

Empowerment and Self-Management of Diabetes

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In spite of the great strides that have been made in the treatment of diabetes in recent years, many patients do not achieve optimal outcomes and still experience devastating complications that result in a decreased length and quality of life. Providers often struggle to give the recommended level of diabetes care within the constraints of a busy office setting. Because our health care system is designed to deliver acute, symptom-driven care, it is poorly configured to effectively treat chronic diseases such as diabetes that require the development of a collaborative daily self-management plan. Providers also struggle with the realities of dealing with a chronic disease for which daily care is in the hands of the patient. In spite of our attempts to encourage, cajole, and persuade patients to perform self-care tasks, we are often frustrated and discouraged when patients are unwilling to follow our advice and achieve the desired outcomes.

Traditionally, the success of patients to manage their diabetes has been judged by their ability to adhere to a prescribed therapeutic regimen. A great deal of effort has been spent in developing methods for measuring compliance and techniques and strategies to promote adherence. Unfortunately, this approach does not match the reality of diabetes care. The serious and chronic nature of diabetes, the complexity of its management, and the multiple daily self-care decisions that diabetes requires mean that being adherent to a predetermined care program is generally not adequate over the course of a person's life with diabetes.

This is particularly true when the self-management plan has been designed to fit patients' diabetes, but has not been tailored to fit their priorities, goals, resources, culture, and lifestyle. To manage diabetes successfully, patients must be able to set goals and make frequent daily decisions that are both effective and fit their values and lifestyles, while taking into account multiple physiological and personal psychosocial factors. Intervention strategies that enable patients to make decisions about goals, therapeutic options, and self-care behaviors and to assume responsibility for daily diabetes care are effective in helping patients care for themselves.

Models of Care and Education

In the past, most health professional training was based on a medical model designed to treat acute health care problems. In this model, the health professional was the authority responsible for the diagnosis, treatment, and outcomes patients experienced. Patient education was generally prescriptive (e.g., "Do as I say.") and therapeutic goals were set by health professionals. As chronic illnesses became more prevalent, this same model was extended to those patients as well. This model promoted the idea that

health professionals know best, and great effort was made to encourage patients to follow the recommendations of health professionals. This approach was based on the belief that patients have an obligation to follow the direction of their providers and that the benefits of compliance outweigh the impact of these recommendations on patients' quality of life. Education was designed to promote compliance or adherence using motivational and behavioral strategies in an effort to get patients to change.

As the large literature in noncompliance indicates, these models were not effective in diabetes care.¹⁻³ A new approach was needed that recognized that patients are in control of and responsible for the daily self-management of diabetes and that, to succeed, a self-management plan had to fit patients' goals, priorities, and lifestyle as well as their diabetes.

This approach is based on three fundamental aspects of chronic illness care: choices, control, and consequences.⁴ The choices that patients make each day as they care for diabetes have a greater impact on their outcomes than those made by health professionals. In addition, patients are in charge of their self-management behaviors. Once patients leave our offices, they are in control of which recommendations they implement or ignore. Finally, because the consequences for these decisions accrue directly to patients, they have both the right and the responsibility to manage diabetes in the way that is best suited to the context and culture of their lives.

IN BRIEF

A gap currently exists between the promise and the reality of diabetes care. Practical interventions that facilitate collaborative relationships and foster patient-centered practices are the key to closing this gap.

Empowerment is a patient-centered, collaborative approach tailored to match the fundamental realities of diabetes care. Patient empowerment is defined as helping patients discover and develop the inherent capacity to be responsible for one's own life.⁵ Since initially proposed in diabetes, there has been a growing recognition that, although health professionals are experts on diabetes care, patients are the experts on their own lives.⁶ This approach recognizes that knowing about an illness is not the same as knowing about a person's life and that, by default, patients are the primary decision-makers in control of the daily self-management of their diabetes.

