

Chronic Illness Management: What Is the Role of Primary Care?

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An estimated 99 million Americans live with a chronic illness. Meeting the needs of this population is one of the major challenges facing the U.S. health care system today and in the future. Dozens of studies, surveys, and audits have revealed that sizable proportions of chronically ill patients have not received effective therapy and do not have optimal disease control. The consistent findings of generally substandard care for many chronic conditions have spurred proposals that care be shifted to specialists or disease management programs. Published evidence to date does not indicate any clear superiority of these alternatives to primary care.

The defining features of primary care (that is, continuity, coordination, and comprehensiveness) are well suited to care of chronic illness. A rapidly growing body of health services research points to the design of the care system, not the specialty of the physician, as the primary determinant of chronic care quality. The future of primary care in the United States may depend on its ability to successfully redesign care systems that can meet the needs of a growing population of chronically ill patients.

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An estimated 99 million Americans live with a chronic illness (1). Through improved knowledge and treatment, people with chronic diseases are living longer. Meeting the needs of this population is one of the major challenges facing the U.S. health care system today and in the future. This challenge is made more difficult because most chronic illnesses increase in prevalence and severity in old age, and treatment includes advance care planning and management of many comorbid conditions. A majority of Americans with major chronic illnesses are probably not receiving appropriate or effective management (2). The consequences are poor disease control, exacerbations, and complications that far exceed those seen with appropriate care. The U.S. Institute of Medicine has described this difference between usual and appropriate care as the “quality chasm” (3).

Most people with major chronic illnesses such as diabetes, asthma, and depression receive care from primary care clinicians. The Institute of Medicine states that primary care is “the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients and practicing within the context of family and community” (4). If realized in practice, these defining features of primary care—that is, continuity, comprehensiveness, and coordination (5)—match the care needs of chronically ill persons. The complexity of chronic illness and the frequent involvement of more than one caregiver and institution make coordination a cornerstone of high-quality medical care (3).

However, primary care has fallen short in performance and in the eyes of consumers (6). Specialty care has expanded in number of physicians, length of interaction, and territory and often competes directly with primary care for patients. This and the backlash to managed care gatekeeping have fueled arguments about whether the care of patients with major chronic illnesses should be centered in primary care or in specialty practice. In the first part of this paper, we consider evidence that may shed light on this issue. The second part of this paper discusses the charac-

teristics of practice systems associated with better chronic illness care and describes a conceptual model for improving such care.

WHY PRIMARY CARE?

Efforts to improve the care of the chronically ill must begin with the fact that the large majority of such patients (for example, more than 90% of diabetic patients in the United States [7]) receive the bulk of their care in primary care practices and are likely to do so for the foreseeable future. Approximately 58% of all office visits in 1999 were to primary care clinicians (8).

Coordination of care across clinicians and sites is a defining characteristic of primary care and is of critical importance for persons with chronic disease. Consumers place great value on having a clinician or a team of clinicians that is familiar with the “whole” patient and his or her family and is able to communicate and coordinate medical activities across settings and caregivers; in some settings, such a system is associated with better outcomes (9, 10). However, consumers report diminishing satisfaction over time with this integrative function of primary care (6).

The clinical epidemiology of major chronic diseases also suggests a central role for primary care. First, diseases such as diabetes and arthritis have a broad spectrum of severity, with most patients at the less severe end. Second, for most patients with the most prevalent chronic illnesses, pharmacologic regimens involve a limited number of widely used and relatively nontoxic agents. Thus, primary care practitioners can readily meet the clinical needs of most patients with chronic illnesses. However, patients requiring more complex regimens may benefit from a transfer to specialist care. Third, most adults with major chronic diseases have more than one chronic condition. For example, more than half of patients with type 2 diabetes mellitus have concurrent hypertension and another one third or more have clinically apparent coronary artery disease. In addition to increased needs for care coordination, patients

with more than one chronic condition may benefit from primary caregivers who have more general training and clinical experience. Fourth, expertise in behavioral change and self-management support is central to successful care. Primary care clinicians, especially more recent graduates, usually have more training in these areas than specialists.

Arguments favor keeping primary care a principal focus for chronic disease management; however, current performance suggests otherwise. Although we know that a majority of Americans with major chronic illnesses are not receiving appropriate or effective management (2), most studies of the quality of chronic illness care have made no distinctions regarding sources of care or the specialty of the primary clinician. The few available comparative studies of primary and specialty care make it clear that the quality chasm pertains to both.

