

Barriers and Facilitators to Asthma Care After Hospitalization as Reported by Caregivers, Health Providers, and School Nurses

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OBJECTIVES: To develop a comprehensive understanding of the barriers and/or facilitators for asthma management for the health professionals and caregivers of children with >1 hospitalization.

METHODS: Individual interviews were conducted with family caregivers and health professionals. Focus groups were conducted with school nurses. The interview and focus group guide were used to probe for barriers and facilitators of asthma management. Interviews were recorded, transcribed, and coded by using qualitative software. Themes were identified by using content analysis in the interviews and descriptive qualitative analysis in the focus groups.

RESULTS: Caregivers ($n = 10$), asthma educators ($n = 4$), physicians ($n = 4$), and a payer ($n = 1$) were individually interviewed. School nurses were interviewed via a focus group ($n = 10$). Children had a median age of 7 years, mean length of stay of 1.9 days, and 56% had a previous hospitalization in the previous 12 months. The “gaps in asthma knowledge” theme (which includes an inadequate understanding of asthma chronicity, activity restrictions, and management with controller medications) emerged as a theme for both caregivers and health professionals but with different health beliefs. School nurses reinforced the difficulty they have in managing children who have asthma in schools, and they identified using the asthma action plan as a facilitator.

CONCLUSIONS: Caregivers and health professionals have different health beliefs about asthma knowledge, which raises challenges in the care of a child who has asthma. In addition, school nurses highlight specific barriers that are focused on medication use in schools. A comprehensive understanding of the barriers and facilitators of asthma management that families experience after hospital discharge is crucial to design better efforts to support families.

ABSTRACT

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Asthma is the most common pediatric chronic disease, affecting 8% to 9% (~6 million) of American children who are <18 years of age,¹ and it disproportionately impacts urban, minority, and disadvantaged children.² Despite the evidence-based guidelines for standardized care from the National Institutes of Health,³ the overall morbidity rate among youth who have asthma, whether it is measured by attack rates, emergency department (ED) visits, or hospitalizations, has decreased only modestly in the last decade.² Patients hospitalized with an asthma exacerbation represent a group that is at risk for future health care use (specifically, a history of asthma hospitalization in the past 12 months is the most significant independent predictor of admission rates across a range of time intervals⁴⁻⁶); therefore, focusing on patients who are hospitalized for an asthma exacerbation may be a crucial step to reduce future hospitalizations for these children.

During hospitalization, a key aspect of asthma management is asthma education, and the creators of the National Asthma Education and Prevention Program guidelines highlight that asthma education needs to be done consistently through multiple points of care.³ Asthma education includes knowledge of basic facts about asthma and the roles of medications, but knowledge alone is not successful at reducing asthma readmissions; asthma education needs to be linked with asthma self-management skills^{7,8} as well as opportunities to increase medication access (eg, promoting medications in hand after hospitalization).^{9,10} Despite the promotion of self-management in these guidelines, the uptake by patients and caregivers remains low. The authors of a recent systematic review identified common barriers and facilitators of asthma self-management across diverse populations and highlighted several key themes, including partnerships between patients and health professionals, issues with medications, education about asthma, and health beliefs.¹¹ Understanding the barriers and facilitators of asthma management through the eyes of families who have experienced >1 hospitalization is crucial to designing improved interventions

to care for these pediatric patients as they transition from the hospital to home.

Driven by our goal to create a patient- and/or family-centered intervention at our institution, we aim in this study to build a comprehensive, qualitative understanding of the barriers and facilitators of asthma management from the perspective of both family caregivers of children currently hospitalized with an acute asthma exacerbation as well as the health professionals involved in the care of children with high asthma morbidity in Washington, District of Columbia (DC).

METHODS

Setting

This study was conducted at Children's National Health System (CNHS), a free-standing academic children's hospital with >300 inpatient beds in Washington, DC. CNHS is the site of >1% of all hospitalizations annually for children and adolescents who have asthma in the United States, with ~1400 children who are hospitalized for asthma exacerbations. The prevalence of asthma among children who are <18 years of age is higher in Washington, DC, than nationwide, with a prevalence of 10.3% in Washington, DC compared with 8.7% nationally. In addition, ED visits and hospitalization rates for children who have pediatric asthma vary widely by zip code within Washington, DC, with a 10-fold difference between children living in the affluent northwest part of Washington, DC compared with children living in inner-city areas. A higher burden of disease exists in southeast and southwest Washington, DC, which represents an at-risk population of children who are primarily insured by DC Medicaid, and this is our target population for which we aim to intervene and improve outcomes. This study received Institutional Review Board approval at CNHS.

Study Design

Convenience and purposeful sampling methodology were used to conduct individual semistructured interviews and focus groups that were led by our research team (K.P., N.F., and D.W.). Caregivers were interviewed in individual semistructured

interviews. Health professionals were interviewed in either individual semistructured interviews or focus groups (only school nurses).

