

What Is Left Unsaid: An Interpretive Description of the Information Needs of Parents of Children With Asthma

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Abstract: Parents of children with asthma provide the vast majority of day-to-day asthma care. Understanding their information needs is an essential step to provide meaningful and effective family-centered asthma education. To gain insight into the information needs and information deficits of parents of children with asthma, we conducted an interpretive descriptive study to capture the perspectives of 21 parents from diverse backgrounds whose 23 children with asthma had a range of illness trajectories and management scenarios. Parents were purposively sampled from two asthma clinics and one pediatric emergency department in a large urban center in North America. Semi-structured interviews were conducted in 2011–2012. In data analysis, parents' self-identified information needs were distinguished from analysts' interpretations of information deficits. Participants' knowledge did not always reflect time since diagnosis, and information needs and deficits persisted for years. Parents often reported receiving little or no education about asthma and its management. An asthma management information hierarchy was identified, starting with the most foundational, recognizing severity; followed by acute management; prevention versus crisis orientation; and knowing "about" asthma. In the absence of adequate and accurate education, parents' beliefs about the nature of asthma as an acute rather than chronic condition shaped their asthma management decisions and information-seeking behaviors. Information deficits were affected by interactions with health care providers. These parents' pervasive unmet information needs and deficits highlight the need for comprehensive, problem-oriented asthma education. © 2015 Wiley Periodicals, Inc.

Keywords: asthma, pediatric; asthma education; knowledge deficit; family management; health-seeking behavior; qualitative; interpretive description

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Over the past twenty years, substantial strides have been made in understanding childhood asthma, including its pathophysiology and effective therapies (Clark, Mitchell, & Rand, 2009), but this progress has inconsistently resulted in improvements in children's asthma management or reduction in healthcare utilization or disease prevalence (Clark et al., 2009; Nicholas, Dell, Fleming-Carroll, & Selkirk, 2009; Toole, 2013). The prevalence of childhood asthma continues to rise globally, and the

associated disease burden for asthma is increasing (Centers for Disease Control and Prevention, 2011; Garner and Kohen, 2008).

The trajectory of childhood asthma is one of sub-acute chronicity, interspersed with acute exacerbations of variable severity (Swerczek et al., 2013). Asthma management in children remains suboptimal (Peterson-Sweeney et al., 2007; Stewart, Letourneau, Masuda, Anderson, & McGhan, 2011; Swerczek et al., 2013) and poor control

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has been reported in up to 75% of cases (McGhan et al., 2006). Exacerbations associated with inadequate at-home asthma management are a primary reason for emergent medical treatment and school absenteeism and place financial burden on the family and healthcare system (Bloomberg et al., 2009; Stewart et al., 2011; Toole, 2013).

Asthma exacerbations can be mitigated by minimizing exposure to allergen or irritant triggers, maximizing preventative measures, recognizing asthma-related signs and symptoms, and knowing how to manage acute exacerbations. For families of children with asthma, these complex aspects of management, as well as integrating asthma into the family context and understanding asthma as a chronic illness, are considered necessary components of comprehensive parental education (Brown, Gallagher, Fowler, & Wales, 2010). Parents¹ often serve as proxies for their children and assume responsibility for their care, and education therefore should follow a family-centered approach (Kumar, Edelman, & Ficorelli, 2005), but inadequate family-centered asthma education continues to hamper management efforts (Cleveland, 2012; Peterson-Sweeney et al., 2007; McMullen et al., 2007).

The majority of childhood asthma management is done by families outside of hospital settings, so optimizing parents' capacity to manage asthma day-to-day is essential. Evidence to date on information needs of North American parents of a child with asthma (Archibald & Scott, 2014) indicates a pervasive need for education, but little is known about parents' perceptions of their knowledge gaps. This study was designed to identify parents' self-identified information needs.

Education of Parents of Children With Asthma

Education improves asthma management (Boyd et al., 2010; Nicholas et al., 2009; Cleveland, 2012), including knowledge, self-efficacy, and medication adherence (Toole, 2013). Conversely, lack of knowledge is linked to poorer child health outcomes, parental fear, anxiety, and uncertainty (Berg, Anderson, Tichacek, Tomizh, & Rachelefsky, 2007). Anxiety and uncertainty are common at the time of asthma diagnosis and, in the absence of appropriate education, may persist due to the complexity and variability of the disease trajectory (Berg et al., 2007).

