

Catching the Asthma: Family Care for School-Aged Children With Asthma

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The purpose of this study was to explore how families with school-aged children diagnosed with asthma incorporate asthma care into their daily lives. Twelve families with a school-aged child who had asthma participated in this study. Data collection involved a series of three in-depth interviews with family members in which the process of catching the asthma before it gets out of hand was uncovered, clarified, and validated. Learning the ropes, dealing with asthma, and coming to terms with asthma are the tasks engaged in by parents and their children to catch the asthma.

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ASTHMA is characterized by airway inflammation and increased sensitivity to stimuli that results in reversible bronchoconstriction. It affects 4.2 million children in the United States (ALA, 1995). The paroxysms of coughing, progressive wheezing, increased work-of-breathing, and the variability of asthma episodes are stressful for families. At the same time that the family is facing situational crises arising from asthma exacerbations, family members continue to confront "normal" developmental crises. How do families negotiate these conflicting needs when faced with a chronic health problem? The purpose of this study was to explore how families with school-aged children diagnosed with asthma incorporate asthma care into their daily lives.

THEORETICAL PERSPECTIVE

Management of a family member's illness-related needs has been studied extensively. However, the care provided within families constitutes a broader range of activities than illness management or caregiving tasks. Family caring is the theoretical construct explored in this study through a symbolic interactionism framework.

Pepin (1992) presented the construct of family caring to represent the affective and instrumental care provided by nonprofessionals to a significant other. Caring within families is part of a reciprocal

relationship (Nolan, Keady, & Grant, 1995) in which each member contributes to the work of the family to the level of their abilities. Caring is a basic mode of human being (Roach, 1984) and is essential for human survival and ongoing development (Gaylin, 1979). Bowers (1987) studied caregiving by adult children of their parents to uncover the range of caring in families. Family caring consists of many "hidden" activities not captured in studies of caregiving, including anticipatory, preventive, supervisory, and protective actions (Bowers, 1987). Although caregiving has been studied extensively, the affective or supportive aspects of family caring are just beginning to be explored.

Family caring takes place within interactions among family members. Symbolic interactionism is a philosophical framework that posits that one does not merely react to an event; rather one interprets an event on the basis of one's experience, knowledge, and affective response to the event; this interpretation influences one's actions (Charon, 1989; Hutchinson, 1993). The actions taken in response to a diagnosis of asthma in a child is based on cognitive interpretations or the meaning of the illness for the family members and their affective responses to the diagnosis. Therefore symbolic interactionism is the framework selected to guide this exploration of family caring when a school-aged child has a diagnosis of asthma. The literature review includes a discussion of the meaning of illness, parents' responses to chronic illnesses in children, and concluding with those contextual factors that influence children's self-care.

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0882-5963/98/1306-004\$3.00/0*

Meaning of Illness

The meaning assigned to the illness, although shaped by past experiences and knowledge, can also influence future experiences of family caring for ill members. In a study comparing 15 Canadian residents of European descent with 16 recent immigrants from China, the parents' interpretations of the impact of a chronic illness on the child's life were found to influence family interactions. The Chinese parents viewed the illness from a global perspective in which the negative aspects of the illness were seen as pervasive and severely limiting the child's adult-functioning potential. Alternately, the European Canadian parents viewed the illness from a narrowed perspective in which the illness was seen to affect limited areas of functioning rather than all aspects of life (Elfert, Anderson, & Lai, 1991). In another study of adolescents and young adults diagnosed with cystic fibrosis ($n = 21$), the participants did not define themselves or their futures as limited, even while acknowledging a potentially shortened lifespan owing to the disease process (Admi, 1996). Rather, these young people highlighted their past accomplishments and emphasized their abilities in attaining future successes.

The meaning assigned to the illness influences the parents' decision making, which can affect the illness trajectory. In a study of 63 families of children with chronic illnesses, parents' interpretations ranged from seeing the chronic illness as a challenge to be mastered to seeing it as a burden to endure (Knafl, Gallo, Breitmayer, Zoeller, & Ayers, 1993). Parents who see themselves as successful managers were more comfortable supporting their children's involvement in age-appropriate activities within the limitations of the illness (Miles, D'Aurig, Hart, Sedlack, & Watral, 1993), whereas parents who viewed the illness as a burden restricted their children's participation in age-appropriate activities (Knafl et al., 1993).

