Final Contract Report

Patient Self-Management Support Programs: An Evaluation

Prepared for:
Agency for Healthcare Research and Quality
U.S. Department of Health and Human Services
540 Gaither Road
Rockville, MD 20850
www.ahrq.gov

Contract No. 282-00-0005

Prepared by:
RAND Health
Santa Monica, CA

Marjorie L. Pearson, PhD, MSHS
Soeren Mattke, MD, DSc
Rebecca Shaw, MA
M. Susan Ridgely, JD
Shelley H. Wiseman, BA

Acknowledgments

The authors acknowledge and thank the following individuals who participated in interviews for this report. We are grateful for the time, knowledge, and expertise on self-management support programs that they so generously shared.

Contents

Appendixes

Figure

Tables

Patient Self-Management Support Programs: An Evaluation

Summary

Managing a chronic illness is a time consuming and complex process. Yet, often it is chronically ill patients themselves who are called on to manage the broad array of factors that contribute to their health. Individuals with diabetes, for example, provide close to 95 percent of their own care. Common sense suggests—and health care experts agree—that the chronically ill should receive support to help them manage their illnesses as effectively as possible.

Programs that provide this support—so-called "self-management support"—have been developed in recognition that treating chronic illness requires a new model of care. In 2003, the Institute of Medicine defined self-management support as "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support." Self-management support programs are expected to reduce costly health crises and improve health outcomes for chronically ill patients with conditions such as asthma, cardiovascular disease, depression, diabetes, heart failure, and migraine headaches.

Many policymakers, providers, insurers, employers, and payers such as Medicaid are enthusiastic about the new model. But a limited evidence base related to these programs translates into uncertainty about programming features and wide variation in the way they are designed, delivered, and evaluated. This situation is challenging for providers who are developing funding announcements for programs, negotiating contracts with program vendors, or planning or managing their own self-management support programs.

The Agency for Healthcare Research and Quality (AHRQ) commissioned this report to identify and examine the factors that purchasers and builders of programs should consider when they are deciding on program components. The report was prepared for AHRQ by the RAND Corporation. The authors conducted a literature review and interviews with self-management support experts to identify and evaluate the range of program models and their features. They also identified measures that are used to judge the effectiveness and efficiency of the programs. Key findings and recommendations for developing a self-management support program are discussed here.

Self-Management Support Programs Aim to Change Patient Behavior

Self-management support programs assume a complex sequence of effects. Developers expect these programs to change patients' behavior by increasing the patients' self-efficacy and knowledge. Improved behavior is expected to lead to better disease control which should, in turn, lead to better patient outcomes and reduced utilization of health care services, particularly preventable emergency room visits and hospitalizations, and ultimately to reduced costs.

This sequence of assumptions gives self-management support programs multiple objectives and multiple endpoints for evaluation. The pivotal objective, however, is to change people's behavior.

Basic Models Will Differ According to Program Position

An initial step in choosing or building a self-management support program is to decide where in the health care system the program will be positioned. Will it be managed and administered within the patient's primary care setting or external to it? This distinction often has important ramifications for the degree to which the self-management support is integrated with other aspects of the patient's chronic care and thus who the players are, the quantity and kind of data available to support it, and the nature of administrative oversight and support.

Where a program is located may depend to some extent on where in the health care system the purchaser or developer is located. A health plan or employer whose eligible population is thinly spread across numerous independent primary care settings might well consider an external model for practical reasons. A medical group or independent delivery system is likely to have more options for organizing the self-management support program either within or outside the primary care setting.

Programs Should Provide Both Coaching and Patient Education

Other decisions about the program will pertain to factors such as:

- Staffing.
- Content of the support.
- Patient population served.
- Information support.
- Protocols for how staff members are to provide the support.
- Staff training.
- Communication with patients.
- Communication between primary care physicians and self-management support staff.

For a program that seeks to change patient behavior, a key underlying consideration is the need to include both supportive coaching interventions and educational interventions as part of the program content. While patient education is necessary, it alone is not sufficient. Rather than being prescriptive or hierarchical, coaching interventions should be patient-centered and tailored to the needs and concerns defined by the patient and his or her situation. As coaches, the care managers therefore must have timely access to information on patients' behaviors, priorities, skills, and needs. In addition to information, they may need to provide such support as skills training, collaborative decisionmaking and goal setting, problem solving, motivation and confidence building, reinforcement, and followup.

Staffing decisions should take into account the need for coaches who have the psychosocial skills to facilitate a patient's change in behavior, as well as teaching skills. The information a coach needs for an educational intervention may be disease-specific, but the core skill set needed for

coaching may be the same no matter what the disease or condition. Providers and program developers might consider differentiating the self-management support tasks and looking for people with different skills for different tasks.

Training and protocols for the care managers are important program components. Training is especially important since many coaching skills are not taught in professional schools such as nursing schools. Protocols bring consistency to the way the program is delivered, provide a structure within which care managers can apply their coaching skills, and enhance the managers' training.

Measures Are Needed to Evaluate the Success of the Program

The measures used to assess the success of the program should align with the goals of the program. If the pivotal objective of self-management support is to help patients change their behavior and manage their disease, then evaluation should start with measures of patients' behavior changes. For example, whether or not patients comply with their medication regimen is a better indicator of a program's success than whether a physician prescribes medication, since a change in provider behavior usually is not the primary objective of self-management support. In addition, measuring only patient visits to the hospital or the costs of various aspects of patient care would be overly narrow, especially in the short term.

Likewise, the measurement timeframe needs to match the timeframe in which the self-management support objectives can be attained. Some changes happen sooner, some later. For example, patient self-efficacy and behavior need to change before reduced hospitalizations and costs can be realized. To evaluate the success of a program based on hospitalizations and costs before evaluating and improving patient self-efficacy and behavior might result in premature and unnecessarily negative results. Match measurement to the time course in which change is happening, with longer, realistic time allowances for the long-term outcomes.

The best approach is a portfolio of measures that address the different, sequential objectives of self-management support. This approach should include measures of whether patients get better at managing their disease and allow sufficient time to assess if patients' changed behaviors lead to the hoped-for long-term outcomes.

Finally, it is important to carefully consider the potential for bias when selecting measures of patients' changed behavior. Whenever possible, rely on information that is directly available from an objective source (e.g., pharmacy records) rather than a patient's own report. When it is necessary to rely on patient self-report, try to avoid collecting this information through the coaches (some patients may exaggerate their good behavior in an effort to please their coaches) or only from those who agreed to participate in the program (to avoid selection bias).

Looking Ahead

The research evidence base for the design of self-management support programs and their evaluation is very limited, and more and better research in most of the areas discussed above is sorely needed. Further research will provide critical guidance to those who are struggling to design optimal self-management support programs, to change behavior, and to improve the health of the chronically ill.

Patient Self-Management Support Programs: An Evaluation

Introduction and Purpose

Chronic illnesses require ongoing attention that differs from traditional, encounter-based care for acute illnesses. Patients with chronic illnesses such as asthma, cardiovascular disease, depression, diabetes, heart failure, and migraine headaches play a central role in managing the broad array of factors that contribute to their health. Individuals with diabetes, for example, provide close to 95 percent of their own care.[1] It makes sense, then, that one way to improve health outcomes for individuals with chronic illness is to provide them with the support they need to manage their illnesses effectively. Indeed, given that the health care system is overburdened and clinician time is limited, some experts regard patient self-management as the only arena where there is available capacity within the U.S. health care system for improving quality of care and reducing costs.

Many "self-management support" programs have been developed in recognition that treating chronic illness requires a new model of care. These programs are intended to prevent the costly health crises (for example, trips to the emergency room) that result from poor management of chronic conditions and to improve long-term outcomes for patients. Recent reviews suggest that self-management support can improve outcomes for different chronic conditions, but much remains to be learned about the relative effectiveness of specific program components. There is little information available to those who are interested in implementing or purchasing such programs to help them decide how to design or structure their programs. Similarly, evaluating program success is complex, and there is little guidance for choosing a set of measures that can reasonably assess whether the program is accomplishing what it was designed to do.

The purpose of this report is to present a number of key considerations for developers and purchasers of programs to take into account when deciding on program components. We examined the current state of patient self-management support programs, including what is known about the programs and what remains unknown. We reviewed relevant research literature and interviewed individuals who have knowledge of self-management support programs.

This report describes the variety of commercial and "home grown" self-management support programs used by health plans, insurers, employers, public providers, and payers such as Medicaid to improve the quality of care for patients with chronic diseases. The goal is to:

- Identify how self-management support programs are structured and describe the most common models and basic features of the programs. Four basic models and specific examples of each are described.
- Outline the choices faced by developers and providers of the programs.
- Identify measures that are used both in research and by existing programs to evaluate the effectiveness and efficiency of self-management support programs.

- Suggest research priorities to both develop the empirical basis for self-management support programs and to assist program sponsors in making program design decisions.

Better understanding of programming options and program evaluation measures should help those implementing or purchasing self-management support programs to better choose components that are appropriate to their goals and to better evaluate the impact of these programs.

Background

Patients with Chronic Illness Could Use Some Help

Managing a chronic illness is time consuming, complex, and difficult. Self-management involves "the tasks that individuals must undertake to live well with one or more chronic conditions. These tasks include having the confidence to deal with medical management, role management, and emotional management of their conditions".[2] Individuals with chronic illnesses may be asked to:

- Closely monitor symptoms.
- Respond with appropriate actions (adjust medications, initiate call to a health care coach, schedule a doctor visit) when symptom levels indicate a problem.
- Make major lifestyle changes (e.g., stop smoking, reduce alcohol consumption, modify diet, lose weight, and increase exercise).
- Adhere to medication regimens, some of which are inconvenient or produce side effects.
- Make office visits for lab tests, physical exams, and clinician consultations.
- Patients often have difficulty performing these tasks. For example, patients with diabetes should monitor their blood glucose regularly, but only 60 percent of patients report that they self-monitor their blood glucose at least once per day.[3]

Self-Management Support Is More than Patient Education

Most individuals need help and encouragement to actively participate in their care and successfully perform a variety of tasks. So-called "self-management support" is "the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem-solving support."[4]

Although in the early days, diabetes self-management support primarily focused on providing information, subsequent research demonstrated that these educational interventions affected patients' knowledge but not their self-care behavior. Patient knowledge came to be seen as a necessary but not a sufficient contributor to behavior change.[5] It was found that behavior related to self-management was affected by numerous other factors such as social support, motivation, environmental obstacles, emotional adjustment to diagnosis, self-management skills, self-efficacy, and whether there was followup with the patient to answer any questions or address obstacles that got in the way of the patient's self care.

Today, the emphases of self-management support programs have moved away from pedagogical education with educational content defined by health care professionals to an individualized approach that addresses needs and concerns defined by the patient and his or her situation. Patients may interact with a nurse, social worker, or other professional for some of their treatment rather than relying solely on a physician. The interaction is likely to include a strong element of coaching, with the goal of educating and empowering the patient and increasing his or her self-efficacy for self-management behaviors.

Most programs draw on psychological models of behavior change related to persuasion, skills training, provision of information, stages of change, behavior modeling, goal setting, and problem solving around barriers and difficulties. Such models include Social Cognitive Theory with its focus on self-efficacy[6]; the Transtheoretical Model[7,8]; the Health Belief Model[9]; the Locus of Control Theory[10]; and Personal Models.[11,12,13]

Self-Management Support Has Strong Advocates

Self-management support is strongly emphasized by the Chronic Care Model, a framework for re-engineering chronic care delivery systems proposed by Wagner and colleagues at the MacColl Institute for Healthcare Innovation.[14,15,16,17] The underlying principle of the Chronic Care Model is that improved outcomes will result from more productive interactions between informed, engaged patients and prepared, proactive, practice teams. Enhancements in self-management support—bolstered by information support, delivery system redesign, decision support, links with community services, and health system support—constitute a core feature of the Chronic Care Model.