The focus of qualitative research to date on families of children with asthma has been on experiences of caring for a child with asthma (e.g., Peterson-Sweeney, McMullen, Yoos, & Kitzman, 2003; Berg et al., 2007), symptom and illness representation (e.g., Peterson-Sweeney et al., 2007; Yoos et al., 2005; Yoos et al., 2007), and the effectiveness of educational initiatives (e.g., Brouwer & Brand, 2008;

Clark et al., 2008; Nicholas et al., 2009). When provided, parental education often reflects the medical priorities of health care providers (HCPs) and may not incorporate parental perceptions and priorities (Yoos et al., 2007; Nicholas et al., 2009). For instance, education based on guidelines for asthma management "represents the professional model for asthma management" (Yoos et al., 2007, p. 168). Parents and HCPs use different words to describe symptoms, and how these symptoms are identified and interpreted may differ (Yoos, Kitzman, McMullen, Sidora-Arcoleo, & Anson, 2005). Understandings of asthma control also conflict; parents may overestimate the degree of their child's asthma control (Davis, DiSantostefano, & Peden, 2011).

Although the views and priorities of HCPs and parents differ, they can be further aligned through the provision of family-centred asthma education (Peterson-Sweeney et al., 2007). Thus, the purpose of this study was to explore how parents of children with asthma understand their asthma-related information needs, and to identify areas where further information about asthma is needed (information deficits).

Methods

Study Design

Interpretive description (Thorne, 2008) guided this qualitative study. This applied qualitative approach is intended to foster understanding of a clinical phenomenon in relation to its context. In our review of previous research, we identified a need to more thoroughly understand the information needs of parents of children with asthma (Archibald & Scott, 2014). In response to this practice-oriented problem, we aimed to gain insight into how parents understand their asthma-related information needs and identify lingering information deficits relevant to childhood asthma management. We adopted the role of learners situated within the health disciplines (i.e., nursing, medicine) during this process.

Recruitment and Sample

An eligible participant had a child with any form of asthma (e.g., mild episodic or severe persistent) and spoke English. Data collection and analysis occurred iteratively over the year from September 2011 to August 2012 to capture seasonal variations in pediatric asthma. Ethics approval was received prior to recruitment.

Purposive and convenience sampling approaches were used. Two pediatric asthma clinics and one pediatric emergency department (ED) in a large Canadian urban center (population 1,159,869) were purposively selected to reflect the diverse patient demography in the area and to capture families expected to have greater knowledge

¹Adults who defined themselves as parents of children with asthma, whether biological parents, step-parents, foster parents, guardians, or adoptive parents, were eligible to participate in this study and are described as parents in this report.

deficits and unmet information needs than in other health care sites. Pediatric asthma clinic C1 was located in a lower-income area and served a larger number of immigrants than the other recruitment sites, a pediatric ED and a second asthma clinic (C2) on the opposite end of the city. We theorized that this combination of sites would enable access to parents of diverse income brackets and socioeconomic status, given that disparities in asthma management have been documented (Bloomberg et al., 2009).

In the ED, clinical team members located eligible participants via the ED Information System and notified the researcher so that potential participants could be approached after triage. At one pediatric asthma clinic (C1), asthma nurses distributed brochures to potential participants, and the researcher was on-site during clinic days to discuss the study with parents directly after their appointments. In the central pediatric clinic (C2), the asthma nurse educator distributed brochures to potentially eligible participants, who could then contact the research team.

We intentionally maximized variation in the recruitment process to achieve diversity in time since diagnosis and parental education level. The sample consisted of 20 families, including 20 mothers and one father of 23 children with asthma. Parents' education and income levels, and length of time since receiving their child's asthma diagnosis were diverse. The demographic characteristics of participants are presented in Table 1.

