3. Organizing Care for Patients with Chronic Illness

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CHRONIC ILLNESSES CONFRONT PATIENTS AND THEIR caregivers with a restricted and uncertain future and the burdens associated with controlling the disease. We will consider the difficulties encountered by medical care providers, including organized health systems, in meeting the demands placed on patients and families by chronic illness. We have culled examples from the literature in order to examine comprehensive approaches to reorganizing care delivery that have improved the outcomes of patients with chronic illness. Of particular interest are efforts either to design new care systems for patients with chronic illness or systematically to reorganize existing care systems. We find that successful intervention programs share common characteristics, which we organize in a heuristic model for improving care. Each of these elements is discussed, and the evidence for their contribution to enhanced patient outcomes is examined. We conclude with a consideration of the questions and challenges faced by health care organizations in designing and implementing comprehensive care improvement programs for chronically ill patients along the lines suggested by the model.

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The Need for Integrated, Patient-Centered Care of Chronic Illness

Patients facing the discomforts and demands of chronic illness struggle to maintain a productive, hopeful life. The effective management of their illness requires that they receive appropriate clinical care while they and their families appropriately cope with the illness and its therapies. These self-management tasks have been described and placed in four categories by Clark and colleagues (1991):

1. Engage in activities that promote health and build physiological reserve, such as exercise, proper nutrition, social activation, and sleep.
2. Interact with health care providers and systems and adhere to recommended treatment protocols.
3. Monitor their own physical and emotional status and make appropriate management decisions on the basis of symptoms and signs.
4. Manage the impact of the illness on their ability to function in important roles, on emotions and self-esteem, and on relations with others.

The achievement of optimal outcomes in the management of chronic illness requires the successful accomplishment of these tasks (Center for the Advancement of Health 1996). Yet available evidence suggests that usual medical care often fails to include the intervention components that contribute to more effective self-management. For example, physicians frequently fail to gather information about patients' ability to function (Wasson, Keller, et al. 1992; Rubenstein et al. 1989), their understanding of the illness (Cameron and Gregor 1987; Connelly 1987; Smith and Hoppe 1991; Cohen et al. 1994), or their insights into self-management (Cassell 1991). Many professional caregivers also feel unprepared or are too rushed to meet the educational, behavioral, and psychosocial needs of chronically ill patients and their caregivers (Orleans et al. 1985), so they fail to provide opportunities for patients to receive educational and supportive services (Sobel 1995) or to share experiences with other patients (Ruberman 1992; Spiegel 1995).

In addition to limitations in meeting patients' self-management needs, widespread deviations from available standards in the medical care of patients with chronic illness have long been recognized. Surveys and audits have repeatedly documented the failure of practitioners to comply with well-established guidelines for the clinical aspects of care for patients with hypertension (Stockwell et al. 1994), diabetes (Kenny et al. 1993), asthma (Perrin et al. 1984), frailty in the elderly (Hirsch and Winograd 1992), and other chronic conditions.

While deficient training contributes to these deviations, a more critical factor derives from the culture and structure of medical practice, which limit caregivers' ability to meet the clinical and self-management needs of chronically ill patients. Medical practices, especially those in primary care, are generally organized to respond to the acute and urgent needs of their patients. The emphasis is on diagnosis, ruling out serious disease, and curative or symptom-relieving treatments. Because primary care practices and practitioners are so oriented to acute illness, they may not differentiate their clinical approaches to patients with acute and chronic illness, relying instead on patient-initiated visits, relief of symptoms, normalization of aberrant physiological measures, and assurance that there is no urgent medical crisis. Kottke, Brekke, and Solberg (1993) argue that the health care system "prioritizes urgency over severity [and] encourages physicians in clinical settings to be respondents, not initiators." This focus leaves little time or intellectual energy for addressing the less urgent, but nevertheless predictable, needs of patients with chronic illness in managing their condition and preventing deleterious sequelae.

Amidst the press of acutely ill patients, it is difficult for even the most motivated and elegantly trained providers to assure that patients receive the systematic assessments, preventive interventions, education, psychosocial support, and follow-up that they need. Litzelman and colleagues (1993) invoke "dual task theory" to explain why dealing with symptoms "distracts attention from" preventive or physician-initiated actions. Dual task theory suggests that when confronted with multiple tasks, individuals first perform those in which they have the greatest emotional investment. Scheff (1984) has argued that physicians fear missing serious illness more than other types of errors, which may explain the preference for "symptom swatting" over routine assessment, counseling, and other elements of good chronic illness care.

Office staff and systems are also geared to react to acute illness and urgent care. Most practice teams have neither the time nor the inclination to meet with each other, and thus have not organized themselves for care that requires some degree of planning. Because nonphysician staff are occupied with managing access and patient flow, the responsibilities for planning care, counseling, and follow-up are not delegated and, by default, fall to the physician. The information necessary for organizing or planning care is buried in a paper medical record, which is likely to be staggeringly thick for patients with chronic illness. The lack of organization and information reinforces the focus on immediate symptoms and physiological abnormalities, which in turn encourages the addition of empirical pharmacological remedies, thereby contributing to the chronically ill patient's drug burden.

