IMPROVING SUBSPECIALTY HEALTHCARE: LESSONS FROM CYSTIC FIBROSIS

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Citing numerous studies that showed deficiencies in the utilization of evidence-based treatments and large variations in the outcomes of care, the Institute of Medicine concluded in 2001 that "Between the health care we have and the care we could have lies not just a gap, but a chasm."[1] A recent report from the Commonwealth Fund makes it clear that comparable quality problems exist in healthcare delivery for children and adolescents, including those with chronic disease.[2]

There are an estimated 15 million children in the United States with complex or serious medical problems requiring pediatric subspecialty attention. Although pediatric subspecialists care for a number of conditions whose treatment is uncertain, for many diseases there are specific aspects for which an optimal therapeutic approach has been identified (either by evidence or expert consensus). In these cases, patients are best served by attempts to ensure that their medical care is provided in a systematic and uniform way. Recent analyses of data from the Children's Oncology Group and the Vermont-Oxford Neonatal Network suggest that the value of these research consortia, which were established primarily to expedite enrollment of subjects into clinical trials, extends beyond research alone. In fact, the standardization of care that results from the use of research protocol-based regimens facilitates the application of optimal treatment approaches and reduces practice-to-practice variability, thereby improving outcomes in control as well as intervention groups.[3,4]

The system that has been evolving for the care of children with cystic fibrosis (CF) offers an example of how subspecialists can organize and share knowledge that leads to significant improvements in outcomes. In this report, we provide an overview of the components of the CF system, discuss the central role played by the CF registry in showing variation of practice patterns and outcomes, and discuss how the use of collaborative methods can be applied within such a system to support the consistent application of optimal approaches to care. We believe that the CF system provides an example that may be applicable to other pediatric subspecialties that wish to take better advantage of existing knowledge to improve health outcomes for the children for whom they care.

See editorial, p 279 and related articles, p 302, p 306, p 312, p 316, p 321, p 327, p 332, p 396, and p 402.

CYSTIC FIBROSIS

Treatment advances have dramatically improved patient survival since CF was first described in 1938 (Figure 1), changing the face of the disease in a relatively short period of time.[5-7] The median predicted survival age was 33.5 years in 2003, and about 40% of patients with CF are currently over the age of 18. Nonetheless, there is considerable variability in age at death among the CF population (Figure 2). Much of this variation can be explained by individual patient differences in genetic constitution and environmental or sociodemographic exposures,[8] but there is a growing appreciation of the degree to which average patient outcomes differ among accredited CF care centers[9] (Figure 3). There are, in fact, some centers that achieve uniformly superior results across all performance measures. These centers are not necessarily the largest or best known, they differ in size and geographic location, and they do not share a specific unique treatment method. What they have in common is a highly developed system of care that is well adapted to local conditions and allows the consistent and methodical application of therapies based on the best evidence available.[10]

System of Care for Children with CF in the United States

Much of the care for children with CF in the United States takes place within centers accredited by the CF Foundation (CFF).[11] The CFF was created in 1955 by a consortium

CF	Cystic fibrosis	CFF	Cystic Fibrosis Foundation

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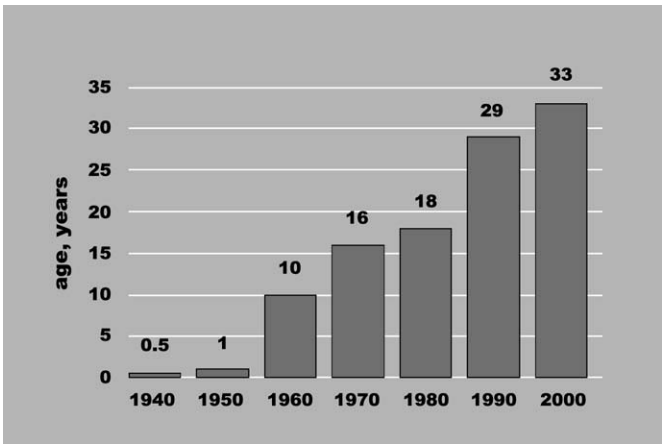

Figure 1. Median age at death of patients with cystic fibrosis, by year.

of parents and physicians with the initial primary goal of encouraging CF-related research, but it quickly broadened its mission to support clinical care and foster teaching about the disease.[12] The CFF has grown tremendously over the years in resources, and its influence is pervasive. It guides the research agenda by interacting with the National Institutes of Health, and, more recently, industry, to solicit and fund a significant portion of all CF research, and it works to ensure the general availability of high-quality medical care for patients with CF through its accreditation system.