Data Collection

Parents completed demographic information forms after consenting to participate. The first author conducted 20 semi-structured interviews, each lasting approximately 25 minutes. Interview duration was not predetermined and was guided by parents' willingness and ability to participate.

The semi-structured interview guide was based on a literature review (Archibald & Scott, 2014) and designed to capture data in two main domains. First, we explored how parents expressed and understood their information needs. We inquired about inquiring about the information they received at the time of diagnosis and in subsequent health care encounters, how information was provided, what information they found important to asthma management, and their knowledge about childhood asthma. Second, we explored each parent's experiences of caring for a child with asthma (e.g., at the time of diagnosis, asthma exacerbations, health care encounters). Data from the second domain provided contextual understanding of the parents' information needs. Interviews were audio-recorded, and field notes were taken.

Data Analysis

All interviews were transcribed verbatim and uploaded to NVivo data management software. Data analysis followed

Table 1. Demographic Characteristics of Sample of Parents of Children with Asthma (N = 21)

Variable	n	%
Age		
20–30	6	28.6
31–40	9	42.9
>41	6	28.6
Current age of child with asthma		
<1 year	1	4.3
1–2 years	1	4.3
>2 years	4	17.4
>5 years	7	30.4
>10 years	10	43.5
Age of child with asthma at diagnosis		
<1 year	7	30.4
1–2 years	4	17.4
>2 years	7	30.4
>5 years	3	13.0
>10 years	2	8.7
Years since diagnosis		
<1 year	1	4.7
1–2 years	4	19.0
>2 years	3	14.2
>5 years	6	28.6
>10 years	7	33.3
Household income		
\$20,000–\$39,999	3	14.2
\$40,000–\$59,999	6	28.6
\$60,000–\$79,999	2	9.5
\$80,000–\$99,999	3	14.2
\$100,000 and up	7	33.3
Marital status		
Married	14	66.7
Single	3	14.2
Divorced	2	9.5
Separated	2	9.5
Highest level of education		
Did not finish high school	2	9.5
Completed high school	4	19.0
Attended college or technical school	3	14.2
Graduated from college or technical school	5	23.8
Attended university	2	9.5
Graduated from university (bachelor's degree)	5	23.8

four steps and involved two authors. First, transcripts were read in detail several times. Second, the first author conducted open coding of all transcripts and then grouped codes into preliminary categories to facilitate within-case understanding. Third, preliminary categories across cases were grouped into a beginning organizational framework according to explicit information needs (e.g., asthma triggers; medications), while writing analytic memos and summary notes to capture impressions and decisions. Fourth, data were classified by "time since diagnosis," which enabled comparison across cases in the following three categories: inexperienced (2.5 years or less), moderately experienced (2.5–5 years) and experienced (5 years or more). Throughout the analysis process, analytic rigor was enhanced by discussions between the first and fifth

authors, in which the coding framework, analytic procedures, preliminary findings, and interpretations were reviewed. Particular attention was paid to the disciplinary and pragmatic relevance of the findings to practice settings (Thorne, 2008).

This analytic approach enabled us to differentiate between parents' description of their information needs and our interpretation of these information needs. In reporting this interpretive study, we discuss these descriptive and interpretive levels of analysis in tandem. The descriptive level of analysis refers to parents' self-described information needs. The interpretive level refers to the information deficits perceived by the research team. These often reflected a professional standard of what parents ought to know, and frequently related to aspects of asthma care unrecognized by parents but important to a child's well being.

Results

For many parents, the information they felt they needed and the gaps identified during the research teams' interpretation were not the same. Some gaps in knowledge were long-standing, in some cases persisting for years following diagnosis.

Parent-identified and clinician-identified lack of knowledge fell into a hierarchy of four areas. The most foundational was recognizing severity; followed by acute management; prevention versus crisis orientation; and knowing "about" asthma (Fig. 1). Parents were more likely to identify a need for procedural knowledge (e.g., how to use an inhaler) than for propositional knowledge (e.g., asthma facts). Parents' ability to recognize their information needs was mediated by their interactions with HCPs, as discussed below, and their beliefs about the nature of asthma, which were a pervasive influence on their approach to asthma management.

