

Improving Chronic Illness Care

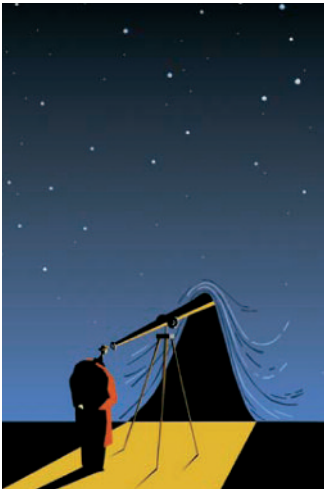
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Editors' Introduction

One of the Robert Wood Johnson Foundation's priorities is improving the quality of care delivered to people with chronic illnesses. Improving quality of care was one of the three priorities approved by the board in 1972, shortly after the Foundation became a national philanthropy, and it has been a Foundation concern ever since. Among its other efforts, the Foundation has supported quality-measurement standards developed by the National Committee for Quality Assurance, commissioned major studies on quality of care by the Institute of Medicine, and funded *The Dartmouth Atlas of Health Care*, which is the subject of the previous chapter in this *Anthology*.

In this chapter, freelance journalist Irene Wielawski, a frequent contributor to the *Anthology* series, explores a Foundation-supported initiative called Improving Chronic Illness Care, a pioneering effort spearheaded by Dr. Edward Wagner of the Group Health Cooperative in Seattle to provide medical care for chronically ill people, whatever their condition. In tracing the history of the Foundation's efforts to improve quality of care, Wielawski concludes that many of the Foundation's past efforts focused on specific illnesses such as asthma, diabetes, or depression. In contrast, the chronic care model developed by Wagner, around which the Improving Chronic Illness Care Program was built, applies to a broad range of chronic illnesses and serves as a roadmap for physicians to organize their practices to meet the often complex needs of chronically ill people.

In fact, the chronic care model calls for a structural change in the way people with illnesses are cared for, and the participation of nurses, social workers and patients themselves. This chapter highlights how difficult it is to change what goes on in physicians' offices and to modify practices that have been entrenched for many years. The challenge is now one of moving an apparently effective way of improving quality from an experiment carried out primarily in health maintenance organizations to the mainstream of health care practice.

To hear Carolee Ross tell it, she had to come to “Podunk” to get a proper diagnosis for symptoms that she had experienced for several years: persistent thirst, frequent urination, ravenous hunger, and a shaky, sweaty feeling that would come over her without warning. These are classic symptoms of diabetes, an illness that runs in Ross’s family. But in all the years that she had been complaining, none of her doctors in an affluent suburb of New York City did a thorough workup.

What Ross considers Podunk is a rural section of southern Rhode Island known as Chariho, for the three towns—Charlestown, Richmond and Hopkinton—that send children to the regional high school. Ross landed there in 2002 after she and her husband were downsized out of their corporate jobs. By selling their pricey home and relocating to a place like Chariho, Ross figured that they could buy a nice house, start a home-based business, and still have money left over for expenses. It didn’t work out that way. Health insurance remained out of reach, forcing a reluctant Ross to seek care at the local sliding fee scale clinic, Wood River Health Services.

“I never thought I’d find myself in that kind of place,” says Ross, who had prided herself on going to only the best private doctors. But what seemed like a huge comedown turned out to be a stroke of luck.

The physician’s assistant who conducted the new patient interview immediately flagged Ross as a possible diabetic. He then ushered her into tests that confirmed it, which brought the clinic’s diabetes team into play. The comprehensive education and treatment plan they devised quite literally changed Ross’s life, helping her confront lifestyle excesses that were ruining her health—as well as prejudices about medical care quality that she had brought from her past life.

“I had a wonderful, caring relationship with my doctor, but I’m sorry to say she never took my diabetes symptoms seriously,” Ross says. “All she did was a simple urine test, and when it came back negative, she suggested stress might be the explanation—as if this was all in my head!”

That Ross was diagnosed so quickly at Wood River is no accident. The health center and the state of Rhode Island are among several dozen loosely aggregated collaborative projects in a national experiment called Improving Chronic Illness Care, or ICIC. In 1998, the Robert Wood Johnson Foundation authorized \$25 million over five years for ICIC. The program’s purpose was to address one of the standout areas of illogic in American health care—the treatment of patients with ongoing but incurable illness.

The idea behind ICIC is to marry medical science with redesigned health care delivery systems so chronic patients in any setting—clinic, hospital, physician’s office, or health maintenance organization—can receive prompt diagnoses and care that helps them avoid debilitating and expensive complications. The logic is powerful, backed by research and demographic trends foreshadowing more chronic patients as the baby boom generation ages. A “no-brainer” is how national proponents like to sum it up.

But the grantees who took up ICIC’s challenge to reengineer their health care organizations aren’t so breezy. Indeed, their descriptions of what it has taken to upend health care business as usual sound

more like the rhetoric of the Prussian military strategist Carl von Clausewitz than modern health reform theory. Among the obstacles they cite are a century of clinical and cultural maxims about the role of physicians, extreme fragmentation of purpose and incentives in American health care, and a payment system that runs in the opposite direction.

