

Clinical Contributions

Vohs Award Winner--Multiple-Region Category: **Chronic Disease Self-Management Program: From Development to Dissemination**

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Introduction

Chronic disease--the principal cause of disability and the major reason for seeking health care--accounts for over 70% of all health care expenditures.¹ Although the aging population has contributed to these increases, the prevalence of chronic disease has risen in virtually every age group. Almost 75% of people aged 65 years and older have at least one chronic illness, and about 50% of people aged 65 years and older have two chronic illnesses.² Although major advances have been made in medical and surgical care of chronic disease, there are great opportunities to enable patients to manage chronic diseases over the long term. For example, patients must cope with discomfort and disability and must follow treatment regimens regularly. In addition, patients must modify their behavior to minimize undesirable outcomes; adjust their social and work lives to accommodate their symptoms and functional limitations; and cope with the emotional consequences.

Although health professionals are primarily responsible for medical management of disease, patients are primarily responsible for day-to-day management of their illness. In one domain--living with a chronic disease--patients become the true experts. The highest-quality care for chronic conditions requires a strong, active partnership between informed health care professionals and active patients. However, two patients with the same disease and similar physical impairment may be very different in their ability to function, to enjoy life, and to partner with their physicians. Why? The difference often lies both in a patient's attitude toward the disease and toward life and in the skills he or she uses for managing day-to-day challenges. Some of the skills and attitudes necessary to live a healthy life despite chronic medical conditions are best learned from other patients who have learned how to cope successfully.

Building on the experience and evaluation of the Arthritis Self-Management Program, the Stanford Center for Research in Patient Education and Kaiser Permanente began, in 1990, to develop the Chronic Disease Self-Management Program (CDSMP). The program consists of a group patient education course led by specially trained lay leaders. The program was initiated in Northern California, has been extended to multiple Kaiser Permanente (KP) regions, and is known in different regions by various names. Examples of these names include *Healthy Living with Chronic Conditions*; *Healthier Living: Managing Ongoing Health Conditions*; *Living Well with Chronic Conditions*; and *Ways to Feel Better: A Self-Management Course for People with Chronic Health Conditions*.

Development, implementation, and evaluation of the CDSMP were complex processes undertaken by a multidisciplinary, interregional team led by David S Sobel, MD, MPH, and coordinated interregionally by Mary Hobbs, MPH; in addition, each participating region had designated coordinators (Table 1). Physicians, nurses, health educators, volunteer coordinators, care managers, and Health Plan personnel have collaborated to review, implement, and recruit for this program.

CDSMP Focus and Underlying Theory

The program content concentrates on patients' self-defined needs and self-management options for common problems and symptoms such as pain, fatigue, sleeping problems, anger, and depression--symptoms which extend across specific medical diagnoses. Patients learn skills to maximize their functioning and ability to carry out normal daily activities. Relaxation and imagery are both taught and practiced in the group sessions. Patients participating in the program also learn how to manage emotional and other changes brought about by illness, including anger, depression, uncertainty about the future, changed expectations and goals, and isolation.

Instead of providing solutions for problems, the sessions are highly interactive: Patients receive practice and feedback in decision-making and problem-solving skills. Similarly, the program focuses on increasing patients' self-efficacy and confidence in their ability to manage their medical conditions. Patients also develop skills to enhance physician/patient partnership by monitoring and accurately reporting changes in their condition and by actively sharing concerns, questions, and treatment preferences. The content of the course has been published as a book, *Living a Healthy Life with Chronic Conditions*,³ which is used as a text for course participants.

CDSMP addresses core challenges and coping issues encountered by patients with specific chronic conditions (eg, arthritis, diabetes, heart disease, hypertension, and chronic obstructive pulmonary disease (COPD)). Although the program focuses on these general issues, patients are also encouraged to seek additional targeted information and skills related to their own medical conditions. The course prepares patients to collaborate with their health care professionals and with the health care system to improve health outcomes.

The program is based on self-efficacy theory and incorporates skill mastery, reinterpretation of symptoms, modeling, and social persuasion to enhance patients' sense of personal efficacy. These techniques include guided mastery of skills through weekly "action planning" and feedback on progress; modeling of self-management behaviors and problem-solving strategies; and social persuasion through group support and guidance for individual self-management efforts. This process is documented in a detailed protocol published as *Chronic Disease Self-Management Leader's Manual*.⁴

Program Methods Qualitative and Quantitative Measures

The program was originally provided in seven (later revised to six) weekly sessions, each 2-1/2 hours in duration. No formal reinforcement, "booster session," or intervention was given after the course concluded. Each course was attended by ten to 15 participants, including any family members who wished to attend. The course was taught by a pair of trained volunteer lay leaders or by a lay leader and a

professional. Most leaders had one or more chronic diseases. Course content and methodology were developed on the basis of results of needs assessment, which relied on literature reviews as well as on information obtained from 11 patient focus groups.