I. Recognizing Severity

Many parents had difficulty interpreting the meaning and severity of asthma symptoms. This was most common immediately following diagnosis but for some parents persisted for years. Recognizing severity was interpreted as the foundational information need (Fig. 1) because without it, parents' ability to manage an asthma attack and employ preventative measures was hindered.

Recognition of symptom severity generally improved over time (e.g., participants 3 and 4), but initial deficiencies placed the child at significant risk. For instance, one mother reflected on a frightening incident that occurred three years earlier:

He just kind of laid around. He didn't *do* anything ... that night ... he was breathing so hard that his body was shaking my bed ... his stomach like he was sucking it in and I didn't know anything. I was like stop it. (participant 14)

Similarly, another parent stated,

We weren't really informed of the severity of her condition ... we brought her home and said well we'll rest her, it's nothing ... until the doctor said, you know, we need to get her uh, to get her to the hospital *right away*. (participant 15)

Parents discussed not knowing hallmark symptoms of an asthma exacerbation or how to interpret a low oxygen saturation level. Often, hallmark asthma symptoms were attributed to non-asthma causes or regarded as normal. Some parents had noticed black circles under the child's

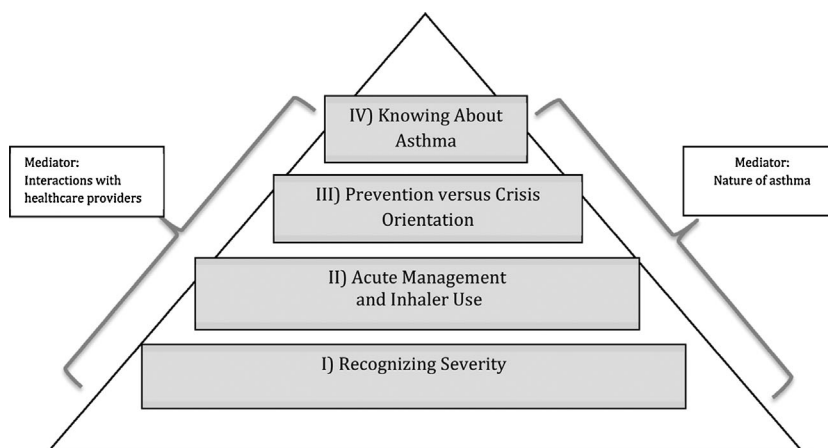


Figure 1. Hierarchy of information needs of parents of children with asthma.

eyes (e.g., participants 4 and 17), or lips turning blue (participant 13) but did not view them as symptoms of concern. Peri-orbital dark circles can be indicative of allergies and fatigue in children with asthma (Canadian Lung Association, 2014; Jacobson, 2010), problematic as the former is an asthma trigger. In the more severe cases, parents did not recognize severity until they were told that the child was “close to having cardiac arrest” (participant 9) or they were urgently instructed to seek emergent medical care.

II. Acute Management and Inhaler Use

Many parents lacked confidence in their ability to manage acute exacerbations. They described not knowing what to do during an asthma attack, panicking in the moment, not having the inhaler on-hand, and being unsure of proper inhaler technique. When asked what she would do if her child had an attack, one mother responded, “I’d probably just panic and take her to the emergency ... like I don’t have a clue” (participant 4). Similarly, another parent stated, “I don’t know, I don’t have his Ventolin ... I’m a panicker” (participant 14).

The majority of parents reported that at some point since diagnosis they had not known when or how to properly use an inhaler. One parent whose child was diagnosed five years earlier confessed, “I still don’t know how to use an inhaler” (participant 10). This was commonly attributed to not being instructed on technique. As one parent stated during an ED visit, “They say, here’s a pump, here’s a chamber, she needs to take, you know four times day of whatever it is, um, but no one actually stops to show you how to use it” (participant 15).

Participants expressed that HCPs used different inhaler techniques and infrequently assessed parents’ inhaler techniques. Parents were confused because “every practitioner does it differently.” Other parents felt that they would have benefited from hands-on learning with HCPs. As one mother stated after unsuccessfully managing in the community for over five years, “They gave her ... these inhalers which we didn’t know how to use” (participant 4), an information need that persisted until the family attended a pediatric asthma clinic.

