Facilitating Self-Care in People With Diabetes

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Why is diabetes management so difficult for most people with diabetes, and what can we as health care providers do about it? These questions probably cross your mind numerous times every day.

The answer to the first question is pretty clear—diabetes is a demanding disease. It is there all the time, 24 hours a day, 365 days a year (or 366 days a year on Leap Year, as an 8-year-old patient recently pointed out to me). My son once told me he has to stop what he is doing and deal with (or at least think about) his diabetes at least once every 15 minutes. The demands are not only continuous, they are often unpleasant as well, whether they be shots, finger sticks, or lifestyle changes.

As if that were not enough, even doing all that hard work does not guarantee normal blood glucose levels and freedom from immediate and long-term problems. We all know that there is no way to perfectly manage all the factors that affect blood glucose levels and other risk factors. Even participants in the Diabetes Control and Complications Trial, with all their motivation and all the support they received, did not achieve normal HbA_{1c} levels as a group.

Continuous, unpleasant demands and unpredictable results—that is a recipe for what I call *diabetes overwhelmus.* Many people with diabetes are simply overwhelmed by the demands of diabetes management.

Diabetes overwhelmus often triggers a negative cascade. Many patients tell me that when they feel overwhelmed, they take a "to hell with it" attitude toward diabetes self-care. Few people give up altogether, but many say they are less active in caring for their diabetes when they are feeling overwhelmed. Less active self-care generally leads to blood glucose levels farther from normal. That tends to increase the physical and emotional burdens (including guilt) of diabetes, further exacerbating the *diabetes overwhelmus.*

I believe that *diabetes overwhelmus* is the key barrier to effective self-care and improved physical health and quality of life for many people with diabetes.

What can we do to protect our patients from *diabetes overwhelmus?* Here are some techniques I've found most helpful.

Ask questions.

Diabetes overwhelmus strikes when a person's stress level is so high that coping mechanisms break down. I start by trying to identify the main source of stress. I ask, "What is the hardest thing for you right now about living with diabetes?"

Be specific.

The ideal answer to this question is something specific, such as, "I can't resist snacking while watching television at night." Such "sticking points" are real problems because they seem to sap motivation and trigger *diabetes overwhelmus* and the downward spiral described above. So identifying and resolving sticking points can go a long way toward reversing that spiral.

Some people are able to identify diabetes sticking points quickly and easily. Others say that nothing is hard about diabetes. This group includes some people who are in what many call denial; they are afraid, and they are managing their fear by avoidance. Anything you can learn about the specific things a person fears can help identify ways to cope.

At the opposite end of the spectrum from the person who claims no diabetes-related problems is the one who responds, "Everything!" to my question about the hardest part of living with diabetes. When working with such a person, I introduce the concept of "sticking points," offering examples. Then I ask the person to identify a diabetes sticking point of his or her own. I almost always get a more specific answer than the first one, such as "My diet."

Now we are on the right track, so I ask the person to take the next step: describe a true diet sticking point, something so specific I could take a photograph or make a videotape of it. Constant visits to the candy dish at work might be an example. The specificity of the sticking point makes it easier to deal with, and it is always easier to help people solve a problem they want to solve.

We can help people identify diabetes sticking points. We can also help them identify the most effective ways to get unstuck.

Once again, our patients have the answers, so we must ask the right questions. I start with this one: "Has there ever been a time when the sticking point you just mentioned wasn't so sticky?"

The answer is almost always "yes," even if those times were rare. As the person describes the specific circumstances of those less sticky occasions, we almost always find things to try more consciously and consistently. The person might mention a time he or she brought a healthy alternative snack to work, or a period when he or she was actively trying to get fit for the softball season, or the time a coworker was dieting, and everyone agreed to put away the candy for a month. These solu-

tions are the ones most likely to work for that particular person because, at least on occasion, they already have.

Plan for change.
At this point, I ask which of the things that worked in the past are worth trying now. We then begin planning for change.

