
Minnesota Senior Health Options

**Self-Efficacy/
Self-Health Care
Among Older Adults:
A Literature Review**

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Definition of Terms

Self-health care has been described as “including all the actions and decisions that an individual takes to prevent, diagnose, and treat personal ill health; all individual behaviors calculated to maintain and improve health; and decisions to access and use both informal support systems and formal medical services” (Coppard et al. 1984).

Informal services are described as “a complex network of assistance from family, friends, and neighbors” (Kart and Engler 1994).

Medical self-care has been described as what people do to recognize, prevent, treat, and manage their own health problems (Mettler and Kemper 1993). Anyone who has ever taken an aspirin for a headache has practiced self-care. In fact, most healthcare problems (an estimated 70–95 percent) are managed at home without professional advice (Williamson and Danaher 1978; Demers 1980; Sobel 1995).

Self-management has been defined as “learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition” (Lorig 1993).

Self-efficacy in healthcare can be defined as the belief that one can carry out a behavior to achieve a desired goal related to one’s health (Clark and Dodge 1999). Self-efficacy is a function of an individual’s attitudes, beliefs, characteristics, and innate abilities, as well as education, knowledge, training, and learned skills.

Self-concept is defined as “the relatively stable self-image that determines the kind and quality of experiences that are perceived.” It is an important factor for a patient assuming roles that support self-care behaviors (Dracup and Meleis 1982).

In current healthcare literature, “self-care” is the term de rigueur, but we use it in this review only sparingly since some have taken exception to it. Seniors are currently wary about healthcare plans and providers, and the word “self-care” may conjure up images of older people needing to fend for themselves—whereas “self-efficacy” or “self-management” connotes a sense of personal ability or empowerment. The terms do have different meanings, however, and we have tried to remain true to the meaning that the authors intended.

Concept and Theory

The Theory of Self-Efficacy

Noreen Clark and Julia Dodge (1999) explain the theory behind self-efficacy, describing it as part of a reciprocal process that determines behavior—a person feels confident in his or her ability to carry out a behavior and to achieve a desired result. This confidence comes from the interaction of personal, behavioral, and environmental factors. Their self-efficacy model illustrates the continuous nature of the process of self-efficacy in preventing disease and managing one's own care. A person draws upon his or her own knowledge and feelings, obtains technical advice and support, and then tries out a behavior. That person then observes the results, makes judgments, and draws conclusions. If the behavior produces the desired results, it is more likely to be tried again—and the person's belief in oneself (self-efficacy) presumably increases.

Self-efficacy is described as something that is very specific to a given behavior—not a general trait. For example, a person can feel confident about following a prescribed course of medication but not feel confident about following through on an exercise program.

Building Self-Efficacy

An important component in building self-efficacy and promoting self-health care is patient education. In her book entitled *Measurement Tools in Patient Education*, Barbara Redman (1998)

makes several important observations about patient education.

First, there is now an impressive body of research demonstrating that patient education can contribute significantly to positive health outcomes. Second, there are increasing expectations and, at times, requirements for informing patients about care and treatment and providing education to follow through on that treatment. Third, the field of patient education services does not have a tradition of evaluation—especially outcome evaluation—but will need to develop same, given the pressure for evidence-based practice being felt throughout the healthcare industry. Finally, there are measurement problems in patient education research, particularly in that the content of “usual care” (which forms the comparison group) is rarely described in the research study.

Redman raises questions about the traditional behavioral approach in medicine that establishes compliance with prescribed treatment as the goal of patient education. She explains that a rapidly evolving alternative view is that “education and care should address the impact of [the condition] on the totality of the person's life. Under this model, relevant skills include the integration of [the condition] into a healthy life and managing the stress caused by living with [the condition].” This is a more comprehensive view of the focus of patient education.

Redman and Lang and Marek describe the purposes of patient education as attainment of health outcomes shown to be affected by patient education, including:

- physiological, psychosocial, and functional status
- behaviors, such as coping and problem solving
- knowledge
- symptom control
- home maintenance
- well-being and quality of life
- patient satisfaction
- facilitation of patient decision-making
- optimization of patient and family care skills about health, and how to manage a regimen
- optimization of use of resources

A Model of Self-Care in Chronic Illness

Catherine Connelly (1993) created and tested a model of self-care which focuses specifically on chronic illness.

