Managed Care and Chronic Illness: Health Services Research Needs

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The chronically ill may have the most to gain or lose by the changes now occurring in the organization of medical care. My purpose is to define and discuss the major health services research questions associated with care of chronic illness. Health services research charged with assessing the safety and effectiveness of different ways to organize or finance care for patients with chronic illness and disability should address questions in three areas:

1. *What accounts for the generally poor level of care for chronic illnesses in this country, and why have integrated, managed health systems thus far failed to do better than disorganized, fee-for-service care?* What are the barriers to meeting the needs of chronically ill patients in the organization and financing of medical care?
2. *What works and what doesn't among the many approaches to improving chronic illness care being tried by organized health systems?* Are "disease management programs" marketing gimmicks or substantial steps forward?
3. *What are the effects of newer managed care structures and strategies on patients with chronic illness?* Are more vigorous efforts to find lower-cost providers or curtail utilization depriving ill patients of a supportive relationship with their provider or access to needed services?

Following the failure of health care reform, we are experiencing unprecedented, unevaluated tinkering with basic care models and values. Patients with major chronic illnesses and disabilities are most at risk if this tinkering disrupts critical health care relationships or reduces access to or the quality of needed services; yet the chronically ill may benefit the most if these changes correct previous deficiencies in care.

The Quality of Chronic Illness Care

The first question arises from the fact that study after study of usual medical care, whether managed or not, has repeatedly found serious deficiencies in both the process and outcomes of care for major chronic illnesses. Available evidence suggests that chronically ill patients receive limited assistance from their providers in their efforts to maintain function and quality of life as they cope with their illness (VonKorff, Gruman, Schaefer, et al. [in press]). For example, practitioners often fail to assess their patients' understanding of their illness (Cohen, Tripp, Smith, et al. 1994), their ability to function (Rubenstein, Calkins, Young, et al. 1989; Wasson, Keller, Rubenstein, et al. 1992), or their insight into self-management (Cassell 1991). As a result, functional deficits and the need for rehabilitative, supportive, and educational services go unrecognized. In addition, surveys and audits regularly reveal failures to comply with well-established guidelines for the critical clinical aspects of care for patients with a host of chronic conditions (Stockwell, Madhavan, Cohen, et al. 1994; Kenny, Smith, Goldschmid, et al. 1993; Hirsch and Winograd 1992, for example). Thus, the growth of managed care is taking place on a background of generally suboptimal care for the chronically ill, frail, and disabled.

While deficiencies in provider training play a role, the acute care orientation of medical practice limits the ability of medical care to meet the clinical and self-management needs of chronically ill patients (Wagner, Austin, and VonKorff 1996; Wagner 1996). Medical practices, especially those in primary care, are oriented and organized to respond to acute illness, which fosters a culture and office systems that rely on patient-initiated visits and actions, and emphasizes relief of symptoms rather than assessment and improvement of function. Responsibilities for planning care, counseling, and follow-up often fall to the overburdened and underprepared physician. Information necessary for planning care is either unavailable or buried in a cumbersome paper medical record. The orientation to acute illness of usual primary care practice conflicts with the needs and priorities of chronically ill patients.

Group/staff model HMOs have defined populations, comprehensive services, a preventive orientation, data systems, and centralized resources like patient education and newsletters (Lawrence 1991; Schoenbaum 1990). In comparison with fee-for-service care, these structural advantages of HMOs have resulted in cost savings and improved preventive care (Miller and Luft 1994). However, head-to-head comparisons of the processes and outcomes of care for patients with many chronic illnesses reveal few if any differences be-

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tween HMO and fee-for-service care, or between types of HMOs (Greenfield, Rogers, Mangotich, et al. 1995; Horwitz and Stein 1990; Retchin, Clement, Rossiter, et al. 1992; Udvarhelyi et al. 1991; Ware, Bayliss, Rogers, et al. 1996). It is not clear why high-quality HMOs, such as those involved in the MOS (Greenfield, Rogers, Mangotich, et al. 1995; Ware, Bayliss, Rogers, et al. 1996), have failed to capitalize on these structural advantages. While studies demonstrating deficiencies in care are myriad, studies defining the critical obstacles to effective chronic illness care have been rare.

System Barriers to High-Quality Chronic Illness Care

Efforts to improve chronic illness care will be enhanced by quantitative and qualitative observational research that identifies system and practice barriers to high-quality medical care in both fee-for-service and capitated plans. This research is urgently needed as the marketplace seems to have already concluded that the care of common chronic diseases is best handled by specialized disease management programs or companies. The following represent possible barriers worthy of further study.