First, we identify the goal in concrete terms. For the person I've been talking about, the goal might be to avoid eating candy at work 3 days a week, having it only on Mondays and Fridays. The goal should be realistic; setting an initial goal of never eating candy at work when it has been a daily occurrence is probably unrealistic and could be counterproductive.

Next, we try to identify things to do that will make reaching the goal easier: taking a healthy, delicious snack to work on no-candy days perhaps, or asking coworkers to put away their candy dishes.

I always encourage people to identify behavioral goals because they are more controllable than metabolic outcomes, such as weight or blood glucose level. We know these latter outcomes tend to follow changes in behavior, but because the relationship between effort and outcome is not perfect, I think we should focus on what people are doing. The result in most cases will be more weight loss and closer-to-normal blood glucose levels.

I think rewards are wonderful. Treats keep us motivated, and this is certainly true when it comes to sticking to the demanding work of diabetes management. I ask my patients to think of the rewards they will get (or give themselves) for their efforts. Rewards can range from the material to the ethereal, from a new outfit to more self-confidence to a trip down the Amazon. The most effective rewards are short-term as well as long-term, so I ask people to think about rewards they will give themselves for reaching the goals they have set for the next few weeks as they are starting to change behavior.

Experiment.
No plan ever works perfectly. The process of making real change involves conducting a series of experiments. The plan you and your patient first put together is based on the best information you have at the time, but it needs to be tested so you can work out the bugs. And bugs there will inevitably be. Acknowledging this reality from the start can help prevent the disappointment—and even discouragement—that many patients and providers feel when a plan does not work perfectly.

The man whose candy cravings I've described might find that he ate his healthy snack and the candy, too, on the first day he tried to implement his plan. He needs to be ready. He needs to be ready to remind himself that this is par for the course and not an indication of failure; ready to try another approach to his goal, such as asking coworkers to put away their candy; and ready to call for help before discouragement sets in.

People who see diabetes management (or any major life challenge) as a series of experiments in living well generally succeed in living well. They experiment to make diabetes care easier or more effective, and they use the results of each experiment to plan further refinements and solve new problems as they arise.

Thomas Edison, who had type 2 diabetes, personified this attitude. A reporter came to his lab and questioned Mr. Edison about his years of then-fruitless effort to develop the incandescent light bulb. "Mr. Edison," the reporter asked, "Why don't you give up? How can you stand to fail 2,000 times?" To which Edison responded, "I haven't failed once. I am 2,000 steps closer to the solution!" And so he was. The power of a motivated experimenter and problem solver should not be underestimated.

The concept of experimentation applies as much to our efforts to build our skills at preventing and treating *diabetes overwhelmus* as it does to our patients' efforts to build their self-care skills. Many of us were not trained in psychology or counseling. You may not feel confident using the techniques I mention. You may even have tried some and found that they did not work. No technique works perfectly, but these techniques and others can help make your work more effective and more satisfying, especially if you apply Edison's example and learn from each experiment. See the list of suggested readings at the end of this article for resources that can help, and consider taking a workshop in motivational interviewing or communications skills, if that appeals to you.

Involve the family.
Diabetes is a family disease. That is true genetically, of course, but also emotionally. Diabetes affects everyone who lives with, loves, and cares for someone who has diabetes. And the way all those people relate to the person with diabetes affects how that person manages it.

Family members may be involved in many different ways, from offering wonderful support to attempting to over-control to ignoring diabetes altogether. Helping people with diabetes get what they need from family and friends can go a long way toward facilitating diabetes self-care.

Involving family members in your consultations with patients can be helpful. You can also ask your patients questions to help them get more practical help and emotional support. I have found these to be useful:

- What does your family do that truly helps you with your diabetes?
- What does your family do that makes it harder to manage your diabetes?
- What more could your family do (realistically) to help you with your diabetes?

Support groups—real and virtual—can also provide practical and emotional support. Recommend any local groups or Websites you consider worthwhile.

