

# CHALLENGING CASE: CHRONIC DISEASE—DEVELOPMENTAL AND BEHAVIORAL IMPLICATIONS

## Recurrent Episodes of Asthma in a 10 Year Old\*

### CASE

Peter's asthma has always been a concern to his parents. Since his diagnosis of asthma at 2 years of age during his first hospitalization for pneumonia, his mother often reminds doctors that "they said he was very sick—that if we hadn't taken him to the hospital that night, he may have died." Now 10 years old, Peter has had 5 subsequent brief hospitalizations for status asthmaticus. His pattern of illness is predictable: an upper respiratory illness followed by wheezing not completely controlled by inhalation home medication; he spends not more than 2 days in the hospital. He has had only one other episode of pneumonia. Emergency room visits seemed clustered around moments of family disruption. His parents' separation and divorce when he was 5 years old, his mother's loss of her job when he was 7, and his older sister's auto accident when he was 8 were each accompanied by 1 to 3 emergency room visits for asthma. At other times, asthma exacerbations were managed at home. Peter's pediatrician, and subsequently an allergist, provided his mother with a written plan for maintenance and acute treatment medications, as well as attention to household allergen elimination, with limited success. Recently, Peter refused to take his inhaler to school. He resisted going to the school nurse for medication as needed. In the 4th grade, his behavior in class was on occasion disruptive, and he demonstrated less interest in school work. His teacher reported that Peter was often short of breath after playing at recess. Peter now lives with his mother and older sister. His mother works full time as a medical assistant. Since the divorce 5 years ago, Peter spends 1 weekend each month with his father, who lives in a nearby town.

### Dr. Martin T. Stein

Not long ago, a generation of pediatricians with a psychological perspective concerning chronic disorders might have conceptualized Peter's noncompliance, school refusal, and disruptive behavior in terms of an anxiety disorder with roots in a dysfunctional parent-child relationship. Emotionally traumatic experiences, both associated with and isolated from episodes of asthma, would be the focus of a psychosocial interview. Peter's behavior would be explored in the context of an asthmatic child who was emotionally restricted and prone to manipulate

his environment with recurrent episodes of wheezing and dyspnea.

The medical perspective on childhood asthma changed dramatically during the past 30 years from an episodic psychosomatic disorder with a predisposition to allergic individuals to a disorder of chronic bronchial inflammation and airway hyper-reactivity. In the current medical model, asthma exacerbations are triggered by allergens (airborne and ingested); respiratory infections; toxic pollutants, including tobacco smoke; and psychological factors. Psychosocial events are no longer interpreted as primary etiologic factors but rather as potentially contributing to an exacerbation in a susceptible individual. A recent prospective study provided empirical evidence documenting a link between early parenting and the subsequent expression of asthma in a genetically susceptible group.<sup>1</sup>

Asthma is no longer seen as a psychosomatic disorder associated with specific personality traits. Those who study children with chronic disorders have pointed out that substantial clinical benefits might be found from a generic approach to children and families with chronic disorders, in contrast to an approach that views each disorder as distinct.<sup>2</sup> This model derives from a recognition that quality of life can be elaborated in categories that are shared by children and families with chronic disorders. With a clearer definition of these quality of life factors, management strategies can be designed to fit the individual child and family.

Asthma is the most common chronic disorder in primary care pediatric practice. It requires a precise knowledge of the chronic bronchial inflammation and hyper-reactivity of the disease; the causes of symptom exacerbations; multiple management strategies, including the removal of putative environmental factors; and the mechanics involved in the use of inhaled medications.<sup>3</sup> Because asthma medications are effective in a variety of different forms and are prescribed optimally in different amounts and intervals depending on symptoms, clinicians must assess each child's capabilities, psychosocial make-up, and family structure to assure optimal care. Asthma is found in approximately 5% of children, so the challenge to pediatricians can be significant.

Peter's asthma has been poorly controlled for several years. His mother's longstanding perception of Peter's vulnerability, a history of asthma exacerbations associated with major life-event changes, and recent evidence of disruptive behaviors and resistance to medication at school provide important clin-

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ical clues to management. Two pediatric specialists comment on Peter's case.

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#### Dr. Eli O. Meltzer

Asthma is a common illness affecting as many as 12 million persons in the United States, more than one-third of whom are children.<sup>1</sup> There are, on average, 500,000 hospitalizations annually in the United States for asthma, with more than one-third involving individuals less than 18 years old.<sup>2</sup> An estimated 1.8 million Americans require emergency room services for asthma, and nearly 50% of these are pediatric patients.<sup>2</sup> There are also approximately 6.5 million visits in the United States each year to physicians for asthma, with expenditures amounting to almost \$200 million. Of these expenditures, one-third are for persons 18 years old or younger.<sup>2</sup> Peter is only one representative of the many individual children who produce these troubling statistics.

As disturbing, however, as the case report is (acute difficulties that result in hospitalizations and emergency visits), these events are only the tip of Peter's iceberg, because asthma is a chronic inflammatory disease. It is Peter's persistent airway hyper-reactivity that predisposes him to his acute exacerbations, decreases his ability to play vigorously, and requires him to take maintenance medications.