Embracing this philosophy requires that health care professionals practice in ways that are consistent with this approach.⁷ Empowerment is not a technique or strategy, but rather a vision that guides each encounter with our patients and requires that both professionals and patients adopt new roles. The role of patients is to be well-informed active partners or collaborators in their own care. The role of health professionals is to help patients make informed decisions to achieve their goals and overcome barriers through education, appropriate care recommendations, expert advice, and support. Professionals need to give up feeling responsible *for* their patients and become responsible *to* them.

Diabetes care then becomes a collaboration between equals; professionals bring knowledge and expertise about diabetes and its treatment, and patients bring expertise on their lives and what will work for them. To effectively implement this approach, patients need education designed to promote informed decision-making, and providers need to practice in ways that support patient efforts to become effective self-managers.

Self-Management Education and Support for Patient Empowerment

Diabetes self-management education is the essential foundation for the empowerment approach and is necessary for patients to effectively manage diabetes

and make these decisions. The purpose of patient education within the empowerment philosophy is to help patients make decisions about their care and obtain clarity about their goals, values, and motivations.^{5,8} Patients need to learn about diabetes and how to safely care for it on a daily basis. They also need information about various treatment options, the benefits and costs of each of these strategies, how to make changes in their behaviors, and how to solve problems.⁹ In addition, patients need to understand their role as a decision-maker and how to assume responsibility for their care.

Approaches to education within the empowerment philosophy incorporate interactive teaching strategies designed to involve patients in problem solving and address their cultural and psychosocial needs. Using patient experiences as the curriculum helps to individualize group educational programs and ensure that the content provided is relevant for the needs of the group.

Behavioral experiments offer opportunities for patient involvement and help teach the behavior-change skills needed for ongoing self-management. As an example, a recent program we conducted among urban African Americans was designed as a culturally specific, problem-based educational program.¹⁰ All content was presented in response to issues and questions raised by participants; no lectures were presented. At the end of each of the six sessions, patients were encouraged to choose a short-term goal as a behavioral experiment for the week. Each subsequent class began with a group discussion of the results. These experiences and other problems and questions raised by the group were then used as the curriculum to discuss self-management, psychosocial issues, coping, and other concerns.

While diabetes education has been shown to be effective for improving metabolic and psychosocial outcomes¹¹⁻¹³ and is an essential first step for self-management¹⁴ and empowerment, a one-time educational program is

rarely effective to sustain the types of behavioral change needed for a lifetime of diabetes self-care. Patients need ongoing self-management support from their providers and the entire diabetes health care team to maintain gains achieved through education.

Part of this ongoing care and educational process includes setting goals with patients. Goal setting is an effective strategy; patients who participate in the selection of goals and have clarity about them are more likely to be successful in achieving their goals.¹⁵

Goal setting within the empowerment approach^{5,7} is a five-step process that provides patients with the information and clarity they need to develop and reach their diabetes- and lifestyle-related goals. The first two steps are to define the problem and ascertain patients' beliefs, thoughts, and feelings that may support or hinder their efforts. The third is to identify long-term goals towards which patients will work. Patients then choose and commit to making a behavioral change that will help them to achieve their long-term goals. The final step is for patients to evaluate their efforts and identify what they learned in the process.

Helping patients view this process as behavioral experiments eliminates the concepts of success and failure. Instead, all efforts are opportunities to learn more about the true nature of the problem, related feelings, barriers, and effective strategies. The role of the provider is to provide information, collaborate during the goal-setting process, and offer support for patients' efforts. A behavior-change protocol^{16,17} is included in Table 1.

Practice Design for Empowerment and Self-Management

Providers can also design their interactions with patients and their practices to better support self-management efforts. A first step for providers and their team is to define their shared vision of diabetes care and education. We express our vision in each encounter with

Table 1. Behavior-Change Protocol¹⁷

Step I: Explore the Problem or Issue (Past)

- What is the hardest thing about caring for your diabetes?
- Please tell me more about that.
- Are there some specific examples you can give me?

