

Collaborative Management of Chronic Illness

[Perspective]

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Outline

- Abstract
 - Collaborative Management
 - Behavioral Principles
 - Essential Elements
 - Collaborative Definition of Problems
 - Targeting, Goal Setting, and Planning
 - Creating a Continuum of Self-Management Training and Support Services
 - Active, Sustained Follow-up
 - Critical Next Steps
 - Performance Indicators and Incentives
 - Technical Assistance
 - Practice Guidelines and Systems
 - Increased Community Involvement
 - Conclusions
 - REFERENCES
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Abstract□

In chronic illness, day-to-day care responsibilities fall most heavily on patients and their families. Effective collaborative relationships with health care providers can help patients and families better handle self-care tasks. Collaborative management is care that strengthens and supports self-care in chronic illness while assuring that effective medical, preventive, and health maintenance interventions take place. In this paper, the following essential elements of collaborative management developed in light of behavioral principles and empirical evidence about effective care in chronic illness are discussed: 1) collaborative definition of problems, in which patient-defined problems are identified along with medical problems diagnosed by physicians; 2) targeting, goal setting, and planning, in which patients and providers focus on a specific problem, set realistic objectives, and develop an action plan for attaining those objectives in the context of patient preferences and readiness; 3) creation of a continuum of self-management training and support services, in which patients have access to services that teach skills needed to carry out medical regimens, guide health behavior changes, and provide emotional support; and 4) active and sustained follow-up, in which patients are contacted at specified intervals to monitor health status, identify potential complications, and check and reinforce progress in implementing the care plan. These elements make up a common core of services for chronic illness care that need not be reinvented for each disease.

Chronic conditions, defined as illnesses that last longer than 3 months and are not self-limiting, affect almost half of the U.S. population. Persons with chronic illnesses account for three quarters of health care costs in the United States [1]. Experimental studies have shown a gap between the health care services intended to improve outcomes in chronic illness and the care that patients usually receive. This disparity calls for reassessment of the current organization of health care so that chronically ill patients are more likely to receive services that help them live as well as they can for as long as they can.

Patients and their families are the primary caregivers in chronic illness [2-4]. Self-care [2,3,5,6] refers to 1) engaging in activities that promote health, build physiologic reserve, and prevent adverse sequelae; 2) interacting with health care providers and adhering to recommended treatment protocols; 3) monitoring physical and emotional status and making appropriate management decisions on the basis of the results of self-monitoring; and 4) managing the effects of illness on the patient's ability to function in important roles and on emotions, self-esteem, and relationships with others. Self-care and medical care are sometimes viewed as competing rather than complementary strategies. When self-care implies limited access to health care, it may carry negative connotations for patients and health care providers. At the same time, medical care for chronic illness is rarely effective in the absence of adequate self-care. Self-care and medical care are both enhanced by effective collaboration among chronically ill patients and their families and health care providers. Collaborative management occurs when patients and care providers have shared goals, a sustained working relationship, mutual understanding of roles and responsibilities, and requisite skills for carrying out their roles.

We identified essential elements of collaborative management of chronic illness in light of behavioral principles and empirical evidence about enhancement of self-care. Although families and lay caregivers play a critical role in managing chronic illness, we focused on the role of health care systems in improving care. We then discuss critical next steps to improve care of chronic illness in organized health care systems.

Collaborative Management

Behavioral Principles

Interventions that improve outcomes of chronic illness have been developed on the basis of social learning and self-regulation theories [7-14]. Key principles of these theories include the ideas that 1) illness management skills are learned and behavior is self-directed; 2) motivation and self-confidence (or self-efficacy) in management of illness are important determinants of patients' performance of self-care; 3) the social environment of the family, workplace, and health care system can support or impede self-care [15-17]; and 4) monitoring and responding to changes in disease state, symptoms, emotions, and functioning improves adaptation to illness.

For many chronic conditions, interventions developed on the basis of these principles have been shown to improve medical, emotional, and functional outcomes [7,18-40], particularly when providers and patients work together toward shared goals. For example, Vinicor and colleagues [41] compared three diabetes interventions to usual care: a patient intervention that emphasized goal-setting and contracting, a physician intervention that emphasized problem-oriented protocols, and an intervention that incorporated patient and physician approaches. Relative to usual care, both patient and physician interventions improved fasting blood glucose, glycosylated hemoglobin, body weight, and blood pressure at 26 months; the greatest benefit occurred when patient and physician interventions were combined.

Health care providers can use behavioral techniques to improve self-care in chronic illness. Such techniques as setting goals; checking the patient's readiness for self-care; breaking self-care tasks into small, manageable steps; getting personalized feedback; self-monitoring; enlisting social support; and checking patient commitment to key tasks are helpful [42-46]. These techniques may be used singly or in combination: Montgomery and coworkers [47], for example, gave patients with Parkinson disease a computer-generated, individualized self-care program that used many of these behavioral strategies. The program was delivered by mail along with educational materials. Relative to controls, patients who received the intervention had reduced side effects of medication, decreased disease severity, increased levels of exercise and activity, and increased self-confidence in disease management at 6 months of follow-up. In addition to improved disease outcomes, many studies [7,10,22,24,39,48,49] have found that behavioral interventions improve psychosocial outcomes.