Existing disease management programs include a strong emphasis on self-management support as well. The Disease Management Association of America includes as one of six necessary disease management components "patient self-management education (may include primary prevention, behavior modification programs, and compliance/ surveillance)."[18]

Self-Management Support Can Improve Patient Outcomes and Control Costs

The current enthusiasm for self-management support is based on a number of arguments, but chief among them are that it improves patient outcomes and reduces, or at least controls, costs.

Evidence is emerging that self-management support programs improve a variety of outcomes for different chronic conditions.[19,20,21,22,23,24,25,26,27,28] See Appendix 1 for a bibliography of recent reviews of the research in this area. Data also show that the patient's sense of engagement and self-efficacy are strong predictors of outcomes.[29] Quality improvement interventions that have attempted to improve the outcomes of chronic care without a component that supports patient self-management have not been found to affect patient outcomes.[30] Many view self-management support as inherent to good care processes. The inclusion of recommendations for self-management support in a number of guidelines solidifies self-management support as a key dimension of chronic care quality. Institutionalization of clinical practice guidelines, quality

reporting, and pay-for-performance programs encourage the provision of self-management support.

Another goal of self-management support programs is to reduce health care costs and workplace costs related to the reduced productivity of chronically ill workers. Offering patients better support will help them stay healthier, prevent expensive exacerbations and complications, and decrease utilization of health care services, thereby reducing costs for providers, insurers, employers, and other large purchasers of health care services, as well as for the patients themselves. Similarly, some view self-management support as a feasible approach to managing the workplace productivity of chronically ill workers by reducing absenteeism (absence from work) and presenteeism (reduced performance at work).

Figure 1 illustrates how a self-management support program may affect both quality of care and costs. The structure of the program and the support processes provided (A and B) influence the patient's ability and motivation to improve his or her own care (C), which affect his or her behavior (D1). The provider may react to the patient's behavior by improving his or her own behavior (D2). As the patient and provider change their behaviors, the patient's disease likely will be better controlled (E). The patient will have fewer exacerbations and make fewer trips to the emergency room or hospital. Many patients will be healthier as well (F), with increased productivity and decreased utilization of medical services (G). A healthier patient more in control of his or her chronic condition, leading a more productive life and using health care services less, results in cost savings (H and I).

Figure 1. Chain of self-management support effect

8
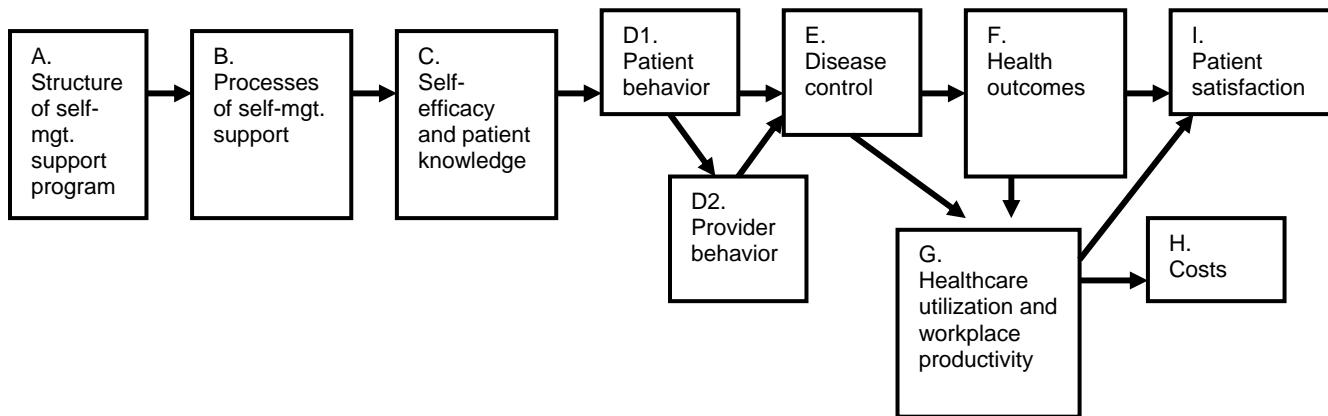
Much Remains To Be Learned About the Effectiveness of Program Components

Evidence on the effectiveness of specific self-management support program components is still sparse and diverse. Appendix 1 includes reviews of specific components of self-management support. They provide some evidence for the greater effectiveness of specific diabetes program components such as self-monitoring of blood glucose,[31] patient collaboration, regular reinforcement, additional contact time between the diabetes educator and the patient, computer-assisted patient education,[32] and group-based education.[33] Asthma reviews suggest that the self-management support programs that were most effective utilized written action plans (individualized plans for self-management), self-monitoring by patients, and interventions customized to the individual patient. The reviews' findings on the effectiveness of asthma action plans were not consistent,[27,34] but action plans were found to have a positive effect on the knowledge and self-care behavior of people with chronic obstructive pulmonary disease.[35] A quantitative review of computer-based interactive health communication applications found evidence for their effectiveness.[36]

A meta-analysis of self-management support programs for older adults investigated whether self-management support programs with specific program characteristics were more effective than self-management support programs without these characteristics. The program characteristics examined included tailoring of interventions to patients' specific circumstances, group setting, feedback to patients, psychological emphasis, and medical care (receiving the self-management support intervention directly from a physician or primary care clinician). While across-condition analysis suggested a trend towards increased benefit of programs with these features, the differences were not statistically significant. The authors discussed their findings as follows:

> We found sufficient evidence to conclude that chronic disease self-management programs for older adults probably result in clinically and statistically significant improvements in blood glucose control and blood pressure control, although this evidence is tempered by our findings of possible publication bias for these two outcomes. However, supporters of chronic disease self-management programs need to acknowledge that the evidence base regarding the necessary components of such programs is very thin, which limits the ability to design programs for maximal effectiveness and cost-effectiveness.

Methodology

To supplement a limited evidence base, we examined the variation in the current state of self-management programs to better understand the programming options currently in use. We did so by reviewing the recent literature on existing programs and interviewing a diverse group of key experts in the field.

Literature Review

We conducted a systematic literature search of multiple bibliographic databases, including MEDLINE, Cinahl, and the New York Academy of Medicine (NYAM) Grey Literature Collection, Sociological Abstracts, and Social Services Abstracts. Search terms included "self-

management," "disease management," "chronic care management," "self-efficacy," "self-care," "telehealth," "telemonitor," "telemedicine," *and* "chronic disease," "chronic illness," "high risk obstetrics or pregnancy," "diabetes," "asthma," "health failure," "depression," "depressive disorder," *and* "program" *and* "support." We limited the search to English-language articles published in the last 5 years and studies conducted in the United States.

The search netted approximately 900 citations, which were screened first by topic and then by abstract and full review. To be included in our study, articles had to provide information on self-management support program design in real-world settings or describe evaluation measures used in real-world programs or in research on such programs. Reviews of the effectiveness of self-management support interventions were examined for the purpose of gathering background information; 80 articles met these inclusion criteria. From these studies, we abstracted information on the research design, self-management support program or intervention features, evaluation measures, and study setting and population.[a]

Interviews with Self-Management Support Experts

We interviewed 44 people knowledgeable about self-management support programs provided through health plans, insurers, employers, public providers, and payers. To produce a list of initial interviewees, we turned to our existing network of experts in the area of chronic disease self-management support, contacts from the 2005 Disease Management Leadership Forum, and the annual lists of DMAA awards for program performance in the field of disease management.[37] A "snowball" approach was used to expand this group of interviewees with additional experts identified either in the initial interviews or through the literature review. We identified 55 people as potential interviewees; 44 consented to be interviewed.

We developed a comprehensive interview guide from which we selected items appropriate to each interviewee's expertise. The interview guide was structured to address the multiple domains of self-management support programming choices. Interviewees were recruited by email and interviewed by telephone. Each interview lasted approximately 60 minutes and was conducted by a two-person team consisting of an investigator and a research associate. The RAND Human Subjects Protection Committee approved the recruitment and consent procedures, interview guide, and data safeguarding procedures. Web site searches, articles identified in the literature review, and materials obtained from interviewees were used to supplement the interview data.

Design Options for a Self-Management Support Program

In both the literature and interviews, we found wide variation in the design of current programs. In particular, programs vary with respect to:

- The location of the program within the health care system; i.e., what entity offers the service and manages it.
- The extent to which the program is provided through personal interaction between coaches and patients.

---

[a] The form used to abstract these data is available from the author on request: mpearson@rand.org.

- Staffing.
- Content of the support.
- Patient population served.
- Information support.
- Protocols for how staff is to provide the support.
- Staff training.
- In what manner and how often coaches communicate with patients.
- Nature of the communication between primary care physicians and self-management support staff.

These factors are discussed in more detail below. The programs also vary in terms of the performance measures used. Program evaluation is discussed in the main section that follows.

Program Location and Extent of Personal Interaction Between Coaches and Patients

Programs vary with respect to:

- Where they are located within the health care system; i.e., who has responsibility and authority for their day-to-day operations.
- Whether or not self-management support is provided through some form of personal interaction.

Some programs are located within primary care practices, some are run by other health care organizations such as plans or hospitals, and others are run by commercial vendors. For purposes of this discussion, we will distinguish between those programs that are located within the primary care setting and are under the responsibility of the local provider (e.g., physician group or clinic) and those that are located outside of the local setting (e.g., through a plan or commercial vendor or centralized within an independent delivery system).

In addition, some programs include telephone contact or face-to-face contact but are distinguished from programs that rely entirely on technology or written materials without any person-to-person interface. Personal interaction may be further characterized by whether it involves face-to-face meetings or relies on contact by telephone or computer.

These first two factors combine to create four models of self-management support delivery most frequently seen in the United States today. The four models are summarized in Table 1 and described further below.

Table 1. Four models of self-management support

		Extent of personal interaction between patient and coach and physician		
		Face-to-face	*By telephone*	*None*
Position of program within the health care system	**Responsibility of patient's primary care provider**	1. Internal, primary care model		
	Positioned outside of patient's primary care setting	2. External "on-the-ground" model	3. External call-center model	4. Remote model

Primary care model. In the primary care model, self-management support is usually provided directly by local providers' offices and usually includes face-to-face contact in the primary care office setting. The patient may be referred to additional self-management support resources. Action plans are often used as tools for collaborative goal setting, patient activation, and communication, and clinicians have ready access to patients' self-management assessments and goals. Group sessions (group visits, classes, support groups) can be offered in these local settings. The coaches may work on teams with clinicians.

Current database and information technology constraints in many primary care practices may limit the availability of patient information to support the self-management support coaches' decisions. Program objectives are more likely to be framed in terms of quality rather than return on investment. The development of primary care, office-based mechanisms for self-management support frequently occurs as part of efforts to implement the Chronic Care Model in primary care practices. These programs are initiated by the local, primary care practice (or by the delivery system of which the local practice is a part). Plans, employers, and other payers can use contracting mechanisms or possibly incentives, such as pay-for-performance, to encourage this local self-management support programming, but they usually do not purchase it directly. An example of a real-life primary care model is described in the following box.

External on-the-ground and external call center models. In contrast to primary care model programs, programs in the external on-the-ground and external call-center models are managed from outside the local primary care setting and are likely to be referred to as "disease management" programs. Such programs differ from each other in the nature and degree of personal interaction between the self-management support staff and the patient.

In the external on-the-ground model, self-management support is provided by an organizational entity external to the local provider and usually outside of the primary care setting. The support generally is more intensive than in the other models and involves face-to-face and telephone interaction. The coaches have their "boots on the ground" in that they may go to where the patients are, providing support in homes, primary care offices, and community settings. More medical care management and coordination may be provided. This model usually uses large electronic databases, allowing identification of full populations with given diagnoses and often patient-specific data on visit and prescription utilization to guide self-management support interactions. Although outreach and some self-management support, such as written materials, an educational Web site, or possibly a hotline or call-in number, may be offered to everyone identified with the diagnosis, only a defined subset of the patients receive the services of the health coach. Program objectives are likely to be framed in terms of return on investment and quality improvement. External call-center programs may be developed internally in plans and independent delivery systems or purchased from vendors by plans, independent delivery systems, employers, or government payers. Purchasers of health care also can use contracting mechanisms to obtain such services. The box below presents an example of this model.

