Improving Chronic Illness Care: Translating Evidence Into Action

Interventions that encourage people to acquire self-management skills are essential in chronic illness care.

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ABSTRACT: The growing number of persons suffering from major chronic illnesses face many obstacles in coping with their condition, not least of which is medical care that often does not meet their needs for effective clinical management, psychological support, and information. The primary reason for this may be the mismatch between their needs and care delivery systems largely designed for acute illness. Evidence of effective system changes that improve chronic care is mounting. We have tried to summarize this evidence in the Chronic Care Model (CCM) to guide quality improvement. In this paper we describe the CCM, its use in intensive quality improvement activities with more than 100 health care organizations, and insights gained in the process.

THE NUMBER OF PERSONS WITH CHRONIC ILLNESS is growing at an astonishing rate because of the rapid aging of the population and the greater longevity of persons with many chronic conditions. Fortunately, the effectiveness of care of major chronic illnesses such as hypertension, congestive heart failure, depression, and diabetes has been enhanced by much recent progress in clinical and behavioral interventions. But many persons receiving care for these conditions are not reaping the benefits of these advances. For example, recent surveys suggest that fewer than half of U.S. patients with hypertension, depression, diabetes, and asthma are receiving appropriate treatment.[1]

Why is care for chronic conditions so deficient? A recent Institute of Medicine (IOM) report attributes the quality gap to (1) the in-

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creased demands on medical care from the rapid increases in chronic disease prevalence and the complexity of the underlying science and technology; and (2) the inability of the system to meet these demands because of our poorly organized delivery system and constraints in using modern information technology.[2]

Our care systems were organized historically to respond rapidly and efficiently to any acute illness or injury that came through the door. The focus was on the immediate problem, its rapid definition and exclusion of more serious alternative diagnoses, and the initiation of professional treatment. The patient's role was largely passive. Since the full clinical course often played out over days or weeks, there was little urgency to develop patient self-management skills or tracking programs. Most practices continue in this vein despite the rapid aging of the population and growing prevalence of chronic disease.[3] According to the IOM, if the fundamental problem is the design of the system, then improvements in care "cannot be achieved by further stressing current systems of care. The current systems cannot do the job. Trying harder will not work. Changing systems of care will."[4] Improvements in the quality of chronic illness care require more than evidence about efficacious tests and treatments. They also require evidence about the system changes that produce better care and quality improvement methods to implement such changes.

In this paper we describe system changes associated with improvements in chronic illness care, the organization of these changes into a framework to guide quality improvement (the Chronic Care Model), and the use of the model by more than 100 health organizations in collaborative quality improvement activities. We also discuss the lessons learned through these efforts and their policy implications.

Derivation Of The Chronic Care Model

■ **Needs of patients with chronic illness.** Regardless of age at onset, whether their etiology is known or whether their manifestations are primarily physical or psychosocial, essentially all chronic conditions present a common set of challenges to the sufferers and their families—dealing with symptoms, disability, emotional impacts, complex medication regimens, difficult lifestyle adjustments, and obtaining helpful medical care. Many chronically ill persons wrestle with the physical, psychological, and social demands of their illness without much help or support from medical care. More often, the help received, while well intentioned, fails to afford optimal clinical care or meet persons' needs to be effective self-managers of their illness.

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A colleague with rheumatoid arthritis likens the experience of living with chronic illness to flying a small plane. If it is flown well, one gets where one wants to go with the exhilaration of mastering a complicated set of challenges. If it is flown badly, one either crashes or lands shakily in the wrong airport, reluctant to ever leave the ground again. The patient must be the pilot, because the other possible pilot, the health care professional, is only in the plane a few hours every year, and this plane rarely touches ground. If chronically ill patients must pilot their planes, then the role of health care is to ensure skilled pilots, safe planes, flight plans that safely get the pilots to their destinations, and air traffic control surveillance to prevent mishaps and keep them on course. Medical care then must assure that persons with chronic illness have the confidence and skills to manage their condition; the most appropriate treatments to assure optimal disease control and prevention of complications; a mutually understood care plan; and careful, continuous follow-up. Well-designed interactions between practice team and patient will be needed to complete the important clinical and behavioral work of modern chronic illness care. Evidence suggests that the typical acute problem–oriented visit is a barrier to such care.

