

Creating a Culture of Improvement

Experience of a Pediatric Cystic Fibrosis Center

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Quality improvement (QI) efforts at the University of Alabama at Birmingham/Children's Hospital Cystic Fibrosis Center began in the spring of 2004, with a collaborative sponsored by the Cystic Fibrosis Foundation. As the authors gained experience with QI processes, significant system changes ensued. In this article, we describe how the center created a culture of improvement that has resulted in significant improvements in clinical outcomes in our patient population. **Key words:** *clinical outcomes, collaboration, cystic fibrosis, quality improvement*

CYSTIC FIBROSIS (CF) is a genetic disease affecting approximately 30,000 children and adults in the United States. The median life expectancy of CF patients has improved from early childhood, when first described in the 1940s, to the mid-30s today. The improved survival has been the result of continuous advancement through biomedical research and the development of clinical practice guidelines for the care of CF patients. In this regard, the Cystic Fibrosis Foundation has been instrumental in supporting research and clinical initiatives.

In addition, for more than 50 years, the Cystic Fibrosis Foundation has maintained a detailed data registry of more than 100 accredited CF centers. This registry reveals a

wide variation in 2 key clinical outcomes indicators: the rate of pulmonary function decline and percentage of malnourished patients. Analysis of the registry also reveals wide variation in the use of pulmonary and nutritional therapies. To decrease this variation, the foundation is committed to accelerating the rate of improvement of clinical care through the development of training grants in the form of a quality improvement (QI) collaborative known as the *Learning and Leadership Collaborative* (LLC). The yearlong collaborative is led by faculty from the foundation and Dartmouth Medical School Center for Evaluative Clinical Science. Its key strategies include (a) building a shared vision of exemplary care, (b) developing leadership, (c) identifying and enabling best practices, and (d) providing decision support for front-line clinical care teams.¹

This QI initiative fosters the development of clinical microsystems, small, functional frontline units that provide healthcare. The University of Alabama at Birmingham/Children's Hospital (UAB/CHS) Cystic Fibrosis Center, a Cystic Fibrosis Foundation-accredited center caring for more than 400 patients, considers itself a clinical microsystem. The center microsystem includes

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physicians (pulmonologists), advanced nurse practitioners, clinic nurses, other clinicians (nutritionists, social workers, respiratory therapists, and pharmacists), administrative support personnel, a data manager, and patients and families. The center is involved in all aspects of inpatient and outpatient CF care as well as education and research.

In spring 2004, the center applied for and was awarded an LLC grant as 1 of 14 centers in the second group of participants in the LLC. The collaborative adapted business models of QI to healthcare. Each team involved in this training chose an area to improve patient outcomes. The clinical goal chosen by the UAB/CHS team was to improve assessment and outcomes of nutritional status, consistently prescribing the most appropriate therapies for patients with nutritional failure.

With this objective, the center assembled a 3-member team (the authors) charged with the QI initiative. For the last 3 years, this effort has led to a comprehensive diagnosis of how care is delivered, with the many limitations and shortcomings of the old system, and has identified and prioritized specific actions that have resulted in a significant improvement in our patients' clinical outcomes. However, equally impressive has been the creation of a culture of improvement, an environment in which all team members take responsibility for improvement and have the freedom for innovation.² This culture has developed as the 3 members, who participated in the LLC, have shared QI techniques and results with the larger CF team, administration, patients, and families, as well as team members beyond the microsystem core team.

LEARNING AND LEADERSHIP COLLABORATIVE

With funding provided by the Cystic Fibrosis Foundation to cover the cost of travel and accommodations, the yearlong collaborative involved quarterly 2-day classes, with assignments related to a QI project centered on patient outcomes. The classes focused on an aspect of the model of improvement, in-

creasing the depth of knowledge and refining skills in each quarter. Coaching calls between the LLC faculty and the participating CF centers were completed between classes. Other assignments were also completed between classes, requiring 48 to 96 hours of commitment from each participating CF center.

