything. It's normal for me. A lot of people in my class have asthma." Child 13 "Something I will wish for is ... maybe for people to learn more about other people's asthma." Child 3
Domain: Barriers		
Lack of support from others	Lack of support from teachers and school staff	"A substitute teacher came in and I went out for recess, I was having an asthma attack and she told me that I didn't have asthma at all." Child 1 "I wish that my teachers ... would take care of my asthma a little bit and they would know when I would have asthma ... Like, they could – when I have an asthma attack, they will sit me right away without me telling them to get my asthma pump." Child 4 "I have never been to the nurse for my asthma in all my time of being at [school] because I can mostly control it myself. If I can't, my mom most likely helps me." Child 13 "[The school] can maybe be more concerned about [my asthma]." Child 4 " ... now that, I agree on." Child 6
	Lack of support from peers	"It makes me feel scared when ... I try to take my asthma because ... probably they'll laugh at me." Child 10 "When I was taking my inhaler, [another student] was slapping at me and teasing me." Child 15
Difficulty accessing inhaler	Inconvenient storage	"[my wish] would be a drone. If I'm coughing and I have a problem breathing, I could just send in a drone to carry my asthma pump and I don't have to get it all the way ... If I'm really far away ... I'd just have a little remote to just send in my drone for my asthma [pump]. When it gets to that location, I could just grab my asthma [pump] and then start taking it." Child 8 "Some fears that I have is actually having an asthma attack and not having my inhaler around me." Child 13
	Risk of inhaler loss	"Mom says I can't keep my inhaler in my backpack because I might lose it and somebody might take it ..." Child 8 "We have someone to watch [our inhalers] for us when we go to gym." Child 15
	Requirement for permission	"I tell my teacher whenever I'm in gym ... and I need my pump. So either they send somebody to get it if I can't – if I'm not in the ability to go get it or I go to the office and get my emergency inhaler ..." Child 9 "Sometimes when we're outside, I ask my teacher if I can go upstairs really quickly, but if they say no because there's no supervision around me, they tell me to just sit on the wall for a little so I can breathe." Child 15
Perception of being different		" ... [using my inhaler] is embarrassing ... because some of the kids don't have asthma." Child 11 " ... when I'm running or when I'm doing an activity that I really, really like, I feel like I don't want to take it and I don't want to have asthma at that moment because I'm really having fun. So I just put it to the side and wait to take my asthma pump when it's done – when I'm done." Child 7 "I feel sad because every time I cough or wheeze, my asthma gets worse. I don't want to sit out on stuff because of my asthma." Child 10

Facilitators to asthma management

Facilitators identified by participants were encompassed by three central themes: support of others, self-efficacy, and perception of being normal.

Support of others. One major facilitator to asthma management at school was support by various individuals, including teachers, staff, parents, and peers. Students were aware that teachers and staff undergo

training about asthma management and thus viewed them as trustworthy and knowledgeable. One child described her teacher as a “good support that can help you if you’re having trouble and you can trust them.” (Child 5). Students also described instances where teachers make special exceptions due to their asthma, like allowing more frequent breaks. Along with facilitating asthma management, this special treatment made children feel trusted and taken seriously by their teachers. One child stated: “The teachers that I tell about my asthma, they trust me, so it feels good.” (Child 4). Children also explained the role of other school staff, for instance, describing the principal “goes out of her way to make sure everyone has a safe environment whenever they’re having an attack so everybody can be safe in this school.” (Child 9).

Another key individual who students described as supporting school asthma care was their parent/guardian. Children explained that parents often inform school staff of their asthma status, and, if symptoms occur at school, parents are contacted to help with management. Some students shared that their parents have the best understanding of their asthma, explaining “...if I’m still not feeling well after that, I’ll ask [my teacher] if I can go and call my mom, because she knows more about my asthma than, like, actually me.” (Child 13).

Peers were also described to play a key role in supporting students’ asthma management at school. Many children shared their asthma diagnosis with at least one friend and had friends help with medications. One participant said: “I tell [my friends] that I have my inhaler because if sometimes I’m somewhere and they are nearby, they can run up to my classroom. They know where my inhaler is.” (Child 3). Children also explained the role of friends in defending them from bullying, explaining: “She teased me; but everyone else, instead of laughing at me with her...they just told her to stop laughing at me because it isn’t funny... They all gave me a hug and they let me finish taking my pump.” (Child 15).

