

Patient Self-Management: A Key to Effectiveness and Efficiency in Care of Chronic Disease

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The present health care system is neither effective nor efficient. The dominant reason for this is a contradiction between the principle problem confronting the system—chronic disease—and the system's methods of operating, which were designed for acute disease. Resolution of the contradiction requires a different practice of health care, with new roles for the patients, for physicians and other health professionals, and for health services.

Until the middle of the last century, acute disease was the major health problem in the United States. Then chronic disease began to emerge as the central health care issue. Now, chronic disease is the major cause of disability, the principle reason why patients visit physicians, and the reason for 70% of health care expenditures.^{1,2} The present health care system, designed early in the last century to cope with acute disease, did not change when chronic disease became the major issue. As a consequence, discontinuity and fragmentation of care are widespread. Technology is often applied unnecessarily. Community and home-based care are poorly developed. Costs mount without obvious commensurate benefits for patients. And a large segment of the population is unable to obtain appropriate health care.

Why is this so? The answer begins to emerge when we examine the differences between acute and chronic disease, as outlined in Tables 1 and 2. Among the many differences, the most crucial are:

- There is no cure for chronic disease; instead, management over time is essential.
- For effective treatment of chronic disease, the patient must engage continuously in different health care practices.
- The patient knows the most about the consequences from the chronic disease and its therapies, and must apply that knowledge to guiding the management over time.
- To achieve effectiveness and efficiency in treatment, the patient and health professional must share complementary knowledge and authority in the health care process.

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Table 1. Acute disease characteristics

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- Abrupt onset
 - Limited duration
 - Usually single cause
 - Diagnosis and prognosis commonly accurate
 - Self-limited, or specific therapy available
 - Technological intervention usually effective (laboratory testing, imaging, medication, surgery)
 - Cure likely with return to normal health
 - Minimal uncertainty
 - Profession knowledgeable; laity inexperienced
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This situation creates new responsibilities for both patients and health professionals. With acute disease, the patient is inexperienced, the health professionals are knowledgeable, and they apply that knowledge to a passive patient. With chronic disease, those roles are no longer appropriate. The patient should be an active partner, applying his or her knowledge continuously to the care process. But initially, the patient is inexperienced in this new role, and must learn how to be an effective participant. Health care professionals and public health programs, in addition to providing professional guidance, now become teachers, aiding the patient in developing skilled health practices. The crux of appropriate care for chronic disease is a partnership between patients and health professionals in management over time. The bedrock is continuity and integration of care by the participating health professionals.

To make these views practical, some background information is useful. Table 3 outlines the consequences of a chronic disease for a patient. These consequences impact virtually every area of the patient's life. The patient's responsibilities (Table 4) mirror these consequences. The patient's success in meeting the responsibilities will determine the outcome for the patient and the family over a period commonly measured in years.

The advent of chronic disease dominance has dramatically changed the scope of outcomes to be sought from health care. Five categories of outcomes include: physiology, symptoms, physical and emotional function, personal health perceptions, and quality of life. The first two are the typical outcomes measured for acute disease. Usually, the patient returns to normal, or occasionally, dies; sometimes the acute disease transforms into a chronic disease. It wasn't until the 1960s and 1970s, with chronic disease rising in prevalence, that functional capacity was recognized as important. It recognizes that, persisting over time, the chronic

Table 2. Chronic disease characteristics

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- Gradual onset common
 - Unfolds over time
 - Multivariate causation, changing over time
 - Undulating course
 - Diagnosis often uncertain; prognosis obscure
 - Indecisive technologies and therapies with adversities
 - No cure; management over time necessary
 - Uncertainty pervasive
 - Profession and laity partially and reciprocally knowledgeable
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disease impacts patients' ability to engage in normal activities. Instruments were designed to measure functional capability; however, when those instruments were applied to patients with chronic disease, another outcome emerged. The patient's attitude or perception of his or her situation was a determinant of function. If the patient's self-perceptions were positive and the patient strove to overcome the problems caused by disease, the outcomes were better in terms of both function and survival. On the other hand, if the patient was disconsolate and inactive, health and survival were worse. Then the concept of quality of life emerged. It tends to summarize the first four outcomes and represents the patient's judgment of the overall impact of the chronic illness on her or his life. This is not an easy outcome to measure, and judgments about quality of life remain highly individual and difficult to generalize.