Individual Semistructured Interviews

One-on-one interviews were conducted with family caregivers during their children's inpatient hospitalization. Children hospitalized with the admission diagnosis of asthma were identified through an automated daily report, and patient family caregivers who met eligibility requirements were approached for participation. Primary family caregivers of children admitted for asthma were eligible if the child (1) was aged 4 to 12 years old and had been admitted to the hospital for an asthma exacerbation, (2) was a resident of Washington, DC within identified zip codes of high asthma morbidity, (3) had a previous hospitalization for an asthma exacerbation, and (4) was insured by 1 of the DC Medicaid managed care organizations. Our team decided to focus on children who were ≤12 years of age to minimize the autonomy shift and unique management barriers that may develop with children in adolescence. Patients were excluded if they had underlying comorbidities or complex medical conditions (eg, sickle cell disease, immunodeficiency, cancer, or congenital heart disease). A patient's family caregiver was defined as being the child's primary home asthma caretaker. Parents were approached if they spoke English. Interviews were performed in the child's inpatient room, and caregivers received an incentive gift card for participating.

Interviews were conducted with participating health professionals as well to understand their perceived patient and/or family barriers of a successful transition to the home after hospitalization. One-on-one interviews were conducted with the following health care professionals: physicians (both inpatient and outpatient providers who had experience and expertise with asthma management), asthma educators (both inpatient and outpatient asthma educators who are certified health education specialists and either work in our outpatient asthma specialty clinics or as a dedicated inpatient

asthma educator), and a payer representative, who is a senior staff leader from 1 of the largest DC Medicaid managed care organizations. These health professionals were recruited on the basis of their roles and involvement in the care or management of children who have asthma in Washington DC and were approached if they work with children in the zip codes of Washington, DC that have the highest asthma morbidity. Only the payer interview was conducted via phone, and all other one-on-one interviews were conducted in person. Interview items were derived to identify the perceived facilitators and barriers of asthma management for the families for whom the health professionals care, and the interview guide was reviewed with a qualitative researcher (P.S.H.) and an asthma care expert (S.J.T.).

Focus Groups

Focus group methodology is a qualitative method that is used to get in-depth insights into the perspectives of individuals. School nurses were each interviewed in 2 focus groups with 5 participants, and the focus group lead moderator had previous training in focus group methods (D.W.). Focus group methodology was selected for this group of health professionals because of convenience in terms of incorporating multiple viewpoints from the school nurses and the desire to have consensus ideas emerge from the group.¹² In addition, focus groups work well for colleagues who are discussing a nonsensitive topic because the process facilitates idea generation and development.¹² Although the school nurses were selected from schools in Washington, DC zip codes that had the highest burden of asthma, school nurses were not necessarily involved with the care of the patients whose caregivers had been interviewed. Focus groups were led by 2 moderators, and a scribe was present. Building on the discussion guide for the semistructured interviews, the questions used to direct the focus group discussions were focused on asthma in the school setting. The moderators used probes to expand on emerging issues with participants.

Data Collection

The discussion guide for the semistructured one-on-one interviews and focus groups consisted of open-ended questions. Questions focused on aspects of the experience of caring for a child who has asthma and the perceived causes that led to a recent exacerbation (for caregiver interviews only), the facilitators and barriers of asthma management for the family, and concerns about the transition period after hospital discharge. Interviews and focus groups were conducted in person and were digitally recorded, transcribed, and entered into qualitative software for coding. The Dedoose Web application (www.dedoose.com) for managing and analyzing qualitative data was used (SocioCultural Research Consultants, LLC, Manhattan Beach, CA).

Data Analysis

Two approaches to analysis were used in this study on the basis of interview format (individual one-on-one interviews and focus groups). For the individual interviews, a content analysis approach was used as described by Krippendorff,¹³ and for the focus groups, a descriptive thematic analysis was used as described by Krueger and Casey.¹²

On the basis of quantitative content analysis as described by Krippendorff,¹³ one-on-one interviews were analyzed to interpret meaning from the content of the text data. Transcripts were coded independently to identify emergent themes and salient concepts. Primary level codes were established independently and then merged into themes through repeated and iterative discussions. Transcripts were reviewed by a multidisciplinary team of 3 researchers, including a pediatric hospitalist attending (K.P.), a clinical research coordinator (J.P.), and a qualitative methods expert (D.W.). Investigators read and reviewed transcripts to identify and define initial codes, and the study team met regularly to make coding decisions. Throughout this phase of analysis, the codebook was modified iteratively as investigators added and condensed codes. Codes were refined, and related codes were grouped together under themes. Interviews were conducted until

thematic saturation across all participants was achieved for both family and health professional caregivers. For each interview question, the unit of response was the answer to the question, and the unit of analysis within each response was the phrase; thus, each coded sentence could have a single or several coded phrases. Frequencies across all units of analysis by unit of response in the individual interviews were counted by occurrence.

On the basis of thematic analysis as described by Krueger and Casey,¹² focus group transcripts were analyzed. A line-by-line analysis of the focus group transcript was completed and within the response to each posed group interview question. First-level codes were generated; consistently co-occurring codes with overlapping meaning were combined into themes. Conceptual definitions were generated for each theme. All themes and conceptual definitions were generated through study team member coding and conceptual definitions until consensus was achieved regarding the theme labels and definitions. We identified themes that were common across stakeholders and sought to better understand the differences in these common themes by stakeholder.

