

ORIGINAL ARTICLE

Living on the edge of asthma: A grounded theory exploration

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Abstract

Purpose. Most asthma-related emergency department (ED) visits and hospitalizations for asthma are preventable. Our purpose was to develop a grounded theory to guide interventions to reduce unnecessary hospitalizations and ED visits.

Design and Methods. Grounded theory inquiry guided interviews of 20 participants, including 13 parents and 7 children.

Results. *Living on the edge of asthma* was the emergent theory. Categories included: balancing, losing control, seeking control, and transforming.

Practice Implications. The theory provides the means for nurses to understand the dynamic process that families undergo in trying to prevent and then deal with and learn from an acute asthma attack requiring hospitalization or an ED visit.

Severe asthma episodes are one of the most common causes for children to visit a hospital or emergency department (ED; Centers for Disease Control and Prevention [CDC], 2011, 2012). In the United States, asthma currently affects 7.1 million children (10%) under the age of 18 years (CDC, 2012). Approximately half of all children with an asthma diagnosis will have one or more asthma attacks every year (CDC, 2012). Each year, more than 640,000 children with asthma will seek medical care at an ED, and more than 157,000 will be hospitalized for asthma (CDC, 2011). Once a child has been hospitalized for asthma, their risk for subsequent hospitalizations increases (CDC, 2011; Primono, Johnston, DiBiase, Nodolf, & Noren, 2006; Shaw, Daratha, Odom-Maryon, & Bindler, 2013). With appropriate prevention and treatment, most asthma-related hospital admissions can be avoided (CDC, 2012; Herrod & Chang, 2008). Considering that one out of five children with asthma visited an ED for acute asthma-related care in 2009, current health and economic outcomes related to children with asthma and their families are unacceptable and

represent a considerable public health burden that needs to be addressed (CDC, 2011, 2012).

The study described in this article stemmed from a prior observational cohort study focusing on variables impacting subsequent hospitalizations among pediatric patients with asthma. The previous study examined the risk of rehospitalization among children admitted for a primary diagnosis of asthma as compared with a reference group of children admitted for all other diagnoses (Shaw et al., 2013). Our research team utilized the Washington State Comprehensive Hospital Abstract Reporting System (CHARS) to obtain patient data for the study. The CHARS contains admission and discharge information for every patient hospitalized in all private and public hospitals throughout Washington State. Findings clearly demonstrated children with asthma are at an increased risk for rehospitalization when compared with other hospitalized children who do not have an asthma diagnosis (Shaw et al., 2013). The asthma cohort had a 33% (hazard ratio = 1.33 [99% confidence interval (CI) 1.21–1.46]; $p < .001$) increased risk of subsequent hospitalization from

2004 to 2008, as compared with children who were admitted for all other diagnoses (Shaw et al., 2013).

Although our findings and other national studies demonstrated that pediatric patients with asthma are a high-risk population for subsequent hospitalization (e.g., Bloomberg, Trinkaus, Fisher, Musick, & Strunk, 2003; Merrill & Owens, 2007; Shaw et al., 2013; Wang et al., 2008), no research to date has clearly explained why this population comes to the hospital, what preventative interventions occur during the hospital stay, and what nursing measures are taken or could be done after discharge from the hospital in terms of follow-up to prevent future hospital visits. Based on our findings, we believed the next logical step would involve taking a qualitative, grounded theory (GT) approach to further describe and clarify the complicated and multifactorial issues surrounding this process by providing the family and patients' important perspectives. The purpose of this study was to identify predominant categories involved in the process leading up to a hospitalization and/or an ED visit, categories arising during the hospital experience, as well as those occurring postdischarge of children (0–18 years) who had recently experienced an acute asthma attack requiring hospitalization or an ED observation. The GT produced by this study provides specific key areas to guide the development and testing of successful nursing interventions.

METHOD

Study design

GT, according to Corbin and Strauss's (2008) approach, was used for this study. GT is a qualitative method developed by Glaser and Strauss (1967) for deriving theory emergent from data (Corbin & Strauss, 2008). This method describes the meaning placed on participants' experiences by identifying predominant categories directly from the interview data (transcripts), describing relationships among categories, leading to the final analysis step of theory development (Corbin & Strauss, 2008). This approach provided in-depth detail of important components involved with the process leading to hospitalization and/or an ED visit, issues arising during the hospital stay, and important areas involved with follow-up and other events occurring after discharge of children with asthma. Predominant categories and concepts identified from the data were then used in the development of a GT. The University Institutional Review Board granted human subject approval for the research study.

