The Hidden Value of Variation in Practice

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Although new disease modifying therapies offer promise, current management of cystic fibrosis (CF) lung disease is largely based on 2 strategies: first, decreasing the day-to-day burden of inflammation and mucus in the airways and, second, managing pulmonary exacerbations: acute episodes of increased symptoms thought to reflect periods of inflammation associated with bacterial infection. A mainstay of treating CF exacerbations has been using ≥1 intravenous antibiotics in the hospital accompanied by supportive measures, including intensified airway clearance. Investigators using the Epidemiologic Study of Cystic Fibrosis[1] and the Cystic Fibrosis Foundation (CFF) Patient Registry[2] have previously pointed out variation in CF care practices, particularly in therapies used for outpatient care. In this issue of *Pediatrics*, Cogen et al[3] ("Characterization of Inpatient Cystic Fibrosis Pulmonary Exacerbations Using the Pediatric Health Information System Database") use a novel data source from children's hospitals to document surprising variation in many aspects of the inpatient management of CF exacerbations among 38 children's hospitals participating in the CFF Care Center Network.

Why is there such variation in inpatient care for CF exacerbations among centers in a network that encourages best practices? Some variation may represent predictable differences among centers. Variation among centers in patient age or stage of disease, bacterial sensitivity patterns, and insurance coverage probably contribute. For instance, the length of inpatient stay might be affected by pressure from families or managed care organizations to complete therapy at home.

An important source of variation is the lack of evidence of the optimal treatment of exacerbations. Although consensus guidelines for pulmonary exacerbations were published in 2009,[4] they largely served to point out the weak evidence base for treatment approaches used historically. There are few convincing data on such important issues as when signs and symptoms justify intravenous antibiotic therapy, the optimal monitoring of response and length of therapy, or the choice of antibiotics.

Cogen et al[3] point out that the variation they identified in the management of CF exacerbations may represent an opportunity for improvement. The idea of reducing variation as a path to improvement will not be new to CF providers. The CFF has supported CF Centers for over 15 years in embracing improvement science. Dr. Gerald O'Connor, who played a central role in those efforts, was among the first to apply to CF care the concept of "variation as a treasure."[5]

Standardization of CF exacerbation management at a national level is likely to depend on more specific evidence-based guidelines. In some areas, current research is promising. In the future, choice of antibiotics and the initiation and timing of therapy may be based on techniques of assessing the entire CF airway microbiome (including anaerobic organisms) by using methods that

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do not have the limitations of sputum cultures. On the other hand, although the CFF Therapeutic Development Network has become a model for developing novel CF therapies, questions raised by the consensus guidelines have been largely ignored, in part due to a lack of pharmaceutical company investment. Many questions regarding "best" inpatient treatment could be answered by support for an inpatient trial network that treated every pulmonary exacerbation as an opportunity to learn and improve care by systematically examining outcomes (and cost).

Many of the benefits of standardization, however, need not wait for additional research and national consensus. At a local level, the recognition of variation in care processes can lead to improved efficiency and effectiveness of care even (and, perhaps, particularly) when convincing evidence for best practices is lacking. Variation is amplified by differences in practice style among CF providers. In many centers, CF patients are assigned to a specific provider who decides all aspects of care, including antibiotic choices and length of hospital stay; other centers use a team approach with multiple providers practicing from the same "playbook." In such centers, providers as a team compromise personal preferences, agree on protocols and reasonable approaches, and cooperate to develop their playbook.[6] This might include efforts to standardize the definition and recognition of exacerbations, the choice of antibiotics (based on local microbiology and sensitivity patterns), the appropriate monitoring and length of therapy, a role or lack of role for corticosteroids, and what to do when a patient does not improve as expected. Such standardization at the local level will have benefits because patients, providers (including those covering for weekends and vacations), house staff, nursing staff, and allied professionals will all have a clear concept of the process and their roles. In the best of worlds, when centers are able to decrease variation locally, differences in outcomes between centers might inform and accelerate studies to determine best practices.

Former Speaker of the House, Tip O'Neil, was fond of saying, "All politics is local." The same thought is true for improving our clinical practices.

ABBREVIATIONS

CF: cystic fibrosis
CFF: Cystic Fibrosis Foundation

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