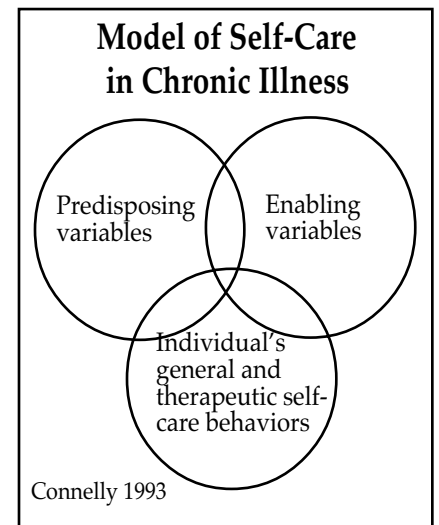
She expanded on the Health Belief Model, which is a conceptual framework initially created to predict compliance with medication and preventive health behaviors. The Health Belief Model asserts that, in order to decide whether to engage in a certain health behavior, people weigh the value of engaging in that behavior against the barriers and costs of undertaking that behavior (Hochbaum 1956; Becker 1974). Connelly explains that the Health Belief Model has been tested; evidence supports the utility of this model (Janz and Becker 1984). Others have found that a person's perception of the severity of illness also affects whether the individual complies with medical treatment or engages in self-management behaviors (Alogna 1980; Harris and Linn 1985).

Connelly describes major issues influencing self-care, including:

1. *Treatment in chronic illness tends to be complex, frequently requiring multiple behavioral innovations such as medication, diet, exercise, and habit change.*
2. *Patients need to continue their usual social roles; responsibilities limit their opportunities to assume a "sick" role.*
3. *Patients must incorporate the recommended health/illness behaviors into the repertoire of their daily lives.*
4. *Supervision, support, and reinforcement are available only through regularly or sporadically scheduled appointments over varying periods of time, not on a daily basis.*
5. *Patients are the primary, direct providers of their care.*
6. *Healthcare workers function as educators and facilitators.*
7. *Families, friends, and others significantly impact the health and illness behaviors of patients.*
8. *Care effectiveness depends on the extent to which patients follow recommendations and engage in self-care.*

Like Redman, Connelly is interested in a constellation of self-care behaviors and outcomes, not only compliance. She looks at "general" self-care behaviors (e.g., proper diet and exercise) and "therapeutic" self-care behaviors (i.e., those prescribed specifically for the treatment of an illness or disease). She illustrates her model of chronic illness self-care with three overlapping circles. One circle depicts predisposing variables, such as health motivations, the patient's perception of seriousness, and the patient's self-efficacy. The second depicts enabling variables, such as the patient's psychosocial status, his or her social support system, and the system characteristics. The third depicts the person's general and therapeutic self-care behaviors.

From her Model of Self-Care in Chronic Illness, Connelly developed and tested a Self-Care in Chronic Illness Questionnaire. In a correlational study to examine the efficacy of the model, 181 patients



completed this self-administered instrument over a six-month period. Randomly selected patients ranged in age from 26 to 88 years. The most common conditions were arthritis, hypertension, heart disease, and diabetes. Connelly examined general, medication, and dietary self-care behaviors.

Connelly found that patients' perceptions of the seriousness of their illnesses and their vulnerability to consequences were significantly related to measures of therapeutic self-care. Overall, however, only a small portion of the variance in self-care behaviors was explained. Connelly explains that this finding supports prior research results emphasizing the complexity of self-care behaviors in ambulatory patients.

Personal Attitudes and Goals

Respecting Patient Self-Determination

Teresa Brady (1990) discusses the issue of patient control of treatment and self-determination and how this is a dilemma, especially in treatment of patients with chronic diseases. She argues that patient control of treatment is essential in chronic disease because

The patient is the expert in his or her own goals and values; the sick role is inappropriate in chronic disease and may have devastating emotional consequences, and in actuality, the patient is the healthcare provider.

Brady discusses the tradition of medical paternalism, which is based on the principle of beneficence—that the physician should do what he or she thinks is in the best interest of the patient according to his or her ability and judgment. In contrast, the patient's right to control treatment is based on the principle of autonomy—which includes respect of freedom and an individual's right to self-determination. Brady argues that this is an essential ethical principle that providers must give priority over other relevant principles.

Healthcare professionals may have not only a right, but a responsibility to give advice and make decisions that they feel are in their patients' best interests. Brady asserts that patients also have a unique area of expertise—what they as individuals hope, fear, want, or will accept. Clinical interventions are, naturally,

directed at how the clinician defines a problem, yet the problem may not be a priority to the patient. Brady writes:

Each patient [with chronic illness] must continue to manage his or her complex daily existence, of which chronic disease is just one part. The patient may decide that in his or her value system and life-style, the costs in terms of time, money, energy, pain distress, or inconvenience of following the total treatment regime outweigh potential benefits. Despite good intentions, healthcare professionals cannot make that decision.

Attention to Cultural Differences

The concept and practice of self-care/self-efficacy will likely be approached differently by people from different cultures. This is an important concept to understand when promoting self-health care among people who have non-American cultural backgrounds. Self-health care programs would need to be modified or refocused to incorporate the cultural beliefs, communication style, and goals of the target group of patients.

