Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success

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About the Foundation

The **California HealthCare Foundation**, based in Oakland, California, is an independent philanthropy committed to improving California's health care delivery and financing systems. Formed in 1996, our goal is to ensure that all Californians have access to affordable, quality health care. For more information, visit us online at **www.chcf.org**.

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Executive Summary

ABOUT 45 PERCENT OF THE U.S. POPULATION has a chronic medical condition, and about half of this group—or over 60 million people—have multiple chronic illnesses.[1] This number is rapidly rising. An estimated 150 million people will have at least one chronic condition in 2015, and by 2030 the number is estimated to grow to 171 million.

People living with chronic conditions need more than medical treatment from their health care providers; they need support in mastering and sustaining the complex self-care behaviors that are necessary to enable them to live as healthily as possible. These behaviors (often referred to as "self-management") include following complicated medication regimens and some-times-stringent diet and exercise programs, monitoring and responding to symptoms, and coping effectively with stress.

Studies show that without sustained support, many adults will not succeed in managing their conditions well, leading to worse health outcomes, including expensive hospitalizations and avoidable complications.[2] Unfortunately, for doctors and other health care providers to provide this support on a one-on-one basis is often too costly in time and money. Interventions that mobilize and build on peer support, however, are proving to be both effective and relatively inexpensive and are therefore an ideal way for health systems to help their patients manage chronic conditions. These peer support interventions combine traditional peer support—meaning support from someone who also has the same condition or shares other important characteristics—with a more structured program of education and assistance.

Well-designed and executed peer support interventions empower patients to improve the management of their health and provide meaningful opportunities for patients to help others facing similar challenges. In addition, peer support interventions are significantly less expensive than traditional case management models because they train and mobilize volunteers or staff members who are not health care professionals. In this regard, peer support models are especially promising for safety-net providers and for public health systems facing severe resource constraints in the face of great needs among patients living with chronic conditions.

This report introduces clinicians and health care managers to some of the theoretical and empirical work on the benefits of peer support for chronic disease management, discusses seven models that have been tested by health systems and clinics. These models include professional-led group visits, peer mentors, reciprocal peer partnerships, and models of peer support using email and Internet exchange. The report concludes with some central lessons and recommendations to guide clinicians and health care managers in developing, implementing, and evaluating peer support interventions.

I. Introduction

Ms. Quinn is a 51-year-old woman with type 2 diabetes, hypertension, hyperlipidemia, and coronary artery disease. Upon waking every morning, she must prick her finger and place a drop of blood on a test strip to assess her blood-sugar level. After reading the results, she must prepare and inject herself with the appropriate amount of insulin and remember to take seven oral medications, some several times a day. While balancing her demanding job and the activities of her three school-age children, she must prepare healthy meals for herself that her family is also willing to eat, engage in some structured physical activity, and cope effectively with the fatigue and other physical symptoms that can sap her energy and make her feel frustrated and depressed.

THE SUCCESS OF MANY THERAPIES FOR CHRONIC diseases depends in large part on the ability of patients such as Ms. Quinn to follow often-complicated self-care recommendations. These recommendations can include complex medication regimens, careful self-monitoring to identify emerging health crises, and diet and exercise programs. To complicate matters, many patients face additional challenges such as multiple co-morbidities, physical limitations, lack of resources, and poor social support.

It is not surprising, then, that many patients find it difficult to follow the treatment plans that their health care providers recommend for them. It is not simply a lack of motivation that can cause these failures (though lack of motivation may play a part). A host of other factors can contribute. For example:

- The patient might not have sufficient knowledge of the condition or its treatment.

- The patient might lack the self-confidence or skills to manage the condition well.

- The patient might not have adequate support from family members or friends to initiate and sustain demanding behavioral changes such as eating a healthy diet.

- Physical impairments such as poor vision may complicate necessary tasks such as weighing oneself, preparing insulin, or monitoring blood-sugar levels.

- Lack of financial resources may make it difficult to buy the medications and supplies necessary to follow health care providers' recommendations.

Whatever the reason, research shows that when patients with chronic diseases do not follow recommended treatment plans—by not taking their medication as instructed, for example, or by not following a recommended diet—their health suffers, sometimes significantly.[2] Many avoidable hospitalizations for chronic disease exacerbations are the direct result of poor adherence to diet or medications. Moreover, poor chronic disease self-management contributes to avoidable and costly complications such as kidney disease, heart attacks, amputations, and blindness in diabetes. Not surprisingly, a 2003 World Health Organization report argued that improving patient chronic disease self-management would have a far greater impact on the health of the population than any improvement in specific medical treatments. Similarly, the Institute of Medicine, in its 2003 report *Priority Areas for National Action: Transforming Health Care Quality*, stated that enhancing support for patient self-management is a top priority for improving health care quality in the United States.

Unfortunately, physicians and staff members often do not have the time or resources during routine office visits to provide sufficient support for patients' self-management. The time allotted in an outpatient visit is often inadequate to address all of the questions that a patient has about self-care, and nurses and care managers have the challenge of regularly communicating with a large, dispersed panel of patients and tailoring that communication to each individual's needs.

Although research has shown that intensive care management interventions (such as face-to-face or telephone contact with a nurse care manager between medical visits) are effective for patients with high-risk chronic diseases such as diabetes

Patients Are Faced with Many Challenges

Many adults with chronic diseases do not take their medication as prescribed. For example, about 50 percent of patients do not follow their diabetes medication prescriptions,[3,4] and between 20 and 90 percent of adults with hypertension do not take their blood-pressure medications regularly. As many as half of treatment failures to control blood pressure are caused by poor patient medication adherence that goes unrecognized by the health care provider.[5] A variety of factors cause these failures, including drug side effects, low health literacy, high medication costs, and regimen complexity. Failure to follow prescribed medication plans can lead to disease progression, avoidable hospitalizations, premature disability, and death.

and heart failure,[6,7] these programs are labor- and resource-intensive and therefore may not be practical for increasingly strapped clinicians and health systems. In the face of burgeoning numbers of patients with one or more chronic conditions and the significant resource constraints facing many health care systems, a broader range of evidence-based strategies is required to improve chronic disease care in ways that complement staffing models.

In the face of these challenges, interventions that mobilize and build on peer support are an especially promising way to improve self-management support for patients with chronic conditions. These peer support interventions combine traditional peer support—meaning support from someone who also has the same condition or comes from similar circumstances—with a more structured program of education and assistance.[8]

The advantage of peer support interventions is that, if well-designed, they can be as effective as they are economical. For example, peer support interventions have been found to reduce

problematic health behaviors and depression.[9-11] And they help patients follow their medication prescriptions and adhere to diet and exercise plans.[12-14]

Peer support is so effective in part because of the non-hierarchical, reciprocal relationship created through the sharing of experiences and knowledge with others who have faced or are facing similar challenges. This exchange promotes mastery of self-care behaviors and improves disease outcomes.[15,16] In addition, people often learn better when they are taught by peers with whom they identify and share common experiences. The more homogeneous the peers are (for example, sharing similar life experiences and age), the more likely it is that the support will lead to understanding, empathy, and mutual help. These findings are consistent with the long-standing tradition of group therapy and mutual support groups as a means of improving psychosocial outcomes for patients with substance abuse and other chronic conditions. Thus, both the intensity and mechanisms linking peer support to health outcomes are different from and probably complementary to those provided by clinical care services from professional health care providers.