A Fragmented Approach to Treating Chronic Illness

Like Ross's former doctor, the health care system is geared to hard evidence of medical need. That's great if you've been pulled broken and bloody from a car wreck, but not so great if you're in the early stages of diabetes or asthma or heart disease. Though similarly life threatening, these illnesses erode health over years, not minutes. Symptoms may be subtle, delaying diagnosis by busy clinicians. Treatment is often laborious; chronic conditions can complicate even the most routine of medical procedures. And there's little reward for conscientious clinicians because the so-called "acute" care bias in the health care system extends to its payment formulas. Simply put, doctors and hospitals make more money amputating the gangrenous limbs of poorly controlled diabetics, performing bypass surgery on patients with advanced heart disease and hospitalizing asthmatics than they do helping these patients avoid such acute exacerbations of underlying illness.

The acute care bias persists despite scientific evidence that early diagnosis and management of specific chronic conditions not only is good for patients but also has the potential to significantly restrain growth in the nation's health care bill—now \$1.9 trillion,¹ or 16 percent of the gross domestic product—by reducing hospitalization and other costly measures. The math here is complicated and quite theoretical, since there has been no long-term test of researchers' projections across the full spectrum of chronic illness. Demographics, however, add force to their arguments for improving the care of people like Carolee Ross. An estimated total of 133 million people in the United States—nearly half of all Americans—have at least one chronic condition, and that number is expected to swell to 171 million by 2030 as a result of the aging of the population. Moreover, researchers believe that these projections understate the potential demand on disease management services. It is estimated that nearly one third of the people suffering from diabetes alone remain undiagnosed.²

Health care leaders have long been aware of this trajectory. Chronic illness has displaced the 19th century acute threats that spawned our health care system: contagious disease, farm accidents, blade and bullet mishaps and so on. People a hundred years ago simply didn't survive cancers, flaws in metabolism, or failing organs. The 20th century brought rapid progress in medical science—the development of antibiotics and life-sustaining drugs such as insulin, surgical interventions, and a host of new technologies that made it possible for the chronically ill to live longer. The new challenge was to minimize the disruption of illness at home and at work.

At the Robert Wood Johnson Foundation, ICIC was preceded by two decades of programs to invent or refine services for patients in need of extra help. The Foundation categorized them as "special populations," including the elderly, children, people with physical or mental handicaps, and those with chronic illness. Among the chronic illness initiatives were several that experimented with new approaches to specific diseases such as AIDS or asthma. Others took aim at systemic gaps, and sought to augment support for people with long-term illness. A particular need was for help in

day-to-day medical management. Physicians and other clinicians sometimes were too rushed to discuss diet, exercise, or self-care techniques, and their offices weren't organized to connect patients with services in the larger community.

To address these deficiencies, the Foundation funded experiments in case management and patient education, as well as integrated social and health services needed by complex patients. The Chronic Disease Care Program (1979–1984) used nurse managers to organize consultations and other services for severely ill patients, and also teach them how to care for themselves. The goal was to reduce hospitalizations and institutionalization, but it proved to be an uphill battle because doctors and administrators weren't part of the program and didn't always back the nurses. The Program for the Health-Impaired Elderly (1980–1985) moved case management work out of the medical office and into community organizations that also saw to transportation, meals and other needs of geriatric patients. The Chronic Mental Illness Program (1985–1992) worked similarly on behalf of people with psychiatric illness, helping them to navigate the maze of existing federal, state and local programs, all with different funding streams and eligibility criteria. The Health Care for the Homeless Program (1983–1990) targeted people living on the streets and in shelters. But the homeless program emphasized primary medical care. Mental health problems, although rampant in this population, were not addressed.³

A number of initiatives targeted social needs of fragile or medically impaired populations. The Supportive Services Program in Senior Housing (1987–1995) sought to build capacity for services beyond the standard landlord-tenant relationship so that, for an additional fee, elderly residents could receive help with housekeeping, repairs and miscellaneous chores. The Program on Dementia Care and Respite Services (1987–1992) promoted adult day care centers for severely demented persons still living with their families.

What stands out from a review of these programs is how scattershot they were, addressing the isolated needs of people with particular handicaps but offering no systematic solution for patients, families, health care facilities and clinicians to collectively meet the challenges posed by chronic conditions. There also was little effort to utilize lessons across programs. After all, if residents in senior housing need help with chores and repairs, it's likely that people with health or mobility problems do, too. It wouldn't be stretching it to describe the Foundation's early chronic illness portfolio as an "acute care" approach to the symptoms of health system failure that ignored the underlying disease—an antiquated structure that divides patients by diagnosis and circumstance instead of comprehensively addressing chronic patients' needs. Anne Weiss, the senior program officer who heads the Foundation's quality team, characterizes these earlier initiatives as a form of "parallel play," borrowing a phrase used by developmental psychologists to describe toddlers playing side by side but with no apparent interaction. The Foundation's chronic illness initiatives of the 1980s and early 1990s, she says, "had general common ground, but some were systems-oriented and some were patient education-oriented and some had a different focus altogether."

This piecemeal approach was mirrored nationally as scholars, institutions, advocacy groups, and government agencies sought variously to address weaknesses in health care quality and delivery but stopped short of solutions that could be applied to all chronic conditions. At Dartmouth Medical

School, John Wennberg pioneered the study of regional variation in medical practice, showing, for example, differences in the rates of specific medical procedures such as coronary artery bypass surgery and hysterectomy that lacked scientific rationale. Donald Berwick, at the Institute for Healthcare Improvement, focused on medical errors and strategies to improve patient care safety. Federal and state officials explored ways to tweak reimbursement formulas in order to encourage better care of chronically ill patients covered by Medicare and Medicaid. Finally, there was the broad public education effort that accompanied managed care to convert sick people into informed consumers of health care services.