There are currently nearly 120 CFF-accredited CF care centers in the United States. Accreditation requires an on-site evaluation to ensure the presence of a multidisciplinary provider team, which includes subspecialty physicians, nutritionists, social workers, respiratory therapists, and physical therapists, as well as adequacy of microbiologic techniques, sweat chloride testing, and other care practices. As survival into adulthood has become commonplace, the CFF has been a strong advocate for the establishment of adult CF care centers to complement existing pediatric clinics, and there are now more than 90 approved adult care programs. Furthermore, the CFF supports the spread of knowledge regarding state of the art care by sponsoring the development of clinical practice guidelines and organizing the annual North American CF conference, which brings together healthcare providers and researchers from all disciplines to an annual assembly with strong international participation. The multidisciplinary "networking" facilitated by the NACF meeting leads to the rapid spread of innovative ideas for care; past examples include the adoption of high fat diets in the 1970s and of more aggressive treatment of Pseudomonas airway infection in the 1990s. These novel approaches, initially advocated by a small minority, were then rapidly adopted by the mainstream of CF care centers as word of successes was shared among colleagues.

National CF Patient Registry

A national patient registry containing demographic and clinical data on patients attending accredited care centers in the United States was begun in the mid 1960s; its content

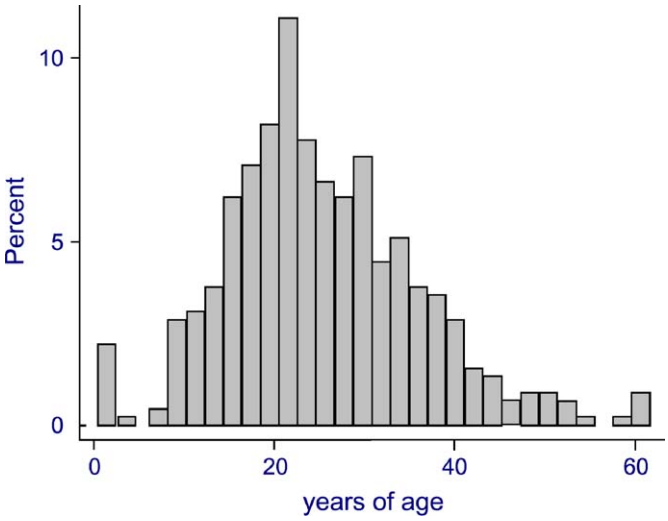

Figure 2. Distribution of age at death for patients with CF dying in 2001 as listed in the National CF Registry.

and use have evolved over the years. It was initially used to generate basic descriptive data regarding the CF population, for example, average age of diagnosis, survival, and microbiologic information, but in the last decade it has been increasingly used for analyses by epidemiologists seeking to identify risk factors and generate hypotheses regarding disease pathogenesis. In its earliest form, the registry was used to show improvements in mortality rate among centers that had evolved a comprehensive treatment program for CF care, which facilitated the spread of this approach.[13] However, comparisons of outcomes between care centers were deemphasized until 1998, when Gerald O'Connor, a health services researcher with experience in quality improvement, was engaged to perform analyses of the Registry data. Current registry reports now display patient data in ways designed to raise awareness of center-based differences in practice patterns and outcomes (Figure 3 and Figure 4 are examples) and have thus transformed the registry into an important tool to promote quality improvement activities. The registry is now evolving further into a visit-based, web-enabled clinical information system that can provide care centers with data for monitoring individual patients as well as well as feedback on aggregate center performance of procedures and outcomes.

