MANAGEMENT OF CHRONIC DISEASE BY PATIENTS

Noreen M. Clark
University of Michigan School of Public Health, Ann Arbor, Michigan 48109-2029;
email: nmclark@umich.edu

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■ **Abstract** Chronic conditions dominate health care in most parts of the world,
including the United States. Management of a disease by the patient is central to
control of its effects. A wide range of influences in the person's social and physical
environments enhance or impede management efforts. Interventions to improve man-
agement by patients can produce positive outcomes including better monitoring of
a condition, fewer symptoms, enhanced physical and psychosocial functioning, and
reduced health care use. Successful programs have been theory based. Self-regulation
is a promising framework for the development of interventions. Nonetheless, serious
gaps in understanding and improving disease management by patients remain because
of an emphasis on clinical settings for program delivery, neglect of the factors beyond
patient behavior that enable or deter effective management, limitations of study designs
in much work to date, reliance on short-term rather than long-term assessments, and
failure to evaluate the independent contribution of various program components.

MANAGEMENT OF CHRONIC DISEASE BY PATIENTS

Control of chronic disease continues to dominate the agenda of health care sys-
tems; this is because primary prevention and cure are not available for many
diseases, and because the population worldwide is living longer with accompany-
ing chronic conditions. Just as it is difficult to put what we know about primary
prevention fully into practice (e.g., change behavioral patterns related to diet, phys-
ical activity levels, smoking, etc.), so too is it difficult to put into practice what
is known about secondary prevention, that is, preventing and managing effects
of disease. This chapter explores the factors that enable people with chronic dis-
ease to keep their conditions under control. Optimum disease management by the
patient for purposes of this discussion is defined as the means to achieve the high-
est degree of functioning and lowest level of symptoms given the severity of a
condition.

Worldwide the leading causes of death are heart disease, cancer, and stroke, even
in countries where infectious diseases rage. A range of other diseases, although
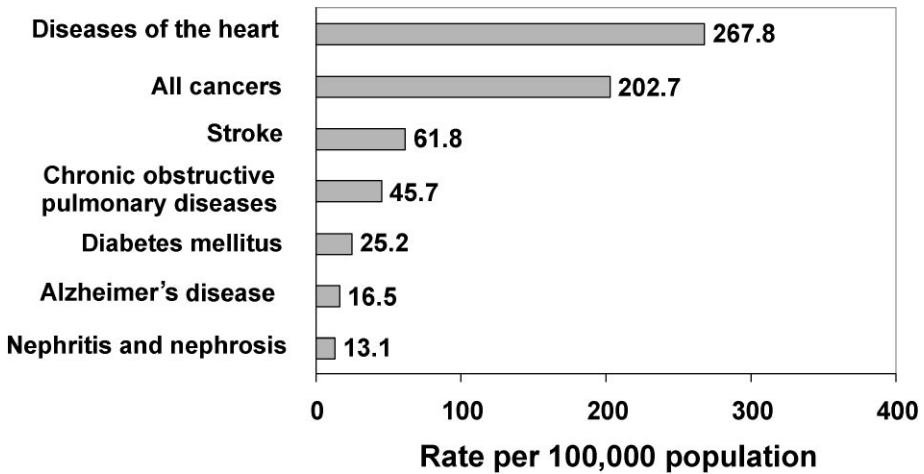intrinsically less likely to lead to premature death, are exceedingly costly in terms

Figure 1   Most common causes of death, United States. Rates are age adjusted to 2000 total U.S. population. These data are adapted from (53).

of human suffering and economic productivity. Arthritis, diabetes, and asthma are good examples; HIV/AIDS is another. Although an infectious disease, the potential for slowing progression has caused HIV/AIDS to become a chronic condition as well.

The overall burden of chronic disease in the United States is substantial. Figure 1 illustrates the numbers of cases of the major chronic conditions seen in the United States (54). Further, a host of other diseases, each striking smaller numbers of individuals (Parkinson's disease and cystic fibrosis are examples), collectively comprise an additional significant number of cases evident in the United States in any given year.

