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Review

Why Clinical Practice Guidelines Hinder Rather Than Help

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EDUCATIONAL AIMS

THE READER WILL COME TO APPRECIATE:

- that asthma is the major cause of hospitalization in children
- that current poor asthma outcome is a primarily a problem of health care delivery
- That asthma is generally well managed with decreased urgent care and hospitalizations when managed in specialty programs

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SUMMARY

Asthma is the leading cause of hospitalization among children. Recognition of inadequate control of asthma stimulated the development of Guidelines by an Expert Panel convened by the National Asthma and Prevention Program of the National Institute of Health. Those Guidelines with several revisions spanning 24 years were well-intentioned but ineffective at altering the continued high prevalence of urgent care and hospitalization among children with asthma. Meanwhile, there is strong evidence that specialists, with their greater clinical experience and knowledge have demonstrated excellent outcome compared with non-specialist care. It is time to recognize that there is strong evidence-based data that asthma specialty programs and not Guidelines disseminated to generalists alter the outcome of asthma.

CURRENT STATUS OF ASTHMA OUTCOME

Asthma continues to be the leading cause of hospital admission for children in the U.S. More than 5% of all pediatric admissions have a diagnosis of asthma based on two national databases, the Kids Inpatient Database (n = 2,684,000) and the Pediatric Health Information System (n = 512,945) [1]. Those databases also describe admissions for pneumonia at about the same frequency as asthma. Critical examination of pneumonia diagnoses by emergency care and primary care clinicians often finds abnormalities more consistent with viral respiratory infection induced lower airway disease, a common manifestation of asthma. [2–4] Our experience has been that 30% of young school-age asthmatic children have prior inappropriate diagnoses of pneumonia, often multiple. [5] These misdiagnoses both cause underreporting of asthma and the excessive use of antibiotics that children with asthma frequently receive. [6] Moreover, the prevalence of asthma at major children's hospitals has not been decreasing (Figure 1).

EFFECT OF THE GUIDELINES

These concerning statistics persist despite very detailed guidelines that purport to provide the methodology to improve asthma outcome. Practice guidelines for asthma by the National Asthma Education and Prevention Program (NAEPP) have been published in Expert Panel Reports beginning in 1991, [7] with several updates. [8–10] The most recent release is a 415 page Expert Panel Report. [10] There is reason to question if these Guidelines benefit patients, or if these well-intentioned efforts by the expert panelists represent an exercise in futility since their repeated efforts have had little impact on overall outcome.

An example of a well-intentioned but futile application of a specific component of the Guidelines was reported by the Joint Commission on Accreditation of Hospitals (JCAH) during examination of quality measures at children's hospitals. They found "moderate compliance" with provision of a home management

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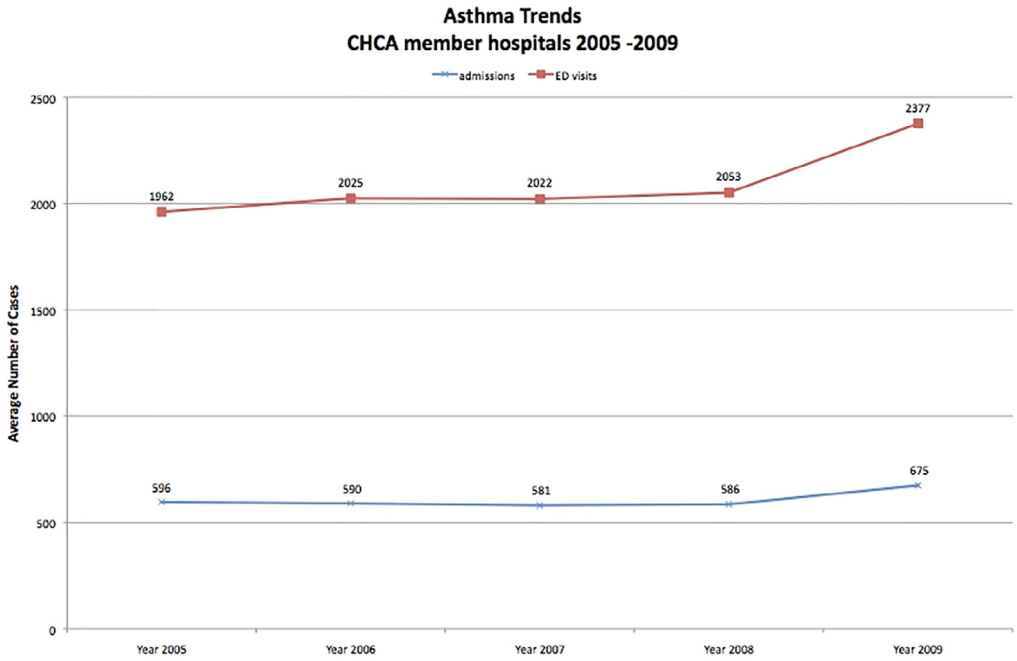

Figure 1. Asthma admissions and emergency department (ED) visits at the 40 largest children's hospitals (from Weinberger, Arch Pediatr Adolesc Med 2011;165:473-475). CHCA – Children's Hospital Corporation of America.

plan at discharge but no association between the provision of that plan and either subsequent asthma-related emergency care or hospitalization. [11] A report by Sheares et al [12] also reported no benefit from written action plans, but as I indicated in a letter to the editor, "the devils in the details." [13] Who wrote the plan and what did it say." There were no data to indicate that the instructions, verbal or written, had been subjected to critical assessment and demonstrated to be a valid and effective means of effecting asthma control. Simply following a Guideline therefore does not assure a successful outcome.