Example of an External on-the-Ground Model

An example of an external on-the-ground program is a diabetes disease management program developed and run by an independent delivery system. During the period under study, the program employed 51 RNs as primary care nurse educators and case managers. Each nurse was responsible for 1-15 primary care sites. The nurses provided self-management support at the primary care clinic in one-on-one encounters or in group sessions. A nurse saw each patient from one to four times, depending on disease severity and patient and physician preference. Self-management education focused on "the appropriate use of a glucose meter, the role of diet and exercise, the importance of HbA1c testing, medication management, the management of hypoglycemia, and teaming closely with physicians in the use of staged diabetes management clinical guidelines to achieve optimum blood glucose control." The nurses documented every encounter in the patient's medical record, and physicians were asked to review and co-sign the entries. Each nurse also collected information from the patient and the medical record for entry into a registry. This support was part of a larger disease management program that also included nurse promotion of diabetes clinical practice guidelines in their day-to-day interactions with patients and physicians, specialty clinic referrals, and CME sessions.[38,59]

External call center model. In this model, self-management support is provided under the authority of an organizational entity external to the local provider and usually outside of the primary care setting. Self-management support is provided by phone from a centralized call center, rather than through face-to-face interaction. The self-management support provider, usually a commercial vendor or an independent system or plan, is external to the local health care provider, and communication with the patient's primary care clinician varies. In most other respects, this model is similar to the external on-the-ground model. Self-management support staff have access to large databases. All identified patients may be offered some form of support, but only a small subset receives personal coaching or support. In some cases, calls may also be "inbound"—that is, patients may call the center. A high return on investment is an important objective for the program sponsor. Such programs are usually offered at the initiative of a large payer and are purchased from a vendor (see the following box for an example of this model).

Example of an External Call-Center Model

This external call-center program was established by a health plan and a disease management vendor to offer self-management support to the plan's members. Members with asthma are identified through claims data and provider referrals. All individuals identified are given immunization reminders and educational materials. Claims data are used to identify a high-risk subset of members defined by recent emergency room utilization or inpatient admissions for asthma. This subset is offered the vendor's telephone support program on an opt-out basis. These services include 24-hour access to telephone consultation with a registered nurse, as well as an initial assessment by the nurse, an individualized care plan, regularly scheduled monitoring for early signs of problems, and assessment of asthma-related knowledge, behavior, and health status. According to an article reporting research on this program, the registered nurses were employed by the disease management organization, averaged more than 20 years of experience in health care, and received specialized training focused on one or more chronic diseases. The program was described as based on the National Heart, Lung, and Blood Institute's clinical practice guidelines for asthma and emphasizes "teaching appropriate self-management behavior that includes the avoidance of triggers; the correct use of medications, inhaler, and peak flow meter; understanding of the signs and symptoms of exacerbations; knowing when to seek medical assistance; smoking cessation; avoidance of secondary smoke; and adherence to treatment plans." The nurses use computerized care manager software that contains standard queries and response sets. Primary care providers are sent a summary of the most current clinical practice guideline and alerts summarizing areas of concern. The disease management organization sends the health plan monthly and quarterly reports of care management measures, such as the percentage of individuals who have an action plan, flu vaccinations, a rescue inhaler, and who use daily controller medications.

Remote model. With their person-to-person interactions, the primary care, external, on-the-ground, and call-center models are the primary focus of this report. However, we mention the remote model to complete the picture of self-management support programs. Programs in the remote model are characterized by use of the Internet and/or electronic databases, scripted content, limited focus, and little feedback from patients. The support is provided via technology (e.g., computer-generated mail or automated phone calls) with no personal interaction. Reflecting their considerably lower cost, these programs usually are offered to the entire identified population, rather than a subset. In employer settings, this model may extend to people identified (often through health risk assessments) as at-risk for disease or complications.

Comparing the models. Key experts in this field identify different strengths and limitations with each of these models. Since care management is the sole focus and core competence of the external programs, self-management support may be better planned and executed than it is in primary care settings where it is only one of a myriad of tasks that need to be accomplished, often within severe time constraints. External program staff have access to large plan or employer databases with claims, pharmacy, and sometimes laboratory data. These data allow external programs to readily identify and reach out to whole populations of patients with specified diagnoses and risks and thereby to offer a population-based framework for self-management support. Often these databases, in combination with technological investments such as predictive modeling software, offer greater economies of scale to external programs.[39] In the case of external programs, patients are identified by their plan membership or employer, rather than their primary health care provider. As the plan or employer is at financial risk for the patients' health care, the external models provide a way for them to target for self-management support those individuals (and only those individuals) for whom they hold risk.

The primary care model differs from the external models primarily with respect to its integration within the primary care practice. This integration offers the possibility for the self-management support staff and the physician to more closely coordinate the self-management support with medical care and to provide support and reinforcement in both directions. Local providers have face-to-face access to patients. Medical records are housed in the practice setting, and self-management support staff there may have direct access to better clinical information (e.g., test results, recorded symptoms, physical findings, and treatment plans), as well as to discussions with clinicians. These data offer extensive decision support to staff for providing and customizing self-management support but are more difficult to use for population identification if electronic medical records are not in use. Practices implementing the chronic care model frequently create and maintain registries (of varying capacities) of populations with specified diagnoses. Without an electronic medical record or registry, self-management support in primary care settings may be limited to patients who present to the office and thus fall short of a population basis. Self-management support in the primary care model is less likely to be focused on a population subset established through predictive modeling.

The fact that the patient populations in the external models usually are defined through health plan membership may make it difficult for local providers to interface with and support the external self-management support efforts. Given that their patients may be covered by many different plans and some of these plans may use different external programs for different

diagnoses, a local provider organization might have 20 or more external programs serving their patients. Some observers argue that care may be further fragmented when employers change health plans and external programs change as a consequence. The primary care model also may allow self-management support staff to be better informed about local community resources and thus encourage better patient utilization of such resources.[40]

A major challenge for the primary care model is the lack of clear-cut mechanisms for primary care practices to be reimbursed for the staff time and other resources needed to provide self-management support. While reimbursement for external self-management support is structured through contractual mechanisms, no similar contract arrangements are currently negotiated with most organizations providing primary care. Current reimbursement mechanisms do not easily accommodate direct reimbursement of primary care staff tasked with self-management support. Local providers, in fact, usually are not reimbursed for many care support services. Moreover, while employer purchasers may use their contracts with plans to obtain self-management support services or purchase such services directly from disease management vendors, they do not contract directly with local physician groups and clinics and thus cannot purchase the primary care model of self-management support directly. Although plans do contract directly with local providers, one plan's contract often covers only a small proportion of the provider's patients.

The tradeoffs between the two external models revolve around the advantage of in-person communication versus the disadvantage of its cost. Proponents of the external on-the-ground model stress the effectiveness of face-to-face interaction in getting people to participate. Arranging settings for face-to-face support and sending health coaches out to the various settings, on the other hand, can be considerably more expensive than a centralized call-center approach. A key consideration in the choice of models is the targeted population, as the higher intensity models are typically only used for high-risk patients.

The primary care, external, and remote models are not necessarily mutually exclusive. It has been suggested that more combinations might be seen in the future. As an example, all of a primary care practice's patients with chronic disease might be encouraged to participate in self-management support sessions offered through the practice, while those needing more support could also receive additional coaching from an external program.

Staffing

Staffing addresses the people who actually provide the support to patients. Within the primary care model, self-management support responsibilities often are delegated to a non-physician member of the staff—such as a nurse or possibly a medical assistant—who can devote more time and attention to self-management support than the physician. But the primary care physician often plays a role as well. An action plan frequently is used to facilitate collaborative decisionmaking between the primary care physician and the patient and to facilitate followup in subsequent primary care visits. In many cases, limited office resources for self-management support are supplemented by referral or collaboration with other resources in the community.

Many external programs staff their call centers with nurse care managers, but the programs differ with respect to the qualifications sought for these positions, seemingly reflecting uncertainty in

16

the field regarding care manager core competencies. While some programs seek nurses with backgrounds in the specific disease—e.g., 2 years in acute care cardiac settings—others stress the importance of interpersonal skills over medical knowledge, i.e., the ability to focus on a patient's goals rather than solely on the disease. Some programs distinguish care management skills (with the focus on coaching and behavior change) from prescriptive educational skills and/or more traditional nursing skills. Others distinguish between generalists and specialists, seeking primary care and "broad rather than deep" backgrounds rather than masters-level nurses. Some emphasize motivational skills and the ability to foster self-efficacy rather than patient dependency. Other attributes include empathy and compassion, as well as computer and telephone communication skills.

A Request for Proposal (RFP) for a self-management support contract may determine staffing levels and qualifications, including whether and how non-nursing staff will be used. Some programs use staff with other backgrounds to help provide self-management support. These include social workers, pharmacists, dieticians, behavioral or mental health specialists, licensed practical nurses, medical assistants, and patient coordinators. Programs may use non-nursing staff in the call centers, along with nursing staff; staff with less medical knowledge focus on tasks such as prompting or "nagging" and transition the call to one of the nurses in the center when a medical care issue arises. Some programs specifically look for people with roots in the community—e.g., nurses who know the community resources, in some cases, and lay health workers or "promotoras,"[b] in others.

Staffing decisions involve a number of tradeoffs. On the one hand, nurses have greater medical knowledge and may be viewed as more acceptable to primary care physicians whose support the programs want to obtain. On the other hand, nurses are expensive and in short supply. Some individuals interviewed for this report also argued that nursing training frequently does not emphasize behavior change interventions. Some characterized nursing education and the nursing profession as hierarchical and prescriptive and questioned whether other backgrounds might not be better suited to work collaboratively with patients. One informant stressed that staffing should be based on an assessment of major problems in the population and areas needing improvement. More than one informant discussed the need or potential for greater specialization in self-management support, differentiating self-management support tasks and looking for people with different skills for different tasks. The argument here is that coaching people on exercise takes different skills than discussing medication side effects; remote self-management support interaction requires different skills than face-to-face self-management support. Staffing levels and qualifications are directly linked to cost issues, and the argument in favor of specialization emphasized the possibility of greater reach for the same amount of investment. Smaller caseloads also are more expensive but are needed for high levels of personal interaction.

Content

The multiple staffing considerations described above reflect the wide variety of tasks that self-management support staff are frequently expected to perform and the variety of services patients may receive. Together, these make up the program content.

---

[b] Promotoras are outreach workers in Hispanic communities who are responsible for raising awareness about health and education issues.

The first column in Table 2 shows the different kinds of content commonly ascribed to self-management support programs. These content areas reflect the dual purpose of most programs: one, to educate people and thereby increase their knowledge, and two, to coach people to change their behavior.

Educational content (at the top of column 1) primarily consists of information on the disease, its treatment, medications, and self-management. Much of the information provided is disease-specific. The second column shows some of the commonly mentioned prerequisites for providing this content:

- Medical knowledge of the disease, its symptoms, treatment, medications, medication side effects, outcomes, medical terminology, and so forth.
- Knowledge of the self-management tasks needed and their benefits.
- Knowledge of the applicable clinical practice guidelines.
- Knowledge of resources that are useful and available.
- Ability and resources to communicate such information so that people will understand it.

Content areas frequently described as needed in order to support and coach people's behavior change are listed under "supportive interventions" in column 1. Much of the specific content of these supportive activities is patient-specific and relies on the results of the assessments. Thorough assessment of multiple factors (i.e., the patient's perceptions, knowledge, motivations, confidence, skills, needs, and goals) is needed to support many of the subsequent tasks. While many of the prerequisites for the educational content are disease-specific, the prerequisites for the supportive interventions tend to be described as a core set of skills applicable across diseases. A common terminology for describing these skills is lacking, but they generally are described as psychosocial skills, including the ability to motivate, persuade, emotionally support, reinforce, build confidence, problem-solve, and work collaboratively. Programs frequently use self-management support protocols, software and information system support, and staff training to promote these skills and tasks.