We hypothesize that these deficiencies in the delivery of routine care for patients with chronic illness contribute to suboptimal outcomes for the following reasons:

1. delays in the detection of complications or declines in health status because of irregular or incomplete assessments or inadequate follow-up
2. failures in self-management of the illness or risk factors as a result of patient passivity or ignorance stemming from inadequate or inconsistent patient assessment, education, motivation, and feedback
3. reduced quality of care due to the omission of effective interventions or the commission of ineffective ones
4. undetected or inadequately managed psychosocial distress

Successful Chronic Illness Care

The literature evaluating interventions to improve outcomes in chronic illness tends to focus on specific elements in the overall care of the patients: a provider educational program, a computer reminder system, a patient education activity, and the like. More comprehensive efforts to develop or reorganize medical care systems for chronically ill patients have been much less common. However, the literature does provide some potentially useful models: randomized intervention trials testing drugs or other specific therapies; organized programs of care for a given chronic illness; and efforts to improve the primary care of patients with chronic illness in western European national health care systems.

Randomized Controlled Trials

Randomized clinical trials (RCTs) in chronic disease have tested complex treatment regimens and achieved major improvements in outcomes. Two such examples are the Hypertension Detection and Follow-up Program (HDFP) (HDFP Cooperative Group 1979), which evaluated stepped care for mild to moderate hypertension, and the Diabetes Control and Complications Trial (DCCT) (DCCT Research Group 1993), which assessed the efficacy of intensive insulin management for Type 1 diabetes. Beyond the specific treatments being tested, trials like these wrap the specific therapy in a carefully delineated care model to assure consistency of management and support for patients. Because these two trials achieved impressive improvements in outcomes, an examination of their "wrappings" may provide important evidence about better ways of organizing and delivering care for chronic illness.

In both trials, experimental subjects received their care from specialized clinics established to meet their needs and assure concerted application of the protocol. Critical features of the care models employed were the provision of care in accord with an explicit plan, which includes regularly scheduled follow-up, systematic assessments, and attention to the self-management needs of patients. Patients were encouraged to discuss problems with therapy and were given instruction, with their families, using materials and methods designed by behavioral scientists (Diabetes Control and Complications Trial 1987; Shulman et al. 1982). The plan, or protocol, was executed largely through delegation of key care functions to nonphysician members of the practice team. The systematic delegation of major aspects of the protocol to nurses, pharmacists, and other members of the practice team is a hallmark of randomized trials and other successful efforts to improve chronic illness outcomes. Information systems tracked critical processes and outcomes. The predictability and homogeneity of care in RCTs contrast vividly with the variability and ad hoc nature of patient care in usual practice. RCT programs achieved high rates of compliance with therapy, high rates of blood pressure and blood sugar control, and significant reductions in the long-term complications of the conditions.

The HDFP, for example, reduced all-cause mortality by 17 percent; almost 40 percent of the reduced deaths could be traced to noncardiovascular causes. The reduction in noncardiovascular mortality prompted

British critics to assert that the HDFP "is perhaps as much a trial of medical care as of antihypertensive drugs"(Peart and Miall 1980). We agree. Current accounts of the trial often dismiss the HDFP as flawed because it compared a protocol and care system with usual care rather than making the classic drug versus placebo comparison; these criticisms overlook the impressive impact on patient longevity associated with planned, organized care for this important subpopulation.

Chronic Care Programs

Successful programmatic efforts to improve chronic disease care share many of the same features as RCTs. Twenty-five years ago, innovators like Frank Finnerty (Finnerty and Shaw 1973) and John Runyan (Runyan et al. 1970) demonstrated better outcomes for low-income patients with chronic illness through the establishment of specialized clinics. Like the RCTs, these clinics depended on regular, protocol-driven care provided largely by nonphysician providers. Similar special clinics, especially for hypertension, have been established within large systems like the Veterans Administration health system (Stason et al. 1994) or the Mayo Clinic (Shultz and Sheps 1994), in communities like the Mayo Three-Community Hypertension Control Program (Krishan et al. 1981), or in work sites (Alderman and Schoenbaum 1975; Logan et al. 1983; Brown et al. 1989; Fielding et al. 1994). These clinics, like the RCT clinics, employed nonphysician practitioners working closely with physicians to execute explicit protocols for care. The protocols and clinics emphasized attention to behavioral change and medication selection and adherence. Regular, planned follow-up was assured. In addition, the evaluation of the VA clinics suggested that the clinics achieving higher rates of follow-up and blood pressure control had practice team members who met together and felt supported, spent more time counseling patients, and used reminders and other tools to assure follow-up (Stason et al. 1994).

Programmatic Primary Care Approaches in Western Europe

The care of chronically ill patients was gravitating from primary care to hospital-based clinics run by specialists in some Western European national health systems. A clinical trial in Britain showed that diabetic patients randomized to hospital clinic care enjoyed better outcomes than patients randomized to receive care from their general practitioner (GP) (Hayes and Harries 1984). Concerns about costs and fragmentation of care spurred efforts in several countries to improve the management of chronic illnesses in primary care and return care to GPs (Yudkin et al. 1980; Rosenqvist, Carlson, and Luft 1988). Some British GP leaders recognized the differences in orientation and structure between hospital clinics organized expressly to meet the needs of patients with diabetes (or other chronic illnesses) and busy, unstructured primary care. Interventions attracting their attention included regular assessments, patient education, and ready access to ancillary services (Thorn and Watkins 1982; Gibbins and Saunders 1988; Farmer and Coulter 1990; MacKinnon 1990; Hurwitz, Goodman, and Yudkin 1993). Chronic disease miniclinics, used by general practitioners in Great Britain for over 20 years (Thorn and Russell 1973; MacKinnon 1990), provided one structure for these interventions. "Miniclinics" or "clinic days" integrated into a GP's practice are blocks of practice time devoted to, and organized for, the care of patients with particular conditions. After being identified through disease registries maintained by the practice, these patients are invited to attend the clinic. The widespread adoption of "miniclinics" received official recognition in 1990, when they became reimbursable through the National Health Service, and their use appears to be expanding (Haynes 1993).

