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Parent/Guardian Experiences With the Healthcare System and Community Supports for Pediatric Asthma Management

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Abstract

Determinants of pediatric asthma management include child, family, healthcare, and community factors. The purpose of this study is to investigate how parents/guardians are impacted by and act on these factors to aid in their child's asthma self-management. Interviews were conducted in Fall 2020 with 12 female parents/guardians of Black/African American children who participated in a community paramedic pilot study with their child in South Carolina. Children in the initial study had an asthma diagnosis of moderate persistent asthma, had Medicaid insurance, and were determined high-risk for emergency room presentation. Inductive and deductive qualitative analysis identified that child management self-efficacy and independence, parent/guardian health literacy, parent and child negative experiences related to asthma diagnosis and management, asthma management tools, and social support from multiple sources impact child self-management. Findings from this study highlight the importance of clear asthma education and management tool recommendations from healthcare and community providers, particularly for parents/guardians with low health literacy. Health literacy impacted parental responses and likely how families comprehend Medicaid and clinical asthma guidance.

Keywords

pediatric asthma management, health literacy, patient–provider relationships, Medicaid, asthma education

Introduction

Pediatric asthma management involves regular clinical follow-up, medication adherence with a well-formed plan, avoidance of environmental triggers, and continual patient and parent/guardian education (1). As outlined by the Pediatric Self-Management Model, asthma management behaviors are impacted by modifiable and nonmodifiable child, parent/guardian, healthcare, and community factors (2). Prior research suggests that by age 15 years, youth will have assumed about 75% of asthma medication self-management behaviors, up from 20% at age 7 years, but children may assume responsibilities earlier due to economic or relational factors (3).

Children with asthma who are Black/African American, younger, and have Medicaid insurance are more likely to experience emergency room visits for asthma exacerbations (4). Those with Medicaid insurance may have difficulty accessing resources for asthma self-management (5,6) because of gaps in Medicaid coverage (5), and difficulty navigating Medicaid policies with medication refills (7,8).

Prior qualitative pediatric asthma research focuses on parent/guardian barriers and facilitators to asthma management. Parents/guardians often report a lack of understanding of asthma symptoms and low self-efficacy handling an asthma exacerbation (7–10). Parents/guardians have reported difficulties with provider communication and asthma

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education, such as low child engagement during visits (11,12), minimal time with providers (7,13), and overwhelming amounts of information (7). Multicomponent community interventions have been associated with positive child asthma outcomes (14). The purpose of this study is to describe how parents/guardians perceive and act on child, family, healthcare, and community factors that impact their child's asthma self-management.

Methodology

Study Population

A convenience sample of parents/guardians was recruited from an existing randomized pediatric asthma community paramedic pilot study in South Carolina. In this study, community paramedics with chronic disease training provided home-based asthma management check-ups and asthma education to patients with their families between clinic visits. The intervention was an extension of the children's primary care clinic, which offers a multidisciplinary, family-centered asthma program that works with residents and a respiratory therapist for asthma management. Child inclusion in the pilot study included an asthma diagnosis of moderate or severe persistent asthma, Medicaid insurance, and were determined to be high-risk for emergency room presentation by their primary care provider. All children in this study had a moderate persistent asthma diagnosis at their most recent clinic visit. Children with moderate persistent asthma experience daily asthma symptoms, have some limitations with normal activity, and are on a daily inhaled corticosteroid or long-acting Beta-agonist prescription (15).

Primary caregivers of a child enrolled in the 7 to 11 age group of the pilot study (therefore met all the previous criteria) who spoke English as a primary language were eligible for this study. The study focused on this age period when children are gaining more asthma self-efficacy and responsibilities. Parents/guardians were excluded from the study if their child was withdrawn from the initial pilot study for any reason. The pilot study obtained written study consents from parents/guardians and assent from their children. Parents/guardians provided verbal consent for the qualitative interviews in this study. Ethical approval for this research was obtained from the Prisma Health Institutional Review Board (IRB#: 00075195).