An engaging article about the effects of cultural differences on illness behavior was written by two clinicians from different cultural backgrounds who had treated the same patient (Nilchaikovit and Holland 1993). The two clinicians had vastly different perceptions and interventions in mind after evaluating their patient, a Korean woman with leukemia. The

emphasis of the article is on Asian-American differences.

The authors examine the differences between Eastern and Western concepts of self—contrasting the centripetal-interdependence concept of the East with the centrifugal-independence concept of the West. They also discuss the tremendous importance and influence of the family in the Eastern culture and explain that, in Asian cultures, the sense of self is much more interconnected with others than in American culture, which values self-determination and individualism. Asian cultures stress interdependence, cohesion, and harmony/unity. There is also a hierarchy of relations and an expectation of superior/subordinate roles. In Asian cultures, seniority, virtue, and wisdom are the ideals.

There are striking differences in communication style and expression of emotion between the Asian and American cultures. While American culture tends to encourage open and direct expression—both verbal and physical—of a full range of emotions, Asian culture values subtle, indirect expression and encourages the suppression of “negative” emotion, especially anger.

The clinical implications of these differences are many. First, the physician-patient relationship will be different. In American culture the physician-patient relationship is based on a contractual agreement between equal parties who value autonomy. There is an implied agreement that both parties will negotiate and participate. In contrast, the Asian physician-patient relationship will be hierarchical, with an emotional

connectedness between the superior (physician) and the subordinate (patient). The physician is seen as an authority figure endowed with knowledge, wisdom, and experience who will give generously of his or her help and will demonstrate compassion and concern for the patient. In return, the patient will show respect and deference and express gratitude. Asian people will expect the physician to enter into a personal relationship with the patient, whereas to American people, this might be misinterpreted as an inappropriate breach of the professional relationship established.

Second, since Asian people value stoicism, it may be especially difficult for the physician to gather the necessary medical history and information from the patient who will tend to be quiet and passive. To overcome this difficulty, the authors suggest that the physician establish a trusting relationship with the patient and family first and respect that patient’s wish to become more open over time.

Third, Asian and American cultures have different attitudes toward illness and death, and this may impact how the patient views treatment. While Americans consider illness and death a disruption in a normal life, Asians consider these events part of the normal life cycle. Americans may seek control, fight illness, and explore many avenues for healing, whereas Asians will try to respond to illness with stoicism and serenity. Where Americans will expect to be active participants in treatment, Asians may expect to cooperate with prescribed treatment that has been established in their best interest.

Finally, the role of the family is

critically important in many Asian cultures. The authors advise that it is extremely important to inform and discuss with the family the assessment and treatment plans and to include them in every major decision. However, they state that “this does not mean that the patient should be interviewed in the presence of other family members. In many cases it would be good to interview the patient alone first, and talk with the family later.” The authors suggest that the sense of obligation to family can be used as a motivating factor to the therapeutic goal.

Programs and Techniques that Promote Self-Efficacy

Supportive Materials and Counseling

Mettler and Kemper (1993) describe techniques and strategies that support self-health care, including handbooks, workshops, and counseling. They note that several medical self-care handbooks have been written specifically for the older adult. These handbooks list common health problems and help the reader determine when it is appropriate or necessary to seek professional advice. Studies on the use of these handbooks find that they are used and appreciated by seniors, especially when reinforced by the physician or nurse. In addition, self-care workshops can improve communication skills of the patient in discussing their needs with healthcare professionals. Patient coaching / care counseling has also been used as an approach to providing support to older people making major medical decisions. Nurse care lines (providing telephone advice and triage) have also been shown to be effective.

Group Visits— A New Care Model

One program, which focuses on changing the paradigm for providing primary care, appears to improve patients' knowledge about symptoms and their ability to respond to changes in their conditions. This is the group visit model—which has been tested for chronically ill patients enrolled in a group model HMO (Kaiser).

A randomized study was conducted of 321 health plan members who were over age 65 and had at least one of the following chronic diseases: heart disease, lung disease, joint disease, or diabetes (Beck et al. 1997). Patients were further selected based on high healthcare utilization within the preceding 12 months. To control for differences in physician practice styles, patients selected were randomized within each provider panel to provide equal numbers of group visit as compared to “usual care” patients for each participating physician. Six internists (out of eight) and their nursing staffs agreed to participate in the study.

One hundred sixty-one patients participated in the control group (usual care), and 160 patients were in the experimental (group visits) group. Baseline data on the two groups showed no significant differences in gender, living situation, self-reported physical or emotional health, functional status, or depression. The experimental group was slightly younger (average age of 72 versus 75 years) and had a higher incidence of heart problems than the control group. Those who had declined participation were also evaluated, and the nonparticipants were found to be more likely to have a history of stroke, have some confusion about their medications, report depression, be limited in mobility, and be less able to read.