A more traditional educational approach was tried in Sweden (Rosenthal and Carlson 1988). The Swedish National Board of Health and Welfare developed a primary-care-based diabetes program, with special emphasis on diabetes training and education. A Stockholm-area study demonstrated that provider education alone did not increase compliance with guidelines (Carlson and Rosenqvist 1988). In an attempt to explain the program's failure to affect diabetes care, the investigators engaged in qualitative research, which revealed that most practices had no capacity even to consider new approaches to care, much less plan their incorporation into busy practice. An organizational development effort aimed at encouraging practice team meetings and redesigning practice systems improved compliance with guidelines and patient self-management behaviors (Carlson and Rosenqvist 1988).

The Germans approached the improvement of primary care for chronic illness by developing "structured teaching and treatment programmes" for patients with diabetes (Kronsbein et al. 1988) and hypertension (Muhlhauser et al. 1993). These programs, which emphasize group patient education conducted by the practice, are supported by an extensive provider education effort and financial incentives. By 1991, nearly all German insurance funds covered physicians' fees for structured education programs, as well as reimbursing the costs of teaching materials to patients (Gruesser et al. 1993). These multisession group education programs have been well received by both patients and providers and have resulted in significant weight reduction and improved disease control (Kronsbein et al. 1988; Muhlhauser et al. 1993; Gruesser et al. 1993).

Components of High-Quality Chronic Illness Care

Whether the improved patient outcomes are the result of RCTs, special chronic disease programs or clinics, or European programs to improve the primary care of chronic illness, there appear to be significant similarities among these organized efforts. The common elements fall repeatedly and consistently into five general areas:

1. the use of explicit plans and protocols
2. the reorganization of the practice to meet the needs of patients who require more time, a broad array of resources, and closer follow-up
3. systematic attention to the information and behavioral change needs of patients
4. ready access to necessary expertise
5. supportive information systems

Figure 1 summarizes these elements, which have their basis in the needs of patients with chronic illness and the interventions found to be effective in meeting these needs.

Evidence-Based, Planned Care and Guidelines

A consistent feature of the trials and programs we reviewed for this article is a protocol or plan that provides an explicit statement of what

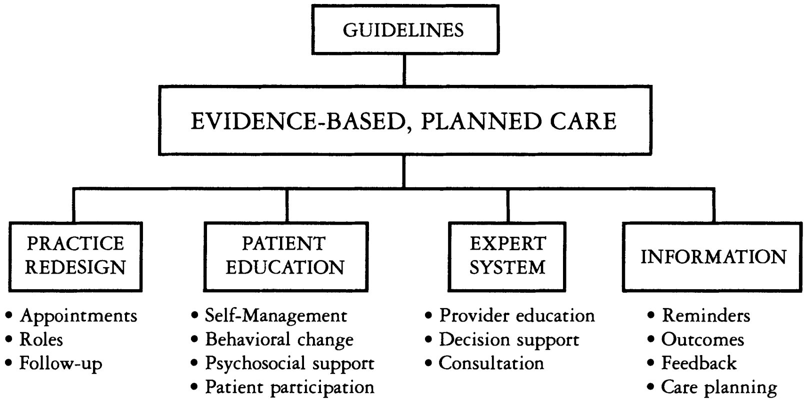

FIG. 1. Improving outcomes in chronic illness.

needs to be done for patients, at what intervals, and by whom. Most practices do not operate by protocol, and many practitioners resent the notion that care should be homogenized. Rugged individualism leads to practice variation and failures to adhere to guidelines. The acute care orientation of practice reinforces the conviction that patients are unique, that their problems are idiosyncratic, and that good care is highly individualized. In contrast, planned care requires the doctor to make the intellectual leap from constantly thinking and worrying about specific patients to considering all patients with specific clinical features or needs and how those needs might be met. This leap is facilitated by the use of practice protocols or guidelines based on scientific evidence of effectiveness (Eddy 1992). The shift to evidence-based, planned care should be eased by working within a care system or group practice that values guidelines and has created a plan at the organizational level to assist practitioners in their efforts to comply with guidelines. Some of this assistance, like information systems or provider training, will be discussed more fully below.

Physicians, nurses, and other staff working in RCTs or special programs are accustomed to working by protocol. Such is not the case in busy practices where the implementation and acceptance of guidelines remain a major challenge (Gottlieb, Margolis, and Schoenbaum 1990). Evidence suggests that guidelines alone have little, if any, impact (Grimshaw and Russell 1993). Guidelines more often contribute to improvements in the process and outcomes of care when used as part of more comprehensive practice improvement interventions like those depicted in figure 1. Clinical improvement strategies that enhance the ability of a practice to incorporate guidelines into its fabric—perhaps by delegation to office staff or through reminders—enhance the likelihood of sustained adherence to the guideline.