Recruitment

The recruitment goal was 12 parents/guardians with 5 to 7 parents from each arm of the pilot study. There were 37 eligible children enrolled in the 7 to 11 age group; of those, 28 children had a primary English-language speaking parent/guardian. The recruitment goal was set to reach just over 40% of those eligible. Eligible parents/guardians were contacted via text message and invited to participate in an interview about their child's asthma management. A total of 22 parents were contacted before the desired number was reached; of the ones who agreed to participate, all identified as female and had a child who was identified as Black/African American in their medical chart. Demographics are presented in Table 1. Participants received a $25 gift card after the interview to acknowledge their time.

Data Collection

All interviews were guided by a semistructured guide with 7 questions to discuss experiences related to diagnosis, current household asthma management behaviors, healthcare usage experiences, and engagement with community organizations for asthma. Follow-up questions were asked as needed. The guide was presented to a hospital-based patient review panel prior to the study for feedback.

Due to COVID-19, virtual interviews were conducted with each parent/guardian. A total of 10 parents/guardians were interviewed over the phone and 2 over a video call. Interviews ranged from 24 to 59 min and were recorded and transcribed verbatim. All interviews were conducted by the same trained researcher.

Qualitative Analysis

Thematic analysis was completed using a hybrid inductive and deductive approach; this methodology combines data-driven codes with theory-driven ones to identify overarching themes (16). Deductive codes were guided by an application of the Pediatric Self-Management Model, with inductive codes added to capture elements that arose during interviews. A preliminary coding round was completed to evaluate the draft codebook. The primary coding round was completed by a three-person coding team, with 1 researcher coding all 12 interviews and the other researchers splitting the interviews, yielding an overall 84.6% agreement.

Axial coding, completed in Atlas.ti 8, explored thematic meaning units and instances of code co-occurrence (17).

Table 1. Child and Interviewee Characteristics.

Parent/Guardian Characteristic	
Parent/Guardian type	
Mother	11 (92%)
Grandmother	1 (8%)
Child Characteristics	
Insurance Coverage Type—Medicaid	12 (100%)
Asthma Diagnosis—Moderate Persistent Asthma with ICS or LABA prescription	12 (100%)
Sex	
Female	5 (42%)
Male	7 (58%)
Race—Black/African American	12 (100%)
Comorbidity—Allergies	12 (100%)

Codes were reviewed for both frequency and content to construct themes to address the research questions.

Results

In considering how child, family, healthcare, and community factors impact pediatric asthma self-management, the emerging themes were child management self-efficacy and independence, parent/guardian health literacy, parent and child negative experiences related to asthma diagnosis & management, management tools, and social support. Figure 1 demonstrates these themes, their relationships, and patterns used in theme construction.

Theme 1—Child Management Self-Efficacy and Independence

Children in this age group are gaining self-efficacy in their management behaviors, but are still heavily reliant on their parents/guardians. Parents/guardians described the behaviors their children engage in and their child's confidence, autonomy, skill, and willingness to do these behaviors. As expected, all parents/guardians reported their children relied on a caregiver for part of their asthma management. A few parents/guardians acknowledged improvements from when their child was younger, though most described asthma management as a continued shared responsibility.

All parents/guardians talked about their child administering their own medications and approximately half discussed their child engaging in symptom monitoring and determining their health needs. Parents/guardians primarily saw their role as reminding children to take controller medications (this was true with both younger and older children in the age group) and helping their child navigate asthma symptoms and/or exacerbations. Similarly, about half of parents/guardians discussed their child communicating about their asthma with other adults (teachers, school nurses, healthcare providers, and other caregivers). Few parents/guardians discussed their child navigating triggers on their own, with almost all responsibility delegated to adults. Several parents/guardians had difficulty naming specific triggers.

Parents/guardians described their child's healthcare team as providing education for them and their child while they gained familiarity and confidence. As one parent/guardian described, "When she wasn't able, she couldn't understand or recognize the issue, they would tell me. And then once she got older and they realized that she let them know how she's feeling, they started explaining it more to her."

Theme 2—Parent/Guardian Health Literacy

Parent/guardian ability to obtain, process, and use health information (health literacy) was an underlying factor related to child asthma management behaviors. Most asthma information received by parents/guardians was attributed to their child's primary care clinic, though several parents/guardians mentioned childhood experiences of family members or themselves managing asthma. Though not formally measured, health literacy varied with parents.

