The Robert Wood Johnson Foundation Diabetes Initiative

Demonstration Projects Emphasizing Self-management

Purpose

The purpose of the Diabetes Initiative of the Robert Wood Johnson Foundation is to demonstrate feasible and sustainable approaches to promoting diabetes self-management in primary care and community settings.

Methods

The Diabetes Initiative of the Robert Wood Johnson Foundation includes 14 demonstration projects in primary care settings and in community-clinical partnerships. Projects serve predominantly indigent populations from varied cultural and linguistic backgrounds in urban, rural, and frontier settings around the United States. This report describes the Initiative, its ecological perspective on self-management, and implications for program development, sustainability, and dissemination.

Results

Ecological perspectives stress varied levels of influence ranging from individuals to communities and policies. Based on this, the Initiative has identified key resources and supports for self-management (individualized assessment, collaborative goal setting, enhancing skills, follow-up and support, community resources, and continuity of quality clinical care). Lessons learned include the central roles of community health workers, integration of healthy coping and attention to negative emotion and depression in self-management, community partnerships, approaches to ongoing follow-up and support, organizational factors in sustaining programs, and the utility of a collaborative learning network for program development. Sustainability stresses organizational and policy supports for the program.

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Dissemination of lessons learned will stress collaboration among interested parties, stimulating consumer understanding and demand for self-management services as central to diabetes care.

Conclusions

The Diabetes Initiative demonstrates that effective self-management programs and supports can be implemented in real-world clinical and community settings, providing models of worthwhile, sustainable programs.

The Diabetes Initiative of The Robert Wood Johnson Foundation was designed to demonstrate sustainable diabetes self-management programs in real-world settings (Robert Wood Johnson Foundation Diabetes Initiative Call for Proposals). Through 14 demonstration projects around the country, the Initiative examines ways to advance diabetes self-management in primary care settings and to improve the network of community supports for self-management. Six projects were selected to demonstrate that comprehensive models of diabetes self-management can be delivered in primary care settings and can significantly improve patient outcomes. Eight projects were chosen to build supports for diabetes management in communities in recognition that diabetes management takes place primarily in settings of individuals’ daily lives. All sites chosen for the Initiative serve patient populations who are predominantly indigent, medically underserved, and/or from varied cultural and linguistic backgrounds. This article reviews the background for the Initiative and the ecological framework that has guided the Diabetes Initiative. It also provides a general overview of the Initiative and the grantees’ projects, including the approaches the Initiative has taken to facilitate quality improvement and evaluation. It then revisits the ecological framework as it points to the importance of organizational factors that are key to sustaining programs and are thereby key to maintaining self-management. It then closes by describing plans for disseminating lessons learned.

Background

Although neither the Diabetes Control and Complications Trial (DCCT) nor the Diabetes Prevention Program addressed self-management of type 2 diabetes per se, both demonstrated the success of patient education and self-management interventions. This has encouraged interest in such interventions for ongoing management of diabetes as well as other chronic diseases. In addition to these major national trials, patient education programs to promote diabetes self-management have reported strong and wide-ranging effects including improvements in self-efficacy, self-management, metabolic control, patient satisfaction, and quality of life.

Long-term (12-month) reductions in glycated hemoglobin similar to those reported in DCCT have been achieved through self-management training programs. Other controlled studies have demonstrated lasting improvements in quality of life as well as glycemic control. Such benefits have been demonstrated with older type 2 patients and ethnic minorities.

Additional support for the importance of patient education, patient behavior, and self-management in diabetes care is provided by 2 recent meta-analyses. To set criteria for inclusion of reports in these meta-analyses, self-management was defined as entailing (1) an explanation of the importance of self-management as a background to management efforts and (2) instruction in key skills for self-management, including weight management, physical activity, medication management, and blood glucose monitoring as well as other tasks specific to diabetes management. These meta-analyses demonstrate the importance of patient education and self-management for long-term maintenance of benefits. Within the diabetes interventions, the only program feature that was uniquely predictive of success was duration of contact. “Interventions with regular reinforcement are more effective than one-time or short-term education.” The prediction of benefit by length as well as by variety of treatment has also been observed in meta-analyses of smoking cessation interventions and of a variety of patient education programs addressing health risks or health-promoting behaviors (eg, breast self-examination). Thus, self-management does not equip individuals somehow to become autonomous diabetes management machines. Rather, self-management is dependent on ongoing encouragement, reinforcement, and facilitation for the rest of the individual’s life, which is critical for maintaining health benefits for patients with chronic conditions such as diabetes.

Chronic disease requires chronic care.

