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Patient Self-management of Chronic Disease in Primary Care

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Patient Self-management of Chronic Disease in Primary Care

The nation's 65-year-and-older population will swell from 35 million in 2000 to 53 million in 2020 as the baby-boomer generation reaches the age of increased chronic disease prevalence. Many baby boomers bring to the health care system a high level of sophistication. In the view of one analyst, baby boomers "will accelerate the movement and awareness of self-care and wellness and will irreversibly alter the traditional doctor-patient relationship."¹

What is the "irreversibly altered doctor-patient relationship"—a consumerist fad or a genuine transformation of health care? Will primary care physicians—who care for most people with chronic illness—be ready for this new relationship?

In this fourth article of the series "Innovations in Primary Care," we resume the discussion of chronic illness management initiated in the article "Improving Primary Care for Patients with Chronic Illness: The Chronic Care Model."² According to the Chronic Care Model, optimal chronic care is achieved when a prepared, proactive practice team interacts with an informed, activated patient. The new patient-physician relationship for chronic disease features informed, activated patients in partnership with their physicians.

This article begins by discussing 2 versions of the patient-physician relationship in chronic disease, the tradi-

Patients with chronic conditions make day-to-day decisions about—self-manage—their illnesses. This reality introduces a new chronic disease paradigm: the patient-professional partnership, involving collaborative care and self-management education. Self-management education complements traditional patient education in supporting patients to live the best possible quality of life with their chronic condition. Whereas traditional patient education offers information and technical skills, self-management education teaches problem-solving skills. A central concept in self-management is self-efficacy—confidence to carry out a behavior necessary to reach a desired goal. Self-efficacy is enhanced when patients succeed in solving patient-identified problems. Evidence from controlled clinical trials suggests that (1) programs teaching self-management skills are more effective than information-only patient education in improving clinical outcomes; (2) in some circumstances, self-management education improves outcomes and can reduce costs for arthritis and probably for adult asthma patients; and (3) in initial studies, a self-management education program bringing together patients with a variety of chronic conditions may improve outcomes and reduce costs. Self-management education for chronic illness may soon become an integral part of high-quality primary care.

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tional relationship and the patient-professional partnership. These are, in fact, poles of a spectrum rather than wholly distinct concepts. The contrasting paradigms are described in relation to 2 aspects of chronic illness management: clinical care and patient education. This first section of the article ends with a description of self-management education in chronic disease. The second section of the article explores whether self-management education can improve clinical outcomes or reduce health care costs.

In Chronic Illness, Patient Self-management Is Inevitable

Ralph Brothers' parents both died of acute myocardial infarctions at an early age. Ralph inherited dyslipidemia and

glucose intolerance, and his blood pressure is above normal. Determined to prevent an early death, he has altered his diet, initiated regular exercise, purchased glucose and blood pressure monitoring devices, and he also takes blood pressure medications regularly. He has a happy family and work life with a comfortable income.

Ralph's brother Ricky, with identical chronic problems, is divorced and

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cares for his developmentally disabled son with serious behavior problems. Even though he visits his family practitioner on a regular basis, Ricky has gained weight, developed diabetes, and has been unable to control his lipid levels, glucose levels, and blood pressure. He views his main problem as his son rather than his chronic illnesses.

Patients with chronic conditions self-manage their illness. This fact is inescapable. Each day, patients decide what they are going to eat, whether they will exercise, and to what extent they will consume prescribed medications. According to some researchers,

Patients are in control. No matter what we as health professionals do or say, patients are in control of these important self-management decisions. When patients leave the clinic or office, they can and do veto recommendations a health professional makes.³

The question is not whether patients with chronic conditions manage their illness, but how they manage. Ralph manages well; Ricky does not.