The group visits, called the Cooperative Health Care Clinic (CHCC), replaced the usual one-on-one patient to physician office visit. Group visits were held monthly, over the course of a year, and were scheduled with all participants at the first visit.

The general group visit two-hour format included

- 15 minutes for warm-up and socialization
- 30 minutes for a presentation of a specific health-related topic
- 15 minutes for a break during which the nurse took blood pressure readings, reviewed patients medical records, and determined any immediate care needs
- 15 minutes for questions and answers
- 15 minutes for planning the next meeting
- 30 minutes for brief one-to-one visits with the physician as needed

Where necessary, the nurse scheduled individual physician visits for the patient and also completed medical-related paperwork requested by the patients. The physician circulated in the meeting, attending to individual concerns of patients. In addition, all patients were given their own summarized medical record to keep and bring to each visit for review and updating.

The results of the study showed that the CHCC was associated with: reduced use of ambulatory services such as acute and specialty office visits, fewer emergency room visits, fewer repeat hospitalizations, and higher levels of patient and provider satisfaction. There were increased nurse visits and telephone contact as compared to the control group,

as patients appeared to see the nurse and physician as a team and have increased confidence in the nursing staff. There was also a greater level of immunization among the experimental versus the control group. An unintended benefit of the study was the patients' perceptions of improved access to care and to clinical expertise.

The authors discuss some limitations of the study, including drop-out rates. Thirteen percent of participants never showed up for any visits, and another 12 percent discontinued coming before the study period ended. The authors ascribe some of this attrition to patients who never really wanted to be part of the group visit format but were "being nice" and to those who became too ill to attend.

The group visits have continued at Kaiser. The authors conclude with the following:

The primary care physician has multiple roles in the exercise of the art of medicine. Currently the managed care environment is emphasizing the roles of diagnostician, healer, and gatekeeper. The equally important, and often more satisfying roles of comforter, confidant, educator, medicator, and cleric are being threatened by economic imperatives. There is neither the time nor reimbursement for the full exercise of this art. The specter of a seven-minute doctor office visit, during which government-imposed checklists and managed care clinical pathways must be addressed, is not a welcome development for many physicians caring for older patients or for the patients themselves. The group model of care, as an alternative to the traditional doctor office visit, provides the necessary time to address critical geriatrics issues, such as preventive care, management of chronic illness,

loss of independence, death and dying, and concerns of the family—at less cost.

This model of providing primary care, patient and family education and teaching, and socialization and support shows promise. It invites shared learning between the patients themselves, as well as between the clinicians and the patients.

Inviting the Patient's Perspective

Another method for improving the nature of primary care is offered by Tom Delbanco (1992). Dr. Delbanco draws upon his experience and work with the Picker Institute for Patient-Centered Care to recommend that physicians incorporate an organized and systematic consideration of the patient's perspective into their clinical encounters. Delbanco and his colleagues at the Institute conducted a literature review to determine what features of care patients could evaluate and to identify those features that patients judged to be most important. To ensure that the items identified met a reality test, the researchers conducted focus groups of recently discharged patients (discharges were from hospitals), as well as patients' family members, nurses, physicians, social workers, health administrators, and others. Researchers learned that patients were not simply concerned with "pretty waiting rooms" but rather key dimensions of their care. Factors or issues fell into seven categories as follows:

1. Respect for patients' values, preferences, and expressed needs
2. Coordination and integration of care
3. Communication and education
4. Physical comfort

5. Emotional support and alleviation of fears and anxieties
6. Involvement of family and friends
7. Continuity and transition

Delbanco calls for clinicians to incorporate these elements of the patient's perspective into their practices and urges physicians to conduct a "patient review" so that there will be an explicit discussion and understanding about these elements—not an assumed or implied understanding. He concludes with the following:

As practices change to involve patients more actively and patients' reports become integrated into ongoing measures of quality, patients themselves, along with their families and friends could play a creative part in crafting solutions to problems. They are a varied lot; they bring broad experience and expertise. They also hold an extraordinary personal stake, and many would be eager not only to report on their experiences but also to join health personnel in addressing and solving problems.

Communicating with Older Patients

Communication between a patient and his or her physician or primary professional caregiver is clearly critical. The quality of communication will affect diagnosis, treatment, care outcomes, and satisfaction.