Programs appear to vary in the relative emphasis they put on these different content areas. Some programs are primarily educational, and information is the main content of the support. While all programs include some education, some programs place considerably more emphasis on supportive interventions directed towards behavior change. Even within these programs, there is variation in the types of supportive interventions. The most notable variation with respect to self-management support content has to do with emphasis on collaborative decisionmaking. Some program interviewees stressed the centrality of collaborative decisionmaking, while others never mentioned it. Where collaborative decisionmaking is key, the program (often through the care management software) is specifically designed to involve the patient in selecting and prioritizing the problems to work on, as well as the intensity and sequencing of the activities. The problem most pressing to the patient, rather than the clinical priority, is addressed. While traditional education alone may emphasize the provider's agenda, patient compliance, and provider decisionmaking, supportive interventions—particularly those involving collaborative goal setting and shared decisionmaking—move health care interactions to a focus on the patient's agenda, the

patient's self-efficacy and confidence in his or her ability to change, and collaborative decisionmaking between patients and providers.[41]

Table 2. Self-management support content and prerequisites for coaches

Content areas	Prerequisites to provide the content
Information on: • The disease and symptoms • Benefits of self-management • Areas needing self-management (diet, physical activity, smoking, environment, medication compliance, etc.) • How to self-manage • Medications and side effects • Resources available	• Medical information on the disease, symptoms, medications, side effects, outcome, medical terminology, etc. • Information on self-management tasks needed and their benefits • Applicable clinical practice guidelines • Information on resources available • Information on the patient's condition, comorbidities, and information needs • Ability and resources to communicate
Supportive interventions: • Assessment of perceptions, motivations, confidence, abilities, needs, and goals related to living well with condition • Building motivation to self-manage (e.g., alter behavior, comply with meds, monitor symptoms, etc.) • Increase confidence and self-efficacy for the specific self-management behaviors needed • Collaboratively define problems and barriers to self-management • Collaboratively set self-management goals • Develop problem-solving skills and help with problem-solving • Provide emotional support • Facilitate stress management • Provide followup regarding reassessment, goals, problem-solving, reinforcement, prompts, and reminders	• Assessment tools and skills • Skills and ability to work collaboratively with patients (garner trust, listen carefully, solicit and accept patient's own priorities) • Psychosocial skills, abilities, and tools to engage patients and enhance motivation, confidence, and self-efficacy • Stress management knowledge and skills • Information and technology to prompt and inform followup • Information on patient's prior goals, problems, needs, knowledge, behavior change successes and failures, meds compliance, and visit compliance • Protocols for synthesizing assessment data into priorities for supportive interventions • Protocols for providing support (for motivating, building confidence, problem solving, setting goals collaboratively, etc.)

Patient Population Served

Who is to receive the self-management support? Most of the primary care model programs target everyone with a specific diagnosis or diagnoses. Some may offer more support to those who are more ill, but predictive modeling is not common. One primary care program, however, is developing a stratification approach, based on patient-reported data, which divides patients with chronic disease into three categories and distributes resources differently to each category. The

strata are defined by patients' financial status, confidence in self-care, and presence of bothersome pain and psychosocial problems.[42]

Within the external models, there is variation in determining who is eligible for self-management support. Most interviewees asserted that their programs were designed to target a subset of a population with a particular diagnosis, but the definition of the subset appeared to differ. A number of interviewees said that their programs focused on those with the highest severity of illness. Still others described their target population in different terms, such as those at highest risk, with greatest potential cost savings, "likely to have the greatest benefit," "whom they can help," "most impactable and engageable," or most receptive to change. Most programs use proprietary algorithms to identify patients with a chronic condition from claims data and employ commercial predictive modeling software to triage patients for services. (Some programs even develop and maintain their own predictive modeling software.) The specific combination of methodology for identifying and triaging patients, however, is considered the "secret sauce" and is said to vary from one program to the next. The proportion of the population that is included in the targeted subset varies too. One informant said that the number of patients selected for personal contact—"how far down the list they go"—depends on the specifications of each contract.

Self-management support programming is customized to the categories identified through predictive modeling. The external programs differ in whether they limit their self-management support services to the subset or provide something to everyone in the identified population but reserve more intensive self-management support for those in the top subset. Programs may offer written materials, Web site access, or possibly one phone contact to those below the threshold. For those above the threshold, the intensity of the outreach, engagement contacts, and coaching contacts may vary with the severity of illness. As an example, an external call-center program for heart failure patient support stratified participants (people identified with heart failure who agreed to enroll) into three categories of high, medium, and low risk. The protocols specified that individuals at high risk were to receive 16 calls per year; patients at medium risk were to receive seven calls, and patients at low risk were to receive two calls.[43]

Patient engagement in the program is generally considered to be a major challenge. External programs usually use phone calls and mailings to get people to participate in the program. Programs differ in the perseverance that is demanded of the outreach staff, most notably in the number of contact attempts. They likewise differ in the speed of engagement. While some programs require participants to "opt-in," others use a more passive "opt-out" approach. Programs also differ in approach. At least one self-management support provider, for example, begins using motivational interviewing techniques during the initial contact to encourage program participation.

Incentives are considered useful for encouraging program participation and increasing self-management effort and activities. Small incentives—such as water bottles, totes, and baby shoes—were mentioned. One informant expressed the opinion that substantial dollar amounts would be needed to have a substantial impact. Employers have begun to offer reductions in health insurance contributions to employees who participate in such programs. Distinct from the self-management support programs, some employers are offering financial incentives to

employees to encourage better medication compliance (e.g., instituting changes in formularies to ensure that critical chronic care drugs are on the least expensive tier and eliminating co-pays for generic drugs).

Information Support

Information databases for self-management support population identification and decision support vary considerably and may be nonexistent in primary care model programs. Registries are a common approach to developing a database and vary from paper-and-pencil versions to sophisticated electronic registries. When registries or electronic databases are missing, the reach of the program may be limited to those seeking care.

In all models, data commonly are collected by interaction with patients (e.g., signs and symptoms of the disease). External model programs, on the other hand, characteristically rely on large electronic databases to identify the target population. Most, if not all, use claims data, which are convenient but frequently limited by inconsistencies in reliability and validity and time lags in reporting. Some access pharmacy records, lab reports, hospital admissions records, health risk assessments, and/or other data as well. These same data may be used for decision support.

As with identification of the eligible population, the data available affect the type and amount of decision support available to the self-management support providers for their interactions with patients. Our interviewees suggested that there is great variation in decision support provided within the external models. While not all programs have computerized decision support, a number of our interviewees stressed the critical importance of utilizing timely patient information in self-management support contacts. Timely access to patient information is one of the factors that distinguish self-management support from traditional didactic education. The kind of patient information used varies and includes:

- Visit, testing, and prescription utilization data that allow reminders and followup of the patient's management of health care processes.
- Clinical data, such as lab results, that are used to guide contact frequency and coaching content.
- Patient assessment data that guide collaborative decisionmaking and problem-solving, motivational interviewing, and other self-management support content.

In some programs, the care managers input patient assessment data into care management software. This, in turn, helps to define and/or prioritize the patient's self-management problems, contributes to the design of a care plan, assists in implementing self-management support activities, and helps to guides reassessment.

Some care managers have access to data from remote monitoring devices, and some have data from electronic medical records. One informant noted that the program shared these care management data with the patient's primary care physician.

Protocols

What are the guidelines for self-management support programs? When asked about protocols, many interviewees referred to clinical practice guidelines, which they see as underlying their self-management support programs. Self-management support programs vary in the degree to which they build on clinical practice guidelines, and for the most part, the clinical guidelines call for self-management support activities such as patient education, but do not fully prescribe how these self-management support activities should be conducted. As an example, the following box presents the sections of the American Diabetes Association (ADA) guidelines that pertain to self-management support. National guideline development efforts have yet to focus on detailed self-management support guidelines.

Self-Management Support Provisions of the American Diabetes Association (ADA) Guidelines

ADA guidelines for diabetes care state that any diabetes management plan:

… should recognize diabetes self-management education (DSME) as an integral component of care… A variety of strategies and techniques should be used to provide adequate education and development of problem-solving skills in the various aspects of diabetes management. Implementation of the management plan requires that each aspect is understood and agreed on by the patient and the care providers and that the goals and treatment plan are reasonable.[44]

The ADA's specific recommendation for DSME follows:
• People with diabetes should receive DSME according to national standards when their diabetes is diagnosed and as needed thereafter.
• DSME should be provided by health care providers who are qualified to provide the DSME based on their professional training and continuing education.
• DSME should address psychosocial issues, since emotional well-being is strongly associated with positive diabetes outcomes.
• DSME should be reimbursed by third-party payers.

The national standards are structural criteria:

ADA-recognized DSME programs have staff that includes at least a registered nurse and a registered dietitian; these staff must be certified diabetes educators or have recent experience in diabetes education and management. The curriculum of ADA-recognized DSME programs must cover all areas of diabetes management, with the assessed needs of the individual determining which areas are addressed. All ADA-recognized DSME programs utilize a process of continuous quality improvement to evaluate the effectiveness of the DSME provided and to identify opportunities for improvement.

Self-management support protocols vary by contract, but many contract negotiators know little about protocols. Purchasers may leave a number of the protocol specifications up to the vendor (or the protocol decisions essentially may follow from the choice of vendor), but a number of vendors also made reference to specifications included in a Request for Proposal (RFP).

Guidelines for how to provide self-management support appear in training materials, care management software, other decision support tools (e.g., scripts), and documentation formats for assessments, contact logs, goal summaries, action plans, treatment plans, and so forth. Possibly because they are somewhat "buried" in the software and materials, protocol variations may be

difficult for prospective purchasers to discern. They also may be considered proprietary information. Protocol specifications may vary with the goals of the program and the contract under which the program is provided. For example, how many outbound calls does an employer want to pay a vendor/health plan to provide?

Programs particularly vary in the frequency and intensity of contact, the degree of scripting they provide for support staff, and the content of the communicated support. Frequency and intensity of contact are affected by the goal of the program (e.g., wellness, risk prevention, or disease management) and the contract/business arrangements of the program including the intended reach of the program. The interviews and literature review suggest that most programs have at least one initial outbound call. Subsequent calls are largely determined by the program contract and the alerts raised by monitoring of patient data, often assisted by decision support tools. Patients at higher risk and those with more severe/complex diseases generally get more contacts.

Interviewees rarely spoke in detail about the specific content of sequential sessions. Some literature was more explicit. A 7-week, small-group, self-management support program for patients with one or more chronic diseases, for example, is guided by a detailed manual and covers the following topics: overview of self-management and chronic health conditions, creation of an action plan, relaxation/cognitive symptom management, feedback/problem solving, anger/fear/frustration, fitness/exercise, fatigue management, healthy eating, advance directives, communication, medications, making treatment decisions, depression, informing the health care team, and working with health care professionals.[45,46]

In addition to assessment forms and questionnaires, many programs provide scripts to their self-management support staff. Although some programs provide explicit scripts to be used during phone calls with patients, the majority of programs have scripts that include typical dialogue for a given interaction (e.g., high-risk patient, or early vs. late-stage interaction), and support staff are encouraged to "use their own words" and personalize the conversation to the patient. In general, there appear to be differences in the degree of prescriptiveness of program protocols. While some emphasize that protocols are useful for monitoring self-management support staff performance and ensuring uniformity in program implementation, concern was also expressed that prescriptive protocols may reduce flexibility in a service that needs tailoring and personalization.

Staff Training

Although a number of the primary care model pioneers received training through the Institute for Healthcare Improvement or government-sponsored quality improvement collaboratives, non-collaborative training opportunities are not numerous, and much of the training is on-the-job. Training is available for facilitators of some structured workshops, such as the Chronic Disease Self-Management Program and Tomando Control de su Salud.[47] One informant stated that a good self-management support training school with a good curriculum and trained instructors is sorely needed.