Control of most, if not all, chronic disease requires adequate medical intervention. However, it is neither clinicians nor health systems that manage chronic disease, but rather patients themselves. Unless psychopathology is present and unless medical care is unavailable or of greatly inadequate quality, patients can become expert managers of their conditions. The success of individual patients is determined in large part by factors—and people—in their social and physical environments. The patient is always at the center of chronic disease control efforts (Figure 2). Depending on age and type of disease, a range of influences affect the patient's ability to manage disease and thereby control symptoms. The most influential factor is the family. An extensive body of literature describes the role and significant influence of partners, parents, children, and siblings on the disease management of a chronically ill person. And although families play an important role, most know from personal knowledge, the experience of clinicians, and from research that family members can help or deter disease management (68). Disease control entails mobilizing families to be of the most positive help to patients.
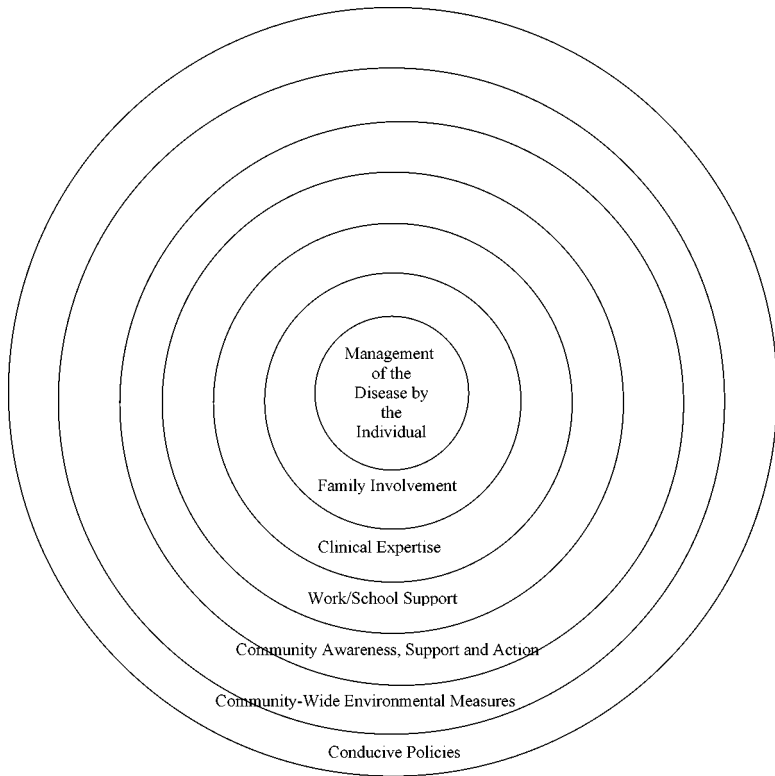
Figure 2   Concentric circles of influence.

Of great influence is the clinical community, particularly the physician primarily providing the patient's medical care.

A voluminous literature on patient-physician relationships accumulated over 50 years describes the interactions between the two (59). In the early days of exploration of disease management, theories and models tended to overstate the role of the health professional, reflecting the acute care orientation of clinicians and researchers alike.

In recent decades, the kinds of health care system (66), the special role of the clinician, and the particular set of clinical skills needed to enable patients to manage chronic disease have been acknowledged (21). Essential to chronic disease management is a partnership between the patient and clinician (37), and a central role for most clinicians is to encourage and facilitate effective management by their patients. Many in the clinical community, however, need to be trained to help their patients manage better (8).

The circles of influence reach beyond families and clinicians into the patient's day-to-day environment. People in the workplace or school need to understand

what to do in an emergency and recognize when their coworker or classmate needs some instrumental assistance or just some moral support and encouragement (40).

Community awareness and action are also important. Environmental measures are sometimes needed, e.g., measures to reduce air pollution and other factors that exacerbate lung disease, together with conducive policy. In some parts of the country, for example, children with asthma are not allowed to use their medications at school. A child may be a very fine manager, but school policies may prevent the child from managing at the optimum level. The points here are that individual families cannot manage the range of influential factors on their own, and control of chronic disease goes beyond individual and clinical approaches.

SELF-REGULATION AND DISEASE MANAGEMENT BY THE PATIENT

At least four questions deserve attention related to the patient's individual efforts to manage chronic disease. What comprises management? What predicts it? Does it lead to desired health outcomes? And if so, how do we increase its use?

What Comprises Management by the Patient?

A MATTER OF DEFINITION   Self-regulation and disease management strategies need to be distinguished. Terminology and definitions have simultaneously clarified and confused those trying to understand chronic disease management by patients. An early form of confusion was using the terms self-care and self-management synonymously (14). Self-care—now generally defined as action by an individual to capture or maintain a desired level of health independent of interaction with a health professional—is usually deemed an inappropriate term for chronic disease management given that most conditions demand the full involvement of a medical practitioner and use of accepted therapeutic regimens as part of the patient's regimen. A current source of confusion is the term disease management, which, in some quarters, refers not to what the patient does, but what clinicians and health care systems do (29). A third area of confusion derives from the interchangeable use of the terms self-regulation and self-management when, in fact, they are quite different. For this discussion, the phrase disease management by the patient will refer to strategies that an individual or family employs to control a disease and its effects. Self-regulation will refer to ways in which a patient derives the management strategies he or she uses. Disease management by the health care provider will refer to what the clinician and medical care system do. Self-care will not be used inasmuch as a partnership between health care provider and patient is assumed to be central to chronic disease control.

A SELF-REGULATION MODEL OF MANAGEMENT OF DISEASE BY THE PATIENT   Placing management by the patient into a conceptual framework may help to clarify how he or she decides on and takes certain actions and rejects others, and may

illuminate the patient's reasons for making a given decision. Figure 3 provides a model. It is not the only model nor is it necessarily the best model, but it puts into perspective the interaction of the most critical resources, motivations, and skills that enable or prevent individuals in managing their chronic conditions.

The model's central feature is self-regulation. Self-regulation means being observant and making judgments based on observation (versus habit, fear, tradition, etc.) and entails reacting appropriately to achieve a personal goal when attempting to change one's own behavior (2). The processes comprising self-regulation are continuous and reciprocal. Information, behavior, understanding, feelings, conclusions generated from any one element of self-regulation (i.e., observing, judging, reacting) as defined in the model continually influence the other elements. A person is motivated to be self-regulating by a desired goal or endpoint. The more salient the goal, the more self-regulating the person will try to be. The power of the goal is associated with how closely held a value it represents for the individual (23).