III. Prevention Versus Crisis Orientation

A crisis orientation to asthma management was common and placed near the top of the “levels” of knowledge types represented in Figure 1. Emergency-focused management, misguided beliefs about the nature of asthma, and a lack of preventative strategies characterized this orientation. Parents who did not know what to do in case of an asthma exacerbation generally did not know how to prevent exacerbations either. In this way, acute management was the foundation for preventive management.

For instance, eight years after her child was diagnosed with asthma, one mother proclaimed,

Basically emergency stuff, that’s what we had been doing ... that worked out well because you know when stuff like that happens they take you in right away, so we didn’t have to stress out about waiting to see the doctor. (participant 5)

Use of an inhaler was equated with asthma management by some parents, to the exclusion of other approaches to management and prevention.

The belief that asthma is an acute rather than chronic condition was reflected in a crisis orientation to asthma management, and for these parents, approaches to prevention were rarely pursued. Some parents were aware of particular asthma triggers but did not prevent exposure to allergens or irritants, believing that a physical barrier, like a door, offered sufficient protection. A common strategy for family pets was to “limit the pets in the room” (participant 4). Another mother expressed “I do have a lot, quite a few animals. I raise animals ... but nothing in the room with them ... nothing sleeps with them in bed” (participant 19). Another parent’s view of asthma as an acute condition was supported by her observation that they “got rid of the cat ... (and now) he’s cured” (participant 14).

Some parents who were aware of triggers to asthma exacerbation offered rationalizations for not eliminating them or identified incomplete efforts. As one mother confessed, “Smoking can make it worse, I know ... I never smoke in my house ever. Um, I have to quit smoking in my vehicle” (participant 19). This mother recognized the need to quit smoking, particularly around her child with asthma, but had not yet changed this behavior. Other parents rationalized their lack of prevention or planning by referring to a child as being tough or a trooper. For instance, when asked if he kept an inhaler at his child’s school and daycare, a parent proclaimed, “Well we haven’t done that because... she’s just a spry little girl and um, she’s also very tough” (participant 15).

Many parents said they often “forgot” aspects of their children’s asthma management, such as to take rescue inhalers with them on walks or administer preventative medications. Regarding bronchodilators, a mother “didn’t think of it ... but I think that it should be probably have it with me ... I always forget it” (participant 14). Later, the same mother recalled,

We just went on a walk, uh a long walk, it was like three hours out in the park ... near the end, we’re slowing down, ‘cause he just wasn’t keeping up anymore ... I guess in that sense I should have had his inhaler, because it might have probably helped him. But I’m really not smart to plan ahead.

Consistently administering daily preventative medications such as inhaled corticosteroids was even more challenging

for parents and particularly so during periods of symptom remission. As one mother, whose child was diagnosed with asthma five years before, said,

They were meant to be supposedly on the daily medications ... then they'd go through a time where they were symptom-free ... you're meant to carry on and we get carried away with life and the asthma inhalers have fallen under their beds. (participant 10)

Similarly, one mother lamented that "the hardest thing for me is keeping up the regular twice daily preventative, because I'm dealing with my own stuff" (participant 11).

IV. Knowing "About" Asthma

While recognizing severity and managing in acute scenarios gradually, albeit unpredictably, improved over time, propositional knowledge, such as what asthma is, generally did not improve in the absence of education. Many parents were unable to describe what many HCPs consider basic asthma knowledge. Some parents recognized this as an information need, with statements like, "I don't even know what asthma is" (participant 10, five years after diagnosis), or "side effects, I have no idea" (participant 15, one year after diagnosis). When asked, they said this information was relevant, but parents were less likely to express a need for this knowledge type than for procedural knowledge about asthma care (e.g., how to use an inhaler). One mother did identify a need for both: "I need to be comfortable with myself to know at least what is going on with him ... and what can help him" (participant 1).