RESULTS

Participants

A total of 19 family caregivers or health professionals participated in this study with individual interviews. Ten family caregivers of 9 children who were admitted to CNHS participated. Of these 9 patients, 4 were girls (44.4%), the median age was 7 years, and the mean length of stay was 1.9 days. Five children (55.5%) were hospitalized with an asthma exacerbation in the year before the index hospitalization, and 7 children (77.1%) had an ED visit for an asthma exacerbation in the year before the index hospitalization. One additional family caregiver declined to participate because her child was preparing for discharge. Patients and caregivers included in this study resided in zip codes in the southeast and southwest parts of Washington, DC; based on data from the US Census Bureau, the median income of these included zip codes ranged from \$33 832 to \$34 952, and

individuals below the poverty level ranged from 29.4% to 34.5%.¹⁴

The following health professionals participated in the study: physicians ($n = 4$), a payer ($n = 1$), asthma educators ($n = 4$), and school nurses (2 focus groups with 10 total participants). Health professional interviews were conducted at a prescheduled time either face-to-face or during a telephone call (only the health care payer interview was conducted over the telephone), and none of the professional caregivers who were approached refused to participate. The school nurse focus groups were held at 1 of the Washington, DC school buildings to increase the participation of the school nurses.

A total of 21 first-level codes for barriers and 16 first-level codes for facilitators were identified in the one-on-one interviews. In the focus groups with school nurses, 22 first-level codes for barriers and 17 first-level codes for facilitators were identified. This initial analysis evolved iteratively into 10 main barrier themes and 9 main facilitator themes among caregivers and health professional stakeholders who were interviewed, and 2 unique barriers and 1 unique facilitator from the school nurse focus groups.

Themes Emerging From Family Caregivers via Individual Interviews

Family caregivers reported 4 major barrier themes for asthma management at home: inadequate asthma knowledge, not recognizing environmental triggers, lacking access to care, and balancing life needs. Family caregivers also reported 3 major facilitator themes for asthma management at home: having asthma knowledge, using asthma preventive behaviors, and trusting the medical team (Tables 1 and 2).

Themes Emerging From the Health Professionals via Individual Interviews

Health professional caregivers reported 5 perceived caregiver barrier themes of asthma management; specifically, inadequate asthma knowledge, not knowing environmental triggers, balancing life needs, lacking access to care, and difficulty with managing asthma in schools. Health professionals also reported 5 perceived

caregiver facilitators of good asthma management at home: having asthma knowledge, supporting the parent and/or family, accessing health care, managing social issues, and having communication between child providers and school nurses. Of note, barriers with school management and facilitators with school nurse communication were unique to the health professionals and were not reported by the caregivers (Tables 3 and 4).

The payer identified facilitators of supporting families during the hospital-to-home transition that are represented in supporting the parent and/or family, accessing health care, and managing social issue facilitator themes reported by health professionals. The payer identified the following specific facilitators to support families: connecting families to community resources for assistance (both legal and housing), authorizing 2 inhalers for school-aged children (1 for home and 1 for school), providing medication cabinets in EDs for ease of medication dispensing during exacerbations, employing nurse practitioners who conduct home visits, and establishing a care management team for in-depth assessment for the development of a unique treatment plan for a child and his or her family. These are programs that are currently ongoing in the payer's organization.

Themes Emerging From the School Nurses via Focus Groups

School nurses identified unique barriers that are represented in the "having difficulty managing asthma in school" barrier theme that was identified by the health professionals in the one-on-one interviews. Further analysis of the school nurse focus groups revealed difficulties with both preventive asthma exacerbation management as well as the transition back to school after hospitalization. School nurses identified the following specific barriers in the difficulty with preventing asthma exacerbations: not having knowledge of a student's asthma history, not having prescription medications or orders for asthma management, secondhand smoke exposure at home, needing to work with parents who do not believe that their

child has asthma, as well as managing challenges with the self-administration of medications in the school setting. School nurses identified the following specific barriers in the difficulty of the postasthma exacerbation transition back to school: poor communication between providers and the school, the inability to manage acute exacerbation because of a lack of medications or treatment orders, the inability to adhere to a postexacerbation medication schedule, and the child not feeling well enough to participate in school (Table 5).

Theme With Different Health Beliefs Between Caregivers and Health Professionals: Asthma Knowledge

During the continued and iterative processing of the text data from both the one-on-one interviews and the focus groups, the interdisciplinary team identified relationships within "asthma knowledge" because asthma knowledge was identified as both a barrier and a facilitator among included stakeholders.

Specific findings from our interviews reveal differences in the application of asthma knowledge between the family caregivers and the health professionals (Fig 1). This difference emerged from not having a shared understanding of asthma knowledge; specifically, we found that family caregivers and health professionals have a different understanding of the diagnosis and management of asthma for a child and that these different perspectives affect the ability to appropriately care for a child who has asthma.