Practice Redesign

Successful chronic illness programs, in contrast to usual primary medical care, organize their systems and work to meet the needs of patients with chronic health problems and to comply with a protocol or guidelines. To accomplish this while caught up in busy medical care, physicians must reconsider their practices and plan the basic ways they do their clinical work. This includes the organization of the practice team and the allocation of tasks among them, the management of patient contact (appointments, follow-up), and the use of other health professionals. We call such planned deviations from delivering care as usual "practice redesign."

Practice redesign strategies differ in the extent to which continuing responsibility for care of the chronically ill patient remains in primary care and the degree to which specialized providers like medical specialists or case managers are involved. Practice redesign approaches for chronic illness then range along a continuum from efforts to enhance usual primary care at one end to separate, specialized care programs at the other. In the middle of the continuum are models that add specialized personnel to primary care teams.

The arguments for specialization are multiple and compelling. Specialist physicians have been shown to be more knowledgeable about efficacious interventions for major chronic illnesses and tend to adopt new approaches more quickly (Ayanian et al. 1994; Markson, Cosler, and Turner 1994). Hospital care provided by specialists has been associated with improved outcomes in stroke patients (Horner et al. 1995) and intensive care patients (Brown and Sullivan 1989). Institutions and providers who are more experienced with the disease or treatment have repeatedly been shown to have better outcomes (Stone et al. 1992), although a recent study of generalist care for HIV/AIDS suggests that it may not require experience with large numbers of patients to achieve good outcomes (Kitahata et al. 1996). Finally, more specialized care provided in the context of organized programs like hospital-based clinics (Hayes and Harries 1984; Verlato et al. 1996), work-site programs (Alderman and Schoenbaum 1975; Logan et al. 1983; Brown et al. 1989; Fielding et al. 1994), nurse-therapist clinics (Schwartz et al. 1990), and specialized team care (Peters, Davidson, and Ossorio 1995) often demonstrate better outcomes. However, in examining studies that show improved outcomes with more specialized care, it can be difficult to disentangle the relative effects of increased knowledge and more experience with the condition from the impact of better-organized care.

In those few studies where usual generalist care has been compared with *usual* care from more specialized providers, the results have generally shown little difference. For example, the Medical Outcomes Study found minimal differences in process or outcomes among diabetics or hypertensives cared for by generalists versus those cared for by specialists (Greenfield et al. 1995). Several studies have examined allergist versus generalist care for asthma without consistent findings (Freund et al. 1988; Engel et al. 1989; Zeiger et al. 1991; Mahr and Evans 1993). No advantage was seen for specialty care in a study of outcomes of chronic obstructive pulmonary disease (Strauss et al. 1986). The cost-effectiveness of case management of frail elders remains uncertain (Austin et al. 1985; Kodner 1993). These data suggest that usual outpatient specialized care may be no more planned or organized to meet the needs of patients with chronic illness than is usual generalist care. The discipline of primary providers may be less important than the organization of the practice.

Specialized programs and providers for chronic illness, while appealing, challenge basic health care values. The issue was highlighted by a recent study of hypertension control among insured New York City health workers. The authors found poor levels of hypertension awareness, treatment, and control, leading them to recommend separate, special programs because "the medical care system, as it presently exists, is poorly suited to meet the needs of the vast majority of hypertensive patients it serves" (Stockwell et al. 1994). On the other hand, another New York study found that the strongest predictor of hypertensive complications was the lack of a relationship with a primary care physician (Shea et al. 1992). Patients value having a single source of care for multiple needs (Wasson et al. 1984; Starfield 1992; Hjortdahl and Laerum 1992), and evidence supports the health and economic advantages of continuous primary care (Becker, Drachman, and Kirscht 1974; Wasson et al. 1984; Starfield 1992).

The question, then, is whether those elements of successful specialized care can be incorporated into primary care, and, if so, whether that would reduce the differential in outcomes achieved. One important consideration is the way in which the practice team organizes itself and uses all of its members (Eisenberg 1995). The delegation of key tasks to appropriate members of the practice team, especially nonphysicians, appears to be a central feature of successful programs and is an important element of team care planning (Payne et al. 1995). Most successful chronic disease programs rely heavily on nurses. The work of Carlson and Rosenqvist in Sweden found that measures of staff interaction and involvement in decision making correlated with the extent to which a diabetes control program in primary care was implemented (Carlson and Rosenqvist 1988, 1991). Practice team meetings using the principles and some of the tactics of industrial quality management may be an important step in achieving guideline-driven changes in chronic disease care (Payne et al. 1995; Hedrick et al. 1994). The occurrence of regular team meetings was also a significant predictor of better care and outcomes in British studies of primary care for diabetes (Farmer and Coulter 1990) and among the VA hypertension clinics (Stason et al. 1994). Seemingly sensible and obvious functions, like team meetings and clinical planning, are new to most practices.