Participants with information deficits from a HCP's perspective would readily admit they knew "nothing really" (participant 20) but only when asked pointed questions (e.g., "How important is it to know what asthma is?"). When questioned, many parents' knowledge "about" asthma, including what asthma is, medication side effects, or how medications work in the body, was absent or incomplete. They sought information only when they identified a gap. As one mother exclaimed, "I don't really look up information ... everything I need to know I can find it if I need to find it, I just don't really know everything I need to know" (participant 1). Conversely, parents who recognized their information needs generally had more experience with asthma and took an active role in seeking information, both during and beyond visits with HCPs (e.g., participants 3, 7, and 8). This information-seeking was often motivated by a change in clinical status or by an emotional motivator, such as a desire to be comfortable with an aspect of asthma management.

Mediator: Interactions with health care providers. Parents expressed that their asthma knowledge was affected by how and whether asthma education was provided by HCPs. Most parents reported receiving little

to no education at time of diagnosis or during subsequent visits to the ED. Most made comments such as, "I can't say anyone came out and did any teaching" (participant 18), "I know from using it but they don't explain" (participant 19), and "He never explained to us what the medications do, what the side effects were ... it was just 'here, give this medication to her'" (participant 21). In contrast, one mother proclaimed that while she knew very little about asthma at the time of diagnosis, she "knows a whole lot now" (participant 3), which she attributed largely to interactions with a HCP through the asthma clinic.

The reported lack of education by HCPs hampered parents' ability to identify their information deficits and limited the information they sought during interactions with HCPs. As one parent stated, "The thing is, what questions do you ask?" (participant 15). When asked if they had sufficient information about childhood asthma, others responded "I think so, but it's hard to know what you don't know" (participant 1); "I just don't really know everything I need to know" (participant 13); or, "I can't even articulate what I think I should know right now ... or what I would like some help with" (participant 20).

Parents' ability to recognize their information needs generally improved with experience over time. Some parents became aware that they needed to direct their interactions with HCPs or specifically ask for more information. As one participant stated, "I have to do a lot of thinking before we come to make sure that I have all my questions ready to go" (participant 6). Another mother of a child with uncontrolled asthma proclaimed that "(HCP) provided me with the information that I wanted and, yeah it's been good so far" (participant 2). Only the few parents who were able to identify their information needs were able to formulate and ask questions during HCP visits.

Misconceptions about asthma were prevalent and at times reinforced by HCPs. For example, many parents viewed asthma as an acute condition, and approximately half believed that their children would grow out of asthma, a misconception reinforced through interactions with HCPs who were not asthma specialists. Seven years after diagnosis, one participant said she had previously thought of asthma as a lifelong, chronic condition, but her doctor said that her daughter might grow out of it. "I think the biggest awareness for me was that I didn't know if it was childhood asthma or a big deal. No one made that clear" (participant 11).

Impact of asthma clinic education. All parents who had received referrals to asthma clinics commented on the impact or quality of the education received, although information deficits were still evident for some to varying degrees. Their core knowledge of "recognizing severity" and intermediate knowledge of "acute management" improved over time if they practiced careful observation, which generally was enhanced by these referrals. Parents said their inhaler administration technique and

related confidence improved following asthma clinic attendance. For instance, one mother realized she had been using inhalers incorrectly for five years: "We didn't know how to use (the inhalers) until we went to the asthma clinic" (participant 4).

Parents provided testimonies to the power of education received there. One mother realized that she had "no idea, no clue, none at all" (participant 13) what her child's medications were for, despite administering them for three years. Another parent said, "Until we came to the children's asthma clinic after those bad attacks we didn't know much. They just said it was bad ... we didn't understand how it worked until the asthma clinic showed us the models where you can see the difference" (participant 11). Parents valued the personalized nature of the visits and the follow-up they received, and they described increased confidence in their asthma knowledge. This positive effect was linked to receiving information tailored to the child in a non-emergency context in which the child's particular presentation and treatment responses were evaluated by consistent HCPs.