Organization of Care Around the Patient-Initiated 15-Minute Visit. Most medical care is organized around a 15-minute visit requested by the patient. While perhaps appropriate for acute illness, such visits discourage the comprehensive assessment, counseling, and care planning that characterize successful chronic illness care. Do longer, better-organized visits improve process and outcomes? And what impact do they have on subsequent utilization? Also, many practices and managed systems place the responsibility for initiating follow-up on the patient, when the available evidence strongly indicates that practice-initiated follow-up is far more satisfying to patients and may, in fact, reduce utilization (Wasson, Gaudette, Whaley, et al. 1992; DeBusk, Miller, Superko, et al. 1994; Weinberger, Kirkman, Samsa, et al. 1995). It is not clear why practice-initiated patient contacts, commonplace in dental and veterinary practice, are so unusual in medical practice.

Reliance on the Physician. Successful chronic illness care programs rely heavily on non-physician personnel to conduct routine assessments, take responsibility for key preventive tasks, provide support for self-management, and assure follow-up (Schwartz, Raymer, Nash, et al. 1990; DeBusk, Miller, Superko, et al. 1994; Weinberger, Kirkman, Samsa, et al. 1995; Stuck, Aronow, Steiner, et al. 1996). In many practices, non-physician staff time is consumed with managing access to visits and the flow of visits, and staff are being reduced. We need research to clarify the physician's role in chronic illness management, what is best done by the doctor and what is best delegated to trained non-physicians. The National Cancer Institute's program of research on the physician's role in smoking cessation may be a good model.

Access to Expertise. Providers caring for chronic illness and their patients require timely access to medical specialists, social workers, behavioral therapists, and other experts. Traditionally, these are located off-site and do most of their clinical work in the context of consultation visits. This may not be the most effective or efficient way to assure that patients receive technically proficient care and that providers receive continuing education. And it may be further restricted by managed care approaches. The relationships between primary care providers and specialists is an area of AHCPR interest that has major relevance in improving chronic illness care.

Inadequate Information. Limited access to key clinical information makes it difficult for even the most motivated providers to create and maintain care plans, comply with guidelines, and meet the self-management needs of patients. Health plans are spending millions of dollars to develop clinical computing systems. These systems generally focus on providing the necessary information and capabilities to make care of the individual patient more efficient. Whether these systems, based generally on the existing medical record, will lead to improved chronic illness care is uncertain. We urgently need research that identifies those capabilities of clinical computing systems associated with improved process and outcomes.

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 to provide counseling and educational activities in support of self-management. Productivity measures and reimbursement continue to focus on the number of visits and technical procedures, while telephone calls and counseling activities are frequently not even recorded. What financial and non-financial incentives motivate practice teams to provide better care for their chronically ill patients? Conversely, what financial and other characteristics of practice provide disincentives to good care?

What Works and What Doesn't in Chronic Illness Care?

In an effort to identify efficiently interventions that work, researchers should both design and test innovative strategies and evaluate the explosive growth of disease management programs instituted by health systems and technology companies in response to pressures from patients and purchasers. The latter vary widely, and many do not appear to be based on solid empirical evidence.

If we are to learn anything from this flurry of activity, these efforts must be characterized and evaluated.

We have reviewed the literature on the management of chronic illness in an effort to delineate and categorize the characteristics of programs and interventions that have improved outcomes (Wagner, Austin, and VonKorff 1996). There appear to be significant similarities among those organized efforts that improve patient outcomes. The common elements seem to fall in five general areas: (1) the use of explicit plans and guidelines based on evidence; (2) the reorganization of the practice to meet the needs of patients requiring more time, a broad array of resources, and closer follow-up; (3) systematic attention to the information, behavior change, and psychosocial needs of patients; (4) ready access to necessary expertise; and (5) supportive information systems.

These common elements were found across programs addressing a wide variety of chronic conditions and might serve as a framework for analyzing current disease management efforts. In some of these areas, there has been relatively little research. The apparent similarities of effective interventions across a variety of conditions raise a critical research question. To what extent will a generic approach to chronic illness management meet the needs of patients with very different conditions who have very different clinical requirements? If programs that improve diabetes care are substantially different than programs that improve asthma or coronary disease care, it will make systemwide improvement much more difficult.

Evidence-Based, Planned Care. AHCPR has supported research on the implementation of guidelines. The results of current and past efforts should be synthesized and reviewed to assess the most promising directions for future research. A synthesis of earlier studies (Grimshaw and Russell 1993) and our experience (Horowitz, Goldberg, Martin, et al. 1996) suggest that future research should give more emphasis to innovative organizational and system changes that support guideline adherence, and less to provider education. Planning care for groups of patients *and* for individual patients appear to be critical steps toward improving care for chronic illness. Research that examines provider training, practice reorganization, computer systems, or other innovations that enhance care planning for groups of patients (Greenlick 1992; Vogt 1993; Payne, Galvin, Taplin, et al. 1995; Wagner 1995) and for individual patients should be given high priority.