■ **Systems of care that meet the needs of the chronically ill.** Decades ago, pioneers such as John Runyon recognized that the effective management of chronic illness requires a new kind of practice designed expressly to help patients meet the challenges of chronic disease.[5] More recently, stronger evidence suggests that busy practices can redesign their care and do much better than "care as usual." For example, a recent Cochrane Collaboration review carefully examined the more rigorously tested interventions to improve primary care for diabetes.[6] Among the forty-one studies examined, many showed increases in recommended care processes such as the prevalence of eye or foot examinations and a few improved health and disease-control outcomes. For example, in a few recent randomized controlled trials the group receiving the experimental program achieved average improvements in blood sugar control (reduction in HbA1c of 1 percent or more) that, if sustained over time, would result in a 21 percent reduction in mortality, a 14 percent reduction in myocardial infarction, and a 37 percent reduction in microvascular complications.[7]

The successful approaches identified by the Cochrane review team were most often multifaceted. They included one or more of the following: provider-oriented components such as continuing education or physician feedback, organizational changes in personnel or the management of visits and follow-up, information systems changes, and patient-oriented interventions of an educational or

supportive nature. The researchers concluded that the more comprehensive the intervention, the more likely it was to be successful. Combinations of various forms of provider education, computerized tracking and reminder systems, and organized approaches to follow-up achieved the greatest success in improving process indicators such as foot and eye exams.

The Cochrane diabetes review also found that even complex interventions that only target providers' behavior did not change patient outcomes unless accompanied by interventions directed at patients. This critically important observation confirms our observation based on reviewing earlier literature that chronic disease interventions that positively affect patient well-being necessarily include systematic efforts to increase patients' knowledge, skills, and confidence to manage their condition.[8] The Cochrane researchers conclude that "there are a number of multifaceted models [now] being tested. The choice of components within the models has often not been based on a theoretical or empirical rationale. Future research should...evaluate reproducible complex interventions and encourage replications of using the same model."[9] We had independently arrived at the same conclusion in our efforts to improve chronic illness care at Group Health Cooperative.

The Chronic Care Model

The lack of a common performance improvement framework is not unique to diabetes and has been a barrier to quality improvement efforts in chronic disease. With support from the Robert Wood Johnson Foundation (RWJF), we have tried to develop a guide to chronic care improvement (the Chronic Care Model, or CCM) that is consistent with the literature and useful to diverse health care organizations wanting to improve the care of their patients with chronic illness. The RWJF then gave us the opportunity to use and extend the model in a national program whose goal is to help large numbers of health plans and provider groups, especially those that serve low-income populations, improve their care of the chronically ill.

The national Improving Chronic Illness Care program consists of three major components: (1) a quality improvement-evaluation program in concert with the Breakthrough Series run by the Institute for Healthcare Improvement (IHI); (2) a dissemination program to provide technical assistance and support to interested organizations; and (3) a research grants program to address specific, field-relevant questions in chronic illness management.[10] A central activity of the program is the use of the CCM in collaborative chronic disease improvement programs involving large numbers of diverse health care delivery organizations.

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■ **Assuring productive interactions.** What characterizes effective chronic illness care? The recent IOM report listed ten rules for creating a higher-quality health system.[11] Of particular relevance to chronic care, these rules stress continuous relationships with the care team, individualization of care according to patients' needs and values, care that anticipates patients' needs, services based on evidence, and cooperation among clinicians. What would chronic illness care look like if these rules were in place?

We assume that every chronically ill person has a primary care practice team that organizes and coordinates their care. Whether led by a generalist physician, a nurse practitioner, or a medical subspecialist, this team tries to optimize patient outcomes through a series of interactions during which they (1) elicit and review data concerning patients' perspectives and other critical information about the course and management of the condition(s); (2) help patients to set goals and solve problems for improved self-management; (3) apply clinical and behavioral interventions that prevent complications and optimize disease control and patient well-being; and (4) ensure continuous follow-up.