Discussion

Findings from this study are congruent with the major components of the Health Belief Model (Janz & Becker, 1984) used extensively since the 1950s to explain individual health behaviours (Stretcher & Rosenstock, 1997). In this model, perceived susceptibility (belief about vulnerability to a health condition), perceived severity (belief in the seriousness of the condition), perceived benefits of engaging in health recommended behaviors, and perceived barriers to participating in the associated health initiative are the dominant dimensions influencing health behaviors. Cues to action are often included in the model but have not been extensively studied (Stretcher and Rosenstock), and perceived self-efficacy was later included when the model's use extended to situations where long-term behavior change was required (Stretcher and Rosenstock). In the present study, participants' underlying beliefs related to illness susceptibility and perceived seriousness of asthma, as well as benefits and barriers to information seeking and management decisions influenced parents' ability to successfully manage their child's asthma.

These findings both reinforce and add to existing literature on childhood asthma management and education. Parents' information deficits were evident in their comments and the self-reported frequency of ED visits for acute asthma exacerbations. Their perspective that asthma was an acute and episodic condition and their reported lack of asthma education at critical time points (e.g., diagnosis) were particularly worrisome. Previous experiences, such as having another family member with asthma, enabled a few parents to manage at home as soon as they received the diagnosis. More commonly, however, parents did not know

what to do in the event of an asthma exacerbation, and this deficit persisted for years. Education had a positive impact for those parents who received it but was not consistently provided to parents in our sample.

Learning through trial and error enabled some parents to improve their management of acute asthma exacerbations. In contrast, knowledge about asthma (e.g., propositional knowledge) did not consistently improve over time. HCPs may use time since diagnosis to predict clients' level of knowledge, but the present findings suggest that this may be problematic and contribute to failure to provide necessary education. Similar findings have been reported in previous studies assessing asthma knowledge (e.g., knowledge about asthma medications; Deis, Spiro, Jenkins, Buckles, & Arnold, 2010). Although Deis and colleagues reported that parents' confidence in managing asthma exacerbations improved over time, our findings suggest that confidence may at times be misplaced and at other times may be developed only after unnecessary periods of trial and error.

Recognizing Symptom Severity

Parents felt that they received insufficient education on how to recognize symptom severity, and this was most pronounced in participants who had not received referrals to asthma clinics. Classic symptoms of asthma, such as night-time cough, and other signs of respiratory distress were often overlooked by parents until an emergency occurred. Similarly, in previous qualitative research, parents expressed inadequacy and uncertainty in the acute aspects of asthma management, which they attributed to a lack of asthma knowledge and education (Berg et al., 2007). Parents also overestimated the degree of asthma control and underestimated symptom severity in children, despite regularity of symptoms and unscheduled health-care use (Davies et al., 2011). Similarly, HCPs have been found to underestimate at-home symptom severity (Halterman et al., 2006), which may further reduce the quality of asthma education provided.

Inaccurately estimating asthma symptoms and severity is a barrier to appropriate asthma care and a significant threat to a child's well being. Consistent with the Health Belief Model (Janz & Becker, 1984), the extent to which parents perceived symptoms as threatening a child's well being may be compounded by underestimating a child's susceptibility to harm. Working with parents to promote an aligned interpretation of asthma symptoms may promote parental understanding and self-efficacy in asthma management and decrease the use of rescue medications and ED visits.

The Nature of Asthma

The perception that asthma is an acute condition resulted in a crisis orientation to asthma management. The other

misconception of “growing out of asthma” common in these findings has been widely reported (Berg et al., 2007; Toole, 2013). These beliefs may negatively affect follow-up and medication adherence by deemphasizing asthma’s chronicity (Bloomberg et al., 2009). For instance, the inconsistent use of inhaled corticosteroids in this sample was concerning, as this significantly decreases their effectiveness (Klok, Kaptein & Duiveiman, 2014). Reorienting parents to the chronic nature of asthma may have a positive impact on these asthma management behaviours.

Highlighting the benefits of a specific action can positively influence outcome expectations and contribute to greater self-efficacy, according to the Health Belief Model (Janz & Becker, 1984). Reinforcing why preventative medications should be administered daily as prescribed, even in the absence of symptoms, may be particularly beneficial to parents who are concerned about administering “unnecessary” medication to a child who appears healthy. Collaboratively developing strategies to promote these behaviors and attending to underlying concerns regarding medications are particularly important. For instance, understanding of asthma triggers and developing a written asthma action plan can aid in understanding asthma symptoms and contribute to parents’ self-efficacy while improving their asthma care (Klok et al., 2014).