First, the understanding of asthma chronicity was interpreted as being a facilitator for family caregivers and yet was perceived as being a barrier for health professionals. For example, family caregivers were overly optimistic that their children would "grow out" of asthma; this belief may adversely influence their ability to appropriately manage this chronic illness because they do not see the need for controller medications when the child is well-appearing. Health professionals reported that families' lack of understanding of the chronic nature of asthma limited the

TABLE 1 Barriers to Asthma Management Reported by Individual Interviews With Family Caregivers (*n* = 10)

Theme	Definition	Frequency		Quotes
		No. Caregivers Reporting	No. Occurrences	
Gaps in asthma knowledge	Understanding of asthma diagnosis, triggers, and management	—	—	—
Not understanding asthma diagnosis	Parent or caregiver is unclear that the patient has an asthma diagnosis	1	1	“Since she doesn’t have flare-ups and it’s not ongoing and it’s not a full diagnosis of asthma... she just plays until I just recognize the coughing and the vomiting. And that’s like a telltale sign for me. So, until that shows up, there’s no precautions or anything like that. Unless if she was diagnosed as full-blown asthma, then I will take the precautions.”
Not understanding child-specific triggers	Uncertainty of child’s triggers or what led to exacerbation	5	9	“Oh, God, it’s hard to tell because she’s in camp. Maybe the weather... it’s kind of pretty much seasonal. I can’t say... She loves animals so she’s always petting dogs when we go in the house or whatever. I don’t know if any other children in the camp have any symptoms or anything going on, I don’t know. I don’t know. I’m just going to be honest. I really can’t say.”
Lacking clarity on asthma management	Unaware of how to treat or manage asthma symptoms and exacerbations in both acute and chronic states	6	12	“It seemed like everything was a short-term treatment, you know what I mean? It’s like a Band-Aid... They were giving her steroids. We’re going to get her this Flovent or albuterol. I don’t know the difference between them both. They have explained, though, I just haven’t retained it... But it just seemed like everything was short-term. Our main concern was what were we going to do long-term, what’s the long-term plan?”
Not knowing and recognizing environmental triggers	Unsure of causes of exacerbations, for example, viral URI, seasonal allergies, carpets, pets, smoke	4	6	“Other than a cold, the changing of the seasons. And I think it’s because the weather is not just 1 steady temperature; it’s like constantly changing, constantly throughout the season.”
Lacking access to care	Issues accessing care or pharmacy	4	6	“When he comes home from the hospital sometimes, it’ll be good if they kind of like rushed to get him an appointment since he just got out of the hospital. But sometimes they don’t always have appointments available. So they may make you wait a week to 2 weeks to get an appointment.”
Balancing life needs	Family has competing, nonhealth priorities	4	7	“A lot of times it’s not the fact that parents want to be lazy. It’s the fact that they don’t get... they’re not able to spend a lot of time with their kids now. So by them putting an extra workload per se on them or a certain task, you know, it’d be easy for them to manage it or deal with it or accept it if it’s already laid out for them. Because they already have a lot on their plate.”

URI, upper respiratory infection; —, not applicable.

TABLE 2 Facilitators to Asthma Management Reported by Individual Interviews With Family Caregivers (*n* = 10)

Theme	Definition	Frequency		Quotes
		No. Caregivers Reporting	No. Occurrences	
Having asthma knowledge	Understanding pathophysiology of asthma and medication and its proper use, symptom recognition, triggers	9	28	"I just have to be, you know, more so cautious of everything and making sure I'm giving her Flovent every day since it is important to take that every day."
Asthma preventive behaviors	Parent-initiated actions to protect the child, specifically	—	—	—
Avoiding triggers	Parent actively avoids child's to prevent exacerbation	4	4	"Keeping him away from around things that triggers. He doesn't really run around that like, but like dust, pollen, animals, certain food, his allergies that he have, because that triggers, too. So basically the basics, like whatever that triggers [him], keep him away from around that."
Being prepared	Parent takes precautionary measures to prevent or deal with exacerbations as they happen	2	3	"It's like a mental piece for me because I have to be on point with her mentally when it comes to situations in here... Man, now she has asthma, I just have to [be] mentally prepared, as well as physically prepared, emotionally prepared for catching it in that moment."
Limiting activity	Parent attempts to keep child calm and/or limits activity to avoid asthma exacerbation	2	2	"I would say just keeping him calm [keeps his asthma in control], because he's real hyper. He likes to run all day. When he's at school he's different, but once he's home, he doesn't like to keep still at all."
Trusting medical team	Parent expresses trust and confidence in health care team and providers (at hospital, PCP)	3	3	"I feel confident that the doctors would never let her go if they weren't confident that she could be okay once she got home."

PCP, primary care physician; —, not applicable.

families' ability to continue to use controller medications when the child was well-appearing because families assumed that the child no longer had asthma. Second, activity limitation was highlighted as a facilitator by family caregivers and a perceived barrier by health care professional caregivers. Family caregivers voiced limiting their child's physical activity to avoid exacerbations and felt this was a facilitator for good asthma management; conversely, health care professionals voiced concern that family caregivers managed by limiting activity, highlighting a difference in asthma management. Third, views of asthma management, specifically the role of controller medications, also differed between family and health professional caregivers. Family caregivers did not understand the role of controller medications and were concerned about side effects, although health professionals noted that family caregivers do not continue with

medications or follow-up appointments when the child is symptom-free.

