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Perspectives on Self-Management From the Diabetes Initiative of the Robert Wood Johnson Foundation

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Purpose and Method

Review and highlight findings from the projects of the Diabetes Initiative of the Robert Wood Johnson Foundation[®] described in this special supplemental issue.

Results

The broad framework for self-management around which these programs were developed, "Resources and Supports for Self Management," includes individualized assessment, collaborative goal setting, building skills for self-management, ongoing follow-up and support, community resources, and continuity of quality clinical care. Lessons learned include the central role of community health workers in self-management, the importance of ongoing follow-up and support to sustain self-management, varied program approaches to depression and negative emotion, the importance of organizational infrastructure to support self-management programs, and the contributions of clinic-community partnerships. Several emergent themes include the value of providing choices among "good practices" as opposed to one best practice, the role of the physician as part of the self-management team, and the importance of broad efforts in promoting dissemination of self-management programs. Finally, self-management will benefit from replacing categorical distinctions, like good and bad control, proven and unproven treatment, with thinking in terms of key dimensions, like level of control and continued quality improvement.

Conclusions

Diabetes Initiative projects have shown that diabetes self-management can be promoted in the "real worlds" of community agencies and primary care settings serving diverse and disadvantaged populations.

Perspectives on the Diabetes Initiative of the Robert Wood Johnson Foundation

The purpose of the Diabetes Initiative of the Robert Wood Johnson Foundation was to show that diabetes self-management can be implemented in real-world settings including those serving ethnic minority and groups living with disadvantage.¹ The 14 grantees of the Initiative have made clear the feasibility of a variety of specific approaches to self-management in their settings, many of them challenged by limited resources and service to populations facing varied and substantial economic and social challenges. The articles in this supplement tell the stories of the Initiative. In addition to the broad lesson that self-management programs can be implemented in real-world settings, the articles provide many specific lessons regarding how it may be done. This article will summarize key perspectives and lessons learned in the Initiative and then describe broader perspectives that emerge from the grantee projects and their implications for growing support for self-management in practice settings, systems, and policies. General information regarding the Initiative and program resources for the field are available through its Web site, <http://diabetesinitiative.org>.

Resources and Supports for Self Management

Imagine an earnest health care executive eager to learn about self-management and attending a meeting of the American Association of Diabetes Educators (AADE) or, perhaps, the Society of Behavioral Medicine. In symposia, paper sessions, and casual conversations during the meeting, the earnest executive hears a variety of messages that the AADE 7 Self-Care Behaviors™ are critical, that the Chronic Care Model is the answer, that Lorig's chronic disease self-management program will show the way, that

motivational interviewing is the secret for helping people "get off the dime" and act to improve their health, that the transtheoretical model of Prochaska and colleagues is the way to develop programs that meet the needs of individuals regardless of their readiness for change, that the physician-patient relationship and goal setting within the medical encounter are critical, that the diabetes educator is central, that nothing will be sustained without social support, that communities and worksites may be critical settings for improving self-management, and on and on. We may easily imagine the still earnest but now highly confused executive beginning to think that the health care system's pharmacy formulary looks simple!

The Diabetes Initiative faced a similar dilemma as the executive. Amid the vast literature on patient education, self-management, and related interventions in diabetes and other areas of health care, how could one identify key approaches to diabetes management that could provide some guidance to 14 grantees in diverse settings and, at the same time, provide them ample room to tailor their programs to the populations they serve, their settings, and their organizational strengths?

In response to this challenge, the National Program Office of the Initiative recognized the advantages of identifying not key intervention techniques or approaches but key functions that those techniques need to serve. Thus, for example, tailoring of goal setting to the individual may be accomplished by motivational interviewing,² an intervention based on the transtheoretical model,³ or an interactive e-health resource.⁴ What counts is not so much which of these is most effective in a trial in a university research setting but that the one chosen is generally effective, is feasible in the setting in which it is to be used, and is pertinent and acceptable to the population for which it is intended.

