

# Self-Management: A Comprehensive Approach to Management of Chronic Conditions

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For both clinical and economic reasons, the increasing number of persons living with chronic conditions represents a public health issue of growing importance. Emphasizing patient responsibility, and acting in concert with the provider community, self-management represents a promising strategy for treating chronic conditions—moving beyond education to teaching individuals to actively identify challenges and solve problems associated with their illness. Self-management also shows potential as an effective paradigm across the prevention spectrum (primary, secondary, and tertiary) by establishing a pattern for health early in life and providing strategies for mitigating illness and managing it in later life. We suggest ways to advance research methods and practical applications of self-management as steps in its future development and implementation. (*Am J Public Health.* 2014;104:e25–e31. doi:10.2105/AJPH.2014.302041)

Improvements in health care have resulted in greater numbers of people living with multiple chronic conditions for longer periods of time. With this change, chronic illness is now a major focus of health care.<sup>1</sup> At the same time, increased attention has been concentrated on approaches to manage chronic symptoms to maintain patient independence and quality of life over longer periods of time. Approaches to managing chronic illness are shifting from the traditional provider–patient relationship to a paradigm in which individuals with chronic conditions play a key role in guiding their care, in partnership with health care providers.<sup>2,3</sup>

Many prevalent chronic conditions, such as heart disease, diabetes, and arthritis, though unique in their own attributes and demands, share common challenges associated with their management. These include dealing with symptoms and disability; monitoring physical indicators; managing complex medication regimens; maintaining proper levels of nutrition, diet, and exercise; adjusting to the psychological and social demands, including difficult lifestyle adjustments; and engaging in effective interactions with health care providers.<sup>4,5</sup>

The identification and elaboration of common patient-centric strategies to deal with these challenges is the focus of the field of self-management.<sup>6,7</sup> Regardless of the chronic

condition, the development of a generic set of skills has proven successful in allowing individuals to effectively manage their illness and improve health outcomes.<sup>8</sup> A 2010 report by the Department of Health and Human Services included self-management as one of 4 goals in a strategic framework for improving the health status of individuals with multiple chronic conditions.<sup>9</sup> More recently, the 2012 Institute of Medicine report “Living Well With Chronic Illness: A Call for Public Health Action” included self-management<sup>10</sup> as one of several models of living well interventions, noting that self-management programs instill individual responsibility and offer tools for patients to use in caring for their chronic illness.<sup>10</sup>

There is increasing recognition that chronic illness, including its prevention, treatment and management, represents a public health as well as a clinical issue.<sup>11,12</sup> Indeed, the Institute of Medicine report noted that a population health perspective for developing strategies, interventions, and policies to combat chronic illness is critical.<sup>10</sup> Community-based self-management intervention programs are one aspect of a population-based approach addressing the larger public health problem of chronic conditions in the United States and across the globe. There is an extensive body of literature related to self-management of chronic conditions, but our intent

with this article is not to provide a comprehensive review, but rather to highlight the unique contribution of nurse scientists to the field.

Nursing science has enhanced the care of individual patients and has tested interventions that can be scaled up for implementation at the population level. We present examples of nursing science that demonstrate effectiveness, promise sustainability and scalability, and set the foundation for implementing wide-reaching public health actions for managing chronic illness.<sup>12</sup>

There is increased awareness of the need to promote conceptual clarity regarding self-management and its integration into clinical practice. Equally important is the requirement to develop more sophisticated models of self-management, tailored to various health conditions and situations. Fundamental to the development of such models and their practical application is the need to conduct research that informs self-management practice and contributes to health policy.

The nursing community, comprising both researchers and clinicians, plays a crucial role in efforts to provide the evidence base for innovative self-management practices, and is ideally positioned to implement those advances in a practical manner. Over the course of its history, the National Institute of Nursing Research (NINR) at the National Institutes of Health (NIH) has promoted self-management science as one of its core areas of investigation, supporting research to improve and manage symptoms of acute and chronic illness.<sup>13</sup> Recognizing that self-management represents a topic of ever-increasing importance, a goal of NINR is to advance the science of self-management and, ultimately, disseminate results widely for translation into clinical practice.

Recently, a group of nurse scientist leaders assembled to discuss “The Science of Chronic Illness Self-Management” as the topic of the 2013 National Nursing Research Roundtable. The Roundtable is an annual meeting with the

purpose of providing a regular forum of communication about the direction and conduct of nursing research. Discussions from this year's meeting resulted in a set of recommended areas of focus and approaches to advance the field and practice of self-management (see the box on this page).