In addition, peer support among patients with the same chronic health problem can combine the benefits of both receiving and providing social support. This is important because many patients with chronic conditions lack effective social support, which is a risk factor for poor self-care behaviors and increased morbidity and mortality.[17-20] Lack of social support predicts psychological distress and depression and increases the likelihood of lost work time. In contrast, receiving social support decreases morbidity[21-24] and mortality rates[17,18,20] and increases life expectancy, self-efficacy, medication adherence, and self-reported health status. Furthermore, improved social support decreases loneliness, which, in turn, may decrease[25] depression and

unhealthy behaviors.[26] In particular, higher levels of social support—especially illness-specific or regimen-specific support—are associated with better chronic disease self-management.[27-31]

There is also growing evidence that providing social support to others may result in health benefits comparable to—or even greater than—receiving support. Individuals who provide social support through volunteering experience less depression,[32] heightened self-esteem and self-efficacy, and improved quality of life, even after adjusting for baseline health status and socio-economic status.[33,34-36] Furthermore, providing support to others can lead to improved health behaviors and health outcomes on the part of the helper.[37,38]

Finally, peer support interventions, by training and mobilizing volunteers or staff members who are not health care professionals, are significantly less resource-intensive than traditional case-management models. In this regard, peer support models are especially promising for safety-net providers and public health systems facing severe resource constraints.
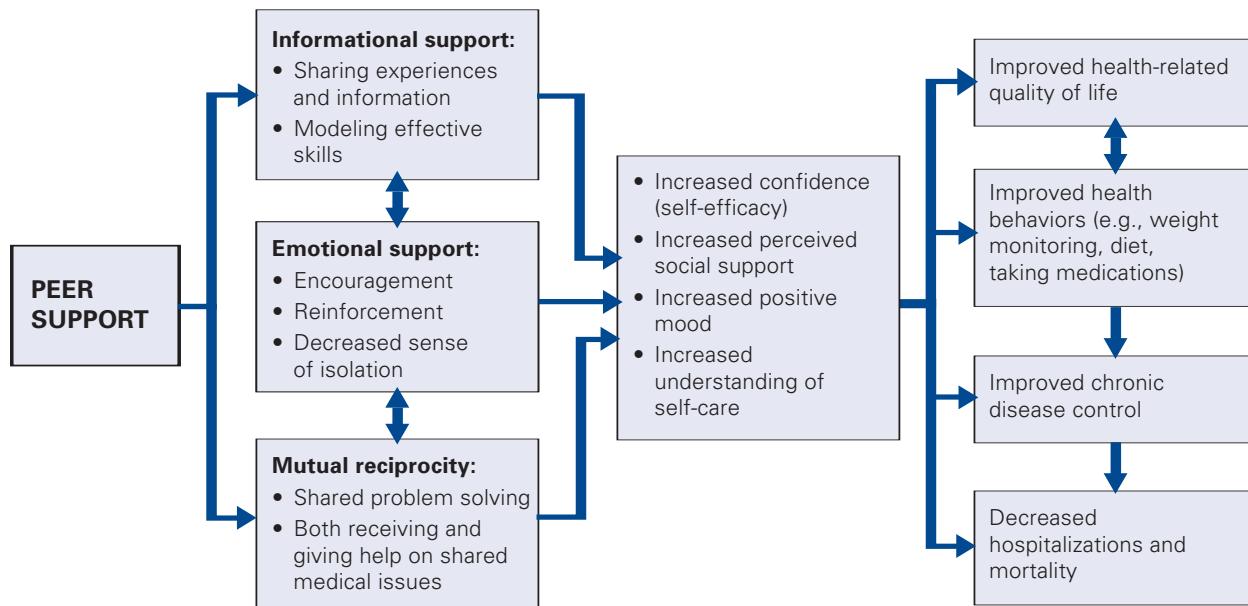
Figure 1 summarizes how peer support helps patients manage their chronic disease for improved health.

Methodology

This report informs clinicians and health care managers about seven models of peer support programs for patients with chronic illnesses. This report draws on the following resources:

- A systematic search of online database Medline to identify randomized trials and reviews addressing different models of peer support programs among adults with chronic diseases;

- Program descriptions of different specific peer support programs; and

Figure 1. How Peer Support Can Improve Chronic Disease Outcomes

Semi-structured interviews with representatives from health care systems and health plans that have developed and are testing especially promising peer support programs at their facilities.

In recent years, significant interest and support have grown for instituting different peer support models in a wide range of health systems. This report focuses on models for which there is evaluation and research. Some models presented here have been more extensively researched than others, and the information provided in this report reflects those differences.

Seven Models of Peer Support

Peer support models build on and seek to mobilize the power of peers. In many cases, those peers share the experience of living with a chronic condition. In the case of community health workers, the peers share the experience of living in the same community and being in the same cultural or ethnic group. This report discusses seven basic models:

1. Professional-led group visits with peer exchange;

2. Peer-led face-to-face self-management programs;

3. Peer coaches;

4. Community health workers;

5. Support groups;

6. Telephone-based peer support; and

7. Web- and email-based programs.

These models differ in the extent and type of formal training that peers receive, in whether peers are paid members of the health care team or are volunteers, in the type and extent of time commitment required of the peers, and in the principal method of peer support (for example, face-to-face contact versus telephone contact).

II. Professional-Led Group Visits

Description

PROFESSIONAL-LED GROUP VISITS BRING PATIENTS who share the same chronic condition and who face similar self-management challenges together with a health care provider or team of providers. The group format allows patients to obtain emotional support from people with similar experiences, to learn from each other, and to use the experiences of others as a model. Group visits can be both a time- and cost-efficient way to enhance chronic-disease-management and self-management support.[39,40] Group visits incorporate many of the core components of high-quality chronic-disease care, including:

- Planned, scheduled contact with clinicians;

- A targeted focus on improving necessary self-management skills; and

- Peer support from and interaction with other patients facing similar self-management challenges.

Typically, the health care team creates the group by inviting patients based on their chronic disease history. Patients usually remain together in the same group, although sometimes new members are added when original members leave.

Depending on the practice setting and the goals, a health care team has a variety of group visit models to choose from. Some of the possibilities include:

Cooperative health care clinic. In this model, a group of 15 to 20 patients meets for 90 minutes to two hours per month with a primary care provider, registered nurse, or nurse educator, and, occasionally, other ancillary staff members (for example, a pharmacist, a physical therapist, or a dietician). After a 45-minute warm-up discussion and presentation on a topic chosen by a provider or by the group, providers circulate and address individual questions for about 15 minutes. Then participants exchange experiences and information as a group, discussing topics such as diet strategies, ideas for becoming more physically active, and ways to remember to take medications and engage in other self-care tasks. Participants also get brief one-on-one time with a physician.

Drop-in group medical appointments.
A group of 8 to 12 participants meets weekly or monthly with a primary care provider, a medical assistant, a psychologist, a social worker, a registered nurse, or some combination thereof. During a 90-minute visit, an assistant takes patients' vital signs and retrieves charts, and a facilitator (perhaps the social worker or psychologist) encourages participants to discuss issues they are facing with their health management. The provider then meets individually with patients while the facilitator discusses topics with the group. Topics are determined by medical issues and needs raised by attendees, including topics relating to treatment and physical and emotional stress.

Continuing care clinic. In this model (which is also referred to as a chronic care clinic), a group of 8 to 12 patients meets three or four times a year for half a day. Group members receive one-on-one time with a primary care provider, pharmacist, and nurse, and they participate in group discussions facilitated by a nurse or social worker about the self-management challenges that they are facing.

Self-management group visits. In this model, a group of 10 to 18 patients meets for about two hours once a month. The visits focus on self-management and are led by a nurse educator, who also calls the patients between visits. During the program, various health care team members (for example, a podiatrist, a pharmacist, and a nutritionist) will come to provide assistance and information on their areas of expertise. A primary care provider reviews the individual cases to deliver one-on-one care when necessary.

The Group Visit Starter Kit

Several excellent resources provide step-by-step guidance in planning and implementing a group visit for patients with chronic conditions. A comprehensive guide is *The Group Visit Starter Kit: Improving Chronic Illness Care,* which can be downloaded for free from **www.improvingchroniccare.org**. Another is *Group Medical Appointments: An Introduction for Health Professionals* by Dee Ann Schmucker (Jones and Bartlett Publishers, Sudbury, MA, 2006).

Group visits offer many advantages over traditional one-on-one visits:

- Group visits enable providers to give information at one time to a larger group of patients; traditional one-on-one visits often require providers to repeat the same information at each individual visit.

- Group visits allow more time for processing and clarification of information and patient education than do shorter individual visits.

- Group visits give patients additional contact with the health care team without increasing the already heavy workloads of health care providers.

