Death Due to Asthma in Children: What the Pediatrician Can Do

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Asthma is a common disease, occurring in 5% to 7% of children in the United States. Its prevalence and often mild clinical course have led to a widely held belief that patients do not die from asthma. Osler even stated in the early 1900s that "the asthmatic pants into old age." Actually, death due to asthma has been known to occur since the early days of medicine, with the problem described in medical writing since the 12th century.3

Rackemann's work in the 1940s and 1950s reacquainted the medical community with the reality of deaths due to asthma.4,5 In addition, he was the first author to note that death due to asthma could occur in children.5 Death in children, especially adolescents, has become a particular concern since the "epidemics" of asthma deaths that occurred in England and Wales in the 1960s6 and in New Zealand in the 1970s.7 Adolescent deaths have increased, as deaths due to asthma in younger children have decreased dramatically. Deaths in adolescents most often occur outside the hospital and therefore have not been affected by improvements in hospital care.

With the realization that death can result from asthma, research has focused on identifying risk factors and preventing deaths. The purposes of this article are to describe how patients can place themselves at high risk for dying by their behavior, to review features of physician care and the medical system that may place patients at risk, and to recommend an approach to individual patients that can effect a more favorable outcome. This approach to patients can also reduce morbidity from asthma, repeated emergency room visits, and hospitalizations.

**Characteristics of Patients Who Died**

Although patients of any age, sex, and race can die from asthma, there are differences for rates of death by race and sex.8,9 In the United States, blacks have a higher rate of death from asthma (2.1 per 100,000) than whites (1.2).9 Interestingly, this increased rate in blacks is mirrored by an increased rate in nonwhites (Maori and Polynesians) in New Zealand in the recent asthma death epidemic there.7 The death rate is somewhat higher for females (1.5) than males (1.2), although this difference has not been as constant over years as that between races.

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The foremost risk factor for death from asthma is severe disease. Although death is quite rare when considering the entire population of asthmatics, approximately 1% to 2% of severe asthmatics will die as a result of their disease.\textsuperscript{10,11} The asthma observed in these patients is clinically diverse; however, two general groups are apparent. The first group had a near death episode requiring resuscitation. Sudden severe asthma of this type may or may not be accompanied by ongoing severe symptoms. Twenty to thirty percent of patients who have died of asthma have had previous threatening events.\textsuperscript{12} The second group is those individuals who require corticosteroids for control of chronic severe symptoms.\textsuperscript{13} These patients may also have a history of hypoxic seizures, respiratory failure requiring ventilation, severe nighttime wheezing, or wide rapid fluctuations in pulmonary functions from normal to abnormal. Some patients do not fit into either classification and had extremely poor control of their asthma in the month before their death.\textsuperscript{14} Many were recently hospitalized.\textsuperscript{15}

Poor self-care, another major risk factor,\textsuperscript{13} is typified by missed appointments, incorrect use of medications, and poor knowledge of asthma. Disruption in the physician-patient relationship may result in disregard of the physician's instructions. This is particularly relevant when self-initiated reduction of steroids occurs. Also, inappropriate response to symptoms by either disregarding wheezing or using asthma to manipulate others increases the risk.\textsuperscript{13}

Psychological problems have often been noted in both the children and their families. In a study by Strunk et al,\textsuperscript{13} thorough evaluations of physiologic and psychological features were available for a group of 21 adolescents who died of asthma. Case controls were matched for age, sex, and severity of disease. Records for the 21 cases and 21 controls were evaluated for 43 physiological and 14 psychological criteria. Of these 57 variables, 14 were present in significantly different percentages in the group of children who died of asthma when compared with the controls. Eleven of the 14 differentiating criteria reflected the psychological adaptation of the child or the child's family with only three characterizing the physiologic status of the child or the severity of the asthma. The psychological variables were grouped into three clusters:

1. Self-management problems were apparent in three separate variables (disregard of perceived asthma symptoms, self-care inappropriate for the age of the child, and use of asthma to manipulate parents or teachers);

2. Poor family support for asthma management was apparent in difficulties in family cooperation with the medical plan (parent-staff conflict), more general examples of parent-child conflict (eg, fights over asthma treatment), and overall family dysfunction or crisis (eg, physical abuse and neglect, alcoholism, intense marital conflict, mobile family, fatalistic attitude, and inability to cope with financial difficulties);

3. Psychological problems of the children were apparent from a psychiatric diagnosis, observations of depressive affect and excessive sensitivity to loss or separation.

Wheezing with stress was noted more frequently in children who died in the controls. Furthermore, discriminant analyses indicated that the physiologic disease severity variables alone did not identify the patients who died unless there were also psychological difficulties present.