DISCUSSION

Using qualitative methods, we sought to understand the barriers and facilitators of asthma management after hospital discharge for children who had >1 hospitalization for an asthma exacerbation in an urban setting. Our findings reveal different health beliefs for similar themes by family caregivers and by health professionals; specifically, these stakeholders do not have a shared mental model of what the diagnosis and management of asthma represents for a child. Not having the shared understanding of the diagnosis and management of asthma leads to varying health beliefs and differences in caring for a child who has this chronic condition. In addition, our findings reveal unique barriers and facilitators reported by school nurses for

asthma management in schools, specifically focusing on the challenges with preventive asthma management as well as posthospitalization transition back to school.

Through the one-on-one interviews, we identified 3 main domains within asthma knowledge that are viewed differently between caregivers and health professionals: asthma chronicity, activity limitations, and asthma management.

Chronicity of Illness

Asthma is a chronic illness that requires management even when the child is well-appearing, yet we found that family caregivers had varying understandings of the chronicity of asthma. Health professionals acknowledged the chronic nature of asthma and noted this perceived difference in understanding to be a barrier; on the other hand, family caregivers often did not fully understand the chronic nature

TABLE 3 Barriers to Asthma Management Reported by Health Professionals by Interviews (n = 9)

Theme	Definition	Frequency		Quotes
		No. Health Professionals	No. Occurrences	
Asthma knowledge	Understanding of asthma diagnosis, management, and chronicity	—	—	—
Not understanding asthma and/or management	Gap in asthma education and/or unaware of how to manage asthma	6	24	"[There is a] lack of understanding of exactly what the controller medication does and why it's important that they maintain being on their medication [...] There are many times, in my interactions with the family, where they have confused a controller for the rescue, or they say that they were on the controller, but that wasn't working." — Physician
Having misconceptions about asthma	Not understanding chronicity of asthma	7	21	"To think that your child would need to be on something every day [or] would have some condition... when all you see is these episodes, you don't see a day-to-day problem. But I think sometimes the understanding that people come away from the hospital with is that this is just for this next period of time, and then the prescription runs out and that's it. Their perception is you finish it and then you're done, and then you move on, as opposed to needing to continue it on for any longer." — Nurse practitioner
Limiting child's activity	Parent prevents exacerbations by limiting child's activity	3	3	"I'd say they want their kids to be able to do more, but I think a lot of parents get very used to restricting their child's activity when their child has asthma and they're sort [of] often uncomfortable having that label on... keeping their child in and keeping their child from doing organized activities. Certainly some, that's an issue for; they want their kids to be able to do stuff I don't mean to discount that, but I feel like often I'm the one encouraging people to let their child be more active. And that doesn't always rise up for the parents as a primary goal. It may be for the child, but not always for the parents. And sometimes it's because they live in unsafe areas and they don't want their kid going out anyway." — Nurse practitioner
Having difficulty managing asthma in schools	School nurses have barriers to managing students' asthma including not having prescriptions or not knowing which students have asthma	3	32	"... better communication with school nurses is needed...that transition back to school and making sure that families have medicine and appropriate permission to give medicine in school, and that the school nurses get that, if they go back to school the next day, they're going to be on it every hour, while they're in that immediate postdischarge period, but that we're clear with the school nurse, that it gets communicated and they have medication..." — Nurse practitioner
Difficulty knowing and recognizing environmental triggers	Identify causes of exacerbations: viral illness, seasonal allergies, carpets, pets, smoke	8	19	"... first I think the parents' understanding of triggers and how those work. I think there can be a disconnect between hearing what triggers the asthma and then going home and not realizing that these triggers can be everywhere, like dust, for example. Sometimes we think of dust as like a super dusty surface that you can move your finger on and draw pictures, versus dust that just might be settling on a pillow that we can't see." — Asthma educator
Balancing life needs	Family has competing, nonhealth priorities	9	22	"Once they get back home, they're often facing a multitude of challenges that take priority over... And they are good parents, and they want to do the right thing. But you know, there's just a lot going on." — Payer "It's hard for any family to constantly [remember]... a med that needs to be given twice a day, and I think it's hard to stay adherent, or just constantly remember that it needs to be done... I'm working, I'm tired. All or most of our families are working and exhausted. They've got multiple kids to tend to, maybe multiple asthmatics. How they keep track of everybody, you know." — Physician
Lacking access to care	Issues accessing care or pharmacy	6	14	"...insurance issues are a factor. You know, sometimes insurance has lapsed, or they were not able to obtain their medications for some reason, and they don't have them." — Physician

—, not applicable.