Richard Hodes, Director of the National Institute on Aging (NIA), and his colleagues (Hodes, Ory, and Pruzan 1995) discuss the challenges facing clinicians and researchers in communicating with older patients in an editorial in the *Journal of the American Geriatrics Society* (Hodes, Ory, and Pruzan 1995). Given the range of health conditions and cognitive and

functional abilities among older people, as well as the diversity in cultures, educational levels, and socioeconomic status, Hodes states that communicating with older people can be complex. Since the quality of the communication between older people and their physicians is so key, the NIA and the Agency for Health Care Policy and Research held an invitational conference in 1995 where participants reviewed studies documenting the importance of the doctor-patient relationship and examined patient recall, satisfaction, compliance with medical regimens, health outcomes, and healthcare utilization.

They found that as of 1995, much of the research on the physician-patient encounter had been conducted on the general population—little research focused specifically on the older patient. Nonetheless, there were lessons to be learned about physicians' attitudes and patient communication. For example, in a study of 128 cancer specialists, John McKinlay (1995) and his colleagues from the New England Research Institutes found dramatic variability in the intensity of care provided to patients. The researchers used professionally trained actresses to simulate both clearly defined and undefined cases of breast cancer. Results showed that the specialists offered significantly less care (e.g., surgery, chemotherapy, diagnostic tests, follow-up, reconstruction) to older patients than to younger patients. There were also "profound" differences relating to race and socioeconomic status. However, when the patient added a simple, but assertive statement during the encounter, virtually all of the differences in level of care offered were eliminated. This statement

was: "I want you to tell me what all my options are because I am willing to do whatever is needed to get this taken care of."

The NIA is supporting intervention research to determine how healthcare providers can effectively influence older people to change their behaviors and lifestyles. Different interventions are being used for those who are ready to change as compared to those who are not interested in modifying their behaviors.

Do Older Adults Practice Self-Health Care?

Carl Kart and Carol Engler (1994) explored the use of self-health practices among elderly Americans in a national study of older adults.

Data were collected through telephone interviews with 714 noninstitutionalized adults, aged 55 years and older. The average age of the sample group was 68.3 years. Sixty-four percent of the sample were female and about 11 percent were non-White. Most respondents were married (53 percent), and one in four remained employed outside the home. Sample respondents reported being in good health, with a great majority (82 percent) reporting that they had no difficulty with any of the activities of daily living.

Three different indicators of self-healthcare were used: actual self-care behavior, normative self-care, and global self-care. Global self-care was derived from the answer to the following question: "How good a job do you feel you are doing in taking care of your health? Would you say excellent, very good, good, fair, or poor?" Responses showed that 53 percent chose the term excellent or very good, while only 12.5 percent

described their efforts as fair or poor.

Fifteen predisposing characteristics were examined within the study population, including age, gender, education, marital status, race, retirement/work status, living arrangement, number (if any) of children, existence of a multigenerational family, family supports, non-family supports, number of chronic illnesses, sensory deficits, and the person's perceived control over health.

Data from this national sample supported the assertion that many illness symptoms do not lead to a professional medical consultation. More than five in six (86 percent) of respondents had experienced at least one illness symptom within the past six months but employed self-care only for this symptom. Age was found to have a direct effect on only one measure of self-health care, global self-care, and this was a positive effect. That is, the older respondents generally had more positive global self-health assessments than did the younger respondents. In this study, women employed more actual self-care than men and had more positive assessments of their capacities to provide self-care. Experience with chronic illness and sensory deficits showed direct positive effects on actual self-care—perhaps because chronic illnesses require self-health care efforts to be maintained for benefit. Finally, respondents who perceived themselves as having little control over their own health reported the least amount of engagement in actual self-care.

Who is Motivated to Act?

Are all patients ready to improve self-care behaviors and take a more active role in managing their

chronic illness? Researchers say no. The individual must be ready to change. A readiness to change scale is described in an article by Marcia Ringel (1997) as a continuum from precontemplation, to contemplation, to preparation, to action, to maintenance, and eventually to ending the behavior at some point. In the article, James Prochaska, professor of clinical and health psychology and director of the Cancer Prevention Research Center at the University of Rhode Island in Kingston notes that being diagnosed with a chronic illness can be overwhelming. A person with such a diagnosis initially may not be prepared to change his or her behavior. Expecting too much, too soon, he says, "can quickly demoralize [patients]."

Ringel gives several tips for providers to motivate change in their patients:

1. *Resist the traditional authoritarian manner of giving orders to patients. Listen for cues suggesting the likely extent of adherence.*
2. *Approach patients with open-ended questions aimed at eliciting a stated desire to self-manage their disease.*
3. *Recognize that people occupy different stages of readiness to make any significant lifestyle change. Work with patients over time as they progress through the continuum.*
4. *Encourage office/clinic support staff to learn and use techniques that enhance patient adherence.*
5. *Consider each patient's personal situation, such as financial limitations and time constraints, when devising drug and other regimens. Offer alternatives, as appropriate, explaining the differences among available regimens.*
6. *Explain the reasons for recommended self-treatment measures. Provide take-home and other educational materials.*

7. *Include the patient's family in discussions of the disease and prescribed regimens.*

8. *Connect patients with other individuals who have the disease, with peer support groups, and with associations specializing in the disease.*

Self-Management Programs

Self-management programs also show promise in improving health behaviors of people with chronic disease.