High-quality chronic illness care is characterized by productive interactions between practice team and patients that consistently provide the assessments, support for self-management, optimization of therapy, and follow-up associated with good outcomes. These interactions do not necessarily require face-to-face visits. Ample evidence documents the effectiveness of using the computer or telephone for this purpose.[12]

Interactions are more likely to be productive if patients are active, informed participants in their care. Patients must have the information, skills, and confidence to make best use of their involvement with their practice team. On the other side of the interaction, practice teams must have the necessary expertise, relevant patient information, time, and resources to act, rather than just react, to ensure effective clinical and behavioral management.

Assuring productive interactions that consistently provide evidence-based clinical care and self-management has proved to be extremely difficult in current medical practice. Based on our reviews of effective chronic disease interventions in the literature and by surveys of reputable programs, we posit that they achieve better disease control, higher patient satisfaction, and better adherence to

guidelines by redesigning delivery systems to meet the needs of chronically ill patients.[13] Such interventions appear to cluster in six areas: health care organization, community resources, self-management support, delivery system design, decision support, and clinical information systems. These areas resemble the categories used by the Cochrane diabetes reviewers, albeit with different labels.[14] For example, we use the term "decision support" to describe interventions directed at improving the knowledge and skills of providers. The Cochrane reviewers called these "provider-oriented." What the Cochrane reviewers called "patient-oriented," we call "self-management support." "Clinical information systems" appears in both schemes. We also divided interventions that the Cochrane reviewers labeled "organizational" into two groupings: "delivery system design" changes in clinical personnel and patient flow, and "health care organization" to encompass changes at the larger organizational level. We also added a new area of importance for many chronic diseases, linkages with "community resources."

We then attempted to define the specific interventions within each category associated with better outcomes and to suggest how the components affect patients, providers, and their interactions in producing better care. The result, the CCM, is a synthesis of evidence-based system changes intended as a guide to quality improvement and disease management activities.[15] The CCM is not an explanatory theory. It is, like an evidence-based guideline, simply a synthesis of the best available evidence. It is intended to be flexible and subject to change when new evidence emerges. The development of the model and the important role of a large group of advisers in its development have been described elsewhere.[16]

■ **The CCM elements.** The CCM depicts the health system as part of the larger community and the practice as a part of a health organization, even a small one such as a one- or two-provider office. Effective chronic illness management requires an appropriately organized delivery system linked with complementary community resources available outside the organization. The CCM represents the enhancements to the organization and its practices that contribute to productive interactions between providers and patients.

Effective self-management support and links to patient-oriented community resources help to activate and inform patients and families to better cope with the challenges of living with and treating chronic illness. Traditional patient education emphasized knowledge acquisition and didactic counseling. Mounting evidence indicates that while such interventions increased knowledge, they were unsuccessful in changing behavior or improving disease control and other outcomes.[17] More recent theoretical and empirical research has

shifted the focus from patients' knowledge of the disease and its treatment to their confidence and skills in managing their condition.[18] The interventions that have emanated from this research reinforce the patient's (and family's) crucial role in managing the condition, help patients to set limited goals for improving their management of their illness, identify barriers to reaching their goals, and develop a plan to overcome the barriers.

To enable practice teams to have productive patient interactions, the organization must assure that the teams have the expertise to provide appropriate clinical and behavioral management. The effective control of most chronic diseases requires appropriate medical therapy as well as competent self-management. Guidelines or protocols are useful starting points. But effectiveness studies consistently show that introducing guidelines has only a minimal impact on quality unless guidelines are integrated into the practice through education, reminders, specialist involvement, or other decision-support interventions.[19]

Most practices do not have standardized or organized approaches to collecting, summarizing, and reviewing individual or aggregate patient data to facilitate care. Effective programs assure access to timely, relevant data about individual patients and populations of patients from clinical information systems. A computerized disease registry that includes critical information about each patient and the performance and results of important aspects of care enables care teams to call in patients with specific needs, deliver planned care, receive feedback, and implement reminder systems.