ALTERNATIVES TO PRIMARY CARE

Specialty Care

Many articles and editorials in the specialty literature advocate shifting the care of chronically ill persons from primary to specialty care. The empirical argument for such a shift can be found in the growing body of evidence demonstrating that specialists are more knowledgeable about the management of conditions associated with their specialty, more aware of guidelines delineating such management, and more likely to use tests and medications in accord with guidelines (11, 12). Evidence also suggests that specialists more quickly change practice to adjust to new developments.

It has been more difficult for investigators to demonstrate differences in clinical and health status outcomes by specialty. In their review of the literature on specialty differences in care, Harrold and colleagues (11) found that specialist-treated patients had better outcomes than generalist-treated patients for myocardial infarction, stroke, and asthma but not for hypertension, diabetes, chronic obstructive pulmonary disease, unstable angina, and low back pain. What might account for the variability in findings? The evidence regarding specialty differences in diabetes care may be instructive. Two large studies found minimal differences between specialists and generalists when both were practicing in typical practice settings, such as health maintenance organizations or private practice (13, 14). Conversely, endocrinologists practicing in specialized diabetes clinics with access to a full range of multidisciplinary resources provided substantially better care and achieved far better disease control than did generalists in the same geographic area (15, 16). These differences suggest the importance of the practice environment or system in determining the nature of care and its consequences.

Arguments opposing the shift of chronic illness care from generalists to specialists include concerns about the receipt of preventive care, the care of comorbid conditions outside of the specialty focus, and cost. The evidence on

specialty differences in preventive care is mixed. Some evidence suggests that specialists are less likely than generalists to provide general preventive services (17, 18). Conversely, several studies have found that specialists are more likely to perform preventive procedures related to their specialty; for example, obstetricians and gynecologists are more likely to provide clinical breast examinations, mammography, and Papanicolaou smears than generalists (19–21). Lafata and coworkers (18) found that diabetic patients cared for by an endocrinologist were more likely to receive diabetes-related preventive measures (for example, retinal examinations) than patients seeing only a generalist but were less likely to receive general preventive measures (for example, Papanicolaou smears).

We were unable to identify any evidence comparing the performance of generalists and specialists in management of comorbid conditions outside the focus of the specialty group. A Canadian study found that patients with diabetes, emphysema, and severe mental disorders were less likely than patients without these conditions to receive estrogen replacement therapy, lipid-lowering medications, or treatment for arthritis (22). Although these data suggest that there may be deficiencies in the care of comorbid conditions, the study did not provide evidence about whether the specialty of the primary caregiver affected the results. Regarding costs, specialist care uses more resources and diagnostic tests and involves longer hospital stays than generalist care (11).

Several commentators have suggested that shared care between primary care physicians and specialists may produce the best outcomes (23, 24). Katon and associates (25) tested a shared care model for the management of patients with major depression. Alternating care between psychiatry and primary care led to substantial increases in the proportion of patients receiving appropriate therapy and in the incidence of recovery from a major depressive episode. Lafata and coworkers (18) examined the care of diabetes in the Henry Ford Health System and found that diabetic patients who saw both a primary care clinician and an endocrinologist were more likely to receive appropriate diabetes-related preventive care and general preventive care services than those seeing either type of clinician alone. Willison and colleagues (26) found that patients in health maintenance organizations who had acute myocardial infarction and were cared for by generalists with cardiology consultation were more likely to receive guideline-directed care than patients treated by generalists alone. The efficient involvement of specialists on primary care teams may offer the optimal combination of knowledge and skills that chronically ill persons need.

Disease Management

Disease management refers to discrete programs directed at reducing costs and improving outcomes for patients with particular conditions. In a recent review, Bodenheimer (27) estimated that there are now more than

200 commercial disease management firms. Many health care organizations have added internal disease management activities as well. However, in California, a mature managed care market, only half of the major health care organizations are using any kind of interdisciplinary team for case or disease management (28). Most often, these teams provide physician feedback and focused educational or case management services for patients with a given condition. Programs vary in the extent to which the primary care practice team is informed and participates in decision making. They range from highly integrated services operating in close collaboration with primary care to “carve-out” models that are separate, condition-specific delivery systems (29). Published evidence of the effectiveness of commercial programs remains scant, but there is growing evidence of the effectiveness of noncommercial clinical case management services that provide clinical management by protocol, self-management support, and close follow-up (30–32). Therefore, disease management or, more specifically, clinical case management services may play an important part in improving care of chronically ill persons, especially if they reinforce rather than undermine continuity and coordination of care by the primary caregiver. Careful study of this issue is urgently needed.

