Editorial: Management of chronic diseases

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 management 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 behaviour 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.

Control of chronic disease continues to dominate the agenda of health care systems; this is because primary prevention and cure are not available for many diseases, and because the population worldwide is living longer with accompanying chronic conditions. Just as it is difficult to put what we know about primary prevention fully into practice (e.g., change behavioural patterns related to diet, physical 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 disease 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 highest 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 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. Numbers of cases of the major chronic conditions seen in the United States. 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. 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. Disease control entails mobilizing families to be of the most positive help to patients. 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. 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, the special role of the clinician, and the particular set of clinical skills needed to enable patients to manage chronic disease have been acknowledged. Essential to chronic disease management is a partnership between the patient and clinician, 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.

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.

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.

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. 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. 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. 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.

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 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 studied 93 type 1 diabetics and found no predictors of regular monitoring 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 explored monitoring in 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 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.

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. 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; a mutual exchange of experience and information between patient and clinician through which both parties bring their respective knowledge and skills to disease control.