- During group consultations, patients seen together over one to two hours can benefit from longer exposure to a wider array of health professionals, exchange among fellow patients, and interactive problem-solving exercises. During individual visits, patients do not get the benefit of peer support.

- Spouses and other relatives are often welcome to participate in group visits and may learn important ways to support their family members with chronic disease management.

- By facilitating economies of scale and contributing to improved health outcomes among participants, group visits are more cost-effective than individual visits.

In designing a group visit intervention, the composition, frequency, and duration of the group must be addressed. These factors will vary depending on internal resources, staff availabilities, and the goals the group visits are aiming to meet. Consider the following questions:

- Should the group be disease-specific, or should it include patients with a range of conditions?

- Should there be the same members every time, or can patients drop in?

- Will the group have an end date, or will it continue indefinitely?

- Which health professionals will be present at each group meeting?

- Who will facilitate the group?

In addition, it is necessary both to identify a champion who will take charge of mustering staff support for and initiating the program and to assign a project manager to help organize and set up the program. Ensuring administrative support is also vital to success. An initial meeting with principal administrative staff members and leaders is essential. At this meeting, talk about resources, finances, access to care, and disease outcomes. Then explain how group visits will affect these things.

Know from the outset how the program will be evaluated and what it will mean to be successful. Decide how data will be gathered on such measures as who attends the group and how often. Include some disease outcome measures that can be easily tracked through electronic databases (for example, changes in HbA1c) or gathered from the participants themselves (such as the participants' progress in meeting their self-management goals).

Costs and Reimbursement

Group visits can be coded and reimbursed by both private and public health insurance plans. Physicians, mid-level providers, or nurses who participate in group visits get reimbursed in the same way as in individual appointments: They must match documentation to the billing code, and they must chart vital signs and other routine data. In addition, clinicians must create a progress note. All providers must enter on an encounter form an ICD-9 and CPT code. The following CPT codes are generally used for follow-up appointments conducted as group visits: 99212, 99213, 99214, and sometimes 99215, depending on the level of service rendered.

Case Study

The Cleveland Veterans Affairs Medical Center has group medical appointments for high-risk patients with diabetes. The groups are diabetes-specific so that participants can help each other with shared management challenges and exchange of diabetes information. The medical team consists of an internist, a health psychologist, a nurse practitioner, and a clinical pharmacist. Participants learn about the group through their primary care physician and the clinic medical director. In addition, the care

team calls diabetes patients at the center to encourage them to attend the group. Because the number of patients from the group who actually attend a meeting varies, the center likes to have at least 25 patients in a group, with the expectation that 10 to 16 patients will be present at any given meeting. To reinforce cohesion and interpersonal relationships, the center tries to have the same group of patients and facilitators at each session. In general, 60 to 75 percent of the patients attend any given meeting. If a clerk calls patients the day before the meeting, the attendance rate is closer to 80 percent.

Each group session has four phases:

1. A staff member welcomes the participants, introduces them to the diabetes-related topics on that day's agenda, and solicits input from participants on additional topics to include on the agenda.

2. A facilitator encourages participants to raise and discuss problems they are facing related to the day's agenda topics.

3. The patients share questions and experiences with the group.

4. The facilitator summarizes main points raised in the session, gives suggestions for follow-up "homework," discusses the next appointment, and helps patients schedule individual visits with the physician, nurse practitioner, or clinical pharmacist.

Group members set individual self-management goals and develop short-term action plans for their behavioral goals in front of other patients and with assistance from the health psychologist. A physician or other health care provider briefly talks individually with each patient about his or her goals and then documents the goals in the chart. All of the patients go home with a written action plan outlining short-term specific behavioral strategies to meet their goals (for example, they might have set a short-term goal to walk for ten minutes after lunch five days a week).[41] Patients discuss their lab values and goals with the group. If a patient needs to make medication adjustments, that is done during a one-on-one session with a staff member. Nurse case managers, attending physicians, and nurse practitioners rotate through the group sessions to encourage staff buy-in and exposure to the group visit model. Patients who have met their goals lead parts of the discussion. Health professionals repeatedly tell patients: "You are the expert." After patients have reached their goals, they are discharged from regular group visits, but they return intermittently.

The medical center is in the process of evaluating the program's clinical outcomes and cost-effectiveness compared to traditional care. Preliminary results have found that after four group visits, participants on average have a 1.4 percent drop in A1c values compared to those not invited to participate. Dr. Susan Kirsh is an internist who leads some of the group sessions at the medical center. She points to the bond between the patients as being the primary reason for the program's success:

> What could be stronger than patients looking at each other and talking about their experiences? Who are patients most likely to be convinced by: their healthy, often young, doctors? Or fellow patients who describe their complications from diabetes and conclude that "After I had a kidney transplant, I got serious"?

III. Peer-Led Self-Management Training

Description

MANY PROGRAMS USE PEERS INSTEAD OF HEALTH care professionals to train patients about self-management techniques. Sometimes these programs are disease-specific, but other times they provide more general information and develop problem-solving skills for managing chronic conditions, regardless of the condition.

In general, self-management training programs seek to provide information and promote behavioral skills that will help patients carry out the tasks necessary to live as well as possible with chronic illness. These skills include dealing with stress, managing and monitoring symptoms, carrying out all necessary biomedical tasks, navigating health systems, and working with health care providers. Although some programs are led by health care professionals, this report focuses on those that are led by peers who also live with a chronic condition and who have received training to lead the sessions.

Peers are especially effective as leaders for self-management programs. As people who are themselves living with chronic conditions, they serve as excellent role models for participants. Moreover, peer leaders can more easily hold group sessions outside of normal working hours than can health care professionals, allowing more courses to be offered at a variety of times. Because even the most effective self-management programs require follow-up contact to sustain improvements in health behaviors,[42] peers can also maintain contact with program graduates to continue to provide them with self-management support.

Although some systems have a health professional join the peer in leading the programs, this pairing has often proved problematic because the professional sometimes assumes the role of teacher while the peer leader assumes the more subordinate assistant role. Moreover, the class dynamic can change, with participants seeking answers from the health professional rather than working together to develop effective problem-solving techniques and strategies. Many programs report that

health professionals are often more difficult to train than peers because they are more used to didactic, directive approaches to encouraging sustained behavioral changes ("As the expert, I think you should...") and may focus less on process, interactive exercises, and developing patients' own problem-solving skills than peer leaders do.

Successful peer-led self-management programs share important elements. They have a dedicated staff position (at least one-quarter time) whose job it is to make the program work and get buy-in from organizational leaders. Health system staff members—not the peer leaders—take care of important organizational tasks, such as scheduling, delivering materials to the class site, and arranging tables and chairs in advance so the peer leader can focus on providing information and facilitating a good session. Peer leaders are often recruited through notices in newsletters, posters, and referrals, and many programs actively recruit participants who have successfully completed the program to become trainers.

Peer-led programs usually have periodic special events to recognize peer leaders. In addition, they provide ongoing support to peer leaders, giving them access to health care professionals through pagers and, perhaps, home phone numbers. Many programs also have regular dinners, telephone contacts, newsletters, and refresher training. They sometimes invite peer leaders to health center seminars. In addition, many programs provide regular opportunities for peer leaders to exchange experiences and discuss issues. Leaders come together in a group to share challenges they are facing. As one master trainer emphasized:

It is very important to look after the wonderful group of peer leaders that we have. It is important to respect their views, to take into account their preferences for times, location, and other leaders they like to work with. It is important to keep them informed, to develop a relationship based on confidentiality and openness and one that is transparent. They need to know that they are a highly valued part of our team.

Many of the now-hundreds of peer-led programs throughout the world follow a model that was first developed and evaluated by Kate Lorig and colleagues at Stanford University (http://patient education.stanford.edu): the Chronic Disease Self-Management Program (CDSMP), or *Tomando Control de Su Salud,* the Spanish version. The CDSMP is a program for patients with different chronic conditions given in 2.5- hour sessions once a week over six weeks. Its content includes design of individualized exercises and cognitive symptom management programs; methods for managing negative emotions such as anger, fear, depression, and frustration; and discussion of such topics as medications, diet, health care providers, and fatigue.

