

Finding Common Ground: Patient-Centeredness and Evidence-Based Chronic Illness Care

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ABSTRACT

Health outcomes for patients with major chronic illnesses depend on the appropriate use of proven pharmaceuticals and other therapeutic technologies, and effective self-management by patients. Effective chronic illness care then bases clinical decisions on the best, rigorous scientific evidence, or evidence-based medicine. Effective support for patient self-management includes efforts to increase patient participation in care and collaborative goal-setting and planning of treatment. These interventions appear somewhat consistent with recent conceptualizations of patient-centered care. The consistent delivery of proven therapies and information and support for self-management requires practice systems organized for that purpose. The Chronic Care Model is a compilation of those practice system changes shown to improve chronic care. This paper explores the concept of patient-centeredness and its relationship to the Chronic Care Model. We conclude that the Model is both evidence-based and patient-centered and that these can be properties of health systems, and not just of individual practitioners.

INTRODUCTION

Chronic illness challenges traditional medicine

The rapid increase in the prevalence of chronic illness has altered medical care irrevocably. Sadly, much of Western medicine struggles in antiquated practice systems to care for growing numbers of patients with ongoing health problems and increasingly complex treatment regimens. Traditional practice systems and concomitant professional attitudes developed in an era when acute, infectious diseases and injuries were predominant. The course of illness generally played itself out over a matter of days or weeks. Medical science had little to offer. Patients were to rest and recuperate and, above all, follow the doctor's orders despite the flimsiness of the scientific justification for those orders.

This paradigm fits poorly with the care needs of people with chronic ongoing health problems and the current state of biomedical and behavioral science.¹ We now have biological and behavioral management approaches that can reduce suffering, increase function, and prolong life for many

individuals with chronic physical, mental health, and behavioral disorders. A central tenet of modern chronic illness care is to assure that patients be given information about and access to the most effective treatments for their conditions. "Most effective" is now determined by the application of rigorous evaluation of scientific evidence, rather than the accumulated experience of an individual practitioner. One hallmark, then, of high-quality chronic illness care is that it be evidence-based.²

Chronic illnesses place a different set of demands on patients and their loved ones than do acute illnesses and injuries. They are different in their time course and severity, but also in their requirements for nearly continuous decision making and adjustments to changing circumstances by patients.³ Self-management is now the accepted term used to describe the day-to-day decisions and activities engaged in by patients with the help of loved ones to live with and control their illnesses.⁴ The quality and effectiveness of these decisions and behaviors are strong determinants of health outcomes. Self-management is an active process, and activity restrictions and withdrawal from day-to-day life play

only a little role in achieving optimal outcomes. In fact, activity restrictions are often seen as counterproductive in managing most chronic conditions. The passive and deferential patients of yore are less likely to be successful in managing chronic illness.⁵ The paradigm for high-quality chronic illness care now seeks to promote a fuller understanding of the patient's life and preferences, "activation"⁶ or "empowerment"⁷ of patients, and tailoring of management to patient preferences. These are concepts often associated with the term *patient-centered*.

Mounting evidence assembled by the Institute of Medicine (IOM) confirmed that large proportions of people with chronic illness do not receive either proven biomedical or behavioral interventions or adequate information and support for self-management.⁸ These deficiencies in care produce unacceptably high rates of inadequate disease control and preventable exacerbations and complications. We and

others noted the mismatch between the needs of patients with chronic problems and the traditional practice systems caring for them.⁹ We searched the literature for studies of practice innovations and interventions associated with improvements in care and outcomes.^{1,9-12} Although successful improvement strategies were quite diverse, the changes that improved patient outcomes fell into a limited number of elements or areas of practice change. Key elements included support for patient self-management, delivery system redesign, provider decision support, and clinical information systems, with these key elements put in place by effective health system leadership and supported by linkages to relevant community resources. We organized the elements of effective health care systems for chronic illness care into a visual guide to practice change—the Chronic Care Model (CCM) (Fig. 1). The goal is to shift the orientation and design of practice in order to promote a system-