The model presented in Figure 3 suggests that intrapersonal and external factors give rise to and are modified by the observations, judgments, and reactions of the individual, leading him or her to undertake disease management strategies (including modification of the physical and social environments) to achieve a desired endpoint or goal. One reaction is to determine whether or not the action taken produced the expected outcome (outcome expectation). Another reaction is whether or not one feels the confidence (self-efficacy) to continue the action (3). Over time, continuous observation, judgment, and reaction lead to modification of management strategies and sometimes to modification of the goal itself. Each component of the self-regulation model of management of disease by patients is discussed in more detail below.

INTERNAL AND EXTERNAL FACTORS   The model posits that when taking a disease management action an individual is influenced by internal factors, that is, information and beliefs concerning the specific problem (64). For example, when attempting to manage asthma, people will use (or not use) antiinflammatory drugs based, in part, on what they know about the role and importance of inflammation in asthma control and about use of a metered dose inhaler (22). The action is influenced as well by what the person believes to be the benefits of using the medicine to reach his or her personal goal and his or her belief that the benefits outweigh the costs (e.g., safety of the medicine, side effects, financial burden, etc.) (5). The extent to which the person holds the requisite knowledge and beliefs to support an action depends, in part, on a range of external factors. These may include role models that can be observed making efforts in asthma situations; interpersonal relationships through which emotional and instrumental social support is given and received; and, almost certainly, technical advice from a clinician who provides therapeutic recommendations (56). Availability of money and other material resources (e.g., the price of medicine and access to the pharmacy) also will influence the person's behavior.

Figure 3 The continuous and reciprocal nature of self-regulation processes in disease prevention and management.

MANAGEMENT STRATEGIES   Management strategies comprise the individual's means to keep the disease and its effects under control (13, 43). These strategies may be effective or ineffective and may or may not be consistent with clinicians' recommendations. Some people left to themselves will derive ways to achieve disease control that physicians or health educators would applaud (e.g., a susceptible asthma patient removing environmental precipitants to symptoms from the living quarters), whereas others do not (e.g., the person overusing bronchodilators in an effort to reduce symptoms). The point here is that a management strategy evolves from the person's observations, judgments, and reactions given the aforementioned internal and external factors. Other associates (family and/or friends) can influence the strategy chosen, but the individual's personal goals, combined internal and external resources, and the experiences of self-regulation will ultimately dictate which management strategy will be derived and further employed. In addition, self-regulation is very specific to particular problems and may not generalize from one behavior, e.g., using medicines, to another, e.g., modifying environmental factors. Self-regulation (including self-efficacy as part of the self-regulatory process) is not considered a personality trait or characteristic such as being Type A or having low or high self-esteem (3). Rather, it comprises abilities that are applied to a specific goal and problem within a given context. One's ability to be self-regulating in a specific circumstance may prepare or help that individual to be more self-regulating in another circumstance. However, this result is not necessarily so.

ENDPOINTS   The motivating factor in taking a disease management action is a personal goal. Goals are highly idiosyncratic. When the goal of an educator or clinician (or any other person attempting to assist with disease management) differs from that of the individual, the opportunity for successful goal attainment is attenuated. Evidence illustrates that clinical and personal goals are not always compatible. The clinician has a given clinical goal (say a better peak expiratory flow rate in a patient with asthma), and a patient a given personal goal (say spending time with an acquaintance whose cat precipitates asthma symptoms). Data show little relationship between clinical measures such as scores on pulmonary function tests in asthma patients and the patients' own ratings of the quality of their lives (42). When the clinician or educator focuses on achieving the patient's personal goal, the chances are greater that the therapeutic regimen will appeal to the interests of the patient and be implemented by him or her.

Sometimes people will disclose their goals to others, and sometimes they will not. Most reasons underlying human action are covert, that is, known only to the acting individual (70). The personal goal may be shared by the individual's clinician, the medical facility where the person receives service, the larger health care system, or other stakeholders in the person's health. For example, the type of health care used may be a shared interest. Patients usually dislike going to the Emergency Department (ED) and clinicians, medical facility administrators, and insurers usually prefer not to have patients use this expensive form of care.

The endpoints of likely concern to patients, as well as to clinicians and other stakeholders, include the person's level of day-to-day functioning, perceptions of quality of life, physiological status (e.g., severity of disease) and, as mentioned, use of clinical services. However, reaching these goals may or may not appeal sufficiently to an individual's motives to act. The primary motivating factor will be his or her highly personal goal. The assumption of the model presented here is that to enable people to be the best managers of their disease requires (*a*) helping them to improve their self-regulation skills so that personal goals can be achieved and (*b*) modifying external factors so these influences enhance the ability to be self-regulating.