The meaning assigned to a diagnosis and the associated illness and treatment experiences greatly influence family interactions. The individual's interpretations also influence the view of self and therefore can have an impact on actions taken.

Parents' Responses to Illnesses

Within families, the meanings of the illness and the affective responses evoked vary across family members and will result in different responses to illness-related events. Copeland and Clements (1993) found that families used energy releasing,

reasoning or knowledge enhancement, and relating strategies to respond to critical times in the illness trajectory. Critical times occur with diagnosis, exacerbations, developmental transitions, and changes in family structure. Fathers ($n = 19$) and mothers ($n = 19$) reported relying on different strategies for confronting critical episodes of their child's illness: Fathers used more reasoning strategies and mothers used more relating strategies (Copeland & Clements, 1993).

Over time as the illness symptoms and treatments are interpreted, meanings assigned, and strategies created for dealing with events that emerge, parents develop parenting interaction styles. Parents can exhibit compensating, restricting, or normalizing parenting styles (Clawson, 1996). In a study with 31 mothers of children with a chronic life-threatening illness, Miles et al. (1993) found that parents used normalizing and compensating parenting styles as they learned about and responded to different aspects of their children's illness. The normalizing parenting style involved giving children every opportunity to be like other children despite the illness. The compensating parenting style involved doing extra or special things for the child, or reducing the age-appropriate demands on the child. Robinson (1993) also found that parents ($n = 40$) emphasized the normal activities in which children participate while minimizing the problems associated with chronic conditions. However, Anderson (1981) found that parents, while defining their children as normal, were enacting restrictive parenting styles such as secluding the child from others to reduce contact with germs.

Normalization is a widely reported strategy used in family caring. Normalizing strategies include reorganizing daily routines to meet the child's needs (Anderson, 1981; Deatrack & Knafl, 1990), having family members share in the treatment regimen, including the child in decision making, preparing the child for stressful events, reducing stigmatization by promoting interactions with peers (Krulik, 1980), and engaging in activities that emphasize normal functioning (Knafl & Deatrack, 1986). Families work to prevent future disease complications, maintain a normal family life, and minimize negative effects of the treatment regimen on family members (Gallo, 1990).

Family caring is shaped by affective responses to a diagnosis of chronic illness. Interactions that arise from the meanings assigned and affective re-

sponses to illness experiences can either promote or inhibit children's development.

Contextual Factors Influencing Self-Care

As they mature, children with chronic illnesses are expected to become adept at monitoring and treating their condition while also mastering age-appropriate developmental tasks (McCarthy, Williams, & Eidahl, 1996). This work is not done in isolation; rather contextual factors, such as other's responses to them or to their illness and societal expectations can affect children's work in becoming adept at self-care.

Turner-Henson, Holaday, Corser, Ogletree, and Swan (1994) found that children with chronic illnesses ($n = 365$) experienced discrimination in schools in the form of prejudice and barriers. Prejudice was the negative attitude toward these children, and barriers were aspects of the physical or social environment that prevented the children from fully participating with peers. Some barriers were misplaced "good intentions," for example, when a teacher was being overprotective. McCarthy et al. (1996) studied teachers' ($n = 29$) concerns in dealing with students' chronic illnesses. The most common concerns were dealing with medical emergencies (62%) and worry about the impact of absenteeism and fatigue on learning (48%). One can see how such teacher-related concerns would contribute to the barriers described by Turner-Henson et al. (1994).

Becoming responsible for self is a basic social expectation ascribed to children as they mature. However, when a child has a chronic illness, this picture is compounded. Congruent with the normalizing parenting style, health care professionals and parents expect children to become adept at the day-to-day tasks of managing their chronic illness. However, during exacerbations, adults enact a compensatory caregiving style as they reinforce dependency needs in an effort to comfort the child (Rew, 1987). Additionally, the fluctuation in illness experience has the potential to delay a child's growth and development as opportunities for learning in academic and social encounters are missed (Turner-Henson & Holaday, 1995). Children with chronic illnesses have many hurdles to clear in their efforts to become proficient in self-care.