The chronic morbidity of asthma in children is as devastating to their behavior and development as are the acute exacerbations. The National Allergy and Asthma Network/ Mothers of Asthmatics in a survey of the members reported that almost 50% of the children feel some embarrassment when using an inhaler in front of their friends or school mates; approximately 60% of the children miss between 1 and 10 days of school because of asthma (among

American children 5 to 17 years old, asthma accounts for a loss of more than 10 million school days<sup>2</sup>); more than 70% of the children are somewhat limited from spending the night at a friend's house because of asthma.<sup>3</sup>

For many years, the assessment of the chronic morbidity of asthma has been based on the rating of symptoms, the need for medications, and the evaluation of airway physiology. None of these reports how the patient feels and whether the patients are actually able to function better in their day-to-day lives. Health-related quality-of-life measures are newer scales, which aim to quantify those effects. They give numeric values to a set of items that describe physical symptoms, a set of functional items that review activity and role limitations, and a component of items that assess the distress and emotional impact of the disease and its management.<sup>4</sup>

There are at least 10 pediatric asthma quality-of-life questionnaires,<sup>5</sup> with documentation of at least one instrument's sensitivity to change over time.<sup>6</sup> Many of the available questionnaires are designed to be child completed, while others are answered by parents.<sup>7</sup> Developmental factors, reading ability, and adult assistance can all influence the child's responses.

The evaluation of quality of life is an emerging behavioral science. Therefore, although it adds a useful patient-generated dimension to our understanding of the impact of asthma in children, it should be recognized that no single measure can assess all of the complex physical and psychosocial dynamics observed in pediatric asthma.

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#### Dr. Ruth E.K. Stein

Peter presents a number of interlocking problems that complicate his care. He has asthma triggered by upper respiratory infections, exercise, and emotional stress, and he feels stigmatized by taking medications in school. He is not adhering to the prescribed therapy, and he is behaving disruptively in school. These issues are occurring against a backdrop of parental divorce that results in being raised by a

single parent and having monthly episodes of transfer of caretaking responsibility to his noncustodial parent. Furthermore, at least one parent views Peter as a vulnerable child. Most pediatricians faced with this constellation of issues will at least momentarily be overwhelmed, especially during the middle of busy office hours. What can help the practitioner get beyond that initial reaction? What are the manageable steps toward helping this child and his family?

First, it is important to inventory the problems and their potential interaction to appreciate the complexity of the issues and to assure yourself that none of the problems is an acute emergency. It is equally critical to recognize that all of the issues cannot be dealt with simultaneously and that they have occurred over a considerable period of time. The practitioner must be realistic in recognizing that helping Peter and his family will require a long process. The key task is to figure out how and where to begin.

There is no single approach or recipe that guarantees success, but I would like to try to schedule a longer office appointment to do a more complete assessment. At that time, the objective would be to identify what Peter's mother and Peter think are the things that they most want to see changed. I like to have the family identify three concerns, because then it is likely that at least one of them might actually be quite easy to address. It is important that the agenda be identified by the patient and the caretaker, because the major challenge is to begin to have a shared agenda and to develop a contract for working together. Because the practitioner's concerns are usually not the same as those of the patient or family, our efforts are likely to be futile without knowing their priorities. On the other hand, if we succeed in addressing something that is perceived by the family as a problem (no matter how trivial or tangential it seems to us), we substantially improve the chances of developing an ongoing opportunity to address our concerns over time. After an initial success, most families are willing to focus on another issue or two, and at that point the practitioner's agenda might be addressed alongside the family's with a greater chance of success. Furthermore, just as it is overwhelming for the practitioner to deal with all of the issues at once, the family will be stymied by trying to change everything simultaneously.

Although I would start with the family's agenda, it is essential to prioritize your own agenda as well and then to try to work through it gradually but persistently. The goal is to make progress on each of the issues identified over time. For example, in terms of Peter's asthma, the practitioner might aim to help the family members, including the father who cares for Peter one weekend a month, to understand that asthma is a chronic condition, not an episodic illness, and that it can be most successfully treated by consistent administration of appropriate antiinflammatory medication. It is helpful to explain that treating Peter's asthma even when he is not actively wheezing is likely to reduce the number of acute episodes and emergency visits. To execute this, the pediatrician must understand what each of the family members sees as the obstacles to doing this and when and

why they think the plan falls apart or is impractical. Some modifications might be necessary, such as providing a schedule that minimizes the need for in-school administration of inhaled medications. Consistent adherence to a program of medications before and after school and at bedtime or changing to long-acting preparations might provide sufficient control to allow the school-based medications to be discontinued and to reduce Peter's shortness of breath during recess. Small successes in improving adherence and in problem solving need to be encouraged and reinforced. It might also be useful to have the family identify the triggers to Peter's asthma attacks and to develop a plan for the family and practitioner to implement when Peter has a cold or goes through a stressful time.