The Patient-Physician Partnership

Traditional views regard physicians and other health professionals as experts, with patients bringing little to

the table besides their illness. In chronic disease, however, a new paradigm is emerging: people with chronic conditions are their own principal caregivers, and health care professionals—both in primary and specialty care—should be consultants supporting them in this role.⁴

This partnership paradigm embraces 2 components that are conceptually similar but clinically separable. The components are collaborative care and self-management education. Collaborative care is a description of the patient-physician relationship in which physicians and patients make health care decisions together. Self-management education takes place in the realm of patient education and includes a plan that provides patients with problem-solving skills to enhance their lives.^{5,6}

Collaborative Care

The partnership paradigm credits patients with an expertise similar in importance to the expertise of professionals. This paradigm implies that while professionals are experts about diseases, patients are experts about their own lives.

If physicians view themselves as experts whose job is to get patients to behave in ways that reflect that expertise, both will continue to be frustrated. . . . Once physicians recognize patients as experts on their own lives, they can add their medical expertise to what patients know about themselves to create a plan that will help patients achieve their goals.⁷

Sometimes called “patient empowerment,” this concept holds that patients accept responsibility to manage their own conditions and are encouraged to solve their own problems with information, but not orders, from professionals. The paradigm views internal motivation as more effective for lifestyle change than external motivation (making changes to please the physician).^{8,9} The ideas of patients and physicians interact, building upon each other to create a better outcome.

In traditional care, medical professionals may blame patients for their shortcomings.¹⁰ They may say things about patients like: “He’s noncompliant with his pills” or “She refuses to check her blood sugars.” In collaborative care (TABLE 1), when physicians accept the validity of patient-defined problems, the concepts of compliance and adherence—based on physician identification of problems and patients failing to solve physician-defined problems—no longer apply.³ For a diabetic patient, avoiding a terrifying hypoglycemic reaction today may have a higher priority than tight glycemic control to prevent renal disease 15 years from now. Hypoglycemia, not future renal disease, is the patient’s view of the problem. For some patients, the treatment (diet, swallowing pills, going to physicians), rather than the disease, is the main problem. “Noncompliance,” appearing irrational to the professional, may be a rational choice from the patient’s viewpoint.¹⁰

Dr Marjorie Fine, Ricky’s primary care physician, regularly performed all of Ricky’s periodic diabetic studies, patiently counseled him on diet and exercise, and prescribed the most effective medications at the correct doses. Dr Fine tried her best to help Ricky

Table 1. Comparison of Traditional and Collaborative Care in Chronic Illness

Issue	Traditional Care	Collaborative Care
What is the relationship between patient and health professionals?	Professionals are the experts who tell patients what to do. Patients are passive.	Shared expertise with active patients. Professionals are experts about the disease and patients are experts about their lives.
Who is the principal caregiver and problem solver? Who is responsible for outcomes?	The professional.	The patient and professional are the principal caregivers; they share responsibility for solving problems and for outcomes.
What is the goal?	Compliance with instructions. Noncompliance is a personal deficit of the patient.	The patient sets goals and the professional helps the patient make informed choices. Lack of goal achievement is a problem to be solved by modifying strategies.
How is behavior changed?	External motivation.	Internal motivation. Patients gain understanding and confidence to accomplish new behaviors.
How are problems identified?	By the professional, eg, changing unhealthy behaviors.	By the patient, eg, pain or inability to function; and by the professional.
How are problems solved?	Professionals solve problems for patients.	Professionals teach problem-solving skills and help patients in solving problems.

solve the obvious problem of inadequate management of chronic illness.

When Dr Fine left on maternity leave, the physician who replaced her started by asking Ricky, "What is your most important problem?" Never having been asked that question, Ricky's instinct was to say, "Weight too high, cholesterol too high, sugar too high, and blood pressure too high." Instead, he began to describe the trouble he had last night preventing his son from throwing his dinner on the floor and the daily battles he faced caring for him. It became clear that Dr Fine's perception of Ricky's main problem was quite different from Ricky's perception.

Allowing patients to define their problems can be eye-opening. When asked "what is your main problem," a chronically ill patient of one of the authors answered: "Caring for my spouse with severe Alzheimer's dementia." Another said: "My husband died 6 months ago and I am terribly lonely." In these cases, as in Ricky's situation, physicians defining the problem as poor adherence with a medical regimen are missing the boat.