Most parents/guardians had difficulty naming their child's asthma prescriptions (all children in this study were prescribed a daily controller inhaler, rescue inhaler, and allergy medications). A couple of parents recalled their child's inhalers by the color instead of by name. Albuterol was the most remembered medication name and parents/guardians often referred to their child's inhaler as an "asthma pump." While some parents could not name their child's medications, most could describe a process for how their child takes their daily controller medication.

There were variations in interpretations of clinic-provided trigger management. Most parents/guardians remembered at least one trigger mentioned by clinic staff. Active management guidance included cleaning to minimize dust and allergens, using mattress and pillow covers, replacing carpet, and limiting stuffed animals. Parents/guardians recalled providers mentioning limiting child exposure to cigarette smoke, perfumes, pets/animals, weather, and pollen. Most parents/guardians discussed which of these behaviors they engaged in for their child; several insisted their child did not have triggers, but described how their child was impacted by the weather, seasonal changes, and physical activity.

Some parents/guardians sought information and explanations for their child's asthma beyond their child's healthcare team. One parent/guardian described alternative medicine solutions to manage her child's asthma, at the suggestion of her mother. Another parent/guardian described how smoking during pregnancy caused asthma when she was asked about how the clinic talked about asthma management.

Theme 3—Parent & Child Negative Experiences Related to the Healthcare System

When asked about their child's asthma diagnosis or a recent emergency room experience, most parents/guardians described a scary or negative instance. Almost all parents/guardians recalled their child being diagnosed with asthma at the hospital or a primary care follow-up appointment following an emergency room visit. Three parents/guardians remembered their young child's face or lips turning blue before going to the hospital. Most negative experiences were related to diagnosis, though a few parents/guardians mentioned issues with their primary care clinic.

One parent/guardian expressed frustration related to race/cultural competency in her child's primary care clinic. During an asthma visit, a doctor described how White/Caucasian children, but not Black/African American children, turn red during asthma exacerbations. During the interview, the mother exclaimed "… my kids are nothing like that. My kids are not Caucasian … they're … they're Black. Come on now … let's … let's get something better." She further