The project included a self-evaluative component consisting of four studies: 1) a six-month randomized clinical trial, 2) a two-year longitudinal study, 3) a dissemination/replication study, and 4) a qualitative study of the implementation process.

Six-Month Randomized Clinical Trial

Methods: This study⁵ compared treatment subjects with wait-list control subjects. Participants were 952 patients (about 50% of whom were KP members) aged at least 40 years who had physician-confirmed diagnosis of heart disease, lung disease, stroke, arthritis, or a combination of these conditions. Self-administered questionnaires were mailed to study participants to measure their health behavior, health status, and health service utilization. Self-reported utilization was validated by comparing responses with patients' medical records and with computerized data sources for a subpopulation.⁶

Results: Results of this study are shown in [Table 2](#). Compared with control subjects, treatment subjects showed improvement at six months in several measures: weekly minutes of exercise ($p < .0003$), frequency of cognitive symptom management ($p < .0001$), communication with physicians ($p < .006$), self-reported health status ($p < .02$), health distress ($p < .001$), fatigue ($p < .003$), disability ($p < .002$), and social/role activity limitations ($p < .0007$) ([Table 2](#)).

Patients who participated in the CDSMP also had fewer hospitalizations ($p < .047$) and spent, on average, 0.8 fewer nights in the hospital ($p < .01$). Assuming hospital cost of \$1000 per day and program cost of about \$70 per participant, savings in the first six months was approximately \$750 per participant--more than ten times the cost of the intervention.

Longitudinal Study

Methods: This study⁷ provided long-term follow-up for the patients participating in the original, six-month randomized clinic trial by combining findings from two groups: subjects initially randomized to the CDSMP and the control group, who later received the CDSMP. Data were collected at four points: immediately before entering CDSMP, at six months, at one year, and at two years. Three categories of outcomes were assessed: health status, health services utilization, and perceived self-efficacy to manage different aspects of health and functioning. All data were collected from previously tested, self-administered questionnaires that had been mailed to CDSMP participants.

Results: Results of the two-year longitudinal study are shown in [Table 3](#). Compared with their baseline status, participants showed significant reduction in health distress ($p < .001$), showed increases in perceived self-efficacy, and made fewer visits to physicians and emergency departments ($p < .006$ at one year, $p < .036$ at two years). Self-rated health status and energy/fatigue levels were also marginally improved at the second-year assessment. Increase in disability was observed at one year and is comparable with increases in disability observed in similar older, chronically ill populations. Of particular note is the evidence that CDSMP participants-

-who had a mean 2.2 chronic medical conditions and increased disability--did not show deterioration in any other health state variables, as would be expected during a two-year period. Nor did CDSMP participants have statistically significant increases in number of hospitalizations or days in the hospital. Despite worsening of participants' physical disability during the first year, they maintained or improved all other aspects of their health status and reduced their utilization of outpatient health services. In addition, their activity levels and role functions did not decline.

Each year, participants made fewer visits to emergency departments and physicians despite increased disability. The total reduction over two years was approximately 2.5 visits per participant. For cost estimates, we assumed that no eliminated visits were emergency department visits (which are costlier than physician office visits) and that the cost for an outpatient visit was \$80. Thus, through reduced number of outpatient visits at least \$200 in savings was realized per participant. In actuality, savings were probably greater because our analysis assumed that without the CDSMP, visit rates would have remained unchanged. Evidence from other studies of patients with chronic medical conditions indicates that the visit rate would not decrease but instead would probably increase by a mean 2.5 visits per participant.

Participants in this study--who served as control subjects in the six-month study--had a mean 0.34 more hospital days during the six-month control period, whereas patients who received the self-management program had a mean of .15 fewer days in the hospital; total difference was thus a mean of .49 days during the six months of the original study. Assuming that a day of hospitalization costs \$1000, the reduction in hospitalization saved about \$490 in medical utilization per participant compared with baseline costs of medical utilization. Number of days in the hospital remained below baseline levels during the second six months of this study and were not substantially increased at two years when compared with baseline levels. Stated in conservative terms, the two-year cost savings resulting from reduced number of hospital days and outpatient visits was about \$690 per participant (ie, \$490 in hospitalization savings and \$200 in outpatient visit savings). The CDSMP costs between \$70 and \$200 per participant, depending on economies of scale. Therefore, actual two-year savings per participant were between \$490 and \$620.

