

**EXECUTIVE SUMMARY**  
**THE SCIENCE OF SELF MANAGEMENT IN CHRONIC DISEASE**  
**WORKGROUP MEETING**  
**NATIONAL INSTITUTE OF NURSING RESEARCH**  
**Bethesda MD**  
**November 9-10, 2004**

**Purpose:**

The National Institute of Nursing Research (NINR) sponsored a two day working group meeting with self management and related science experts to examine current knowledge and provide recommendations to further advance the science in chronic disease self-management.

**Objectives:**

1. Describe and discuss the state of the knowledge regarding:
  - ◆ Comprehensive self-management for chronic diseases,
  - ◆ Self-management components and skills such as self-efficacy, adaptation and coping, burden of care, self-monitoring, problem solving, decision making, provider-client partnership, resource access and use, acute and chronic symptom management, and health maintenance behaviors,
  - ◆ The role of ethnicity/race, geography, socioeconomic status, age, and gender on self-management, and
  - ◆ Biobehavioral outcomes for self management research.
2. Identify the research gaps that must be addressed to move chronic disease self-management research forward to further improve effective self-management, quality of life, and related health outcomes.

**Executive Summary**

The invited participants included experts in self management research or related science from the fields of nursing, psychology, behavioral science, and statistics. Representatives from the Centers for Disease Control, the National Heart Lung and Blood Institute, and the National Cancer Institute at NIH attended the meeting. The meeting was held over one and one half days in Bethesda MD on December 9-10, 2004.

The Centers for Disease Control (CDC website, 2004) state that seven of every 10 Americans who die each year, or more than 1.7 million people, die of a chronic disease. More than 90 million Americans live with chronic illnesses. In addition, chronic, disabling conditions cause major limitations in activity for more than one of every 10 Americans, or 25 million people. Furthermore, the medical care costs of people with chronic diseases account for more than 75% of the nation's \$1.4 trillion medical care costs. These facts underscore the need for research to assist individuals to learn and to maintain self management of their chronic diseases in order to enhance their health outcomes and quality of life.

NINR has a long history of supporting research on chronic disease management. One of the early studies supported by the then *National Center for Nursing Research* was entitled *Nursing Intervention: Exercise for Stress Incontinence*. Thelma Wells, the principal investigator, was one of the individuals in the 1980s who proposed that the patient could do something proactive about her own health condition, in this case specific exercises to reduce urinary incontinence. In the decades prior to the '80s, the focus was on patient compliance to therapeutic orders. The patient simply followed, or did not follow, medical orders. "Noncompliance" was often a diagnosis in the hospitalized patient. Thomas Creer, however, first used the term self management in the mid-1960s (Lorig, Holman, 2003) in relation to children with asthma (Creer, Renne, Christian, 1976). The self management concept did not gain widespread acceptance until much later as it became obvious that the patient with a chronic disease needed to play a more active self management role.

As chronic diseases became more prevalent with the growing and aging U.S. population, research began to take into account the lifelong management requirements of chronic diseases, especially those such as diabetes, arthritis, and asthma that required daily management activities. More recently, the increasing incidence and prevalence of conditions such as obesity in adults and children, type 2 diabetes in all ages, and increasing allergies and respiratory diseases, along with the numerous other chronic diseases, has highlighted the need to study further how to facilitate proactive and sustainable self management activities in individuals.

During the past several years NINR, and other NIH institutes, have supported a number of intervention studies aimed at improving self management activities in individuals with chronic disease. The studies have included a number of variables and strategies such as problem solving/decision making, self management skills, resource utilization, self-efficacy, cognitive behavior therapy, and coping skills training. Outcome factors have varied but usually include measures of disease control, life satisfaction, quality of life, depression, and self efficacy among others. Studies have consistently shown that self management interventions have been effective, including those measured over one to two year time periods. These results led NINR to convene a meeting of a group of experts in self management research as one means of obtaining information to assist in planning for the next stage of research in this area of science.

Individual presentations on the following topics stimulated discussions: history of self management (SM); SM in special populations such as arthritis, diabetes, and asthma; the Institute Of Medicine<sup>1</sup> and other definitions; tailoring interventions and research integrity; critical SM components; research issues in special populations, and research

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<sup>1</sup> Self-management is defined as the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions.