Step II: Clarify Feelings and Meaning (Present)

- What are your thoughts about this?
- Are you feeling (insert feeling) because (insert meaning)?

Step III: Develop a Plan (Future)

- What do you want?
- How would this situation have to change for you to feel better about it?
- Where would you like to be regarding this situation in (specific time, e.g., 1 month, 3 months, 1 year)?
- What are your options?
- What are barriers for you?
- Who could help you?
- What are the costs and benefits for each of your choices?
- What would happen if you do not do anything about it?
- How important is it, on a scale of 1 to 10, for you to do something about this?
- Let's develop a plan.

Step IV: Commit to Action (Future)

- Are you willing to do what you need to do to solve this problem?
- What are some steps you could take?
- What are you going to do?
- When are you going to do it?
- How will you know if you have succeeded?
- What is one thing you will do when you leave here today?

Step V: Experience and Evaluate the Plan (Future)

- How did it go?
- What did you learn?
- What barriers did you encounter?
- What, if anything, would you do differently next time?
- What will you do when you leave here today?

patients and in the relationships that we create and our interactions in them.

For example, we often start out an interaction with a new patient by saying, "I understand that living with diabetes is difficult. You have many decisions to make each day that will have a huge impact on your future health and well-being. We are here to help you. We know a great deal about diabetes and how to care for it. But you know yourself better than anyone; you know what you want and what you are able and willing to do to care for your diabetes.

By combining what you know about yourself with what we know about diabetes, we can come up with a plan that will work. If it doesn't work, it does not mean that you are not doing the best that you can or that we are not doing all that we can. It simply means that we need to keep trying until we figure out a plan that will work for you. We are partners and we need to work together." Reflecting on what we believe our role to be, what we have the right to expect of our patients, and what our patients have the right to expect of us helps to clarify our

vision and can then be used to guide practice redesign.

In the empowerment approach, there are both strategies that can be used by providers and strategies that can be implemented within a practice to promote patient empowerment.¹⁸⁻²¹ First and foremost, we need to listen to our patients and ask what they need to obtain from their interactions with us to better manage their diabetes.⁴ Patients have identified that they have many concerns and issues about living with their diabetes that are rarely addressed by their providers.²² Even patients who are achieving desired metabolic and other outcomes may struggle with the demands of a chronic illness and the uncertainty that it adds to their lives. In addition, providers can become more patient-centered and collaborative and thereby improve patient outcomes and satisfaction with their care.

We can also show that we care about our patients as individuals first and about their diabetes second. Rather than beginning the visit with a review of the patients' blood glucose record and laboratory results, we can ask how they are feeling (psychologically as well as physically) and how they believe they are doing in reaching their self-selected goals and caring for their diabetes. This not only acknowledges their expertise, but also conveys that they are viewed as more than just a blood glucose number.

As providers, we also need to spend more time listening and less time offering advice.²³ Asking questions and using active listening techniques can help patients reflect on issues or problems and lead to identification of effective strategies to which patients are willing to commit.

In addition, during patient visits, providers can:

- Stress the importance of patients' role in self-management and daily decision-making. Describe our role as coach or partner in the care process. Acknowledge the patients' right and responsibility to make self-care choices and to be the primary decision-makers.