Table 1. Content of Chronic Disease Self-Management Program

Workshop Overview

	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Overview of self-management and chronic health conditions	✔					
Making an action plan	✔	✔	✔	✔	✔	✔
Using your mind to manage symptoms	✔		✔		✔	✔
Feedback/problem-solving		✔	✔	✔	✔	✔
Difficult emotions		✔				
Fitness/exercise		✔	✔			
Better breathing			✔			
Pain			✔			
Fatigue			✔			
Nutrition				✔		
Future plans for health care				✔		
Communication				✔		
Medications					✔	
Making treatment decisions					✔	
Depression					✔	
Working with your health care professional						✔
Working with the health care system						✔
Future plans						✔

Source: Personal communication from Kate Lorig, Stanford University.

In a typical peer-led program, leaders teach the courses in an interactive manner designed to enhance participants' confidence in their ability to execute specific self-care tasks (or "self-efficacy").[43] The class sizes range from 10 to 15 patients and can include participants' family members and friends. Participants receive written course materials, exercise and relaxation audio-tapes, and illustrated booklets of exercise routines. In the model developed by Lorig and colleagues, the goal is not to provide disease-specific content but rather to use interactive exercises to build self-efficacy and other skills that will help participants better manage their chronic conditions and live fulfilling, active lives. Other effective programs, such as that developed by Latino Health Access, also provide disease-specific information and support. (See Case Study in Section V.) A vital element among all programs is promoting exchange and discussion among participants and with the peer leaders.

In most programs, two trained peer leaders teach the program in a clinical or community setting (such as a church or neighborhood center). Usually, these leaders are also patients living with one or more chronic conditions. To become a leader, an individual must undergo training in course content and process. Peer leaders teach in pairs; this arrangement not only provides two role models but also allows a division of labor in an interactive course that is labor-intensive. In addition it helps ensure that they do not provide incorrect medical information to participants (although in practice, there have been few reports of this kind of problem). Requirements and training vary depending on individual program needs. For the CDSMP all peer leader training is four days. Often peer leaders have successfully completed the CDSMP class as an active participant and then have completed additional training, including practice teaching. Peer leaders often receive ongoing supervision and support from a master trainer (who may attend some class sessions). These master trainers often supervise peer leaders every week while the class is in session. Master trainers attend 4.5 days of training. Programs often provide subsequent refresher training, including practice teaching and discussions with master trainers. Some programs pair a newly trained peer leader with an experienced leader for the first few courses. Once the new leader feels competent and can show proficiency, he or she then leads a course with a less experienced leader. At the end of each course, the leaders are evaluated.

In recent years, multiple trials have shown the positive impact of self-management education programs on improving chronic disease outcomes.[6,44,45,46,47,48,49] The most successful programs, such as the CDSMP, emphasize strategies to enhance self-efficacy.[6,43,50] The CDSMP has been evaluated in several randomized controlled trials. In the late 1990s this program was evaluated for about 1,000 adults with heart disease, lung disease, stroke, or arthritis.[45] Outcomes of the six-month randomized controlled trial and the two-year longitudinal follow-up evaluation found that participants had significant improvement in health behaviors and health status as well as reduced health care use.[51]

Costs and Reimbursement

Program costs for peer-led self-management programs consist largely of staff salaries, leader recruitment and training expenses, and materials and facilities expenses. In addition, leaders receive a stipend. Leaders also receive reimbursement for their parking. Some health systems encourage leaders to meet with each other and provide a meal at these meetings.

For health systems to receive reimbursement for conducting the sessions, they must negotiate with each individual insurance company and make the case that the program is a product worth paying for. Health plans such as Kaiser Permanente currently cover the programs as a benefit for enrollees with chronic diseases.

Case Study

Some health systems have effectively incorporated peer-led self-management training and support into broader community-based, nurse case management programs. A good example of this phenomenon is Project Dulce, which helps primarily Latino adults with diabetes in San Diego County, California. Project Dulce developed and tested a culturally sensitive approach to improving diabetes care and outcomes among underserved racial and ethnic populations. Primary care providers and the county's medical assistance program for indigent populations directly refer patients to the program, which combines nurse case management with peer-led self-management training.

The nurse case management component consists of a nurse-led team with a registered nurse or certified diabetes educator (R.N. or C.D.E.), a bilingual or bicultural medical assistant, and a bilingual or bicultural dietician who travels to each clinic site to see patients. Each participant undergoes a baseline visit to assess demographic information, history of diabetes, weight, blood pressure, foot status, A1c and lipid profiles, and proteinuria. At each subsequent visit, the nurse reviews self-monitored blood glucose results, self-management goals, provides recommendations for changes in diabetes medications, and orders follow-up lab studies. Prescriptions are approved and signed by primary care physicians. For complicated patients, follow-up visits are scheduled within two weeks, with a minimum of four visits.

The peer component uses individuals with diabetes to be peer leaders. Other than being able to read and write, there are no educational qualifications. These peer educators then complete a four- to six-month training program and have to pass competencies and written tests. They have to demonstrate that they can measure blood sugar on a meter and conduct a finger stick using universal precautions. Peers lead training classes, health fairs, talk on the radio, and deal with other types of media inquiries. They meet with patients in two-hour sessions, with one session per week over 12 weeks. Classes cover diabetes and its complications and include discussions on the importance of diet, exercise, medication, and blood glucose monitoring. There is a strong emphasis on promoting discussion among patients about their personal experiences, fears, and beliefs about diabetes. Peers leaders must help patients overcome non-congruent cultural beliefs, such as fear of using insulin or *nopales* (prickly pear cactus) in treating their disease.

Project Dulce has been very successful in improving participants' clinical outcomes. One evaluation showed significant within-group improvements in A1c, diastolic blood pressure, total cholesterol, LDL cholesterol, and triglycerides. Compared to a control group, the Project Dulce group had significantly improved A1c, total cholesterol, LDL cholesterol, and triglycerides at one year. The project also achieved 100 percent adherence to American Diabetes Association (ADA) standards of care for A1c checks twice per year, lipid panel, urinary microalbumin-to-creatinine ratio, foot exam, and monofilament exams.[52]

IV. Peer Coaches

Description

IN CONTRAST TO THE STRUCTURED SELF-MANAGEMENT training groups described above, a more informal, flexible means of providing peer support for patients with chronic conditions comes from peer coaches, or mentors. Peer coaches meet one-on-one with other patients to listen, discuss concerns, and provide support; they have been effective with patients suffering from such chronic conditions as HIV, cancer, stroke, and chronic kidney disease and with patients facing organ transplants.[53] Peer coaches are usually individuals who have successfully coped with the same condition or surgical procedure and can be positive role models. They also provide hope and understanding that could not be provided by someone with no personal experience with the condition. Candidates to be peer mentors are often referred by clinicians or social workers who recognize them as successfully coping with the condition.

Many programs, such as the Peer Mentoring Program of the National Kidney Foundation, provide anywhere from 8 to 32 hours of training for the volunteer peer mentors. The training focuses on communication skills, including empathic listening, helping participants clarify their values and life goals, problem solving, and assertiveness. Teaching the skills necessary to support patients is emphasized, rather than having the mentor try to assume the role of a health care provider. Ensuring that patients understand their chronic conditions is also important to minimize misinformation provided by mentors. The training covers such topics as grief and loss, sexuality and relationships, and working with health care providers. The training also provides opportunities to explore good and poor listening skills in ways that decrease new coaches' anxiety and highlight the new coaches' own listening strengths and limitations. In addition, the training helps new coaches see how they themselves view what it means to be ill or disabled and what learning and skills each brings to new patient relationships. The aim is for peer coaches to finish the training with a strong commitment to working with others to enable them to lead satisfying and meaningful lives with a chronic condition.