While each of these efforts attempted to improve the quality of medical care, they lacked a coordinated action plan that would meld the interests of patients and their families in obtaining good care with those of hospitals and clinicians juggling twin mandates to practice good medicine *and* make a living under restrictive payment formulas.

The Chronic Care Model

Could such a plan be devised and implemented within the existing structures of health care in the United States? This was the question posed by the Foundation in the early 1990s to Edward Wagner, an internist and director of the Seattle-based MacColl Institute for Healthcare Innovation at the Center for Health Studies, Group Health Cooperative. Wagner is a longtime proponent of chronic disease management to minimize acute illness. He first came to the Foundation's attention in 1992 as a grantee under the Chronic Care in HMOs program, during which time he identified specific shortcomings of primary care offices and organizational changes needed to enhance services for chronic patients.

Among the problems identified by Wagner:

- The typical primary care office is set up to respond to acute illness rather than to anticipate and respond proactively to patients' needs. Chronically ill patients, however, need the latter approach in order to avoid acute episodes of illness and debilitating complications.
- Chronically ill patients aren't sufficiently informed about their conditions, nor are they supported in self-care beyond the doctor's office. This lack has consequences beyond preventable exacerbations of illness. Children with poorly controlled asthma, for example, can end up permanently sidelined from sports, playground games, and other activities important to physical and social development.
- Physicians are too busy to educate and support chronically ill patients to the degree necessary to keep them healthy.

Wagner's solution is to replace the traditional physician-centric office structure with one that supports clinical teamwork in collaboration with the patient. The concept extends beyond the health care organization to collaborative relationships in the community—say, with the local YMCA's cardio-fitness program. Wagner called his design the “chronic care model.” Under the model, physicians, nurses, case managers, dietitians, and patient educators collectively share responsibility for patients' well-being. They are supported in this mission by administrative staff and technology relevant to the task. For example, Wagner's model calls for investment in computerized patient records and special software to organize disease data and alert members of the care team to patients' needs.

The chronic care model defines six elements whose coordination is necessary for high-quality disease management:

- **Community Resources.** Doctors' offices and clinics should identify existing programs and encourage patients to participate.
- **Health system.** Health care organizations must make excellence a priority and pursue it visibly. Essential to achieving this is top management support and open communication on error and failings as well as strategies for improvement.
- **Self-management support.** Clinicians should set a tone of collaboration with chronic patients, and encourage their participation in setting goals and fine-tuning treatment.
- **Delivery system design.** To move from the one-on-one doctor/patient relationship to teamwork, the clinical staff needs defined roles and tasks. Follow-up with patients is essential so they feel supported in self-management efforts outside the medical office.
- **Decision support.** To link treatment to research evidence, clinicians must have explicit guidelines, whether the question is scientific (drug doses) or psychosocial (how best to motivate overweight diabetics to diet).
- **Clinical information systems.** Computers can efficiently deliver disease management information, including care guidelines, test results, and even pop-up reminders about individual patients. They also facilitate so-called population studies of, say, all diabetics in the office; the care team can measure their performance against quality benchmarks.

By integrating these elements into primary care practice, Wagner says, health care organizations are better able to stay on top of clinical responsibilities while helping patients become active participants in their care. The result is win-win all around, he says. Patients are healthier, providers are cheered and motivated by evidence of a job well done, and the health care system saves money.

The Improving Chronic Illness Care Program

Wagner's early trials of the chronic care model took place at Group Health Cooperative, a 590,000-member health maintenance organization based in Seattle. He chose to test it on diabetes, a long-term chronic illness with known complications related to poor disease management. Some 15,000 diabetics spread among 200 primary care providers in 25 affiliated clinics participated in the experiment. Over a five-year period, the percentage of these patients with up-to-date screenings for eye, foot, and other complications rose; blood sugar levels and the regularity of monitoring improved; patients reported higher satisfaction with their care; and the utilization of acute care services decreased. Specifically, Wagner and colleagues reported, inpatient admissions went down 17 percent for diabetic patients, and office visits also declined, for an overall cost savings of \$62 per member per month.⁴

Tracy Orleans, a senior scientist/program officer and distinguished scholar at the Foundation who had previously worked on chronic disease management programs, said that she had "never seen more exciting work" than Wagner's. It coincided with growing disenchantment at the Foundation with its "let a thousand flowers bloom" approach to improving chronic illness and a search for something "more prescriptive," Orleans says. After funding the chronic care model's initial trial through the Chronic Care in HMOs program (1993–1997), the Foundation offered Wagner additional grant support to refine the model. This work took place between 1994 and 1998. It included compiling

best practices guidelines from the research on chronic illness management, and a conference of experts who provided valuable feedback on the model.