An additional strategy in identifying key functions was doing so from the perspective of the individual. The authors sought to identify not the key ingredients in one organization's program but the things individuals need—from their families, communities, health care providers, etc.—to live good lives with diabetes. This strategy was also intended to reflect the breadth of settings encompassed in the Initiative and provide a common framework with which to work in collaborative quality improvement processes.

Based on review of the literature, the key functions identified have been framed as the "Resources and Supports for Self Management" that individuals need to

manage their diabetes.³ The grantees were not given specific approaches to each of these but were encouraged to identify specific approaches from extant literature and from a consideration of the specific needs and preferences of the populations they serve as well as their own organizational resources and capacity. The Resources and Supports for Self Management are outlined in Table 1 along with key observations from other articles in this issue illustrating each.

This approach reflects the principle of equifinality observed in organizational development and behavior⁴; that is, there are multiple effective approaches to reaching similar ends, and what is often critical is not the variation in operational detail but the common end or function operations achieve.

Within the broad range of resources and supports for self-management, the projects of the Diabetes Initiative have generated numerous lessons learned about approaches to specific resources and supports, program development, and program implementation.

Key Lessons Learned

Central Role of Community Health Workers in Diabetes Self-Management

As described in an article by Davis et al⁷ in this issue, community health workers (CHWs) offer unique services and functions not provided by traditional health care teams. The most common roles of CHWs entail substantive contributions to Resources and Supports for Self Management, such as

- teaching and helping patients practice diabetes self-management skills, such as those dealing with physical activity, healthy eating, monitoring blood glucose, and taking medicines appropriately;
- problem solving and providing assistance in problem solving to fit management plans into patients' lives and providing encouragement and motivation for diabetes management that is "for the rest of your life"; and
- emotional support including support for healthy coping and coping with depression and other negative emotions.^{7,8}

Ongoing Follow-up and Support

As described in the article by Fisher et al⁹ on this topic in this issue, a reliably observed predictor of sustained self-management and benefits from it is the duration

and variety of interventions. Grantees have developed program extensions that take into account the fact that individuals need convenient access to talk to someone when they need to get a question about their diabetes answered. At the same time, they need to be contacted periodically to see how they are doing even if they have not had the time to check in with their diabetes team. Thus, both routine contacts by the provider as well as as-needed options for patients are key to sustained self-management. *Choice* is the operative word.

Additional Lessons Learned

In addition to the central roles of CHWs and ongoing follow-up and support, several other lessons learned from the Diabetes Initiative are not addressed extensively in articles in this issue but are important to self-management programs. They include the following.

Attention to depression, negative emotion, and healthy coping as key parts of self-management. While research suggests that about 25% of people with diabetes are also depressed, that percentage was as high as 70% in some of the sites of the Diabetes Initiative.¹⁰ There is very little in practice guidelines about attending to depression and negative emotions in diabetes management. Diabetes Initiative projects are implementing a number of intervention strategies, including (1) use of CHWs on the team to screen, support treatment plans, and provide education, follow-up, and support; (2) incorporation of psychologists, social workers, or other counselors into the patient care team, augmenting medical treatment with behavior therapy; and (3) support groups led by behavioral health specialists. Nine of the 14 sites collaborated in a workgroup on depression. All 9 of these were able to implement some type of psychosocial intervention as well as screening and prescribing of antidepressants where appropriate.¹⁰

In addition to dealing with depression, virtually all 14 sites are incorporating attention to healthy coping as a routine part of their self-management programs.