Because the peer coaches are volunteers, the program staff discusses with the peer coaches the amount of time they can put into the program, what they are most interested in doing, and things that might be uncomfortable for them. For example, working with children or those at the very end of life can be particularly difficult for some peer mentors. The program staff also tries to match peer coaches with their particular areas of interest. For example, some peer mentors very much enjoy sharing their experiences in educational seminars for new patients. In some programs, mentors will have caseloads of patients whom they either meet with or call regularly. In addition to listening, peer mentors do a variety of other helpful tasks, such as sending cards to hospitalized patients, developing exercise activities, and convening arts and crafts or support groups. Often, the tasks that peer mentors choose are the very ones they would have wanted for themselves as patients. As with other peer interventions, holding regular follow-up meetings among peer mentors is important to allow the mentors to share experiences, solve problems, and provide mutual support.

Peer coaches have proven particularly adept at alleviating new patients' fears and helping patients of all ages successfully adapt to a diagnosis. For example, peer mentors have helped patients deal with their fears about renal transplants and breast cancer surgery. Peer mentoring is especially effective with non-white individuals who have a historic cultural mistrust of predominantly white health care systems.[53] And for all races and cultures, peer mentors foster trust of the health care staff and enhance coping and health outcomes among patients with breast and prostate cancer, women with postpartum depression, and patients with HIV/AIDS.[53] Peer mentors have also been shown to improve heart failure self-care among heart failure patients.[54]

Peer mentors can be especially effective at helping patients develop strategies to incorporate complex treatment regimens into their everyday routines. Peer mentors play an especially important role in educational activities to introduce patients to a new, potentially frightening medical task (for example, starting dialysis). They discuss their own experiences and address patients' concerns and fears. Volunteer peer mentors also are frequently available beyond normal clinic hours when patients usually do not have access to the health care staff. Peers promote the clinic as a caring health community. Moreover, as is the case with other forms of peer support, peer mentoring may help both the patient and the mentor. As noted earlier, a growing body of research shows that patients who help others in turn receive benefits for themselves.

When instituting a peer mentor program, it is crucial to generate support from the health system staff. To ensure staff buy-in, it may be useful to send the staff an initial survey describing the proposed peer mentor program. In addition, ask the staff to recommend patients whom they think would be good mentors. It is also useful to ask the staff about any concerns they might have about a peer mentoring program. Once the staff has been consulted, operate a pilot program with one very qualified peer mentor before launching a broader program. This helps the staff understand the program and its value to other patients and their organization. Once the broader program is launched, formally introducing the peer mentors to patients is critical. For example, a program might put a picture of the peer mentor in the lobby or provide a box in which patients can drop questions for the peer mentor. Regular follow-up and support to peer mentors from the professional staff is necessary, with appropriate recognition of the mentors' time and efforts. Programs need to recognize that peer mentors themselves are often sick and may not be able to perform all scheduled tasks.

Costs and Reimbursement

Peer mentors usually volunteer their time, so program costs are minimal. Usually, the health system must secure liability insurance and cover mentor expenses, such as parking fees. Health systems will also have costs associated with recognizing the efforts of peer volunteers such as lunches, dinners, and gift certificates, along with staff time for supervising peer mentors.

Case Study

In the National Kidney Foundation's peer consulting program, renal social workers identify dialysis patients and transplant candidates who are successful role models and recruit them to be peer mentors. These mentors undergo eight hours of initial training; subsequently, they receive brief booster sessions and feedback from the social workers working with them. Mentors average three to four years of volunteer service. Peer mentors in dialysis units will mentor other patients who attend dialysis sessions during their same shifts. The mentors are often present in the dialysis units and make themselves available to visit and talk with patients undergoing dialysis. Peer mentors report back to their renal social workers through structured forms in person or via email to give feedback on activities and patients served and to alert the health care team to any issues or needs that they have observed that may require staff intervention or education.

V. Community Health Workers

Description

COMMUNITY HEALTH WORKERS, OR PROMOTORAS, are community members who work as bridges between their ethnic, cultural, and geographic communities and health care providers to promote health, usually among groups that have traditionally lacked access to adequate health care. Community health workers do not always have chronic conditions, but they are peers to the populations they serve in other important respects: They often speak the language, share the culture, and come from the same communities as the patients with whom they work.

Community health workers have five often-overlapping roles in the treatment of chronic disease:

1. Caring for and supporting patients by doing such things as identifying resources, managing cases, reaching out to patients by telephone, documenting patient care, and providing patients with disease-specific information;

2. Educating patients about self-care and helping them learn self-care skills;

3. Supporting the care and education provided by health care professionals;

4. Coordinating care and acting as a liaison with the health care system; and

5. Providing social support by being available to listen and talk through problems that patients are experiencing.

Even with access to health care, there may be multiple individual and community barriers to adequate self-care of chronic diseases. People may lack transportation to attend regular clinic visits, have unstable work or home situations, or lack knowledge of available resources. Studies suggest that community health workers can help overcome these barriers by developing trusting, close relationships with the people they serve. Indeed, community health worker programs have improved health care access, prenatal care, pregnancy and birth outcomes, health status, and health and screening-related behaviors among participants in the programs.[55] Community health workers educate their peers, encourage them, and help

them effectively use and navigate community and health resources. They improve the quality of life of the patients they serve and are particularly helpful in vulnerable populations, such as the elderly. There is also some evidence that community health care workers reduce health care costs.[55]

Often in this country, the focus of community health workers has been on prevention, but there is increasing recognition that they can help patients with chronic conditions. The Institute of Medicine recommends that health care systems support the use of community health workers to address racial and ethnic disparities in health care, stating that "community health workers offer promise as a community-based resource to increase racial and ethnic minorities' access to health care and to serve as a liaison between health care providers and the communities they serve."[56] A 2006 systematic review of community health worker programs serving adults with diabetes found that, in five of the seven studies reporting outcomes, patients who worked with a community health worker had more knowledge of their disease and better self-care skills (for example, in areas such as diet, exercise, and blood glucose monitoring) than those patients who had no contact with a community health worker. Patients connected with community health workers had fewer emergency room visits.[57] This review also found improved provider monitoring of glycemic control and rates of retinopathy screening.[57]

When community health workers are combined with nurse-led services, the results are even more dramatic. In one such program, African American patients with diabetes who received the combined community health worker/nurse manager intervention had greater declines in A1c values, cholesterol, triglycerides, and diastolic blood pressure than did routine-care groups or those led solely by either community health workers or nurse case managers.[58]

Although they are most common in nonprofit and public health programs, community health workers are also becoming increasingly common in managed care settings. These workers can link managed care to their communities by providing outreach, patient education about managed care systems and health issues, and follow-up services. In addition, a growing number of community health centers serving predominantly ethnic and racial minority populations, such as Asian Health Services and La Clínica de la Raza in Alameda County, California, use community health workers in their clinics, having them work closely with the health care team under the supervision of a health care provider. In this way, clinics are able to better integrate community health workers into the clinic staff, identify community members eligible for health care coverage, and ensure that patients with health care coverage receive all necessary services for which they are eligible.

Individuals who make excellent community health workers are those who:

- Have demonstrated a previous commitment to the community (through volunteering or other community involvement);

- Have shown leadership qualities such as effective organization skills, clear communication skills, and charisma;

- Are already perceived as natural leaders in their communities (such that many people already are informally turning to them for advice and assistance); and

- Have demonstrated healthy behaviors and thus serve as excellent role models.

There are no set educational qualifications for being a community health worker; often, community health workers have no formal education beyond high school.

Community health workers are trained in health related topics and are taught skills that promote positive human relations. After the initial training, community health workers receive periodic booster training sessions. They also get feedback from the health system and from the community they serve, and this feedback is incorporated into additional training sessions.

Although each individual program will have its own particular requirements for community health workers, all programs want their community health workers to have the following: the ability to facilitate and accurately teach a class using the principles of adult education; the ability to organize a community meeting; and the ability to incorporate the skills of residents when planning activities. Being able to maintain accurate documentation, to organize reports, and to write weekly plans is also important.

Community health workers need financial, human, and technical support from the supervisor, other staff members, co-workers, and community members. Accountability and evaluation are crucial. Supervisors must provide ongoing training, planning, feedback, resources and materials, administrative support, mechanisms for accountability, and fair evaluations.