## THE SCIENCE OF SELF-MANAGEMENT

Nursing science contributes to the field of self-management through research that defines the concept, describes its theoretical underpinnings, and develops and examines the effectiveness of

self-management interventions in various settings.

As a concept, self-management has been described and considered for more than 40 years with the term first used by Thomas Creer to suggest that patients are active participants in their own treatments.<sup>14</sup> Today, the term self-management is used widely and is described by a variety of definitions and conceptualizations, which contribute to a lack of clarity and agreement in the literature.<sup>15</sup> At a broad level, self-management is defined as the day-to-day management of chronic conditions by individuals over the course of an illness.<sup>5,14</sup>

Although self-management is often used interchangeably with terms such as self-care, self-regulation, patient education, and patient counseling, self-management has evolved beyond the practice of merely providing information and increasing patient knowledge. Although the concepts are related, self-care is interpreted by many authors as consisting of those tasks performed at home by healthy people to prevent illness, rather than merely managing existing illness.<sup>5,15,16</sup> Self-regulation is more distantly related, referring to the capacity to control and manage thoughts, emotions, or behavior. Adding to the lack of uniformity in the use of the term self-management is its use in referring to (1) the process of self-management, (2) self-management intervention programs, and (3) the description of outcomes gained by engaging in self-management practices.<sup>15</sup>

Conceptual and theoretical descriptions of self-management with reference to components, processes, and outcomes have expanded and evolved from the 1980s, when Corbin and Strauss<sup>17</sup> identified 3 sets of tasks associated with the work of living with a chronic illness. The tasks included (1) medical management of the condition, (2) behavior management, and (3) emotional management. Five core self-management processes were later broadly outlined by nurse scientists and included problem solving, decision-making, resource utilization, partnerships with health care providers, and taking action.<sup>14</sup>

Another theory, the Individual and Family Self-Management Theory, proposed that self-management consists of 3 dimensions: context, process, and outcomes with the contextual

### Recommended Areas of Focus and Approaches to Advancing Self-Management

#### Conceptual clarity

Standardize language by incorporating uniform, agreed-upon language into the National Library of Medicine's medical subject headings.

#### Key areas of research

Expand comparative effectiveness studies of interventions to compare

Outcomes

Quality of care

Cost

Identify the most valid measures of self-management.

Explore the use of statistical modeling to simulate intervention outcomes.

Identify and study relevant biological and genetic variables.

Identify mediating factors

Related to sustaining self-management

For tailoring to individuals

Identify and incorporate elements of program scalability, sustainability, cost-effectiveness, and reach.

Expand research to widen the application of self-management technology (Internet, social media).

#### Methodologies for future studies

Implement a collaborative, multidisciplinary methods approach.

Use statistical modeling: systems-based modeling—for connecting underlying complex elements of self-management.

Conduct pragmatic clinical trials and use common data elements across studies.

#### Dissemination and communication of research

Disseminate research results widely to include policy and clinical practice audiences.

Publish in high-impact clinical journals and seminal science publications.

Coordinate with professional organizations to disseminate results and sponsor public forums to broaden awareness of self-management.

Provide communication, outreach, and media training to encourage and enhance communication to lay audiences.

#### Translation into clinical practice

Enhance evidence to improve clinical care.

Identify self-management interventions most likely to improve health outcomes.

Emphasize evidence-based professional training curricula.

Incorporate self-management into primary care.

Engage patients to share self-management experience.

Serve as a resource for local self-management support information.

Tailor self-management to individual needs.

Consider cultural norms and traditions.

Engage patients as to their functional goals.

Transition health care system policies and practices to incentivize and promote self-management.

Use self-management programs as a way to decrease or stabilize costs to payer.

Reimburse providers for prescribing proven self-management techniques.

Use interprofessional approach to developing self-management intervention programs.

factors influencing the process and outcomes of self-management practices.<sup>15</sup> This theory also expanded the specificity of the processes to include knowledge and beliefs, self-regulation skills and abilities, and social facilitation, and it further defined outcomes as proximal and distal.<sup>15</sup>

More recently, researchers have expanded current descriptions of self-management processes from the perspective of individuals living with chronic conditions. These include (1) focusing on illness needs, (2) activating resources, and (3) living with chronic illness.<sup>18</sup>

Self-management is also one of the 6 essential elements identified in the Chronic Care Model.<sup>19</sup> The Chronic Care Model seeks to improve quality and outcomes by focusing on system-level changes that have an impact on patient-related and provider-related factors<sup>4</sup> and is increasingly being used as the framework for identifying elements of the system believed to affect chronic disease outcomes.<sup>10</sup>

