

# The interdependent roles of patients, families and professionals in cystic fibrosis: a system for the coproduction of healthcare and its improvement

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## ABSTRACT

A quality healthcare system is coproduced by patients, families and healthcare professionals working interdependently to cocreate and codeliver care. Cystic fibrosis (CF) patients and families rely on healthcare professionals to provide the best possible care and timely, accurate information. They know that the care at home and in clinical settings needs to be seamless, using shared information and decisions. A parent's journey of better care begins with her son's diagnosis and moves to her involvement to improve the systems and processes of care for others. She reflects on this work and identifies five elements that contributed to the coproduction of improved care: (1) mental and emotional readiness to engage; (2) curiosity and the search for insight; (3) reframe challenges into opportunities for improvement; (4) listen and learn from everyone, bringing home what is relevant; and (5) personal participation. Joined with the reflections of an improvement scientist, they note that chronic care relies on informed, activated patients and prepared, proactive healthcare professionals working together and that it is more than 'patient-centric'. They propose a model for the coimprovement of systems of care.

## QUALITY CYSTIC FIBROSIS (CF) CARE IS ABOUT PEOPLE WITH CF AND FAMILIES

My son Jack was born in 2000 at Dartmouth Hitchcock Medical Center. The labour and delivery went smoothly, and Jack was healthy and beautiful. Just before discharge, the nurse noticed that his stomach had become distended. Nobody thought it was serious, and my husband and I were not worried. We were shocked when the attendant arrived

and asked us whether we had a family history of CF. We did not.

The next 18 h were a blur of activity. We went from the birthing centre to the neonatal intensive care unit, from radiology to surgery. And we endured the requisite torment of countless hours in waiting rooms not being able to be with our newborn son. After Jack underwent surgery for a bowel blockage, the surgeon told us his blockage was likely due to CF. As first-time parents, our dreams were shattered. As a mother, my first instinct was to hold my baby—to comfort him and make everything better.

We immediately went to see Jack. He was tiny, hooked up to IVs and on a respirator. He looked so vulnerable. The only thing we had wanted to give each other was a beautiful, healthy baby. Now it felt like we had failed each other and, worst of all, our little boy. Every parent of a child with CF has a similar story and feels a sense of helplessness, but like all parents, we want the best for our child.

In a sense, Jack himself showed us the way to go forward. In a matter of weeks, he grew stronger. He was—and is—a fighter.

We met the CF healthcare providers at Dartmouth and learned the daily routine of care. We spent hours reading about CF, talking with our providers, reviewing the Cystic Fibrosis Foundation's materials, learning as much as we could about the science, current treatments and how families were living with the disease. In retrospect, we were entering a time of partnered coproduction of the care that Jack needed—not just bringing him to a place of care that was 'centred' on him.<sup>1–3</sup>



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## OPPORTUNITIES FOR SHARED LEARNING: PATIENTS, FAMILIES AND PROVIDERS

The more we learned, the more questions we had: Was our centre a good centre, did it provide the best care? How were the standards of care set and evaluated? How were the data collected at every visit being used to help children with CF? It became evident in our interactions with the healthcare system that all participants, including us, had to learn about Jack's best possible care and its continuous improvement.

Shortly after Jack's third birthday, I joined Gerald O'Connor, Ph.D., D.Sc., and Hebe Quinton, M.S., at Dartmouth as a quality improvement (QI) programme manager for the Northern New England CF Consortium (NNECF).<sup>4</sup> I had worked with Gerry for 3 years as an analyst with the Northern New England Cardiovascular Disease Study Group.<sup>5</sup> Gerry and Hebe were engaged on behalf of the Foundation to analyse data collected in the CF Patient Registry to be shared annually with the wider CF community, both caregivers and the general public.<sup>6</sup> They created displays that helped people 'see' the variation among centres in important medical outcomes.<sup>7</sup> They also characterised the survival implications of the centre variations and helped the Foundation identify where an 'achievable benefit' had not been achieved.

Gerry strongly believed that variation in outcomes data provided an opportunity for learning, not judging. Working with members of the NNECF, he promoted data transparency among the consortium's five centres to reveal the variation in practice as an opportunity to learn from one another. Gerry's mentorship had a profound effect on me, both as a first-time parent trying to sort out how to ensure the best possible care for my child and as a professional working side by side with CF care providers from various centres.

Working with Gerry and the NNECF helped me appreciate care delivery from the provider's perspective and the challenges of improving care in a constrained system. I gained the patience to see care improvement as a process that involves listening to and considering all points of view and testing ideas and measuring their impact.