While some experts voiced the opinion that external model staff training is critical because much of the self-management support content and skills are not taught in nursing school (or other

professional schools), there was uncertainty about the length and format of training needed. The content appears to parallel the staffing qualifications emphasized: care management skills, motivational interviewing, cognitive skill-building, disease knowledge and clinical updates (including common comorbidities), medications, self-management skills, program protocols and standards, care management software, and computer skills. Additional content items mentioned included exercise, nutrition, sensitivity to patient issues, skills with lower literacy patients, and behavioral health information. Subcontracting out for training was infrequently mentioned. Descriptions of internal training varied considerably. One informant said that self-management support provider training came under the responsibility of the nursing director for ensuring nurse education. Two interviewees said their programs provided a 6-week training program plus subsequent mentoring. Others mentioned ongoing presentations, monthly meetings, onsite mentors, call monitoring, shadowing, and feedback of nurse-specific outcomes data. One informant claimed that there are lots of care manager training programs on the Internet, but their content and quality vary.

Communication with Patients

Program components in the primary care model may include various combinations of communication (face-to-face education, phone followup, Web site access, group visits or sessions, and referrals to classes and/or community resources). Patients may receive action plans, visit reports, and/or tools such as calendars or diaries that combine recording opportunities for self-management monitoring (e.g., recording of daily weights) with information to support decisions on when to take specific actions.

Many external model programs offer Web site access and written education materials in addition to telephone contact and face-to-face contact (in the case of the external on-the-ground programs). Some also use other modes of communication, such as e-mail and telephone hotlines. Group visits, classes, and home visits are used less frequently.

Communication Between Physicians and Self-Management Support Staff

Given its location within the primary care setting, the primary care model usually involves communication between the self-management support staff and the primary care physician. The primary care physician often plays a collaborative role in the self-management support (through use of action plans, for example, or reinforcement of goals and efforts to change behavior). The self-management support providers and primary care physicians may share treatment plans, as well as action plans. The nature and degree of their interaction may vary from a team structure with extensive collaboration to exchange of information through charting or electronic records.

External model programs differ considerably in their approach to communicating with the primary care physicians. Some programs foster little or no communication between the self-management support staff and the patient's primary care physician, while others strive for a collaborative relationship. One of the arguments voiced by representatives of programs that minimized communications with primary care physicians is that in order to foster independence, the patient, not the self-management support program, should communicate with the primary

care physician. If the patient is having difficulty communicating with the primary care physician, the appropriate role for the self-management support provider, according to this argument, is to coach the patient and help him or her build the skills needed for good communication. A different reason for minimizing communication with the primary care physician rests with the claim that physicians do not want such communication; they already are bombarded with paper and telephone calls; since they only have a few minutes with each patient, they do not want to use part of that time to talk about the self-management support program. On the other hand, proponents of communication with the primary care physician argue that physician participation is critical; patients trust their physicians, and physician reinforcement of self-management support leads to better outcomes.

The increasing prevalence of pay-for-performance programs that reward physicians for compliance with guidelines creates an incentive for primary care physicians to collaborate with external self-management providers, as those providers may be able to identify patients that require certain tests or drugs.

In those programs that encourage communication with the primary care physician, the form of the communication may differ. Not all programs notify the primary care physician when patients enter the self-management support program. Some program protocols call for sending information to the primary care physician in the form of assessment summaries, relevant clinical practice guidelines, identified risk factors, gaps in care, acute symptoms, or self-management issues being addressed. Communication may be by mail, fax, telephone messages, or e-mail. Some externally run programs provide self-management support in primary care settings. Other communication strategies mentioned include:

- Provide the primary care physician with access to patient data. (One program is putting its system on the Internet so the provider has access to data gathered by the program.)
- Send reminders and alerts about possible treatment gaps.
- Support the primary care physician's treatment plan.
- Give decision-support software to community providers.
- Request patient data from physicians.
- Put administrative personnel in physician offices to check clinic schedules, print patient data, and put data in charts.

As part of the self-management support provided, some programs prepare the patient for their visit with the primary care physician. One program encourages patients to prepare to ask three questions at every primary care physician visit and works with them to prioritize their questions beforehand. Another program will occasionally conduct three-way calls (with patient and primary care physician) to facilitate the patient's communication. Others simply review issues with the patient before a primary care physician visit. In one program, the nurse may accompany the patient into the exam room to help with the patient-primary care physician communication.

In programs with physician communication, self-management support staff members typically build relationships with non-physician personnel in primary care physician offices. While two-way communication may be a goal for some programs, most of the communication at this point is one-way; self-management support providers generally receive little information or response from the primary care physicians. Some programs are considering pay-for-performance or "pay-

for-participation" incentives to get physicians to collaborate with self-management support providers.

Program Evaluation

Ongoing program evaluation is just as important for self-management support programs as it is for other service delivery programs. Purchasers and builders will want to routinely receive information that allows them to assess the program's operation and performance, especially whether it ultimately benefits patients with chronic illnesses. Yet there is at present no standard format for such information, and a purchaser or builder of a self-management support program will find a broad array of possible evaluation measures. To some extent, the choice depends on the program's main goals, but a selection of endpoints may lead to the best understanding of how the program is working. In the following section, "Evaluation Measures," we describe the range of evaluation measures revealed by our literature review and expert interviews and discuss the key issues that were raised. Additional methodological issues are discussed in the next section, "Evaluation Methodology."

Evaluation Measures

Program success may be assessed at many points along the chain of effects presented in Figure 1 (see page 4). One can examine whether:

- Program structure matches what was called for in the contract.
- Coaches are engaging eligible patients and performing the self-management support activities.
- Patients' knowledge and self-efficacy have increased.
- Patients' health-related behaviors have changed.
- Rates of provider adherence to guidelines have increased.
- Disease control has improved.
- Patient health outcomes have improved.
- Patient satisfaction has improved.
- Utilization has declined, and patient productivity has improved.
- Health care costs have declined.

Each of these interim and long-term goals is important and provides a possible endpoint for evaluation. They are discussed in more detail below.

Tables 3a and 3b provide an overview of the endpoints that are examined in the recent literature on existing self-management support programs. The columns in the table parallel the boxes in Figure 1. It can be seen that endpoints all along the chain of effect (following program structure) have been utilized by researchers. Among our interviewees, some use of each category was reported. Neither our literature review nor our interviews identified research on programs that measured endpoints in all categories. Utilization, costs, provider behavior, and disease control endpoints received the greatest emphasis, most likely reflecting considerations of data availability, reliability, and other tradeoffs associated with different data sources.[48]

Table 3a. Examples of evaluation measures for self-management support programs for common chronic conditions

A. Structure of self-management support program	B. Processes of self-management support	C. Patient self-efficacy and knowledge	D1. Patient behavior	D2. Provider behavior and guideline conformance
- Staffing ratios - Caseload - Staff qualifica-tions - Hours of training	**Reach** - Initial contact rate - Enrollment rate - Completion rate - Appropriate referrals to self-management support program **Assessment** - Knowledge, gaps - Self-efficacy barriers - Attitude and behavior barriers - Documented staging **Education** - Education sessions - Content covered **Coaching** - Contact frequency - Call duration - Call content - A written action plan - Spacers and peak flow meters distributed - Smoking cessation counseling	**Knowledge** - Patient knowledge - Asthma knowledge acquisition - Diabetes knowledge and beliefs - Diabetes knowledge deficiency **Self-efficacy** - Self-efficacy - Health locus of control	- Prescription drug purchase/refills (e.g., beta agonists, inhaled corticosteroids, leukotrine modifiers, oral steroids, other asthma drugs) - Persistency of medication use - Time to refill - Self-management practices regarding diet, foot care, physical activity, glucose monitoring, M.D. visits, diabetes health exams - Smoking rates - Quantity and frequency of exercise - Stress management - Breakfast eaten - Patient-provider communication - Ownership and use of peak flow meter - Cognitive symptom management	**Provider behavior** - Prescribing of medications - Documentation of asthma diagnosis - Resolution of gaps in care **Guideline conformance** - Frequency of specified testing - Eye exam rate - Foot exams - HbA1c tests - Procedures performed (allergen immunotherapy, pulmonary lab procedure, ventilator, perfusion imaging, influenza immunotherapy, pneumonia immunotherapy) - Adherence to American Diabetes Association standards of care - Blood pressure tests - Microalbumin tests

Table 3b. Examples of evaluation measures; additional categories

E. Disease control	F. Health outcomes	G. Utilization* and productivity	H. Costs	I. Patient satisfaction
- HbA1c values - BP values - LDL values - HDL levels - Random blood glucose - Weight - BMI - Cholesterol levels - Trigly-ceride levels - Self-reported severity of symptoms - Shortness of breath	- Depression scale - Sleep loss - Quality of life and well-being - Health status, including SF-12 and SF-36 - Household and leisure time functioning - Functional impact (emotional well-being, daily work, social and physical activities) - Self-reported health - Fatigue - Pain - Activity limitation - Migraine disability - Degree of worry - Complications rate - Mortality	**Utilization** - Hospital admissions - Emergency room visits - Physician or clinic visits - Length of stay - In-patient bed days - Asthma inpatient admits - Asthma inpatient bed days - Asthma ER visits - Urgent care visits - Scheduled physician or clinic visits - Readmissions - Annual rates of foot-related hospitalizations - Number of heart failure clinic visits - Ophthalmology visits - Diabetes specialty clinic visits - Number or insurance claims for medication **Productivity** - Work limitations - Days missed - Days less productive	- Overall health care costs - Detailed financial performance measures - Medical cost savings - Projected cost savings - Cost for hospitalization and ER visits	- Program satisfaction - Perceptions of migraine management - Patient satisfaction with care

* Utilization measures sometimes are used as surrogate measures of patient health outcomes.
Note: for this table, common chronic conditions are defined as asthma, cardiovascular disease, depression, diabetes, heart failure, and migraine headaches. Examples are taken from the literature.

Measures of program structure. Commonly, purchasers of external services look for accreditation of a program as a measure of the program's structural soundness. While few studies in the literature used structural measures for program evaluation, a purchaser or developer might want to monitor whether the program has the components and features that were called for in the original plan or contract. One might also question if the features are plausibly capable of supporting the kinds and extent of self-management support activities desired. Are the staff and caseload as expected? Do staff members have the qualifications and training to perform their duties? Can they reasonably be expected to support the kinds of activities envisioned for the intended number of patients? Are procedures and protocols in place to ensure that coaching tasks, as well as education, are performed? Structural measures also may be used to assess whether claims about the program's success based on other measures are plausible.

Most structural measures rely on information from the program's management. Patient self-report is another data source to consider. The Disease Management Association of America

(DMAA) Participant Satisfaction Survey, for example, asks patients if their program has a toll-free number they can call.[49]

Self-management support process measures. Another approach to evaluation is to monitor the performance of the program staff by examining the extent to which they perform the tasks and activities intended; i.e., how well the process of providing support to chronically ill patients actually works. Not only are program process measures critical for program supervision and management, they also can tell purchasers and developers if the program is being implemented according to plan. Measures of reach and implementation can help reveal factors that contribute to success or failure and be useful for monitoring of staff performance and program improvement. As shown in Table 3, process measures in the program literature have focused on the reach of the program, processes for assessing patients' self-management skills and needs, education processes, and coaching processes.

Measures of "reach" are intended to assess the extent to which the self-management support program reaches the people it is intended to serve. Examples include the percent of the eligible population successfully contacted with an offer of self-management support services, enrollment rates (or opt-in or opt-out rates), completion rates, and drop out rates. As an example, the study of the asthma call center program described earlier reported that 474 of the 1,303 member population with asthma actually enrolled in the program, and 196 of these enrollees were stratified to the high risk subset for telephone support.[50] An intermediate implementation measure of the program's attempts to engage patients (e.g., the number of attempted calls that resulted in the reach figure) also may be helpful for monitoring program performance in relation to reach.