IMPROVING CHRONIC ILLNESS CARE IN PRIMARY CARE

In our view, the extensive rhetoric and posturing on both sides of the generalist–specialist debate miss the point. Care is subpar regardless of the specialty of the caregiver. Is the problem cognitive—that is, are many primary care practitioners simply unaware of effective interventions—or does the root of the problem lie elsewhere? If unfamiliarity with effective therapies were the principal explanation for poor quality, one might expect more bimodal distributions of quality ratings. Instead, the variation in chronic illness care and outcomes from patient to patient within individual practices generally exceeds the variation from practice to practice (33, 34). These findings strongly suggest that even knowledgeable practice teams have difficulty consistently providing optimal care to all of their patients.

Although some of the variation is clearly patient related, we believe that it is principally a function of the organization and orientation of practice. We (35) and others (3, 36) have speculated that primary care systems were originally organized to react to acute illnesses and remain that way despite the increased prevalences of most major chronic diseases. In primary care, attention continues to focus on defining the problem; excluding more serious diagnoses; and initiating treatment, usually in the form of drug prescriptions. In a study of representative family physician visits, Yawn and coworkers (37) found that while visits for diabetes and other chronic conditions included slightly more time for lifestyle and medication counseling than did acute illness visits, total average visit lengths were 10.5 to 11 minutes versus 9.7 minutes, respectively. In

addition, more problems were addressed in the chronic illness visits than in the acute care visits. As a consequence, the care of chronic illnesses is often a poorly connected string of episodes determined by patient problems.

In contrast, high-quality chronic disease care ensures that patients have the confidence and skills to manage their condition; the most appropriate treatments for optimal disease control and prevention of complications; a mutually understood care plan; and careful, continuous follow-up. This requires a longitudinal and preventive orientation manifested by well-designed, planned interactions between a practice team and a patient in which the important clinical and behavioral work of modern chronic illness care is performed predictably.

What characterizes effective chronic illness care? Members of a primary care practice team organize and coordinate patient care through a series of interactions during which they elicit and review data concerning patient perspectives and other critical information about the course and management of the condition or conditions, help patients set goals and solve problems for improved self-management, adjust therapy to optimize disease control and patient well-being, and ensure follow-up.

SYSTEM CHANGES THAT WOULD SUPPORT MORE EFFECTIVE CHRONIC ILLNESS CARE

The literature suggests the need for multifaceted, interconnected changes to the organization and functioning of practice to ensure routine performance of the tasks that are critical to chronic disease care. System changes that lead to improvements in the process and outcomes of chronic disease care are similar for most conditions. To illustrate, consider care for diabetes and for depression, two seemingly different conditions that have been the subject of the largest volume of quality improvement research in primary care.

A recent Cochrane Collaboration review examined 41 studies of interventions to improve diabetes performance in primary care (38). Most studies demonstrated some degree of improvement in care processes, such as hemoglobin A_{1c} testing or the performance of retinal or foot examinations. A few studies showed significant improvements in disease control, such as reduced hemoglobin A_{1c} levels, blood pressure, or lipid levels. The interventions that resulted in the largest positive changes tended to be complex and involved four areas: activities directed at changing clinician behavior, changes to the organization of practice, information systems enhancements, and educational or supportive programs aimed at patients. The most successful interventions addressed all four of these areas. Of particular interest, the only interventions that achieved improvements in such patient outcomes as glycemic control were those that had a strong patient-oriented component. No specific intervention, if used alone, led to major improvements in the quality of chronic illness care. The im-

portance of patient educational and supportive interventions found in the Cochrane diabetes review is consistent with the growing body of literature demonstrating the positive effect of systematic efforts to increase patients' knowledge, skills, and confidence in managing their conditions (39, 40).

Recent reviews of research to improve the care of depression in primary care practice have come to conclusions remarkably similar to those for diabetes (41, 42). For example, Callahan concluded that "achieving guideline-level therapy requires the substantial participation of an informed and motivated patient working in concert with a health care team and health care system designed to care for chronic conditions" (41). On the basis of their reviews of the research, Callahan (41) and Von Korff and colleagues (42) each proposed multicomponent models for depression care that include system changes directed at activating the care system, clinicians, and patients and families. Callahan's proposed system depends on trained, multidisciplinary primary care teams directed by guidelines, performance feedback, and other decision support. These teams ensure that patients receive support for self-management, monitoring, and outreach. Von Korff and colleagues propose the use of the quite similar chronic care model (42).

One of the current authors, along with colleagues, independently arrived at the need for a model to guide efforts to improve diabetes care at Group Health Cooperative in Seattle, Washington (43, 44). On the basis of the literature, interventions were initially tried in a variety of areas, such as registries, guidelines, and patient education, but without an overall vision for the optimal care system. The process of care for Group Health Cooperative's 18 000 diabetic patients improved while costs decreased (45). We then tried to categorize the practice enhancements that improved patient outcomes and organize them in a way that would help guide quality improvement. Our initial categorization, like that of the Cochrane diabetes review (38), included interventions directed at the clinician (guidelines, expert systems), patient (patient education), organization of care (practice redesign), and information systems.