VARIATION IN CARE IS ASSOCIATED WITH VARIATION IN OUTCOMES

Reports from both the CF Registry and the Epidemiologic Study of CF (ESCF), an industry-sponsored patient registry that operates independently of the CFF, demonstrate that patients with CF do not consistently receive optimal care. For example, although the CF Foundation has formulated relatively conservative guidelines for the regular monitoring of clinical status (timing of clinic visits, pulmonary function testing, airway cultures, and so forth), these routines are followed in only 58% to 79% of patients.[14] Furthermore, surveillance and treatment intensity varies dramatically among

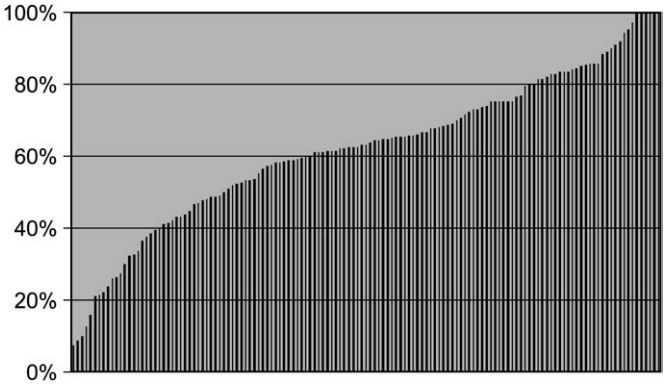

Figure 3. Percentage of patients with weight below the 5th percentile receiving supplemental nutritional feedings at each CF care center with >50 patients. Each vertical bar represents one CF center. Centers with <50 pediatric patients are not shown. The mean for all centers is 61.9% ± 21.3%.

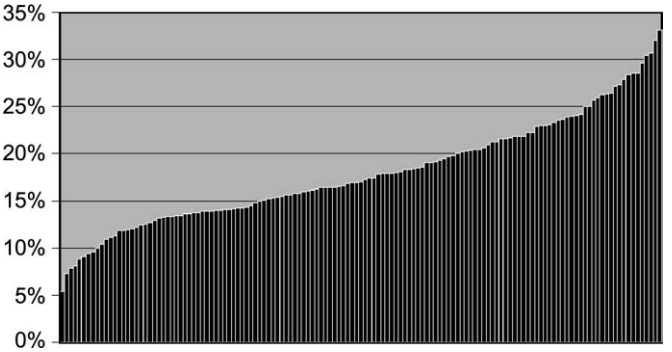

Figure 4. Percentage of patients below the 5th percentile for weight at each CF care center with >50 patients. Each vertical bar represents one CF center. Centers with <50 pediatric patients are not shown. The mean for all centers is 18.0% ± 5.6%.

different CF care centers, and those sites with the highest median age-adjusted pulmonary function generally monitor patients more consistently and prescribe more courses of intravenous antibiotics than other centers.[15]

The CF Registry provides other examples to illustrate this point. High calorie nutritional supplements are of proven benefit for improving weight gain in pancreatic-insufficient patients with CF.[16] Yet, centers' reported rate of use of nutritional supplements in patients who are below the 5th percentile for weight varies from 7% to 100% (Figure 3). It is not surprising that this variability in the use of dietary supplements is mirrored by variation in nutritional outcomes: Some CF centers have very few children below the 5th percentile for weight, and others have a prevalence in excess of 40% (Figure 4). It is important to point out that these differences in weight are not explained by case severity mix. Center performance can be adjusted for the prevalence of patients with high-risk characteristics, but when this is done, the variability in outcomes remains wide and the relative center performance changes minimally.[17] Furthermore, there is no evidence that centers with better outcomes have greater knowledge of CF care than others. All of the centers represented in the figures are CFF-accredited care centers with subspecialty physician directors supervising a knowledgeable multidisciplinary specialty team as mandated by the CFF. Furthermore, centers that might be expected to have greater expertise, either because they are large and have broader experience or because they perform more CF-related research and thus might be considered more "academic," do not necessarily stand out as superior performers in the CF Registry.[17]

Clinicians who care for children with a devastating illness such as CF are passionately committed to providing the best care possible, and the suggestion that this might not be the case is disconcerting. A major value of the CF Registry is that the data are good quality and representative of the entire CF population at each center, thus making it relatively easy to counter the initial defensive protests that data problems account for the observed variation. Furthermore, data are supplied by center clinicians, who thus bear responsibility for the accuracy and are motivated to maintain it at a high level. Longitudinal analysis of CF Registry data shows that patients with CF cared for at certain centers consistently have short-term and long-term outcomes that are significantly better than the national average (unpublished data). The implication is that if the methods used at these centers were adopted by others, the result would be a dramatic and relatively rapid improvement in life expectancy and quality of life for all patients with CF. Although the response among CF healthcare providers has been mixed, most have accepted this as a call to action, and the CFF has begun actively testing methods of accomplishing this goal.