Children enact self-care strategies in contexts that are defined by others. Because school-aged children spend much of their waking hours in school settings, teachers' interpretations of and responses to the children's health conditions can

influence the quality of their experiences in both healthy and ill situations. The social message to children is to "act your age," but barriers arise when they experience illness exacerbations because age-appropriate expectations for children's self-care in illness has not been well defined.

METHODS

Children who have a diagnosis of asthma have many symptom-free days and can lead robust active lives. The quality of their lives is influenced by the family caring they experience. Family caring is revealed in the strategies enacted and meanings ascribed by parents and children to a child's emerging health needs as families learn to manage asthma episodes while promoting healthy development. Grounded theory methods are based on the assumptions of human interactions as defined by symbolic interactionism. The goal of grounded theory is to clarify those processes created by groups for handling psychosocial problems that emerge in their lives (Hutchinson, 1993).

Sample

Study approval was obtained from a Human Assurances Committee. English-speaking families with a school-aged child with asthma, who were engaged in asthma management, were the criteria for study enrollment. Theoretical sampling was not used in this study; rather nominations of potential participant families for study inclusion were solicited from private physicians and pediatric nurses who obtained parent permission to provide their names and telephone numbers to the researcher. Half of the sample ($n = 7$ families) was drawn from the rural area and half ($n = 5$ families) from a densely populated urban center of a southern state.

The 12 families had 15 children with asthma ranging in ages from 6 to 18 years, and 8 healthy children ranging in ages from 3 to 9 years. Three families had one child, seven families had two children, and two families had three children. There were three single-parent families, one extended family, and eight nuclear families: There were 12 mothers, 6 fathers, and 1 great-aunt. Three families were of African descent and nine families were of European descent. Signed informed consent was obtained from adults, and signed assent was obtained from minors after parent permission was obtained. Confidentiality of individuals' data and anonymity of family participation outside the family unit were maintained.

Data Collection

Data were collected through a series of three in-depth interviews, each lasting 60 to 90 minutes and were conducted in the families' homes. All of the interviews were audiotape recorded and then transcribed verbatim within 1 week of the interview. Sample interview questions included these:

1. What does it mean to have asthma (have a child who has asthma)?
2. How are health and illness needs of all family members met (family caring)?

Family members were interviewed in group interviews during the first interview. Questions based on data from the first group interview were included in the second interview to determine consistency among responses and to clarify earlier data (Lincoln & Guba, 1985). The second interview included private interviews with the older school-aged children (9 years and older), private interviews with parents, and family interviews with the younger children who participated with their parents present. Ten families were enrolled at the beginning of the study, and two families who were identified late in the study were included only in the final interview session. A summary of the entire study findings was given to all 12 families before the final interview session. Ten families who participated in the first and second interviews verified the researcher's data interpretation (Lincoln & Guba, 1985). The two families enrolled late in the study validated the transferability of the data (Lincoln & Guba, 1985) and confirmed that *Catching the Asthma Before it Gets Out of Hand* reflected their experiences with asthma as well.

Data Analysis

The researcher read the transcriptions line by line to identify substantive codes (Hutchinson, 1993). For example, one mother related, "I was giving him his medicine during all the constant monitoring, now it's pretty much in his hands. I can leave him with that control." This was initially coded giving control to child. Credibility and dependability of the data were confirmed through constant comparison of substantive codes (Lincoln & Guba, 1985). Each transcript was searched for similar experiences in which the parent was giving control or responsibility to the child. In this way, the variability of giving control was uncovered for children of different ages. Structured analysis of the substantive codes yielded categorical codes (Strauss & Corbin, 1990). For example, giving control to child became an element in becoming responsible. In the last interview session, the emerging core

variable of *Catching the Asthma* was validated with all 12 families (Lincoln & Guba, 1985).