Events within any outcome category are not stable. Each consequence of chronic disease can change as it unfolds over time, can interact with other consequences, and can sometimes affect the disease biology. For each patient, therefore, a changing clinical mosaic emerges; some features are shared across pa-

Table 3. Consequences of chronic disease for the patient

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- Persistent symptoms; no cure
 - Continuous medication use
 - Behavior change (e.g., diet, exercise, leisure)
 - Changed social and work circumstances
 - Emotional distress
 - Responsibility to interpret effects of the disease and treatment (e.g. trends, pace of change, consequences)
 - Responsibility to participate in decisions
 - Participation in decisions about medical management
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Table 4. Responsibilities of the patient in the presence of chronic disease

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- Using medications properly
 - Changing behaviors to improve symptoms or slow disease progression
 - Adjusting to social and economic consequences
 - Coping with emotional consequences
 - Interpreting and reporting symptoms accurately
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tients and some are unique to the individual. Furthermore, outcome events are not just measures of what has happened, but also determine the next steps in therapy. This unfolding complexity is not usually captured by experience with acute disease. In particular, it underscores the importance of the patient's role in assessing and selecting management directions.

Given the difficult and uncertain terrain that the chronically ill patient traverses, what do experienced patients say they want as a part of their preparation for that journey? Table 5 summarizes their views. Such needs are rarely if ever met by present health services. Individual health professionals may do so, but the health care system does not, and neither do academic training programs.

How might we best meet patients' needs? The answers are not yet clear. However, experience and various studies begin to point the way. Both conceptual and experimental approaches have arisen.^{3,4} The latter have included guidelines to direct physician and health professional practice, special physician education programs, reminder systems for physicians and other health professionals, education programs for patients, and efforts to judge the quality of practices. Of particular interest is evidence that the physician's attentiveness to the patient's concerns and interests is associated with better outcomes.⁵

Some of these studies have yielded successes. However, few if any place the patient at the center. Evidence of inadequate quality of health care persists⁶ and the prevalence of chronic disease and health care costs has continued to rise. And, sadly, there has been little substantial response by health care systems or by the bulk of professional or academic leadership. Two very important exceptions are analyses and proposals by the Institute of Medicine⁷ and the Robert Wood Johnson Foundation.² These are of enormous importance and point the way we must go. Central to both is the need for change in the ways medicine is practiced.

Three experimental studies illustrate the direction of needed change. The first is the Arthritis Self-

Table 5. What do patients want?

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- Access to information concerning:
 - diagnosis and its implications
 - available treatments and their consequences
 - potential impact on patient's future
 - Continuity of care and ready access to it
 - Coordination of care, particularly with specialists
 - Infrastructure improvements (scheduling, wait times, billing, prompt care)
 - Ways to cope with symptoms such as pain, fatigue, disability, and loss of independence
 - Ways to adjust to disease consequences such as uncertainty, fear and depression, anger, loneliness, sleep disorders, memory loss, exercise needs, nocturia, sexual dysfunction, and stress
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Management Program, later redesigned to cover persons with other chronic diseases.⁸ The program involves six two-hour sessions over six successive weeks facilitated by trained peer leaders. The material, taught in an interactive manner, is outlined in Table 6. Outcomes of the program for 401 participants four years after their start of the course are summarized in column 2 of Table 7. Four years later, pain remained 17% below their baseline despite a 9% increase in measured physical disability. Crucially, their visits to physicians were more than 40% below the baseline rate prior to participation in the program.⁸ Similar but less dramatic results have been obtained by mixed groups of patients with different diseases.^{9,10} Notably, emphasis in these programs has been on understanding and coping with consequences, not medicinal use. Because the programs are quite inexpensive, this represents

Table 6. What is taught in the Arthritis Self-Management Program?

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- Disease-related problem solving (e.g., interpreting symptoms, maintaining activities)
 - Managing medications (e.g., adherence, adversities, barriers)
 - Cognitive symptom management (e.g., relaxation, distraction, reframing)
 - Exercise
 - Management of emotions (e.g., emotions as symptoms, fear, self-doubt)
 - Communication skills (e.g., building partnership with physician)
 - Use of community resources
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both a substantial benefit to patients and a substantial cost savings.