Wagner says this lead-up to ICIC was a period of great uncertainty. Would clinicians oriented to treating individual patients be receptive to systematizing disease management by diagnosis category, and even across chronic conditions? “Everything at the time was in disease silos,” Wagner recalls. “Patient education was in a funny state because there was evidence that it wasn’t working and that the field was floundering. There was a *Journal of Chronic Disease* that actually changed its name to *Journal of Clinical Epidemiology* to go along with the fashion of the time. In short, there was no field called chronic disease management.” But Wagner says interest built as he and his team began to publish their ideas. Several organizations interested in health care quality and system reform eventually joined ICIC as collaborators, including the Institute for Healthcare Improvement, the Bureau of Primary Health Care of the U.S. Health Resources and Services Administration, the Joint Commission on Accreditation of Healthcare Organizations, and the National Committee for Quality Assurance.

The final design for ICIC included three major components:

- A grant program for research on system barriers to state-of-the-art chronic disease care. These included studies of how to integrate community resources into clinical practice, adapt disease management tools to small physician practices, use Web-TV technology to teach self-management techniques to isolated rural patients, and enhance the flow of medical information as patients move from one health care setting to another.
- Real-world tests of the chronic care model in a range of practice settings—private physicians’ offices, government-subsidized clinics, hospital-based outpatient clinics, and other places where the chronically ill might go for medical care. To teach grantees how to re-engineer their work environments, ICIC teamed up with the Institute for Healthcare Improvement to run training programs called the Breakthrough Series. These included national meetings, group coaching, and feedback for clinical leadership teams designated by their health care organizations. Their assignment was to implement the chronic care model in their workplaces, but also to stay in touch with the other teams as part of an idea-sharing collaborative. As of January 2006, more than 1,300 health care organizations had participated in ICIC collaboratives.
- A technical assistance center to help others utilize the lessons of ICIC. The center maintains a public access Web site, www.improvingchroniccare.org, with links to current research, resources, and reports on the experiences of ICIC grantees.

While the chronic care model is certainly prescriptive, dictating criteria and processes for changing medical office design and practice, ICIC presented it as a flexible tool, designed for adaptation to the great variety of primary care settings in the United States. For example, grantees were encouraged to modify the recommended form for interviewing new patients. The only condition was that these modifications had to be scientifically tested to document better results—Carolee Ross, say, receiving a prompt diagnosis of diabetes after years of neglect.

This opened the door to innovation at every level of ICIC, creating the same dynamic collaboration between the national program office and its grantees that the chronic care model espoused for patients and the health care team. Grantees said they were energized by this freedom to tailor the model to their work environments. ICIC, in turn, disseminated grantee contributions in papers and

via its Web site, enabling a three-physician practice in Montana, say, to learn from a similar operation in Rhode Island.

Among many lessons from the field was that such small practices lacked sufficient capital (for data collection and information systems) and staff (for patient education and support) to comprehensively implement the model. Partly in response to this, ICIC shifted its collaborative base from nationally scattered experimental sites to local, regional, and statewide collaboratives. The thinking, according to Wagner, was that collaboratives linked by geography and markets would have a better chance of influencing health insurers and government and private sector agencies to kick in up-front financial support on the evidence of cost savings down the road.

“Money isn’t the problem; misdirected money is the problem,” says Wagner, who estimates that for certain chronic illnesses, notably congestive heart failure, a \$300 to \$500 investment per patient per year yields health care system savings of up to \$1,000.

The ICIC Battlefield

While no blood was shed during ICIC’s experiments with the chronic care model, participants sometimes reached for warlike metaphors to convey how wrenching the process was for individuals and organizations to change longstanding ways of practicing medicine. The fact is that ICIC was as much an experiment in social change as a clinical trial, despite its emphasis on quantifying proof of better disease management. Patients didn’t necessarily jump at the chance to become collaborators and self-managers after years of following doctors’ orders. Nor were physicians immediately comfortable with transferring clinical responsibilities to colleagues traditionally viewed as subordinates. Michael Tronolone, medical director of the Polyclinic, a Seattle physicians’ group and ICIC grantee, said the clinic’s chronic care team sometimes had to resort to “guerilla warfare” to bring resistant physicians around. “It’s really a tactical issue,” he said. “You take on one physician at a time.”

Pat Schultz, a nurse at Wood River Health Services in Rhode Island, where Carolee Ross learned that she had diabetes, says the chronic care model’s emphasis on clinical teamwork explodes medicine’s traditional hierarchy, forcing recognition of other health care professionals as equal or superior to physicians in certain patient care tasks.

“Years ago, it was always nurse is handmaiden to the doctor,” Schultz says. “You did no more and no less than you were told. This requires us to put our titles and our hats aside to figure out how to make things better for patients, not easier for us as providers or better for us as a business.”

Much has been published about ICIC’s experience and clinical results, as well as the arduous process of changing entrenched but no longer useful ways of doing business. The experiences of selected patients and sites can serve to illuminate both the difficulties and the promise of improving chronic illness care. The accounts that follow all involve diabetes, predominantly type 2, or adult-onset, diabetes, a widespread chronic illness that has typically afflicted middle-aged and older Americans but now is showing up in younger patients.