Participants

Study participants included 10 families who met the inclusion criteria of having a child with asthma (ages 0–18 years), who had been hospitalized and/or visited an ED in the previous 6 months, and who were English speaking. Thirteen parents/guardians and seven children participated in the interviews. Recruitment of participants was done initially by purposeful sampling, focusing on families who met the inclusion criteria (Streubert & Carpenter, 2010). Parents, guardians, and the child with asthma participated in the interviews if they were able and consented. Three out of the 10 children were 3 years old or younger and were therefore unable to participate in the interviews as they were not old enough to adequately verbalize. All of the children who participated were given pseudonyms to maintain confidentiality. Family annual income ranged from less than \$20,000 per year to greater than \$60,000 per year (mean income of \$36,000 per year). Parent education level ranged from a general education diploma (GED) to a 4-year college degree. Two parents held GEDs, two had graduated from high school, six had some college education, and three had obtained bachelor of arts degrees. Asthma severity classification was determined at the beginning of the interview by utilizing the National Asthma Education and Prevention Program Expert Panel Report 3: Guidelines for the Diagnosis and Management of Asthma (National Heart, Lung, and Blood Institute, 2007). See Table 1 for demographics of the child participants. All of the interviews were completed by the first author in the participants' homes.

Data collection

Theoretical sampling was used as data collection continued. This is a method often used in GT to broaden the scope of data collection to fit newly emerging areas identified in the initial interviews (Corbin & Strauss, 2008). Our team collected further data from new participants and followed up with previously interviewed families to clarify new leads identified in the data. A semi-structured interview guide was developed initially with questions focusing on the purpose of the study. Interviews were digitally recorded and lasted for approximately 60 min. Digital recordings were transcribed verbatim as soon as possible after completion of each interview. As interviews continued, new leads emerged and the interview questions were then modified or new questions were added to the guide.

Table 1. Demographic Characteristics of Child Participants

Pseudonym	Age	Gender	Race	Asthma severity
Emily	15	Female	Caucasian	Mild persistent
Kaitlin	9	Female	African American	Intermittent
Carly	3	Female	Caucasian	Intermittent
Brooke	2	Female	Native American	Moderate persistent
Chloe	9	Female	Japanese	Mild persistent
Nathan	2	Male	Caucasian	Moderate persistent
Emmitt	15	Male	Caucasian	Moderate persistent
Kyle	5	Male	African American	Intermittent
Jacob	11	Male	Caucasian	Severe persistent
Nick	10	Male	Caucasian	Severe persistent

This is a common procedure in GT because analysis builds upon each interview (Corbin & Strauss, 2008). Participants continued to be recruited and interviewed until theoretical saturation occurred (all predominant categories and concepts become clearly defined and no new leads were emerging from the data) (Corbin & Strauss, 2008; Streubert & Carpenter, 2010). As data were collected, memos were typed to capture the researchers' new ideas and to leave a clear documentation path of the process of theory development throughout data collection. Digital recordings were randomly cross-checked against transcriptions to maintain data clarity.

Data analysis

Data analysis began with the first interview and continued throughout the entire project. GT interpretation is a continuous process that builds upon each interview as new leads and general categories begin to emerge from the data (Corbin & Strauss, 2008). As categories began to be thoroughly supported by the data, lower level concepts were also identified. Similar to the primary author's previous GT studies, analysis methods consisted of early coding, constant comparison, open coding, theoretical integration, and final refinements of the emergent theory (Shaw & Davis, 2011).

After the first interview was completed, beginning coding involved identifying rudimentary categories from the data. Based upon the thorough analysis of the first transcript, new ideas for future interviews were documented. As the interviews continued, the authors held weekly meetings to compare analysis findings of emergent categories. Open coding occurred by incorporating prior analysis into each new transcript review. This was accomplished by either continuing to observe supportive quotes evident in the data or deciding a possible category

was no longer supported as the new data were analyzed. Constant comparison of findings occurred throughout the analysis and heavy discussion ensued during the weekly meetings to assist in clarifying categories and lower level concepts. Theoretical integration occurred once the categories and lower level concepts were identified and thoroughly described consistently throughout the data. This step also involved identifying relationships among the core category and all other categories and related concepts. The final step of theory refinement focused on revising the final product and comparing findings to relevant literature. We assessed our emergent theory to review for adequate fit with all of the data and to ensure the categories and concepts were logically depicted in the figure displaying a visual of our findings.