Dissemination/Replication Study

This study,⁸ supported by the Garfield Memorial Fund, was designed to evaluate if the successful CDSMP could be replicated and disseminated nationwide throughout KP facilities.

Methods: In 1997, 11 KP regions were invited to attend a master trainer program for implementing the CDSMP. Nine KP regions participated in a training designed to teach the CDSMP, to teach others how to teach the program, and to show how to administer the program in individual KP regions. Six KP regions (and Group Health Cooperative of Puget Sound) subsequently implemented the program and evaluated participants in a cohort study that used a pre/post design and previously validated self-administered questionnaires. In 1998, 68 CDSMP programs were offered for 703 study participants. Attendance was high: a mean 5.3 of 7 sessions were attended by each participant. The course was taught either by two lay leaders (42% of sessions); by one lay and one professional leader (43% of sessions); or by two professional leaders (15% of sessions). No clinically significant differences in participant outcomes were seen on basis of type of session leader.

Results: [Table 4](#) presents results of this study. At one year, participants in the program had substantial improvement in health behaviors (exercise, cognitive symptom management, and communication with physicians), self-efficacy, and health status (fatigue, shortness of breath, pain, role function, depression, and health distress) and had a mean of 0.1 fewer visits to the emergency department ($p < .05$). Participants showed a trend toward fewer outpatient visits to physicians (0.4 fewer, $p = 0.19$) and toward fewer days in hospital (0.5 fewer, $p = 0.12$). Reduction in number of days of hospitalization in the treatment group was greater than in the six-month randomized trial, and the trend toward fewer days of hospitalization occurred while secular trends showed increasing length of stay.

During the one-year period, study participants had a mean 0.97 days fewer hospital days and 0.2 fewer emergency department visits. Assuming \$1000 as the mean cost per hospital day and \$100 for the mean cost of an emergency department visit, savings of \$990 per participant would be expected in the first year. Estimating the cost of the intervention within the KP system at approximately \$200 per participant (including administration, recruitment, and some use of professional group leaders), savings for the 489 subjects who completed the study were nearly \$400,000--a 1:4 cost-to-savings ratio.

The magnitude of improvement of subjects in the replication study was greater for most health status and utilization measures than in the first (six-month) randomized trial.

Qualitative Study of Implementation

As part of the replication and dissemination study of CDSMP, successful dissemination of CDSMP innovations were studied qualitatively.

Methods: This study used interviews and questionnaires completed by lay leaders, trainers, site coordinators, and regional health education directors. The data were analyzed thematically to identify the most common issues influencing implementation.

Criteria were established to determine if sites had successfully implemented the program. These criteria included availability of master trainers, availability of leaders, effective participant recruitment mechanism, effective leader recruitment mechanism, designated CDSMP coordinator with allotted time to manage the program, ongoing funding mechanism, ongoing plan for training new leaders, evidence of courses scheduled for the coming year, courses given at least twice per year, satisfied leaders, and satisfied participants.

Results: Dissemination and implementation of the program was not always easy or successful. Some KP regions and sites elected not to participate or to delay implementation primarily as a result of competing priorities and lack of local staff and funding. Staff turnover, change in leadership, and even the loss of entire KP regions compromised implementation. The variable success of implementing and sustaining the program has provided a valuable opportunity to better understand the process of program dissemination. Preliminary analysis has identified some possible key dissemination factors: degree of leadership buy-in and support; adequacy of program infrastructure (staff time designated, selection of program champions, creation of a mechanism to manage staff turnover, and provision of resources for interregional coordination); individual commitment and passion for the program;

critical mass of master trainers and lay leaders; and a successful mechanism for recruiting program participants.

After the initial decision was made to implement the program, inadequately supportive infrastructure (eg, excessive staff turnover and insufficient funding) and inadequate participant recruitment were major barriers to sustaining the program as well as involvement of lay leaders. Relying on physician referrals as the primary source of patient recruitment for the course did not appear to be successful. Community outreach, including direct mail recruitment to patients identified from disease registries and medical utilization data sources, appeared to be the most effective way to drive recruitment and the program itself. Recruitment was somewhat hampered by the program's "generic" focus (as distinguished from a disease-specific focus) and by competition with other disease-specific patient education programs. Both these factors created confusion in the minds of physicians and patients as to the program's role. At many sites, lack of support for lay leaders also hindered implementation.