Infrastructure to support self-management. Health care systems must have an infrastructure to support patient self-management. Grantees of the Diabetes Initiative developed an assessment and quality improvement tool for use in primary care settings to help teams identify ways in which they can improve organizational

Table 1

Resources and Supports for Self Management and Examples and Program Materials From the Diabetes Initiative

Resources and Supports for Self Management	Programmatic Examples and Program Materials From the Diabetes Initiative
Individualized assessment, in consideration of individual's perspectives and cultural factors Collaborative goal setting	Use of the transtheoretical model ²⁶ Diabetes Initiative individual assessment resources ^a Staff training on goal setting ²⁷ System changes to promote goal setting for self-management ²⁸
Building skills for self-management, including skills for healthy coping and problem solving	Diabetes Initiative goal-setting resources ^b Diabetes self-management classes ^{c,d,e} Community health worker interventions ^{7,14,29} Diabetes Initiative issue brief: <i>Healthy Coping Skills: Essential for Self-management</i> ^f Diabetes Initiative skill-building resources ^{g,h,i,j,k,l,m}
Ongoing follow-up and support to help individuals maintain diabetes management	Social support provided by community health workers ^{7,8,28,n} Multiple intervention options to provide choice of type and intensity ¹⁵ Group medical visit and planned visit models ^{26,o} Medical group visits: a team approach to promote self-management ^p Diabetes Initiative issue brief: <i>Ongoing Follow-up and Support: Strategies for Successful Self-management</i> ^q
Community resources	Clinic-community partnerships ^{19,r} Peer interventions in community settings ^{8,29,s} Community member engagement in program planning and implementation ^t Spread through community partners ^{4,u} Diabetes Initiative issue brief: <i>Clinic-Community Partnerships: A Strategy for Building Community Supports for Diabetes Care</i> ^v
Continuity of quality clinical care	System changes to increase provider time for goal setting and supporting self-management during patient visits (grantee paper in development) System changes to integrate self-management into procedures of primary care ^{13,16,17} Tools for measuring organizational capacity for self-management ^w Diabetes Initiative issue brief: <i>Organizational Capacity for Diabetes Self-management in Primary Care</i> ^x Group medical visits ^{30,31}
<p>a. http://diabetesnpo.im.wustl.edu/resources/topics/IndAssessment.html b. http://diabetesnpo.im.wustl.edu/resources/topics/GoalSetting.html c. http://diabetesnpo.im.wustl.edu/programs/DICAA.html d. http://diabetesnpo.im.wustl.edu/programs/DIGalveston.html e. http://diabetesnpo.im.wustl.edu/programs/DIMT-WY.html f. http://diabetesnpo.im.wustl.edu/lessons/documents/Coping_10-25.pdf g. http://diabetesnpo.im.wustl.edu/resources/tools/patientEdMaterials.html h. http://diabetesnpo.im.wustl.edu/resources/topics/PhysicalActivity.html i. http://diabetesnpo.im.wustl.edu/resources/topics/HealthyEating.html j. http://diabetesnpo.im.wustl.edu/resources/topics/HealthyCoping.html k. http://diabetesnpo.im.wustl.edu/resources/topics/SmokingCessation.html l. http://diabetesnpo.im.wustl.edu/resources/topics/SelfManBehaviors.html m. http://diabetesnpo.im.wustl.edu/resources/topics/GoalSetting.html n. http://diabetesnpo.im.wustl.edu/programs/documents/LAC-AADE.2006forWEB.pdf o. http://diabetesnpo.im.wustl.edu/programs/DISPFM.html p. http://diabetesnpo.im.wustl.edu/programs/documents/24-WV-GrMedVisistsDeltaCommission.pdf q. http://diabetesnpo.im.wustl.edu/lessons/documents/Follow_Up_And_Support_10-25.pdf r. http://diabetesnpo.im.wustl.edu/programs/DIRichland.html s. http://diabetesnpo.im.wustl.edu/programs/documents/GALV-AADE.2006forWEB.pdf t. http://diabetesnpo.im.wustl.edu/programs/documents/CPSTN-MAIC.final.pdf u. http://diabetesnpo.im.wustl.edu/programs/documents/10-WV-HELPHYOURSELFUpdate9-05APHA.pdf v. http://diabetesnpo.im.wustl.edu/lessons/documents/Partnership_1-17-07_000.pdf w. http://diabetesnpo.im.wustl.edu/lessons/tools.html x. http://diabetesnpo.im.wustl.edu/lessons/documents/Org_Capacity_1-17-07_000.pdf</p>	