Chronically ill patients need time with their providers, regular assessments of clinical, behavioral, and psychosocial variables, and ready access to other resources like pharmacists, nutritionists, and social workers. Special clinics enable providers to meet these needs. The British Chronic Care Clinic or "miniclinic" (Thorn and Russell 1973) mentioned above also changes the orientation and design of primary care practice, but it does so periodically in order to meet the needs of chronically ill patients. A group of patients with a given condition is invited to their primary care practice at regular intervals to participate in specially designed visits, which are structured to include a planned set of assessments, visits with various health professionals, a group meeting, and a plan for follow-up. Although some observational studies have shown no positive effect of these clinics (Chesover, Tudor-Miles, and Hilton 1991), more publications have linked diabetes miniclinics with benefits like better glycemic control (Bradshaw et al. 1992; Pringle et al. 1993), reduced hospitalization (Farmer and Coulter 1990), and improved process measures, indicating better follow-up of patients (Koperski 1992).

Successful programs assure regular follow-up through planned, often practice-initiated, contacts with patients. Follow-up can take the form of return visits, home visits, or telephone calls. A variety of interventions—patient reminders, outreach workers, physician reminders, or patient orientation—have been shown to reduce losses to follow-up (Macharia et al. 1992). Telephone calls have important cost and logistical advantages that are only beginning to be appreciated. For example, Wasson's group showed that substituting regularly scheduled follow-up phone calls for irregular follow-up visits substantially improved health status and reduced costs for chronically ill patients (Wasson, Gaudette, et al. 1992).

Patient Self-Management and Behavioral Change Support

Reducing complications and symptoms from most chronic diseases requires changes in lifestyle and the development of self-management competencies by the patient and family. Essentially all successful protocols or chronic illness programs provide some sort of educational programming to meet these needs.

We have recently completed a review of over 400 meta-analyses, review articles, randomized trials, and observational studies of self-management support interventions in chronic illness (Center for the Advancement of Health 1996). The evidence is substantial that structured self-management and behavioral change programs improve important outcomes in diabetes (Brown 1990), hypertension (Linden and Chambers 1994), arthritis (Mullen et al. 1987), coronary heart disease (DeBusk et al. 1994), and other chronic diseases. The method of delivering the intervention—whether by class, one-on-one counseling, or computer program—may be less important than its ability to identify and respond to the individual needs and priorities of patients.

Successful programs provide, to varying degrees, four essential elements:

1. Collaborative problem definition (Inui and Carter 1985; Giloth 1990; Clark et al. 1991): Both patients and providers contribute their perspectives and priorities to defining the issues to be addressed by clinical and educational interventions. Questionnaires

(Montgomery et al. 1994), interactive computers (Glasgow 1995), and patient-centered interviewing techniques (Miller and Roonick 1991) can contribute to enhancing the patient's participation in this process.

2. Targeting, goal setting, and planning (James, Thorn, and Williams 1993; Glasgow et al. 1995): Approaches that target the issues of greatest import to both patient and provider, set realistic goals, and develop a personalized improvement plan are more likely to be successful, particularly if the process is guided by a consideration of the patient's readiness to change and his or her self-efficacy (Ruberman 1992).
3. A continuum of self-management training and support services: For most chronic illnesses, this should include instruction in disease management, behavioral change support programs (e.g., smoking or dietary interventions), exercise options, and interventions to deal with the emotional demands of chronic disease.
4. Active and sustained follow-up: Evidence suggests that follow-up that is reliable, occurs at regular intervals, and is initiated by the provider leads to better outcomes (Wasson, Gaudette, et al. 1992; Stuck et al. 1995).

Sustained, active, and personalized attention to the self-management needs of patients differs conspicuously from the more typical concentrated dose of didactics at the time of diagnosis with barely any follow-up.

Surprisingly, the link between self-management support for chronic illness and the patient's routine medical care has received relatively little attention (Kronsbein et al. 1988; Muhlhauser et al. 1993; Gruesser et al. 1993; Weinberger et al. 1996; Glasgow et al. 1996). A related area, the role of the primary care physician in counseling for smoking and other primary prevention issues, has been studied intensively. The prevention literature strongly suggests, on the one hand, that personal physicians are an important source of motivation and feedback and that their involvement enhances the effectiveness of behavioral programs (U.S. Preventive Services Task Force 1989). On the other hand, physicians are generally neither well trained nor confident behavioral counselors. Many behavioral researchers feel that the influence of the physician, and the opportunities for education presented by the frequent visits of chronic disease patients to their physician, make office-based, integrated programs particularly attractive (Kottke, Brekke, and Solberg 1993).

We could not find empirical evidence about the impact of personal physician involvement on patient education program effectiveness in chronic illnesses. In many studies of patient education, the personal physician is actually blinded to the intervention group of his or her patients. However, evidence from Germany, cited above, suggests that the integration of diabetes and hypertension education into primary care practice can be effective (Kronsbein et al. 1988; Muhlhauser et al. 1993; Gruesser et al. 1993).