Nourish emotional coping skills.
Feeling emotionally exhausted is the hallmark of *diabetes overwhelmus*. Sometimes, that emotional exhaustion is so severe that a person may be clinically depressed. While major depression is two to four times more common in people with diabetes than it is in the general population, it is underdiagnosed and undertreated in people with diabetes.

This situation should not continue. Valid, easy-to-use, and easy-to score depression screening questionnaires are available and can often be

obtained free from companies selling antidepressant medications. These questionnaires take less than 10 minutes to complete and about 2 minutes to score.

People who score high on a depression screening questionnaire should be referred for diagnosis and treatment. Recent studies show that both counseling (cognitive behavioral therapy) and antidepressant medication are effective in resolving depression and improving glycemic control in people with diabetes.

So *please* screen patients for depression and treat or refer those who are depressed. Relieving depression often resolves *diabetes overwhelmus* and triggers a positive cascade of feelings, behaviors, and metabolic outcomes. Helping patients resolve their depression is also an effective treatment for *diabetes overwhelmus, type 2*— the kind we health care providers suffer from when we are overwhelmed trying to help patients who are stuck.

Some other psychological problems, such as anxiety disorder, are also more common in people with diabetes. Other problems, such as eating disorders, while perhaps no more common (at least in their full-syndrome manifestations) are especially dangerous for people who have diabetes. The list of suggested readings at the end of this article contains sources of additional information on these disorders and their treatment.

Identification and treatment of psychological disorders is facilitated when care is provided by a multidisciplinary team, because several professionals see the patient. Having a mental health professional on the team is especially helpful, because the whole team is made more aware of emotional issues.

Even with subclinical, garden-variety *diabetes overwhelmus*, nurturing emotional coping skills—especially feelings of hope and humor—is essential. I ask patients about the main sources of hope and faith in their lives, when they feel most hopeful about diabetes, and what they can do to draw more effectively on their feelings of faith and hope. Faith in a higher power, in medical science and technology, or in oneself can all help people cope more easily and effectively with the daily demands of diabetes. Again, specific examples from the person's experience are the most helpful.

Humor and diabetes might seem an odd combination, but how often have you heard people in difficult situations say, "The only thing that saved me was my sense of humor?" I think faith and humor are the closest things to magic in the world. When our patients have both in good measure, their lives are good.

I am always interested in what makes people laugh, what they find funny. Then I encourage people to get more of whatever that might be. There is no such thing as too much laughter.

Sometimes, there are even things about diabetes to laugh about. I collect good diabetes stories, and the funny ones are my favorites. So I will close this article with one you might enjoy. I like it because it shows that humor can (and often does) arise in the most unlikely circumstances.

A woman who has diabetes awoke in the middle of the night shaking, sweating, and confused, her blood glucose level very low. She realized that she could not stand up and get downstairs for the juice and crackers she needed, so she woke her husband. He staggered out of bed and proceeded groggily down to the kitchen.

As the minutes passed, the woman lay in bed shaking and waiting. Finally, after 10 minutes, she was just about to try crawling down the stairs in search of her food and her husband, when he came staggering back up the stairs empty-handed.

When the woman shouted, "Where is my food?" her husband cried, "Oh no! I ate it myself." Needless to say, it took but a moment for the man to return with food for his wife. A few minutes later, the woman's blood glucose level was headed back toward normal, and the couple started to laugh about their experience.

Suggested Readings

Anderson BJ, Rubin RR (Eds.): *Practical Psychology for Diabetes Clinicians: How to Deal With the Key Behavioral Issues Faced by Patients and Health-Care Teams.* Alexandria, Va., American Diabetes Association, 1996

Anderson R, Funnell M: *The Art of Empowerment: Stories and Strategies for Diabetes Educators.* Alexandria, Va., American Diabetes Association, 2000

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Lowe E, Arsham G: *Diabetes: A Guide to Living Well.* Third ed. New York, John Wiley & Sons, 1997

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