Effective chronic illness management calls for a delivery system design that encourages and enables productive interactions. The multiple tasks involved are more likely to be accomplished with the delegation of care from the physician to others on the team. Several studies have demonstrated the added benefits of ready access to nurse case managers and other professionals who have the skills and time needed for optimal self-management support and assistance with disease control.[20] Chronic disease management also benefits from innovations in the scheduling and organization of visits.[21]

The longer time horizon and fluctuating course of many chronic illnesses requires regular interaction between caregivers and patients. The IOM report described this as a "continuous healing relationship" and argued for the increased use of methods of interaction other than face-to-face visits.[22] The use of the telephone, for example, allows for more intensive, yet cost-efficient, follow-up of chronically ill patients and has been associated with improved outcomes in a variety of chronic diseases.[23]

Making the necessary changes in these areas is difficult, if not

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impossible, without strong leadership, appropriate incentives, and effective improvement strategies from the health care organization.

■ **Using the CCM to improve chronic illness care.** The quality improvement component of Improving Chronic Illness Care has afforded opportunities to examine the validity, utility, and effectiveness of the CCM for several chronic diseases among diverse health care systems. The Breakthrough Series (BTS), developed by the IHI, brings together groups of health care organizations that share a commitment to making major, rapid system changes.[24] In collaboration with the IHI, we have completed three national chronic condition BTSs involving a total of 104 health care organizations in twelve-to-thirteen-month quality improvement programs. Each organization used the CCM to design and test system changes to improve the care of a single chronic condition such as diabetes or asthma.

Each organization's quality improvement team works on the improvement plan involving a pilot population of approximately 100–500 patients with the particular condition and their caregivers. From the outset, faculty urge organizations to engage in comprehensive system change by implementing changes in all six areas of the CCM. Teams regularly collect data from the pilot population on predefined indicators of success and submit monthly reports that include their updated measures and the changes undertaken.

The first chronic illness BTS included twenty-six organizations working on diabetes and six on preventing frailty in the elderly; the second involved sixteen organizations working on congestive heart failure and ten on diabetes care; and the third included twenty-three organizations working on asthma and another twenty-three working on depression.

Participating organizations varied widely in size, and most were predominantly reimbursed by fee-for-service (FFS). Nearly half were community health systems supported by the Health Resources and Services Administration's (HRSA's) Bureau of Primary Health Care (BPHC). The remainder included twelve managed care organizations, fourteen academic health center practice organizations, twenty hospital systems, and thirteen others. The experience of the organizations working on diabetes in the first national BTS has recently been published.[25] Participating organizations achieved substantial increases in evidence-based practice and improvements in

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glycemic control. We have recontacted these organizations to assess the extent to which the changes made in the BTS have been continued and spread to other parts of the organization. Two-thirds of the organizations reported that changes spread both to other parts of the organization and to other clinical conditions.

Lessons Learned About The Chronic Care Model

■ **The need for comprehensive system change.** Our experience in the three BTSs confirmed the premise that effective chronic illness management requires comprehensive system changes that entail more than simply adding new features to an unchanged system focused on acute care. Many organizations initially hoped that relatively noninvasive system enhancements such as the introduction of guidelines or disease registries would produce changes in their goal attainment measures. It became apparent to them that changes in process and outcomes would not occur unless preceded by fundamental changes to the design of practice and the provision of self-management support. In the end, most organizations did make significant changes in all six elements of the CCM, but it took some organizations time to see the connections between the changes made across model areas.[26] Early efforts would include unconnected plan-do-study-act (PDSA) cycles such as the introduction of flow sheets that neither eliminated the need for writing a separate note in the chart nor provided data to feed the registry. Eventually, most organizations appreciated the interconnectedness of model components and created changes that capitalized upon or contributed to it.

■ **BTS success and organizational size and structure.** We have often heard it said that the CCM may be useful for large managed care organizations such as Group Health Cooperative but may be inappropriate or unattainable in smaller practices, especially if reimbursed largely by FFS. Our BTS experience confirmed the relevance of the CCM as a guide to system change in delivery systems of diverse size and financial structure. Whereas smaller systems faced greater challenges in obtaining access to expertise and resources such as computerized data, their more visible leadership, shared vision, camaraderie, and relative absence of bureaucracy were advantages. Small systems performed as well as did larger ones. Most BTS participants received the majority of their revenues through FFS arrangements yet were able to make comprehensive system changes and demonstrate improvements in care. However, FFS payment clearly created disincentives to test different ways of using existing personnel or organizing visits or follow-up.