Self-efficacy. Another identified facilitator was students’ confidence in their ability to care for their asthma. Many students shared they felt comfortable making their own decisions on how and when to address asthma symptoms. This confidence stemmed from knowing how to manage asthma and having easy access to medications. Students who kept their inhaler with them or had immediate access expressed more comfort in managing asthma at school. One girl explained: “I just feel fine because I know that I have my asthma pump with me.” (Child 4).

Along with addressing symptoms, students cited that their ability for self-management extended to preventing asthma symptoms. Some students described modifying their behaviors, such as running slower or limiting outside activities, to avoid symptoms of difficulty breathing, coughing, or wheezing. One child described: “...sometimes when I play with my friends it involves running and all that stuff...I tell them sometimes like I’m going to run slow because I have asthma.” (Child 5). Others desired to reduce dust at school, revealing an awareness of triggers and efforts to improve asthma care at school.

Perception of being normal. A third theme about facilitators to asthma care in school was the normalcy of asthma. Students were more willing to manage their asthma openly and seek support when they felt accepted in the school. Several students described feeling comfortable because their peers either knew about asthma or had asthma themselves. One student stated: “It’s not really that much of a deal to my friends... It’s okay [to take my inhaler] in front of my friends. They won’t laugh or anything. It’s normal for me. A lot of people in my class have asthma.” (Child 13).

Students also expressed a desire to build a support community among students with asthma. Many children described the focus group as beneficial because it provided a space to share feelings about and experiences with asthma without fear of judgment from peers. One student stated: “So my... wish is to know everybody who have asthma so we could have a meeting or talk.” (Child 2).

Barriers to asthma management

Barriers fell into three themes: lack of support from individuals in school, challenges with accessing inhaler, and perception of being different.

Lack of support from others. One significant barrier to school asthma management described by students was lack of support from individuals within school. Students perceived that some teachers, nurses, and peers do not support their asthma care or obstruct their ability to manage their asthma. Some children expressed a wish that all individuals at school would take asthma symptoms and treatment more seriously.

Students explained some teachers dismiss their asthma needs; for example, one participant explained: “[Teacher name] can get a really bad attitude and not let us go to get our pump or not have a concern about the problem.” (Child 7). Some students communicated a desire for school staff to show more concern

about and involvement with asthma care. Notably, students reported the school nurse did not serve as a significant source of support or as a barrier to asthma management in school. Although students were aware the nurse was a potential source of support and care, many chose not to utilize her services. Several students plainly stated: “I don’t go to the nurse.” (Child 3, 4, 6 and 7)

Peers were also described by some students as a barrier to school asthma management. Their actions ranged from making students with asthma feel uncomfortable about their condition to bullying or teasing. Specifically, students described that peers made them feel uncomfortable about using their inhaler by staring or ignoring them the rest of the day. One child described: “One time in 3rd grade, I... use my inhaler... in front of everybody. Everybody would just look at me taking my inhaler. I think I would creep out because they’re looking at me taking my inhaler. It almost scared me.” (Child 14). In some cases, these actions escalated to bullying focused on inhaler usage. A few students also described peers causing chaos during instances when they use an inhaler or have symptoms in the classroom, heightening situational stress.

Difficulty accessing inhaler. Another theme about barriers to school asthma care was difficulty accessing inhalers. Students identified three challenges pertaining to their inhaler: inconvenient storage, risk of loss or theft, and need for permission to retrieve.

First, students described differences in where the inhaler is stored (e.g. pocket, backpack, school office) and accessibility to it when children are in the classroom, physical education, and lunch. Depending on inhaler location, some students stated they had difficulty accessing their inhaler independently and often depended on others for assistance. Some students wished for better solutions to retrieve their inhaler quickly, further illustrating the challenges students face with access. One student stated: “I would wish for an emergency box. Instead of going down to the office or to go get [the inhaler] out of our bookbags, [I wish that] we have a box in the classroom so if you’re having an asthma episode, you can easily grab it and go.” (Child 9).

Second, the location of inhaler storage, and thus inhaler access, is impacted in part by the students’ need to protect their inhalers from getting lost or taken. Rather than simply thinking about the optimal location for easy inhaler access, students explained they also needed to consider if that location was safe. One student said, “...you can’t always trust people

with your stuff... [my teacher] keeps my inhaler inside a drawer and it’s locked so nobody will get it.” (Child 8). The additional need for protection sometimes prompted teachers/staff to lock inhalers in school office drawers, teachers’ desks, or students’ lockers for safe keeping; however, students cited this storage location limited accessibility to the inhaler in times of need.