RESULTS

The components of the emergent theory will be described, including the core category, predominant categories, the categorical properties or concepts, as well as the relationships among categories. The theory, *living on the edge of asthma*, is displayed in Figure 1. This theory depicts the process families go through as an outcome of having a child who has experienced one or more acute asthma attacks requiring a hospital or ED visit.

Summary of theory

The emergent theory attempts to explain the challenges and triumphs encountered by families as they navigate through the experiences of having a child undergo an emergent medical event in the form of an asthma attack leading to the decision to visit the hospital. Part of this process also includes the health-care experience undergone while in the hospital, followed by the events that occur after discharge

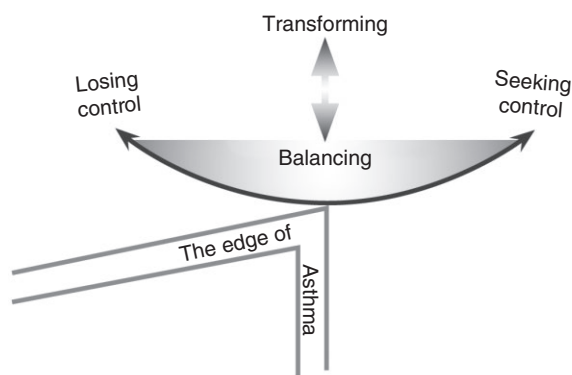


Figure 1 Living on the Edge of Asthma.

home. Families' stories describe these experiences as a sense of teetering on the edge, whereas they either go over that edge, or they regain control before having to make a trip to the hospital or ED. The process of living on the edge of asthma is the theory that emerged from the predominant categories consistently identified and supported throughout the data. The theory's categories and lower level concepts all influence the theory as they may overlap, and lead to actions, as well as outcomes.

Four categories were identified as factors affecting the process of living on the edge of asthma. Predominant categories included balancing, losing control, seeking control, and transforming. Categories depict how family members take various actions that lead to outcomes dependent upon the contextual variables and the uniqueness within each family. There is no order to the four categories as they are all continuous and overlap and intertwine throughout this process. Depending upon how families viewed asthma, they either strive to control the chronic disease, or they view asthma as an acute event only, with the perception that control cannot be obtained.

Core category: on the edge of asthma

The overarching concern described in the data from the families is the focus on how heavily asthma has taken over the family. Participants shared how asthma requires planning and often places restrictions on family activities. Families described the difficulties in trying to prepare for and prevent the next asthma attack. This includes working with school personnel, healthcare providers, coaches, others who care for their children, their children's peers, and insurance personnel. The core category of *on the edge of asthma* provides a general umbrella theme under which the four predominant categories and

their specific concepts fall. In other words, all of the categories and concepts influence the core category. Families described varying degrees of this category dependent upon the status of their child's asthma at the time of interview. The core category can be described as the families' ability to remain balanced by controlling their child's asthma, or the loss of control experienced during an acute attack. Living on the edge of asthma is a constant balancing act that affects the entire family as well as the child with the asthma diagnosis. Interestingly, one of the parents stated, "So she was kind of always on the edge of asthma, she gets sick, all these things just push her over." This father was describing how they had to be on guard for the next attack, especially when his child was exposed to cats or an upper respiratory infection. Another parent described her assessment of the seriousness of her child's condition as: "She's getting a lot better, she still got a cough coming back and a runny nose again. So if it doesn't go away in the next day or two, we'll probably start using her albuterol again." Her words demonstrate how she has to process the physical symptoms her daughter is experiencing in relation to her child's asthma control and how she plans to treat the condition. This participant knows her child's asthma could flare if not well controlled and she realizes it's up to her to watch for clues as to how to move forward in hopes of preventing an acute attack. All of the families interviewed expressed some form of concern of the overarching fear of being on the edge of asthma.

Category: balancing

Balancing is how families maneuvered through the asthma experience with their child prior to the final decision to seek immediate medical care through a hospital or ED visit. The category involves all aspects of the families' background that may influence the decisions made up to the point of an acute asthma attack. Each family interviewed shared detailed accounts of the events leading up to their child's acute asthma attack. Their stories describe the process of the child being "healthy" and then the physical and behavioral changes (subtle and profound) of the initial asthma flare through the acute attack. Children over the age of 3 years were all able to self-identify specific triggers leading to the asthma attack. Balancing included the concepts of the child's story, family history, and making judgments.