Most chronic disease patient education programs target specific knowledge and behaviors associated with the disease and its treatment. Diabetes programs, for instance, concentrate on medication management, home glucose monitoring, diet, and exercise. Asthma and hypertension programs emphasize adherence to medication and home monitoring of peak flow rates or blood pressure levels. The goals of these specific programs are increased knowledge, better adherence to the regimen, timely adaptation of the regimen to change in disease status, improved disease control, and, ultimately, reduced complications. The assumption underlying such programs is that knowledge facilitates behavioral change, and that changes in behavior improve disease outcomes. From their intervention work with arthritis patients, Lorig and colleagues (Lorig and Holman 1993; Lorig, Mazonson, and Holman 1993) posit that increases in self-efficacy—the sense of mastery and the confidence that one can manage the illness—may be the common medium by which self-management is improved, key behaviors are changed, and illness outcomes affected. Their interventions for arthritis patients have proved to be effective and cost-effective (Lorig, Mazonson, and Holman 1993) and are now widely disseminated. The arthritis program has been altered to meet the needs of patients with a variety of chronic illnesses and is currently being tested. This intervention differs from conventional patient education programs in its use of lay leaders rather than health professionals and its emphasis on patient empowerment and psychological status.

A critical element of successful self-management is to help patients become more active participants in their care. Greenfield and Kaplan (Greenfield, Kaplan, and Ware 1985; Greenfield et al. 1988) have examined the impact on disease outcomes of an intervention that offers patients information and skills and encourages them to discuss important questions and concerns with their physician. The intervention not only increased patient involvement in the interaction but also improved disease outcomes.

Clinical Expertise

It is unlikely that medical specialists receive more training or devote more attention to practice organization, the use of guidelines, counseling, or the other aspects of care associated with better outcomes in chronic illness. Therefore, the debate about generalist versus specialty care for chronic illness is about the importance to outcomes of specialized clinical knowledge or expertise. As discussed above, evidence suggests that specialists do have greater knowledge of effective therapies than generalists. Differences in knowledge, if generalizable to other conditions, must be addressed by primary-care-based models, even if clinical expertise is less important than other aspects of the care process in determining patient health and satisfaction.

Nonetheless, interventions that increase the expertise of generalist providers or widen the availability of expertise may well lead to better outcomes. Certainly the most common approach to increasing expertise has been continuing medical education in various forms. There is now general agreement that conventional didactic, or lecture, approaches have no enduring effects on practice style (Davis et al. 1992). Large-scale provider education programs in Western Europe have had mixed results (Rosenqvist, Carlson, and Luft 1988; Carlson and Rosenqvist 1991; Sawicki et al. 1993). The success demonstrated by the German approach (Sawicki et al. 1993) may have been more closely related to its emphasis on establishing a system of patient education. More personalized physician education through tutorials (Inui, Yourtee, and Williamson 1976), academic detailing (Soumerai and Avorn 1990), consultation conferences (Vinicor et al. 1987), and related interventions does seem to have some impact, although several of the more successful studies involved residents and faculty. Some training of providers, preferably using more personalized, hands-on methods, would seem to be an important initial step.

These educational strategies, however, cannot meet the ongoing needs for expertise in the management of specific patients. Conventional referral or consultation remains the dominant source of expert assistance in managed care as well as fee-for-service practice. Referrals, however, run the potential risk of further fragmenting care, may not increase the skills of the referring physician, and contribute to increased costs. Alternatives or complements to referral have been tried. These include innovations in generalist–specialist interactions. For example, the DI-

ABEDS program used a "hotline" to increase access of residents to expert advice on diabetes (Vinicor et al. 1987). Most promising are strategies that make expertise available to primary care practices through the development of a cadre of specially trained local experts or "gurus" (Stuart et al. 1991), or collaborative care, whereby specialists and generalists manage patients together in the primary care setting (Katon et al. 1995). At Group Health Cooperative, the diabetes improvement program relies on a three-tiered system consisting of an expert team (diabetologist and nurse specialist), who spend most of their time in the primary care setting supporting local experts (generalist physicians with a particular interest in diabetes and certified diabetes educators), educating generalist providers, and seeing difficult patients with the primary care teams (McCulloch et al. 1994). Such models of distributed expertise may prove to be far more cost-effective for common chronic illnesses than the more conventional specialty care or specialty referral models.

Finally, computer decision support systems may meet some day-to-day needs for expert advice. The evidence suggests that simple computer reminders are consistently effective in promoting recommended behaviors, while more complex diagnostic and therapeutic decision support programs have had more variable effects (Johnston et al. 1994). Work at the Regenstreif Institute (McDonald et al. 1988; Litzelman et al. 1993), the Harvard Community Health Plan (Barton and Schoenbaum 1990), and elsewhere strongly support current efforts to develop integrated clinical information systems that incorporate guidelines in the form of "advice rules" or reminders. Randomized trials have consistently shown that computerized physician reminders increase the likelihood that patients will receive preventive interventions (Johnston et al. 1994).

Information

Information about patients, their care, and their outcomes is an essential ingredient of all population-based strategies to improve chronic illness care. Without a list of all patients with a condition—a registry—providers are forced to be responsive, waiting for patients to present for care. Successful strategies are proactive, inviting or reminding patients to participate in accord with an explicit plan of care. The advantages of patient registries were recognized long before the computerization of medical practice (Fry 1973). The presence of a defined practice population, as in capitated care or in national health plans like Great Britain's, greatly facilitates the creation of registries.

The availability of a list of all patients and a few other critical data elements presents opportunities to remind patients and physicians of needed follow-up or preventive interventions. The use of registries and reminders to maintain surveillance of hypertensive patients has consistently been shown to improve the care of high blood pressure (Glanz and Scholl 1982; Macharia et al. 1992; Stason et al. 1994; Johnston et al. 1994). Yet proactive efforts to assure follow-up of hypertensive patients are not in common practice, even in prepaid care, which has the advantage of a defined population.