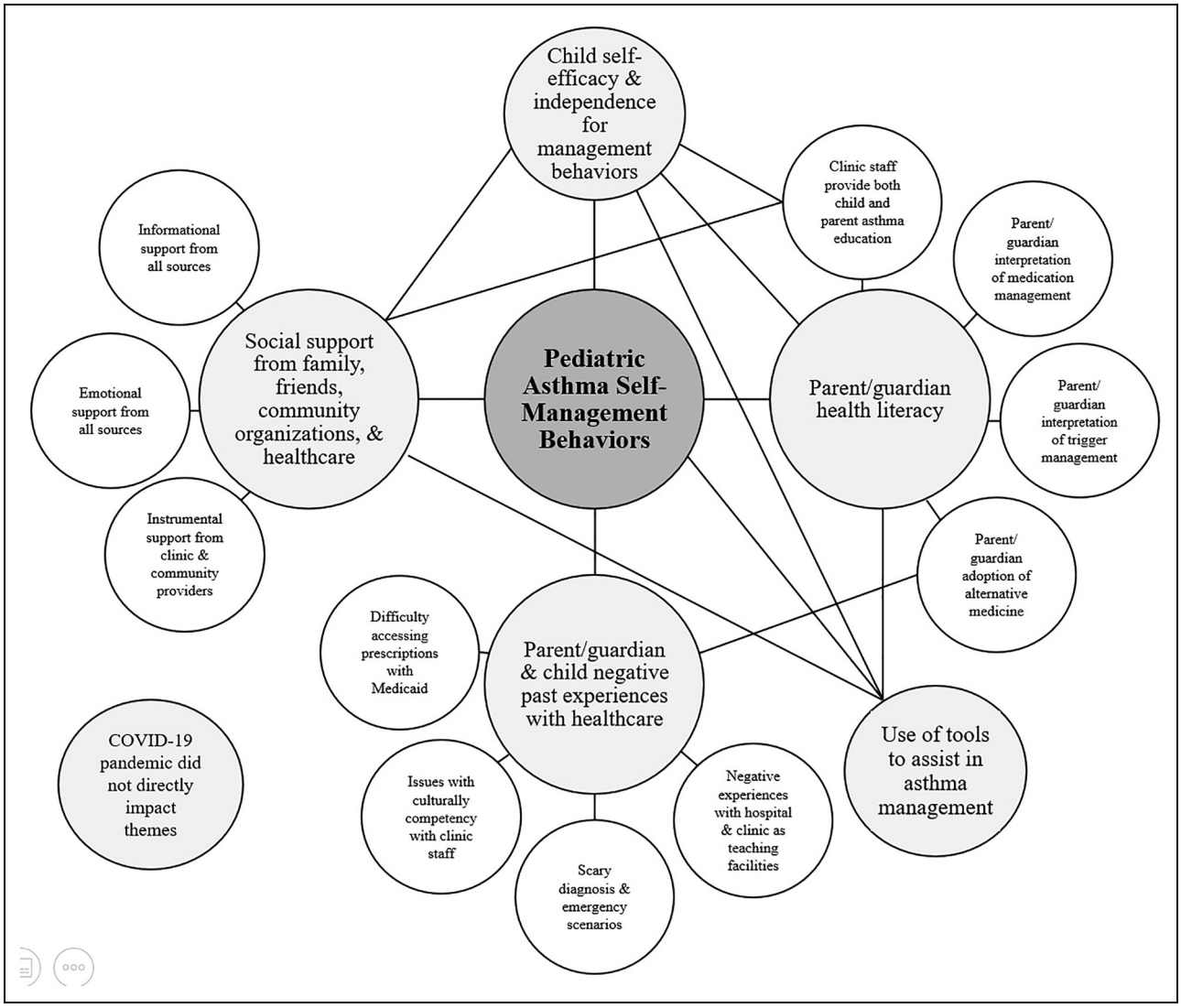

Figure 1. The image presents the theme map of qualitative analysis from parent/guardian interviews. Each connected theme has modifiable elements that can be addressed to improve pediatric asthma management behaviors.

expressed frustration related to the medication prescribing process: "If it wasn't for me speaking up for (child's name) they would put [them] as an experiment dummy … And what I mean by that is, they would test all these different medications on this kid, on … on these kids and it don't help them." These experiences, in addition to emergency room wait times, influenced her to seek natural remedies with red onions and saltwater. This parent/guardian was 1 of 2 participants who negatively discussed that the hospital and primary care clinic were teaching facilities. Teaching facilities were described as time-consuming (and thus longer wait-times) and inconveniencing, as they often had to repeat information to multiple staff.

Over half of the parents/guardians recalled having difficulty filling an asthma medication prescription. For some parents/guardians, this was confusing because Medicaid only covers certain medicines. As one parent/guardian described: "if a doctor prescribes a certain medicine, I think that health insurance should cover that medicine if they're prescribing that one. I mean, I think they want them to use that one and not have to do a substitute or something different." Several parents described the process of working with their child's healthcare providers to fix this.

Outside of a few negative experiences with care and prescriptions, almost all parents/guardians described primary care providers as helpful and supportive. Most parents/guardians reported that their child's providers answered all their questions during visits and repeatedly praised the respiratory therapist in the office who helped them.

Theme 4—Self-Management Tools

Asthma management tools, such as Asthma Action Plans, phone applications, and medication organizers recommended

Table 2. Examples of Pediatric Asthma Self-Management Tools.

Asthma Action Plan	"They just gave me like this paper of, you know, what he needs to take, how many, how much of it he need to take every single day." (*Describing working with medical home providers*)
	"Yeah, I would normally take her to the doctor's office. We were following the action plan and we had tried everything there, but it still wasn't getting any better." (*During an exacerbation*)
	"We'll do down her list of stuff—to the little sheet that I have—we'll walk through that. If I need to give her whether red, green, umm zones so we'll go from there." (*Following an exacerbation at school*)
Medication Organizers	"Like I keep his action plan on the frigerator, it's there and they know what to give him, what not and then I already have like … for like two weeks, already have his medicine all ready in those Monday, Tuesday, Wednesday little planners, I already have them in that."
	"Oh they have their medicine sorted because my oldest son has a lot of medications too, so they have their medicine sorted, so once we have breakfast, everybody takes their medicine."
Phone Apps	"(*identifies clinic respiratory therapist*) that we've been working with, uh at the pediatric center for asthma and she actually downloaded an app on my phone … It's like a … it's on both …. It's on her inhalers and so you put this thing on inhalers and you set a time and every day at that time it goes off." (D*iscussing the Propeller app*)
Daily Alarm	"I have to remind him because some days, he will forget to take his inhaler." So I have an alarm set on my phone to be like "hey, did you take your medicine."
	"Most of the time, she forgets, but I have an alarm set on my phone so she can take her medicine" … "And now she has the iPhone now so you got an alarm on hers now so if I'm not at home, she can take her own medicine."