One informant emphasized that it is important for all aspects of evaluation to take into account at the beginning the number of people who are eligible for the program—that is, the opportunity for making an impact based on the total number of people the program might serve and what portion of the total the program plans to enroll or engage. Different data sources may lead to different definitions of the total population. Programs that rely on claims data will limit the total to individuals who have been diagnosed (or received some specific treatment). Yet, a significant proportion of individuals with some conditions go undiagnosed. If the intent is to capture all people with the condition, as advocated by many proponents of the chronic care model, then health risk assessments or other screening mechanisms may be necessary to identify the total population.

Who is being reached is another consideration. It is important that the people reached were, in fact, part of the target population. Another critical issue is whether the people reached are disproportionately those who already are most likely to self-manage, a difficult question to assess from most datasets. Some evaluation research has utilized propensity scores based on analysis of predictors of program enrollment,[43,50] but it is not clear if propensity scores have been incorporated into program performance reporting.

In addition to reach, other program process measures assess the extent to which the self-management support interventions were implemented as intended. They essentially assess the

program's performance of the self-management support processes called for in the program protocols. Examples of implementation measures reported in the program literature include the:

- Number of education sessions provided in person or by telephone.
- Frequency of coaching telephone calls.
- Duration of the telephone calls.
- Content of the telephone calls.

An evaluation of a depression telecare program sponsored by an employee coalition, for example, reported that 100 of 102 eligible enrollees received at least one nurse call. They averaged 11.1 calls per patient (with a range of 0-22), and calls lasted 6.5 minutes on average.[51] An evaluation of a diabetes disease management program reported the number of educational mailings distributed, the number and average duration of telephone interactions, the average number of telephone interactions with individuals in the highest severity category, and the number of patients who could not be reached.[52] Many studies assessed implementation by measuring the documentation of self-management support processes, such as patient education provided, action plan completed, patient goals collaboratively agreed on, smoking cessation counseled, referrals suggested, blood glucose self-monitoring training provided, and spacers and peak flow meters distributed. The asthma program described as a call-center model regularly reported to its sponsors the percentage of patients with a care plan, but the program did not use this measure in their study.

Staff also may be surveyed about the performance of self-management support processes. One study[53] reported the results of a survey that asked staff to report the frequency with which the following self-management support processes occurred:

- Support was promoted through problem-solving and empowerment methodologies.
- Patient self-management needs were assessed.
- Individualized written care plans were prepared.
- A written care plan was made available to primary care and urgent care staff.
- Spacer techniques were taught.
- Low-cost peak flow meters, spacers, and nebulizers (self-care tools) were made available to patients.

Alternatively, similar measures may be based on reports by patients that they have received specified self-management support services. The DMAA Participant Satisfaction Survey, for example, includes items soliciting patients' reports of the frequency of different types of contact with program staff (such as receipt of educational materials, scheduled calls, and face-to-face meetings), which lifestyle changes have been emphasized by program staff (e.g., improving diet, taking medications as prescribed, getting annual check-ups, weight management), and whether specific biometric monitoring devices were provided (such as glucometers, peak flow meters, digital weight scales, or home cholesterol screening monitors). Inventory counts also may be used to measure the distribution of patient education materials or self-management support tools.

Measures of patient self-efficacy and knowledge. The principal goal of a self-management support program is to increase patients' knowledge and self-efficacy for self-management, and it

makes sense to measure its ability to do so. Measures of self-efficacy assess people's confidence in their ability to perform or adhere to specific behaviors such as exercise, diet, or stress management or to overcome obstacles to the performance of these behaviors. Measures of knowledge and self-efficacy were used in some of the studies we reviewed. For example, when an independent delivery system implemented a 7-week, small-group self-management support program for patients with one or more chronic diseases, the evaluation included a self-efficacy measure of perceived adaptability to manage pain, fatigue, emotional distress, and other aspects of chronic illness.[45,46] The patient's readiness to change also was assessed in a number of studies. Self-management, problem-solving skills, and self-management barriers were also assessed.

It is important to identify measures that are validated, but it may be more difficult for this program area. More than one informant mentioned patient activation measures currently being developed and validated. According to interviewees, some programs use patient surveys to collect information on the patients' knowledge and self-efficacy. For several programs, routinely collecting such information is part of their program, e.g., the responses are recorded in the self-management support software or entered into the interactive computer programs. Patient surveys often are expensive, but relying on patients' responses to their coaches raises the potential for added bias, since patients may be less likely to be truthful with their coaches. One administrator (in a primary care model program) said they anonymously administer a small written survey to a portion of patients each month to measure their confidence in their ability to self-manage. They switched to the anonymous questionnaire after becoming suspicious of the very high levels of confidence reported by patients in response to in-person queries by coaches.

Measures of patient behavior. The American Association of Diabetes Educators (AADE) considers changes in patient behavior to be the outcome most sensitive to its diabetes self-management support. Diabetes educator-researchers recommend that measures of seven self-care behaviors be used to determine the effectiveness of self-management education at the individual and population levels. These behaviors include monitoring blood glucose, problem solving, taking medicine, psychosocial adaptation, reducing risks of complications, being active, and eating. Table 4 shows the AADE's specific recommendations for measures and methods of measurement for assessing these intermediate outcomes.

The DMAA recommends that disease management programs evaluate change in medication adherence and lifestyle behaviors (diet, exercise, and smoking status, at a minimum.) Its recent Outcomes Guidelines Report states:

> Disease management programs frequently measure whether patients receive prescriptions for medications identified in evidence-based guidelines for specific conditions (e.g., beta-blockers for patients who have had an acute myocardial infarction), but the prescription will not promote better health outcomes or reduced costs unless the patient takes the medication as prescribed. Accordingly, medication adherence is a component of patients' self-management of their chronic conditions, an important target for disease management patient education efforts and thus, an important metric to be assessed in evaluation of these programs.[54]

In the literature on real world programs, evaluations have measured a variety of behaviors. Examples have included measuring self-monitoring of dietary intake and physician activity,

attendance at self-efficacy classes, patient-initiated telephone contact, foot care, glucose monitoring, self-management strategy use, use of self-management tools, insulin dose adjustment, medication compliance, controller use, physician visits, communication with the physician, diabetes health exams, eating and dietary behaviors, physical activity, frequency of exercise, and tobacco use. In the example of a call center asthma program described earlier, pharmacy data were used to create measures of use of beta agonists, inhaled corticosteroids, leukotrine modifiers, and oral steroids. An evaluation of a disease management program sponsored by a pharmacy benefit management company used measures of medication compliance (84 days of therapy in a 114-day period in the acute phase and 180 days of therapy during a 231-day period in the continuation phase), persistency of medication therapy (lack of a 90-day or longer gap in prescription refills during the 7-month observation period), and patient refill timeliness (time to first refill).[55] In the evaluation of a 7-week, small group self-management support program implemented within an independent delivery system, the measures of patient behavior focused on exercise (e.g., minutes per week of aerobic exercise and range-of-motion exercise), cognitive symptom management, and communication with physician. Smoking behavior, quit rates, and daily weighing were some of the behavior measures mentioned in the key informant interviews.

Table 4. AADE recommended measures and measurement methods

Diabetes self-care behavior	Measures	Methods of measurement
Monitoring blood glucose	- Frequency of missed tests - Frequency and schedule of tests (times/day, days/ week) - Planned, unplanned testing - Review of pharmacy refill record	- Review of log book - Meter memory review or printout - Self-report - Demonstration of technique
Solving problems	- Blood glucose testing - Adjusting food, medication, activity - Contact with health care provider for resolving problems - Checking meter and strips for function - Number of blood glucose tests per month requiring assistance - Number of times that ketones are tested (when appropriate) - Missed days from work or school	- Patient self-report - Review of log book (unreliable) - Meter memory review or printout - Review of medical chart - Frequency of medication adjustment
Taking medication	- Adherence to medication regimen - Dose accuracy	- Pill count - Review of pharmacy refill record - Demonstration - Self-report - Blood glucose, medication records - Observation, role playing

Table 4. AADE recommended measures and measurement methods (continued)

Diabetes self-care behavior	Measures	Methods of measurement
Living with diabetes	- Depression score - Stress - Quality of life - Functional measurement - Treatment self-efficacy - Patient empowerment - Self-report	Validated instruments (e.g., SF-12, SF-36, Zung/Beck Depression Scale)
Reducing risks of diabetes complications	- Smoking status - Frequency of foot self-exam - Aspirin therapy - Eye exam - MD visit - Diabetes educator visit - Registered Dietician visit - Lipids checked - Blood pressure checked - Flu vaccine, pneumonia vaccine - Urine check for protein - Prepregnancy counseling	- Patient self-report - Chart or exam code audit - Demonstration of self-care activities
Being active	- Type of physical activity - How often - How long - How intense	- Patient self-report - Observation - Pedometer
Eating	- Type of food choices - Amount of food eaten - Timing of meals - Alcohol intake - Effect of food on glucose - Problem solving and special situations	- Patient self-report - Observation - Food and blood glucose records - 24-hour recall, food frequency questionnaires

Source: Mulcahy et al. 2003.[56] (Derived from Table 4: AADE Diabetes education core outcomes measures for diabetes self-care behaviors, pages 776-9.)

Most of these measures rely on pharmacy data or patient self-report. If use of pharmacy data is feasible, then it is sensible to use these data for evaluating the program's effect on patients' medication behavior. Administrative data might provide a similar source of data on clinic visit behavior, although attention should be given to the extent of the time lag evident in the data reporting. Reliable sources of data on other aspects of patient behavior (e.g., physical activity or diet) are less available. As with measures of patient knowledge and self-efficacy, patient self-report may be the only feasible source of data on many of the patient behaviors targeted by the self-management support. To the extent possible, care should be taken to minimize potential bias from a patient's recall difficulties or the desire to please.

Not only is changing certain behavior important for many patients with chronic conditions, but sustaining behavior change is critical as well. Several experts stressed the need to evaluate whether behavior change is sustained over time.

Measures of provider behavior and guideline conformance. A number of the studies that we reviewed assessed programs by investigating changes in provider behavior or conformance with guidelines. Many studies examined physicians' medication prescribing, diagnosis documentation, referrals, and rates at which they performed various procedures (HbA1c tests, eye exam rates, foot exams, allergen immunotherapy, and pulmonary lab procedures). One study of an asthma program, for example, compared the performance of allergen immunotherapy, pulmonary lab procedure, ventilation and perfusion imaging, influenza immunization, and pneumococcal immunization. In the interviews, respondents mentioned using such clinical process indicators as performance of clinical diagnostic tests, lab tests, medication prescribing, or, more generally, processes called for in clinical practice guidelines. Some respondents said their organizations use measures from the Health Plan Employer Data and Information Set (HEDIS) developed by the National Committee for Quality Assurance for use in accreditation and certification of health care organizations.[57]

To the extent that changing provider behavior is a target of the self-management support program (e.g., if coaches assist and encourage diabetes patients to remind clinicians that they are in need of a foot exam), these measures may be appropriate for evaluating effectiveness. Many of the measures are based on administrative data and may be readily accessible for numerous programs. Much of self-management support, however, targets patient behavior, and patient behavior alone does not determine whether these clinical processes are performed.

Measures of disease control. Researchers have used measures of HbA1c, lipids, blood pressure, weight gain, chest pain, cough, dizziness, shortness of breath, peak flow readings, asthma symptom scores, nighttime symptoms, self-reported severity of symptoms, and body mass index to assess disease or symptom control. Several of these measures also were mentioned in the interviews. Symptom control measures, along with clinical process measures, are emphasized by major national measure sets. The National Committee for Quality Assurance, American Diabetes Association Provider Recognition Program (ADA PRP), Diabetes Quality Improvement Project (DQIP), and National Quality Forum (NQF) diabetes measurement sets all include HbA1c and lipid control indicators as well as HbA1c, lipid, urine protein, and eye testing. Clinical data (laboratory or medical record data) are needed for a number of these measures, however, and such data are difficult to collect, particularly for external model providers of self-management support, unless an electronic medical record is available. While patient self-report is reasonable for a number of these measures, such as chest pain or shortness of breath, it is unlikely to be reliable for other disease control measures such as cholesterol levels or other lab values.