Initial results about the effectiveness of community health worker programs for chronic disease management are encouraging. A great need still exists, however, for more rigorous evaluation of health outcomes and of what type and intensity of training community health workers should receive. Research also needs to be done on the optimal type and level of support for these workers.

Community health workers are most likely to be useful as a cadre of health care providers when they have an effective health care intervention to deliver. Community health workers are most effective in settings where infrastructure is already in place, particularly one involving well-developed community networks and strong social ties among members. Most successful community health worker programs use a community-based, participatory model in which community members and health care and other agencies have shared values, equity, planning, and participation.

Some populations, such as many recent immigrant groups, are more likely than others to turn to informal health care systems, and the community health worker model may fit these populations best.

For a community health worker program to succeed, senior managers must support it and be committed to it. Before developing the program, understand the current health care situation and the community's needs. Continue to monitor these issues as the program progresses, and be prepared to make modifications as requirements change. To ensure that community health workers receive adequate support and are integrated into the health care team, involve formal health care providers in the program design, training, and implementation. Give community health workers ongoing feedback both through formal evaluations and through staff and patient comments. To increase community awareness and support of the program, invite local media representatives to such program events as graduations and classes. Use a formal and well-evaluated community health worker training program. Document and evaluate processes of care and program implementation and impact. Put systems in place to encourage feedback from the community health workers themselves, and incorporate their suggestions into the program design and implementation.

Costs and Reimbursement

Some programs employ their community health workers full-time, paying them salaries and benefits. Other programs schedule their community health workers for only a certain number of hours per week, paying them by the hour and reimbursing them for their expenses.

Case Study

Latino Health Access (LHA) in Santa Ana, California, runs a successful community health worker program. LHA works with 30 paid community health *promotoras*, who are selected in part because of their commitment to community service. *Promotoras* receive training in teamwork, motivational interviewing, and leadership skills. They also learn about outreach, health promotion, disease prevention, family dynamics, community mobilization, problem solving, and program administration. *Promotoras* might be assigned to a specific health concern (such as diabetes or immunizations), or they might be assigned to a specific neighborhood to work on more general health issues. Depending on their assigned area, they will receive additional training, and they will have to show competence in those areas. (For example, a *promotora* who is focusing on diabetes might have to demonstrate how to draw up insulin and check blood glucose.)

In one LHA program, doctors in a managed care plan send Latino diabetes patients to a series of classes that are conducted in Spanish by *promotoras* who themselves have diabetes and are graduates of the program. The participatory classes train individuals with diabetes and their families to understand, prevent, and manage this condition.

VI. Support Groups

Description

MUTUAL HELP OR SUPPORT GROUPS ARE VOLUNTARY gatherings of people who share common experiences, situations, or problems and who offer each other emotional and practical support. Most effective support groups have the following characteristics:

- Even if professionals initiate and provide some structure for the groups, they are largely run by and for group members. Professional providers may participate in the self-help process at the request and sanction of the group.

- Meetings include discussion, sharing of information and experiences, and other activities that promote mutual support and empowerment.

- The group is open to anyone who has shared in the experience.

- The groups do not charge for participation, although a nominal donation or dues may be requested to cover expenses.

Support groups have been successfully sponsored by many different health systems. These groups provide an arena within which participants can both provide and receive support. More than 25 million Americans have been involved in support groups, with positive outcomes found for participants with chronic illness,[59] substance abuse,[60] diabetes,[13] and depression.[61]

Peer support groups provide members the opportunity to give and receive, both of which lead to better health outcomes. They also give members an opportunity to develop friendships and build social networks. Participation in support groups may lead to greater improvements in general well-being and symptom control, coping skills, and overall well-being than do groups led by professionals.[61]

Most patient support groups meet at least once a month. Average attendance runs from 10 to 15 people. Groups pursue strategies to maintain active membership at group meetings. They sometimes recruit new members through word of mouth, newspaper and magazine listings, referrals from health care professionals, and flyers and brochures. Other recruitment techniques include calling, visiting, or writing potential new members, producing television and radio spots, and distributing newsletters. Many health systems sponsor or provide space for support groups.

A 2000 survey of 252 self-help groups found that 27 percent of them were led by peers with no professional involvement; 34 percent of them were led by peers but with some professional involvement; 28 percent were led by professionals; and 11 percent had shared leadership between peers and professionals.[61] Although support group members should be in charge, health system professionals can provide important support: for example, providing meeting locations, helping to facilitate meetings, providing information about meeting times and places, and referring people to groups. As F. Reissman and D. Carroll, noted experts in self-help organizations, emphasized in their 1995 book *Redefining Self-Help:*

> Certainly, it is useful for a self-help organization to facilitate the inner strengths of its membership and to remain self-reliant. But not to be ignored is the value of outside resources as well—outside knowledge, advice, expertise, and financial support.

Most groups give members emotional and social support, information and education, and networking opportunities. In addition, group members often support each other between meetings through telephone contact, peer counseling, visitation and outreach, buddy systems, training seminars, and social events. Groups often provide an informal, consistent parallel system of peer support to complement professional help and social support from family and friends.

Costs and Reimbursement

Most self-help groups operate with minimal funds with limited or no costs. Health systems often provide free meeting space. Peer group leaders are volunteers and generally do not get paid. When professionals attend peer-led group meetings as speakers on a specific topic, they do not charge the group. When professionals lead a group, they usually do so as part of their professional duties and do not charge the group. Some groups pass a basket for donations and use the money for refreshments, literature, postage, or a special event. There may also be optional annual dues for people who wish to become members of a national organization.

Case Study

At several community hospitals in San Diego, monthly support groups are held among people with diabetes. A psychologist takes the initiative to organize them, sending out emails and flyers providing information about the support group and meeting times and locations to all affiliated health care providers to inform their patients. Flyers are also put up at clinics and throughout the hospitals. The hospitals provide the meeting location and refreshments. Usually, 15 to 50 patients participate. The groups are facilitated by at least one diabetes educator or psychologist. Each support group starts with a presentation on a topic of interest chosen by the support group members (lasting about 30 minutes), a facilitated discussion among the group (45 minutes), and then a period for more free-form socialization and exchange among group members. There is no fee for the support group members. Some participants come every month, and others come just once or participate intermittently. Other groups of eight to ten people meet weekly to grapple with living with diabetes. A professional facilitator is always present at these groups as well to ensure that everybody has the chance to participate and that some people do not monopolize the conversation. Facilitators receive initial training to become hosts and attend mainly to encourage structured discussion among group members. It is not a didactic session or lecture, although there may be an initial presentation on a specific topic of interest.

VII. Telephone-Based Peer Support

Description

IN TELEPHONE-BASED PEER INTERVENTIONS, patients receive support through regular phone calls. Sometimes, a peer or peer counselor makes calls as the sole form of intervention. Other times, the telephone intervention is a complement to another type of intervention. For example, participants in mutual support groups, self-management training classes, and group visits may exchange phone numbers and provide support between scheduled visits. In this way, telephone-based peer support can provide an important source of self-management support between scheduled face-to-face group visits, self-management training programs, or other clinic-based programs.

Telephone-based programs are sometimes preferable to face-to-face interventions because they address the access barriers that many patients face in attending face-to-face programs, and many patients prefer the relative anonymity and privacy of talking on a phone. Traditional telephone-based programs, however, have limitations. [62-65] Patients may be reluctant to share their telephone numbers and pay the cost of long-distance calls. Moreover, many patients may be willing to participate in peer support calls but lack the initiative or organization to ensure that they make contacts regularly. From a health system perspective, telephone peer support programs can be difficult to monitor, and few, if any, have been designed to interface with standard outpatient nursing care.

One way to address these limitations is to use an interactive voice response (IVR) exchange platform with Internet monitoring. With this technology, participants do not share phone numbers, and they can block calls during certain hours. The IVR system can also generate automatic reminder calls to participants who have not contacted each other in a given period. IVR-facilitated telephone peer support may be an ideal adjunct to promote more effective use of standard nursing services and give patients additional help without requiring health systems to hire more workers. Such programs might also be used to extend the reach of ongoing face-to-face self-management programs.