TABLE 4 Facilitators to Asthma Management Reported by Health Professionals by Interviews (n = 9)

Theme	Definition	Frequency		Quotes
		No. Health Professionals	No. Occurrences	
Having asthma knowledge	Understanding the pathophysiology of asthma and medication and its proper use, avoiding triggers, and symptom recognition	8	25	"Families] understanding what other triggers are. I think there are so many potential triggers, in terms of fragrances, cleaning products, as I mentioned, smoking, other things within the home, mold, carpeting, that families don't always appreciate what their child's triggers are. They just often think colds, allergies, because those are the big ones that happen." – Physician "The biggest thing I've seen is, from our end, is really having appropriate medications being taught, how to use medications appropriately, and actually having them available at home. There are some barriers for a lot of our patients with actually getting the appropriate medicine and knowing how to give them, either themselves or from the care providers." – Physician
Supporting the parent and/or family	Providing services and resources to support a parent in managing his or her child's asthma	5	12	"I think, is making it easy as we support parents. Because once they get back home, they're often facing a multitude of challenges that take priority over... And they are good parents, and they want to do the right thing. But you know, there's just a lot going on. So we just have to help." – Payer
Accessing care	Creating ease of making appointments, getting medications, flexible appointments, after h lines	4	7	"Over the years, we've been able to expand our hours of operation. And so we offer evening hours, Monday through Thursday, until 8 PM. And then we're also open on Saturdays as well, in an effort to convince our families that we're here, we're available, and we can manage these issues within our medical home." – Physician "We've tried to do other things that are more in the managed care organization realm, like we authorized, over a year ago, we made the decision to authorize an inhaler to be at school and at home. Because I said the cost of me paying for 1 additional inhaler is a lot less than paying for another ED visit, right, nor the human cost for these families when the child... Because usually we're talking about a lot of single heads of households. So if they have to take Johnny to the ED, they've got to take the other kids too, you know. And so that's really disruptive to the home environment." – Payer
Addressing social issues	Addressing housing issues, legal issues, and insurance lapses	4	4	"Those kids, when I've seen rapid improvement, it's not so much the meds that I've put them on, but it's really either they get a lot of home remediation, or they end up moving homes." – Physician
Communicating between the child's providers and school nurses	Infrastructures that allow for more coordination of a child's disease management across settings	2	2	"The school nurses having someone within the school settings, you know, where kids spend a large majority of their time engaged with the primary care providers, and everyone on the same page" – Physician

TABLE 5 Unique Barriers and Facilitators to Asthma Management Reported by School Nurses via Focus Groups

	Theme	Definition	Quotes
Barriers	Having difficulty with asthma exacerbation prevention in schools	School nurses have barriers to managing students' asthma, including not having prescription orders or medications	<p>"I've even had EMTs want to have altercations with me, verbally, "why don't you have an inhaler in here that you can use?" I said, "But I can't take somebody else's medication and give it to this student. And not only that, I don't have a prescription on order." That puts us in a legal bind since you really feel like your hands are tied." – School nurse focus group</p> <p>"That's their only inhaler and they want to leave it with us. That's the only one. They won't have one. So I'm like, okay, are we supposed to give this every 4 hours for 72 hours? You're giving me this inhaler. What are you doing when he goes home?" – School nurse focus group</p> <p>"You don't have anything. They come into the health suite and going through an asthma episode and you don't have anything." – School nurse focus group</p>
	Having difficulty with the transition back to school after an asthma exacerbation	School nurses have difficulty with teachers and parents when children are improving from hospitalization, but not well enough yet	<p>"Kids come straight back to school from the hospital. And when they do come back, the parents come to me and I'll read the orders, and I know they just come out, discharged from the hospital. Sometimes the child's still sick. So I would suggest, Mom, your child does not look like he's ready to be back in school environment. Maybe you should allow him to stay home for 24, 48 hours. Continue to give him medication and then return him to the classroom. Because all he's going to do is go upstairs in the classroom. The teacher going to observe that he's not participating like he normally does. And, they're going to send him to the nurse." – School nurse focus group</p> <p>"I had a student and she was in the ICU and the parent brought her back. They had discharge instructions. She went ICU step-down, and they brought her back the next day. And they must have been up late because she was like so exhausted. They came home after midnight. She looked really tired, and she was sleeping. He tried to send her to class because he had to go to work. The teach was like, "This is not going to work because she is sleeping in class." And she still looked pretty sick." – School nurse focus group</p>
Facilitators	Using asthma action plan	School nurses value the asthma action plan as a tool in management	<p>"[The asthma action plan is] very helpful. You get multiple layers of how to treat the student... It's the protocol. So it makes it very... it's spelled out very clearly." – School nurse focus group</p> <p>"We like the asthma action plan data. I follow the action plan." – School nurse focus group</p>

EMT, emergency medical technician.

of asthma and expressed that the child will outgrow the asthma and that medications or follow-ups were not necessary when the child was well. Although we acknowledge that the authors of previous studies have shown that as many as 60% of preschool-aged children who are diagnosed with asthma will grow out of the diagnosis,^{15,16} the median age in this study was 7 years old, so it is likely that this study population will need to continue with asthma management for a minimum of a few years. This discrepancy in understanding asthma chronicity has been previously noted between parents and health professionals. In a study of >200 families, health professionals noted that asthma is a chronic illness and that the disease is present even when symptoms are controlled and not currently apparent; in contrast,

parents described asthma as consisting of episodic, acute, and uncontrollable symptoms.¹⁷ This lack of understanding of the chronicity of asthma is crucial because it links to poorer health outcomes.¹⁸ Family caregivers in our study did not have a complete understanding of the chronic nature of asthma, and this could impair their ability to successfully manage their children's asthma. In designing future programs, we need to better address the "no symptoms, no asthma" belief among family caregivers to better equip them to manage their children's asthma.