Application of Methods for Improving Outcomes

Traditional CME activities focus on individual clinicians attending didactic sessions, in the belief that knowledge will somehow lead to improvements in practice and consequently to improved patient outcomes. Studies of the effectiveness of such efforts confirm that they rarely achieve their intended goal.[18,19] Multifaceted, health care systems–oriented approaches to changing the process of care delivery at multiple levels are more effective in improving outcomes than passive approaches.[19,20] Several recent, randomized trials have demonstrated the efficacy of teaching provider teams continuous quality improvement methods to adapt evidence to their local practice setting.[21,22]

Recognizing this, the CFF has begun to establish an infrastructure to promote the development and spread of quality improvement methods within the CF community and to train centers in their application. The foundation is funding its own "Learning and Leadership" collaborative projects involving care centers from around the country, as well as two major external initiatives: the Northern New England CF Consortium, and a "Breakthrough Learning Collaborative"[23] supported by the University of North Carolina's Center for Children's Healthcare Improvement (NC CHI) and the National Initiative for Children's Healthcare Quality (NICHQ). The CFF is also working with Cincinnati Children's Hospital Medical Center, which is the recipient of a "Pursuing Perfection" grant from the

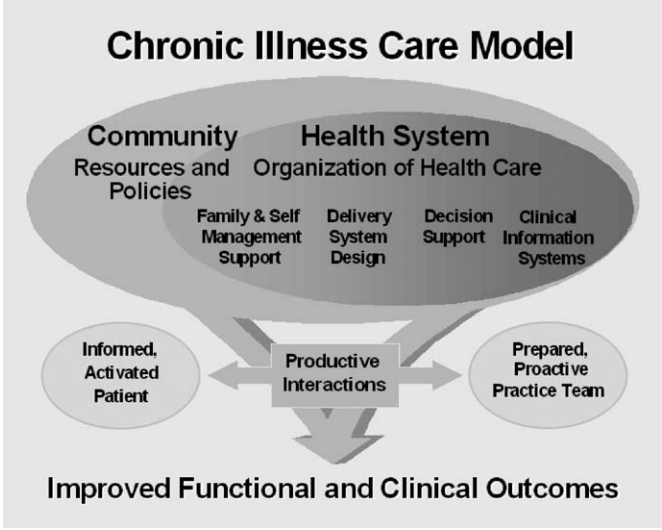

Figure 5. Wagner's chronic care model envisions provider teams and patients interacting in an environment where community resources and policies exist alongside and foster a healthcare delivery system that provides self-management support, an efficient delivery system design, decision support for providers, and a clinical information system that allows tracking of healthcare data on the individual patient and also on the aggregate population served by the provider team.

Robert Wood Johnson Foundation to improve care throughout the institution, with CF as one of the targeted conditions.

These projects all have their own specific approaches that may have differing emphases, but all build on the following theoretical and methodological principles of quality improvement.[24]

1. *Appreciate that changes must be made to the system of healthcare delivery.*

   The first step, and one that is often the most difficult for physicians, is to understand that simply working harder within a nonsupportive system will not yield the results desired. We depend on the functioning of a healthcare delivery system whose complexity has increased exponentially as growth in technology has accelerated, and chronic disease care comprises an increasing proportion of our clinical activities. The archetype of the individual physician who by force of intellect and will establishes the correct diagnosis and prescribes the appropriate therapy to cure a patient is anachronistic and inappropriate to the contemporary realities of providing care for children with chronic disease. Multiple caregivers must communicate and integrate a complex set of data and then prescribe therapy, based on the appropriate use of that data. Although it is incumbent on the system to ensure that providers are knowledgeable regarding ideal (or best) practices, it further needs to support consistent application of those interventions that the providers know to be optimal. Variation in outcomes (when adjusted for variation in risk) is then due to variation in the system's ability to provide this support in a consistent manner.[1]