Health outcome measures. Researchers have used a variety of health outcome measures, including functional status, complications such as organ damage or lower extremity amputations, physical and mental functioning, quality of life, mortality, disability, pain, restricted activity days, days in bed, and self-reported health status. Fewer outcome measures were mentioned by the interview respondents. These measures included global health scores, days sick at home, quality of life, and measures of physical functioning. The DMAA recommends use of one of the short-form health status surveys (SF-8, SF-12, or SF-36) to evaluate change in patients' health status.[54]

Improved health outcomes are unquestionably a prime goal for self-management support programs; however, a serious problem with using health outcomes for evaluation purposes is that it may take years for many of these outcomes to show the effects of improved self-management.[58] An assessment that uses a relatively short followup period (a year, for example), as most do, is unlikely to be able to detect improvement in such outcomes.

Patient satisfaction measures. Measures of patient satisfaction with care and quality of life were utilized in research and mentioned by a number of interview respondents. The DMAA recently released a new assessment tool for measuring participant satisfaction with disease management. This tool includes a number of items designed to evaluate patients' experience with the program staff, the usefulness of the services received, access to program services, and satisfaction with the information received.[49]

Utilization and productivity measures. Measures of health care utilization included hospital admissions, emergency room visits, inpatient days, lengths of stay, outpatient visits, readmissions, and cardiac procedure rates. As an example, the asthma call center study used inpatient admissions, inpatient bed days, emergency room visits, asthma inpatient admissions, asthma inpatient bed days, and asthma emergency room visits. Utilization may be impacted by a self-management support program if the patient's health outcomes improve or if he or she feels more confident and able to handle an exacerbation of symptoms without using clinical services such as emergency rooms.

With most of these measures, program success is assessed in terms of reduced utilization. However, in some cases, outpatient visits may be expected to increase from better self-management. Utilization measures frequently are used to evaluate self-management support programs, partly because they rely on readily accessible administrative data. To the extent that the reduced utilization is expected to result from an outcome that improves over a long time period, these utilization measures will miss detecting benefits in a short followup period

Measures of productivity included days lost from work, days absent from school, and days less productive. Patient-reported productivity items included in the DMAA Participant Satisfaction Survey, for example, focus on days missed from work and normal activities due to health problems related to the medical condition being managed and health-related limitations affecting work (e.g., overall effectiveness, ability to concentrate, ability to handle the workload).

Measures of cost. The literature reported that various financial variables were used, including the dollar amount of claims in 1 year per patient, encounter costs, pharmacy costs, inpatient costs, outpatient costs, emergency room visit costs, radiology costs, home health care costs, charges for health care services, and costs for the program. An article on a plan's diabetes self-management support program reported per member per month paid claims, inpatient admissions per-patient per-year, inpatient days per patient per year, emergency room visits per patient per year, primary care visits per patient per year, and HEDIS scores for HbA1c tests and lipid, eye, and kidney screenings.[59]

Stakeholders generally are interested in financial outcomes. Most interviewees focused on return on investment, and many mentioned the need for a standard methodology for calculating return

on investment. Most interviewees also reported utilization statistics, such as emergency room visits, hospital admissions, hospital days, length of stay, neonatal intensive care unit days, readmissions, and/or prescription drug use. While utilization data often are used to project savings, at least one expert argued that actual changes in utilization costs should be reported. Actuarial models for evaluating cost savings from disease management programs have been utilized in the disease management field.[60,61,62] In its recently released consensus guidelines for measuring disease management outcomes, the DMAA recommended that financial impact be assessed in terms of health care cost outcomes, and that such outcomes be measured by changes in total dollars (or per-member-per-month charges) using medical and pharmacy claims data. Possible cost measures for which some benchmarks exist include hospital claims (total dollar amount of hospital claims paid), pharmacy claims (total dollar amount of pharmacy claims paid), and total expenditures (total dollar amount in claims paid).

Evaluations using short followup timeframes will miss savings that result from long-term benefits in health outcomes or utilization.

Combination of measures. When selecting measures, it is important to consider their sensitivity to the changes targeted by the program goals. A recent review of disease management program indicators found that, in a substantial portion of studies, the indicators used did not conceptually link to the aims of the program as described in the articles. The authors recommended that selection of evaluation indicators be based on their expected sensitivity to the specific design and goals of the intervention. For intermediate endpoints, such as patient knowledge and self-efficacy, patient behavior change, and improved disease control, indicators should be ones that might plausibly be expected to be influenced by the program components and that are associated with the expected changes in outcomes.[63]

Purchasers and providers of new programs will want to be sure that the structure of the program and the services actually provided match what the contract stipulates. In the mid-term, providers of the programs will want to know if patient self-efficacy and provider behavior have changed. In the longer term, it will be important to evaluate whether the program has improved patient health outcomes and well-being and whether it has reduced costs.

Outcome measures alone should be interpreted with caution, particularly given the usual methodological constraints in real-world program evaluation. The absence of significant change in outcomes may not indicate program failure, for example, if the followup period necessary to show improvement in outcomes is longer than the evaluation timeframe. Monitoring change in multiple dimensions (including such intermediary links in the chain of effect such as change in patient behavior) offers more opportunity to assess the plausibility of assumptions about effect and to increase confidence in judging program success or failure. Analysis of these data can lead to better understanding of if and how different dimensions mediate outcomes. Measuring multiple dimensions also provides more comprehensive data for improving the program and providing performance feedback to staff.

Evaluation Methodology

Measures are just one component of a program evaluation. In evaluations of program impact, a number of other methodological issues, such as the overall evaluation design and sample selection, require careful consideration because they affect the ability to attribute any changes found to the program itself. Self-management support program evaluation and disease management program evaluation share many of these methodological issues, as well as some of the same challenges, such as selection bias and regression to the mean.

One controversy in disease management evaluation has resulted from measuring performance based on biased samples of patients.[64] Bias occurs if an unobservable or unmeasured characteristic of a patient makes it more or less likely that this patient has a positive (or negative) treatment effect and a higher (or lower) probability of responding well to the program intervention. A sample that only includes patients who agreed to participate in the program risks selection bias, for example, because these participants are likely to have greater motivation to take care of their health and, therefore, are more likely to benefit from the program intervention than the overall patient population. If so, analysis of the difference between that group and a comparison group will overstate the true effect of the intervention.[65]

Another evaluation problem results if disease management programs concentrate their efforts on patients whose health costs were high in the baseline period (e.g., those recently hospitalized) and only include such patients in their analysis. Since high-cost events in medical care tend to be non-recurring, a certain proportion of those patients would end up with lower costs in the next period without program intervention, and the analysis will again overstate the effect of the intervention.

Including all eligible patients in the analysis ("intent to treat" analysis) addresses these problems. For further information on these methodological issues and guidance in how to address them, see Arnold, et al, 2007.

Conclusions

In the absence of extensive evidence on the most effective ways to design and evaluate self-management support programs, we turn to existing programs to illustrate a wide variety of program designs and evaluation measures. This situation is challenging for providers who are developing Requests for Proposals (RFPs) for programs, negotiating contracts with vendors, or planning or managing their own programs. They need to make decisions about how to structure and evaluate their programs, which features to include, and whether the programs will be useful for meeting their goals in their settings. Even in the absence of extensive evidence, consideration of the following key points can aid decisionmaking.

Support Programs Aim to Change Patient Behavior

Self-management support programs assume a complex sequence of effects (Figure 1). They expect to change patients' behavior by increasing patients' self-efficacy and knowledge. Improved behavior is expected to lead to better disease control, which in turn, should lead to

better patient outcomes, improved utilization, and reduced costs. This sequence of assumptions gives self-management support programs multiple objectives and multiple endpoints for evaluation. The pivotal objective, however, is to change people's behavior.

Begin by Considering the Basic Model

An initial step in choosing or building a self-management support program is to decide where in the health care system the program will be positioned—that is, who will manage and administer the program and where will the care be provided—internal or external to the patient's primary care setting. This last distinction frequently has important ramifications for the degree to which the self-management support is integrated with other aspects of the patient's chronic care and thus who the players are, the quantity and kind of data available to support the coaching intervention, and the degree of administrative focus and support.

Program location may depend in part on where in the health care system the purchaser or builder is located. A plan or employer whose eligible population is thinly spread across numerous independent primary care settings might well consider an external model for practical reasons. A medical group or independent delivery system might have more options for organizing the self-management support program either within or outside of the primary care setting.

Provide Coaching in Addition to Patient Education

Other decisions about the program will pertain to factors such as:

- Staffing.
- Content of the support.
- Target population of patients.
- Availability of information systems support.
- Protocols for how program staff are to provide the support.
- Staff training.
- In what manner and how often coaches communicate with patients.

Coaching intervention is one of the most important factors in determining a program's success in changing patient behavior. Patient education is necessary but is not sufficient by itself. Rather than being prescriptive or hierarchical, coaching interventions are patient-centered and tailored to the needs and concerns defined by the patient and his or her situation. Coaches therefore must have timely access to information on patients' behaviors, priorities, skills, and needs.

Coaches should have teaching skills and the psychosocial skills necessary to facilitate a patient's change in behavior. While the information needed for the educational interventions may be disease-specific, the core skill set needed for coaching may be applicable for all diseases. Providers and program developers might consider differentiating the self-management support tasks and looking for people with different skills for different tasks.

Training and protocols for the coaches are important program components, especially since many coaching skills are not often taught in professional schools such as nursing schools.

Choose Measures for Evaluating the Success of the Program

The measures used to assess the success of the program should align with the goals of the program. If the pivotal objective of self-management support is to help patients change their behavior and manage their disease, then evaluation should start there. Whether or not patients use their medications is a better indicator of a program's success than whether a physician prescribes medication, since a change in provider behavior usually is not the primary objective of self-management support. In addition, measuring only patient visits to the hospital or the costs of various aspects of patient care would be overly narrow, especially in the short run.

Likewise, the measurement timeframe needs to match the timeframe in which the self-management support objectives can be attained. Some changes happen sooner, some later. For example, patient self-efficacy and behavior must change before lower costs and fewer hospitalizations are realized. To evaluate the success of a program based on hospitalizations and costs before evaluating and improving patient self-efficacy and behavior might result in premature and unnecessarily negative results. Match measurement to the time course in which it is happening, with longer and realistic time allowances for the long-term outcomes.

The best approach is a portfolio of measures that address the different, sequential objectives of self-management support. This approach should include measures of whether patients get better at managing their disease and allow sufficient time to assess if patients' changed behaviors lead to the hoped-for long-term outcomes.

Finally, it is important to carefully consider the potential for bias when selecting measures of patients' changed behavior. Where possible, rely on information that is directly available from an objective source (e.g., pharmacy records) rather than a patient's own report. When it is necessary to rely on patient self-report, try to avoid collecting this information through the coaches (some patients may exaggerate their good behavior in an effort to please their coaches) or only from those who agreed to participate in the program (to avoid selection bias).

Looking Ahead

The range of choices currently available for the design of self-management support programs reveals the extensive uncertainty that underlies self-management support programming. The research evidence base for program and evaluation design is very limited, and more and better research across most of these areas is sorely needed. Appendix 2 lists a number of the research needs that were highlighted in the interviews that RAND conducted with individuals knowledgeable about self-management support programs. Further research addressing these needs will provide critical guidance to those who are struggling to design optimal self-management support programs, to change patient behavior, and to improve the health of the chronically ill.

References

[1] Anderson RM, Funnell MM, Butler PM, et al. Patient empowerment. Results of a randomized controlled trial. Diabetes Care 1995;18(7):943-9.

[2] Adams KG, Greiner AC, Corrigan JM, eds. Report of a summit. The 1st annual crossing the quality chasm summit: a focus on communities; Jan 6-7, 2004. Washington, DC: National Academies Press; 2004.