The need for ongoing support and resources in diabetes management leads to recognition of needs for continuity
of quality clinical care; support from family, peers, and friends; community resources such as attractive, safe places for physical activity and accessible sources of healthy food; and ongoing patient education and counseling to address problems in management and changes in life circumstances (such as retirement or widowhood). It also leads to a heightened interest in the organizational and policy influences that may sustain patient education and self-management programs. These concerns lead to an ecological perspective in framing self-management and programs to promote it.18

Ecological Framework

Ecological perspectives link the multiple levels of influence on individual health behavior. The philosophical underpinning of an ecological model is the concept that behavior does not occur within a vacuum.19 At the individual level, the behavior of the adult with diabetes is influenced by education and clinical care and perhaps personal counseling, as well as by the individual's own history, genetics, and personality characteristics. But additional influences include the family, neighborhood, coworkers, and organizational and community policies regarding, for example, care of diabetes in the workplace or access to attractive places for physical activity. In addition, community- and policy-level influences determine the kinds of health care and health services available to the individual. Thus, an individual's healthy eating—or glycated hemoglobin value—is affected by a range of factors extending through family and friends to workplaces, communities, and governments.20 As will be discussed in more detail, considering these multiple ecological levels may be especially helpful in addressing ways to sustain programs and supports to management efforts of individuals.

In recognition of these multiple influences, the Diabetes Initiative developed a model of a person's needs for resources and supports for self-management (RSSM). These include services delivered at the individual level as well as supports and access to resources at the level of family, community, and policy. RSSM include the following:

- Individualized assessment, including consideration of cultural perspectives and other characteristics of individuals’ lives that may frame self-management.
- Collaborative goal setting, including emphasis on specific plans for self-management that are developed with the individual.
- Skills for self-management, including disease-specific skills (eg, self-monitoring of blood sugar and medication management) and more general skills, such as those related to healthy diet, physical activity, weight management, problem solving, healthy coping, and cultivating healthy relationships.
- Ongoing follow-up and support, including social support, motivation, and encouragement of healthy behaviors. Ongoing follow-up and support are critical predictors of both maintenance of behavior as well as clinical improvements in health promotion programs.15-16
- Community resources, including safe, accessible, and affordable opportunities for physical activity, convenient and affordable sources of healthy food, and supplies needed for diabetes management, such as for blood glucose monitoring. Community linkages and coordination among providers of services and resources are important facilitators of access to resources.
- Continuity of quality clinical care, including having a regular source of primary care, planned visits, and routine laboratory visits for monitoring with providers who are patient centered and provide linkages to supportive services that facilitate patient self-management.

As can be seen, there is some correspondence between individual RSSM and the several ecological levels. For example, collaborative goal setting tends to be addressed at the individual level or, in some cultural settings, the family level, whereas access to resources for physical activity and healthy food may best be addressed at the community and policy level. But the real contribution of the ecological perspective may be not its identification of multiple levels of influence but its emphasis on interaction among those levels.21 Thus, assessment and goal setting, teaching of self-management skills, and ongoing support and monitoring of both self-management and clinical status are provided not just through interactions between patients and health care providers within the clinical setting but also through a host of social, organizational, and policy influences outside that setting. As discussed below, considering all ecological levels of influence is especially important in planning how to sustain RSSM.

Grantees of the Diabetes Initiative

Reflecting the breadth of ecological influences on diabetes management, the Diabetes Initiative includes 2 programs: one focused on promoting self-management in primary care settings (Advancing Diabetes Self-management) and the second promoting self-management and diabetes care through community-based partnerships (Building...
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Community Supports for Diabetes Care). Together, these include 14 grantees in diverse locations and address diverse audiences, outlined in Table 1. From more than 300 applications received in September 2002, 14 were awarded and commenced a 15-month planning phase on February 1, 2003. They each began 30-month implementation phases of their projects on May 1, 2004. The Diabetes Initiative National Program Office at Washington University in St Louis and the University of North Carolina at Chapel Hill oversees and provides technical assistance to the 14 grantee organizations, all of whom use the same general framework of RSSM but with approaches tailored to the needs and strengths of individual program sites and the populations they serve.

Technical Assistance via a Collaborative Learning Network

Wagner’s chronic care model has gained substantial attention in recent years as an approach to integrating multiple systems changes and organizational factors underlying quality care. Technical assistance for the Diabetes Initiative has drawn from this approach. The components of the chronic care model emphasizing self-management support and community support have posed challenges to implementation and quality improvement. Thus, part of the rationale for the Diabetes Initiative was to identify feasible program models in these areas and approaches to providing technical assistance that would promote self-management and community supports.