Self-management of chronic illness does not exist in a vacuum, but rather within the context of other people and influences.<sup>20</sup> Fundamental to its success are the relationships among the patients and their health care providers (primarily nurses), friends and community, and family members.<sup>21-23</sup> Family is an important source of support for people with chronic conditions. Individuals with higher levels of family support have greater adherence to self-management<sup>24</sup> and better control over their conditions.<sup>20,25,26</sup> This is particularly important in long-term self-management where family emphasis on self-reliance and personal achievement, family cohesion, and attentive responses to symptoms have been associated with better patient outcomes.<sup>27</sup>

Researchers have placed a greater emphasis on the critical role of family and community self-management research. Self-management within this context has identified significant risk and protective factors as contributing to outcomes. These factors influence individuals' and families' abilities to manage chronic illness and, as such, may be potential targets of intervention.<sup>28</sup> The Individual and Family Self-Management Theory blends individual and family self-management,<sup>15</sup> recognizing that enhancing individuals' and families' self-management results in more positive outcomes. Such theories and family-centered self-management

studies are important for the development of interventions that address the need for patients with chronic illness to overcome family barriers and emphasize the use of positive supportive techniques by family members.<sup>23,27</sup>

### Clinical Intervention and Targeted Programs

The framework built by theoretical and conceptual self-management research has provided platforms for developing and testing clinical intervention programs by nurse scientists, who are ideally positioned at the intersection of clinical research and the implementation of interventions. Two of the most successful and well-known self-management programs are the Arthritis Self-Management Program (ASMP)<sup>29</sup> and the Diabetes Self-Management Program,<sup>30</sup> developed with NINR and NIH support by 2 pioneers in the field (Kate Lorig and Margaret Grey, respectively).

Early evaluation studies of ASMP participants showed that they experienced reduced pain, increased perceived self-efficacy and quality of life, fewer visits to physicians, and, in some, reduced disability, all of which remained for at least 4 years after initial participation in the program.<sup>29</sup> The ASMP was the precursor for the development of the current self-management programs offered by the Stanford Patient Education Research Center for people living with diabetes,<sup>30,31</sup> HIV/AIDS,<sup>32</sup> and chronic pain.<sup>33</sup> Community-based self-management intervention programs for people living with chronic conditions such as heart disease, lung disease, stroke, arthritis, or multiple chronic conditions have also been developed.<sup>8,34,35</sup>

The Chronic Disease Self-Management Program was designed to meet the needs of managing day-to-day treatment and maintaining daily life activities and has proven successful at improving health behaviors and health status, resulting in fewer hospitalizations overall and fewer days spent in the hospital.<sup>8</sup> These findings demonstrated the feasibility of self-management intervention programs that cut across a variety of chronic illnesses, leading to positive health outcomes, many of which persist for years, with an added benefit of reduced health care costs.<sup>34,35</sup> Both the ASMP and the Chronic Disease Self-Management Program interventions are proven models of successful self-management programs and have

been adopted by health care systems in the United States, Canada, Australia, New Zealand,<sup>29</sup> the United Kingdom,<sup>1,36,37</sup> and other countries and translated into numerous languages for use around the world.<sup>1</sup>

Self-management programs tailored to specific groups and with a variety of delivery strategies have proven successful at improving health outcomes in targeted populations. With support from NINR, a community-based peer-led Spanish-language diabetes self-management program was developed for Latinos with type 2 diabetes. Randomized trials showed that the program improved health outcomes including improvements in hemoglobin A1C levels, health distress, symptoms of hypo- and hyperglycemia, and self-efficacy that persisted in later follow-up studies.<sup>38</sup> This program has since been translated into English<sup>30</sup> and was recently adapted into an online program.<sup>39</sup>

Early research by Grey and colleagues on coping strategies of school-age children and adolescents with diabetes<sup>40-43</sup> formed the basis for the later development of diabetes<sup>44,45</sup> and obesity<sup>46,47</sup> intervention programs in these populations. More recently, Grey's use of Internet-based intervention programs for diabetes<sup>48-50</sup> and obesity<sup>47</sup> has contributed to the use of the Internet as a promising tool for delivering self-management interventions to younger populations. One advantage to Internet-based programs is that they might allow greater participation by youths who might not otherwise be able to or desire to meet in a group setting.