Classes and assignments during LLC training included assessing 5 areas of the practice microsystem: patients, purpose, processes, people, and patterns.³ Assessment of patients was carried out using data of patient outcomes from the CF data registry and satisfaction surveys. The purpose of the center was defined with an improvement theme of decreasing the numbers of patients with nutritional failure and specific goals for improvement in nutrition outcomes. The center's processes and patterns were assessed with flowcharts and fishbone diagrams. Finally, the center's team was fully described with a provider satisfaction survey and an activity survey to determine each member's role and function in patient care.⁴

Simultaneous to the assessment of the CF center microsystem, small planned changes were implemented related to the goal of improving nutritional status. Changes to improve patient care were accomplished with the improvement model Plan-Do-Study-Act (PDSA) acquired in the collaborative. The assessment of the microsystem was used to create a plan for a small cycle of change. Then the plan was studied as it was implemented to determine problems, successes, and surprises, which were used to act on the next cycle of change. Measures for each assessment cycle were determined, data collected, and then reported and displayed to the extended CF center staff and additional personnel at the institution.

In 2006, the outcomes data from the Cystic Fibrosis Foundation registry became public on the foundation's Web site. Summary reports of process and outcomes data were initially provided to the CF center staff on a quarterly basis in the form of presentations. These reports are now presented in monthly

CF center leadership meetings as well as in the weekly clinic planning meeting. Finally, progress reports are presented annually at CF Parent Education Day, routinely in a display center in the clinic waiting area, in the CF center newsletter, and at its Web site. This ensured that results and progress were available to center staff, hospital personnel, and patients and families.

The knowledge gained from the collaborative has allowed the CF team to embrace the science of QI as a method to deliver care. It has allowed the team to participate and deepen its knowledge of QI with attendance at National Institute for Children's Healthcare Quality conferences, participation in the Institute of Healthcare Improvement's (IHI's) New Health Partnerships collaborative, and upcoming participation at an IHI-sponsored training at the Institute for Healthcare Delivery Research Center. In addition to expanding our own knowledge of QI, the team has succeeded at spreading the science of QI throughout the institution by presenting our project and results.

MANAGING UP

As a part of the work of QI through the collaborative, the CF team was encouraged to "manage up" by presenting the center's involvement in LLC and QI efforts to the senior administrative staff at the CHS. Managing up is learning to build a positive, mutually advantageous working relationship with supervisors and senior personnel.⁵ The process of managing up started during the authors' participation in the LLC. As part of the collaborative training, the CF team invited the CHS administration including the chief executive officer, chief operating officer, and various vice presidents to a presentation of center outcomes and plans to improve these outcomes.

This exercise had a significant and positive impact that gave the center additional opportunities to present and raise awareness of our project to several other management units within the institution, including the Per-

formance Improvement Committee. This effort culminated with an invitation to present the center's QI initiative to the hospital board of directors, first in February 2005 and for follow-up presentations in January 2006 and 2007. Now management has become a regular member of the team, joining in activities such as planning meetings and observing processes during clinics. Incorporating management into regular team meetings has not only assisted the momentum of QI but also led to changes in clinic workspace, additional clinical staff, and reallocation of current staff to increase focus and efficiency.

MANAGING OUT

In addition to managing up, lessons from the collaborative also promoted "managing out"—working collaboratively with networks of providers and developing an interorganizational relationship that is mutually advantageous. The goal was the integration of the improvement model into all aspects of CF care.

Initially, the key personnel working in the outpatient CF setting were introduced to QI techniques. Then these concepts were shared with the inpatient nursing care and ancillary team members and a satellite clinic. As QI projects and outcomes were shared, requests from noncore team members to be more directly involved in QI became common. Providers outside the CF team also requested to learn more about improving patient care.

Requests from the team members to be more involved with QI projects developed into an internal QI collaborative. The initial internal collaborative began with 6 ancillary team members from pharmacy, nutrition, inpatient nursing, child life education, advanced practice nursing, and physical therapy. These team members had specific ideas for improving CF care, and each recruited other team member volunteers to work on a small QI project focusing on 1 aspect of CF care (pharmacy, nutrition education, inpatient care, inpatient schedules and compliance, transition of care, and home exercise

plan). The teams received basic education and training on QI techniques, followed by assignments with deadlines and individual coaching sessions.

These projects resulted in increased systematization of care in the inpatient and outpatient areas. For example, the nutrition project was designed to streamline the annual 3-day diet recall. The dietician would mail the form to families and patients before the visit, rather than verbally interview the family or the patient. This resulted in not only decreased clinic time for patients, families, and dieticians but also a more accurate diet history. Two of the projects (transition of care and home exercise plan) were selected for a poster presentation at the Twentieth Annual North American Cystic Fibrosis Conference in 2006. The success of the first collaborative initiated a second internal QI collaborative with projects for phone triage, progression of inpatient physical therapy, patient reported outcomes for inpatient care, transition curriculum, compliance to airway clearance, and pastoral care interventions.