by their child's healthcare providers, helped with asthma management, including parents/guardians with low health literacy (Table 2). Most parents/guardians, without prompting, referenced an instruction paper or "action plan" while talking about their child's management. Some parents used it as a tool to share information with their child's school or other caretakers, but several parents described how they use it in cases of emergency. One parent talked about the Asthma Action Plan as a collaborative document with the healthcare team—"we kind of talk about what they're going to put on the action plan before they give us the action plan, so it's already kind of tailored to us, so it works."

Medication organizers, phone alarms, and phone applications were used to reinforce the time children take their medication. Phone alarms were primarily used by parents/guardians so they remembered to prompt their child to take their medication. A couple of parents/guardians discussed adding these alarms to their child's phone. However, this is not a singular solution for this age group, as one parent discussed how her child loses her phone and forgets to charge it.

Theme 5—Social Support From External Sources

Parents/guardians reported being directly responsible for their child's daily management, but external social support from their child's healthcare team, family and friends, school staff, and community organizations influenced management behaviors. These groups provided a range of informational, instrumental/tangible, and emotional support for parents/guardians and children, as documented in Table 3.

The healthcare team at their child's primary care clinic was described as providing informational, instrumental, and emotional support. Primary care providers were identified as the primary source of information about asthma symptoms, management, and triggers (informational support). The healthcare team provided parents/guardians with Asthma Action Plans to assist with their child's management (instrumental support) and advised on other management tools (Table 2). Several parents/guardians talked about shared decision making with the providers in which their child's healthcare team listened to them and came up with solutions to best fit the families, such as adjusting medication schedules.

Family and friends were mentioned as providing informational, instrumental, and emotional support for parents/guardians and their children. A couple of parents described advice they had received about environmental management, including alternatives to using strong-smelling cleaning products (informational support). One parent/guardian talked about her mother demonstrating alternative medicine techniques to help her child's asthma and keeping the ingredients on hand (instrumental).

Interviews were conducted during the COVID-19 pandemic (Fall 2020) when children were on an all-virtual or hybrid attendance schedule. Parents primarily mentioned school in the past tense, as procedures varied from what they were used to. Several parents/guardians discussed forming relationships with the school nurse because of their child's asthma. School nurses reportedly provide emotional support as a trusted individual when children are at school and are sources of medication (instrumental support). Parents/guardians did not attribute informational support to school nurses.

Community programs, including community paramedics and a statewide asthma education home visit program, were described as providing informational support, instrumental support, and emotional support. Community paramedics were described as providing instrumental support (such as requesting medication refills, informational (asthma education), and emotional support (helping a family navigate worsening symptoms). Most parents/guardians recalled the mattress and pillow covers they received from the statewide program (instrumental support), but only some could describe the environmental trigger management discussed (informational support).

Table 3. Examples of Social Support Within Healthcare and Community Domains.