THE RELATIONSHIP OF SELF-REGULATION TO OUTCOMES   A reasonable question is whether self-regulation elements that give rise to management strategies are associated with health outcomes. In the end, self-regulation is valuable in chronic disease if it is associated with outcomes deemed important to patients, to clinicians, and to the wider society on whom this decision impinges (12, 55). Figure 4 illustrates correlations between the elements of self-regulation as described in the
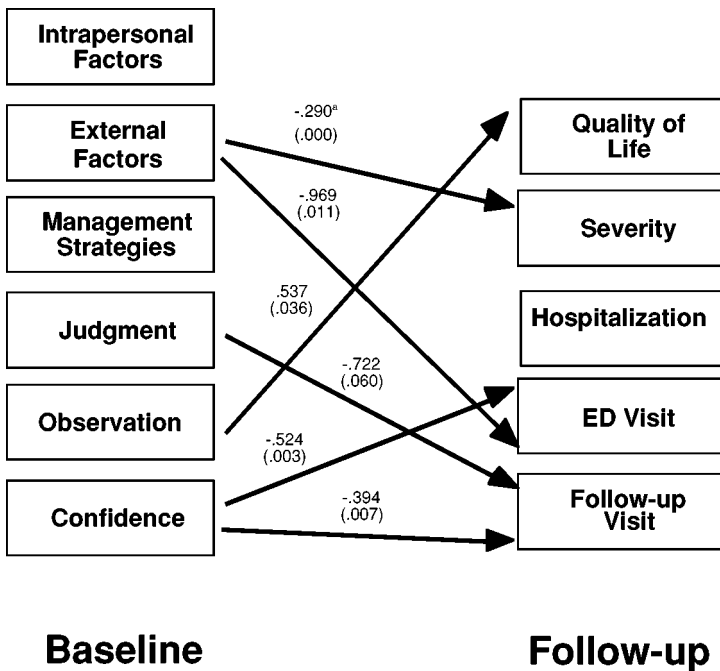

Figure 4   Elements of self-regulation as predictors of outcomes at end point in time. [a]Beta (β) and p values [Exponential (β) can be interpreted as the relative risk associated with one unit increase or decrease if the sign is negative in predictor variable.]

model presented here (observation, judgment, reaction) and use of management strategies, quality of life, and health care use.

Figure 4 depicts findings of analysis of longitudinal data collected over a three-year period from 637 parents of children with asthma (17). The data were used to assess the ability of each component of the self-regulation model to predict one or more of five asthma-related outcomes. Correlations indicate several relationships. External resources (role models, technical advice and service, material resources, etc.) were negatively associated with the severity of a child's asthma. The lower the level of family resources at baseline, the greater the seriousness of the child's disease reported by the parent two years later. External resources were also negatively correlated with use of emergency services for asthma and with severity of the disease. Families with fewer resources at baseline had children with more severe disease and made more urgent visits for asthma in the subsequent two years.

The three self-regulatory elements of the model were associated with outcomes. The higher the parent's baseline score for observing the child in asthma-related situations, the higher his or her quality of life score almost two years later; that is, the less the asthma interfered with the quality of his or her life. Judgment at baseline was marginally predictive. The higher the judgment score, the lower the number of physician office visits in the following two-year period. The greater the parent's level of confidence to manage asthma at baseline, the lower the subsequent use of emergency services and the less frequently the family made physician visits to follow up the child's asthma episodes. The intrapersonal score at baseline was not associated with outcomes. Management strategies at baseline did not predict outcomes two years later. This finding likely reflects the changing nature of management strategies; as patients and conditions change, new means to manage are adopted. The best management strategy is the one that works in the current set of circumstances. Self-regulation gives rise to management strategies that attempt to address salient problems at relevant points in time.

What Characterizes Patients More Likely to Manage Disease Effectively?

No definitive exploration has been made of predictions of "good" disease management in the general population of patients, and as in specific medicine compliance studies, simple demographic explanations will probably not suffice. Diabetes is the condition where studies of disease management have been conducted for the longest period of time. Research related to glucose monitoring has been undertaken and the findings illustrate the lack of strong predictors: no clear pattern of variables that describe the good disease manager is evident in these investigations. Altobelli et al. (1) studied 70 patients aged from 10 to 18 years and found age to be a factor in monitoring, with adolescents less likely to be daily monitors of their diabetes. Clarke et al. (24) studied 93 type 1 diabetics and found no predictors of regular monitoring. Gregg et al. (36) also found no features common to monitoring in a study of 625 African American adults. However, two large

investigations of diabetics have identified factors associated with failure to monitor glucose. Karter et al. (44) explored monitoring in 44,181 adults with diabetes in the Kaiser Permanente health care system. Several characteristics were statistically significant among low-level monitors. The patients had been diagnosed for a longer period of time and were on less intensive therapies; they were also more likely to be male, younger, of lower income, an ethnic minority group member, and have difficulty communicating in English. These patients were also more likely to be smokers. Scorpiglione et al. (62) studied 1384 insulin-treated diabetic patients. Several factors were associated with low levels of monitoring: younger age (less than 50 years), a more complicated regimen (3+ injections per day), and difficulty handling insulin doses. These patients were also more likely to overuse alcohol.

Two or three observations are reasonably clear from decades of studies of adherence to medical regimens: There are no observable characteristics to alert the health care provider that the patient is a complier or non-complier (6); similarly, clinicians cannot predict better than chance alone which patients will actually follow their clinical recommendations (46). Therefore, all patients should be assumed to need assistance to follow medical regimens. The situation regarding effective deployment of management strategies beyond the use of medicines appears to be similar.

Do Interventions Focused on Disease Management by the Patient Yield Desired Health Outcomes?

Understanding the effect of interventions designed to enhance management by the patient is limited by the current state of research. For example, a recent review (4) examined 145 studies of programs to enhance management by patients of 30 chronic conditions. Approximately half were randomized controlled trials with very small sample sizes (20 to 30 patients), and with short follow-up periods (typically 4 to 6 months). Such time frames are clearly inadequate given the duration of most chronic conditions.