Internet intervention programs targeting youths with diabetes have proved successful at increasing self-management participation and skills resulting in positive outcomes. One example of such an Internet intervention is TEENCOPE. This program targets youths with type 1 diabetes who are transitioning from childhood to adolescence and allows them to manage their diabetes more independently. The intervention is based on an in-person group coping skills training strategy shown to lower glycosylated hemoglobin, improve diabetes and medical self-efficacy, and lessen the impact of diabetes on quality of life.<sup>51</sup> Similar to the in-person group coping skills training, youths who participated in the Internet intervention showed improved outcomes in managing their diabetes.<sup>52</sup> Studies evaluating the

effectiveness of tailored self-management interventions have also shown positive health benefits for a variety of populations such as Asian Americans,<sup>53</sup> African Americans,<sup>54</sup> rural populations,<sup>55</sup> and older adults.<sup>56</sup>

Self-management intervention programs continue to be developed, evaluated, and successfully implemented for numerous chronic illnesses and conditions. Indeed, entities such as the Cochrane Collaboration have conducted evidence-based reviews of various self-management strategies, finding merit in programs focused on topics such as oral anticoagulation therapy,<sup>57</sup> asthma,<sup>58–60</sup> bipolar disease,<sup>61</sup> and diabetes,<sup>62</sup> among others.

### Environmental Factors

The ability to self-manage chronic conditions is directly affected by factors related to one's community and home environment and resources. Demographic disparities contribute to the formation of certain environmental barriers that may result in chronic conditions. For example, some populations experience poor access to fitness and recreational facilities and grocery stores that sell fresh fruits and vegetables.<sup>10</sup> Neighborhood safety and fear of violence may also suppress physical activity and adversely affect healthy eating patterns.<sup>10</sup> Such disparities point to the need for environmental considerations when one is developing interventions to support healthy lifestyles in these populations.

The relationship between people managing chronic conditions and disability is addressed in the home through intervention programs that increase the capacity of the individual to function and decrease barriers in the physical environment to create a living environment suitable for self-management. Home- and community-based services play a critical role in enabling individuals to live and work successfully with chronic conditions. Facilitating home- and community-based services is one of the objectives outlined by the Department of Health and Human Services' strategic framework for optimizing health and quality of life for individuals with multiple chronic conditions.<sup>9</sup> In recent years, evidence-based programs and services have been developed to assist those with chronic conditions, especially the elderly, in maintaining healthier and more independent lives.

One example of this type of program is the Community Aging in Place, Advancing Better Living for Elders (CAPABLE) intervention. This intervention represents an innovative multifaceted approach for optimizing self-management and living well. It extends the concept of community to one that includes resources for addressing the immediate physical environment of the home as a means to eliminate barriers to functioning on a daily basis. The CAPABLE program is an interprofessional intervention that emphasizes systematic attention to the individuals' physical and social environments in the design of their treatments and self-management strategies.<sup>63</sup> The program coordinates home visits by an intervention team of occupational therapists, who identify and prioritize physical performance problem areas and environmental issues; nurses, who assess medical issues that affect daily function; and handymen, who provide modifications and home repairs as directed by the occupational therapist. Participants in the randomized controlled CAPABLE trial experienced reduced difficulty in conducting the activities of daily living and improved their quality of life compared with control groups.<sup>64</sup> The study also demonstrated that the intervention was acceptable to participants and has the potential to be tested on a larger scale for future widespread implementation.

### THE SCOPE OF SELF-MANAGEMENT

For more than 25 years, NINR and nursing science have been instrumental in supporting and conducting the research fundamental to the development and broader application of self-management.<sup>65</sup> At the most basic level, the maintenance of health and the management of illness may be viewed as being the responsibility of the individual or, as described by Starfield et al., as the "responsible stewardship of one's health."<sup>11(p582)</sup> Therefore, the concept of self-management is integral to both the maintenance of wellness and the management of illness.

Ultimately, all self-management intervention programs are directed at enhancing the ability of individuals to improve their health status, regardless of where the individual may fall on the health–disease spectrum. Furthermore,

self-management may be viewed as the unifying force behind the 3 processes—primary, secondary, and tertiary prevention—that span efforts to maintain wellness and control symptoms and illness progression. Although definitions of these 3 terms differ, primary prevention may be thought of as efforts to preclude the onset of illness among the asymptomatic, secondary prevention as involving the detection of illness among asymptomatic persons, and tertiary prevention as involving efforts to prevent the deterioration of health in cases where illness is already present.

Self-management has been traditionally linked to secondary and tertiary prevention. Indeed, the association between self-management and tertiary prevention has been noted for approximately 2 decades.<sup>66</sup> However, self-management is no less important within the context of primary prevention, requiring active participation by the individual through the nature of the behaviors and choices made to stay healthy and avoid illness.