Activity Limitation

Using activity limitation as a way to manage a child's asthma is another theme of the differing emphasis between family caregivers and health professionals. Family

caregivers noted that they encouraged their children to not exert themselves as a facilitator in maintaining control over the asthma. However, this is in direct contrast to health professionals, who repeatedly noted that activity should not be limited in the child when well if their asthma is well-controlled. Children who have asthma engage in less physical activity than children who do not have asthma,¹⁹ yet health professionals report that physical activity is beneficial for children who have asthma and that they can be as active as children who do not have asthma. Given the link between childhood obesity and poor asthma control, this activity restriction in children who have asthma can be detrimental.²⁰ Recent work from the United Kingdom has been focused on how best to design a physical activity program in

Care Givers

Health Professionals

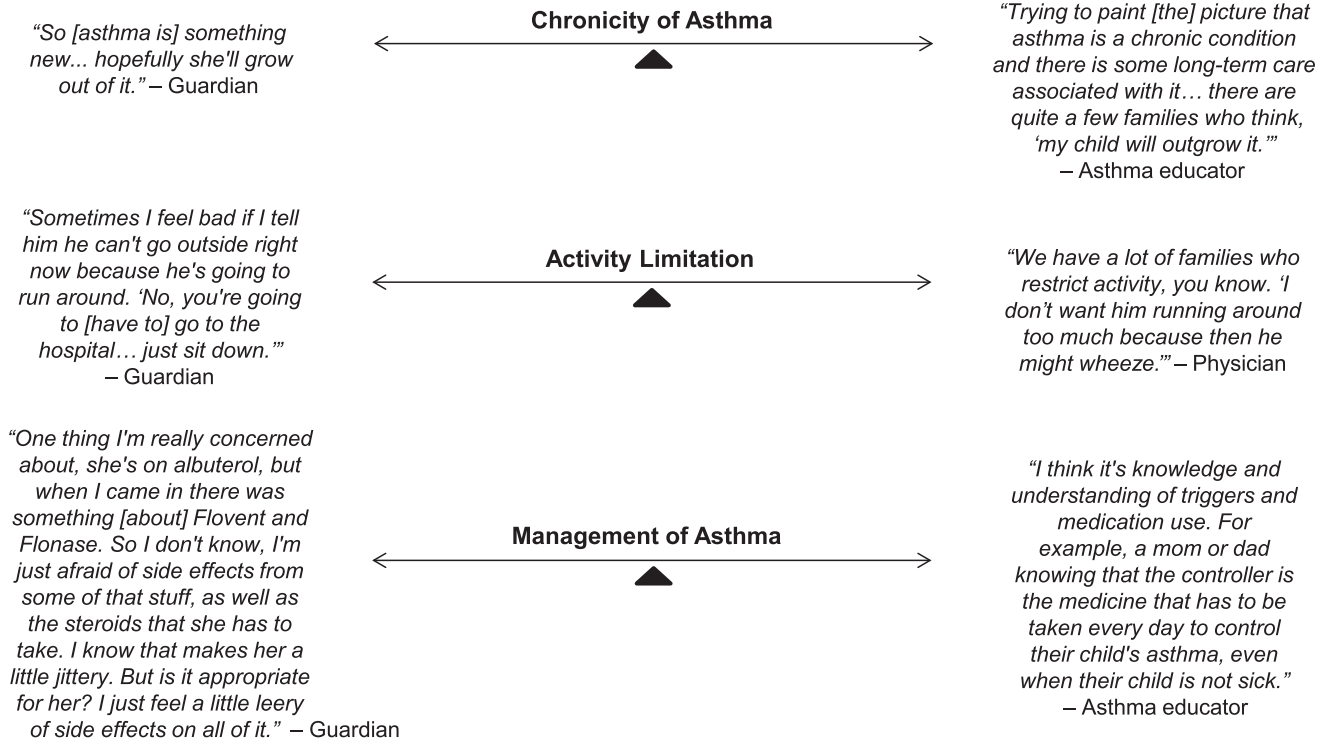


FIGURE 1 Different perspectives in asthma knowledge between caregivers and health professionals.

schools for children who have asthma, and they found barriers to include a lack of parental knowledge and no inhalers at school.²¹ Future programs should incorporate parental education on physical activity in children who have asthma, as well as how to use inhalers as a preventive measure during physical activity; this will support our families and children in the maintenance of physical activity with their diagnosis of asthma.