FINDINGS

Exploration of families' experiences with asthma in school-aged children revealed the work of parents and children as they sought to *Catch the Asthma Before it Got Out of Hand*. The process of *Catching the Asthma* consisted of the overlapping phases of learning the ropes, dealing with asthma, and coming to terms with asthma. Asthma episodes were a central focus of family life while families were engaged in learning the ropes of asthma management. Over time, as families became more adept at recognizing presumptive signs of asthma and potential triggers for asthma attacks and began dealing with asthma in an efficacious manner, asthma moved from the center of families' attention to a more peripheral position. Throughout the process of *Catching the Asthma*, the families began coming to terms with asthma, and, as the children matured, the primary responsibility for daily management of asthma was shifted from parents to children.

Learning the Ropes

Learning the ropes was the first phase of *Catching the Asthma*, which began with the diagnosis of asthma in a child family member. Family efforts were focused on learning about asthma and gaining some control over it. Asthma symptoms and asthma management were a central focus of the families' lives as they followed new treatment regimens and tried out various management strategies in the home. Because children were diagnosed between 15 and 60 months of age, most of the work in this phase fell to the parents. Parents engaged in the tasks of uncovering asthma patterns, coming to know medications, and changing lifestyle/environment; the children's work consisted mainly in relying on others (Table 1).

Uncovering Asthma Patterns

Parents focused on learning their children's asthma patterns (presenting symptoms and elements that trigger asthma) to be able to intervene or get help before the asthma escalated into an unmanageable episode. Parents related that before the diagnosis of asthma was made, they believed their children were having bad colds that lasted longer than usual, with paroxysms of coughing so severe that children vomited, which the parents "did not realize was asthma." Recognizing the significance of presenting symptoms in their child with asthma

was an integral component in learning to manage asthma episodes.

In the three families with two children diagnosed with asthma, one child had moderate/severe asthma and the second child had mild asthma. The parents of these children were having to learn the range of asthma patterns possible. In two families, the older child had the more severe asthma, but in the third family the older child had mild asthma, which was not diagnosed until the younger sibling's more severe asthma was diagnosed. After the diagnoses were made, these families had to match asthma care to the child's presenting symptoms and not over-react during a mild asthma episode.

Coming to Know Medications

With the diagnosis of asthma, the children were started on different medications by their physicians. As they were learning how their children responded to different medications, parents came to understand that their assumptions about medication management were no longer appropriate for managing their children's asthma episodes.

Initially parents treated the symptoms the same way they had treated the earlier "colds." They gave medications only when asthma symptoms were present. With experience the parents became adept at using medicines to prevent asthma episodes. As one mother related her change from reactive treatment to proactive treatment, "It took me a long time to realize you needed to get ahead of it rather than wait until he was knock-down drag-out sick."

Children continued to receive many over-the-counter preparations from their parents to treat the nonpulmonary symptoms such as runny nose and watery eyes. Through a trial-and-error process, parents came to learn which preparations were beneficial and which had untoward effects. As one couple shared: "He lived with a runny nose. . . . I was very frustrated, I would try anything on the market. . . . One night we gave him Sudafed for the first time and he ran up and down the hallway throwing toys. . . . He just went crazy on us." Such experiences profoundly influenced the parents' mastery of learning the ropes.

Relying on Others

Because of their young age, children relied on others to take care of them when asthma symptoms were evidenced. The children were able to indicate when they needed assistance and over time improved the clarity of their communication about their symptoms.

In response to the question, how does Momma know when you're feeling sick, one 6-year-old stated, "I don't know." His mother prompted him with, "You do tell me when your stomach hurts. Every breath is ouch, ouch." However, when this same 6-year-old was asked what he did for asthma, he responded, "I do the breathing machine. I take my medicine." This case illustrates the child's understanding of actions taken, but also his lack of awareness of others' perceptions of the situation, which is not atypical for a young child.

Contrast this example with that of a 9-year-old who also relied on others: "I just tell people that I'm having trouble and I need my inhaler. The teachers sometimes go with me to the nurse." As their experience with asthma increased, the children communicated their needs more clearly and were more proactive in self-care.

Changing Lifestyle/Environment

The impact of context in eliciting asthma symptoms led parents, nursery and school personnel, and extended family members to initiate changes in the environments to reduce the children's contacts with potential triggers. Family members incorporated changes in their homes and lifestyle that affected their daily routines. The most common strategy taken was the implementation of "no smoking" rules in the home. For allergic children, family members modified their home environments to avoid contact with allergens. As one father explained, "We took all of the carpet out of the entire house and we bought the central humidifier system that zapped dust particles as it recycled air."