■ **Reexamination of the six CCM elements.** The experiences of the BTS participants and recent advances in the literature have

prompted a reexamination of the six CCM elements. The specific system recommendations are included under each element below.

Health care organization. Although there is little quantitative evidence documenting the importance to quality improvement of characteristics of the practice organization, those engaged in efforts to improve care regularly observe their significance.[27] Our BTS experience confirmed these observations. The visible support and promotion of the chronic disease improvement project by organization leaders was a major predictor of success. Conversely, lack of leadership support, or turnover in leadership, were primary predictors of failure. Senior leaders were instrumental in securing resources or removing barriers that may stall quality improvement activities. For example, the development of registries and other computer functions often required juggling the priorities of information systems staff. Having chronic illness improvement represented in the organization's goals and business plan encourages senior leaders' involvement and support. Also, financial and nonfinancial incentives to providers are presumed to influence clinicians' behavior in chronic disease care, but evidence is scant. The BTS experience suggests that the removal of disincentives may be as or more important in changing clinical behavior. For example, requirements for providers to see a minimum number of patients in a day discouraged experimentation with proven chronic disease interventions such as group visits or telephone care. Finally, the change methods used by the organization to improve quality of care may have a major influence on their success. Several recent randomized trials have shown that more traditional continuous quality improvement approaches may not be effective in making measurable changes in quality of care.[28] Although self-selected, the BTS participants demonstrated that a quality improvement approach that emphasizes goal-setting, rapid change cycles, and careful measurement of goal attainment may be more effective.

Community resources. In all three BTSs, organizations benefited from a variety of services and resources that were not available in their own organization. Increasing access to effective programming in the community through linkages with the relevant agencies was a cost-effective way to obtain important services such as nutrition counseling or peer-support groups. Similarly, negotiations with other health care organizations in the community were often important to enhance continuity of care and expand services or to gather data useful to the registry. For example, ambulatory care organizations negotiated new relationships with neighboring hospitals or specialty groups to gain access to self-management classes or nurse educator services, or with their commercial laboratories to get

downloads of laboratory data for their registries. Community linkages proved to be especially useful for smaller organizations.

Self-management support. The evidence shifting the focus from didactic patient education to encouragement and support for more effective self-management is relatively new and still incomplete. There is now considerable evidence that individual and group interventions that emphasize patient empowerment and the acquisition of self-management skills are effective in diabetes, asthma, and other chronic conditions.[29] Most of these interventions are relatively brief and conducted outside of medical practice. They generally emphasize the patient's crucial role in maintaining health and function and the importance of setting goals, establishing action plans, identifying barriers, and solving problems to overcome barriers. With a few exceptions, the tested interventions do not include long-term support for patient self-management or efforts to engage the primary care team. Because long-term self-management support from this team appeared to be a logical extension of current research, we encouraged BTS participants to integrate collaborative goal setting, action planning, and problem solving into routine care. Routine assessment of self-management practices and the inclusion of self-management goals in the registry helped many organizations to keep attention focused on self-management. Many organizations believe that they provided self-management support, assuming that it was a new jargon term for traditional, didactic classroom teaching or counseling. We began including self-management demonstrations and role playing in learning sessions to help communicate the differences.

Delivery system design. Delivering high-quality chronic illness care demands planning and the coordinated actions of multiple caregivers. Many of these actions do not require clinical training and could be most efficiently and consistently performed by nonprofessional team members. However, increasing evidence supports the value of access to more sophisticated clinical case manager functions.[30] These functions, generally performed in studies by experienced chronic disease nurses or pharmacists, include support for self-management and behavior change, close follow-up to assess response to therapy and self-management competence, and adjustment of treatment by protocol. Among our BTS participants, the behavioral change and medication adjustment roles were often beyond the training of current practice team members. They responded by delegating functions such as telephone follow-up and severity assessment to existing team members and developing linkages with other parts of the organization or with specialty practices or hospitals to gain some access to the more complex clinical case

manager functions. Most BTS participants used registry information to organize planned individual or group visits. These visits were often used as a vehicle for multidisciplinary care (one-stop shopping) by providing access to services such as nutrition counseling, podiatry, dentistry, and respiratory therapy. Finally, most BTS organizations increased the use of telephone contact to enhance patient follow-up, although the inability to get reimbursement was a barrier.