I remember Gerry's insightful comment when we were reviewing the centre-level variation for nutritional outcomes: "A calorie in Boise, Idaho, should work the same as a calorie in Burlington, Vermont. With the science we have in hand and QI methods, we can achieve more. We need to learn from one another how to make those calories count for every child." I was very grateful to be part of such a trusting and respectful community, all working towards the same end: better care and health for individuals with CF.

## A VISION OF EXEMPLARY CF CARE

In October 2003, I went to my first North American CF Conference (NACFC) in Anaheim, California,

where I was introduced to the Foundation's leadership and attended plenaries, symposia and workshops. I also accompanied Gerry at planning meetings focused on implementing the Foundation's national QI initiative, *Accelerating the Rate of Improvement in CF Care*. Written with input from CF centre clinicians and healthcare improvement experts Donald Berwick, M.D., Brent James, M.D., M. Stat., and Paul Batalden, M.D., the initiative's purpose was to close performance gaps as a means of improving the quality and length of life for individuals with CF.

Important questions were raised at these meetings, and I began to think deeper about my roles as a parent and a professional. Do healthcare professionals see themselves as responsible for the outcomes at their centres, and are they ready to work aggressively on their care processes? What is the role of parents and patients in driving performance? Patients and families should know about the variation in performance—but how, and who should tell them? If patients and families knew that care was better elsewhere, would they leave their usual places of care?

I left the conference with a deeper understanding of the issues on many different fronts. First, that we—my husband, Jack and I—were the most important members of Jack's care team. I was in awe of the thousands of scientists, researchers and healthcare professionals at NACFC and the Foundation's programmes and infrastructure. But my experience in Anaheim confirmed for me that while the search for a cure continued, it was important to maximise the current treatments and therapies every day to give our son the best chance of a long and healthy life.

Second, the Foundation's leadership was committed to pursuing exemplary care at all centres with help from our team at Dartmouth. The meetings I attended with Foundation leaders were thoughtful and frank. There was a sense of urgency about the need to truly accelerate improvement across the entire network of care centres.

Lastly, I had a personal desire to build on my experiences with the NNECF and bring the same level of trust, respect and perspective to the activities of the national initiative.

## ACCELERATING CHANGE AND TRANSFORMING CF CARE DELIVERY

In early 2004, my role with the NNECF had evolved to include supporting the Foundation's national efforts. I was actively participating in the ongoing improvement work among New England centres and in the planning for a national learning collaborative (to be facilitated by Dartmouth). I was also taking part in discussions regarding national data transparency and public reporting.

Keeping pace with the national improvement work, the New Hampshire centre began to organise an advisory council to bring patients, families and care

providers together to plan QI projects. Part of this work involved testing the notion of sharing data and improving care as partners. The first meetings were difficult as the providers, patients and families sat across from each other in unfamiliar roles. The care team had some trepidation that the meetings might consist of one-sided demands and lead to finger-pointing, while patients and families looked through pages of documents and tried to get up to speed on many new terms and concepts.

Adults with CF were most eager to tackle issues relating to inpatient admissions and care processes, some of which were beyond the reach of CF healthcare providers. Sorting out the complexities and tensions of working as a team taught me many valuable lessons and challenged me to reflect on improving care from an adult's point of view, which I was learning involved a lifetime of experiences in a fragmented healthcare system.

To inform the planning efforts, I took a course at Dartmouth with Paul Batalden, M.D., called 'The Continual Improvement of Health Care'. I was introduced to the underpinnings of many of the national reports,<sup>8-10</sup> studied the models of various healthcare improvement institutions<sup>11</sup> and spent countless hours reconciling what I was learning in the classroom with my personal experiences on the frontlines of CF care. Paul was very generous with his time and walked me through a model of improvement (Clinical Microsystems, defined as small groups of people who work together on a regular basis to provide care to discrete subpopulations including the patients) that made sense within my experience of CF care. I was also introduced to Eugene Nelson, D.Sc., M.P.H., and Marjorie Godfrey, Ph.D., and their work with Paul to develop Clinical Microsystems.<sup>12</sup> We met periodically, exchanging ideas and thinking through the application of Microsystems to CF care, wrangling over relevant CF examples and carefully considering the processes and people involved in care delivery.