2. *Work with an appropriate model of chronic care delivery.*

   The current healthcare system evolved out of one that was initially established to provide acute, episodic care. At this time, chronic conditions affect almost half of the US population and 18% of children,[1,25] and are the main focus of pediatric subspecialty care. Yet, there remains a dearth of clinical programs with the infrastructure required to provide the full complement of services needed by children with chronic disease.[26] Physician groups, hospitals, and other health care organizations often provide care with incomplete information about the patient's condition, medical history, services provided in other settings, or medications prescribed by other clinicians. To optimize the care of children with chronic disease, it is useful to conceptualize and work toward instituting an idealized system of healthcare delivery that is composed of several interdependent components inside and outside the practice setting. Furthermore, patient visits should be considered within a long-term continuum and not as isolated and independent events. Wagner's chronic illness care model provides a useful framework for such care[23] (Figure 5). A more detailed explication of this model may be found at http://www.improvingchroniccare.org, but the following highlights are important:

   a. *Community Resources*

      Medical center–based subspecialists should partner with community organizations and primary care providers to supply needed services to patients. In addition, providers should publicly advocate for social policies that improve access to healthcare resources.

   b. *Overall Health Delivery System*

      Organizations should create a permeating culture that promotes safe, high quality care. There should be an open and systematic approach to reducing errors and incentives rewarding high quality care. Care should be coordinated within and across organizations.

   c. *Patient and Family Self-Management*

      When patients and families are informed and empowered as partners in care, they become an enormous resource for assessment, goal setting, and treatment planning. Furthermore, patients' input should be sought in reconfiguring delivery system design to make it optimally effective.

   d. *Delivery System Design*

      Delivery system design includes the structure and function of the clinic, from the telephone to the reception area to the examination room. Team members should have clearly defined roles and responsibilities and ensure that clinic flow is optimized, patient visits are planned to accomplish specific goals, and appropriate follow-up is ensured.

   e. *Decision Support*

      Decision support promotes the application of evidence-based care at the provider-patient interface. This is accomplished through the use of guidelines and algorithms, clinical tools to ensure that reliance on rote memory is minimized, and intended care is actually prescribed.

f. Clinical Information Systems

Clinical information systems function at two levels. For individual patient care, the system should provide ready access to data relevant to care decisions, provide timely reminders regarding routine interval care, and facilitate sharing of data to coordinate care. At the clinic-wide population level, the system should help to identify relevant subpopulations for proactive care and allow providers to monitor performance of the practice team. It is the lack of the latter data that keeps many providers in the dark regarding the true effectiveness of their care.

When informed patients take an active role in managing their health and providers feel prepared and supported with time and resources, their interaction is likely to be much more productive.

3. *Test small changes sequentially and then spread the effective ones.*

An effective organizational change strategy is an essential component of improvement work. Without a disciplined approach, practitioners who are newly aware of the extent of their system's deficiencies will often attempt immediate, dramatic changes that either fail in their planning stage because they get bogged down in endless preparatory meetings, or self-destruct in their implementation phase because of the number of unanticipated problems encountered. Use of the Plan/Do/Study/Act (PDSA) cycle is an approach of proven effectiveness.[27] To implement the process, the first step is to plan the details of a small test of change [plan]. The planned change is then carried out [do]. Once the change is attempted on a small scale, data on its effectiveness is gathered [study]. After discussion of what was learned by the initial endeavor, the change strategy is then modified and reattempted [act]. The repeated use of PDSA cycles provides a scientific basis for testing theories and identifying effective methods that accomplish meaningful improvements in care. The essential key to the success of this approach is the use of small changes that are easily accomplished, followed by the analysis of data to evaluate the impact of the intervention.

4. *Use data to get feedback on the effectiveness of the work.*

The use of data on performance is essential to recognize where opportunities for improvement exist and to garner feedback on what changes truly result in improved outcomes. Once an organization decides to implement specific actions to improve outcomes, it needs to track the consistency with which those actions are taken. Improved performance on these process measures can be measured as a preliminary step to improvement in the outcome measures that are the true goal of the work. Process measures should be selected to be sensitive reflectors of whether effective change is taking place. Feedback must be provided promptly and on a regular basis, and data should be reported visually in a way that can be understood and used by members of the care team as well as interested outsiders.