Self-management support is defined as the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support.

IOM/NAS. *1st Annual Crossing the Quality Chasm Summit: A Focus on Communities* (2004), Board on Health Care Services, Chapter 5, p 57.

challenges and opportunities in SM. In addition, three groups worked to identify (1) critical self management components, (2) research questions or problems for the future, and (3) research issues when studying special populations.

A summary of issues discussed by the workgroup is presented, followed by research recommendations. These summaries represent the discussions and presentations and do not reflect an exhaustive list of topics covered. Items are not listed in any priority order. It is important to note that the focus of this meeting was on self management of chronic disease and that the issue of health promotion, raised by a few participants as important to self management, is not addressed in the summary and may warrant further discussion at another meeting.

### **Factors and issues for consideration in research designs:**

- 1) Test across diseases versus disease specific intervention programs.
- 2) Describe the core elements of an intervention required for appropriate outcomes in clinical practice.
- 3) Consider measurement and analysis: acquisition of SM skills such as problem solving and decision making, appropriateness of measures for various ethnic groups, appropriateness for mediators and outcomes.
- 4) Use long term follow-up to better evaluate the intervention effect over time.
- 5) Add populations that are not frequently represented in research: family; developmentally, sensory, or physically disabled; ethnic groups, different SES groups, rural, groups with co-morbidities, lifespan from childhood through the older adult.
- 6) Explore and clarify theories or models and how they guide the research.
- 7) Explain the role of self efficacy as a mediator for self management success.
- 8) Explore different needs for self management skills, education, and support by age group.
- 9) Examine the family and its impact in self management.
- 10) What is the intervention dose required for efficacy? What components of the intervention lead to what outcomes?
- 11) Delineate the mechanism of action of the intervention.
- 12) Test the fidelity of the intervention and processes for maintaining and assessing fidelity.
- 13) Address the routines, constancy, and lifelong requirements of self management for individuals.
- 14) What is the role of the nurse and other providers in promoting problem solving/ decision making skills in clients.
- 15) The IOM definition of self management is not clear in addressing children and self management of chronic illness. What is the role of the child in self management versus that of the parent or guardian in managing the child's disease?

### **Research Recommendations:**

1. Larger studies with more diverse and representative samples are needed to assess the readiness of interventions for translation to clinical practice and to inform policy.
2. Intervention research that addresses effects and outcomes of intervention elements, intervention fidelity, tailoring issues, essential elements of interventions used across disease conditions and with co-morbidities, intervention dose and duration, and long-term maintenance factors.
3. Intervention research that addresses comprehensive self management processes and roles, with attention to IOM definition.
4. Strategies to introduce and instill self management skills and behaviors required for ethnic groups and/or to address whether culture neutral strategies may be effective across diverse cultural/ethnic groups.
5. Interventions that involve the family as well as the health care team as collaborators in the client's self management.
6. Methodological studies continue to be important in behavioral and biobehavioral science with the changing and increasingly multicultural populations. Self management research in particular would benefit from further development or refinement of behavioral and psychosocial mediator and outcome measures and from more theory based studies.

In summary, the discussion and recommendations of the workgroup participants are relevant to NINR and NIH in regard to the mission to improve the health, health outcomes, and quality of life of individuals with chronic disease through research, the translation of findings into practice, and research data to support policies for chronic disease self management. Recommendations are consistent with the NINR *Themes for the Future* section on self management of chronic illness symptoms and treatment (<http://ninr.nih.gov/ninr/research/themes.doc>) and with the NINR Roadmap document (<http://ninr.nih.gov/assets/Documents/RoadmapImplementationMeeting01.2004001.doc>) section on *NINR Roadmap Areas of Research*.

## References

CDC, National Center for Chronic Disease Prevention and Health Promotion. Chronic Disease Overview (2004). <http://www.cdc.gov/nccdphp/overview.htm> (January 18, 2005).

Lorig KR, & Holman, HR (2003). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine* 26(1); 1-7.

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