Three of the children in this sample were not allergy positive. Their families noted activities, stressful situations (physical or emotional), and

Table 1. Process Phases and Codes of Catching the Asthma Before It Gets Out of Hand

Phases	Learning the Ropes	Dealing with Asthma	Coming to Terms With Asthma
Parent work	Uncovering asthma patterns	Being on alert	Balancing demands
	Coming to know medications	Stepping up treatment	Caring for self
Child work	Relying on others	Judging effectiveness	Limiting rewards
		Changing the response	Becoming responsible
Context issues	Changing lifestyle/environment	Buffering	

weather conditions that seemed to increase asthma symptoms; and they altered their activities to avoid these trigger events. Nursery and school personnel were given instructions about weather conditions and the need for rest intervals during recess or play times to help the children avoid asthma trigger events.

Dealing with Asthma

Although families managed asthma from the time of diagnosis, this second phase indicated that the family had achieved mastery of the basic tasks of managing asthma. The illness duration ranged from 3 to 13 years since the time of diagnosis for this sample. Families became proficient at recognizing asthma patterns; they became more adept at assessing, preventing, and managing episodes. As part of this mastery, parents and children no longer just responded to symptoms as they presented; rather trigger situations were anticipated and preventive strategies initiated. Dealing with asthma included the parents' work of being on alert, stepping up treatment, judging effectiveness, and buffering, and the children's work of changing the response.

Being on Alert

Parents' increased awareness of possible trigger events or precursor symptoms enabled them to intervene much earlier to prevent some asthma episodes and shorten the duration of other episodes. As one mother related, "See at night sometimes a couple of days before she really kicks in [with asthma], at night she wakes up coughing." Recognizing the child's pattern enabled this mother to aggressively treat and reduce the impact of asthma episodes.

This task differs from uncovering asthma patterns in that parents were no longer hypervigilant for any signs of asthma: They were on alert only when their child's asthma triggers were evident. For example, some children were symptom-free during mild warm weather, but when a sudden cold front descended in their area, they began exhibiting asthma symptoms. In this instance, parents only became concerned about potential asthma episodes when they were alerted by reports about changing weather conditions. Other children exhibited symptoms only when in contact with their allergens, which could be a seasonal event and therefore highly predictable. Children were able to support their parents' work of being on alert by communicating subjective symptoms as the children relied on others.

Stepping up Treatment

As a result of being on alert, families stepped up treatment before or with the early onset of presenting symptoms. Stepping up treatment consisted of actions taken by parents to modify the treatment plan in response to possible trigger events. This task flows from the earlier work of coming to know medications wherein parents uncovered their children's unique responses to medications when they learned what was and was not effective. Parents followed previously established guidelines or contacted their physicians for guidance in managing episodes. As one mother shared a typical medication plan for presenting symptoms: "When he gets symptomatic we add in a third Slobid a day or we immediately put him on the nebulizer. [Preventively] we see [MD] for sinus infections to get him on an antibiotic."

Judging Effectiveness

Parents' actively evaluated the effectiveness of medications administered, strategies taken to manage the environment, and behavior strategies used in terms of preventing, reducing, or correcting asthma symptoms. Families did not perform this work in isolation. They formed important partnerships for managing the children's asthma by working closely with physicians in implementing treatments. Through this association they learned how to judge the effectiveness of strategies in reducing the frequency and severity of asthma. As their experience increased, they learned to adapt interventions to fit the children's responses, to titrate medications by season and symptom occurrence, and to judge the effectiveness of their strategies for meeting the children's changing needs.

One father shared his experience with learning about the medication when his child was young as an example of becoming much more cognizant of the need to evaluate his child's response to care: "I thought that some of it was just guessing [about when and what kind of medicine to give]. But the medicine he takes every day, when I missed those two times, he was having bad problems the next morning, so that is when I realized this stuff really works."