Resources and Supports for Self Management (<http://diabetesnpo.im.wustl.edu/lessons/tools.html>), complementing Wagner's Chronic Care Model.¹¹ This tool is currently being used in a number of initiatives nationwide and for a number of health conditions. The tool has helped systems identify and address areas for improvement.¹²

A number of articles in this supplement address issues in organizational support for self-management and integrating self-management into primary care and other settings.¹³⁻¹⁸ In addition, the Initiative has developed an issue brief titled "Organizational Capacity for Diabetes Self-management in Primary Care" that is available through its Web site (http://diabetesnpo.im.wustl.edu/lessons/documents/Org_Capacity_1-17-07_000.pdf).

Clinic-community partnerships. Partnerships between clinical and community settings can make important contributions to building community supports for diabetes care. Partnering expands the capacity of each participating agency—and of the partnership collectively—to support self-management in daily life and to increase community resources for diabetes management. Working together extends the range, variety, and coordination of services and supports available. Diabetes Initiative projects demonstrated various types of partnerships to support diabetes care and self-management in their respective sites. These partnerships range from one clinic working with one community organization to broad networks of agencies working together.¹⁹

General Emergent Themes

In addition to the lessons learned regarding specific programmatic approaches, a number of broader, cross-cutting observations have emerged from the Diabetes Initiative that can help at a strategic level to guide program development. These include the following.

The Law of Halves, Best Practices, Good Practices, and Choice

As Russell Glasgow has pointed out,²⁰ health care is beset by the law of halves, in which, stated broadly, only about half of those for whom an intervention is appropriate will accept it, only about half of those will follow it, and only about half of those will benefit, now down to one eighth of those of concern. One of the major challenges facing diabetes care is the fact that approximately

60% to 70% of patients with diabetes have not received self-management interventions.²¹ It is unlikely that any patient education intervention, subject as they all are to individual preference and choice in acceptance, will break the law of halves and reach most of those who need to benefit. Thus, diabetes self-management needs to include choices for participants among channels and emphases of interventions. From a program-planning perspective, this suggests an emphasis on identifying many good practices that are feasible in their operational settings and pertinent to intended audiences.

Physician as Part of the Team

There is a tendency in the field to see self-management as somehow opposed to or as an alternative to clinical care. An important point of Resources and Supports for Self Management⁵ is its inclusion of continuity of quality care as a resource the individual needs in order to live life with diabetes. Thus, clinical care is a vital ingredient in self-management.

Reciprocally, self-management resources and supports are critical for clinical care. Without them, the physician's best advice and prescription become a wish and a prayer. Moreover, with robust supports for self-management, the physician does not have to "do it all" but can focus on her or his specific contributions to self-management. As one physician at Gateway Health Center in Laredo, Texas, put it, "The self-management program [has] made my life easier—I can focus on being a doctor."

Teamwork in Dissemination

Dissemination entails teamwork both in the groups that have to cooperate in integrating and receiving disseminated practices and in the efforts to promote their acceptance. Just as there is no magic bullet in the behavior change of self-management, so there is no magic bullet in dissemination. The grantees' programs are the strongest evidence for the feasibility of self-management in real-world settings. The tools and lessons learned that have come out of their projects are the building blocks of program dissemination to other settings and populations. The prestige of the Robert Wood Johnson Foundation and the research literature on which it built this program provide credibility to the dissemination effort and gain it the attention of key groups.

On the receiving end of dissemination, no one group is either necessary or sufficient. Professionals, professional

organizations, and voluntary organizations all have key roles in setting and meeting standards for diabetes care. Health provider organizations and payers are critical to supporting programs. Government and policies at national, state, and local levels are critical in accepting and formalizing key lessons learned as regulations able to secure programs that implement those lessons.