In an IVR system, a participant dials a designated toll-free IVR number to contact the partner. When connected with the system, she enters her own home phone number, which serves as

an identification code linking her to the partner's home phone. If, during the call, a question arises for a case manager or other staff member, voice-mail messages can be left immediately by pressing a designated key. A password-protected Web site can be used to monitor the calling process, including when calls were placed, who initiated them, and how long they lasted. If partners seem to have difficulty making contact, a staff person can contact them and address any problems. If either peer partner wishes to discontinue the program for any reason, she can ask a staff person to remove her telephone number from the system.

Any telephone-based peer support program should train participants in using the system and in using peer communication approaches such as empathetic listening and open-ended questions. In addition, the program must instruct participants not to make changes to any prescribed treatments without consulting their doctors. This message can be programmed to play before every IVR telephone call.

In IVR telephone programs, a health system staff person should monitor the frequency of calls and look for any problems that participants are having making contact. A health system staff person must also be available to field questions and concerns.

Costs and Reimbursement

The principal costs of these programs are the costs of purchasing the IVR software or contracting with an IVR company to provide the service, the toll-free line expenses, and staff members to monitor the program.

Case Study

Two large-scale randomized controlled trials of IVR peer support programs are underway at the University of Michigan: one for patients with diabetes and the other for patients with heart failure. One important feature of these interventions is their focus on reciprocal support in light of the evidence that providing social support to others may result in health benefits comparable to-or even greater than-than receiving it.[66,37] The health benefits of extending support to others are especially pronounced among the elderly, who often have fewer opportunities to contribute to others' well-being.

These programs pair patients who have similar disease severity and who face similar self-management challenges. Both patients receive some training in peer communication skills to support each other. After an initial nurse-led group session and training in peer communication skills, participants are asked to contact their partners weekly using a toll-free IVR phone system that protects their anonymity and provides automated reminders if contacts are not made.

The pilot studies underpinning these trials found high levels of participation in and satisfaction with the program.[67] Participants reported that discussing mutual health concerns with a peer partner increased their motivation and confidence in caring for their own chronic conditions and that they found meaning and positive reinforcement in trying to support their partner's self-management efforts. As one participant in the diabetes pilot noted after the pilot period:

> A lot of old people with diabetes like us sit around at home and look out the window. We feel sick and pretty useless. I learned things I could be doing to take care of my diabetes from [my peer partner]. But I also felt that I helped him. I enjoyed talking to him on the phone, and it made me feel inspired to do more.

These pilots suggest that IVR-facilitated peer support is a promising approach that deserves further investigation in conjunction with other chronic disease self-management support strategies.

VIII. Web- and Email-Based Programs

Description

LIKE TELEPHONE SUPPORT, WEB- AND EMAIL-based support can overcome the problem some patients have with face-to-face contact. Over the past decade, there has been significant growth in Internet-based support groups and other uses of the Internet to mobilize peer support. Internet-based interventions are promising because of their low cost and ease of dissemination, and they may provide alternatives to more labor- and resource-intensive clinic programs. Whereas traditional chronic disease support has been enhanced through face-to-face medical care, education programs, and support groups, Internet technology makes it possible to continue this tradition of supportive interaction in conjunction with information and education in a way that transcends the clinic environment.

Internet programs have been developed for diabetes education and self-management support,[68,69,70] for delivering a behavioral weight-loss program, and for individuals at risk of type 2 diabetes.

Preliminary evidence on the impact of Internet programs is promising. A recent study showed that individuals who used an e-Diets Web site more frequently lost more weight than those who rarely used the system.[71]

Results of several recent randomized controlled trials suggest that adding peer support components (sometimes called "e-community" components) to Internet-based interventions can increase their effectiveness.[72] For example, one recent study[72] compared the effects of an Internet weight-loss program alone (providing a tutorial on weight loss, a new tip and link each week, and a directory of selected Internet weight-loss resources) to the same program with the addition of behavioral counseling via email with a weight-loss counselor. Both groups received one face-to-face counseling session and the same core Internet program. During the first month of the program, however, participants in the e-counseling group submitted to the counselor daily diaries of their calorie and fat intake, exercise energy expenditure, and any comments or questions, and the counselor emailed participants five times per week. After the first month, the e-counseling participants submitted daily or weekly diaries, and the counselor sent weekly emails for the remainder of the program. Counselor emails provided

feedback on the self-monitoring record, reinforcement, recommendations for changes, answers to questions, and general support. The behavioral e-counseling group lost more mean weight at 12 months than the basic Internet group and had greater decreases in percentage of initial body weight (4.8 percent vs. 2.2 percent), body mass index, and waist circumference.

Another study showed that membership in a moderated email discussion group for patients with low back pain resulted in improvements in pain, disability, role function, and health distress as well as improvements in self-efficacy.[73] Similarly, several studies have found that individuals with chronic diseases and their family members find Internet discussion groups a useful mechanism for finding emotional support.[59,74]

Based on such promising findings, several health systems have begun to integrate Internet-based programs as a technological extension of their ongoing support programs for patients managing chronic conditions. Internet programs studied so far often combine several elements:

- Disease-specific information and resources (for example, decision-making aids and a library of information);

- Access to self-management personal coaches and health experts; and

- Peer social support resources such as facilitated or professionally monitored online support groups, email, chat rooms, or professionally moderated Internet discussion groups.

Because of liability concerns, a program sponsored by a health plan should use health care professionals to moderate the program. These moderators review postings, reply to direct questions from participants, or correct faulty information posted by participants on message boards. Moderators can also step in if exchanges become hostile or insulting.

These are some benefits of Internet-based programs:

- They are more convenient to participate in than in-person interventions.

- Participants can take comfort in the anonymity of the group.

- The faceless quality of Internet-based interventions allows participants to be valued for the strength of their contributions rather than physical appearance or disabilities.

- Internet-based programs are not limited by a local community's size, geography, or social services.

- These programs give people with chronic conditions a choice of delivery modes and may therefore reach more people than in-person programs.

- Patients who cannot or will not attend a small-group or other face-to-face program can participate in an Internet-based program.

- As computers and the Internet become more accessible, this form of education becomes available to a larger population.

- These programs can give a public face to health institutions and therefore enhance an institution's public image, encouraging people to receive treatment and other services.

Despite all of the benefits, this type of intervention has some weaknesses, the most obvious of which is that an Internet-based intervention is necessarily limited to those who are computer literate and who have access to the Internet. Still, some studies suggest that older adults and novice computer users will participate in such programs after they receive some basic training and orientation. Moreover, little is known about the risks and benefits of professional moderation as opposed to no moderation, or about what degree of professional moderation is best. Use of professional moderators may be expensive for individual health care programs.

There are many other unanswered questions about Internet support programs. Can health improvements be maintained over time through online support? Are people who seek help online different from those who seek help in person? Can virtual communities replace or complement face-to-face support? How can these online health care services best complement and be integrated into existing health care delivery?

Although research suggests that tailored, personal contact (whether with professionals or peers) leads to significantly better results than an Internet program on its own, the appropriate mix is still not known. Current evaluations of existing Internet programs are addressing many of these questions.

In designing or adapting Internet programs to meet the needs of individual health care facilities, the following questions must be addressed:

- Who is the target audience? What are this group's needs? What is feasible to offer this group?

- What is the optimal use of Internet communications to promote the targeted health behaviors?

- How interactive does the system need to be? Could an expert system providing automated feedback contingent on predetermined criteria produce desired changes?

- What is the optimal combination of Internet and face-to-face techniques?

- From a health plan perspective, programs may need to provide additional safeguards to confidentiality in receiving email counseling beyond just advising participants of the risks to confidentiality. What safeguards—such as encrypted email, an email anonymizer, or password-restricted access to a database in which messages are stored—need to be included in the program?

Costs and Reimbursement

The main expenses for these programs are the start-up costs of purchasing software, purchasing a server to hold it, and developing the program. Programs that use professional moderators will have to pay for their time. One way to offset some of these costs is to outsource development and implementation of an Internet program to a company that specializes in such things. For health systems that choose to outsource in this way, it is important to delineate expected outcomes in the contract. Service agreements should be structured so that the vendor assumes some financial risk for achieving defined program goals.