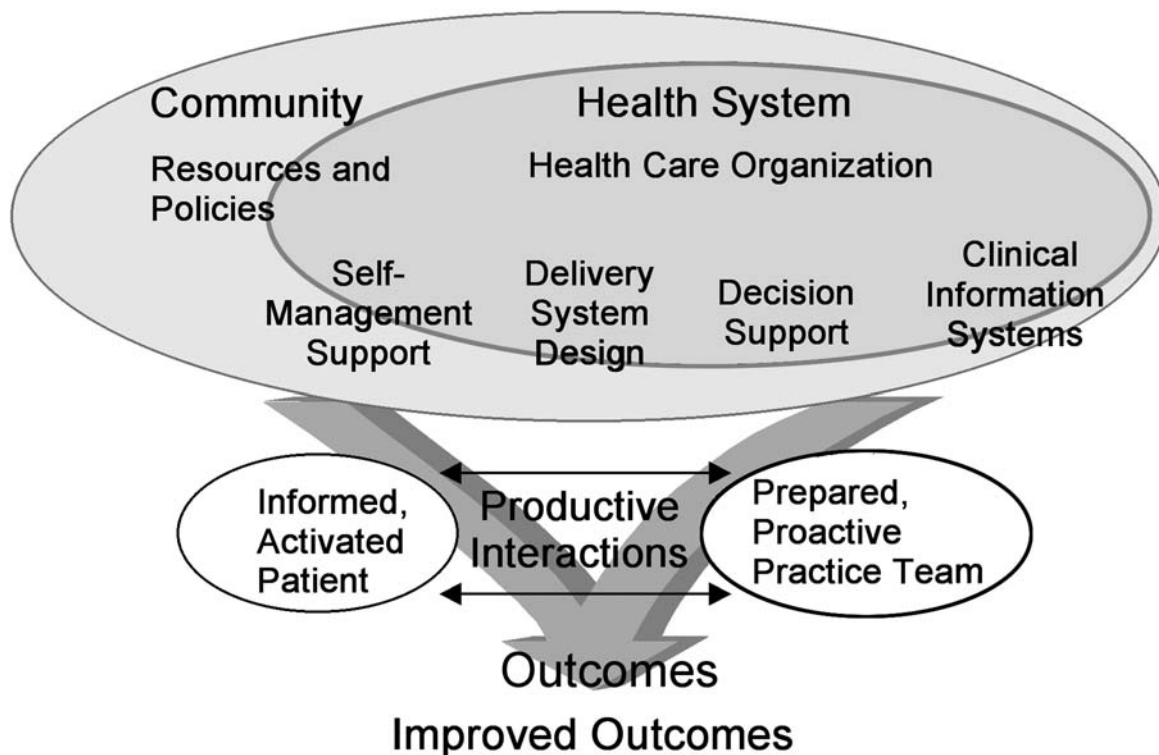


FIG. 1. Chronic care model. Our premise is that good outcomes at the bottom of the model (clinical, satisfaction, cost, and function) result from productive interactions. To have productive interactions, the system needs to have developed four areas at the level of the practice (shown in the middle): self-management support (how we help patients live with their conditions), delivery system design (who's on the health care team and in what ways we interact with patients), decision support (what is the best care and how do we make it happen every time), and clinical information systems (how do we capture and use critical information for clinical care). These four aspects of care reside in a health care system, and some aspects of the greater organization influence clinical care. The health system itself exists in a larger community. Resources and policies in the community also influence the kind of care that can be delivered. It is not accidental that self-management support is on the edge between the health system and the community. Some programs that support patients exist in the community. It is also not accidental that it is on the same side of the model as the patient. It is the most visible part of care to the patient, followed by the delivery system design. They know what kind of appointments they get and who they see. They may be unaware of the guidelines that describe best care, and we should work to change that, and they may be totally unaware of how we keep information to provide that care.

atic, planned approach to care for those with ongoing health problems through productive (planned) interactions between informed, activated patients (and families) and prepared, proactive practice teams.¹³ To be productive, interactions must assure consistent delivery of evidence-based treatments in tandem with support for patient self-management. The literature on effective self-management support, with its emphasis on patient activation or empowerment and active participation in setting goals and developing action plans, appears consonant with emerging concepts of patient-centered care.¹⁴