In late 2004, Margie, Gene and I were invited by the Foundation to serve as instructors for the Learning and Leadership Collaborative (LLC), offering a yearlong QI learning programme for 12 CF care centres and helping develop Quality Coaches—CF healthcare professionals trained in QI methods. My experience with the LLC solidified for me that improvement is about people and it is personal. To create the conditions for organisational improvement, you need to start with people and emphasise the things they can do to make a difference.

At the close of 2004, three important milestones marked the transformation of CF care for me: a plenary session at the NACFC featured a physician and parent speaking about their experience working together as equal partners to improve CF care; the *New Yorker* published an article about how sharing data with patients and families could change the

dynamics of improving healthcare; and the Foundation committed to publically reporting centre-specific outcomes. Looking to promote the idea of patients as improvement partners and highlight the work Cincinnati Children's under a grant from the Robert Wood Johnson Foundation, the Foundation invited Cincinnati's CF centre director, James Acton, M.D., the mother of a child with CF, Honor Page, and Paul Batalden, M.D. to give a keynote plenary session at NACFC in St. Louis. Their presentation, 'It's All About Annie', described what it means to put the patient at the centre; what is involved in the actual redesign of care; and what conversations, promises and forgiveness were necessary if everyone worked toward the shared goal of 'getting it right for Annie's health and well-being'.

Around the same time, the *New Yorker* magazine published a widely read article, 'The Bell Curve', by Atul Gawande, who also wrote about Annie Page as he described the important set of dynamics when patients and professionals begin to have real conversations about data and system performance in healthcare. And, lastly, the Foundation announced the formation of a committee of CF clinicians, parents and biostatisticians to explore case-mix adjustment and public reporting of centre-specific data from the Patient Registry by 2006.

Making centre data publicly available was a controversial topic for many care providers despite regular updates with directors and calls for input and feedback. I participated in the first public meetings to review our centre's data and attended a few other centre meetings in New England. These meetings were heartily attended by centre leaders and healthcare professionals and many parents and partners of adults with CF. Across the board, participants' reaction was very straightforward: "Thank you for showing us where we are today. Now, let's figure out how to get better." It was a joy to hear that people from the CF community embraced these results with honour and courage, a response that reflects in part the CF Foundation's leadership in creating a culture of learning, which, in the long run, will benefit those who are living with CF and their families.

Over the next few years, participation of parents and individuals with CF continued to grow. In 2007, the CF Foundation expanded the Patient Registry information and QI resources for patients and families on its website. It also added improving care and engaging patients and families to its accreditation standards for care centres. Today, all Foundation-accredited centres routinely report improvement aims and process and outcome data over time, and they outline activities of patients and families serving as members of the improvement team or as advisors to centre improvement efforts. The Foundation also invited patients and families to join its clinical care guidelines committees. Convening with healthcare providers, patients and families to review the

evidence and debate the merit and grading of clinical care recommendations.

In 2010, the Foundation commissioned the development of a national patient and family experience of care survey.<sup>13</sup> The national survey is currently embedded in the accreditation process, and data reports are shared with the centre and Foundation leaders. In addition, the Foundation organised a Saturday Advisory Track at NACFC to further engage patients and families to reflect on how to improve their care experience and learn more about CF with their healthcare providers. Engaging healthcare professionals, patients and families is at the core of continuous QI—finding ways to stimulate learning and growth.

### ENTERING ADULTHOOD: FORGING NEW PARTNERSHIPS AS A PATIENT AND FAMILY

Today, nearly half of all people with CF are age 18 years or older. Jack is now 13 and by all measures an adolescent. He is a healthy, active young man, who has a deep love of running and Nordic skiing and blushes at the mention of a special girl in his class. He is learning to take care of himself and talk with his healthcare providers in his own words, telling them what he does every day, how many times he does it and why he is doing it.

Jack now meets with his providers alone during clinic visits. He shares with us a summary of what was said, any changes to his treatments and his plan of care. As he matures, we will hand off more responsibility to him, such as scheduling appointments and navigating refills and insurance. As an adult, Jack will make his own decisions. We, his family, friends and healthcare providers, will be involved to the extent that he desires: he will truly be the leader of his care team.

As a parent and a professional, I want a system that is safe and reliable—the right care at the right time—and a healthcare journey that is uninterrupted. I want the years of collective knowledge of Jack's goals, preferences and values, along with his medical history, to be part of the system, not fragments pieced together by each provider or caregiver. I want a system that continues to embrace and engage in continual improvement and strives for benchmark performance.