The Arthritis Self-Management Program, also known as the Arthritis Self-Help Course (ASHC) was developed in the early 1980s by Dr. Kate Lorig and colleagues at Stanford University School of Medicine. It reaches from 8,000 to 12,000 adults annually who have been diagnosed with a form of chronic arthritis. The ASHC comprises a six-week course (two hours per week) guided by two lay instructors, who have received 18 hours of training and who follow a detailed program of instruction.

There are usually 10 to 15 participants in the course. Topics that the ASHC addresses include such things as nutrition, exercise, pain management, effects and use of medications, relaxation, and methods for solving problems that arise from the illness. Studies have demonstrated the effectiveness of these programs in improving self-efficacy. (For more information, see the section of this literature review titled "Evidence of Effectiveness.")

Evidence of Effectiveness

The value of improving self-efficacy/self-care capabilities among people with chronic conditions and their family members is multi-faceted. Molly Mettler and Donald Kemper (1993) describe these benefits in an article on self-care in *Generations*. They state that benefits can include

- Prevention of complications at home
- Improved decision-making skills
- Assurance that patients seek out care when it is appropriate
- Better preparation for office visits and diagnostic tests
- Higher provider satisfaction
- Higher patient satisfaction
- Lower cumulative costs of care

They briefly discuss several studies showing that active patient involvement results in better medical outcomes and a greater level of patient satisfaction and that evaluations of basic self-care programs consistently find the programs result in first-year savings due to lower healthcare service utilization (Greenfield et al. 1985, 1988; Kaplan, Greenfield, and Ware 1989; Kemper 1982; Vickery et al. 1988).

The Arthritis Self-Help Course

Another body of research has focused on the Arthritis Self-Help Course (ASHC), mentioned previously.

Early studies of the ASHC found that participants had significant increases in certain health behaviors, such as the practice of exercise and of cognitive pain management, as well as a decrease in pain levels. However, since changes in behavior were correlated with changes in pain, another qualitative study was conducted that focused on how the ASHC affected health status. The findings from this study led the researchers to hypothesize that changes in self-efficacy might be responsible for the positive outcomes of the course. Lorig and others then developed three arthritis-specific self-efficacy scales which were applied to the ASHC participants. This study showed improvements in self-efficacy and a correlation between changes in self-efficacy and changes in health status. In a final study, researchers followed ASHC participants for four years and found that the participants retained improvements in both pain level and self-efficacy even after this extended period of time. In addition, participants had fewer arthritis-related outpatient visits to physicians, as compared to a control group (Lorig, Holman, 1993).

In a study examining the cost-effectiveness of the ASHC, researchers used a decision model

and evaluated effectiveness over a four-year analytic horizon from two perspectives: that of society at large and that of the healthcare system. The researchers used the decision model to compare expected costs and reduction in pain for those enrolling in the ASHC to those not enrolling in the program. For the societal perspective, they included: the cost per enrollee of the program, the costs for physician visits for arthritis over four years, and the costs for personal time and transportation for ASHC meetings or arthritis-related physician visits. For the healthcare system perspective, they included only the program and physician visit costs.

To calculate costs, the researchers used an average cost per physician visit of \$50 and the average cost for the ASHC program. They estimated the number of physician visits to be from two to four visits for people enrolled in the ASHC and four to six visits for people not enrolled in ASHC. These estimates were based on previous studies of the program. The health outcome measured was the perceived level of arthritis pain, using a 10-point visual analog scale.

Results showed positive benefit from participating in the ASHC, from both the societal and healthcare system perspectives. From the societal perspective, the study showed an estimated four-year arthritis-related cost per person for people not enrolled in the program to be \$1,445, with a pain level unchanged at 5.0. The base case cost of people enrolled in the program was derived to be \$1,125, with a pain level of 4.1. From the healthcare system perspective, the study showed an estimated four-year arthritis-

related cost per person without the program to be \$957, with pain remaining at 5.0 on a 10-point scale. The base case cost of people enrolled in the program was calculated to be \$691 with a pain rating of 4.1.

Best case and worst case scenarios were also calculated for each perspective. Best case scenarios showed even more cost and pain reduction benefits, whereas worst case scenarios showed some minor increased costs, but a maintenance of pain reduction benefit.