In response to the evidence of poor-quality care, the IOM recommended a bold program of health care system change in their report, “Crossing the Quality Chasm.”² The Committee recommended that six aims guide efforts to improve the quality of American health care. Among them, care must be effective (defined as evidence-based) and patient-centered. Some writers have observed that evidence-based care and patient-centered care appear to be in conflict.¹⁵ The former emanates from the culture and vocabulary of medicine, is largely under the control of professionals, refers to diseases not patients, and stresses standardization of therapy in accord with best evidence. Most definitions of patient-centered care stress patient participation in decision making and individualization of treatment in accord with patient preferences and circumstances. In discussing the apparent conflict between these two paradigms, Bensing noted that they appear to belong to separate worlds.¹⁵

What is patient-centered care?

On the one hand, there is little inconsistency among definitions of evidence-based as “the conscientious, explicit, and judicious use of current best evidence in making decisions.”¹⁶ David Eddy notes that “evidence-based” has been used to describe decisions for populations of patients (policies) and decisions in the care of individual patients. We will return to this important distinction below, but there is little confusion in the medical community as to the meaning of evidence-based medicine.

On the other hand, “patient-centered” medicine or care means different things to different people and disciplines. Regardless of perspective or definition, all represent reactions to the perceived inadequacies of traditional medical care, particularly its focus—some would say obsession—on the identification and treatment of physical disease (the biomedical model) and the domination of the doctor.¹⁷ To some, it means a shift from a focus on disease to the patient’s feelings and experience or illness, or from the disease to the “whole person.” A focus on the whole person means integrating psychological and social factors to achieve a fuller understanding of illness and to guide treatment, and to paying greater attention to health promotion. To understand the patient as a whole person “affords far greater priority to the personal relationship between doctor and patient.”¹⁷ Thus,

an emphasis on the human qualities of physicians and their communication abilities and style figure prominently in definitions of patient-centered care and its measurement.

To many, the primary issue is control over the relationship, communication and decision making, and shifting control from the doctor toward a greater degree of patient influence and participation. The arguments for the promotion of greater involvement of patients in care, and for regarding this as central to the definition of patient-centered care, fall into two major domains:

1. Sociopolitical—doctor controlled communication and relationships are often demeaning to patients and ineffective in achieving desired ends,¹⁸ and
2. Clinical decision making—doctor-controlled communication and decision making is often flawed because it fails to take into account the wisdom, preferences, readiness, and experience of patients.

These ideas were advanced by Moira Stewart et al. who described a patient-centered clinical method.¹⁹ The six components form the basis for the most widely used definition.²⁰ This view of patient-centered care is, in fact, very relationship-centered. The method focuses on the encounter of a patient with his or her doctor, and the nature of the communication during that interaction. Critics might say that, in a nontraditional way, this view of patient-centered care remains doctor-centered. Ian McWhinney, one of the intellectual leaders of this movement, states that the patient-centered model offers (among others) the following advantages: “it defines what doctors do,” and “it simplifies the complexity of the doctor’s job.”²¹ Despite the emphasis on patients as persons with important information, experience, and perspectives on their illness, the patient-centered clinical method says little about the patient as self-manager, or the patient’s activities outside of the health care context. While a change in the character of the primary doctor-patient relationship may well be an important part of moving toward patient-centered care—in our view, the competence of patients as self-managers of their illness is more important to outcomes than the skills of their physicians as communicators. Most patients with chronic illness have relationships with several individuals and institutions helping them manage their illness.

Is the chronic care model patient-centered?