Changing the Response

Over time the children discovered strategies for changing their response to asthma through self-medication and behavioral strategies initiated to alleviate asthma symptoms. While self-medicating was the most commonly used initial action taken by the children, they described other strategies to deal

with their asthma. One 13-year-old shared a visualization technique he had discovered that worked well for him: "I think of being in a quiet place, cool, lying down watching TV or eating, and I think about it and I calm down. But you know if I'm thinking about like playing or something, it'll get worse."

Another 9-year-old boy related that sometimes simply stopping activity or resting was enough to ease the tightness in his chest. Whenever he would take a dose from his inhaler he learned that it was best to rest quietly and allow the medicine to take effect. "Well when I'm real hot and sweaty and I have a little trouble breathing . . . then I'll come in the house and get cooled down. Or I'll take my inhaler sometimes and sit under the fan and cool down."

As the children matured and became more proficient in self-care, they were able to initiate interventions earlier leading to a reduction in the frequency and/or severity of asthma attacks. As one 12-year-old explained his routine in managing an asthma episode: "I had my inhaler and when I feel like I'm catching an asthma attack I would take one puff [of inhaler] and I would inhale and breathe out and I would take another puff. If that wasn't good enough, in about 15 or 20 minutes, I would do my breathing treatment [nebulizer], lie down, and calm down." In a separate interview, this child's mother indicated that his improved skill in taking care of his asthma had resulted in a decrease in hospital visits and hospital stays, which had been a regular occurrence when he was younger.

Buffering

Parents engage in buffering when they smoothed the interface between the families' expectations and values and the policies of external systems such as school and health care systems. Much of this work centered on school systems, although other settings such as little league games or dance classes also required buffering.

Each year, parents, usually mothers, established links with significant persons in the school, such as the children's teachers, counselors, or school nurses with whom they would entrust their children's safe keeping. As one mother explained: "The beginning of school we had to . . . do a lot of explaining each year . . . explaining that he was allergic to dust, and I began to feel there was some emotional ties [family stress] to the illness as well." In this instance, buffering was done to reduce school personnel's anxiety and to promote the child's safe involvement in school.

A few conflicts arose between parents and school personnel concerning the management of children with asthma, which added to the complexity of family care. Another mother shared this episode: "The school nurse, she's an LPN, left him alone in the clinic while she took another child to the doctor's office. She didn't have anyone look in on him, she just left him there by himself and he had been complaining about trouble breathing." In this instance, the mother's buffering consisted of meeting with school administrators to clarify procedures to be followed in maintaining safe care for her child.

Coming to Terms With Asthma

Elements of this phase arose as parents learned the ropes and families dealt with asthma. However, in these previous phases, asthma care was a central focus to the point of providing a framework for daily activities of family life. Families who were at the point of coming to terms with asthma were reviewing the effects asthma had on their lives and refocusing energy on other important issues. The impetus for this phase was the change in responsibility for asthma care within families from the parents to the children with asthma. Not all of the families were at this point in *Catching the Asthma*. Families with younger children were only beginning to initiate some of this work, whereas parents with older children were actively engaged in the tasks of balancing demands, caring for self, and limiting rewards; and their maturing children were becoming responsible.

Balancing Demands

Parents evaluated the needs of self and others and decided what they were willing to expend in terms of time, money, and energy to meet family needs. Many times parents engaged in an appraisal process whereby they would weigh the risks and benefits in each situation to arrive at a sound decision to optimize their children's healthy or normal childhood experiences. Following is an example of one mother's struggle with making such decisions in the face of her daughter's asthma experiences: "She really wants cheerleading, but I'm afraid . . . because it really gets hot out there and she goes and gets a little sweaty and coughs and wheezes. I'm going to let her try this next fall and see what happens." The desire to support normal childhood experiences was a value described by all of the parents in this study.

Managing work role demands was an important component of balancing demands, because all but

two of the study parents worked outside the home. In this sample, the time missed from work for the children's illness was generally viewed negatively by employers, as one single mother shared her tenuous job situation: "I work off and on and sometimes I can't work steady because of him. . . . Because a lot of people don't understand when you say the child is sick and you've got to go. You know they're quick to hire someone in your place." To balance demands of children's caregiving needs with families' income, many parents had a family member provide care, or they found alternative or supplemental employment. In one family the father's job hours were more flexible, so he was the primary caretaker during many of his son's illness episodes.