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- Offer referrals to a diabetes education program and a registered dietitian.
 - Begin each visit with an assessment of patients' concerns, questions, and progress towards metabolic and behavioral goals. Some providers ask patients to complete a short, open-ended one- to three-question form to ascertain any questions or concerns they would like addressed during the visit.
 - Listen to patient-identified fears and concerns.
 - Ascertain patients' opinions about home blood glucose monitoring results and other laboratory and outcome measures.
 - Review and revise diabetes care plans as needed based on patients' and providers' assessment of its effectiveness.
 - Provide ongoing information about the costs and benefits of therapeutic and behavioral options. Acknowledge that there are many options for treating diabetes, and determine patients' interest in or concerns about each option.
 - Take advantage of teachable moments that occur during each visit.
 - Establish a partnership with patients and their families to develop collaborative goals.
 - Provide information about behavior change and problem-solving strategies.
 - Assist patients in solving problems and overcoming barriers to self-management.
 - Support and facilitate patients in their role as self-management decision-makers.
- Link patient self-management support with provider support (e.g., system changes, patient flow, logistics).
 - Supplement self-management support with information technology.
 - Incorporate self-management support into practical interventions, coordinated by nurse case managers or other staff members.
 - Create a team with other health care professionals in your system or area who have additional experience or training in the clinical, educational, and behavioral or psychosocial aspects of diabetes care.
 - Replace individual visits with group or cluster visits to provide efficient and effective self-management support.
 - Assist patients in selecting one area of self-management on which to concentrate that can be reinforced by all team members.
 - Create a patient-centered environment that incorporates self-management support from all practice personnel and is integrated into the flow of the visit.

Making the Shift

Health professionals face several challenges in making this shift to the empowerment model of care. Change is no easier for us as providers than it is for our patients, and it is often difficult to give up our role as the authority and develop an equal partnership with patients. As providers, we have to give up the illusion that we have control of our patients' diabetes self-management decisions and outcomes. While some professionals struggle with this new role, most find that it enables them to be more effective and satisfied clinicians than more directive models of care. These professionals often define success by the relationships they create with their patients, as well as outcomes achieved by their patients.

A common concern raised by professionals is the limited time that they have to spend with their patients. There is a common misperception that addressing

emotional and psychosocial needs will greatly increase visit time. It has been our experience that these approaches actually increase the efficiency of visits and decrease the time spent.²⁴ Time spent offering recommendations that are not relevant for patients or will never be implemented is time wasted.

In addition, addressing patients' agendas at the beginning of visits helps to prevent the "hand on the doorknob syndrome," in which patients bring up an important issue as the provider is concluding the visit. Dealing with problems at this point often doubles the length of the visit. Some providers find that it helps to establish the amount of time the visit is scheduled to take at the beginning with statements such as, "We have 15 minutes to spend today, and I want to be sure that your needs are addressed. Are there issues that you would like to discuss?" Others indicate the length of the visit on the form used to assess patient concerns.

Although we advocate using a collaborative approach, we realize that it presents challenges to providers, as well. Setting goals with, rather than for, patients can be difficult. This is particularly true if patients set goals that are different from what providers would choose or when they choose issues that professionals view as a low priority. It may seem faster and easier to provide answers to our patients' problems than it is to help them use their own problem-solving skills. Also, it can be difficult to listen when patients express negative feelings. Although it is tempting to ignore these emotional concerns or to offer statements to allay rather than address concerns in an attempt to spend the time focusing on other issues, these strategies are rarely effective for any period of time. In addition, patients may continue to bring up these concerns, thereby actually lengthening the visit.²⁵

Although there are potential costs to changing from traditional, expert-directed care to a collaborative approach, there are also benefits. Many

providers find it more satisfying. They find that their frustration with trying to get patients to make changes decreases dramatically once they realize that their patients' behavior is not their responsibility. Patients who are actively collaborating in the decision-making process are better able to achieve the outcomes they identify as important to them. This allows providers to spend less time trying to provide external motivation because patients are able to find internal motivation once they are involved in the goal-setting process. Also, many health professionals are relieved to find that they no longer have to feel responsible for developing solutions to difficult problems. Patients as a whole become the focus of the visit and the encounter, rather than just their diabetes.

Conclusion

The Chronic Care Model has been tested as an effective approach for chronic illness care.²⁶ This approach is based on actively involved patients working with informed, proactive health care teams. The empowerment philosophy is in keeping with this approach to care. It involves establishing partnerships with individual patients and creating truly patient-centered practices. The benefits for patients include better communication with providers, greater satisfaction with care, improved metabolic and psychosocial outcomes, and emotional well-being. The benefits for providers include achievement of recommended standards of care, improved outcomes, and greater professional satisfaction.

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