Even low-intensity behavioral interventions can be effective in changing key health behaviors, such as smoking, medication use, and diet [44,50,51]. For example, Litzelman and associates [52] gave diabetic patients brief education on foot care, developed a self-care contract with patients, and gave monthly reminders by telephone and postcard. Providers were given flow sheets on foot care, and reminder stickers were attached to the medical record. Relative to usual care, patients in the intervention group received foot examinations more often and had fewer serious lesions at 1 year of follow-up. These types of behavioral strategies are more likely to be effective when planned in light of patient readiness for self-care and when the level of support is matched to patient needs [53,54].

Essential Elements

On the basis of the behavioral principles underlying self-care and the results of experimental studies that evaluate self-care interventions, we identified four elements of health care that can enhance collaborative management.

Collaborative Definition of Problems

Collaborative management begins when patients and care providers define problems clearly [11,55-57]. Providers usually define problems in terms of diagnosis, poor compliance with treatment, or continuation of unhealthy behaviors (such as smoking or a sedentary lifestyle). Patients are more likely to define problems in terms of pain, symptoms, interference with functioning, emotional distress, difficulty carrying out treatments or lifestyle changes, or fears about unpredictable health consequences of illness. Patients are more likely to benefit when these two perspectives are harmonized.

Even small steps, such as asking a patient to identify the biggest problems faced in managing illness, may provide a basis for improved collaboration. Greenfield and colleagues [27] had an assistant prepare patients with diabetes for a clinic visit by identifying medical decisions that were likely to arise, relevant lifestyle issues, and patient preferences. Negotiation skills and obstacles were discussed and rehearsed. Relative to controls, prepared patients more effectively elicited information and had better functional and physiologic outcomes at 12 weeks.

Targeting, Goal Setting, and Planning

Focusing on a specific problem, establishing realistic objectives, and developing an action plan for attaining those objectives are beneficial steps in managing chronic illness [3,12,54]. Targeting is critical because patients and providers often initiate many changes at once, which can lead to poor adherence and discouragement. There is growing consensus that targeting should be done on the basis of both the importance of the problem and patient motivation and readiness for self-care [53,58]. Once patients and physicians define a problem and agree that it is important, they can establish a behavioral goal and an

action plan for achieving it that allows patients and providers to monitor progress. Action planning consists of identifying a menu of options for achieving a goal, choosing one option, developing specific implementation plans, foreseeing obstacles, and making a commitment to put the plan into effect [3,6]. Case management and group interventions are effective methods for setting goals and implementing an action plan [7,10,59,60]. Interactive, computer-based methods are being developed to serve these purposes [61-64], but practical experience is limited and adequate testing is needed.

Creating a Continuum of Self-Management Training and Support Services

Patients' abilities to care for themselves are enhanced by services that teach skills needed to carry out medical regimens, guide health behavior change, and provide emotional support. Because needs differ, a variety of services should be available, ranging from minimal, self-help approaches to more intensive case management [54,65]. Many effective ways of teaching skills and providing support exist, including individual and group instruction [3,6,23,66], high-quality educational materials with personalized feedback [47,54], and interactive instruction given by computer [61-63]. Structured programs that target a health behavior relevant to many patients with chronic illness can also be effective. For example, boosting physical activity produces positive effects on patients' physical and psychological health in many chronic conditions [67,68]. Exercise classes, walking groups, and graded exercise programs are effective formats for increasing physical activity [69-75].

It is important that these kinds of services be individualized, tailored to each patient's motivation and readiness [58], and aligned with priorities agreed upon by patient and provider. Glasgow [54] advocated stepped-care approaches in which all patients receive low-intensity interventions and only higher-risk patients receive more expensive and intensive interventions. Such individualized approaches are compatible with interventions that mix patients with different chronic conditions. For example, classes that teach self-care skills to patients with many chronic conditions have been developed [76] and are being tested experimentally with promising results.

Active, Sustained Follow-up

Contact with health care providers that is planned and sustained over time improves patient outcomes. By contacting patients at specified intervals, care providers can obtain information on medical and functional status, identify potential complications early, check progress in implementing the care plan, make necessary modifications, and reinforce patient efforts. Patient follow-up can be accomplished by scheduled return visits, telephone calls, electronic mail, or mailed forms [59,77-84]. Telephone contact has proven particularly effective. For example, DeBusk and associates [59] randomly assigned patients with coronary artery disease to usual care or nurse management for modification of risk factors. After hospital discharge, patients were actively followed by telephone and home visits according to a management plan. Relative to usual care, the intervention had favorable effects on smoking cessation and cholesterol levels at 2 months and functional status at 6 months. Wasson and colleagues [77] evaluated the effects of substituting scheduled telephone contacts for unscheduled clinic visits among elderly male patients. The telephone contacts were scheduled at half the frequency of the unplanned clinic visits. Among patients with fair to poor health at baseline, active telephone follow-up had favorable effects on physical functioning, reduced hospitalization, and showed a trend toward reduced mortality over a 2-year period. Rich and coworkers [84] evaluated an intervention for patients with congestive heart failure that included predischarge planning; a prescribed, individualized diet; a simplified medication regimen; and active follow-up through home visits and telephone contacts. Relative to controls, patients who received the intervention showed increased quality of life and had fewer readmissions over a 90-day follow-up period.