The importance of the psychological issues was also emphasized by a case-control study conducted by Rea et al\textsuperscript{15} in New Zealand in 1982. Patients (aged 15 to 60) who died from asthma were compared with those hospitalized for asthma in the same period. A history of life-threatening asthma attacks and psychological problems distinguished the two groups. The psychological problems included recent bereavement, unemployment, alcoholism, depression, and personality disorders.

The final patient characteristic mentioned by some authors is severe atopy. Investigators from the United Kingdom noted a predominance of deaths in the spring and fall when patients are atopic.\textsuperscript{16} Other authors have noted a history of a large allergen exposure immediately before the deaths of some patients; these patients appeared to die abruptly with rapid onset of severe bronchospasm.\textsuperscript{17,18}

These characteristics are translated into several issues that are apparent on the day of death. Many patients and their parents appear to have been complacent, thinking that the current attack would resolve just as the others had. Apparently, some of the parents had been told that death could not happen. Second, poor assessment of the severity of the attack by the patient and parent resulted in delays in contacting the physician. In many cases, reasons for delays are use of \( \beta_2 \)-adrenergic agents, which provide relief that is progressively less in both magnitude and duration. Third, the attack was poorly treated by the patients and parent, not only in the overuse of \( \beta_2 \)-agonists, but the underuse of corticosteroids. In addition, many patients seemed to be confused about what treatment to use. Finally, some patients have had a wish to die or a premonition of death.

The reasons listed as the basis of final outcome can be derived directly from the issues apparent on the day of death: the course of the attack appears rapid, often because early signs of worsening were not recognized, there is poor access to care, and the patients usually arrive late for the care.

The results of the case reports and the case-control studies suggest that patients with severe disease, particularly life-threatening attacks, are at high risk of death. Disease that is out of control, even in someone who otherwise has more mild illness, is probably an
important factor as well. Psychological factors are frequently mentioned, and many seem to focus on issues that may interfere with the delivery of care, especially in an emergent situation.

PHYSICIAN CARE AND THE MEDICAL SUPPORT SYSTEM

Physicians may place patients at risk by failing to diagnose asthma or failing to recognize severe chronic disease (Table 1). Rea et al found decreased use of objective measures of pulmonary function in patients, ie, pulmonary function tests or peak flow measurements. Shortcomings in supervision and education may result in repeated failure to contact physicians during exacerbations, to recognize severity of deteriorations, or to follow up with medical care.

Acute attacks require prompt attention. Studies have found that some physicians underestimate the severity of an attack, delaying admission or resulting in the inappropriate use of medications. Deaths in hospitals were almost all associated with poor monitoring, inappropriate drug use (especially corticosteroids), and use of sedatives. A case-control study reported by Eason and Markowe in 1987 of hospital care in the Northeast Thames region of the United Kingdom strongly supports the importance of quality hospital care in the outcome of asthma in some patients. Monitoring of the clinical course of the illness, especially with arterial blood gases, was more often deficient in fatal cases of asthma than in the patients who survived an episode of status asthmaticus.

Although some deaths cannot be prevented, common problems of underrecognition of asthma severity and delays in seeking care can be approached with current methods of care. Thorough evaluations should include some assessment of the severity of attacks and rapidity of onset.

RECOMMENDATIONS

A patient approach designed to prevent deaths has three components: educating both patients and parents about asthma, establishing a medical regimen to control the asthma, and scoring for high-risk status. When high-risk status is present, there should also be special planning.

Patient education is more than simply having the patient and family take an asthma education course. Although these courses are valuable, they are not all that is necessary. What is needed is ongoing follow-up, reinforcement of asthma education and, more importantly, its use. Patient technique with metered-dose inhalers should be checked at each visit, and guidelines for use of the drugs and potential adverse reactions (including possible problems of overuse) should be reviewed at regular intervals. Ongoing education intervention includes encouraging compliance, even when overall improvement is evident, by teaching each patient that asthma waxes and wanes over time but seldom completely disappears. Counseling should include the importance of prompt treatment of symptoms and physician contact to obtain supervision.

Like asthma education, the importance of establishing effective maintenance therapy is obvious. The effectiveness of asthma therapy must be confirmed regularly for all patients by both pulmonary function testing at each patient visit and by confirming that the regimen allows ongoing participation in activities of the patient’s choice and minimizes absenteeism from work or school. Since many patients assume that ongoing symptoms and inactivity due to exercise-induced asthma is their burden in life, simply asking if the patient is having problems with his asthma is insufficient. Detailed questions regarding the type and extent of exercise and school or work absenteeism must be asked regularly. Many authors recommend the use of mini peak flow meters at home to aid in detecting increasing airway obstruction so that appropriate therapy can be initiated early in the course of the asthma.