[3] Centers for Disease Control and Prevention. Data and trends; National Diabetes Surveillance System; preventive care practices. 2004 data from CDC's Behavioral Risk Factor Surveillance System. Retrieved Dec 2006 from www.cdc.gov/diabetes/statistics/peventive/fallpractices.htm. See http://www.cdc.gov/diabetes/statistics/preventive_national.htm. Accessed on October 4, 2007.

[4] Institute of Medicine. Priority areas for national action: transforming health care quality. Washington, DC: National Academies Press; 2003.

[5] Krichbaum K, Aarestad V, Buethe M. Exploring the connection between self-efficacy and effective diabetes self-management. Diabetes Educ 2003; 29(4): 653-62.

[6] Bandura A. Self-efficacy: toward a unifying theory of behavioral change. Psychol Rev 1977;84(2):191-215.

[7] Prochaska JO, DiClemente CC. Stages of change in the modification of problem behaviors. Prog Behav Modif 1992;28:183-218.

[8] Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. Am J Health Promot 1997;12(1):38-48.

[9] Bond GG, Aiken LS, Somerville SC. The health belief model and adolescents with insulin-dependent diabetes mellitus. Health Psychol 1992;11(3):190-8.

[10] Tillotson LM, Smith MS. Locus of control, social support, and adherence to the diabetes regimen. Diabetes Educ 1996;22(2):133-9.

[11] Hampson SE, Glasgow RE, Foster LS. Personal models of diabetes among older adults: relationship to self-management and other variables. Diabetes Educ 1995;21(4):300-7.

[12] Glasgow RE, Hampson SE, Strycker LA, et al. Personal-model beliefs and social-environmental barriers related to diabetes self-management. Diabetes Care 1997;20(4):556-61.

[13] Skinner TC, John M, Hampson SE. Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. J Pediatr Psychol 2000;25(4):257-67.

[14] Improving chronic illness care. The Chronic Care Model. Retrieved Apr 2007 from www.improvingchroniccare.org/index.php?p=The_Chronic_Care_Model&s=2. Accessed October 4, 2007.

[15] Wagner EH, Austin BT, Von Korff M. Improving outcomes in chronic illness. Manag Care Q 1996;4(2):12-25.

[16] Wagner EH, Austin BT, Von Korff M. Organizing care for patients with chronic illness. Milbank Q 1996;74(4):511-543.

[17] Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? Eff Clin Prac 1998;1:2-4.

[18] Disease Management Association of America. DMAA definition of disease management. Retrieved Apr 2007 from http://www.dmaa.org/dm_definition.asp. Accessed October 4, 2007.

[19] Norris SL, Engelgau MM, Venkat Narayan KM. Effectiveness of self-management training in type 2 diabetes: a systematic review of randomized controlled trials. Diabetes Care 2001;24(3):561-87.

[20] Weingarten SR, Henning JM, Badamgarav E, et al. Interventions used in disease management programmes for patients with chronic illness-which ones work? Meta-analysis of published reports. Br Med J 2002;325(7370):925.

[21] Norris SL, Lau J, Smith SJ, et al. Self-management education for adults with type 2 diabetes: A meta-analysis of the effect on glycemic control. Diabetes Care 2002;25(7):1159-71.

[22] Warsi A, Wang PS, LaValley MP, et al. Self-management education programs in chronic disease: a systematic review and methodological critique of the literature. Arch Intern Med 2004;164(15):1641-9.

[23] Chodosh J, Morton SC, Mojica W, et al. Meta-analysis: chronic disease self-management programs for older adults. Ann Intern Med 2005;143(6):427-38.

[24] Guevara JP, Wolf FM, Grum CM, et al. Effects of educational interventions for self-management of asthma in children and adolescents: systematic review and meta-analysis. Br Med J 2003;326(7402):1308-9.

[25] McAlister FA, Stewart S, Ferrua S, et al. Multidisciplinary strategies for the management of heart failure patients at high risk for admission: a systematic review of randomized trials. J Am Coll Cardiol 2004;44(4):810-9.

[26] Gibson PG, Powell H, Coughlan J, et al. Self-management education and regular practitioner review for adults with asthma. Cochrane Database Syst Rev 2002;3:CD001117.

[27] Gibson PG, Ram FS, Powell H. Asthma education. Respir Med 2003;97(9):1036-44.

[28] Bravata DM, Sundaram V, Lewis R, et al. Asthma care. Vol 5 of: Shojania KG, McDonald KM, Wachter RM, et al., editors. Closing the quality gap: a critical analysis of quality improvement strategies. Technical Review 9 (Prepared by the Stanford University-UCSF Evidence-based Practice Center under Contract No. 290-02-0017). Rockville (MD): Agency for Healthcare Research and Quality; 2007. AHRQ Publication No. 04(07)-0051-5.

[29] Bandura A. Promotion from the perspective of social cognitive theory. Psych Health 1998;13:623-49.

[30] Renders CM, Valk GD, Franse LV, et al. Long-term effectiveness of a quality improvement program for patients with type 2 diabetes in general practice. Diabetes Care 2001;24(8):1365-70.

[31] Sarol JN Jr, Nicodemus NA Jr, Tan KM, et al. Self-monitoring of blood glucose as part of a multi-component therapy among non-insulin requiring type 2 diabetes patients: a meta-analysis (1966-2004). Curr Med Res Opin 2005;21(2):173-84.

[32] Balas EA, Krishna S, Kretschmer RA, et al. Computerized knowledge management in diabetes care. Med Care 2004;42(6):610-21.

[33] Deakin T, McShane CE, Cade JE, et al. Group based training for self-management strategies in people with type 2 diabetes mellitus. Cochrane Database Syst Rev 2005 Apr 18;(2):CD003417.

[34] Toelle BG, Ram FS. Written individualised management plans for asthma in children and adults. Cochrane Database Syst Rev 2004;2:CD002171.

[35] Turnock AC, Walters EH, Walters JA, Wood-Baker R. Action plans for chronic obstructive pulmonary disease. Cochrane Database Syst Rev 2005 Oct 19;4:CD005974.

[36] Murray E, Burns J, See TS, et al. Interactive health communication applications for people with chronic disease. Cochrane Database Syst Rev 2004 Oct 18;4:CD004274.

[37] Disease Management Association of America. Disease Management Leadership Awards. Retrieved Apr 2007 from http://www.dmaa.org/education_awards.asp. Accessed October 5, 2007.

[38] Franciosi M, Pellegrini F, DeBerardis G, et al. Self-monitoring of blood glucose in non-insulin-treated diabetic patients: a longitudinal evaluation of its impact on metabolic control. Diabet Med 2005;22(7):900-6.

[39] Casalino LP. Disease management and the organization of physician practice. JAMA 2005; 293(4):485-8.

[40] Wexler R, Bean C, Ito D, et al. ME Cares: a statewide system engaging providers in disease management. Dis Manag 2004; 7(2):136-52.

[41] Bodenheimer T, MacGregor K, Sharifi C. Helping patients manage their chronic conditions. Oakland, CA: California HealthCare Foundation; 2005 June.

[42] Wasson JH, Ahles T, Johnson D, et al. Resource planning for patient-centered, collaborative care. J Ambul Care Manage 2006;29(3):207-14.

[43] Berg GD, Fleegler E, vanVonno CJ, et al. A matched-cohort study of health services utilization outcomes for a heart failure disease management program. Dis Manag 2005;8(1):35-41.

[44] American Diabetes Association. Standards of medical care in diabetes, 2006. Diabetes Care 2006;29(1):S4-S42.

[45] Lorig KR, Ritter P, Stewart AL, et al. Chronic disease self-management program: 2-year health status and health care utilization outcomes. Med Care 2001;39(11):1217-23.

[46] Lorig KR, Sobel DS, Ritter PL, et al. Effect of a self-management program on patients with chronic disease. Eff Clin Pract 2001;4(6):256-62.

[47] Stanford patient Education Research Center. Training for self-management programs. Available at http://patienteducation.stanford.edu/training/. Accessed October 15, 2007.

[48] Arnold SB, Folsom A, Bosk E. User's guide for monitoring and evaluating Medicaid fee-for-service care management programs. (Prepared by AcademyHealth under Contract No. 290-04-0001). Rockville, MD: Agency for Healthcare Research and Quality; in press.

[49] Participant satisfaction survey and usage guidelines. Washington, DC: Disease Management Association of America; 2006.

[50] Johnson A, Berg G, Fleegler E, et al. A matched-cohort study of selected clinical utilization outcomes for an asthma care support program. Dis Manag 2005;8(3):144-54.

[51] Pearson B, Katz SE, Soucie V, et al. Evidence-based care for depression in Maine: dissemination of the Kaiser Permanente Nurse Telecare Program. Psychiatr Q 2003;74(1):91-102.

[52] Villagra VG, Ahmed T. Effectiveness of a disease management program for patients with diabetes. Health Aff (Millwood) 2004;23(4):255-66.

[53] Lozano P, Grothaus LC, Finkelstein JA, et al. Variability in asthma care and services for low-income populations among practice sites in managed Medicaid systems. Health Serv Res 2003;38(6 Pt 1):1563-78.

[54] Outcomes guidelines report. Washington, DC: Disease Management Association of America; 2006.

[55] Aubert RE, Fulop G, Xia F, et al. Evaluation of a depression health management program to improve outcomes in first or recurrent episode depression. Am J Manag Care 3003;9(5):374-80.

[56] Mulcahy K, Maryniuk M, Peeples M, et al. Technical review. Diabetes self-management education core outcomes measures. Diabetes Educ 2003;29(5):768, 770, 773-84 passim.

[57] National Committee for Quality Assurance. HEDIS and quality measurement. Available at http://web.ncqa.org/tabid/59/Default.aspx. Accessed October 15, 2007.

[58] An analysis of the literature on disease management programs. Washington, DC: Congressional Budget Office, U.S. Congress; 2004 Oct.

[59] Sidorov J, Shull R, Tomcavage J, et al. Does diabetes disease management save money and improve outcomes? A report of simultaneous short-term savings and quality improvement associated with a health maintenance organization-sponsored disease management program among patients fulfilling Health Employer Data and Information Set criteria. Diabetes Care 2002;25(4):684-9.

[60] Dove HG, Duncan I. Paper 2: Actuarial issuesin care management evaluations. In: Evaluating the results of care management interventions: comparative analysis of different outcomes measures claims, Bachler R, Done H, Duncan I, et al., eds. Schaumberg, IL: Society of Actuaries; 2004 Aug. Available at www.soa.org/research/files/pdf/Paper2-Actuarial-Issues-Care-Mgmt-Eval.pdf. Accessed October 15, 2007.

[61] Duncan I. Paper 6: An actuarial method for evaluating disease management outcomes. In: Evaluating the results of care management interventions: comparative analysis of different outcomes measures claims, Bachler R, Done H, Duncan I, et al., eds. Schaumberg, IL: Society of Actuaries; 2005 Mar. Available at www.soa.org/research/files/pdf/Paper6-Actuarial-Methodology-for-Evaluating-DM.pdf. Accessed October 15, 2007.

[62] Duncan I, Owens R, Dove H. Paper 8: Testing actuarial methods for evaluating disease management savings outcomes. In Evaluating the results of care management interventions: comparative analysis of different outcomes measures claims, Bachler R, Done H, Duncan I, et al., eds. Schaumberg, IL: Society of Actuaries; 2006 May. Available at www.soa.org/research/files/pdf/Paper_8_TestingActuarial%20Methods.pdf. Accessed October 15, 2007.

[63] Steuten L, Vrijhoef B, Severens H, et al. Are we measuring what matters in health technology assessment of disease management? Systematic literature review. Int J Technol Assess Health Care 2006;22(1):47-57.

[64] Lewis A. Return on investment and savings methodology: this is our final answer. Wellesley, MA: Disease Management Purchasing Consortium; 2003.

[65] Mattke S, Bergamo G, Balakrishnan A, et al. Measuring and reporting the performance of disease management programs. Santa Monica, CA: RAND (WR-400); 2006 Aug.