All of the children who were able to participate in the interviews shared stories of their asthma diagnosis and of their acute asthma events that led to

the decision to go to the hospital. Parents, care givers, and children over the age of 3 years were able to recount the *child's story*, including when and how their child was diagnosed with asthma, and the beginning of the acute asthma flare as described through the identification of specific symptoms. The child's story provides background and contextual information effecting how families perceive balancing, or the control of asthma. For example, the parents of an 11-year-old boy who had recently visited the hospital for an acute asthma attack stated:

So whenever he gets a cold, it triggers the asthma and it usually shows itself through the coughing. And so then he does the albuterol inhaler, and then, um it just was not helping. Um, he was just having, not so much wheezing but just it's an asthma cough.

Families and children also described how prior asthma experiences helped them notice the differences between an asthma flare and what may turn into an emergent asthma attack. One of the fathers who participated stated this about his 15-year-old daughter:

So a little history on her, so she's had asthma attacks, what I call an asthma attack, where she has trouble breathing and I can hear wheezing and I start noticing retracting. Like if she starts to become a little compromised and I can feel retracting, then I know she's having some issues. Normally I can get her through.

Family history of asthma included the parents' and other family members' own asthma diagnoses and experiences related to asthma. Personal experiences strongly affected the parents' and caregivers' actions and assessments of the state of their child's asthma. For example, one mother compared her own asthma experience with that of her 10-year-old son, stating, "I have exercise-induced asthma, so I'm able to relate to a lot of it." Families expressed their knowing through their asthma experiences. Siblings of the children who participated in this study often had histories of asthma or other chronic conditions and the family experiences associated with this influenced how the family currently manages the child with uncontrolled asthma. This was demonstrated with parental comments such as, "I know what retractions are because one of my other children has had her pulmonary issues; it was just kind of like this is not, you know, normal for what's supposed to be a healthy kid."

Making judgment refers to the part of the balancing process where families begin to question the severity of the acute asthma attack. Families question the

situation, decipher if they should wait it out, and they often complained of feeling helpless with the inability to assist their child with their asthma. One of the fathers described the difficulties involved with making judgments and how he was thankful he did not wait too long. He stated:

You just don't know, you just think, oh, they're sick and then they'll get better, you know? But you wait three days and it's too long, and you don't think as a parent, oh three days my child could be dead.

Children also expressed the unclear path that asthma may or may not take. Waiting and questioning was shared by all of the children who were interviewed. One of the 10-year-old male participants stated, "Sometimes I just feel like is this going to be an endless cough for a long time, or is this going to be a short one?"

Category: losing control

Losing control can be described as the moment when the families realized that the asthma attack has become severe enough that medical attention must be sought. All of the families shared detailed accounts of when they knew they could no longer wait it out or try and balance the situation. At this point the asthma attack was described as full blown and going over the edge. Previous coping strategies no longer worked and families described the concepts of point of no return and fear as asthma took over and all control was lost.

Point of no return means that the severe symptoms have been identified by the family and child, and there is no longer a way to help control the asthma attack. Action had to occur at this point as the severity of the situation was now realized. Conversation among one of the 5-year-old male participants and his mother reflects this concept well. The child stated to his mother, "Mom, I need to go to the hospital." Mom then said she replied, "What? And he's like, 'I gotta go to the hospital' . . . and I'm like, okay. So we take him to a hospital. . . . and they put him right on a breathing machine as soon as we got there." The child was able to identify the progression of his asthma attack and his mother knew something was seriously wrong when her child requested to seek medical attention. First time parents of a 3-year-old girl described the point of no return as:

And then she just didn't have no reserve, you know? She wouldn't drink water or juice, she wouldn't take her medicine, when I decided she needed to go (to hospital), she was very listless, and it was hard to rouse her out of more of a stupor.

Fear was integrated deeply in this part of the process of losing control. Families described how asthma took over and how they could no longer do anything to help their child. Frustration and anxiety was evident in the interview transcripts, and this was elevated with the waiting that often accompanied medical care. One father of a 15-year-old female participant stated, "She started coughing, started crying a little bit. And I couldn't get her to focus and get control and I got really worried. It just wasn't subsiding at all." Parents often described the uncertainty involved with waiting for the medical treatments to begin to control their child's asthma attack. One guardian described the waiting as, "They said we'll just keep her for just 24 hours to see, it didn't work so they had to end up putting her up in a room and she was there for 4 days."