Asthma Management: The Importance of Controller Therapy

Asthma management (specifically, the importance of controller therapy) is another key concept that is variable between family caregivers and health professionals. Health professionals voiced the need for continued asthma management even when the child is well and symptom-free, whereas family caregivers focused mainly on management during acute

exacerbations and on concerns for medication side effects. Families in our study cohort are dealing with a variety of socioeconomic challenges; therefore, asthma management may not rise to the top of their priority list until it is an immediate issue. This may lead to reactionary behavior instead of proactive behavior. The impact of parental illness representation on asthma management has been studied previously, and 1 domain that was discrepant was attitudes toward anti-inflammatory medications.¹⁷ For example, family caregivers expressed negative attitudes toward anti-inflammatory medications and side effects. In the Yoos et al¹⁷ survey of parents, 27% of parents thought medications should be a last resort in treatment, 33% believed that one should try to get their children off these medications as quickly as possible, and 71% worried about the side effects. To improve medication adherence among children who

have asthma, it is necessary to understand the family caregiver's attitude toward adherence; this will aid the child in both the short-term (reduced exacerbations) and long-term (eventual self-management for the child).²² Future programs should address parental concerns about medications and side effects to increase adherence. Varying health beliefs regarding asthma knowledge need to be addressed to create a successful environment for asthma management in our community.

School Nurse's Perspectives

School nurses in our study raised barriers and facilitators that were unique to this group compared with issues that were raised by family caregivers or other health professionals (specifically, challenges with preventive asthma management and posthospitalization and/or asthma exacerbation management within schools). Studies have revealed that a strong linkage

to the asthma care provider should be established with the school; for example, the authors of a recent pilot study successfully established communication between the school nurse and the primary care team through the electronic medical record²³ and telemedicine visits²⁴ and showed that students had decreased hospital admissions after the strong communication linkages were created between schools and the medical team. In addition, both school nurse focus groups discussed the role of the asthma action plan as a facilitator to identify children who have asthma and have a treatment plan if necessary. Previous work has been mixed on the role of asthma action plans; there was a systematic review that revealed a reduction in acute care visits in groups receiving an asthma action plan,²⁵ but there is limited evidence that reveals that providing families with an asthma action plan during hospitalization impacts subsequent health care use.²⁶ In our study, although neither family caregivers nor other health professionals commented on the benefit of the asthma action plan, the school nurses praised it as a vehicle to be able to administer medications appropriately to children.

After an asthma exacerbation, these children need seamless care coordination so that their symptoms are recognized and managed at home and at school. Yet, researchers of the National Children's Bureau found that school nurses are not confident in helping children who have asthma because of heavy workloads and the need to work across several schools.²⁷ School administrators can offer a strategic point of contact for additional support for patients and their families; of note, school-based programs are a promising strategy to improve asthma management in areas that struggle with high asthma morbidity. Work over the last decade in Rochester, New York, has revealed the profound impact that school-based programs can have because of their ability to reach high numbers of children in a setting where they regularly spend much of their time. This Rochester-based team initially tested directly observed administration of preventive asthma medications in schools to improve outcomes for children who had persistent

asthma in the early 2000s.²⁸ Parents of the children in the school-based therapy group had improvement in their quality of life scores compared with the usual care group, and children in the school-based therapy group missed fewer days of school and had more symptom-free days.^{28,29} Given the positive findings from the school-based asthma treatment programs by Halterman et al,^{28,29} school nurses are clearly a key ally in asthma management for children in underresourced areas that suffer from high asthma morbidity. Future programs should establish strong, bidirectional communication between the school nurse and the primary care team.

We acknowledge limitations to our study. First, this study was conducted at a single tertiary care center in Washington, DC, with a small sample of only English-speaking families. As a result, our findings may not be generalizable to other populations or other geographic regions. However, at our institution, our own surveillance data revealed that ED visits and hospitalizations are heavily concentrated among African American children residing in the socioeconomically disadvantaged neighborhoods of Washington, DC; therefore, our work is representative of the patient population we serve. Future work will address the specific concerns of our non-English-speaking families. Second, we appropriately used qualitative methods to identify themes and relationships but have not yet confirmed these results in clinical care use. However, our interpretive analysis emerged from repeated and iterative discussions with our study team. Our findings will be presented to our stakeholder groups as we begin the design and planning of our intervention. Third, the same patient did not serve as a link between the family caregiver, health professionals, and school nurses, so it is possible that the stakeholders were speaking of different groups of children who have asthma. However, we focused on children who had public insurance in specific areas of Washington, DC with high asthma morbidity, so there are likely similarities in the barriers and challenges identified by the stakeholders.

CONCLUSIONS

Through this patient-centered, qualitative study, we were able to gather information from both family caregivers and health professionals to identify barriers and facilitators of asthma management after hospitalization. Through this process, we have identified a disconnect between the shared mental model of asthma care between parents and health professional caregivers. These gaps in agreement between family and health professional caregivers need to be addressed to create successful programs to improve care for children who have asthma and work toward a shared understanding of the application of asthma education. In addition, partnerships with school nurses need to be strengthened to provide seamless care coordination. By identifying these barriers and facilitators, we hope to create an effective patient-centered and stakeholder-aligned intervention to improve asthma management for children who have been hospitalized with an asthma exacerbation.

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