Nonetheless, interest is growing over the past decade in evidence-based medicine. Much closer attention is now paid to the actual health outcome of various interventions designed to benefit patients. An outgrowth of this interest is the Cochrane Collaboration, an initiative in the United Kingdom supported by the National Health Service. The Cochrane Collaboration, by mobilizing researchers from around the world, has developed rigorous methods for searching data bases (in all languages), selecting studies using strict criteria for inclusion (essentially well-conducted RCTs and CCTs with adequate sample sizes), analyzing data in a standardized form of meta analysis, conducting peer review, and making results available not only in peer-reviewed journals, but also on the web with periodic updates. Of late, Cochrane reviewers have turned their attention to disease management by patients, specifically asthma and arthritis. Two recent Cochrane reviews are instructive for this discussion.

Gibson et al. (33) using Cochrane criteria located 25 trials of patient-management education and regular clinician review for adults with asthma. Analysis of

these data demonstrated that the interventions were associated with reduced hospitalizations, ED visits and unscheduled office visits, fewer absences from work or school, and decreases in nighttime symptoms (an indication of more serious disease). The interventions were characterized by three components that combined to produce the results: self-monitoring using peak flow meters or symptoms to anticipate trouble, regular review by clinicians, and use of written action plans (specific strategies for managing symptoms).

Another group of Cochrane reviewers (58) located 24 studies that met inclusion criteria; these studies assessed the effects of interventions for patients with rheumatoid arthritis. A variety of techniques were combined with educational approaches to comprise formal, structured instruction on how to manage symptoms. Programs could include psychobehavioral methods and could also involve exercise, biofeedback, and psychosocial support. Significant effects were noted related to the patient's degree of disability, number of affected joints, global assessment of health, and overall psychological status. No effects were seen related to pain, anxiety, or depression. An important observation was that long-term effects were not associated with the interventions; most results were short-lived, deteriorating after a year or two. A similar deterioration of results has been observed by other investigators (19) in assessing an intervention for patients with heart disease. Continual change (whether recognized or not by patients) characterizes many chronic conditions. The disease itself evolves over time, the environment in which it is managed is modified, therapeutic regimens advance, the patient him or herself changes as does motivation to manage the disease optimally. At least one exception to the apparent rule that interventions have time-limited effects is evident. Caplin & Creer (11), in a study of a small group of patients, discerned two categories of management: continuers and relapsers. Continuers used the management skills they had been taught for up to 7 years post intervention. However, current evidence related to management programs for patients supports the contention that "booster" interventions are needed to sustain effects of management programs beyond one or two years.

A further search for interventions assessed over the past 10 years to assist patients with the range of major chronic conditions produced additional data regarding the variety of approaches and outcomes of interest that have been evaluated. Table 1 presents 13 studies that add to the evidence of an association between interventions and patient outcomes. At least three relevant themes are highlighted in these studies. First, successful programs have been based on a theoretical understanding of human behavior and how to change it. Eight interventions (20, 30, 32, 40, 41, 47, 61, 63) utilized self-regulatory approaches, one used behavioral control techniques (11), and two (25, 51) used peer group influence and reinforcement. A feature of rigorously evaluated and successful programs to enhance patient management of disease has been the use of theory-based approaches. In practice, a plethora of programs have been devised for patients in health care and community settings. Often these are home grown, created from the personal experience of well-intentioned health care providers and devoid of a theoretical

TABLE 1   Results of disease-management and self-regulation interventions

Investigator(s), (Reference)	Health condition	Target population (N)	Intervention methods	Results
Caplin & Creer (11)	Asthma	53 adults	A 7-week group training program incorporating principles of disease-management with introduction of asthma information and behavioral control procedures. Identification of continuers and relapsers	Continuers exhibited broader repertoires of management skills across an array of settings. All patients continued to use management skills to varying degrees 7 years after they had learned them. Half of the relapsers reported that their asthma was in remission and their management skills were used to monitor and prevent a return of asthma
Clark et al. (19)	Heart disease	636 older individuals	A self-regulation based program employing an interactive group format consisting of 4 two-hour sessions offered at weekly intervals for 6 weeks	Participants experienced less effect of illness on their psychosocial functioning ($p \leq 0.05$), especially emotional behavior ($p \leq 0.05$) and alertness ($p \leq 0.01$). Males experienced improvement in ability to ambulate ($p \leq 0.05$) and frequency and severity of their symptoms
Clark et al. (17)	Asthma	637 patients educated by 74 pediatricians	An interactive seminar for physicians based on principles of self-regulation	Children had fewer hospitalizations ($p = 0.03$). Those with higher levels of emergency department (ED) use had fewer subsequent visits ($p = 0.03$)

Reference	Disease	Population	Intervention	Results
Coleman et al. (24)	Several chronic diseases	295 adults over 60 years of age with frequent utilization of outpatient service	Monthly group visits (8 to 12 patients per group) with a primary care physician, nurse and pharmacist, emphasizing self-management of chronic disease, peer support, and regular contact with primary care team	Patients averaged fewer ED visits ($p = 0.005$) and were less likely than controls to have any ED visits ($p = 0.003$)
Drummond et al. (29)	Asthma	569 asthma patients at outpatient clinics	Patients were shown how to use a mini-Wright peak flow meter along with guidelines to follow when they identified changes in peak flow	Patients taught monitoring with more severe asthma used more oral steroids ($OR = 2.2$; $p < 0.05$)
Evans et al. (37)	Asthma	239 low-income, predominantly Hispanic and black children in New York City	School-based, child-centered, problem solving education program designed for 8-11 year-olds, conducted without parent in attendance	Increased asthma management change ($p < 0.05$) Increased self-efficacy with respect to asthma management skills ($p < 0.05$) Increased influence on parents' asthma management decisions ($p < 0.05$) Better grades in school ($p = 0.05$) Fewer episodes of asthma ($p < 0.01$) Shorter average duration of asthma episodes ($p < 0.01$)