Registries also facilitate the provision of feedback to the practice. Several rigorous studies have shown variable impacts of feedback (Megford, Banfield, and O'Hanlon 1991). The differences among studies may be explained by the study population (e.g., trainees may be more responsive to feedback than mature practitioners) or by the context in which the feedback is given (e.g., personal communication from an opinion leader is more potent than feedback received in the mail). Feedback has often been studied in isolation as the only clinical improvement strategy being tested. Its utility may be greater when used in the context of comprehensive approaches.

An essential element of effective chronic illness care appears to be development of a shared plan of care, providing structure and coherence as the patient negotiates the string of care episodes that characterize chronic illness care. Patient-carried medical records or care plans have been shown to help in this regard (Turner, Waivers, and O'Brien 1990; Dickey and Petitti 1992), and their availability in computerized clinical information systems should produce even more powerful support.

Delivering Chronic Illness Care

The repeated demonstrations of mediocre measures of process and outcomes in usual medical practice and the failure of system-based efforts to improve primary care (Weinberger et al. 1996) suggest that there are major barriers to the delivery of high-quality care for chronic illness. The elements of good chronic illness care, as depicted in figure 1, should be easier to assemble in integrated delivery systems like group- or staff-model HMOs that have defined populations, strong clinical cultures, comprehensive services, a preventive orientation, data systems, and centralized resources like patient education and newsletters (Wagner and Thompson 1988; Schoenbaum 1990; Lawrence 1991). Despite these structural advantages, head-to-head comparisons of the processes and outcomes of care for patients with many chronic illnesses reveal few, if any, differences between HMO and fee-for-service care, or between types of HMOs (Horwitz and Stein 1990; Udvarhelyi et al. 1991; Retchin and Brown 1991; Retchin et al. 1992; Greenfield et al. 1995). The literature, and our own experience in trying to improve chronic illness care in an HMO, suggests that usual medical care, regardless of organizational and financial arrangements, confronts chronically ill patients and their providers with a set of formidable obstacles to achieving effective clinical care and self-management.

Barriers to High-Quality Chronic Illness Care

Organization of Care around the Visit. Medical care is largely organized for the diagnosis and treatment of acute conditions, and managed care is no different. In particular, the organization of care around the conventional 15-minute visit discourages the comprehensive assessment, counseling, care planning, and use of telephone contact that characterizes successful chronic illness care. Most health systems place the responsibility for initiating follow-up on the patient for fear of increasing utilization, while the evidence strongly indicates that practice-initiated follow-up is far more satisfying to patients and may, in fact, reduce utilization (Wasson, Gaudette, et al. 1992).

Successful chronic illness care programs rely heavily on nonphysician personnel to conduct routine assessments, take responsibility for key preventive tasks like immunizations, and provide most of the counseling and support for self-management. In many practices, the time of nonphysician staff is consumed with managing access to visits and the flow of visits, leaving little time for the tasks associated with successful chronic illness care. Medical specialists, social workers, nutritionists, and others in critical disciplines are often located off-site and do most of their clinical work in the context of consultation visits. These characteristics and limited access to longitudinal computerized patient information make it difficult for even the most motivated providers to comply with guidelines and meet the self-management needs of patients.

Inadequate Training. Successful management of chronic illness requires skills that are often not available in usual medical practice. These include the clinical and behavioral skills required to assist individual patients in managing their illness, as well as the organizational and information management skills necessary to assure high-quality care to all patients in the practice. Practices must have ready access to individuals skilled in counseling techniques, like motivational interviewing (Miller and Roonick 1991), that facilitate collaborative problem definition, targeting, and intervention planning.

The skills required to use the scientific literature and practice information to organize care are especially critical in our experience, and most providers have little exposure to these issues in their training. Practice management approaches based on applied epidemiology and health services research may be important in helping busy medical practices change their orientation and behavior as suggested in this article. Such a population-based perspective (Wagner 1992, 1995; Voelker 1994) attempts to improve targeted outcomes by defining the subpopulation of patients to be impacted, identifying the services that are effective for that subpopulation, and assuring their efficient and systematic delivery. Our experience suggests that population-based care planning can be successfully integrated into busy primary care practice, but it requires ongoing training and support, as supplied, for example, by guidelines as well as a registry that indicates each patient's compliance with those guidelines (Payne et al. 1995).

Lack of Incentives. Current approaches to evaluating and financing providers reinforce the acute care orientation of medical practice. Whether under capitation or fee-for-service, providers are generally not rewarded for taking the time to conduct comprehensive assessments of health status or quality of life, or counseling and educational activities in support of self-management. Productivity measures continue to focus on the number of visits and technical procedures, while telephone calls and counseling activities are frequently not even recorded.

At the organizational level, market pressures on health systems have, until recently, emphasized lower cost, selective enrollment of young and healthy individuals, and access to acute care. These market pressures have discouraged efforts to change care for patients with chronic illness.

Fortunately, this is changing through accreditation and report cards that include performance indicators related to chronic illnesses.

The Current Dilemma: Specialized or Generalist Chronic Illness Care?

