National Institutes of Health

Fact Sheet — *Self-management*

Thirty Years Ago

- Many conditions, which are now considered chronic illnesses requiring long-term management, were often fatal in the 1960s, 1970s, and 1980s, such as heart failure, renal failure, or infectious diseases such as HIV.
- The utility and effectiveness of self-management practices were not well studied.
- The use of technology for self-assessment in disease self-management (e.g. automated blood pressure machines for persons with hypertension or blood glucose monitors for diabetics) was almost unknown.
- There were few medications and treatments that patients could use on their own at home.
- Patients were often expected to follow prescribed medication and treatment regimens with little understanding or knowledge of their use or purpose.
- There was little or no capacity for telemonitoring of patients by health care providers.
- Little understanding existed of cultural differences in how persons and families understand and manage chronic conditions.

Today

- Self-management is a major part of the national nursing research agenda, with new discoveries being made in improving treatment regimens and enhancing the evidence base for care.
- Research demonstrated that self-management strategies improve patient outcomes by helping patients understand their disease and its treatment, enhancing treatment adherence, and providing patients and caregivers with the knowledge and skills needed to sustain and promote health.
- One study of elementary school children with asthma demonstrated that an intensive asthma education intervention, which focused on asthma physiology and medications and reducing asthma triggers, was associated with reduced asthma morbidity, improved parent and child symptom identification and self-management, and enhanced appropriate nebulizer medication adherence. The researchers who devised this program also developed an asthma education coloring book to help reinforce the teaching.
- Teens with type 1 diabetes contend with hormonal changes that make them resistant to insulin, social pressures to engage in unhealthy behaviors, and schedules in school and other activities that can disrupt regular blood glucose monitoring, diet, and exercise. Intensive diabetes management training improves metabolic control. However, studies show that control is significantly enhanced when teens undergo coping skills training (CST) as well. CST develops skills in social problem solving and conflict resolution, focusing on dealing with problems rather than on managing a medical condition. CST is now part of routine care by many practices that serve teen patients, and current clinical guidelines on type 1 diabetes now emphasize behavioral training in addition to disease management.
- Arthritis is the leading cause of disability among people of Hispanic origin in the U.S., and a lack of proficiency in English limits the ability of many to take advantage of potentially useful health information. A community-level self-management program administered in Spanish was shown to improve elements of health status (less pain, increased activity levels, and 40% fewer physician visits) while reducing health care costs. Participants also showed improvements in self-efficacy (confidence in being able to manage their disease), general health, exercise, disability, and depression. This approach was widely adopted in the U.S. and other countries, and efforts are underway to extend it to diabetes and other chronic diseases.
- Irritable bowel syndrome (IBS), a functional disorder of the gastrointestinal tract, affects over 10% of women in industrialized nations. A group of women with IBS received a training program that provided education on IBS symptoms, dietary evaluation and counseling, relaxation strategies, and cognitive and behavioral strategies to minimize the effects of IBS. These women reported improved quality of life, and decreased bloating, constipation, bowel dysfunction, and stress.

- Cardiac patients who receive an implantable cardiac defibrillator (ICD) after a cardiac arrest or heart failure often require a period of time to learn new coping skills and make lifestyle changes related to their adjustment to the ICD. An educational and telephone intervention provided ICD patients with an information booklet, weekly nursing telephone support, and 24-hour availability of an intervention nurse by pager for questions and concerns. At one year after hospital discharge, intervention participants reported reductions in anxiety, fatigue, sleep problems, and sexual concerns, and increased knowledge about and self-efficacy in managing the ICD.

- The Women to Women (WTW) website was developed to help older women living with a variety of chronic conditions. The women lived in rural areas with limited access to regular health care. WTW provided the women with internet access and a website that included an on-line chat room among the participants, email access to each other and to the research team, and a separate chat room with a health care expert. Women using WTW for three months had increased self-esteem, social support, and empowerment, and reduced depression, stress, and loneliness.

- Many Blacks with diabetes who live in rural areas are overweight and have poor eating habits. A culturally sensitive dietary program for rural Blacks, "Soul Food Light," provided a series of classes on practical tips for planning, purchasing, and preparing healthy, low-fat foods. The participants lowered their dietary fat intake and their body weight, leading to improved glucose control and lipid levels, two important factors in the effect of diabetes on health.

- Among patients with chronic obstructive pulmonary disease (COPD), dyspnea (difficult or labored breathing) is a common symptom that often decreases activity tolerance and quality of life. A group of COPD patients received education on dyspnea self-management that included discussion of the sensations, precipitants, and recognition of dyspnea, along with an exercise program. In addition, a study nurse called bi-weekly to monitor progress and provide feedback. The patients reported a decrease in dyspnea with daily activities, along with improved physical functioning and health-related quality of life.

Tomorrow

The NIH is poised to make major discoveries to *predict* how patient populations may be better served by self-management strategies, *personalize* individual treatment strategies, and to use this information to *preempt* challenges to disease management.

- *Predicting which self-management strategies better serve different patient populations.* Advancements in self-management strategies that range from short-term therapeutic regimens to long-term symptom monitoring will enhance medical treatment. Advances in the field of genetics will help in the identification of biomarkers of symptoms (genes and gene products) to help inform decisions about treatment options.

- *Personalized individual treatment strategies.* Self-management strategies will be tailored as part of treatment regimens, and adjusted based on monitoring of patient outcomes. For example, telehealth interventions can help health care providers monitor elderly patients for signs of heart failure exacerbation, or transplant patients for signs of rejection. Resources from the telephone to the internet can provide health information and support for patients living in rural areas with limited access to health care services.

- *Preempting challenges to disease management*. Current and forthcoming self-management advances will expand beyond monitoring of blood pressure, blood glucose, or heart rate at home. Patients will record and transmit a wide variety of symptom information to a nurse or physician over the phone or internet. Considering the increasing number of individuals living with chronic diseases in the U.S., the potential use of such strategies could alleviate a large strain on our healthcare system. The key is ensuring that all patients have the knowledge and ability to utilize self-management strategies and resources.