(*Continued*)

TABLE 1 (*Continued*)

Investigator(s), (Reference)	Health condition	Target population (N)	Intervention methods	Results
Israel et al. (39)	Obesity	34 obese children and parents	A multicomponent intervention including parents but with an emphasis on child self-regulation testing a basic and enhanced management intervention	Children in both enhanced and normal interventions achieved reduction in percentage overweight during the treatment period [Enhanced group: 48.1% (18.31) preintervention versus 32.55% (17.35) postintervention; normal group: 45.94% (17.11) pre- versus 33.43% (17.00) postintervention] (standard deviations)
Janz et al. (40)	Heart disease	570 older women	4-week program designed to improve self-regulations skills by focusing on increased physical activity	Program women reported fewer total symptoms (p = 0.01), decreased symptom frequency (p = 0.02), decreased bothersomeness (p = 0.02) Positive intervention effects within the common cardiac (p = 0.103) and rest symptom categories (p = 0.015) of the Sickness Impact Profile at 12 months
Lieberman (46)	Pediatric diabetes, asthma and smoking prevention	146 school-aged children with a chronic health condition	Health education and disease management video games	Children and adolescents improved their self-care and reduced their emergency clinical utilization

Study	Disease	Sample	Intervention	Results
Lorig et al. (49)	Heart disease, lung disease, stroke, and arthritis	952 patients over age 40	A management program for controlling chronic disease provided at community-based sites	Treatment subjects demonstrated improvements in weekly minutes of exercise (change of 16 minutes, $p = 0.0003$), communication with physicians ($p = 0.006$), self-reported health ($p = 0.02$), health distress ($p = 0.001$), fatigue ($p = 0.003$), disability ($p = 0.002$), and social/role activities limitations ($p = 0.0007$)
Magyary & Brandt (50)	Chronic health conditions	65 school-aged children with a chronic health condition and their parents	A school-based, cognitive-behavioral intervention using the peer group process to promote the child's management of the stresses associated with the chronic condition	Children showed significantly higher therapeutic adherence ($p = 0.02$ by parent report and $p = 0.00$ by child report) They also assumed more responsibility in the management of the health condition: decision-making ($p = 0.02$ by parent report) and administration $p = 0.00$ by parent report, $p = 0.02$ by child report)
Sawicki (60)	Heart disease	179 patients receiving oral anticoagulation therapy	An oral anticoagulation disease management group based on a structured treatment and teaching program and international normalized ratio (INR) self-monitoring	Intervention group had INR values within the target range more often ($p = 0.006$) Treatment-related quality of life measures were significantly higher ($p < 0.001$)
Shegog et al. (62)	Asthma	76 children ages 9 to 13 from large urban clinics and schools	A theory-based application of CD-ROM educational technology for pediatric asthma self-management education	Children demonstrated greater self-efficacy management behaviors than controls ($p < 0.05$)

perspective. Such interventions based only on hunches, opinion, and delivery of information have less likelihood of success (16).

A second theme evident across the examples provided on Table 1 is that different interventions produce different outcomes. One cannot assume that any program for enhancing management of diabetes will result in better glucose monitoring, that any asthma educational intervention will reduce ED visits, or that any heart disease management instruction will reduce symptoms. In part, the variety of outcomes seen in studies to date relates to the fact that evaluators are interested in exploring diverse variables, and that individual program developers emphasize particular components of an intervention.

Variability, however, is also associated with some programs being less powerful than others. Elasy et al. (31), in examining controlled trials of diabetes education that used glycemic control as an outcome for descriptions of the education provided to patients, found most programs to be quite conventional. Most focused only on the patient. Only 17% of interventions included family members in the program. In the intervention arms of the studies assessed, 64% were in one-on-one settings (a more expensive form of intervention), 53% were in group settings (a somewhat more difficult format to organize), and 94% were conducted face-to-face. Wilson (69), in studying asthma interventions to enhance management by patients, found that the population assessed preferred the group format for learning and that this format produced slightly better outcomes although few comparisons of formats are available in the literature.

Elasy et al. (31) found lecturing patients to be the form of education used most by professionals (81%). However, one third (30%–33%) involved the more active process of goal setting. A smaller percentage (17%) used cognitive approaches or situational problem solving (42%), both more robust approaches given what has been demonstrated about changing behavior. The reviewers noted that although some interventions produced desirable outcomes, there was no optimal "dose" of education that could be inferred as necessary to produce results. No data were available regarding either the needed intensity or duration of an intervention.

Despite these drawbacks, the outcome data from intervention trials related to chronic disease management by patients suggest that it may now be possible to establish a kind of gold standard for programs. For example, given the evidence now available, it seems reasonable to expect that a diabetes intervention will produce enhanced glucose monitoring, that an arthritis intervention will increase physical functioning, that an asthma program will prevent ED visits. If they do not, they are likely not priorities for continuation. In practice, there are many programs where these minimal outcomes have not been assessed or have not been achieved. This observation suggests that widespread use of proven models for enhancing disease management by the patient ought to be encouraged: Proven models should replace the many unevaluated or inadequate programs increasingly evident in practice. Further, to increase the chance of achieving the results envisaged in the original protocol, data suggest that programs should be followed as intended rather than be adapted with no further evaluation, as often occurs.