Practice Reorganization. Successful chronic illness programs, in contrast to usual primary medical care, organize their practices to meet the needs of patients with chronic health problems. To escape the constraints of the

15-minute visit in busy practice requires significant changes. These include alterations in practice team organization and task delegation, appointment and follow-up systems, and the availability of key specialty resources. Representative research in this area has examined the role of team function (Carlson and Rosenqvist 1988), the use of telephone follow-up (Wasson, Gaudette, Whaley, et al. 1992), and the use of home visits for geriatric patients (Stuck, Aronow, Steiner, et al. 1995). The overarching question is whether these elements of successful chronic care programs can be incorporated into busy day-to-day care. One important factor is the way in which the practice team organizes itself and uses all members of the practice team (Eisenberg 1995). We need a renewed research focus on teamwork in care delivery, but research that emphasizes enhancing the clinical effectiveness of the team.

Patient Self-Management and Behavior Change Support. All successful chronic illness programs provide some sort of educational programming to meet the needs of patients and caregivers for information, behavioral skills, and psychosocial support. 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). There is reasonable evidence that modern, behaviorally sophisticated self-management and behavior change programs improve outcomes. Successful programs provide, to varying degrees, four essential elements (VonKorff, Gruman, Schaefer, et al. [in press]): (1) assessment and collaborative problem definition between patient and provider; (2) targeting, goal setting, and planning; (3) self-management training and support services; and (4) active and sustained follow-up.

Evidence suggests that effectiveness depends on sustained attention to the self-management needs of patients rather than the more typical concentrated dose of didactics at the time of diagnosis with little to follow. Ongoing behavioral research is required to strengthen the theory and methods of these interventions. There are important health services research questions as well. First, the linkage between self-management support for chronic illness and the patient's routine medical care has received relatively little attention (Weinberger, Oddone, and Henderson 1996; Glasgow et al. [in press]). For example, we could not find empirical evidence about the impact of personal physician involvement on patient education program effectiveness in chronic illnesses.

Second, to what extent can chronic disease patient education programs share generic components and approaches? Lorig and colleagues have adapted their effective and cost-effective arthritis education program (Lorig, Mazonson, and Holman 1993) to address the needs of patients with a variety of chronic illnesses. It is currently being tested. Will generic programs of this sort increase the likelihood that patients with a variety of conditions receive psychoeducational interventions?

Third, a critical element of successful self-management is to help patients become more active participants in their care. The work of Greenfield and colleagues (Greenfield, Kaplan, Ware, et al. 1988; Greenfield, Kaplan, and Ware 1985) and others showing the benefits of interventions to increase patient involvement must be extended as it has had little impact on organized health systems.

Clinical Expertise. The critical research question in this area, and perhaps for chronic illness care in general, is whether patients with chronic illness should receive their primary care from specialists, including case managers, or generalists. Arguments for specialization are multiple and compelling. Specialist physicians are more knowledgeable about chronic illnesses (Ayanian, Hauptman, Guadagnoli, et al. 1994), and more specialized care programs such as hospital-based clinics (Hayes and Harries 1984; Verlato, Muggeo, Bonora, et al. 1996), work-site programs (Fielding, Knight, Mason, et al. 1994), and nurse-therapist clinics (Schwartz, Raymer, Nash, et al. 1990) have shown better outcomes. However, it is often difficult to disentangle the relative effects of increased knowledge and increased experience with the condition from better-organized care in those studies showing improved outcomes with more specialized care. What we need to know is whether usual generalist care is inferior to usual specialist care. To date, the results have generally shown little difference (Greenfield, Rogers, Mangotich, et al. 1995). The cost-effectiveness of case management by case managers also remains uncertain (Austin et al. 1985). Specialized programs may well create problems in doctor-patient relationship, continuity, and coordination. Will patients tolerate seeing different providers for their various problems? Research should establish from whom chronically ill patients receive their primary and continuing care.

Innovation and research into methods for increasing the expertise available to the primary care team also remains a high priority. In particular, increased access to expertise through "hotlines" (Vinicor, Cohen, Mazzuca, et al. 1987), specially trained local experts or "gurus" (Stuart, Handley, Chamberlain, et al. 1991), and collaborative care whereby specialists and generalists manage patients together in the primary care setting (Katon, VonKorff, Lin, et al. 1995; McCulloch et al. 1994) would seem to be approaches worth further study. Because of differing clinical requirements, this is an area where different approaches for different conditions may be optimal.