Impact of Asthma Clinic Attendance

Although discrepancies, inconsistencies, and shortcomings in the provision of asthma education and adherence to asthma guidelines and recommendations continue to be reported in the literature (Lob, Boer, Porter, Nunez, & Fox, 2011; McGhan et al., 2006), findings from the present study shed new light on the impact of attending a pediatric asthma clinic on parents’ knowledge and perceived management ability. Parents regarded the comprehensiveness of education provided, the commitment of providers to work with the family, and the continuity of care enabled through seeing a consistent team of practitioners as having a positive impact on their ability to manage asthma. Meaningful HCP-client partnerships and individualized education has been emphasized in previous research (Swerczek et al., 2013; Yoos et al., 2007). Unfortunately, awareness of and referral to these resources was inconsistent for parents in this study and did not follow a discernible pattern.

Many parents may have benefited from an asthma clinic referral. This finding was particularly troublesome when viewed in the context of the pervasive lack of awareness of the seriousness of their children’s condition at some point during participants’ asthma trajectories, and the striking information needs and deficits that persisted over time and often threatened the wellbeing of the child. As similar gaps in accessing needed asthma education have been reported recently (e.g., Stewart et al., 2011), the present findings highlight a troublesome and persistent challenge in this area.

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Application of Information Needs Hierarchy

The hierarchy of information needs provides a pragmatic and problem-based orientation to identifying information needs, enabling parent education to be motivated by the real-life challenges of facing and avoiding asthma attacks. Parents’ ability to recognize the severity of asthma symptoms and identify exacerbations formed the foundation of their learning needs. Without it they were unable to respond appropriately. Over time, as their ability improved to recognize severity and manage acute exacerbations, some moved on to identify a need for information about prevention-focused aspects of care, but knowing “about” asthma was infrequently seen as an information need. The pervasive influence of interactions with HCPs and beliefs about the nature of asthma also are emphasized in the model.

Information categories for parental education have been identified in previous research as summarized in our initial review (Archibald & Scott, 2014), and the present model offers a preliminary understanding of how these information needs are understood by parents. The evidence in the present study for a hierarchical view of learning priorities supports a problem-based approach to learning and identifying learning needs as a fruitful approach to providing asthma education.

Future Interventions

The findings from this study will inform the development of educational material for parents of a child with asthma. Parental experiences from this current study will be used to create the context for the educational material, and specific examples of care experiences will be included. Foundational asthma education will be embedded throughout, to target the information deficits and information needs identified in this study. In this way, the educational intervention will integrate the information needs identified by parents as well as those information deficits identified by the research team as relevant to childhood asthma management.

Limitations and Recommendations

Fathers are underrepresented in this study. We wanted to capture common management scenarios with parents, and in our recruitment sites, mothers most often brought their children with asthma to appointments and emergency visits, perhaps reflecting some commonality in day-to-day management scenarios. We conducted interviews at a single point in time and only with parents who were seeking asthma care. As the majority of parents reported receiving little or no asthma education from HCPs, other forms of data collection (e.g., observation) and a broader participant base inclusive of HCPs might have enhanced our understanding of information needs and how they are assessed and addressed by HCPs. Further, because we sampled

from EDs and asthma clinics, our sample may reflect parents with more pronounced information needs and information deficits than those parents successfully managing in the home environment.

This study raised questions regarding provider-patient interactions. An ethnographic study of how information needs are assessed and addressed during ED visits may be fruitful. Because education can be provided in myriad ways by any one or a combination of individuals, further understanding is needed of which HCPs are involved in asthma education and the potential benefits of team approaches. Given that parents reported that HCPs reinforced the notion of asthma as an acute condition, understanding HCPs' knowledge and discourses related to asthma may be informative. Finally, educational approaches for parents that target their information needs and information deficits are warranted if parental self-efficacy and childhood asthma outcomes are to improve.

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