A final challenge to accessing inhalers was the need to ask teachers for permission. Most children felt obligated to ask teachers before retrieving their inhaler. Students reported teachers usually allowed them to get their inhaler, though some children recalled instances where teachers asked them to wait or denied requests. One child stated: “Sometimes I can go get [my inhaler] and sometimes I can’t. So, if my teacher gives me the signal... that means just wait for a little.” (Child 15). Students shared perceived reasons for this delay or denial, including no supervision, lack of concern, or ongoing lessons.

Perception of being different. A third barrier to school asthma care that emerged was students feeling different from peers due to asthma. Some students shared that this perceived difference was partly fueled by bullying and teasing by peers. One student described: “...they mess with my asthma pump and they laugh at me because I’m probably not normal because I’m, like, different. I’m different than all of them.” (Child 10). This feeling of being different affected students’ asthma management. For example, embarrassment or fear of bullying prompted students to hide inhaler use from peers by moving behind corners or going to the bathroom to use their inhaler.

In addition to hiding inhaler use, some students took additional steps to appear “normal”, such as ignoring asthma symptoms. Students described allowing symptoms to worsen because they did not want to interrupt activities to manage their asthma. One student stated, “... when I’m running really hard or playing basketball or soccer. I feel like I need my asthma pump, but I don’t use it. So, I’m just going to keep pushing myself and when I’m actually done, I do feel stuff and then I take it.” (Child 1). Some students also described feeling left out of activities where they could not fully participate and expressed a desire for more inclusive activities that are safe for those with asthma.

Discussion

This mixed-methods study identifies actionable facilitators and barriers to school asthma management based on elementary school-age children’s experiences

with asthma care. While prior studies explore children's perspectives about living with asthma, this is the first study to examine overall asthma care in the school setting from the perspective of elementary school-age students and to utilize drawings as a direct data source for children with asthma.

Drawing results from this study aligned with the quantitative and qualitative data and reinforced the findings that personal responsibility and external supports are important for school-based asthma care. Beyond drawings facilitating expression of emotions [24,25] and discussion about experiences [15], this study shows that drawing analysis offers a way to triangulate results from other data sources and test the validity of findings [22,32]. This triangulation between the questionnaires, drawings, and focus groups indicates direct drawing analysis can be a valuable data source when conducting research with children with asthma and may have utility for studies of other diseases, as previously demonstrated with anaphylaxis [25].

In addition to data from drawings, the questionnaire and focus group data stressed the critical role of other individuals in asthma care in school, even as elementary school-age students transition toward independent asthma management. Support or lack thereof from others, including teachers and staff, served as a facilitator or potential barrier to care. Teachers were sometimes seen as a knowledgeable source of help and at other times described as having little concern in asthma situations or hindering medication use. These perceptions are consistent with prior studies showing teachers are often unaware of local school policies surrounding asthma and do not feel comfortable assessing or managing asthma situations, especially when no asthma plan is in place [9,10]. These findings are particularly alarming in Chicago schools, where a recent study found only one-quarter of students with asthma had an action plan on file [11]. Our findings illustrate that these gaps in teacher knowledge and competence in managing exacerbations may impact students' asthma care at school. Students described being told to wait to retrieve or use their inhaler, which reveals lack of awareness of or adherence to the self-carry and administration rules in the school district and possibly also poor understanding of asthma care in general. In contrast to teachers, school nurses were less involved in asthma care, according to students; this may be an artifact of the insufficient availability of school nurses, as each nurse is assigned to several schools. Prior studies in this district have identified insufficient availability of

nurses as a challenge for asthma care [33]; thus, this study reveals potential ramifications of limited nursing availability as children do not view them as significant sources of support for medical care at school.