Case Studies

The Joslin Diabetes Center in 1998 established Internet discussion boards (www.joslin.org) for patients with diabetes and their family members. The boards are a technological extension of traditional support groups. The site gives people

with diabetes a place to communicate with each other. Professionals moderate the site, making sure that the content is accurate and appropriate, offering the latest diabetes self-management information and addressing individual questions. Users can read or post messages, ask questions of another user or the moderator, or respond to another person's message. The goal is to have the online experience be comfortable, easy to navigate, and fit into the larger clinic site. Boards focus on diabetes self-care, support for family members, and nutrition. For 74 months, from 1998 to 2004, John Zrebiec tracked the activity and characteristics of user visits to the site and conducted a survey of user satisfaction. Of 791 survey respondents, 74 percent rated participation in the discussion board as having a positive effect on coping with diabetes, and 71 percent rated participation as helping them to feel "more hopeful" or "a lot more hopeful" about coping with diabetes.[59] In the eight years of the program, only one participant has been electronically blocked from attending, and there have been few instances when the moderator has had to step in to manage hostile exchanges. The Joslin program, which has three moderators and a Webmaster, now costs $20,000 to $40,000 a year to maintain.

In a recent intervention, Lorig and colleagues developed an Internet version of their Chronic Disease Self-Management Program (CDSMP) that they hypothesize will be less expensive than yet as effective as the small face-to-face groups. Patients participate in the Internet program in groups of 25, and each group has two moderators. New content is introduced every week for six weeks. People can log on any time they want and post problems on bulletin boards. Participants can engage in problem solving and action planning via bulletin boards. There is also space where people can talk to each other and email each other within a secure program, and the site contains links to other useful Web sites.

The program includes password-protected, interactive Web-based instruction, Web-based bulletin board discussion groups, and a book about living with a chronic condition. The course has similar content to the CDSM program. Two trained peer moderators take part in each workshop and help participants by reminding them to log on, modeling action planning and problem solving, offering encouragement, and posting to the bulletin boards. They also monitor the daily posts of all participants and report inappropriate posts to the investigators. Moderators do not deliver content; this material is already on the Web site.

Lorig and colleagues recently completed a randomized controlled evaluation of the program.[75] Each week for six weeks, participants (about 25 per workshop) who had heart disease, chronic lung disease, or type 2 diabetes were asked to log on at least three times for a total of one to two hours and to participate in the activities for that week. These activities included reading the week's content on Web pages (new content is posted each week), posting an action plan on the bulletin board, checking in with a buddy via email, and participating in any self-tests and activities. In addition, participants could post concerns on the bulletin board. The moderators and other members could respond. The Internet program closely mirrors the original small-group self-management training program, except that it does not require real-time attendance and uses email reminders to encourage participation. After 12 months, intervention participants had significantly improved levels of health distress, fatigue, pain, and shortness of breath. Increases in self-efficacy at six months were significantly associated with improved levels of pain, shortness of breath, fatigue, disability, illness intrusiveness, health distress, and global general health. Improvements in the online group were similar to those achieved in the face-to-face groups.

IX. Conclusions and Recommendations

A RANGE OF POTENTIALLY EFFECTIVE MODELS is available to enhance peer support for chronic disease self-management. This report provides an introduction to some of these models. The unifying feature of these programs is that they seek to build on the strengths, knowledge, and experience that peers can offer. Peer support interventions can effectively extend scarce health system and personnel resources and provide significant benefits both to peer workers/volunteers and to patients. Peer support interventions provide follow-up contact with patients after a clinic visit and increase self-management support between scheduled clinic visits. Although some of the models presented in this report are hierarchical in that a peer reaches out to assist other patients with chronic diseases, there is also growing evidence for the benefits of reciprocal models in which peers both receive and extend support to each other.

To be successful, peer support interventions need to be well-designed with clear and realistic program goals, adequate training and support for peers, clear evaluation benchmarks, and sufficient overall organizational support for the program. Health systems should consider these recommendations before implementing a peer support intervention:

- Peer workers/volunteers must receive appropriate initial and ongoing training in content, principles of behavioral counseling, and communication skills.

- The program must give peer workers/volunteers appropriate support, feedback, and recognition for their efforts.

- Peer support interventions must receive sufficient material and logistical support from the sponsoring organization's professional staff.

- The professional staff must be responsible for program supervision, monitoring, evaluation, and handling of all overall logistics.

- Program expectations and goals need to match the extent of formal support provided to the program and to the peer workers/volunteers.

- Clear procedures for recruiting peers and identifying and reaching target populations for peer services need to be clearly delineated and put in place.

- A health system's administrative and clinical staff needs to accept the program from the beginning, understand and support program objectives, and know the ways in which they are expected to support the program.

- The health system must explicitly consider ways that peer support interventions can complement and extend other clinical services and outreach, such as nurse case management and structured self-management training and education.

- The health system should consider using several methods in peer support interventions, with combinations of face-to-face and telephone contact, as well as Web- and email-based approaches.

- There need to be concrete ways to evaluate the program's use (for example, number and type of peer contacts) and effectiveness (for example, participant satisfaction, reported changes in behavior, changes in health markers, and resource use).

Reimbursement Challenges

One major obstacle to the development and implementation of self-management support programs is the lack of resources to reimburse chronic disease programs, especially for the uninsured and underinsured. In California, for example, the Medicaid fee-for-service program has no method for reimbursing diabetes education programs and few payer-covered disease-management programs. Health care systems often have difficulty making the significant up-front financial investments that such programs require, despite growing evidence showing decreased short-term costs associated with improved chronic disease care.[52] Another obstacle is that many patients who could most benefit from disease-management and self-management support programs, particularly among ethnic and racial minority groups, lack medical insurance or are underinsured and face poor access to formal health care systems.

The ultimate cost of caring for patients with chronic diseases who do not receive adequate care is borne by the entire health care system. Effective approaches may be cost-effective and potentially cost-saving if the clinical benefits are sustained over the medium and long term and if significant reductions in disease-related complications are documented. Developing and financing culturally appropriate chronic disease programs designed for racial and ethnic groups at greatest risk is one of the most significant challenges health care systems and policymakers in California and other states face.

Effective Evaluation of Peer Support Programs

As with any health system program, effective evaluation is critically important. Unfortunately, many initiatives such as peer support programs are established without building in effective evaluation benchmarks and processes. In particular, even if health systems lack significant resources for evaluation, the following are essential:

- The program must have clear and measurable goals and objectives.

- The program must train the staff to evaluate success.

- Those implementing the program must understand evaluation principles and practices.

- The program must use targeted and streamlined data collection forms that do not create significant extra burdens on participants' time and that are easy to complete in the face of pressing service obligations.

- The program must have ways to track and evaluate the process of program implementation. Good process data is essential, with evaluations including concrete measures such as number and types of contacts, total numbers of patients served, and other specific benchmarks.

- Program inputs must be linked with program outputs, and specific short-term and intermediate outcomes (for example, changes in relevant patient health measures, resource use, and satisfaction) must be measured.

- The program must have ways to document expenses (costs) and savings (benefits) associated with delivering services.

- Someone must monitor and document the peer support program's relationship with other clinical services.

- Someone must monitor and document staff time and involvement in programs.

Health systems face numerous challenges in improving care and self-management support for the growing numbers of people living with one or more chronic conditions. Peer support interventions build on the crucial recognition that people living with chronic illnesses have a great deal to offer each other: They share knowledge and experience that others, including many health care professionals, often cannot understand. If carefully designed and implemented, peer support interventions can be a very powerful way to help patients with chronic diseases live more successfully with their conditions.

There is still much to learn about components of effective programs, who benefits the most from peer support interventions compared to other types of support programs, and how best to integrate peer support interventions into other clinical and outreach services. The many health systems and other organizations now instituting and evaluating a wide variety of different peer support interventions will contribute to answering these questions over the next decade and lead to improved models of peer support for chronic disease management.

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