A third theme suggested from studies listed in Table 1 is the potential for success of programs that cross multiple chronic conditions. The success of such interventions [see for example (50, 51)] is further evidence that basic self-regulatory processes underlie effective disease management. These interventions aggregate people with different diseases and, instead of teaching the specific "recipe" of management for a given disease, emphasize the processes by which individuals can develop appropriate strategies. This format of combining groups with various diseases also may provide more efficient means for implementation, as resources, personnel, and teaching materials are the same regardless of condition.

In largest part, interventions to enhance management of disease by patients have been provided in clinical settings. Other venues have been explored to reach greater numbers of patients, including community organization sites and schools. Norris et al. (55) reviewed educational interventions for patients with diabetes in preparation for the report of the ADA Task Force on Community Preventive Services [National Standards for Diabetes Self-Management Education Programs (65)]. Evidence indicated that these programs enhanced glucose monitoring when offered in community gathering places to adults with type 2 diabetes. Programs delivered in the home were deemed effective for adolescents with type 1 diabetes. However, there was insufficient evidence to assess the effectiveness of programs at the worksite or in summer camps for either type of diabetes, or of educating co-workers or school personnel about diabetes.

Arthritis management education offered to patients at community sites has been observed to be effective (50), as has asthma education at school sites (32). No evaluations of chronic disease worksite programs were described in the literature. Overall, the number of rigorously evaluated trials of disease management in interventions for patients offered outside clinical settings is small relative to clinic-based interventions.

The data describing outcomes of comprehensive and organized disease-management interventions for patients introduced into clinical and community settings suggest these can be usefully related to several chronic conditions. Whether patient teaching and counseling by clinicians can achieve similar ends is open to question. Can interventions by health professionals integrated into routine processes of care assist patients to manage better and achieve desired outcomes?

THE ROLE OF CLINICIANS IN FOSTERING DISEASE MANAGEMENT BY PATIENTS

Chronic disease by definition means there is no cure to offer patients. The goal, therefore, is to keep the condition under the best possible control, preventing deterioration and the negative effects of disease on physical and psychosocial functioning. In considering how clinicians interact with their chronically ill patients to achieve this end, at least three types of clinical tasks are called for. First, to tailor the most appropriate and effective therapeutic regimen for the individual, ideally

drawing on the clinician's awareness of and competence in therapies that are the standard of practice. Physicians, however, do not always use the accepted and expected treatments for a given disease. Indeed, significant shortfalls in practice and barriers deterring clinicians from following established practice guidelines have been documented (9, 10, 35). These findings are worrisome in that a good therapeutic regimen is fundamental to control of most chronic diseases.

A second clinical task is to communicate effectively with patients: presenting information, negotiating with the patient to arrive at the best therapeutic option, and fostering in the patient the motivation and skills needed for effective management. This form of communication has been termed partnership (37); a mutual exchange of experience and information between patient and clinician through which both parties bring their respective knowledge and skills to disease control (21).

The third clinical task is to provide specific messages and basic information so that patients with a given disease can understand and follow the therapeutic recommendations. Information that is irrelevant to a patient's personal concerns or that does not affect behavior is not constructive [see (38)] (11, 26). In most if not all major chronic diseases, a core of salient concepts linked to changes in patient behavior comprises the knowledge base for management (38, 49). Although clinicians other than a physician can provide this education, the doctor is usually viewed as the most credible source of medical advice (22), a view likely to prevail as long as physicians remain the prescribers of medicine and architects of the clinical regimen.

A problem in assessing the role and success of clinicians of all types in fostering effective disease management in their patients is separating the effects of their behavior from the organizational features of the practice environment. Determining the relative contribution of each of these interdependent components could enhance the design and delivery of interventions. Interventions whereby clinicians have been assessed on the basis of outcomes for their patients, exclusive of modifications in their practice environment, have received little attention. Furthermore, few studies of organizational modifications have been conducted.

A classic study from the 1970s (39) assessed the level of blood pressure control among hypertensive patients in a trial of education for their physicians based on the health belief model. The patients of physicians in the program group were significantly more likely to monitor their pressure and bring it within desired limits than were controls.

A randomized controlled trial in asthma (18) assessed frequency of symptoms, health care use, and perceptions of medical care in 637 patients of 74 general practice pediatricians. The physicians randomized to the program group participated in an interactive seminar that was based on self-regulation and designed to enhance their ability to carry out the three categories of tasks described above. Two years following the intervention, their patients had significantly fewer hospitalizations, and patients with higher ED use at baseline had fewer subsequent ED visits compared with controls. The clinicians in the program group did not spend a greater amount of time with their patients, rather used time more effectively. They were

more likely to use protocols for delivering asthma education, to write down how to adjust medicines when symptoms change, and to provide more guidelines for modifying therapy. Their patients were more likely to give higher ratings to their clinical performance (18).