The researchers conclude that the pain reduction seen with the ASHC is substantial, and they state that the course should be considered part of a standard intervention for individuals with arthritis, in addition to conventional therapies. They estimate that an insurer or healthcare system that implements the course for 10,000 people "can expect a net savings of more than \$2.5 million over four years while simultaneously reducing pain among clients by 18 percent."

Finally, the researchers express the opinion that this study probably underestimates the value of the course, since they did not study such things as: depression, physical activity levels, use of medication over the long term, joint replacement surgery over the long term, hospital admissions, or other service use (Kruger, Helmick, Callahan, and Haddix, 1998).

A Chronic Disease Self-Management Program

Given the success with the Arthritis Self-Management Program (Arthritis Self-Help Course), Lorig and others (Lorig et al. 1999) expanded on the concept and created a curriculum and program that would address the needs of people with a variety of chronic diseases, the Chronic Disease Self-Management Program (CDSMP). The assumptions underlying the CDSMP include

1. Patients with different chronic diseases have similar self-management problems and disease-related tasks.
2. Patients can learn to take responsibility for the day-to-day management of their diseases.
3. Confident, knowledgeable patients practicing self-management will experience improved health status and will utilize fewer healthcare resources.

The content of the course was developed through literature review and focus groups. Topics included exercise, sleep management, communication, use of cognitive symptom management techniques, problem-solving, decision-making, use of medications, and dealing with emotions. As with the ASHC, this chronic disease course was taught by a pair of trained volunteer lay leaders. The program was given over seven weeks in two and a half hour weekly sessions.

A six-month randomized study of the effectiveness of this CDSMP was conducted at community-based sites. To enter the study, participants had to be at least 40 years old and have a confirmed diagnosis of chronic lung disease,

heart disease, stroke, or arthritis. Subjects' physicians and hospitals were not informed as to their patients' study status (i.e., treatment or control group). Subjects were recruited using public service announcements in the mass media, flyers left in physicians' offices, posters at senior centers, announcements in HMO newsletters, and referrals from county offices. The course was held in several community sites in a four-county area. Data on the participants were collected from self-administered, mailed questionnaires.

Of the 1,140 subjects who entered the study, 952 (83 percent) completed the study. The only statistically significant difference between the treatment and control groups at the beginning of the study was marital status—54 percent of the treatment group were married, compared to 59 percent of the control group.

Results of the study showed that CDSMP treatment subjects demonstrated significant improvement in all four health behavior variables (exercise, stretching and strengthening, cognitive symptom management, and communication with physician). They also showed significant improvement in five of the health status variables (self-rated health, disability, social/role activities limitation, energy/fatigue, and health distress). No significant differences were found for pain and physical discomfort or for psychological well-being. The treatment group also had fewer hospitalizations. There were no significant differences in visits to physicians.

The authors conclude that the intervention, designed specifically

to meet the needs of a heterogeneous group of chronic disease patients, was feasible and beneficial beyond usual care.

Instruments and Measures of Self-Health Care/Self-Efficacy

Sample Items on the SUPPH

- I have confidence in my ability to keep my stress within healthy limits.
- I have confidence in my ability to convince myself I'll be O.K.
- I have confidence in my ability to practice stress reduction techniques even when I'm feeling sick.
- I have confidence in my ability to use relaxation techniques to decrease my anxiety.
- I have confidence in my ability to make my own decision regarding treatment alternatives.
- I have confidence in my ability to decide for myself whether or not to have treatment.
- I have confidence in my ability to experience life's pleasures since I became ill.
- I have confidence in my ability to do special things for myself to make life better.

There are many instruments available to measure self-health care/self-efficacy. The instruments reviewed for this document were often specific to one group of people or a particular disease, condition, or treatment.

As referenced previously in this document, a useful book on measurement tools for patient education and self-care capabilities is *Measurement Tools in Patient Education* by Barbara Redman (1998). Redman collected measurement tools by routine searching of approximately 150 journals, indexes, and databases over a period of ten years. She then contacted 90 authors, received responses from 70, and selected 50 tools to be included in her reference book. Two examples, the Falls Efficacy Scale (FES) and the Arthritis Knowledge Questionnaire (AKQ) appear in her book and are highlighted in the following two descriptions.

Strategies Used by People to Promote Health

An instrument called "Strategies Used by People to Promote Health (SUPPH) was developed to measure patients' confidence in carrying out self-care strategies (Lev and Owen 1996). The initial version of SUPPH comprises 36 items that were derived from an inductive study of 47 individuals who were asked about their own strategies to prepare for receiving cancer treatments. A five-point rating scale was used, ranging

from (1) *very little confidence* to (5) *quite a lot of confidence*.