Over the past decade, I have had the honour to visit many centres and meet with healthcare providers, patients and families and work with them to help improve their processes of care. I have also brought many of their lessons home to my own centre and to my family (table 1).

### COPRODUCING AND THE IMPROVEMENT OF CF CARE: AN IMPROVEMENT SCIENTIST'S PERSPECTIVE

Kathy and I participated in the same effort to improve CF care. We each brought many years of observation and reflective practice: Kathy with her experience as a parent, caregiver and improver for more than a decade, and my experience as a physician, teacher and improver for more than three decades.

My invitation to get involved as an improvement scientist came from Gerry O'Connor, Ph.D., D.Sc., the passionate improvement innovator in CF. His analysis of the data had revealed substantial variation in care across the centres. He knew that those undesirably varied outcomes came from unwanted and unnecessarily variable care processes and systems. His question to me was, "How can we build a shared understanding of the situation and get the cooperation needed to act and change?"

Gerry and his improvement science colleagues began by bringing CF leaders together to create the shared purpose of using this data and these insights about the variation in care together with the emerging science of improving healthcare for the improvement and redesign of CF care. Their leadership invited Kathy and the whole CF community to join the effort.

The care of patients with CF requires the interdependent cooperative work of patients, parents, families and the health professionals who have specialised in one or more aspects of the disease. This coproduction of care involves much more than a shared aim to put the patient 'at the centre'. It actually requires capabilities of the patient and family and the clinical professionals for the 'coproduction' of good care. These capabilities come together in a trusting relationship to produce their effect.

In this case, the 'coproduction' was not limited to the provision of care. The interdependent work

**Table 1** Five elements that lead to activating patients, families and professionals for the coproduction of improved care

Readiness	Be ready mentally and emotionally to engage in improving care. Realise that the ability to engage may change over time as the challenges of living with a chronic disease change
Curiosity	Ask questions and seek answers. Identify sources of trustworthy information that include professionals, parents and people living with the disease
Reframe	Turn challenges into opportunities for learning and improvement. Practice seeing situations from various points of view, looking for ways to identify possibilities and resources for improvement rather than barriers and people to blame
Listen and learn	Seek out new knowledge and ideas. Listen and learn from the experiences of others, bringing the best ideas home for testing, trial and adaptation for local improvement
Participate	Be present and personally participate. Improvement is a team effort and takes time and commitment to see measured results

extended to the improvement of care. Like the coproduction of good care, the coproduction of good improvement requires attention to the elements described above. When patients and families become involved in coproducing the improvement of care, they bring insights from their daily realities of CF care. When improvement is coproduced, improvement professionals, care system leaders and patients work together towards the realisation of a shared aim.

Along this journey to improved CF care, several things became evident to me:

1. The care of a person with CF is not a soloist undertaking. Small systems consisting of those patients, their families and the variety of health professionals involved are the basic building blocks of CF healthcare.
2. 'Patient-centred care' in good CF care really means 'coproduced care'. The child with CF has parents and others immediately involved every day in creating their care. Helpful professionals are key, but the execution of the care plans is in the patient's and family's domain. As the child with CF becomes an adolescent and an adult with CF, the systems change, but the reality of coproduced care remains. We have a lot more to learn about the capabilities needed by both patients and professionals seeking to coproduce healthcare. The CF experience offers important lessons for all.
3. Data can inspire better quality. Centres submitting and experts analysing data offer insight into the patterns and variation of care. When that information becomes widely understandable and transparent, it allows the generation of action and change.
4. Systematic efforts to design and test changes in healthcare can produce favourable desired results while simultaneously contributing to the emerging science, art, pedagogy and practice of healthcare improvement. This work has already informed the models, methods, analytics, leadership and teaching of countless others. This supplement will invite the attention of many others to the phenomenon of coproduced care and coproduced improvement of that care.
5. The data, the systems, the models, the programmes and the centres are all important elements in CF care and its improvement, but the source of vitality in CF care *and* in its improvement are the people involved. The patients and families, the professionals, the system leaders and the improvers are all people trying to do their best. Getting them to work together for change takes people like Kathy and Gerry, and many more.

With QI, the CF community seized the opportunity to improve care. It did not shy away from hard questions or from parents. Instead, by parents, clinical professionals, CF Foundation leaders and improvement

scientists working together, they have been able to unleash a movement that is owned and driven by the community. For those of us who have had the privilege of contributing to and learning from this improvement effort, we have had the joy of seeing care get better and are full of hope as the next decade unfolds.

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