Principally trained in the acute care of hospitalized patients, physicians may have inappropriate expectations of the degree to which patients with chronic disease can change behavior. Patients with a foot fracture must wear an immobilization device and avoid certain activities for several weeks. In contrast, patients with diabetes or hyperlipidemia must change their behavior for the rest of their lives. Ideally, patients—through education about their disease—come to agree with their physician's delineation of the problem as unhealthy behaviors, and collaborative care can create a true partnership in setting goals regarding those behaviors.

Collaborative care does not yet appear to be the dominant approach in primary care practice. One study found that participatory decision making, an important component of collaborative care, occurred in only one quarter of all visits to primary care physicians¹¹ although visits involving chronic ill-

nesses were more likely to demonstrate participatory decision making.

Self-management Education

Traditional patient education imparts disease-specific information and technical skills. Patients with diabetes gain information about diet, exercise, and medications and learn the technical skill of blood glucose monitoring. Analogous to traditional care, health care professionals decide what information and skills to teach.

Self-management education is different (TABLE 2). Whereas traditional patient education offers information and technical skills, self-management education teaches problem-solving skills. While traditional patient education defines the problems, self-management education allows patients to identify their problems and provides techniques to help patients make decisions, take appropriate actions, and alter these actions as they encounter changes in circumstances or disease.¹² Self-management education complements, rather than substitutes for, traditional patient education.

Corbin and Strauss¹³ delineate 3 sets of tasks faced by people with chronic conditions: (1) medical management of the condition such as taking medication, changing diet, or self-monitor-

ing blood sugar; (2) creating and maintaining new meaningful life roles regarding jobs, family and friends; and (3) coping with the anger, fear, frustration, and sadness of having a chronic condition.¹³

A central feature of self-management education is the patient-generated short-term action plan.¹⁴ An action plan is similar to a New Year's resolution, but of shorter duration, such as 1 or 2 weeks. It is also more specific; for example, "This week I will walk around the block before lunch on Monday, Tuesday, and Thursday." The action plan should be realistic, proposing behavior that patients are confident they can accomplish. Confidence can be measured by asking, "On a scale of 0 to 10, how sure are you that you can walk around the block before lunch on Monday, Tuesday, and Thursday?" Experience shows that if the answer is 7 or higher, the action plan is likely to be accomplished. If the answer is below 7, the action plan should be made more realistic in order to avoid failure (K.L.).

An important concept in self-management is self-efficacy, the confidence that one can carry out a behavior necessary to reach a desired goal.¹⁵ In self-management training, patients may be asked to estimate their confi-

Table 2. Comparison of Traditional Patient Education and Self-management Education

	Traditional Patient Education	Self-management Education
What is taught?	Information and technical skills about the disease	Skills on how to act on problems
How are problems formulated?	Problems reflect inadequate control of the disease	The patient identifies problems he/she experiences that may or may not be related to the disease
Relation of education to the disease	Education is disease-specific and teaches information and technical skills related to the disease	Education provides problem-solving skills that are relevant to the consequences of chronic conditions in general
What is the theory underlying the education?	Disease-specific knowledge creates behavior change, which in turn produces better clinical outcomes	Greater patient confidence in his/her capacity to make life-improving changes (self-efficacy) yields better clinical outcomes
What is the goal?	Compliance with the behavior changes taught to the patient to improve clinical outcomes	Increased self-efficacy to improve clinical outcomes
Who is the educator?	A health professional	A health professional, peer leader, or other patients, often in group settings

Table 3. Self-management Education and Adult Asthma Outcomes

	No. of Studies With Intervention Group Improved More Than Control Group	No. of Studies With No Significant Difference Between Groups
With action plans	7	4
Without action plans	4	8
Total	11	12

dence—on the 0 to 10 scale—that they can achieve their action plan. Self-efficacy theory holds that the successful achievement of the action plan is more important than the plan itself. If a physician tells a patient to walk 1 mile each day and the patient fails to do so, little is accomplished except a sense of failure. If a physician and patient collaboratively agree that exercise is desirable and the short-term action plan succeeds, the patient may later propose a revised action plan to walk more—eventually, perhaps, achieving a daily mile. Similarly when helping a patient adhere to a lipid-lowering diet, it may be more effective to decide collaboratively on an action plan to limit cheese consumption to twice a week rather than telling a patient to stop eating cheese altogether.

