



## Yesterday

- In the past, many conditions including heart disease, kidney or liver failure, or infectious diseases such as HIV/AIDS were often fatal.
- The utility and effectiveness of self-management practices were not well studied or accepted.
- Portable, reliable community based technologies for self-assessment in disease self-management (e.g. automated blood pressure machines for persons with hypertension or blood glucose monitors for diabetics) were almost unknown.
- There were few medications, therapies, and treatments that patients could use 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 knowledge existed of cultural differences in how individuals 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 to enhance the evidence-base and improve treatment regimens and quality of life. Research demonstrates that self-management strategies improve patient outcomes by empowering patients to understand their conditions and take responsibility for their health. Currently, self-management research includes studies on individuals with a wide array of conditions, including: organ failure, pulmonary disease, diabetes, HIV/AIDS, cancer, arthritis, pain, and sleep and fatigue.

**Sleep and Fatigue:** Difficulty initiating and maintaining sleep are common symptoms in persons with conditions across the illness spectrum and contribute to negative daytime symptoms and functioning. NIH-supported researchers have demonstrated that self-management can

significantly improve sleep and related symptoms across a variety of populations.

- Persons receiving chemotherapy for cancer often report difficulty with sleep or insomnia. In one study, researchers found that a behavioral sleep therapy program improved perceived sleep quality in breast cancer patients ([http://app1.unmc.edu/publicaffairs/todaysite/sitefiles/today\\_full.cfm?match=5230](http://app1.unmc.edu/publicaffairs/todaysite/sitefiles/today_full.cfm?match=5230)).
- Exercise offers another behavioral self-management intervention for sleep disorders. Researchers found that a walking exercise program reduced sleep disturbances in older breast cancer patients who were receiving hormonal therapy.

**Chronic Disease:** Almost one in every two (133 million) adults has at least one chronic disease. These diseases result in limitations in daily living for about one-fourth of those living with them. Although chronic diseases are among the most common and costly health problems, self-management research has improved our ability to maintain a high quality of life even with these conditions.

*Heart failure affects over 5 million Americans and is associated with poor functioning, negative symptoms, and poor quality of life.*

- Scientists have developed evidence-based self-management interventions for cardiac patients, including those with heart failure (<http://www.mc.uky.edu/Nursing/research/P20Center/>). For example, an educational and telephone intervention helped reduce anxiety, fatigue, sleep problems, and sexual concerns, while increasing knowledge about self-efficacy in cardiac patients who had recently received implantable cardiac defibrillators. In another study, a home-based, nurse-coached muscle strengthening intervention was shown to reduce dyspnea (difficult or labored breathing) in heart failure patients.

*Pulmonary Disease: COPD and Asthma affect 28-40 million Americans.*

- The use of trained health educators in rural areas has demonstrated success in improving children's self-management of asthma (<http://www.utexas.edu/nursing/fachome/html/horners/index.html>). Intensive asthma education interventions can reduce asthma morbidity, improve parent and child symptom identification and self-management, and enhance appropriate nebulizer medication adherence.
- Among patients with chronic obstructive pulmonary disease (COPD), dyspnea is a common symptom that often decreases activity tolerance and quality of life. A group of COPD patients received education on dyspnea self-management along with an exercise program. The patients reported a decrease in dyspnea with daily activities along with improved physical functioning and health-related quality of life.

*Diabetes now affects nearly 24 million (8%) people and 57 million are reported to have pre-diabetes.*

- Group-based and family-based interventions demonstrate promise in improving coping skills, self-management and metabolic control in children with type 1 diabetes. These interventions are particularly important for teens with type 1 diabetes, as they 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 ([http://nursing.yale.edu/Centers/ECSMI/P30/grey\\_3.html](http://nursing.yale.edu/Centers/ECSMI/P30/grey_3.html)).
- Culturally competent clinical interventions that incorporate religion and spirituality may improve glycemic control in African American women with type 2 diabetes. Community-based peer-led programs also improve self-management of diabetes for Spanish speaking Americans ([http://patienteducation.stanford.edu/programs\\_spanish/index.html](http://patienteducation.stanford.edu/programs_spanish/index.html)).

## Tomorrow

The NIH is poised to make major discoveries that will improve health outcomes for individuals experiencing symptoms and chronic conditions, by translating evidence-based therapy to community and home settings as well as advancing available and affordable technologies.

*Translating scientific evidence-based interventions to community and home settings.* Advancements in self-management strategies that range from short-term therapeutic regimens to long-term symptom monitoring will enhance medical treatment. In the community, researchers will partner with community organizations to match successful interventions with needs. At home, patients will record and transmit a wide variety of symptom information to a nurse or physician over the phone or internet. NIH will expand self-management knowledge through: (1) continued support of coordinated, interdisciplinary investigations of self-management in the context of ethnically diverse individuals, families, organizations, and communities, (2) dissemination of research findings to the scientific community, and (3) diffusion of knowledge into clinical practice and policy.

*Advancing available and affordable technologies.*

Considering the rising number of individuals living with chronic diseases in the U.S., increased use of evidence-proven and population-tailored telehealth could alleviate a large strain on our healthcare system. Resources from the telephone to personal portable devices will provide health information and support for patients living in rural and other areas with limited access to health care services. 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. The key is ensuring that all patients have the knowledge and ability to utilize self-management strategies and resources.

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