Dimensions, Not Categories

The field of self-management and discussions of it contain a number of categorical distinctions: good versus bad control, active treatment versus post treatment, new program versus established program, and best treatments versus unproven treatments. Each of these is probably well replaced by a dimension rather than a category. It is known that the relationship between metabolic control and complications is more of a dose-response, linear relationship between blood sugar levels and the probability of complications than a categorical relationship in which crossing some threshold from good to poor control leads to a rise from normal to heightened risk.²² The more days of one's life that blood sugars are in the normal range, the better. Thus, it is closer to the facts to see individuals in terms of the extent to which they are able to achieve near-normal blood sugar levels for many days of their lives rather than in terms of a categorical assignment to good versus bad control. This has implications for interventions. Every day patients can practice self-management; every healthy meal they eat and every walk they take are bits of progress toward managing diabetes and reducing complications.

An important categorization to purge from our thinking is treatment versus post treatment. Diabetes—and self-management of diabetes—are “for the rest of your life.”⁹ Treatments need to be developed that extend into ongoing follow-up and support and that reflect the kinds of supports and resources individuals need for their life-long journey with diabetes.

The distinctions between new and established programs and between best treatments and unproven treatments need to be replaced with recognition that programs, like the people they serve, exist and grow. That growth needs to be guided by continued quality improvement efforts that bring to programs new or expanded approaches as they become available. This kind of continued program growth is more likely to provide the kinds of ongoing resources and supports individuals with diabetes need than an assembly

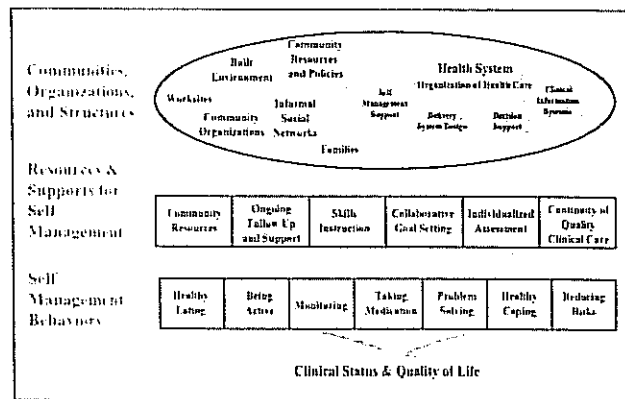


Figure 1. Trilevel model of self-management and chronic care.

of distinct treatments or programs. This perspective also recognizes the importance and, perhaps, the inevitability that programs are rooted in the settings in which they are implemented. Those settings will influence the programs they host. Recognition of this will increase the likelihood that programs provide an effective web of resources and supports in individuals' daily lives.

Self-Management as Central to Diabetes Management

From the perspective of the individual, self-management entails those things she or he can do to live a full and satisfying life with diabetes. As noted above, clinical care is a critical part of the resources and supports the individual needs to support her or his self-management. For the individual, however, the task is self-management, not medical care. Thus, the individual's self-management and all the resources and supports critical to developing and sustaining effective and satisfying lifestyles of self-management are the center of diabetes care. Recognition of this is critical if the many resources and supports for self-management not encompassed by traditional clinical care are to receive the organizational, fiscal, and policy supports needed to make them widely and effectively available.

Figure 1 provides a general perspective on how self-management can be viewed in broad contexts of (1) communities, structures, and organizations that provide the base for (2) the resources and supports that are available to people and (3) the self-management behaviors that result. Wagner's Chronic Care Model¹¹ provides a start at specifying key elements at the community, organizational, and structural level. It details elements of clinical and health



care systems that provide an organizational base for self-management and other important components of patient-centered clinical care. However, to reflect the breadth of organizations and social structures that are pertinent to self-management throughout individuals' daily lives, we have added the built environment, community organizations, worksites, informal social networks, and families. Greater elaboration of the breadth of communities, organizations, and systems that are pertinent to laying the groundwork to support self-management throughout individuals' daily lives is an important area for development of our knowledge and our programs.