Roughly 21 million people, or 7 percent of the American population, suffer from type 2 diabetes, in which the body fails to utilize the hormone insulin or produce it in quantities sufficient to metabolize glucose—an important fuel for cells. People with type 2 diabetes usually still produce insulin, which distinguishes them from the 5 percent to 10 percent of Americans with type 1, or juvenile, diabetes, who don't.⁵ Neither type is curable, and both can lead to dangerously high levels of glucose in the blood. Left untreated, diabetes impairs kidneys, hearts, eyes, nerves, and circulation. Treatment includes synthetic insulin, diet, and exercise, as well as close monitoring for complications. Three-quarters of the ICIC grantees chose diabetes to roll out the chronic care model in their organizations, despite being offered three other chronic illnesses: asthma, congestive heart failure, and depression. Grantees cited its prevalence as one reason, but emphasized a second one in light of ICIC's mandate to measure clinical performance by scientific standards. Diabetes produces unusually hard data, compared to other chronic conditions. Because success can be documented, diabetes has more heft as a driver of system change than other illnesses where the science isn't so clear and the cost of failing to achieve clinical excellence cannot be so cleanly projected.

Patient: Donald W. Bangs

Donald Bangs was still teaching sixth grade at a Seattle middle school when he was diagnosed with type 2 diabetes in 1980. "I'm 6 feet tall and I weighed about 212 pounds, but the weight was going off fast because I was sick and thirsty all the time," he says. "I told my sister because she had diabetes and our father and grandmother had it, so I knew a bit about the symptoms."

Still, Bangs didn't call his doctor right away. Instead, he waited several months, until it was time for his annual teacher's physical. Bangs' own hunch about diabetes was quickly confirmed. He left his doctor's office with a packet of literature about diet restrictions and other measures to control blood sugar—the standard patient education packet at the time. "It was so screwy that I couldn't eat this and I had to eat that," Bangs says, recalling his initial confusion over how to care for himself.

Over the years, Bangs' doctors at Seattle's Polyclinic added new regimens and medications, though still without much explanation. Bangs' need for synthetic formulations of the glucose-metabolizing hormone insulin steadily increased.

"You're always wondering when you've got something like this, 'Am I doing the right thing?' My sister had insulin reactions [from overdosing] all the time. Her sons are on the fire department, and the 911 call would come in and they'd say, 'That's mother.' They'd have to rush over there and feed her sugar and put that glucose needle in her arm. She died in 1999, but her last years were terrible. I went over to visit her one time at Swedish Hospital and it was bad—tubes in her all over the place."

By contrast, Bangs says he's never had an insulin reaction. He attributes this to having taught science, which made him curious about the physiology of diabetes and also a careful reader of informational pamphlets. But Bangs gives much credit to the Polyclinic, which began using the chronic care model in 2001 to manage diabetic patients, and stepped-up emphasis on patient education and self-management. Bangs, who injects himself with insulin four times a day, says he monitors the effects by pricking himself before and after meals to measure blood glucose concentrations. He

records these on a chart provided by the Polyclinic, and also notes what and when he eats each day. He then plots the blood sugars scores on graph paper. Both chart and graph go with Bangs to every Polyclinic visit. The visits include eye, foot, blood pressure, and other screening tests, as well as HbA1c blood tests—a nationally recognized standard of diabetes control that measures blood glucose over time. Normal scores are 5 percent or less; diabetics are considered in good control if they score below 7.

“The numbers show that you really can help your health,” says Bangs, whose HbA1c’s have been as high as 12. Working with the Polyclinic’s diabetes care team has been rewarding, primarily for reasons of health but also, says Bangs, because of the feeling of self-mastery he gets from success: “When my doctor told me one day that I got a 7.1, wow, I felt like I’d won the \$100,000 lottery!”

Physician: Gregory John

Gregory John, a 55-year-old internist, is a partner in the Seattle group practice where Donald Bangs is a patient. He was one of the first Polyclinic doctors to convert his practice to the chronic care model and embrace its systematic team approach to managing chronic illness. But John is quick to note that it was not love at first sight. On the contrary, John says he expected this latest health reform scheme to be little more than a paperwork exercise—time-consuming, for sure, but of little benefit to patients or his practice.

“I already had a very busy practice and I already had to go to a lot of meetings, so I was very resistant to doing all the work involved in learning these new ways to take care of people,” says John, who nevertheless agreed to be a physician leader on the Polyclinic’s ICIC experiment largely because of the enthusiasm of his longtime colleague Mark Cordova. “It was probably a full year into the collaborative before I realized that having a system approach was actually going to save me time and result in better care for my patients.”

John, Cordova, nurse Colette Rush, and several others from the Polyclinic attended training sessions sponsored by the Washington State Collaborative, at which evidence and testimony was presented regarding improvements in diabetes control achieved via the chronic care model. The sessions broke the model down into its elements and explained their value, including how building computerized disease registries and diffusing responsibility for patients to a clinical team facilitated disease management. John says, however, that he came out of the training unconvinced that any of this was going to make a difference in *his* practice. Indeed, his attendance at the Breakthrough Series and subsequent group discussions might have been for naught if not for an insurance company letter that landed on his desk right around the same time.

The letter, from the insurance company’s own quality assurance division, asserted that one of John’s patients was overdue for an HbA1c test. “They were notifying me that this patient had not had a hemoglobin A1c in 18 months,” John recalls.

“My reaction was, ‘That’s ridiculous, of course they did because I know they need it and I would have insisted on it.’ But then I checked the chart and the patient hadn’t been in to see me in

18 months,” John says. “You know, time flies, and you think you saw them just three months ago but in fact I discovered I really didn’t have a way to check on patients who weren’t coming in.”

Better tracking of patients as well as measurable improvements in their clinical status have made John an advocate of the chronic care model’s systematic approach. But he treads lightly in conversations with physician colleagues, remembering his own misgivings about upsetting tried and true practice. He’s also mindful of the group practice culture, in which physician autonomy is prized.