This preliminary scheme was reviewed by a group of advisors and revised (46). Expert systems and guidelines were combined with other interventions to improve clinician expertise under a new rubric: decision support. Patient education became self-management support, reflecting research that shows that information transfer alone was inadequate. Resources in the surrounding community, which are often important to improving care for chronically ill patients, were added. Overarching organizational factors, such as leadership, incentives, and quality improvement strategies, have a major influence on the structure and functioning of practices and care. Finally, many advisors viewed the original framework or model as incomplete because it did not indicate how organizational characteristics and practice system enhancements translated into im-

proved care processes and better outcomes. The current chronic care model and evidence underlying its components have been discussed recently elsewhere (47–49).

The chronic care model posits that better outcomes result from productive interaction with medical care, in which patients routinely receive the assessments, support for self-management, optimization of therapy, and follow-up that are associated with good outcomes. Interactions are likely to be more productive if patients and their families are active, informed participants in care (39). To ensure effective clinical and behavioral management, practice teams must have the necessary expertise, information, and resources to act rather than simply react. The challenge then is to create a delivery system that promotes productive interactions.

The chronic care model includes enhancements to the organization and its practices that contribute to productive interactions between clinicians and patients. Effective self-management support and links to patient-oriented services (for example, exercise programs, hospital chronic disease resources, and support groups) in the community (community resources) help patients and families cope with the challenges of managing chronic illness. Successful practice teams use planned interactions with patients to ensure appropriate clinical and behavioral management and follow-up (delivery system design). Clinical decisions are aided by clear protocols and sufficient expertise (decision support) and access to timely patient and practice information (clinical information system). Making the necessary changes in these areas is difficult, if not impossible, without strong leadership, appropriate incentives, and effective improvement strategies (health care organization).

Several hundred health care organizations have used the chronic care model as a guide to practice change in collaborative quality improvement programs that have addressed diabetes, congestive heart failure, asthma, depression, cardiovascular disease, and arthritis. The experience and lessons learned in these activities to date have been reported elsewhere (50). Both primary care and specialty practices have been involved in these quality improvement efforts. Our experience suggests that motivated practices of all specialties, sizes, and financial arrangements can make an integrated set of system changes in accord with the chronic care model and that most that have done so have experienced improvements in the process and outcomes of care. A rigorous evaluation of these collaborative efforts is under way (51).

THE CARE TEAM

Most successful chronic illness interventions include major roles for nonphysicians, and our quality improvement experience confirms the importance of such persons. The appropriate deployment and use of practice teams seem to be far more important to improving chronic illness care than physician specialty (52). Delegating responsibil-

ity for key tasks in chronic illness care to nonphysician team members (for example, ensuring the completion of disease severity questionnaires, ordering protocol-driven laboratory procedures, or frequent patient follow-up) increases the likelihood of task completion. However, other papers in this supplement point out that physicians have little training or experience with effective team practice and that team practice must be visible to its participants and its patients (6, 29).

New team member functions seem to be required as well. Several studies have shown that nonphysician professionals, such as nurses or pharmacists, who are skilled in modern self-management support and adjustment of therapy by protocol may be critical components of effective chronic disease care (30–32). These clinical case managers are unavailable to most primary care practices, but traditional practice team members, such as nurses, receptionists, and medical assistants, can be trained to perform aspects of clinical case management. For example, investigators have demonstrated improved outcomes when nonprofessionals and computerized telephone systems are used to monitor patients with arthritis (53), diabetes (54), and depression (55). In these instances, standardized assessments were performed and evidence of any difficulties was referred immediately to the physician or a nurse case manager.

CONCLUSION

Demographic shifts are increasing the number of persons with chronic illness, most of whom are receiving the bulk of their medical care from generalist primary care practices. The consistent findings of generally substandard care across many chronic conditions have spurred proposals that care be shifted to specialists or to the growing numbers of commercial or internally developed disease management programs. Published evidence to date does not indicate any clear superiority of these alternatives to primary care. A rapidly growing body of health services research points to the design of the care system, not the specialty of the physician, as the primary determinant of chronic care quality. This same body of research offers guidance in the form of the chronic care model to those committed to changing delivery systems in ways that will improve chronic illness care. These changes attempt to integrate population perspectives and person-centered perspectives and interventions (56). Primary care can play a strong role in chronic illness care, but system support and improvements are critical to its success. The future of primary care may depend on its ability to manage the human and clinical needs of an aging, chronically ill population.

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