Action plans are developed by patients as something they want to do. They are not provided by health care professionals or chosen from a list of options. The purpose of action plans is to give patients confidence in managing their disease, confidence that fuels internal motivation.

To summarize, 2 essential elements define self-management education: (1) patients learn problem-solving skills, useful at identifying problems from their own point of view and using action plans to find solutions; and (2) these skills are applied to 3 aspects of chronic illness: medical, social, and emotional.

How Collaborative Care and Self-management Education Are Related

Conceptual Unity. In both collaborative care and self-management education, the emphasis shifts toward patients as principal caregivers, yet a great responsibility remains with health care

professionals who must use their expertise to inform, activate, and assist patients in the self-management of their condition.⁵ Patients and professionals each bring expertise to the table and problems identified by patients receive priority on the agenda.

Clinical Separability. While collaborative care and self-management education are 2 expressions of the same partnership paradigm, they require distinct clinical processes. Collaborative care permeates and alters the essence of the patient-physician interaction. Imbuing all primary care with the collaborative model is a major challenge.

Providing self-management education is less daunting. Self-management skills can be successfully taught in a 6-session course¹⁶; the role of primary care physicians is to understand and support the self-management education process.

Does Self-Management Education Improve Outcomes?

Asthma. To identify studies of adult asthma self-management, we consulted the Cochrane review “Self-management education and regular practitioner review for adults with asthma,”¹⁷ and a separate review by van der Palen et al.¹⁸ We also searched for controlled trials in the MEDLINE database under the heading *asthma* in combination with the topics *self-management*, *self-care*, and *self-efficacy*. Eliminating studies that had no reasonable control groups and those whose intervention consisted only of traditional patient education, we arrived at 27 studies, of which 12 measured clinical outcomes, 11 evaluated outcomes and health care costs, and 4 measured costs alone.¹⁷⁻²³ A previous Cochrane review concluded that patient education alone does not im-

prove health outcomes in adults with asthma.²⁴

Of the 23 studies measuring clinical outcomes (TABLE 3), 11 demonstrated improvement in asthma symptoms; only 1 study found improvement in measured lung function. Studies with self-management action plans had a greater tendency to improve outcomes than those without action plans. Self-management interventions involving mild to moderate asthmatic patients demonstrated a smaller effect than those involving patients with severe asthma. In a study in which patients took part in a self-management intervention for 1 year and were followed up for 5 years total, improvements at 1 year were only partially maintained at 5 years.²⁰

Diabetes. To evaluate self-management education in diabetes, we consulted a review of 72 studies on “self-management training” in type 2 diabetes, authored by Centers for Disease Control and Prevention (CDC) investigators.²⁵ The CDC diabetes review is not an analysis of self-management, but rather of patient education. Few studies contain interventions in which patients learn problem-solving skills and create action plans; most involve the teaching of diabetes information and technical skills. The term *self-management* in most diabetes literature differs from self-management education described earlier in this article, generally referring to patient mastery of technical skills such as home glucose monitoring.