Critical Next Steps

The elements of collaborative management define general capabilities for chronic illness care in organized health care systems. A common core of services and skills supports collaborative management of chronic illness so that management does not need to be reinvented for each chronic disease. Reforming health care in ways that enhance collaborative management of chronic illness will probably be a long-term process in which new ways of providing care for chronically ill persons gradually emerge. Providers as well as patients will benefit from active participation in this process.

Managed care has a critical role to play in improving chronic illness care, but it remains to be seen whether this promise will be realized. The Institute of Health and Aging [65] observed that

"some HMOs... create support groups for patients; screen enrollees to identify those with chronic problems; [and] provide early intervention services. However, the managed care industry overall has yet to implement these and other practices that would meet the needs of people with chronic conditions."

As yet, no grand strategy exists for reorganizing health care systems to improve collaborative management of chronic illness. An understanding of how to effectively change large health care systems remains limited, and health care leaders, providers, and consumers have roles to play in improving care of chronic illness. Innovative approaches to health care (such as those that we describe) are more likely to be widely adopted if the following critical factors are aligned to support collaborative management of chronic illness in health care systems. These steps were identified during discussions at a Robert Wood Johnson Foundation-sponsored conference in Seattle, Washington, 27 to 28 June 1996.

Performance Indicators and Incentives

Performance indicators and incentives may motivate improved care of chronic illness. Indicators of the quality of chronic illness care that are being developed by the National Committee on Quality Assurance may influence consumer choice of health plans and may be used to assess and reward high-quality care by providers. Health care leaders must better understand incentives that are intrinsic to the ways in which care is organized, financed, and reimbursed and use them to improve care of chronic illness. For example, adequate reimbursement or allocation of resources for such services as patient assessment and care planning, self-management training and support, and active follow-up will be necessary if these services are to become part of routine patient care.

Technical Assistance

Science-based technical assistance, such as the research and extension programs successfully used to improve agricultural productivity [85], may provide a means of disseminating research results and effective programs across health care systems. Administrative and clinical leaders are often unaware of the research evidence about effective ways of caring for patients with chronic illness. They also may not understand how to integrate effective collaborative management practices into large, complex health care systems. Although research has identified effective stand-alone programs that improve chronic illness outcomes, research that evaluates the integration of effective programs into large health care delivery systems is needed.

Practice Guidelines and Systems

Practice guidelines and systems must be developed within a larger strategy of chronic illness care. Efforts to improve care for each chronic condition should be planned so that care for other conditions is also strengthened. For example, Group Health Cooperative of Puget Sound developed a patient

education strategy in which common systems and concepts are used for diverse conditions across preventive and chronic illness care (for example, common systems for patient identification, assessment and targeting, delivery of patient education interventions, and active follow-up). Within an overall strategy of chronic illness and preventive care, efforts to improve services for one condition also improve care for other conditions by building general health care system capabilities. In particular, clinical information systems are needed in preventive and chronic illness care that support such general tasks as identifying patient populations with specific needs, assisting in care planning, and monitoring the provision and outcomes of care [5,64].

Increased Community Involvement

Employers, community organizations, government, and patient advocacy organizations must play a more active role in improving the performance of large health care systems. Employer coalitions have effectively advocated improved mental health services in health maintenance organizations. Patient advocacy groups and community organizations are an important but largely untapped resource. For example, referral paths from health care settings to community resources that help patients and their families manage chronic illness are often inadequately developed. Active cooperation between community-based organizations and health care systems could markedly increase patient participation in community-based services that support chronic illness management. Patient advocacy groups can play a critical role in ensuring that health care systems improve care for chronic illness and that all persons afflicted by chronic illness have access to appropriate care. At present, competitive forces that affect managed care may reward exclusion or underservice of the chronically ill.

In the long run, improved care of chronic illness requires fundamental changes in the organization and delivery of health care services [5]. The growth of managed care increases possibilities for collaboration among patients and their families, primary care providers, and specialists [83], but this potential for improved collaboration has yet to be realized in routine patient care. Changed incentives, performance indicators, technical assistance, research, practice guidelines developed within a larger strategy of chronic illness management, clinical information systems, and community involvement may each contribute to changes to the health care system. Health care systems that align these broader forces for change should have increased ability to implement effective collaborative management practices.

Conclusions

The elements of collaborative management provide a framework for research and innovation to improve chronic illness care. The potential of organized health care systems to improve outcomes of chronic illness will depend on their ability to provide these services to the many chronically ill patients that they serve.

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