A panel of six experts reviewed the items, and two studies were conducted to test the instrument for psychometric properties. The first study included adult patients receiving chemotherapy for cancer in ambulatory settings (N=114). The second study included patients receiving treatment for cancer (N=64) and ESRD (N=97). Acceptable psychometric properties were found for the SUPPH and four factors emerged: coping, stress reduction, decision making, and life enjoyment.

Falls Efficacy Scale

The Falls Efficacy Scale (FES) was developed to measure fear of falling. Falls are one of the most prevalent forms of injury among older people. The authors estimate that 30 percent of community-residing elderly fall each year (Tinetti, Richman, and Powell 1998). Such a fear may result in a self-imposed decline in activity and function. The authors explain that such a fear occurs in 50 to 60 percent of older adults who have fallen as well as those who have not. Fear of falling may be a characteristic that can be modified or remedied.

The 10-item FES has a rating scale of 0 to 10, with 0 meaning *not confident at all* and 10 meaning *completely confident/sure*. The individual responds according to how confident he or she is in doing

each of the following items without falling:

1. Clean house (e.g., sweep, dust)
2. Get dressed and undressed
3. Prepare simple meals (not involving carrying hot or heavy objects)
4. Do simple shopping
5. Get in and out of chair
6. Go up and down stairs
7. Walk around the neighborhood
8. Reach into cabinets or closets
9. Hurry to answer the telephone

Items were generated by asking therapists, nurses, and physicians to name the essential activities for independent living that would be safe and nonhazardous to most elderly persons. There was a high degree of consensus about these items. The FES was administered to 74 people in two pretests. Test-retest reliability was acceptable (0.71).

The authors describe use of a modified four-point rating scale FES in a study where a multifactorial intervention was used to reduce the risk of falling among elderly people living in the community. Interventions included education about use of sedative-hypnotic agents, gait training, and transfer skills training. The authors conclude that the FES may help identify people likely to become dependent upon family, friends, or agencies due to a fear of falling.

Arthritis Knowledge Questionnaire

The Arthritis Knowledge Questionnaire (AKQ) (Edworthy, Devins, and Watson 1998) consists of two forms (part A and part B), each with three subtests: self-management, arthritis knowledge in general, and knowledge of rheumatoid arthritis. There are 41 questions in each part. Part A is completed by the person with arthritis before the planned intervention. It can be used to identify patients who lack understanding of arthritis-related knowledge. Sample questions include (the correct answers are in bold):

1. The most realistic treatment for arthritis is
 - a) One which gives immediate relief.
 - b) One which helps you keep up a near normal life.**
 - c) One with no unpleasant side affects.
 - d) One which cures the disease.
 - e) Don't know.
2. Pain is one of the biggest problems in arthritis. This can
 - a) Never be completely controlled.
 - b) Only be controlled with some type of medication.
 - c) Be controlled by a very few people using a combination of medications and other methods.
 - d) Be controlled by most people using a combination of medications and other methods.**
 - e) Don't know.

The domains of knowledge covered in the AKQ are believed to underlie effective adaptation and arthritis self-management.

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Minnesota Senior Health Options

The Minnesota Department of Human Services has developed Minnesota Senior Health Options (MSHO), which combines Medicare and Medicaid financing and acute and long-term care delivery systems. This demonstration facilitates the integration of primary, acute, and long-term care services for people ages 65 and older who are eligible for both Medicare and Medicaid. Minnesota has received federal Medicare 222 and Medicaid 1115 waivers from the Health Care Financing Administration (HCFA) to put this demonstration into practice. The waivers allow the State of Minnesota to combine the purchase of both Medicare and Medicaid services into one contract managed by the state. Minnesota is the first state ever to be granted such a combination of waivers. This demonstration began serving seniors in the metropolitan area in 1997 and is expected to continue through 2001.

The Robert Wood Johnson Foundation (RWJ), which supported the planning stages for this demonstration, has provided a grant to cover the initial administration and implementation of the demonstration.

National Chronic Care Consortium National Resource Center on Chronic Care Integration

The NCCC National Resource Center (NRC), a subsidiary of the National Chronic Care Consortium (NCCC), is the nation's premier resource for obtaining best practice information, consultation, and tools on chronic care integration. NRC products and services are designed to help emerging health networks restructure their primary, acute, and long-term care relationships under risk-based Medicare and Medicaid financing. These practice-based resources enable health networks to move beyond the merger of assets and authority toward integrating the ongoing management of governance, programs, information, financing, and care for people with chronic diseases and disabilities. This service is provided in response to the emergence of people with chronic conditions as the fastest-growing and highest-cost user segment in healthcare and the need to restructure how we finance, administer, and deliver care to contain cost accumulation and maintain quality.

The NCCC is a strategic alliance of leading nonprofit health systems in the United States and Canada who share a vision of integrated care for individuals with chronic health conditions, from the time of earliest condition awareness until problem resolution or death.

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