The CCM certainly supports and promotes the major premises of patient-centered medicine: the importance of understanding the illness and the person, not just the disease; the need to “find common ground” and tailor care to patient preferences, values, readiness, and experience; and the importance of incorporating prevention in care. But there are important and interesting differences. The motivations for the development of the CCM and patient-centered medicine

appear to differ. Various conceptualizations of patient-centered care seem centered in ideology or theories of illness and human relationships and behavior. In other words, patient-centered care is a desired end in itself, irrespective of its impact on health, because common sense and humanity demand that patient concerns be heard, that patients have a voice in what happens to them, and that they be treated as individuals rather than as laboratory specimens. In contrast, the CCM has its roots in evidence-based medicine, rather than values about desirable qualities of the doctor-patient relationship.²² The model is a visual compilation of evidence about the determinants of effective chronic illness care and the nature of practice systems that facilitate good care. The focus is on what practice systems are necessary to achieve good patient outcomes. If the evidence underlying the effectiveness of the CCM as whole, or aspects of it, change, we will change the CCM accordingly.

There are differences in content as well. The differences are primarily in orientation and emphasis rather than in core principles. The relationship between a patient and his or her physician is the central focus of most conceptualizations of patient-centered care. The CCM defines the characteristics of effective primary medical care systems, and the interactions between the patient and family, the practice team, and the health care organization in which the practice team works, not just the primary care doctor. The focus on the practice team and the health care organization reflects the powerful evidence that effective chronic illness care involves extensive involvement of nonphysician team members, and the organization of practice, as well as other medical specialties.²³ This added complexity presumably increases the difficulty of assuring patient-centered communications and interactions with all the individuals involved in care, although relationships with nonphysician caregivers may mitigate the impacts of suboptimal doctor-patient communication. Team care certainly makes the measurement of patient-centeredness more difficult.

As mentioned above, patient-centered medicine focuses heavily on the behaviors and communication style of the professional although greater patient participation in decision making and better health outcomes are certainly prominent goals. Nonetheless, evaluations of patient-centered medicine vary widely in the selection and use of process measures in an effort to explain any identified relationship between patient-centeredness and better health outcomes.¹⁷ Recent reviews of interventions to make interactions more patient-centered note that explicit mechanisms to explain how interventions that do alter interactions could reduce symptoms or improve outcomes were rarely made explicit.^{24,25} In contrast, the CCM posits that well-designed practice systems better meet the needs of the chronically ill through patient-team interactions that assure evidence-based treatment and collaborative self-management support. While productive patient-practice team interactions are the route to effective chronic illness care, a practice system organized to

meet the needs of chronically ill patients greatly increases the likelihood that such interactions will occur and lead to positive outcomes. The CCM assumes that there is a causal link between the organization of practice and patient outcomes. Patients working with practice teams that routinely encourage patients to be more active participants in the management of their health, work collaboratively with patients to set self-management goals and develop action plans, and provide surveillance and support over time are more likely to have better health outcomes.

The CCM highlights the importance of patient activation or empowerment, which means that patients with chronic illness recognize that they are ultimately the primary caregivers. As primary caregivers, they seek the information and support they need to self-manage effectively. They ensure that their professional caregivers understand their values, life circumstances, needs, and expectations for care. They are comfortable collaborating with their care team in planning and evaluating their care and progress. Mounting evidence suggests that efforts to activate patients result in greater adherence to treatment regimens, more effective self-management, and better disease control.^{5,26–29} Patient activation is more implicit than explicit in definitions of patient-centered care. However, a review of interventions to alter practitioner-patient interactions to achieve care that was more patient-centered found that the majority of interventions used various previsit strategies (e.g., writing down questions or expectations) to encourage patients to take a more active role in the interaction.^{24,25}

Despite these subtle distinctions, we view the CCM as fundamentally patient-centered because of the concordance between the dimensions of patient-centered care and the features of effective self-management support. The six characteristics of patient-centered care proposed by Stewart et al.¹⁹ track well with current thinking about optimal self-management support. Both call for efforts to assess and understand the patient's life circumstances, values, behaviors, definition of problems, and preferences for care and outcomes, and to use this information to individualize treatment. Both emphasize the importance of patient participation in problem definition, setting goals for treatment, and planning treatment. Finally, both emphasize the necessity for "finding common ground" between the scientifically (we hope) grounded advice of the professionals, and the preferences and life circumstances of the patient.

Patient-centered systems?