“Historically, we were a collection of independent private practices under one roof. In the last ten years, we’ve been changing—getting more rules and work production and practice guidelines,” John says. “I don’t resent the clinic suggesting that I do things differently, but some of my colleagues do resent that.”

John opts, therefore, to promote the chronic care model via data demonstrating improved medical care quality: “What I tell the reluctant physician is that you are going to do a better job if you use this system,” he says.

Health Care Organization: The Polyclinic

As one of the nation’s first physician group practices, Seattle’s 90-year-old Polyclinic was an ideal setting in which to test the efficacy—and practicality—of the chronic care model. Most Americans get their health care from private physicians in partnerships like the Polyclinic.

Polyclinic leaders had been looking for a way to improve chronic disease management since the late 1990s, when it became clear that managed care and capitation were failing as cost-control mechanisms in Seattle’s health care market. “We knew costs were going to go up,” says Lloyd David, the clinic’s chief executive. And David knew from experience that if costs went up, the purchasers of the Polyclinic’s services—health benefits managers for corporations, public employee unions, and the like—would react by trying to “pay less for unit prices.”

Not only would that cut into Polyclinic revenues, it also wouldn’t accomplish the objective: cost control. When purchasers pay less for an office visit, health care businesses respond by doing less per visit. So patients end up coming in more frequently, pushing costs back up through increased use of services. “So we saw disease management as a means to improve quality and control cost,” David says. “It’s a win for the patients, a win for the bill payers, and a win for the doctors in improved job satisfaction through improved performance.”

The Polyclinic’s other goal was to remain competitive as a business. “We were willing to take the risk of spending more up front to save money on the total costs and get paid higher unit costs,” David says. Colette Rush, a nurse and longtime case manager, became the clinic’s ICIC liaison. She worked from 2001 to 2002 with physicians Gregory John and Mark Cordova to adapt their practices to the chronic care model. “We tracked 220 diabetic patients on seven to eight measures of disease management, and they improved in all measures,” Rush says. “We then presented our data to upper management and signed on three more doctors.”

By the experiment's second year, the Polyclinic board had seen enough to vote to make the chronic care model clinic policy, though not mandatory, for its primary care physicians. But management turned up the pressure in other ways. The Polyclinic's medical director, Michael Tronolone, says he began issuing quarterly performance reports specific to each of the clinic's 31 primary care physicians and based on quality benchmarks for diabetes management, such as annual eye exams and optimum HbA1c results. Physician identities were coded, but it was easy to figure out where each stood in the ranking, according to members of the clinical staff.

"Feedback to the individual is not sufficient to change the system of medical practice," Tronolone says. "It's got to be wide open—performance, compensation, everything. Once you start doing it, it feeds perfectly into what doctors want: to be better than the others or at least not have the others be better than they are." While management used such tactics internally to bring around skeptics, it also began scrutinizing new hires for their ability and willingness to be team players. The objective here was to change the Polyclinic's historically autonomous physician culture. "We don't have a lot of lone wolves anymore," Tronolone says. "The recruiting message kind of selects them out."

Converting the Polyclinic's diabetics into disease managers was equally time-consuming, according to Nikki Nordstrom, a nurse who is the project's liaison between medical staff and patients. "It was assumed that the physicians would support this, and it was also assumed that patients would be enthusiastic," Nordstrom says. "Truly? It took 18 months to build acceptance. The theoretical models don't roll out that easily."

Nordstrom says she spent weeks calling diabetic patients to explain the new chronic care system. She emphasized the self-management side of the chronic care model, and invited them to one-on-one educational meetings as well as group seminars on topics such as foot care. "I'd go through all this and the patient would say at the end, 'Who are you again? Why isn't my doctor calling me?'" Over time, however, patients caught on and began to welcome the attention from others besides their doctors.

"One of the first things we did was tell the patients with diabetes that they had to come in for four visits a year, and that they needed to get their blood work done ahead of time so they could discuss the results with their doctor," Nordstrom says. This helped change doctor-patient dynamics by enabling face-to-face discussion of test results in contrast to a thumbs-up, thumbs-down note in the mail. Physicians also made a point of asking patients to choose their own self-management goals—losing five pounds, say, or adding 100 yards to their daily walk.

Members of the medical staff say clinical results for diabetes have been impressive, leading to a new experiment in secondary prevention for patients with heart disease. And as the Polyclinic lab tallies the evidence of improved outcomes, David, the chief executive officer, is deploying this performance record at the bargaining table, pushing for enhanced fees and year-end bonuses from health insurers if Polyclinic patients stay out of the hospital. He acknowledges the Polyclinic's negotiating advantage as a large and sought-after provider in Seattle's health care market.

“We’re able to have a dialogue with the insurers around this issue of reimbursement,” David says. “Small practices don’t. They just get a take it or leave it letter.”

State: Rhode Island

The objective of Rhode Island’s ICIC project was to implement the chronic care model statewide over time in all primary care settings. It tested the model in a select group of sites, and succeeded in meeting benchmarks for clinical improvement. But project leaders also discovered how taxing and expensive the process can be, particularly in small medical practices. Rhode Island has few large groups like the Polyclinic. Most physician practices are small partnerships, reflecting the national physician workforce. The state also has a network of community health centers at 26 sites, as well as outpatient clinics at its 15 hospitals. Through collaboration with ICIC, Rhode Island hoped eventually to roll out the chronic care model broadly enough to persuade all primary care practices to move to this standard of diabetes care.