REALITY FOCUS: SPECIALIZED CARE PROGRAMS IMPROVE ASTHMA OUTCOME

But some specialized programs, even some preceding the Guidelines, have been associated with outcomes to which the Guidelines aspire but have not attained. In contrast to the apparent overall failure to improve the outcome of asthma during the 24 year period since the Guidelines were developed and disseminated, specialist-based care programs have demonstrated successful asthma control with decreases in urgent care and hospitalization even prior to publication of Guidelines. In 1990, a report was published of 47 inner-city adult patients with troublesome asthma at Bellevue Hospital Center in New York who were randomly assigned to an intensive subspecialty directed outpatient program. Their outcome was compared with 57 patients continuing to receive routine care at the same institution. [14] A 3-fold decrease in readmission was observed in the subspecialty group during 8 months of follow-up compared with those who continued with routine care. An even earlier study demonstrated substantial difference in outcome for adult patients admitted to a U.K. Health Service Hospital. [15] The admitting physician at the hospital alternated between a pulmonologist and a general internist. When the pulmonologist was the admitting physician, the asthmatic was admitted to a pulmonary unit, while on other days patients with asthma were admitted to a general medical unit. Ten-fold fewer readmissions occurred the following year among those admitted by the pulmonologist than among those admitted by the general internist.

Specialty programs have subsequently been quite successful at demonstrating that asthma outcome in children can be substantially improved where comprehensive care is provided by experienced and knowledgeable personnel. This was demonstrated in a controlled trial of 80 children, ages 2-16, on Medicaid in Norfolk Virginia, who were randomly assigned to remain in the general pediatric clinic or assigned to the allergy clinic at the Children's Hospital of the King's Daughters. [16] That study demonstrated more than a 2 fold decrease in ER visits and more than a 3 fold decrease in hospitalizations when compared with those who remained in usual care at the same institution.

A more recent publication demonstrated even greater improvement in asthma outcome in an inner-city pediatric population. This was accomplished by providing specialty-based asthma care in mobile asthma clinics designed to reduce barriers to delivering effective asthma care. [17] Comparing pre- and post-year data, a 66% reduction in ER visits, 84% reduction in hospitalization, and substantial reduction in days of missed school were described.

HOW DOES A SPECIALIZED ASTHMA CARE PROGRAM MAKE A DIFFERENCE?

It has been my impression that specialists are likely to know more about this complex chronic disease, with its variable clinical presentation and often unpredictable fluctuations in symptoms, than those who don't specialize in asthma. Specialists are more likely to monitor the clinical course whereas generalists may be more oriented to seeing the patient primarily when symptomatic. Specialists are more likely to use measurements of airway function for capable patients and be more familiar with the various medication options and gadgets used for aerosol delivery. Specialists will also be more likely to demonstrate the use of specific aerosol delivery devices and assure that the patient can successfully receive the aerosol medication. At a specialty center,

medication instruction is likely to be tailored to the individual based on an assessment from a clinician with experience and knowledge of asthma. [18]

THE PROBLEM

Consideration of how specialist care differs from non-specialist care explains why the prodigious efforts by the NAEPP Expert Panels are not effective. The problem relates to the complexity of the disease we call asthma and the expertise and experience that appears to be required to favorably affect the outcome, particularly for patients with more severe asthma. No disease can be treated adequately if it is not first diagnosed and characterized. The complexity and challenge of defining asthma, particularly in young children, has been discussed extensively by Sears. [19] That complexity is a result of the multiple clinical patterns of airway disease that are recognized as asthma. So asthma can now be defined as a disorder characterized by several phenotypical clinical patterns. While they share a common end-organ abnormality of airway responsiveness and airway obstruction, treatment is not a one size fits all decision.

SINCE THE GUIDELINES DON'T HELP, DO THEY ACTUALLY HINDER?

An often stated cliché is the definition of insanity: doing the same thing over and over again and expecting different results. There is no reason to expect that continuing to treat asthma, as has been done for the past 24 years, with mandates to primary care physicians to "follow the guidelines" will change the relatively static statistics. [20] The various phenotypes of pediatric asthma are generally highly responsive to appropriate management by knowledgeable, skilled, and committed health care personnel. The current status of the high rate of emergency care and hospitalization at major children's hospitals in the U.S. is a function of ineffective health care delivery, not an inherent lack of data or effective therapy.

We are long overdue to recognize that Guidelines, no matter how detailed and disseminated, cannot substitute for experienced and knowledgeable clinicians, especially if supported by a team of health care professionals committed to patient education and monitoring. The need for specialized programs for adults and children with asthma who require urgent care and hospitalization has recently been recognized in the U.K. [21] The published evidence supports development of specialty care centers if the national asthma statistics are to be improved.

Continuing to emphasize Guidelines rather than encouraging development of specialized care programs, especially at children's hospitals, has certainly not improved overall outcome of asthma and has, in fact, hindered progress in improving delivery of care to children with asthma. In fact, 24 years of promoting Guidelines to be used by those without the experience and sophisticated knowledge to manage troublesome asthma has hindered progress in decreasing urgent care, hospitalizations, and even the occasional fatalities in children. The solution is to improve health care delivery for asthma by providing specialist care programs, at least for those not meeting criteria for control in primary care.

FUTURE DIRECTIONS TO IMPROVE ASTHMA OUTCOME

- The development of specialist asthma care centres
- Mandatory asthma management experience with specialist pulmonologists in general pediatric specialist training programs

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