As suggested, perhaps the major difference between the CCM and patient-centered medicine rests in one's perspective on the determinants of quality care. Patient-centered medicine assumes that professionals by virtue of their culture, training, social dominance, job stress, and other factors are traditionally inclined to be controlling and biomedically oriented, and not inclined to explore the nondisease

aspects of their patients' lives or share power. From this perspective, the problem is professional attitudes and behaviors that must be altered. "The patient-centered model of care presupposes a change in the mindset of the clinician."¹⁹ In contrast, the CCM derives from the work of Deming and Shewhart that emphasizes that quality is a property of systems, and that humane, competent people working in flawed systems will struggle and often fail to provide high-quality or safe care.³⁰ Improvement, therefore, begins with changing care systems; in this case, to enable professionals to provide more patient-centered care. This distinction may appear merely academic, since professional training may be a key element of system change. However, the significance of the difference in perspective is most visible when strategies for improvement are considered. Efforts to increase patient-centered care have focused on changing physician and/or patients' attitudes and behaviors. Most often, interventions seek to teach physicians more effective ways of communicating with patients, or patients more effective ways of communicating with physicians.^{24,25} This reduces the problem of achieving patient-centered care to a problem of doctor-patient communication. Are deficiencies in patient-centered care simply "failures to communicate"?

The CCM posits that deficiencies in communication may be symptomatic of broader problems in the organization of health care and the functioning of health care teams. The CCM and related quality improvement strategies begin with changes to the structure, organization, and functioning of practice systems—including their measurement systems, incentives, information handling, visit design, team function, and so on.³¹ Professional communication training might be needed to ameliorate patient experience and outcomes, but more organized interactions, involvement of a supportive practice team, and more accessible patient information may be sufficient.

Can patient-centeredness be a system property, or does it only describe the attitudes and communication features of a particular clinician? We hypothesize that a practice or health system can be patient-centered if the characteristics of the system promote and support the delivery of patient-centered care. So what practice changes may contribute to better perceived communication by patients? We have reexamined the elements of the CCM in an effort to address this question.

Health care organization

Our approach to chronic illness quality improvement emphasizes the essential roles of an activated patient and a collaborative approach to self-management support. Vocal and visible leaders promoting these concepts can help change organizational culture and priorities. Patient involvement in service planning and quality improvement helps keep the focus on their needs.³² A measurement system that maintains surveillance of indicators of the presence or absence of effective self-management support has proven to be an im-

portant motivator for change, especially if augmented with incentives based on performance. For example, some organizations routinely measure patient satisfaction and record self-management goals in the medical record. A growing number of organizations link financial incentives to levels of performance on these indicators, or to improvement in performance. Wise health care systems are identifying practices with low patient satisfaction measures. They often find unhappy, stressed providers who are eager for guidance in how to work with their patients more effectively. Efforts to support, motivate, and educate such providers may lead to more patient-centered care, as well as more satisfied patients and practitioners.

Community resources

Time-limited self-management courses, often involving peer support, have been shown to be effective when based on modern principles of an activated or empowered patient collaborating with health care professionals.^{14,33–37} These programs are most often available in large institutions or in community settings, rather than in primary care settings where most patients are seen. Practices may improve their patients' self-management competence by forging linkages with these programs and by routinely referring patients to community-based programs. Similarly, most practices do not have trained health or nurse educators who can provide the information and support for patients struggling with their chronic illness. Such individuals are more likely to work in hospitals, specialty practices, or community-based programs and can play an important supportive role to patients if reasonable business and professional arrangements for access to these services can be developed.

Self-management support

The features of an effective systematic approach to the provision of self-management support are becoming clearer as evidence accrues.^{14,38} The core is the routine application of the behavioral change strategy first studied with smoking cessation. This well-tested strategy involves five steps, each named by a word beginning with A. Practices should routinely assess patient behaviors, attitudes, and goals; advise patients based on science; agree on the problem, goal, and plan of action; assist patients in developing realistic goals, and identify barriers to and strategies for reaching a goal; and arrange for additional resources, support, and so on. The 5 As can be, and in most cases should be, distributed among the various members of a practice team rather than depending upon the doctor for their execution. This may require additional training for staff. Assessment can be enhanced and routinized through the use of questionnaires or designation of key issues as a "vital sign" to be assessed as part of check-in. Other office tools, such as templates for action plans or referrals to community programs, can facilitate other steps in the process.