To address the financing side, project leaders invited health insurers to be part of the collaborative. These partners included the state’s dominant private insurers, Blue Cross & Blue Shield of Rhode Island and United Healthcare; the quasi-public health plan for low-income families, Neighborhood Health Plan of Rhode Island; and the Medicare oversight commission in Rhode Island, Quality Partners.

“After 20 years in public health, this was the best idea I’d heard,” says Dona Goldman, the health department nurse who spearheaded Rhode Island’s ICIC project. Goldman, head of the state’s Diabetes Prevention and Control Program for more than 20 years, was convinced that standardizing disease management via the chronic care model could significantly improve the health status of Rhode Island’s diabetics, whatever their circumstances.

“Initially, there were docs who felt they had nothing in common with health center docs or clinic docs and vice versa,” Goldman says. “But if we divide ourselves into the haves and have nots, we can’t make this happen, not to mention that we’re all paying the price of not doing this better. So I said, ‘No, we are not going forward divided.’”

Voting with the majority of ICIC test sites, Rhode Island chose diabetes to test the chronic care model. The reasons were historical, epidemiological, and political. The state health department and community health centers were already working to improve diabetes care under a program sponsored by the Centers for Disease Control and Prevention to reduce health care disparities. One in 11 adults in Rhode Island, or 60,000 people, are diabetic, and health officials estimate that 30,000 more have the disease but don’t know it.⁶ There has also been an alarming uptick in prediabetic symptoms among teenagers and young adults, suggesting an even heavier burden of illness to come.

The political arguments, however, nailed the case. In order to keep its broad coalition together, Rhode Island needed the hard data on clinical improvement and cost savings that diabetes uniquely delivers. The strategy worked, and diabetes care demonstrably improved at the project’s test sites. The evidence was showcased at an outcomes conference in late 2005, including better HbA1c scores and

compliance with annual eye and foot exams. Clinicians using the chronic care model to guide diabetes management also testified to learning curves as illuminating as Gregory John's.

But a different set of numbers motivated the behind-the-scenes discussion as Rhode Island's program neared the end of its ICIC funding. Two to one, participants questioned the sustainability of clinical improvements without buy-in on health care's financing side. The numbers they wielded illustrated the perverse incentives of the current system. While office visits to monitor and teach diabetics self-management earn fees of \$75 to \$150, acute events are paid in Rhode Island as follows:

- Hospitalization—\$7,285
- Leg or foot amputations—\$16,288
- Retinal surgery—\$7,420
- Coronary artery disease—\$8,020⁷

"There's a lot of potential reward for *not* doing this," says the obstetrician-gynecologist and co-chair of the collaborative, Deirdre Gifford, who thinks the chronic care model underplays the business imperatives of survival. By ditching the patient education and support and seeing diabetics only when they have problems, "you could have a very lucrative practice," Gifford argues.

Heidi Brownlie, a family doctor and chronic care model champion in a five-physician practice, has similar misgivings. "We are finding this very time-consuming," she says. "The practice hasn't bought into this"—by hiring additional staff—"so it is falling on the providers' shoulders. For me, that means I'm taking 30 minutes rather than 15 with these patients and then I have to cut time with other patients to make up for it."

Having insurers in the collaborative was educational, but yielded no immediate solution to the concerns raised by Gifford, Brownlie, and others. Blue Cross Blue Shield and United Healthcare each made lump-sum donations to augment grant money from ICIC, and more recently began piloting incentive pay formulas with certain physician groups. Beyond that, their efforts have largely been confined to aligning internal monitoring systems with the medical quality standards embedded in the chronic care model. United Healthcare, for example, has built patient education messages into its subscriber Web site (www.myuhc.com). Both companies also track physician compliance with standards of care, and send reminder letters similar to the one received by the Polyclinic's Gregory John.

Private practitioners aren't the only ones worried about sustaining the chronic care overhaul made possible by ICIC grants. Community health centers are also uneasy, despite an organizational structure in which physicians are salaried and some revenue is guaranteed by government subsidy. The sustainability issue curbed everyone's enthusiasm, even those most excited by the evidence of improved health in their patients. "We only get paid for illness," says Ernest A. Balasco, former executive director of Wood River Health Services. "We pray for good flu seasons, we pray for big allergy seasons, because then our office visits go up and we get reimbursed."

Adds Donna Fantel, Wood River’s chronic care coordinator, “In some ways, we are kind of shooting ourselves in the foot by doing this, because we are actually preventing the kinds of visits that are well reimbursed.”

Conclusion

In the early weeks of 2006, the *New York Times* ran a front-page series that neatly framed the mission, the experience, and the wisdom of ICIC.

Published between January 9 and 12, the articles chronicled the escalating toll of type 2 diabetes on lives, families, and health care resources. The January 11 installment dealt with the health care system’s skewed financial incentives. Headlined, “In the Treatment of Diabetes, Success Often Does Not Pay,” the article detailed what ICIC collaborators can rattle off in their sleep: how prevention can be a financially ruinous proposition for health care organizations when insurers fail to adequately cover self-management tools like blood sugar test strips (75 cents apiece), but pay generously for a \$12,923 prosthetic lower leg following amputation.⁸

The *Times* series echoed the points made by Lloyd David at the Polyclinic, Ernest Balasco at Wood River Health Center, and Deirdre Gifford of the Rhode Island Chronic Care Collaborative about the difficulty of going forward with chronic care improvements absent a means to pay the upfront costs. And while there has been no dearth of effort nationally to build the so-called business case for improved medical care quality, theoretical projections of future savings aren’t cutting it in the current political environment. Public panic over health care affordability has everyone clamoring for savings now.