The Initiative uses a collaborative learning network as an innovative means of providing technical assistance to grantees. The term collaborative learning network (CLN) refers to a wide variety of approaches used to facilitate evidence-based and scholarly application of existing and new knowledge to diabetes self-management care by the grantees. Central to this approach are 10 CLN meetings over the course of the 45 months of funding of grantees’ projects. These meetings have 2 main purposes: (1) to explore key issues and challenges facing providers and communities committed to improving self-management care, services, and client outcomes for persons with type 2 diabetes and (2) to facilitate collaborative learning, teaching, creative problem solving, and product development among grantees to improve self-management care, services, and client outcomes for adults with type 2 diabetes. A typical meeting lasts 1.5 days and includes (1) presentations on new materials of interest to the programs and the grantees, (2) breakout sessions in which grantees make explicit plans for using the new materials presented, (3) workgroup sessions addressing key issues that have emerged in working with the grantees (eg, how to address depression, community health worker/promotora/coach interventions, application of the transtheoretical model, and primary care and resources and supports for self-management), and (4) quality improvement sessions on topics such as developing intervention strategies to meet key subgroup objectives.

The quality improvement sessions at the CLN meetings center on planned improvement cycles (PICs). These PICs have been adapted from the Plan-Do-Study-Act cycles of rapid improvement that are used in quality improvement collaboratives of the Institute for Healthcare Improvement. During a PIC, improvement tasks are broken down into key steps. Iterative cycles include (1) brief presentations on each step, (2) 15 to 20 minutes for grantees to plan application of the step within their own project, and (3) general discussion of grantees’ plans, followed by repetition of the cycle with the next step. This process provides grantees the opportunity both to make specific plans for quality improvement around topics under discussion as well as to gain from the examples of their peers within each step. It also provides leaders the opportunity to monitor the grasp of each step in presenting and discussing subsequent steps.

Between meetings, workgroups continue activities focused on specific issues through teleconferences, workshops, Web site postings, and e-mail and telephone contact. The National Program Office has also made site visits to each grantee, focused on helping grantees to identify their own quality improvement and programmatic emphases and to pursue these. Training in the self-management programmatic approach of Lorig has also been provided to 11 of the 14 grantees who have used this not only to implement the Chronic Disease Self-management Program but also to enhance staff skills for a range of self-management activities. Additional training sessions on timely topics are held as new issues emerge (eg, the roles of community health workers in assisting with depression and negative emotions). Grantees play a substantial role in guiding the topics and emphases of the CLN.
Evaluation of the Diabetes Initiative

Supported by a contract from The Robert Wood Johnson Foundation, RTI International is conducting an evaluation across all 14 sites. This evaluation includes a 3-wave survey over the course of the 30-month implementation phases of the grantees’ projects, as well as assessment of clinical outcomes (glycated hemoglobin, blood pressure, lipids, and key diabetes care indicators such as eye examinations). This evaluation will integrate (1) implementation of RSSM, (2) participants’ reports of access to and use of those RSSM, (3) participants’ reports of engagement in diabetes care including self-management patterns, and (4) clinical and quality-of-life outcomes. The many sites of the Diabetes Initiative will make this a powerful database to assess the relationships among implementation and use of RSSM and their impacts on engagement in diabetes care and improved clinical status and quality of life.

In addition to the evaluation across all 14 sites, individual grantees have plans for evaluating their overall programs and/or key components of them. Also, groups of grantees interested in specific topics will collaborate with the National Program Office to evaluate a number of key topics, including the integration of interventions for healthy coping (as in the AADE7 Self-Care Behaviors™, available at http://www.aadenet.org/AADE7/index.shtml) and attention to depression in diabetes self-management, roles and effects of community health workers (promotoras, coaches, lay health workers, etc), approaches to providing ongoing support and encouragement for diabetes management, and organizational resources and supports for self-management in primary care.

Ecological Framework and Sustainability of Programs

As noted in the beginning of this article, a critical need for diabetes management is ongoing access to RSSM. Benefits among individuals will be maintained...
only if programs and activities are themselves sustained. Through their emphasis on relationships among different ecological layers, ecological perspectives highlight the importance of organizational and policy influences in providing or facilitating the kind of ongoing support for disease management that is critical to sustain benefits of self-management programs. Without supports for key RSSM at the organizational and policy levels, individual- and group-level services (e.g., reimbursed patient education) along with group- and community-level supports and resources (e.g., maintenance of neighborhood walking trails) will all wither. Examples of these relationships among ecological levels of influence, RSSM, and individual outcomes are illustrated in Figure 1. It should be emphasized that Figure 1 does not provide a detailed accounting of organizational/policy influences and RSSM but merely examples of how organizational- and policy-level factors may influence availability of RSSM and in turn individual self-management and outcomes.