Category: seeking control

Families began *seeking control* once the acute asthma attack began to subside and as the healthcare team began to provide some relief. Attempts to regain control were demonstrated by families beginning to seek out information, initial attempts at trying to be proactive, as well as branching out and asking for help. Seeking control involved the beginning steps of recovering from the acute asthma event and getting back into balance. This piece of the process continued once families were home from the acute asthma hospitalization event. The data strongly demonstrated this category as evidenced by families all sharing stories of wanting more control but not necessarily ever fully gaining it. The concepts of seeking control included: actions, taking care of it, and allowing others to take control.

Actions refer to the active steps parents and children began to take in order to regain some control over asthma. This often included proactive interventions, seeking out new information, incorporating asthma action plans, and identifying asthma triggers. As part of this concept, families often described a struggle between wanting information and not necessarily having access or the ability to clearly articulate their needs for the information. One father's comments describe his barriers to obtaining information about his daughter's condition while in the hospital. He stated, "But, you know, even the doctors up there, um you could ask them any questions if you had one. I wouldn't have known what to ask them because I didn't know what information. I didn't have any information." Others described changing the environment to try and decrease trig-

gers. Seeking control included actions to change the environment. One of the mothers stated, "Um to finally get it under control we ended up removing both cats from the household. Um, removing the allergens because we went from him being sensitive to extremely allergic." All of the families shared their experiences with how they utilized an asthma action plan. While most of the families knew what an asthma action plan was, many were unclear about where it was located or how to follow the plan. On the other hand, some families clearly felt empowered by the asthma action plan and knew how to follow each step without hesitation. The difference in perspectives related to asthma action plans can be demonstrated by the following two quotes. One mother clearly valued and utilized her 10-year-old son's plan. She stated, "We have one right now and after he's had a few good months we're going to redo, because we established that 220 was his best (peak flow) score and if it was under 120 that's an ED visit." In contrast, a parent of an 11-year-old participant stated, "Right now, um- I'm sure there is some type of plan. I guess I don't feel totally like I get to say step one, step two, step three, but I kind of know in my head."

Seeking control also included the concept of *taking care of it*. Taking care of it covers how families and children with asthma decide to accept and know asthma. Most families shared stories of coming to accept asthma as a chronic condition requiring proactive steps to help maintain balance. On the other hand, some families and children chose to deny the seriousness of asthma and instead shared perceptions of not being able to do anything to prevent an attack. This contrast was evident throughout the interviews. Obtaining proper treatment and care helped families to accept asthma. An 11-year-old boy's mother stated:

I just feel so much more prepared since having this doctor (asthma specialist), um like everything's just under control and the doctor's really following him. But up until this point, I do not feel like it was managed very appropriately. I always felt like we were just reacting instead of being proactive.

Another parent described her beliefs about acute asthma attacks as, "He's a boy and boys go to the hospital, so I'm kind of ready for that, not much you can do to plan for that." Taking care of it included going through the part of the process of accepting the asthma diagnosis:

Asthma never even came close to my-you know, close to the surface of what I thought it could be. It's like, oh,

it's just asthma, just with the attitude, and it's not just asthma. I caught myself thinking, you know, it's really not a good way of looking at it.

This father described how he had to work through knowing asthma because at first he did not want to accept the chronic condition aspect of this diagnosis but after his child's acute hospital event he was reevaluating his outlook.

Other's taking control was described by families as feeling a sense of reprieve or relief by having health-care professionals take over the care of their child experiencing an acute asthma attack. One parent described her relief by stating:

In the hospital, you know, I was a lot more comfortable with them giving him really high doses of the albuterol 'cause they could monitor his heart and make sure that he's doing okay. They seemed to get it under control and he was sleeping really comfortably.

Once their child was hospitalized and the health-care providers began to take over all of the responsibilities associated with an acute asthma episode, many family members mentioned feeling more secure and less stressed. This concept was found numerous times throughout the data and can be supported by the statement of the parent of a 9-year-old participant. She stated, "We get quiet time when we're staying (in the hospital), we get quiet time and we put all of the responsibilities on you all."

Category: transforming

The category of *transforming* can be described as the point in the process where families began to absorb the new information they had been exposed to, made lifestyle changes, and proposed and implemented ideas for prevention of future asthma attacks. Families transformed throughout their children's experiences with acute asthma attacks requiring hospital visits. These events exposed the participants to new knowledge, and transforming occurred through the application of the newly acquired information. Throughout the process, families began to realize what they would have done differently and based off of their lived experiences they proposed ideas for future prevention. The concepts involved with transforming included learning new information, lifestyle changes, and prevention.