Table. Specific goals of the collaborative

Nutrition
- Process goals: At >95% of visits
  - Nutritional status classification is verified
  - Self-management goals regarding diet and use of pancreatic enzymes are reviewed
  - Patients with less than satisfactory nutritional status are documented to have received appropriate evaluation and intervention as described in the 2002 Consensus guidelines
- Outcome goals
  - 50% reduction in the proportion of children with less than satisfactory nutritional status
  - 30% increase in centers' median weight percentile

Environmental tobacco smoke
- Process goals: At >95% of visits
  - Parents' smoking status is documented
  - Patients receive counseling on elimination of environmental tobacco smoke exposure
  - If a smoking parent is present, caregivers utilize the NCI 5A model to help promote cessation
- Outcome goals
  - 95% of patients' families report a clear no smoking policy in their environments
  - 20% of smoking parents quit

5. *Collaborate, and "steal" good ideas shamelessly.*

The synergy that derives from collaboration among workers investigating the same problem is well known to scientific researchers, the most successful of whom are typically embedded in networks of cooperating laboratories within and outside their home institutions. This strategy is equally effective for the development and spread of innovations for improvement in the delivery of health services. The most commonly used cooperative model is one that seeks to identify "best practices" as a means of finding ideas that can be adapted from providers whose outcomes are the best within their field. However, novel, effective ideas for how to accomplish certain specific goals exist even at centers whose overall performance is average, especially if they are actively striving to improve their outcomes. Thus, collaboration among various centers and healthcare workers who are trying to accomplish the same or similar goals is an important and effective strategy to accelerate change.

One Example: The "Breakthrough Learning Collaborative" to Improve CF Care

Collaboration and data sharing underlie the recent development of "breakthrough series" collaborative learning methods, in which multidisciplinary teams from various sites assemble to work together on a problem of common interest.[22,28-30] Teams review the evidence for recommended care practices, are provided with decision support tools, study changes that have proven effective at other sites, and receive training in the quality improvement methods outlined above.

Teams set measurable targets, track their performance, and compare results to gain insights about potentially useful changes. Participants are provided with performance feedback and help in its interpretation and receive ongoing support from medical specialists and experts in medical system improvement. The key aspect is the sharing and collaboration that takes place among sites that are working simultaneously on the same goal: When an effective strategy is discovered by one, it is immediately shared and others have the opportunity to adapt and build on it. The eventual goal is the development of techniques that may then be disseminated throughout the provider community.

The NC CHI/NICHQ CF collaborative chose to focus on improving nutrition and eliminating environmental tobacco smoke exposure in our patients. These goals were chosen because there is clear and convincing evidence that their achievement would improve lung function, the major cause of morbidity and mortality in CF,[7,31-34] and because interventions of proven effectiveness to meet those goals are currently used in an inconsistent manner.[16,35-44] These two goals differ significantly, however, regarding their familiarity to CF care providers. In the case of nutrition, all CF centers have traditionally emphasized its importance and have considerable expertise and experience in its promotion. However, very few have previously considered the importance of intervening to reduce environmental tobacco smoke exposure. Most pediatricians are unfamiliar with smoking cessation counseling and ambivalent about their role in supporting it, particularly because of the need to develop a therapeutic relationship with the smoking parents rather than the patient.

With funding and assistance from the CFF, interested CF care centers from around the country were solicited for participation in this project, and 15 centers joined in the collaborative. This group is diverse in relation to geographic distribution, size of clinic population, and academic and research orientation and baseline performance on nutritional measures. Teams have been trained in the key strategies at "learning sessions," supplemented by regular conference calls and a listserv that allows ongoing discussion. The specific goals of the collaborative are shown in the Table. Significant progress is being made, as reported in preliminary form at NACF meetings.[8,45]

CONCLUSIONS

In its report, *Crossing the Quality Chasm*,[1] the Institute of Medicine identified problems in the system of health care delivery rather than deficiencies in individual physicians' practice as the major impediment to attaining quality health care for all Americans. Effective interventions are available to slow or reverse the progress of many chronic diseases of childhood, and our patients are best served by ensuring that they consistently receive indicated treatment. Variations in disease outcome are a reflection of inconsistency in the application of evidence-based therapies that should be received by all patients.

Although this perspective represents a significant break with the traditional view, it should allow physicians to feel liberated rather than threatened. If a system is in place that ensures that intended routine treatments are reliably provided, then physicians can focus their attention and creativity on the more challenging diagnostic and management problems for which they may currently have insufficient time. Furthermore, methods that ensure the consistent provision of evidence-based therapies for patients with currently incurable diseases such as CF will typically lead to significant improvements in outcomes based on current clinical science while patients and their physicians await future advances in care provided by biomedical research.

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