Informational	Healthcare & Community Paramedic	"To keep from going to the emergency room. And then, when…. with the paramedic…. community paramedic that was also helpful too because anytime I had questions, I could always call them. And if I needed an appointment, they would help me get it or they would contact [respiratory therapist's name] and she would help me get an appointment."
	Healthcare & Family (Community)	"As he got older, I as I was doing something we can't figure out why his asthma's being triggered and why he was having it, so they [*friends and family*] was like "try this and see if that helps." And then the doctor suggestion about the cleaning supplies too so (Interviewer: Yeah) So it was both sides giving information."
Instrumental	Healthcare	"Pretty good, cause I make sure they tell me and I make sure they print it out as well [referring to Asthma Action Plan]. That way, if I, you know, do forget, or if like my mom is at my house, there's something to go by. That helps me a lot as well."
	School	"Oh, she has a rescue inhaler at school, albuterol inhaler at school, and she has to … that she needs and they give her … her pump that she needs at that moment in time. If that doesn't work, they just call me and then I come and get her and give her her exact … See what I need to do."
	Community Program	"They used to come out and do house visits and pretty much talk to us and give us resources and things that we can … Um, we can do, or we can use for asthma. And she would bring him out a mattress cover, pillow covers, books, and anything about asthma"
Emotional	Healthcare	"Oh yeah, I feel like they all because a lot of the people who are we speak to, they have asthmatic kids also, so I feel like they give me good feedback"
	School	"The nurse, I became real close with the nurse that was going to her school and she always checked in on [child's name]. Making sure [child's name] had everything she needed. Um … If [child's name] couldn't focus because something was going on, she'll go to that nurse, so I have a support system at home and at school."
	Community Paramedics	"She'll talk to him; she'll tell him how great he's been doing and stuff like that and they have conversations about school and they'll have conversations about his asthma and stuff like that."

Additionally, one parent mentioned their child attending a hospital-system supported asthma camp (informational support) and another parent discussed their church helping to remove carpet in their home (instrumental support).

COVID-19 Impact

Parents/guardians were not directly asked about COVID-19, but it came up organically in most interviews. COVID-19 reportedly did not impact daily asthma management, but some parents/guardians discussed being more protective over their children. One parent/guardian didn't allow any of her children to attend in-person school because it was a risk to her child with asthma. Some parents discussed how COVID-19 allowed them to control their child's symptoms in the absence of school. Increased caution and less frequent emergency room visits are in accordance with initial COVID-19 studies (18).

Discussion

Parent/guardian health literacy was an underlying theme that influenced the other themes, as well as the interviews themselves. Parents/guardians with low health literacy have been associated with less asthma knowledge and less child asthma control (19). This presents a challenge for providers, as it may be difficult to fully comprehend parent/guardian health literacy and that can impact treatment plans (20). The use of tools (Asthma Action Plans) and educational strategies (such as teach-back methods, short videos, and brief leaflets) can have a positive impact on health literacy (21). In this study, parents/guardians relied on tools such as Asthma Action Plans, phone applications, and alarms to help manage their child's asthma. Health literacy is a modifiable factor and there is a recognized need for comprehensive strategies to improve asthma self-management (22).

Many parents/guardians discussed Medicaid in the context of prescription access and several were thankful for what Medicaid provides their children. However, most parents/guardians did not describe experiences using Medicaid with much, if any, detail. Health literacy may have influenced how parents answered these questions. Prior research suggests parent/guardian health literacy may impact child Medicaid coverage (23), though no parents in this study reported coverage gaps. Service coverage by Medicaid varies by state and plan (24), so effectively managing their child's asthma and advocating for services may require parent/guardian awareness and knowledge of eligibility (a modifiable factor). Healthcare providers can advocate for Medicaid plans to increase asthma service coverage.

The Pediatric Self-Management Model helped identify the importance of collaboration with pediatric asthma

management (child, parent/guardian, healthcare system, and community). Collaboration and different types of support help in developing child self-efficacy towards self-management; evidence suggests that community support interventions can positively impact child self-efficacy (25). In this study, the primary care clinic respiratory therapist was primarily credited with providing consistent support, with supplement support from other agencies. Primary care facilities that serve high-risk asthma populations should consider case management with a trained individual who has a similar lived experience and belongs to the same cultural community that can provide multidimensional support.

Limitations in this study include that the findings may not be generalizable to all populations, as this is a small qualitative study with parents/guardians from a pediatric primary care clinic in the southeastern United States. All interviews were conducted with parents/guardians answering for their child, so there was no input from children on their perspectives and self-efficacy related to behaviors.

Conclusions

This study highlights the importance of clear asthma education and management tool recommendations from healthcare providers, particularly for parents/guardians with low health literacy. Guidance from healthcare and community providers can provide support for children to develop self-efficacy for asthma self-management and parents/guardians navigating best-available resources.

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Supplemental Material

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