As noted, the organizations in which clinicians practice exert an influence their behavior and the course of care for the patient (67). Renders et al. (57) reviewed 41 studies in diabetes that involved interventions directed at health professionals, the structure in which they delivered care, or both. Although few studies assessed patient outcomes and the methodological quality of all studies was in question, several observations are relevant to this discussion. Three studies of interventions directed at clinicians (physicians, nurses, or pharmacists) (7, 48, 52) assessed patient outcomes, but the findings of only one (48) were statistically significant. In this study patients whose physicians received training experienced fewer clinical abnormalities compared to controls (the intervention also included modest organizational initiatives such as patient reminders and prescription feedback, etc). Two trials assessed patient outcomes when clinician-provided patient education and significant modification of organizational routines were combined. One (60) assessed the effectiveness of a multidisciplinary team trained to enhance outcomes through case management and patient education. The team was led by a diabetes nurse educator supported by two diabetologists. Six months subsequent to the intervention, patients in the program group had significantly lower HbA1c levels and fewer hospital admissions than controls. Another study (27) combined revision of professional roles (the functions of nurses were greatly enhanced), a specially designed physical facility where clinical care and education were integrated, and learner-centered counseling. Subsequent to the intervention, patients in the treatment group had higher levels of glycemic control. An ambitious study (28) assessed an intervention involving a trained multidisciplinary team, formal integration of clinical services, follow-up communication with patients, and case discussion among professionals. Two years later, intervention patients had greater glycemic control compared to the nonintervention group.

None of these studies provided data to suggest which of the multiple approaches used produced the results. The fact that the interventions varied dramatically in their cost of implementation lends support to the argument that future research should assess the independent contribution of various approaches for supporting patients in their efforts to control their disease. Such information is needed for determining how to combine approaches, where to place emphasis, and how to deploy resources.

Despite somewhat limited data, there seems to be agreement that success in disease control involves the entire health care system in which a patient receives treatment. Stepped care approaches for chronically ill patients have been proposed (34). Katon et al. (45) have commented that four levels of intensity of care are needed for patients with different levels of complexity of disease. First is screening and diagnosis with preventive services, outcome monitoring, and patient education regarding effective management. Level two is primary care treatment with a

designated health professional providing patient education and support for management. Level three involves specialty consultation in the primary care setting for patients with persistent or complicated disease. The final level entails referral to specialty settings with the appropriate range of intensive services for patients with highly complicated disease or for whom desired outcomes fail to be achieved at lower levels of care. Such schema of coordinated care are not widely in evidence, and outcomes associated with them have not been evaluated. Optimum disease management by patients will likely depend on more robust clinical systems to support their efforts.

An important question regarding efforts to enhance disease management by patients is their cost. Cost implications are a neglected area of research in chronic disease management. Cost analyses are generally not provided in intervention studies or when they are available, are preliminary, e.g., program delivery costs versus cost savings in asthma health care use (15). McAllister et al. (53) reviewed 11 randomized trials of chronic disease management programs for patients with heart failure. They assessed cost-related outcomes and found that two studies reported significant reductions in number of hospitalizations and seven reported reductions in length of hospital stay. They concluded that these disease management programs saved costs, specifically those involving patient education, multidisciplinary teams, and specialized follow-up procedures. However, the level of sophistication of cost analyses related to disease management interventions appears to be quite rudimentary. Many of the interventions discussed here were not expensive to provide, and many produced reductions in health service use. Such programs could therefore produce cost savings, if not benefits, when widely employed. However, data are needed to test this assumption.

CONCLUSIONS

The potential for management by patients to contribute to disease control is well documented, and areas of needed research have been identified. Interventions to enhance management by patients have been shown to be associated with important health outcomes, such as improved monitoring of a condition, fewer symptoms, enhanced physical functioning and psychological status, and reduced health care use. Further, patients have been reached and assisted in a range of clinical settings and a few nonclinical venues. Given the success of many available models, their more widespread use seems warranted. Using proven programs as intended, rather than liberal adaptation without further evaluation, likely increases the chances of achieving desired outcomes. Some interventions have been more theoretically robust and successful than others, and programs have not produced the same outcomes. Most evaluation periods have been short relative to the duration of most chronic diseases. When long-term evaluations have been employed, need for "booster" interventions over time has been evident.

Studies over the past decade have refined the theoretical bases for understanding management of chronic disease by patients. Interventions to assist patients

appear to have matured in the sense that they are more likely to reflect models or at least principles of behavior change. Recent studies have assessed chronic disease interventions comprising elements of self-regulation. The basic precepts of self-regulation offer an explanation for the development of patient's management strategies and may constitute a preferred emphasis for interventions.

Disease management by patients with a range of chronic conditions has been enhanced by direct delivery of interventions that use a variety of approaches and learning methods. Similarly, efforts to integrate clinician training, patient teaching, and practice organization modifications appear to have produced some benefit for disease control. However, few if any studies to date have clearly identified the component(s) of multifaceted programs most responsible for outcomes. Very little investigation has been conducted regarding settings beyond the clinical (i.e., workplaces, schools) as venues for reaching those with chronic disease and assisting them to manage better. These entry points may constitute fruitful channels for disease control.

The costs of implementing effective programs to enhance disease management by patients and/or the capacity of clinicians and practice organizations to foster effective management have not been adequately assessed against their benefits and savings.

Given the worldwide trend of individuals increasingly living longer with chronic disease, research to evolve innovative, effective programs and policies that can efficiently enable large numbers of patients to manage their disease successfully is badly needed.

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