Patients should be scored for high-risk status (Table 2) and such a designation should initiate more frequent follow-up and special planning to treat features that result in high-risk status. There are at least two types of patients at risk: 1) patients with a single life-threatening episode of asthma, regardless of the underlying severity of the disease on an ongoing basis, even if all other circumstances are optimal; and 2) severe asthma of any type, especially if there are

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<th>TABLE 1</th>
<th>When to Refer to an Asthma Specialist and Questions to be Answered</th>
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| When to Refer | 1. Frequent use of systemic corticosteroids is required to control wheezing.  
2. The child has seasonality of symptoms or wheezing clearly associated with specific exposures to allergens.  
3. The child has asthma associated with loss of consciousness, a near death episode, hypoxic seizures, or respiratory failure requiring ventilation. Also if the child has required hospitalization or frequent emergency room visits for asthma. |
| Questions to be Answered | 1. Is there another diagnosis instead of or in addition to asthma that accounts for the difficulty in controlling the child’s symptoms?  
2. What are the precipitating factors for this child’s asthma?  
3. Suggestions for elimination of exposures to reduce symptoms.  
4. Is this child allergic? Are allergy shots indicated to help in control of the symptoms?  
5. Suggestions for drug management. |
TABLE 2
Questions to Ask to Identify a High-Risk Child

1. How severe is this child's asthma?
   A. Has there been a near death episode (sudden onset of asthma requiring resuscitation)?
   B. Have there been seizures (hypoxic) associated with asthma?
   C. Has the patient required ventilation for respiratory failure?
   D. Has there been loss of consciousness associated with asthma?
   E. Has there been frequent use of systemic corticosteroids to control wheezing?

2. Are the child and family compliant with the medical regimen?

3. How well controlled are asthma symptoms?
   A. Has the child been hospitalized for asthma in the last year?
   B. Has the child needed to go to the emergency room for acute asthma in the last year?
   C. How many days of school or work has the child missed because of asthma?
   D. Does this child's medical regimen adequately control asthma so that his lifestyle is unhindered by bronchospasm? Are there any activities the child does not participate in to prevent wheezing?

4. What is the child's and the family's attitude toward asthma?
   A. Are they aware of the severity of the disease?
   B. Do they disregard symptoms?
   C. Do they contact their physician during exacerbations?

5. Are there social problems that might interfere with the delivery of care for the asthma?
   A. Is there a consistent caregiver?
   B. Is the family disrupted?

6. Does this child have psychological problems?
   A. Has he recently expressed hopelessness?
   B. Has there been a recent personality change?
   C. Is there a recent onset of drug or alcohol abuse?
   D. Is the child depressed?
   E. Is the child suffering from a recent loss (e.g., death in family, divorce, stresses at school, geographic relocation)?
   F. Does the child use asthma to manipulate others?
   G. Does the child disregard asthma symptoms?

7. Are you aware of anger, frustration, or antagonism in yourself toward the patient or family?

accompanying psychosocial problems that could yield either poor communication, poor compliance, or hopelessness about the chronic illness. A list of possible psychological problems is presented in Table 3.

TABLE 3
High-Risk Psychological Variables

- Wheezing with stress—when the parents or physician considers stress a frequent precipitating factor for acute asthma episodes.
- Poor self-care—when the parents or physician state that there are regular problems with the child's ability to respond appropriately to asthma symptomatology and to attend to routine, prophylactic care.
- Disregard of perceived asthma symptoms—taking no action to respond to recognized asthma symptoms, such as not stopping exercise after clear wheezing had started; two or more clear instances of such behavior constitutes a positive score.
- Conflict between parent and physician, patient and physician, or patient and parent—positive if conflict is perceived by either the parent or physician. Conflict is defined as ongoing disagreement, frustration, or dissatisfaction with the performance of either of the persons involved.
- Family dysfunction—marital discord, parental support to children, parental drug or alcohol abuse, financial stability, and use of appropriate resources.
- Reaction to separation or loss—if the child frequently had developmentally inappropriate responses to separation from a parent or caregiver, or if there had been a significant loss from which the child had not recovered (e.g., death of a parent or sibling, loss through divorce or desertion).
- Emotional disturbance—if the child is referred for psychiatric treatment.
- Manipulative use of asthma—if the child uses asthma symptoms for secondary gain (e.g., to avoid unpleasant tasks, to pressure others to respond to his wishes). Two reported instances constitute a positive score.
- Depression—either a specific psychiatric disturbance (diagnosed on the basis of symptoms and functioning) or hopelessness/despair and an expressed emotional state of hopelessness, as well as direct or indirect references to suicide.

Special planning is required for the high-risk patient. These patients should be followed more closely, both in frequency and intensity. Features of their case that result in high-risk status should be treated specifically, for example, more intensive education for poor self-care and consideration of psychiatric referral for help in dealing with the psychological problems, especially for family dysfunction that could interfere with compliance with the medical regimen. In developing a plan for an overall approach to these patients, it is often useful to identify an advocate close
REFERENCES