Recently, tertiary prevention has been proposed as a key to strengthening the health care system by improving the quality of care and controlling cost.<sup>67,68</sup> We believe support for such an approach has been demonstrated by the research-based self-management intervention programs described earlier.

Self-management may serve as a model for tertiary prevention by engaging people at the level of their functional status so that they may manage their own tertiary prevention efforts. Such interventions teach problem solving and creativity in managing illness, are transportable to various settings, and facilitate the use of resources in the community. These successful approaches are useful to not only tertiary prevention, but also to all levels of prevention and wellness.

### ADVANCING SELF-MANAGEMENT

Improving quality of life through chronic illness self-management represents an opportunity for nursing science. Among the recommendations for advancing the research and practice of self-management, as discussed at the 2013 National Nursing Research Roundtable, were the need for conceptual clarification through the standardization of terminology that will enable more valid comparison and



assessment of outcomes and intervention programs; the identification of key areas of self-management research to focus resources on those that offer the most promise for advancing the field; use of various methodologies including comprehensive, multidisciplinary team strategies, statistical and systems-based modeling, and pragmatic clinical trials; dissemination strategies that demonstrate effectiveness and have the potential to be sustainable, scalable, and wide-reaching; and ways to translate self-management into clinical practice more effectively. The recommendations are summarized in the box on page e2.

Because most chronic conditions are related to lifestyle, self-management represents an opportunity for direct intervention at the individual level with the potential for favorable impacts on health and health behaviors. An approach emphasizing self-management, tailored to various conditions, populations, and circumstances, may arguably be effective across the prevention spectrum, establishing a pattern for health early in life (primary prevention), and providing strategies for mitigating illness and managing it in later life (secondary and tertiary prevention).

It is important to note that the 3 areas of prevention do not exist in isolation from one another. On the contrary, a complex interrelationship exists among the areas of prevention such that, for example, primary and secondary prevention remain important elements of health care and maintenance of health status even among persons currently afflicted with a serious chronic condition and attempting to self-manage their illness through tertiary means.<sup>69</sup>

As trusted health professionals, nurses have a substantial role in deepening the scope of self-management across the 3 realms of prevention. Nurses are at the forefront of implementing self-management-based illness prevention and wellness programs on a daily basis in clinical and home settings. In complementary fashion, nursing research of ever more sophisticated self-management interventions will advance wellness and prevent illness through provision of the evidence necessary to improve health outcomes.

## CONCLUSIONS

As chronic conditions emerge as a major public health concern, self-management will

continue to grow as a crucial approach to managing these conditions, preventing illness, and promoting wellness. Because chronic conditions are generally slow in their progression and long in their duration, self-management research translated into practice can offer those living with chronic conditions a means to maintain or even improve their capacity to live well over the course of their lives. There is promising evidence, as outlined in this article, for the effectiveness of self-management intervention programs that address specific diseases, as well as programs showing success across multiple chronic conditions. As detailed in the box on page e2, there are key research questions yet to be addressed that will continue to refine both the concept and practice of chronic illness self-management. This should bring greater translation and adaptation of proven interventions, increase the ability to scale up to reach more people in need, and result in more thorough evaluations of intervention program effectiveness.

Self-management has particular value in that it represents an amalgamation of the goals of the patient, family, community, and the clinician with everyone working in partnership to best manage the individual's illness while facilitating comprehensive care. In this respect, self-management reaches beyond traditional illness management by incorporating the larger concept of prevention by emphasizing the notion that those who are chronically ill still have a need for preventive interventions to promote wellness and mitigate the further deterioration of health. Thus, if one considers the nature of self-management in all its elements and practical characteristics, it is not only a logical approach to health and health care, but it is also an optimal way to address chronic conditions as a major issue in public health.

Nursing science plays an important role in the research, translation, and clinical practice of self-management and will continue to contribute to the evidence base for innovative and effective practices. As one of the largest and most trusted groups of health care professionals, nurses are uniquely positioned to bring self-management to individuals and the larger population, whether they are managing a chronic condition or maintaining wellness, by serving as the bridge from research to practice. In this manner, nurses bring the hands-on skills

of self-management to communities and individuals to not just live, but also to thrive in their best achievable state of health and well-being.

With the continued support of the research, clinical, and public health communities, self-management will remain a promising direction for addressing chronic conditions that are a major health and economic concern of Americans. In the process, countless numbers of people will be helped to live well—physically, emotionally, and socially—despite illness. ■

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