Thus, just as individuals need support for self-management behaviors, programs and services in organizations need support from their systems. As an example of how this is being addressed in the Diabetes Initiative, a workgroup of grantees has focused on developing an assessment of primary care resources and supports for chronic disease self-management to assist primary care organizations. This instrument assesses an organization’s capacity to provide self-management services and to identify areas for quality improvement. Grantees are encouraged to identify and cultivate organizational and administrative supports for programs and to develop programs that are sustainable after the end of their external funding.27 In addition, grantees are encouraged to share approaches to building support for programs within their organizations, with local health financing and health provider organizations and with state and regional governmental bodies.

**Dissemination: Lessons to Be Learned and Promoted**

In addition to the broad evaluation of the program and its demonstration of self-management in real-world settings, the Diabetes Initiative will generate lessons to be promoted in a variety of areas. These lessons have emerged out of the CLN and interactions among grantees, the National Program Office, The Robert Wood Johnson Foundation staff, and advisers. They include the following:

1. approaches to integrating attention to depression, negative affect, emotional health, and healthy coping into services promoting diabetes self-management;
2. the roles and contributions of community health workers in diabetes self-management;
3. diverse tactics for providing ongoing support and encouragement for diabetes self-management;
4. approaches for assessing and improving organizational resources and supports for self-management programs and services in primary care settings;
5. program strategies to address the unique cultural features of specific groups;

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6. the value of clinic/community partnerships in supporting self-management;
7. approaches to system changes that incorporate community health workers into the delivery of diabetes self-management programs and services; and
8. the utility of the CLN to foster program improvement around shared themes (eg, diabetes self-management, general approaches to chronic care, prevention through lifestyle risk reduction).

For each of these, papers will describe the various programmatic approaches, barriers encountered, and ways of overcoming them. In addition, program and training models and materials will be made available through the Initiative’s Web site (www.diabetesinitiative.org) or through organizations that may be interested in collaborating to disseminate specific lessons learned. With an eye toward sustainability, development of program materials and models for dissemination will emphasize feasibility of these demonstration projects.

Dissemination may be advanced through the push of data and model programs and actionable recommendations. It may also benefit from the pull of demand for improved services. The public, including those with diabetes, has tended not to recognize the breadth of resources and supports for diabetes management that may be helpful. To address this, an important lesson learned and dissemination objective of the Diabetes Initiative is using the examples of the 14 grantees’ real-world model programs to increase general understanding of what resources and supports should be available for diabetes self-management. Dissemination will encourage wider understanding that high-quality diabetes care is not just quarterly visits to an expert physician, review and revision of treatment regimens, and encouragement of medication adherence and weight loss. Rather, high-quality care also includes such things as (1) access to classes or Web-based services teaching healthy eating, approaches to physical activity, or problem solving and healthy coping; (2) monthly follow-up and encouragement from as well as ready access to a certified diabetes educator or trained community health worker; (3) assistance in identifying resources for buying healthy food and finding places for physical activity in one’s community; and (4) proactive approaches to changing management plans over the course of many years with diabetes and as needs change, such as through retirement or widowhood. In the terms of the “elevator conversation,” people with diabetes need regular medical care that includes collaboration in setting management goals, help in learning the skills they need to achieve those goals, encouragement and follow-up to keep them motivated, help solve problems that emerge, and recognize when plans need to be changed. Greater understanding—and demand— for such resources and supports among those with diabetes, their families, and the general public should facilitate support of improved policies by health care providers and government.

Summary and Conclusions

The Diabetes Initiative is positioned to demonstrate that effective self-management programs and supports can be implemented in real-world clinical and community settings and will provide the field models for implementing and sustaining worthwhile programs. Under this broad umbrella of demonstration that “it can be done,” evaluation and lessons learned will show the contribution to observed improvements of the various categories of RSSM and various strategies for implementing each of those categories. The large data set acquired through the cross-site evaluation should support powerful multivariate analyses examining relationships among the different categories of RSSM, demographic and control variables, and outcomes in metabolic control, engagement in diabetes care, and quality of life. These analyses will also demonstrate components in the chronic care model addressing self-management support and community resources and policies that have been difficult to implement in many settings.

A key concept in ecological models is that the levels of influence are, in turn, influenced by each other. Thus, policy and community factors influence family factors that in turn influence individuals within those families. Ecological models alert us not only to the range of influences on individuals’ self-management but also to the range of influences on programs to enhance that self-management. Thus, the Diabetes Initiative highlights the broad range of influences on the diabetes management of those its programs would help as well as the broad range of influences on those programs themselves.

Diabetes is widely recognized as a model of chronic disease. Almost any topic of pertinence in chronic disease management is present in diabetes management. This includes lifestyle factors in prevention and management, medication management, end-of-life issues, impacts on and influences of family, and coping with a
wide range of complications. Thus, the lessons learned from the Diabetes Initiative should guide chronic disease care in general as, with the aging of the population, chronic diseases become ever greater objects of attention in health and health care.

References