Finally, computer decision support systems may meet some day-to-day needs for expert advice. The evidence to date 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). Efforts to support guidelines with computerized "advice rules" or reminders are clearly effective, and practical approaches to their broader implementation needs further study.

Information. A list of all patients with a condition—a registry—may be a critical first step in assisting practices to make the transition from acute, reactive care to organized, planned care. The availability of a list of all patients and a few other key data elements presents opportunities to remind patients and physicians of needed follow-up or preventive interventions. While registries have a long history, their automation and integration with guidelines and reminders would appear to be a promising direction for further study.

New Managed Care Structures and Strategies

Managed care organizations are attempting to increase market share, reduce costs, and improve quality through a broad array of organizational arrangements and strategies. The constellation of approaches used by a given plan provides a much more informative description of that plan than do the old rubrics—group/staff model, IPA, and so forth. For example, many MCOs rely heavily on aggressive pre-authorization review and financial incentives to curtail utilization, tactics that would be anathema in many traditional HMOs. We do not have data about the impact of commonly used managed care structures or strategies on patients with chronic illness. Many managed care organizations are investing heavily in clinical computing systems and disease management activities. Approaches to disease management programming vary widely, ranging from simple dissemination of a guideline to comprehensive efforts to change primary care delivery to the establishment or purchase of specialized services for the care of specific conditions. Are these efforts moving MCO delivery systems in the direction of the successful chronic disease interventions just described, or are cost reduction and marketing schemes further undermining the care of the chronically ill?

Some cost reduction efforts appear to threaten the basic principles and traditions in American medical care valued by physicians and patients alike—physician autonomy, continuity of care, freedom of choice. The more important issue is whether these efforts, as suggested by the legions of managed care critics, reduce the quality of care and service given to vulnerable patients. Simplistic comparisons of HMOs vs. fee-for-service care no longer will suffice. Instead, we need observational studies and randomized trials capable of isolating the specific impacts of particular managed care arrangements and procedures. The following may pose particular concerns for chronically ill patients.

Contracting with Independent Providers and Practices. Most managed care research to date has involved group or staff model structures where providers relate to a single organization with presumably uniform guidelines, resources, and care management strategies. The rapid growth of IPA and network models has confronted many physicians with the challenge of working with multiple organizations, each with its own regulations and approaches. The impact of this situation on high-risk patients and their providers needs urgent study.

Efforts to Limit Access to Specialty Services. Do efforts to restrict access to specialty services (including so-called ancillary services such as behavioral medicine, social work, podiatry) or to reward primary providers for limiting referrals result in fewer visits to relevant specialty services, reduced compliance with guidelines, and poorer outcomes?

Efforts to Increase Primary Care Access and Productivity. Many MCOs have altered their appointment systems to improve access, especially for acute problems, and have initiated financial incentives or managerial pressures to increase daily visit frequencies by primary care providers. Have such efforts made it more or less difficult for chronically ill patients to receive more thorough care and more regular follow-up?

Efforts to "Carve Out" Care for Specific Conditions. The movement toward establishing or contracting with specialized groups or organizations for diabetes care, HIV/AIDS, mental health care needs to be evaluated. On the one hand, more specialized and experienced providers and more organized programming could well improve process and outcomes. On the other hand, carve-outs disrupt the primary provider–patient relationship, challenging continuity and coordination of care especially for those many patients with multiple chronic problems. What is the net result of these changes on the satisfaction and health of patients with chronic conditions?

Efforts to Limit Staffing. Many MCOs are experimenting with leaner practice staffing, especially limiting the availability of registered nurses. To what extent will changes in practice team composition affect the quantity and quality of care—especially educational and psychosocial support—for chronically ill patients and their caregivers?

Summary

Major natural experiments in the organization and financing of health care and in the care of chronic illness are underway. New approaches to reducing costs are radically changing the face of medical practice. Health care organizations, recognizing the deficiencies and high costs in caring for chronically ill patients, are purchasing or devising a broad array of new care programs. The impacts of these dramatic changes in care delivery on the health and happiness of patients with chronic illness are not known. Despite the absence of rigorous evaluation, the enthusiasm for "benchmarking" is leading organization after organization to emulate untested management strategies. The necessity for appropriately targeted health services research is pressing if empirical evidence, not market pressures, is going to influence the design of medical care for patients with ongoing health needs.

Progress in the research on 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 managed care organization and tactics, and chronic disease management interventions. In addition to clarifying the similarities and differences in organizations and interventions, uniform measures would facilitate meta analyses and syntheses of evaluations of current efforts and future randomized trials of more promising health care systems strategies.

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