Caring for Self

During the early years with asthma, parents focused on meeting their children's needs, fulfilling obligations to employers, following medication plans, and interfacing with school and other external systems. As their children matured and demonstrated proficiency in asthma self-care, parents were able to focus on meeting some of their own needs. As one mother of a 6-year-old with asthma shared: "I have just in the last three months been able to start a regular exercise class three times a week and it is making all the difference in the world. I feel like another person."

The importance of taking time to care for self was expressed by many parents. Some parents of older children had established self-care rituals, which they used for stress relief. As one mother shared her routine: "I take time for myself. I have a quiet 30 minutes, when I get home from work before I start dinner, and the boys know not to bother me then. I'll read, take a short nap, or soak in the tub." The impact of doing tasks to care for self was seen as contributing to family well-being as well: "Not only do I feel better, but everyone else is happier, too."

Limiting Rewards

Parents came to recognize that asthma yielded undesirable "benefits" to the children. As one element of coming to terms with asthma, parents formulated strategies, based on their personal values, to limit these secondary gains.

Because an asthmatic episode is a frightening and dangerous event, children receive a great deal of attention during these episodes. Several parents expressed concern about what their children were learning as a result of the entire asthma experience.

In one case, a mother described parents' concerns about siblings' interpretation of these events: "We are very worried about our other child. When he's sick he immediately thinks that we don't care if we don't give him medicine. I'm so afraid of what this whole situation is turning him into; I mean I see the potential drug abuser in my child because to him a drug is the answer to everything." These parents interpreted that the real source of the problem was the attention the child with asthma received. Their solution was to establish a ritual in which the father and son (nonasthmatic child) spent time together alone every Saturday doing various activities—it became "their time."

Deciding on appropriate discipline to be used was another issue each family confronted in the work to balance their beliefs about parenting with the children's health problems. A mother of an 8-year-old with asthma related a commonly expressed concern: "Well I'm still afraid to discipline him because I worry whether getting him upset by disciplining him will bring on another asthma attack." The father of this child indicated, "We don't spank him, but I enforce restrictions. You can't have a child growing up without any sense of discipline."

Becoming Responsible

As a consequence of dealing with asthma under their parents' guidance and demonstrating increasing competence at managing asthma symptoms, the children took on more responsibility for the daily management of asthma care. However, becoming responsible included other aspects of family work as well.

Younger children began the work of becoming responsible by helping with chores or assisting parents in completing tasks. The sibling of a child with asthma supported the family's work of managing the environment. His great aunt shared his contribution as "vacuuming the house to get dust out of the rugs so it will help (brother's) breathing. He is a good helper."

As they matured, children with asthma took on more responsibility for managing their asthma. As one 13-year-old shared, "I could be playing and I always asked 'what time it was'. And when someone told me it was 7 o'clock, I would quit playing and go in the house and take my medicine." Older children evaluated the effectiveness of measures taken and discussed their interpretations with their parents. As one mother indicated, "I use him as a valid informant. He seems to know when his medicine is at its limit and this is when he comes to

me.” The children were becoming active participants in decision making with the support of their parents.

In summary, learning the ropes, dealing with asthma, and coming to terms with asthma explain the process of *Catching the Asthma Before it Gets Out of Hand*, whereby families learn about and incorporate asthma care into their daily lives.

DISCUSSION

Catching the Asthma describes the process families follow as they confront the problem of asthma getting out of hand. The strategies chosen in the different phases of catching the asthma reflect both cognitive and affective responses of family members to their changing needs. This process was presented as distinct elements, but there is considerable overlap between the phases. For example, in families whose children were diagnosed with asthma at a later age (e.g., 5 years), the parents had to work with school personnel while they were just learning the ropes. Alternately, children continued to rely on others while they were simultaneously becoming proficient at dealing with asthma.