Having a child experience an acute asthma attack requiring a hospital visit led to an influx of information and decision-making for the families. *Learning new information* occurred as a consequence of going through this process. Parents and children learned

valuable lessons every step of the way throughout the acute asthma flare, while in the hospital, and then once the family returned home. Information was gleaned through interactions with healthcare providers and through the decision-making process occurring as symptoms of the attack began to emerge, through deciding to seek medical attention, and through follow-up care after discharge. Parents shared numerous stories of the importance of listening to their child with asthma. One father of a 3-year-old daughter who had recently been hospitalized for her asthma stated, "If she started, you know, turning ash, I mean there's some clear cut signs and I won't wait this time." Families also discussed how their children had learned from the acute asthma attack experience. This was demonstrated when a mother of an 11-year-old boy explained, "He's learned that if he would cry, it tightens up his throat and makes it worse and so he's learned to remain calm." When asked to describe the most important lesson learned while in the hospital, a 9-year-old girl had this to say, "To take care of it by telling people if I'm having an asthma attack or if I don't feel good." Another father summed up what he had learned from the experience as, "Just pay attention, know your kid and ask questions."

Lifestyle changes describe how the families incorporated the newly learned information into actions demonstrated through actual lifestyle changes. After returning home from a hospitalization for asthma, a 9-year-old girl was encouraged by her physician to increase her physical activity. Her guardian stated, "When she first went back to school, the nurse was more, can she play? Can she not play? But I sent the letter to tell them the doctor was saying he wants her to go outside and play." Families also learned to plan ahead for outings or vacations. One family was preparing to go out of the country after their child had been hospitalized for his asthma, and they wanted to be prepared. Their 11-year-old son described his visits with his asthma doctor as, "We usually talk about our medicine and the last couple times I've went, we were going to a different country and I have to get like different medicines to go there." Another mother described how she changed her cleaning habits after her 10-year-old son returned from the hospital, "When the boys are home or going to be home I use vinegar and, um, cornstarch instead of the cleaning chemicals. I have a plastic sheet on his bed and the pillow cover on his pillow."

All of the families interviewed had numerous ideas for *prevention* of acute asthma attacks. After going through the process of having a child hospitalized for

an acute asthma attack, these families were passionate about ways to improve health outcomes for all children with asthma. Many families suggested age-appropriate education for their child with asthma. One of the mothers interviewed brought up the importance of repeating information to children in a way they can understand it. She stated, "The more he hears it, the more he's going to retain it because ultimately he knows what he feels." The difficulty with diagnosing asthma at a young age was brought up by all of the families. Many families discussed how, looking back, they now believe their child had asthma at quite a young age and how they would have liked more education on what symptoms may be associated with an asthma diagnosis. One of the fathers shared this intervention idea based from his experience with his 3-year-old daughter's asthma history: "Well, I think if people have their babies, that if they could give them a pamphlet for asthma saying, you know, you need to watch the reps (respirations) and tell them- show them how to check the reps." Another mother of a 10-year-old boy stated, "I think there needs to be some more information on infants and toddlers. If they're in (the hospital) more than 3 or 4 times in a twelve months period it needs to be looked at." Information on accurate and easy to access online resources was also brought up as an important educational tool. Another mother suggested, "Online support groups and having those more easily accessible instead of tracking through the backwaters to find them would be helpful." Families also suggested providing more information about environmental factors and how they affect asthma: "We would love more information on how to be able to use a woodstove using certain precautions and purifiers."

DISCUSSION

Living on the edge of asthma includes the categories of balancing, losing control, seeking control, and transforming. This theory is similar to family stress and resiliency theories, which explain how stressors, such as a chronic disease, affect families as they learn to adjust to the crisis from the stressor and then adapt to new patterns learned from the crisis (McCubbin & McCubbin, 1993; McCubbin & Patterson, 1983). Living on the edge of asthma examines families in a state of stress, trying to maintain balance while moving from one asthma crisis to the next. This theory gives understanding to a process of making meaning out of a stressor and the resulting actions of the family. It describes the

process families undergo after an emergent visit for asthma in one of their children and how they learn to live with asthma as a constant threat. The categories explain why families go to the hospital, how hospital visits affect the families, how each hospital visit changes families' perspectives about asthma, and how families would like to learn more.