This analysis of the qualitative data is preliminary. We expect to prepare a full article--including recommendations for supporting program dissemination--in 2002.

Discussion

The CDSMP represents an established, innovative, multiregional, multidisciplinary effort which, for more than a decade, has been substantially improving quality and cost outcomes for patients with mixed chronic disease. The project has been objectively documented by results of three studies: a randomized six-month trial, a two-year longitudinal follow-up study, and a replication study involving widespread dissemination of the program throughout KP. The CDSMP has been integrated into patient care and involves each Health Plan member as a partner in improving the quality and effectiveness of care for major chronic conditions. Thus far, four research papers on the CDSMP⁵⁻⁸ have been accepted for publication in peer-reviewed health care journals.

Results of this project showed:

- Health Plan members with chronic illness can be trained to give other members structured educational support for behavioral change.
- These educational interventions can improve health behaviors, quality of life, functional status, and health care utilization/costs in patients with mixed chronic illness.
- CDSMP processes, tools, and techniques can be replicated and successfully disseminated in other KP sites and regions.
- The process of disseminating project results can be studied to better understand how to improve programwide sharing, adoption, and implementation of proven innovations. Although developing a program may be difficult, implementing and sustaining it are often even more challenging.

The program, processes, tools, and techniques of this program have been successfully implemented in a standardized, sustainable way at multiple sites and regions throughout KP. Qualitative analysis provided data on plans to sustain and expand the program. In the course of developing CDSMP, many tools were produced to support ongoing implementation and dissemination. These tools included

standardized training programs, master trainer and lay leader training manuals, a site coordinator's manual, course materials and accompanying book, publicity materials, as well as videotapes for marketing, participant recruitment, and physician orientation (available upon request). In addition, periodic site-coordinator conference calls and an online Internet discussion group provided opportunities for staff to share successes, to jointly solve problems, and to plan ongoing modifications of the program.

Although patient education classes for chronic conditions are common, the CDSMP has several innovative and distinguishing features:

- CDSMP targets a heterogeneous group of patients with mixed chronic conditions. The program focuses on enhancing self-efficacy and self-management skills in patients affected with various chronic conditions. Because CDSMP addresses the needs of patients with any chronic illness, the program has potential use and value for most Health Plan members over the age of 50 years.
- CDSMP uses trained lay or peer leaders who have day-to-day experience in living with chronic conditions. These lay leaders are a cost-effective resource who can effectively model and facilitate peer learning. Although many health care improvements primarily involve change in professional staff practices, this innovation involved KP members as partners in providing support and educational services. The program transforms the view of members as solely consumers of health care resources into providers of health care.
- Improved behavior, health status, and health care utilization/costs for CDSMP participants have been shown in a randomized clinical trial,⁵ in a two-year longitudinal follow-up study,⁷ and in a replication study⁸--all of which have been accepted for publication in peer-reviewed health care journals.
- CDSMP has been widely disseminated throughout several KP regions. At some sites, the program has been successfully integrated into care paths and care delivery for patients with chronic illness. CDSMP has been recognized and designated as a "successful practice" by the KP Care Management Institute (CMI) to further encourage programwide implementation.

The program is the result of a productive, ongoing collaboration of KP with the Stanford Center for Research in Patient Education for more than a decade. Ongoing collaboration with community organizations has also allowed community-based partnerships to disseminate the program. KP and CalPERS, with the support of KP California Division Health Plan Major Accounts Marketing are promoting the program to working and retired members across California. KP, with support of the Direct Community Benefit Investment (DCBI) Program, is partnering with senior centers, faith-based organizations, and a consortium of community clinics to train leaders and offer the program to the larger community.

This fruitful collaboration supports a larger community effort to serve uninsured as well as hard-to-reach members. Such partnerships provide a valuable model for sharing KP quality improvements with the wider community. At the same time, these collaborative activities provide a rich learning opportunity for KP with regard to effective community-based health education strategies.

KP is also collaborating on development of an Internet-based, online version of the CDSMP which promises to provide access for members with chronic illness who might

not otherwise be able to participate in face-to-face groups. We hope to comparatively evaluate the Internet and face-to-face versions in terms of health impact, cost effectiveness, and accessibility.

The Chronic Disease Self-Management Program is innovative, health and cost-effective, robust, and replicable. Leaders, administrators, and managers should ensure availability of this program in their medical centers and communities. Physicians and staff should encourage members with chronic conditions to participate in this proven patient education program.

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The original studies reviewed here were approved by the Institutional Committee for the Protection of Human Subjects in Research at each sponsoring institution, and informed consent was obtained.

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