Increasing educational and improvement opportunities for the CF team and community resources for families has transformed the CF team into a leader in innovation. In addition to improved care of CF patients, the internal QI collaborative team has transformed ancillary team members into essential members of the CF team. These team members have also become resources for others seeking to improve patient care. The center's activities have been identified as a resource for students seeking research opportunities, other care teams needing assistance with QI, and as an innovator among CF centers in the United States. These have been the direct result of the activities the team learned in the foundation's collaborative.

PARENT-PATIENT ADVISORY COMMITTEE

As part of the center's mission to provide family-centered care, a Parent-Patient Advisory Committee (PPAC) was formed. Parents

and patients were recruited for the PPAC by the CF social worker. Efforts were made to ensure that participants were representative of different socioeconomic and cultural backgrounds, as well as various patient ages. Seven participants agreed to a 1-year commitment of service involving quarterly meetings with the CF team. The CF social worker was the primary contact for the PPAC between meetings, both via e-mail and phone.

The PPAC has provided valuable input for change in the CF center. First, the PPAC recommended improving a sense of community among families affected by CF, resulting in the development of a newsletter, a Web site, and bimonthly caregiver and sibling support network meetings. The group also provided invaluable help in the design of patient- and family-friendly surveys and topics for support groups. The PPAC has also assisted in the development of educational materials for improving nutrition including recipes, high-energy diet tips, and behavioral advice.

IMPROVEMENT IN CLINICAL OUTCOMES

A natural result of the sustained focus in evidence-based practices has been the significant improvements in clinical outcomes, with a significant decline in the percentage of patients with nutritional failure (42% at the end of 2003 to 18% in 2007) and improvement in median body mass index (BMI/age %) in the 2- to 20-year-old group (38% in 2004 to 53% in 2007). Similarly impressive has been the gain in lung function, reflected in the improvement of the median percent predicted forced expiratory volume (FEV₁%) in the 6- to 17-year-old group (82% in 2004 to 90% in 2007).

DISCUSSION

The Cystic Fibrosis Foundation is one of many organizations attempting to improve healthcare through the use of QI initiatives. The QI techniques learned in LLC, such as standardized care and support of

management, have been successfully adapted in acute myocardial infarction,^{6,7} hypertension,⁸ and diabetes mellitus.^{9,10} Although these techniques are well documented to improve healthcare, many providers are slow to adopt a standardized method for change.

The UAB/CHS Cystic Fibrosis Center initiated QI techniques, with 3 team members participating in the collaborative. These techniques were shared first with the CF team and then with the management, patients, and families. As the success of standardized care became evident, other CF team members developed small projects for improving CF care. Maintaining the momentum of this QI initiative was dependent on a physician champion as well as a key individual to track QI progress. The accountability of LLC and the internal collaborative served as a catalyst for meeting deadlines, while celebrating success stimulated the desire to maintain change.

However, the adoption of a culture of improvement was not without limitations. First, the language of the CF center had to change to incorporate terms such as fishbone and PDSA. Second, the center functions within a pediatric pulmonary division, which traditionally has had multiple providers, all participating in the care of a wide range of pulmonary conditions. Therefore, the success of the QI initiative required a few team members to become focused only on CF care. Finally, there were a few key individuals who were resistant to change, but were persuaded that QI

techniques were useful as improvements in patient outcomes became evident.

Improvement in care continues to be a top priority at the center. Future plans include participation in an IHI training program, training of the family and patients recruited for the PPAC to increase their involvement in projects, a project to improve lung function, and a second internal QI collaborative.

The success of improved patient outcomes has engaged the CF team in taking responsibility for not only providing patient care but also improving patient care. Including others (such as management, insurance companies, and families) who are not traditionally viewed as part of the process of delivering care has been advantageous to our improvement process. The engagement of the CF team and nontraditional team members has sustained momentum, increased resources and support for the team, and infused fresh creativity and energy. Both managing up and managing out have created a culture of improvement in which failures are viewed as opportunities for improvement, small projects are encouraged, risk taking and challenges to the system are accepted, and innovation is prevalent. The end result of all these changes has been a significant and sustained improvement in the 2 key clinical outcomes indicators, nutrition and lung function, resulting in better quality of life for CF patients seen at our center, undoubtedly one of our biggest rewards.

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