The term "living on the edge" has often meant risk taking or making choices with a severe consequence such as self-mutilation or participating in extreme sports (Brymer, 2010; Derouin & Bravender, 2004), people not following societal norms (Clark, 2011), or people living under the radar of societal consciousness (Kelly, Dudgeon, Gee, & Glaskin, 2009). For the participants of this study, however, living on the edge described an intricate process of dealing with asthma in a child family member. While the process did involve some risk taking by these families (trusting others, trusting one's own choices and actions, and giving up control to health professionals), these families described it as a process of trying to keep everything stable and maintaining control over asthma, before being pushed over to a crisis state of an acute asthma attack, where asthma is in control. There was always the threat of asthma in daily lives. A mom said, "She just stops to cough and continues to go about her way." One 15-year-old, when asked how long he had asthma stated, "My whole life." As previously described in the categories, how families responded to an asthma attack and aftercare, however, was dependent on factors such as whether they believed asthma was a chronic condition or just an acute disease (as a cold), who was responsible for the child's care, knowledge, health-care or social barriers, or use of support services. These factors determined just how far the family went over the edge.

Balancing has been found to be an important concept in other studies. Other studies have shown that when participants attempt to balance health and illness, most people value maximizing quality of life and living a "normal" life (Jeon, Jowsey et al., 2010). Balance for these families was at play between keeping healthy and beginning an asthma attack, between living normally and being limited by asthma, between risk and safety (how long to wait when triggers become known), and even between the family and the ill child. Asthma affects everyone in the family; however, the child is the one with the disease. Often, there was tension between keeping the child safe and initiating early interventions and letting the child have a "normal" life, especially if the child was older. Another study described the balance

between protective and debilitating anxiety for parents of children with anaphylaxis (Mandell, Curtis, Gold, & Hardie, 2005). Similar to this study, more experience and family history of the disorder helped to balance decisions about what to do and when. Understanding just where families decide to intercede in the disease process when symptoms occur and what factors drive that decision are important to developing interventions that are used in individual asthma action plans.

In any chronic disease, patients and families lose control over the disease and seek to regain control. As one example, Jeon, Kraus, Jowsey, and Glasgow (2010) reviewed literature from 1990 to 2008 about participants' experience with chronic heart failure and found that the main impact on everyday life was a loss of control, described as "feeling imprisoned by illness," with feelings of helplessness and a loss of power over decision-making. In losing control to asthma, most families described fear and worry as overwhelming emotions. Frustration occurred at two time points: (a) when strategies failed to work at home and (b) when they entered the healthcare system. Most families also described losing control as a cause for helplessness when in the presence of healthcare providers. Parents described their previous knowledge and experience with their children's asthma and yet, they were often asked to fill out forms and wait outside of treatment rooms instead of being actively included in the healthcare decision-making process. Asthma, in this case, gave expert authority to the medical professionals although the family was the expert about the child. Families wanted to be consulted, made a part of decision-making, and recognized for their knowledge. Other studies regarding chronic disease in family members, especially children, have shown that attitudes of health providers and healthcare system policies that remove patients or caregivers from decisions about medical care crises determine how health care is perceived and whether patients follow care plans (Butz, Walker, Pulsifer, & Winklestein, 2007; Finnvold, 2010; Jeon, Jowsey, et al., 2010; Sleath et al., 2012). Finnvold (2010) found that not only do some parents of children with asthma express frustration and uncertainty with lack of decision-making control during the asthma crisis, they later devise other strategies to learn about the disease and treatment, including changing care providers and finding easier methods for hospital admittance. Although several families in this study stated that they had or were considering a change in providers, none overtly stated finding new ways to get their child admitted to a hos-

pital. Rather, they preferred to be consulted and given credit for what they did know.

Seeking control also had a family dynamic. Older children wanted to make their own decisions and were sometimes at odds with their caregivers. One way that children maintained control was to not discuss their asthma with peers, including symptoms. Several described not following the action plan. Several parents described their anxiety with children's actions and worried about safety issues. Parents have been known to interfere in child-provider communication because of anxiety and wanting to keep their children safe (Butz et al., 2007). It has been found that school-aged children should be included in decision-making with caregivers and health providers as soon as they are able and need appropriate support and education tailored to their own level (Butz et al., 2007; Haughney et al., 2008; Shaw & Davis, 2011).

Living on the edge of asthma incorporates a family perspective of disease prevention, in acknowledging family factors but also undergoing a transformation with a move toward more control and balance over asthma through more education, instruction, and lifestyle changes. Most families reflected on the asthma attack experience and discussed ways to improve care and communication, as well as wanting a place to get accurate information at any time in the process of living with asthma. The level of transformation depended upon how much experience the family had with asthma; those with more experience recalled the experience as a whole, and those who were new to asthma recalled each step in clear detail. Experienced caregivers and older children discussed asthma in terms of what they may have missed and what would be better in the future. Those with newer diagnoses told about the journey, about being grateful for emergency care, and about the "asthma anxiety" that they now carried with them. However, anxiety could be helpful (causing families to invest in learning and following an action plan) or damaging (causing families to blame or overprotect the child), which has been found in other families living with chronic disease (Jeon, Jowsey, et al., 2010). In any event, although the experiences of an acute asthma attack requiring hospitalization were stressful for every family, these experiences all led to a transformation in some way.