Delivery system design

Practices can be organized to provide more patient-centered care. As mentioned above, effective chronic illness care is a team sport.²³ But effective team care requires role definition, coordination, and communication. These do not happen spontaneously in busy practice and need to be planned. Visit time is frequently implicated as a fundamental barrier to more patient-centered interactions. Longer, more structured (planned) visits are an important feature of effective chronic care and provide greater opportunity for assessment of patient concerns and progress, collaborative support for self-management, and treatment planning. Similarly, group visits may enhance patient-centered care despite the presence of others in the room.^{39–41} For instance, they furnish patients with opportunities to interact with their care team over a longer period of time in a different, potentially less intimidating setting than an examination room. It also gives patients the opportunity to interact with their peers and exert greater control over educational opportunities and other aspects of care. A period of more intensive surveillance and involvement by a nurse or other clinical care manager has been shown to improve outcomes for more complex patients with chronic illness.^{42–44} Coordinated care management can enhance the doctor's understanding of the patient's illness, life, and care experience in addition to assuring effective clinical management and self-management support.

Decision support

Decision support refers to efforts by a system to assure that providers have the expertise and memory aids to routinely provide evidence-based care. Providers can be reminded by computer, flow sheet, or patient-completed information to review patient concerns and self-management progress and goals. Patients can be encouraged to state their concerns, expectations for the visit, or other needs prior to the interaction.²⁵ Making patients aware of evidence-based guidelines for the care of their illness, and urging that they demand it, may be an important strategy.

Clinical information systems

Patient-centered care requires that the care team: (1) collect a richer array of information about patients; (2) organize it in a useful way; and (3) have ready access to it. Clinical information system enhancements can facilitate all three steps. They can assist in the routine collection of data concerning patient experience, illness, and expectations and make it available at visits.⁴⁵ Clinic information systems can provide reminders, as well as feedback to practices on their performance and the success of their improvement efforts.

In our work supporting chronic care improvement with hundreds of health care organizations, making practice changes guided by the CCM has improved measures of the

processes of care, outcomes, and patient satisfaction in the majority of participating organizations.^{46–49} These quality improvement results are being confirmed by more rigorous external evaluations.^{50–54} In the largest and most comprehensive evaluation of CCM-based improvement programs, investigators from the RAND Corporation found significantly better patient satisfaction with communication among heart failure and asthma patients in practices involved in system change.^{51,54} This occurred despite the fact that very few practices conducted communication training of their professionals as part of their improvement activities.

Are evidence-based and patient-centered medicine contradictory?

The best chronic illness outcomes are likely to occur when competent self-managers receive and are supported in carrying out the most effective biomedical treatments. Systematic reliance on evidence (evidence-based medicine) provides the soundest strategy to select the most effective treatments and offers guidance on how to support patients in implementing effective treatments as well. Patient-centered medicine that is responsive to patient needs, preferences, readiness, abilities, and knowledge supports the development of competent self-managers. It increases the likelihood that treatment plans will be appropriate, understood, and followed. These two ideas seem so complementary—melding the art and science of medicine. Why would anyone suggest that they are in conflict? Bensing suggests two questions that must be addressed.¹⁵

How patient-centered is evidence-based medicine

While some ideologues argue that a disease focus and randomized trials are inherently not patient-centered, a more cogent concern is whether evidence-based medicine's impetus to standardize care conflicts with patient-centered medicine's emphasis on individualizing treatment. Eddy addresses this concern by differentiating “two different approaches to using evidence to solve clinical problems”—evidence-based guidelines and evidence-based individual decision making.¹⁶ The former is the work of teams engaged in a rigorous, formal process. The goal is to produce generic clinical policies affecting groups of patients for clinical improvement, education, coverage decisions, and other decisions related to clinical care.