To many organized health care systems trying to respond to the growing market pressures to improve health outcomes and reduce costs in chronic illness, the barriers we have described appear insurmountable. As a result, organized systems are developing or purchasing "disease management programs" with two features of potentially great consequence for the future of medical care:

1. They are disease-specific.
2. They are delivered by a team of health professionals that is distinct from the patient's source of primary care.

Two recently published randomized trials epitomize this approach, demonstrate its efficacy, and highlight the dilemmas they pose for integrated delivery systems. In the trials, community-living seniors (Stuck et al. 1995) and hospitalized patients with congestive heart failure (Rich et al. 1995) received comprehensive, nurse-directed programs featuring protocol-driven assessment, care planning, medication management, patient education, and proactive follow-up with ready access to medical and other specialists. The interventions included most of the elements identified in figure 1; both significantly improved critical patient outcomes like institutionalization and quality of life. But these highly successful interventions were delivered by multidisciplinary teams operating independently of the patients' source of regular medical care. In the words of one report, "Only in complex situations did the nurse practitioner or study physicians contact the patient's physician directly" (Stuck et al. 1995).

The success of these specialized intervention programs and their relative ease of implementation raise critical questions as health care organizations consider approaches to improving chronic illness care. Can the elements of successful specialized interventions be integrated into primary care, or will patients with chronic conditions require multiple providers addressing particular clinical issues? Does each chronic condition require different intervention components and staff or are there sufficient generalities across conditions to warrant the establishment of a common approach? These questions require urgent study as health systems begin to put into place programs that may threaten basic values and care models. Managing chronic illness through a set of disease-specific management programs with their own specialists or case managers may dramatically change the nature of primary care and the doctor–patient relationship. This can only increase the challenges to a system of assuring supportive personal relationships and care coordination at a time when the public is concerned about managed care's effects on their relationship with their doctor (Mechanic and Schlesinger 1996).

Some delivery systems, like Group Health Cooperative, are attempting to bring the elements depicted in figure 1 to each primary care practice (McCulloch et al. 1994; Wagner 1995). Primary care strategies may be less expensive in the long run (Franks, Clancy, and Nutting 1992), but they are difficult to implement since they, by definition, involve large numbers of busy health professionals with varying levels of expertise and enthusiasm working in office systems that have not traditionally supported the care of patients with ongoing problems. But concerted efforts by integrated systems to enhance the ability of primary care care practices to care for patients with chronic illness have been infrequent in the United States, and empirical results are sparse.

Organizations implementing condition-specific specialized programs must decide who has ultimate accountability for the patient's health and coordination of care. The care of the many chronically ill patients who have multiple conditions (e.g., 50 percent or more of Type II diabetics are hypertensive; a third or more have clinically significant coronary artery disease) will challenge systems based on the specialized approach. Will patients tolerate seeing different providers for their various problems?

Thus, we see chronic illness care and primary care at a critical juncture. If the care of patients with chronic illness is excised from primary care, like hospital and obstetric care before it, primary care will consist only of primary prevention and acute illness. Most organized care systems are constructed around a basic delivery model that defines the roles and accountabilities of major professional groups, especially physicians. In most models, primary responsibility for the care of each patient rests with a single physician or other primary care provider. Most managed care organizations have adopted the primary care gatekeeper model (Franks, Clancy, and Nutting 1992), in which accountability for patient care and the utilization of resources rests with the patient's primary care provider. Many endeavors to improve the care of chronic disease threaten these basic models by pulling the care of the condition away from the patient's regular care team or by adding new providers to the mix. It is not certain whether the many organizations that are initiating or purchasing disease-specific care programs have considered the implications of these choices for patients or providers.

Next Steps

Major natural experiments in the care of chronic illness are under way. Health care organizations across the country have recognized the deficiencies in this form of care and the costs generated by caring for chronically ill patients, and they are devising and piloting a broad array of care models that have received limited scrutiny. Despite the paucity of rigorous evaluation, the movement to "benchmark" and find good ideas in other places is leading organizations to emulate nascent, minimally evaluated programs.

Systematic efforts to document the characteristics and impact of care management programs for chronic illnesses are urgently needed so that empirical evidence, not only market pressures and political forces, influences the design of medical care for patients with ongoing health needs. We believe that the characteristics of interventions that improve outcomes in patients with chronic illness, as organized in figure 1, provide a useful starting point for designing evaluations, research projects, and innovations in chronic illness care.

Progress in the care of patients with chronic illness will be accelerated by agreement on a standardized set of structure, process, and outcome measures with which to describe and evaluate interventions. In addition to clarifying the similarities and differences in interventions and measuring the effects on the disease under study, such measures should furnish answers to more general questions about the impact of these programs on preventive care, care for other conditions, patient and family satisfaction with the doctor–patient relationship and coordination of care, and the satisfaction felt by various providers with their roles. Agreement on such a set of measures would facilitate meta-analyses and more rigorous syntheses of evaluations of current efforts and future randomized trials of more promising strategies across multiple health care systems.

Most current activity favors specialized approaches. Efforts to integrate the elements of our improvement model into busy primary care are rare. If we are to resolve the dilemma of specialized versus generalist care, we must encourage health systems to design innovative strategies for enhancing primary care and subjecting them to rigorous comparisons both with usual care and with more specialized approaches.

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