Limitations

Although we were able to capture a diverse sample, it is unknown if families who do not speak English or

have other cultural values would have a similar process of trying to maintain family balance while living with asthma in a child family member. Likewise, families whose children have not had recent asthma episodes may not have the same perspectives as families undergoing more frequent health crises.

CONCLUSION

The theory *living on the edge of asthma* provides the means for nurses to understand the process that families go through when their child has an asthma attack. The dynamic process that families undergo, trying to prevent and then deal with an asthma attack, is neither simple nor straightforward. These families do not take the child to the emergency department at the first sign of an attack and they do not ignore the daily requirements of living with asthma. Families' first try to maintain balance by using what they know from previous attacks, including recognizing triggers, using medications, and calling for suggestions from other resources. Once an attack has been perceived as life threatening, the family slips over the edge, loses control of the attack, and seeks medical help. As the attack recedes, they seek control to be able to help get over the attack and to gain more assistance to prevent a new attack. Reflecting on the experience, they transform as they gain new insight along with new information and treatment plans. Our findings demonstrate the importance of including children and their families in the healthcare experience and decision-making process involved with hospitalizations due to asthma. Families should be encouraged to participate and, by doing so, nurses and other healthcare providers can teach families the skills necessary to empower them so they can self-manage the child's asthma. By promoting families to self-manage and gain control over asthma, future hospitalizations may be prevented, costs may be reduced, and overall quality of life may be improved.

How might this information affect nursing practice?

Implications for nursing practice include involving families and children in their healthcare experiences. This includes improving communication with families in acute and primary care settings. It is helpful to learn what family members know and their preferred means to learn new information.

Health literacy is one area for nurses to consider because it focuses on how people obtain, process, and understand health information in order to make health decisions (Nielson-Bohlman, Panzer, & Kindig, 2004). Prior work has shown that patients are still complaining about receiving confusing health information, including information about asthma, often because of the use of medical jargon, which contributes to low health literacy (U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion, 2010). Literature demonstrates that low health literacy in asthma is associated with poor quality of life, higher rates of emergency use, poor self-efficacy, less knowledge, and less use of asthma home treatments (Mancuso & Rincon, 2006). Recognizing families with low health literacy can assist nurses in providing appropriate interventions aimed at increasing understanding. Additionally, giving family members credit for what they do know as experts in their asthma experience can increase trust and confidence in developing asthma action plans. Including the families' input can increase the accuracy of the asthma action plan, making sure it specifically fits the need of the child. The likelihood of actually using and understanding an asthma action plan would most likely increase if the family is actively involved in its development.

Nurses who work with children with asthma are in various roles that may include providing in-home evaluations, initiating referrals, or educating families about how to reduce or eliminate environmental triggers within their homes. This is important, especially early at the initial asthma diagnosis stage, or before being discharged from the hospital, as this would offer education and support that would be key factors leading to actions to prevent or decrease acute care utilization. Broad applications of in-home programs have been successful as disease prevention/health promotion nursing interventions not only in decreasing asthma or allergy symptoms, but also in interventions such as producing positive maternal behavior change and increasing parenting interactions with fathers in children with autism (Elder et al., 2011; Nievar, Van Egeren, & Pollard, 2010; Woods et al., 2012).

From this study, it is evident that more research is needed. Families have various strengths and limitations affecting how they deal with crisis states, including asthma attacks in their children.

Studies focused on discovering which family factors prevent asthma attacks would allow development of nursing interventions designed to assist in reducing triggers leading to asthma symptoms. In-home education following hospitalization has been successful in changing asthma health behaviors and reducing triggers (Polivka, Chaudry, Crawford, Bouton, & Sweet, 2011; Woods et al., 2012). More research is needed looking at cost-benefits and long-term health outcomes of these in-home programs, as well as if initiating nurse-led programs earlier at the time of initial asthma diagnosis may have preventative affects. Thorough assessment of programs and how nurses can increase success by focusing on families' needs and goals, particularly in pediatric asthma care is needed along with "asthma family" input to develop a program that would be understood and used by asthma patients and their families.

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