ICIC grantees had to contend with this political climate. Wagner might be theoretically correct in saying, “Money isn’t the problem; misdirected money is the problem,” but those implementing the chronic care model had to navigate business environments caught up in the national distress over health care costs. While many physicians, nurses, patient educators, clinic managers, and others enthusiastically endorsed the model’s logic, they had a harder time documenting cost savings through better disease management.

The upfront costs, meanwhile, made grantees uneasy. These included salaries for new staff to take on patient education and case management duties, computer upgrades to build disease registries, and expenses associated with being at the leading edge of change. For example, managers said the chronic care model requires training beyond traditional workplace orientation programs to bring new hires into sync with the team approach to patients—investments difficult to justify without clear evidence of payback. The question forever hovered: “How can I sell this to the boss?”

But ICIC’s mission wasn’t to figure out how to treat people more cheaply. It was to treat them better. In order to do so, the environment of primary care had to be re-engineered to one that was more suited to 21st century health threats and remedies. The chronic care model was the means to that end. Reports from the field support ICIC’s premise. Clinicians say that utilizing the model makes their approach to chronic patients more proactive, resulting in evidence of improved medical

care quality. Patients report greater confidence in self-management and greater support from the medical team.

The questions about financing are valid, but they reflect ICIC's external environment more than they are a substantive commentary on the chronic care model. By metronomic repetition, cost control has so dominated the conversation about health care that worthy experiments in other areas struggle to be heard.

It's the government's job to fix the financing. And the work is under way. Congress and the Centers for Medicare & Medicaid Services—standard-setters in health care financing since Medicare was launched in 1965—are in the middle of a large pay for performance research and demonstration project. There are hundreds of test sites in every imaginable health care setting: nursing homes, hospitals, home health care agencies, dialysis facilities, clinics, and physician practices of every size. Code-named P4P, the government's effort is exploring many of the ideas floated by ICIC grantees to build into health care's financing structure incentives and subsidies to improve medical care. The support from health care leaders is such that just about every A-list health care organization has joined the experiment, including the Joint Commission on Accreditation of Healthcare Organizations, the Agency for Healthcare Research and Quality, the National Committee for Quality Assurance, and the American Medical Association.

By contrast, ICIC seems puny. Nevertheless, its contributions to the collective goal of improving health care are significant. ICIC helped show how the architecture of medical care—office organization, staff deployment, hierarchy, and attitudes toward patients—affects the quality of care. The chronic care model offers a process for changing that architecture so that clinicians and patients can work as partners in managing disease and preventing complications. ICIC grantees demonstrated the model's flexibility by adapting it to a wide range of primary care settings.

This flexibility has applicability beyond current medical practice. If there is a given in today's health care environment, it is the rapid pace of developments in science and technology. In diabetes alone, better drugs and devices for monitoring and responding to changes in blood sugar have dramatically improved the precision with which clinicians and patients are able to manage insulin deficits. Looking ahead, it may soon be possible to intervene at the genetic level, before symptoms even appear. Elias Zerhouni, director of the National Institutes of Health, outlined the promise of ongoing research aimed at such "preemptive" treatment in an interview earlier this year in *Health Affairs*.⁹ The chronic care model has the capacity to not only adapt to new science but also to streamline its introduction into clinical practice.

Work remains, however. Among the lingering issues is the slow process of organizational and personal change. The Polyclinic internist Gregory John, now a champion of the chronic care model, says it took him close to a year to let go of professional patterns honed over 25 years of medical practice. Nikki Nordstrom, nurse coordinator of the Polyclinic's chronic care team, pegs conversion time at 18 months for both clinicians and patients. Are there ways to accelerate this?

One answer may come from the next iteration of ICIC—a collaboration with the Association of American Medical Colleges. The goal is to build the concept of proactive team management of chronic illness into medical school curricula and residency training. If the next generation of physicians is educated to expect disease management support for chronic patients, health care organizations will have another incentive to restructure: competition for medical talent.

Another issue is the chronic care model's dependence upon electronic patient records as the structural base for disease registries and population data retrieval. While many medical quality schemes presume a universal patient database, this currently doesn't exist, nor, because of privacy concerns, is there a consensus that it should. Most physician offices in the United States still rely on paper records.

Finally, there is the question of how far ICIC principles of disease management teamwork can extend into the communities where people with diabetes, asthma, and other incurable conditions live and work. Risa Lavizzo-Mourey, president and chief executive officer of the Robert Wood Johnson Foundation, emphasizes the importance of this outreach, saying that she envisions a day when chronic patients are supported in the task of self-management to the degree that those who want to avoid tobacco hazards are aided by public smoking bans.

"Patient-centered care, which is the crux of the chronic care model, essentially comes down to the health system's being oriented to helping patients achieve *their* goals," Lavizzo-Mourey says. "We have to find the baseline elements that cross diagnoses in order to be able to codify systemwide approaches."

Notes

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