Evidence-based individual decision making, by contrast, is done by physicians and other clinicians in the care of individual patients. Evidence-based medicine's central thesis is that clinical decisions should be based as much as possible on evidence of clinical safety and effectiveness. “As much as possible” makes explicit the appreciation that rigorous evidence must be interpreted and adapted to each patient's unique set of demographic, social, psychological, and clinical characteristics. Eddy argues that these two views

should be integrated. Evidence-based guidelines provide the foundation for individual patient-centered clinical decision making, not a demand for slavish adherence to a standard regimen. Wise use of the most effective treatments in most major chronic conditions has prolonged life, improved functional status, prevented complications, and reduced suffering. The systematic application of the best science to policy making and clinical care is in the best interests of patients, and, therefore, patient-centered.

How evidence-based is patient-centered medicine

The concepts of patient-centered medicine did not emerge from rigorous studies of clinical effectiveness. It grew out of negative reactions to traditional paternalistic medicine and the biomedical model's fixation on the disease rather than the patient with the illness. The evidence base is meager for two major reasons. First and foremost, a consensus definition and related set of measures remain elusive. Broader acceptance of a standard definition should accelerate the pace of research.

The importance to patients of satisfying communication with their practitioner is well documented. It is among the major predictors of patient satisfaction. Much of the research on patient-centered care to date has focused on assessments of communication style by experts or by patients, and the evaluation of professional and patient interventions to alter communication in ways assumed to be more "patient-centered." These studies have raised more questions than they have answered.^{17,55,56} Overall, it appears that interventions directed at professionals and patients to encourage greater patient involvement in the dialogue and in decision making do alter the interaction in that direction, increase patient satisfaction, and may positively impact health behaviors and outcomes. But the findings are mixed and the effects disappointingly small. The evidence is neither consistent nor strong enough to recommend major efforts to train or retrain physicians in communication. Encouragement to patients to ask questions or write down expectations and questions for their clinicians was often effective and never harmful in a number of studies.

The mixed effects of provider communication training may be a consequence of the content rather than the quality or intensity of the training. Some studies suggest that patients may not value the patient-centered communication style developed and taught by experts in the field as much as the experts do.⁵⁷ Stewart et al. found that measures of patient-centered communication based on analysis of audiotapes were not associated with improvements in outcomes like symptom relief.⁵⁸ But, patients perceiving that their visit was patient-centered and that they and their doctor had reached agreement had significantly better outcomes. Plainly, we still have much to learn about what patients value and benefit from, but evidence to date is sufficiently promising to warrant efforts to make care more patient-centered.

CONCLUSIONS

Optimizing outcomes among most patients with chronic illness requires an engaged, competent patient receiving the most effective care and treatment. The most humane, egalitarian interactions will not protect a complex diabetic patient from stroke or heart attack without ACE inhibitors, statins, and effective glucose control. Conversely, prescribing the right medications and ordering the right tests will not prevent complications if diabetic patients don't take their drugs appropriately or undiagnosed depression undermines self-management. Effective chronic illness care must be evidence-based *and* patient-centered. The CCM seeks to encompass both perspectives. It views both as system properties, not just skills or attitudes of individual providers. Evidence-based guidelines become organizational policy to be integrated at every available point in decisions that affect patient care. But they pertain to populations of patients and, as a result, must be adapted to the unique characteristics of each individual patient. Such characteristics extend beyond allergies, renal function, and the other biological characteristics that usually influence treatment selection and dosing to include patient values, preferences, readiness, skills, and knowledge. Encouraging active patient participation in care and increasing patient self-management competence and confidence become organizational priorities by assuring that patients have access to proven self-management programs, and practice teams have skilled individuals who can collaboratively manage patients through employment of the five As.

Mitigating the consequences of chronic illnesses requires active, competent management by patients and their health care providers. Since they share responsibility for management, they must share control of clinical interactions and decisions. Both common sense and mounting evidence suggests that such collaboration will result in management goals and plans that are more rational, more likely to be adhered to, and more likely to improve health. Whether this is evidence-based medicine or patient-centered medicine is irrelevant. It works!

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