The second experiment involved group patient visits developed by Dr. John Scott of the Kaiser Health System in Denver. In this program's initial form, approximately 15 patients with chronic disease met monthly with the physician and nurse to discuss an agenda set by the patients. Over time, these discussions encompassed most of the consequences of chronic disease for the participants as well as the information they sought. In particular, patients learned from the experiences of other patients and physicians learned much more about the patients. Column 3 in Table 7 shows how patients' outcomes differed from a randomized control group receiving usual care two years later.¹¹

The third type of experimental program focused on remote care by telephone or electronic means. Once patients become confident that they can interpret and address their medical experiences, remote care can be highly effective. Evaluation reveals equal or better outcomes and large cost savings when compared to office visits.¹²

Results from both the self-management education program and the group visits program occurred in addition to whatever benefits the participants received from their regular medical care. How did these results arise? We were surprised to find that use of activities and behavior changes taught in the self-management course did not correlate strongly with the patients' favorable outcomes. However, at the suggestion of psychologists, we tested the patients' perceived self-efficacy to cope with the consequences of their arthritis and found high correlations with the patients' outcomes.¹³

Table 7. Results of patient learning programs

Outcome	Self-management course (ASMP) 4 years later	Group visits (CHCC) 2 years later
	N = 401	N = 793
Pain	-17%	
Disability	+9%	
Ambulatory visits	-44%	
ADL loss		-58%
Satisfaction		+8%
Hospitalizations		-19%

ASMP = Arthritis Self-Management Program

CHCC = Cooperative Health Care Clinic

ADL = activities of daily living

Perceived self-efficacy is confidence that one can accomplish a particular goal. Thus, it appears that the most important outcome of the learning experience was growth in the participant's confidence that she or he could cope with disease consequences. When participants in both programs were asked which part of the experience was most important for them, they identified learning from other patients and helping other patients.

The prevalence of chronic disease and the scope of its consequences have created a dramatically new situation in health care. Patients, health professionals, and the health service must now play new roles:

1. The patient—who must be responsible for daily management, behavior changes, emotional adjustments, and accurate reporting of disease trends and tempos—becomes the principal caregiver. Expressed in economic terms, health is the product of health care, and the patient, as a principal caregiver, is a producer of health.¹⁴ As in any production system, a producer must be knowledgeable about the product and skilled in the production process.
2. The health professionals, in addition to being professional advisers and partners in the design and conduct of medical management, become teachers in developing the patient's management skills. In the present system, physicians, nurses, and public health workers are not trained for this role.
3. The health service becomes the organizer and financial supporter of the new roles for the patient and health professionals, focusing on assuring continuity and integration of care.

Properly executed, these roles create a true patient-centered care system and achieve both effectiveness and efficiency. Present health-care leadership and policy makers, however, do not attend to these issues. They remain intent on manipulating premiums, benefits, reimbursements, and infrastructures, and focus on creating financial incentives within those structures. In an era of chronic disease predominance, these approaches by themselves will continue to fail. The focus must be on the character of health services, with organizational and financial structures designed to achieve the needed transformation in health care practices.

Attributes of an appropriate health care system include the following:

- Programs to prepare patients to cope with the consequences of chronic disease and to participate as management partners with physicians and other health professionals.

- Redesigned health professional education to train students to be effective teachers and health care partners with patients. No respectable enterprise would allow its two central producers—patients and professionals—to be untrained or inadequately trained. Sadly, the current health care system does.
- A uniform basic standard of health care mandated for all services and insurance policies. Such a standard should not only improve the quality of health care, but is an essential prerequisite for integration and continuity of care. Further, once patients and physicians are properly prepared, appropriate care can often be provided in the community or the home, and by telephone or electronic communication.
- Simple administrative forms and procedures that are standard for all services and insurance policies. This will reduce the present administrative waste that consumes 20% to 25% of health care expenditures.
- Professional and patient advisory bodies at different, crucial administrative levels. This will provide voice where none exists today from those centrally involved in the health care process. Thereby, both decision-making and monitoring will reflect their experiences.
- An electronic record system readily accessible by patients and health professionals that will assure sharing of information and integration of care within and across services.

Who will support such changes? Given its failures, the present system is unlikely to do so. The problems now confronting us require a coalition of health professionals, experienced patients, and skilled managers to design and manage an effective and efficient health care system.

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