Of 46 studies measuring the effect of patient education on patient knowledge and performance of technical skills, the CDC review found 33 studies to show a positive impact and 13 to be negative (TABLE 4). In contrast, only 18 of 54 studies demonstrated that patient education interventions, compared with control groups, improve glycemic control. Collaborative education, which in some cases approaches self-management education, produced more favorable results than didactic education. Patient education led to a reduction in cardiovascular risk

measures (elevated weight, cholesterol levels, and blood pressure) in only 18 of 45 studies. The CDC review indicates that patient education by itself is not sufficient to improve clinical outcomes, and that greater patient knowledge does not correlate with improved glycemic control. This conclusion mirrors that of the Cochrane asthma review on patient education alone, which found no substantial evidence of improved outcomes.²⁴

Two other reviews, categorizing the varieties of diabetes education, corroborate that self-management education, as described above, is not a common feature of diabetes education.^{26,27} A few investigators have studied diabetes education with a focus on goal setting and problem solving,^{28,29} and the American Association of Diabetes Educators has suggested a research agenda to examine which specific educational interventions have the greatest impact on diabetes outcomes.³⁰ At this time, no firm conclusions can be reached about the impact of self-management education on clinical outcomes in diabetes.

Arthritis. To review studies of arthritis self-management, we searched MEDLINE from 1993 to 2001 for controlled clinical trials under the combined headings of *arthritis* and *self-management*, *self-efficacy*, or *self-care*. Some studies examined osteoarthritis or rheumatoid arthritis or both, and 1 article looked at ankylosing spondylitis. Articles were included if they were controlled trials involving patient education or self-management education, which measured clinical outcomes such as pain, physical disability, or overall health status. Articles solely studying exercise programs and those restricted to such intermediate outcomes as patient knowledge, coping, self-efficacy, or use of medications were excluded.

The 18 studies identified were divided into 2 groups: group 1 contained studies in which patients were offered true self-management education including an action plan,³¹⁻⁴⁰ whereas studies in group 2 offered information-only patient education or a weak self-

Table 4. Diabetes Education

	No. of Studies With Intervention Group Improved More Than Control Group	No. of Studies With No Significant Difference Between Groups
Patient knowledge and self-care skills	33	13
Glycemic control	18	36
Improved cardiovascular risk factors	18	27

management program without an action plan.⁴¹⁻⁴⁸ Of the 18 studies, 12 recorded improved clinical outcomes in the intervention group compared with controls. Of the 10 studies in group 1, all demonstrated improved clinical outcomes in the intervention group; in contrast, only 2 of the 8 studies in group 2 found improved clinical outcomes in the intervention group. These findings suggest that true self-management education can improve clinical outcomes for patients with arthritis.

The arthritis self-management program most widely cited in the arthritis literature, developed at Stanford University and disseminated by the Arthritis Foundation, is the Arthritis Self-Management Program (ASMP), also known as the Arthritis Self-Help Program or Challenging Arthritis.³⁸ Of the 10 studies in group 1, 8 used interventions based on the ASMP.

In studies of the ASMP, arthritis patients attending a 6-session self-management class were compared with a usual-care control group. The class offered problem-solving skills, action plans, and efforts to improve self-efficacy. Four years after patients participated in the course, they reported a mean reduction in pain symptoms of 20%; a comparison group did not demonstrate this improvement. Improvement was associated with growth of self-efficacy by improving patient confidence in being able to cope with the chronic condition.³⁸

Chronic Illness in General. Consulting the MEDLINE database, we were able to find only 2 randomized controlled trials that examine the impact of self-management education on patients with a mixture of chronic conditions. In 1 study, derived from the ASMP, patients with a variety of chronic conditions met together in 7 weekly

classes teaching problem-solving skills using action plans. Six months after attending the Chronic Disease Self-Management Program course, participants improved control of their symptoms and demonstrated a reduction in limitation of activity compared with controls.⁴⁹ After 2 years, course participants maintained improved scores on scales measuring self-efficacy and health distress.⁵⁰ In a separate study, a 1-year self-management program (the Health Enhancement Project) for chronically ill frail elderly patients, using collaborative care and the Chronic Disease Self-Management Program course, was associated with higher levels of physical activity and overall health status for the intervention group compared with controls.⁵¹

Does Self-management Education Reduce Costs?

Of the 15 studies measuring the impact of adult asthma self-management education on health care utilization and costs, 8 found reduced hospital or emergency department use while 7 failed to demonstrate cost savings. Six of the 8 studies showing reduced costs included a self-management action plan; 3 of the 7 negative studies involved an action plan.