The meaning of asthma for a family changed over time. As families were learning the ropes, asthma care was a central focus in their lives, with daily routines structured around asthma care activities. As parents and children's proficiency in asthma management increased, asthma care moved from the center of families' attention to become a “background” issue. All of the families were dealing with asthma on a daily or seasonal basis. However, the families with older children were able to focus energy on other aspects of life while also managing the asthma. The sequencing of the phases in *Catching the Asthma* reflects the family's growing proficiency in asthma management.

Caring activities that include more than caregiving tasks is most clearly reflected as families were coming to terms with asthma. The reciprocal nature of family caring is revealed as family members work to meet health and illness needs of all family members. For example, the child with asthma was encouraged to participate in most of the usual childhood activities except when those activities brought the child into contact with trigger stimuli or events. Children contributed to family work as they were becoming responsible for illness care, as well as household responsibilities.

The parents in this study adhered to a normalizing parenting style (Deatrick & Knafl, 1990). Because of the children's ages, home, school,

health care, and extracurricular settings were integral to the families' successes in *Catching the Asthma*. Whereas parents' initial buffering work focused on managing asthma symptoms, later, as families were coming to terms with asthma, parents' buffering work included supporting their children's involvement in normal activities of childhood.

IMPLICATIONS

Nurses who are guided by this substantive theory will be able to (1) promote family members' sense of competence in managing asthma episodes, (2) evaluate the efficacy of family caring strategies in meeting members' needs, (3) assist parents through decision making related to critical issues of discipline and expectations of children as they develop and mature, (4) facilitate children's autonomous self-management of asthma, and (5) educate others who work with families of children who have chronic health problems about the children's needs.

To promote competence in managing asthma episodes, it is necessary to provide families with information that is useful, practical, and “fits” into the framework of their lives (Curtin & Lubkin, 1990). Managing and preventing asthma episodes are largely carried out in non-health-care settings such as the home or school. Nurses can play an integral role as families are learning the ropes by clarifying parents and children's understanding of the condition and treatment plans to be followed. Mastering this complex information is the central task facing families after the diagnosis is made; however, families quickly become aware of other issues that can affect the children's health. Families need support and guidance as they work to provide normal childhood experiences for children. Nurses should provide anticipatory guidance to help parents with buffering as the child returns to nursery school or enters elementary school. Such work by the parents can head off potential problems for their children.

Recognizing and working to meet family members' needs are central components of family caring. Children need to have the opportunity to master predictable developmental tasks to continue growing and developing (Grey & Thurber, 1991; Yoos, 1987). Yoos (1987) indicated that development can be supported in chronically ill children by encouraging regular school attendance, building peer relationships through participation in clubs or other activities, and encouraging self-care as much as possible. In addition, taking on greater responsi-

bility in the home as their "share" of family work reinforces the child's sense of self-worth as a full participant in this reciprocal relationship (Nolan et al., 1995). The families in this study supported normative developmental activities through buffering, balancing needs, and sharing responsibilities.

There is a natural progression in the complexity of responsibilities assigned to children as they mature. For example one may have a toddler "play" at picking up toys, whereas a teenager can take over preparation for some meals. When a child has asthma, the frequency and severity of episodes may demand that the child exhibit far greater autonomy than would normally be expected of another child at the same age. Parents who enact a compensatory parenting style by reducing age-appropriate demands on their children can actually hinder their children's self-management work. Nurses can help parents clarify their expectations for their children and support parents in forming strategies to help their children learn to be responsible.

When children are young, parents take on the primary responsibility for asthma care. As they grow and mature, the children must master self-

management of a complex health problem. Nurses need to explore the child's understanding of asthma care and the meaning of "being asthmatic" to effectively support the child's developing autonomy in self-care.

Nurses are well situated to educate others about the needs of children with chronic health conditions. School personnel, day care workers, and other health care providers need to understand the complexity of the health problem experienced by the children. However, they also need to understand that overprotective strategies can hinder normal growth and development in these children (McCarthy et al., 1996).

In summary, this study of family caring for school-aged children with asthma contributes to a growing body of knowledge about how families incorporate complex illness care activities into their daily lives while also striving to meet the health needs of family members. Nursing care should not only focus on supporting family mastery of illness-related tasks such as symptom management and preventive strategies, but also include assisting families in creating strategies for addressing the health needs of family members.

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