The first level of communities, organizations, and systems provides the base for the next level of the model that addresses resources, supports, or services as they are implemented and available so that individuals may have what they need to do self-management. Resources and Supports for Self Management fit here as the things individuals need to have available to live their lives with diabetes. As an example of these first 2 levels in Figure 1, the alignment of Information Systems and Delivery System Design of the Chronic Care Model may make patient encounters opportunities for self-management. This would provide the base for Resources and Supports for Self Management such as individualized assessment and opportunities for collaborative goal setting. In a sense, the organizational level articulates the organizational means to the service end of providing Resources and Supports for Self Management. Using an example involving community resources, consider a well-funded parks department and city policy to make "our town" a healthy one. This community/organization/system base might support, at the level of Resources and Supports for Self Management, the presence of a walking path in one's neighborhood.

Just as the level of communities, organizations, and systems articulates the means to the end of providing Resources and Supports for Self Management, the Resources and Supports for Self Management level provides the means for individuals to do self-management. Individual-level self-management behaviors comprise the next level, articulated for the purposes of a diabetes focus as the AADE 7 Self-Care Behaviors™.²³ Taken as a whole, the figure outlines layers from organizational, community, and social structures to resources and supports for individual behavior to articulation of the 7 key behaviors that comprise diabetes self-management. These all then lead to clinical status and quality of life.

All 3 levels are needed and complementary. Without organizational grounding, services with behavioral goals will not be integrated into systems and will not receive the underpinnings they need to be provided reliably. They would constitute a plan without a structure to support it. Without identifying the Resources and Supports for Self Management, organizational structures will lack a plan for promoting, teaching, and supporting self-management behaviors. They would be a structure without an operational plan. Without articulation of the self-management behaviors, the organizational structures and the resources and supports will lack objectives to guide exactly what it is they should be promoting, teaching, and supporting. They would be a structure and operational plan with no objectives.

There is a rough correspondence between the levels in Figure 1 and the levels of ecological perspectives,^{24,25} running from communities and policies through systems, groups, and cultures to proximal social influences and, finally, the individual and her or his biological and psychological characteristics and patterns of living. This framework may help make sense of how systems, clinical care, Resources and Supports for Self Management, the behavior of individuals, and the settings of our lives may all be integrated.

Elevator Conversation

Consider again the confusion of the health care executive considering the vast range of self-management interventions and techniques. The fields of patient education, diabetes education, behavioral medicine, and public health need to understand that their many models and favorite approaches are not mutually exclusive or at war but can be viewed as substitutable, complementary approaches to key common functions such as the Resources and Supports for Self Management laid out in the Diabetes Initiative. That particular list of resources and supports is not cast in stone and certainly should be revised. It should be revised with an eye toward maintaining its organization as a compilation of common functions, not as new approaches to meeting them.

To make this all sensible and understandable to the earnest health care executives of the world, policy makers, and those with diabetes who need a way to think about what they need that makes sense in their lives, the authors suggest and close with the following elevator conversation.

Premise: The average individual with diabetes will spend a few hours each year in a physician's office. That leaves somewhat more than 8760 hours each year on your own!

To guide their lives for those 8760 hours per year, individuals with diabetes need

1. good health care,
2. someone with whom to figure out how they want to manage their diabetes,
3. the opportunity to learn the skills they need to manage diabetes the way they want, and
4. ongoing support to help them
 - a. figure out how to implement their plan,
 - b. stay motivated when things get tough, and
 - c. get back in touch with the clinic when they need to.

This simple message may capture what is meant by self-management as more than just good clinical care, and it may do so in a way that makes sense to individuals with diabetes, the families and friends who care about them, professionals, and those responsible for guiding health care systems and communities.

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