Insufficient data are available to judge whether self-management education for patients with diabetes can reduce health care costs. Of the 10 studies offering arthritis self-management education, 3 noted fewer physician visits^{32,33,38} (reduced by 40% in 1 study³⁸) and lower health care costs; the other 7 did not measure resource utilization or costs.

For chronic disease overall, patients attending the 7-week Chronic Disease Self-Management Program had fewer hospitalizations over a 6-month period than controls, resulting in a

6-month net savings of \$750 per patient.⁴⁹ While the reduction in hospital days was not maintained at 2 years following course attendance, a lower rate of physician and emergency department visits continued at the 2-year mark.⁵⁰ The Health Enhancement Project was associated with fewer hospital days and reduced costs for the intervention group compared with controls.⁵¹

Summary of Self-management Impact on Outcomes and Costs

Because interventions are not standardized across clinical trials, it is difficult to generalize about the impact of self-management education on clinical outcomes and costs. A few conclusions, however, can be reached.

1. Patient education programs teaching self-management skills are more effective than information-only patient education in improving clinical outcomes.

2. In certain circumstances, self-management education is effective in improving outcomes, and possibly in reducing costs, for arthritis and probably for adult asthma.

3. In initial studies, the Chronic Disease Self-Management Program can improve outcomes and reduce costs for groups of patients with a variety of chronic conditions.

The self-management literature has important limitations. First, it is unknown how long favorable outcomes and reduced costs continue after a self-management intervention has taken place; some benefits fade as time passes. Second, studies of self-management have been criticized for using volunteers as research subjects and being inapplicable to the—perhaps less motivated—general population.⁵² One analysis, however, found that of patients invited to attend diabetes education programs, a median of 73% actually participated, suggesting that if patients with chronic illness are seriously recruited, many will attend.⁵³ Moreover, all clinical trials, not simply those studying self-management, involve volunteers; yet their conclusions are often translated into evi-

dence-based standards for the entire population. Third, the precise conditions essential for success in self-management education remain to be determined.

Incorporating Self-management Education Into Primary Care Practice

When Dr Fine returned, she encouraged Ricky to think of some short-term action plans to better cope with the care of Ricky's son, including the enlistment of more community and school support services. Eventually, Ricky said that he wanted to eliminate 1 item of junk food each week. This decision marked a first step toward a self-motivated attempt to confront his coronary heart disease risk.

Collaborative care and self-management education are aspects of the patient-physician partnership paradigm. Primary care physicians could begin to incorporate collaborative care and self-management elements into their practice, beginning with such initial steps as asking patients to articulate their view of the problems they face and assisting patients to generate simple and achievable action plans. Moreover, primary care physicians could learn about local resources for self-management education and could advocate for health care providers and health insurance companies to support self-management education programs. Physicians could initiate referrals to self-management classes and learn about the self-management process in order to reinforce self-efficacy and action plans during subsequent medical visits.

Three barriers impede the spread of self-management education:

1. A lack of trained personnel makes self-management courses unavailable in many primary care settings.

2. People with chronic conditions have been socialized into the medical model, fostering dependence on professionals, rather than a patient-physician partnership model; this barrier hinders recruitment of patients to self-management education programs.

3. Medicare, Medicaid, and most private health insurance companies fail to reimburse self-management education.

Efforts are under way to make self-management courses available in the United States and abroad. The Michigan Diabetes Research and Training Center has trained more than 1000 educators to use a self-management curriculum when teaching patients with diabetes.⁵⁴ In England, the National Health Service has proposed the Expert Patient Initiative to provide primary care practices with arrangements for self-management programs.⁵⁵ One of us (K.L.), along with colleagues at Stanford University, has taught several hundred master trainers who in turn train peer leaders for classes offering the ASMP and Chronic Disease Self-Management Program.⁵⁶

Ultimately, self-management education and the patient-physician partnership will become widely adopted only if schools that train health care professionals, provider organizations, and third-party payers create favorable conditions for such a transformation.

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