Decision support. Our BTS experience is consistent with the evidence indicating that guidelines become effective provider behavior change agents only when they are woven into the fabric of patient care. Most BTS participants attempted to do this by incorporating guidelines into the registry, flow sheets, and patient assessment tools. For example, organizations were encouraged to develop or adopt registries that provide reminders of overdue services and generate summary reports at the time of encounters that included reminders. These summary reports were particularly effective if they also served as the visit medical record. Related practice tools included disease severity assessments that link resulting severity indicators with recommendations for changes in treatment.

We urged the teams to improve the relevant skills of practice team members through the use of more effective training methods, but their limited availability in most systems remained a barrier. We also urged teams to develop new relationships with relevant medical specialists, which would ensure appropriate care for the more severely ill and educational opportunities for primary care teams. Some BTS participants developed electronic communications with specialists (such as telemedicine consultations or routine review of automated primary care records of chronically ill patients) or increased communication with local specialty groups or mental health centers. But many participants did not test changes with this aspect of decision support. Although the impacts are not well known, many teams shared guidelines or expectations for care with their patients. Patients' positive responses encouraged continuation of these efforts.

Clinical information system. Nearly all BTS participants had a functioning registry of some type by the end of the year. The availability of personal computer registries using database software greatly aided this. Most organizations used claims diagnoses to populate their registry for lifelong conditions such as diabetes or congestive heart failure. Many organizations working on depression and asthma chose to accrue patients prospectively because of the intermittent nature of the symptoms and, in the case of depression, the insensitivity of diagnostic codes. Creating the capability for the reg-

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istry to produce treatment planning reports that served as the visit record proved to be a critical step in improving care for many BTS teams.

■ **Facilitators and barriers to chronic disease improvement.** We regularly asked BTS participants to identify factors outside of their practice organization that accelerated or obstructed chronic disease improvement. The factors most often mentioned were reimbursement policies and the behavior of health plans and insurers.

The BTS revealed growing discrepancies between current reimbursement policies of the Centers for Medicare and Medicaid Services (CMS, formerly HCFA) and private insurers and interventions shown to improve chronic disease care. These barriers and potential remedies were discussed in detail in the IOM *Quality Chasm* report. The experiences of the FFS participants highlighted three areas of particular concern: non-visit methods of interaction, group interactions, and self-management support. Current policies generally do not provide reimbursement for telephone or other patient-provider interactions that are not face-to-face, care for patients in group settings, or many patient education activities, despite the impressive array of evidence supporting their efficacy and efficiency. This often generated resistance to these changes among senior managers.

Most BTS participants served patients enrolled in multiple health plans and insurance companies. Many plans and insurers provided performance feedback to providers, and some promoted the use of guidelines, plan-specific disease registries, and patient materials among their enrollees with various chronic diseases. Some plans even contracted with disease management companies to provide aspects of chronic disease care. On the one hand, most BTS participants contracting with multiple health plans complained about the confusion and extra work created by disparate, generally uncoordinated, and occasionally antithetical disease management activities. The lack of agreement among guidelines, performance indicators, and other disease management efforts was often cited as a deterrent to delivery system–directed quality improvement activities. On the other hand, we saw several instances in which health plans provided valuable services or tools to participating organizations. Of particular help to smaller practices was information system consultation or support.

THE CHRONIC CARE MODEL is like an evidence-based guideline: a synthesis of system changes to be used to guide quality improvement. Its feasibility and acceptability in helping health care organizations to improve quality have now been affirmed by the positive reactions and behaviors of the organizations

described above and many others. Whether its implementation is followed by diffusion throughout an organization or by long-term improvements in the process and outcomes of care has been and continues to be the subject of study. The experience using the CCM in organized quality improvements described above has helped us to refine and improve the CCM and, more importantly, to develop a better understanding of what it will take to close the quality chasm for persons with chronic illness.

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