As with any chronic condition, the demands on Peter's caretakers are far greater than those on caretakers of a healthy child. This is additionally complicated when parents are separated. More often than not, the tensions that led to the separation interfere with optimal communication concerning the child's health condition. The pediatrician can play a key role in establishing the plan of care directly with each of the parents or offering to meet with two of them, so that they each participate in working out solutions and receive the same information concerning the child's medical condition.

It is also critical to recognize the concern that Peter is a vulnerable child and to disentangle the scare at age 2 years from the current dangers. In each exacerbation, it might be necessary to acknowledge that Peter's mother might be worried that this is like the episode when he was 2 but that he is not in any acute danger now. Failure to address this underlying fear is likely to leave Peter's mother feeling that the potential seriousness of his attack or upper respiratory infection has not been fully appreciated by the treating physician and, therefore, that Peter might again be in danger.

The school and behavioral issues pose significant threats to Peter's long-term functioning and cannot be ignored. They require a thorough assessment in collaboration with the teacher and other key school personnel. The perspectives of these professionals might be extremely helpful in understanding the basis for the problems and suggesting constructive interventions.

Managing a child such as Peter requires considerable patience and skill, and successes might be extremely slow at the start. When the pediatrician is persistent, however, and sets realistic goals, the long-term results can be immensely rewarding.

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The comments of Drs. Meltzer and Stein focus on the need to recognize psychosocial factors that impact on quality of life and disease management. The knowledge that asthma, like all chronic disorders, is a disease that affects family functions and the health

**TABLE 1.** Biopsychosocial Approach to the Child with Asthma

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Asthma is a chronic inflammatory illness.  
Asthma exacerbates with airway hyper-reactivity.  
Prescribe medications that fit the pattern of the child's/family's daily activities.  
Modify medications to reflect changes in symptoms, daily activities, and family patterns.  
Assist the child and family in identifying major concerns (determine the patient's agenda).  
Assess the major concerns (develop a shared agenda).  
Ask the key question: "What would you like to see changed?"  
Initially, address only three concerns.  
Value and build on small successes.  
Be aware of the characteristics of a clinician's effectiveness.  
Skill (helping the child/family to articulate problems and goals);  
Patience (viewing asthma as a chronic illness);  
Realistic goals;  
Persistence (planning follow-up visits or phone calls; periodic reassessment).

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of the child is an important component of a clinician's approach to the individual child. Dr. Meltzer pointed out that, until recently, the medical model of asthma emphasized symptom-rating scores, medications, and physiologic monitoring of airway function. Pediatric allergists are beginning to incorporate quality-of-life measurements into their assessment and management of childhood asthma. These parent and child scales assess the extent to which physical symptoms affect function in school, home, and interpersonal social activities. The use of a questionnaire fits the format of many contemporary subspecialty practices, in which checklists either substitute for or complement a medical interview. For pediatric allergists who are trained primarily in pulmonary physiology and pharmacology, the checklist survey format might be the right start. It will assess limitations in activities, behavioral symptoms, and learning problems that might impact a child with asthma. These surveys, however, do not direct the clinician to the next set of questions, i.e., how can the symptoms and functional restrictions assessed by the survey translate into therapeutic benefits and what does the clinician do with the information?

Dr. Stein's commentary answers these questions in a refreshing, practical manner. Her approach, conceptualized as a biopsychosocial perspective, is summarized in the table. Strengths in the child and the family are discovered during an office visit; limitations are assessed in the context of the child's symptoms and behaviors with an understanding that a change in school, in the family, and in other daily activities might have a significant impact on asthma

control. Importantly, exploring and responding to the parents' and child's concerns is an early and critical step in the evaluation process. An assessment of the child's and family's perception of the "meaning" (or cause) of asthma is also useful in planning therapy. Knowledge of the patient's explanatory model of a disease will enhance patient-clinician communication and, potentially, compliance with recommendations.<sup>1</sup>

With the limited information in the case summary, it is difficult to assess the degree to which Peter's pediatrician and allergist initiated a psychosocial evaluation. That a vulnerable child syndrome is one concern is apparent; whether this was seen as significant for Peter is unclear from the case presentation. In addition, the physicians provided Peter's mother a written asthma management plan for maintenance and exacerbation of drug treatment. A recent prospective study of factors that impact on emergency room visits for childhood asthma concluded that a written management plan that guides parents on early intervention at home for asthma flare-ups is strongly associated with a reduced risk of adverse outcomes.<sup>2</sup>

Another direction to explore would be a history of Peter's behavior just before an asthma flare-up. The role of panic attacks in children with intractable asthma has been described. Hyperventilation associated with shortness of breath, chest pain or discomfort, and multiple autonomic symptoms characterize these children at the onset of an asthma episode. Some of these asthmatic children with panic attacks respond to pharmaceutical treatment, specifically benzodiazapines (clonazepam and alprazolam) and tricyclics (imipramine).<sup>3</sup> Finally, a recent review of psychosocial interventions for children with a variety of different chronic health conditions found positive effects for three educational programs designed to promote knowledge and self-management in childhood asthma.<sup>4</sup>

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