Another key theme that was evident across all three data sources was inhaler access. Children described that limited inhaler access was a barrier to asthma care, particularly when teachers restricted access to inhalers or inhalers were stored far from students. Further, most children indicated they carry their inhaler in a purse or bookbag, but even these storage locations can create challenges when students are separated from their bags (e.g. gym or recess). Poor access to inhalers has been previously described as a barrier to inhaler use for elementary and middle school-age children (8–15 years) at school; however, this was mostly attributed to perceived school restrictions that prohibit inhaler self-carry [13,14,16]. Because students describe that close proximity to inhalers facilitate asthma self-care at school, consideration must be given to ways to enhance inhaler access. The local public school district, in which this study was based, maintains that students have the right to independently carry and administer asthma medications without supervision by school staff [17]. Despite this policy, this study found that limited access to inhalers was still a significant barrier to school-based asthma care. Though this study's sample size is limited, this finding may suggest inadequate policy implementation and necessitates further investigation within a larger population. The findings also suggest that policies are not the only hindrance to medication access, as this study identified additional reasons for poor access, including a desire for safe storage and limited awareness of student rights. In addition to inhaler access, mastering the technical aspects of inhalers can also impact timely and effective medication use [6]. This concept emerged only in drawings, where inhalers were frequently depicted along with technical aspects of device use, possibly indicating children's awareness of the importance of proper inhaler technique.

A third salient theme was the desire of students with asthma to feel normal among peers, which emerged primarily from focus groups. Students' perception of being different from others impacted their comfort with managing asthma symptoms publicly. Similar findings were seen in past studies where Hispanic [13,34] and White [14] students identified feelings of embarrassment when using medications in front of peers, perhaps indicating this is a shared experience for children with asthma across races/

ethnicities. Though Penza-Clyve et al. [14] identified participant-generated strategies to improve medication adherence, strategies to directly address embarrassment or feeling normal with asthma have not been explored. Participants in our study filled this gap by offering student-generated solutions, including asthma education for all students to raise awareness and decrease stigma as well as regular support group meetings for students with asthma to share experiences and feelings. Though the importance of feeling normal was a major thread in focus groups, it was not delineated in drawings or questionnaires, thus pointing to the value of utilizing various methodologies to prompt sensitive or complex topics with children. It may also reveal that children may not depict the emotional challenges of asthma management in drawings, unlike that seen in adults [24].

Finally, prior studies found students had a sense of invincibility and skepticism about the benefits of asthma management behaviors, such as medication use; this was not seen in our results [12,35]. One possible reason for this discrepancy is the young age of our participants; they may be more reliant on inhalers or more willing to unquestioningly follow recommendations at this early age where they are newly transitioning from parental or adult guidance toward self-management. Findings from Ayala et al. may support this theory that age is a predictor, given seventh and eighth graders were found to be more skeptical about the benefits of asthma management tools compared to sixth graders [35].

Limitations to this study include a nonrandom selection strategy and a small sample size that is primarily African-American; thus, results may not be generalizable across a large, more diverse population. However, because African-American children face a disproportionate burden of negative asthma outcomes, this study sheds light on care for a particularly vulnerable population. Further, the asthma morbidity of our study population is similar to local and national statistics, suggesting our sample may be representative of the larger population [30,31]. One notable difference between this study and prior literature exists in inhaler access; most participants (77%) had personal possession of their inhaler at school compared to only 14% of students in five Alabama schools [36]. This difference may be due to the nonrandom selection strategy employed that could bias participants toward students who are more engaged in their asthma care. However, if this bias does exist, discovering barriers in this highly engaged group of students could indicate even more significant challenges for less engaged

students. Further, though only two schools were included in this study, both follow the city-wide asthma policy and offer insights into other Chicago schools under this policy. Finally, the qualitative research design allows for an in-depth look into participants' experiences, and the focus group was chosen to allow participants to prompt and influence each other's responses. However, given the sensitive nature of the subject for some participants, students may have felt uncomfortable sharing their experiences within the group or provided socially desirable answers. Efforts were made to create a safe environment for sharing by laying ground rules and limiting the group to only students with asthma.

Conclusion

This study shows minority students with asthma face considerable barriers to self-management in school. Despite varied access to medications, fears about feeling different, and lack of support from teachers, staff, and peers, students expressed comfort with their asthma management in school when they have easy access to inhalers and strong, educated support from school staff and peers. Therefore, future policy and programing for school-based asthma programs should work to reduce stigma related to asthma with student support groups and asthma education for all students. Further, efforts should be made to optimally enact policies allowing self-carry and self-administration of medications and to ensure school staff and students are educated and equipped to follow existing school policies that support consistent and easy inhaler access. Because children view teachers as a key element of their care, particularly for immediate response to symptoms, there is a heightened importance to deliver effective asthma training for teachers and staff to ensure children receive adequate care. Future research should identify effective approaches to optimize support and medication access to enhance self-management among students with asthma in school. Additional research should also utilize drawings as a data source for children with asthma given its alignment with more traditionally utilized methods.

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