ABSTRACT: Many patients with diabetes are anxious or fearful about the disease. These negative emotions stem in part from the fact that the patient is responsible for many facets of diabetes management, such as exercise, dietary modification, and blood glucose measurement. For example, failure to adhere to a regimen may engender guilt. Up to 30% of patients with diabetes are depressed, and hemoglobin A$_1c$ levels are higher in such patients. Even patients with good metabolic control may not be doing well psychologically. It is thus essential to ask about patients' concerns and fears, identify their psychosocial needs, and provide emotional support.

"After living with diabetes for over 20 years and having suffered numerous serious complications, I had the misfortune of being diagnosed with colon cancer, which was treated first with surgery and then with intense chemotherapy. However, the anger, fear, and frustration that I felt regarding my cancer diagnosis and treatment paled in comparison to the anger, fear, and frustration I feel as a result of my diabetes.

"With the cancer, I submitted my body to my doctors, who did everything they thought necessary. There was nothing else that I could have done. Not so with my diabetes. As an 'empowered patient', there was always something more that I could have done.

"Also, the health care professionals I encountered during the cancer ordeal (including, astonishingly, my diabetes providers) were quick to ask me and my family how we were feeling and whether we needed psychological counseling. Seldom has this occurred in the treatment of my diabetes."

This experience of the second author—a past chair of the American Diabetes Association—highlights a frequently overlooked problem in diabetes care today. Although diabetes commonly gives rise to powerful negative emotions, patients are seldom asked how they are coping with the fear and anxiety associated with this chronic and slowly progressive disease.

NEGATIVE EMOTIONS IN PATIENTS WITH DIABETES

Responsibility, anxiety, and guilt. The nature of diabetes treatment increases the likelihood that patients will experience negative emotions. With a rapidly progressive and deadly disease such as metastatic cancer, control or recovery is largely out of the patient's hands; he or she is not required to do much more than follow the physician's recommendations for chemotherapy, radiation, and/or surgery. With diabetes, however, disease management is largely up to the patient; he is expected to make diet and lifestyle modifications, take actions to reduce risk factors, and adhere to intensive treatment plans that involve blood glucose monitoring and appropriate adjustment of therapy. The latter is especially true for patients treated with insulin: they manage their own insulin dosing based on an algorithm their physician provides, and the physician serves primarily as their advisor. Bearing much of the responsibility for the management of one's disease can easily give rise to anxiety and guilt. Even when a patient's hemoglobin A$_1c$ measurement is below 7%, he may be anxious and worried about maintaining optimal glycemic control; he may need emotional support. Unlike patients with cancer, persons with diabetes are not routinely provided with such support. Eventually, "diabetes burn-out" can occur, resulting not only in poor glycemic control but also a sense of powerlessness and discouragement about the disease, as well as fear of its long-term complications and attendant frustration.

Evidence of negative emotions. The Diabetes Attitudes, Wishes, and Needs (DAWN) study, conducted in 13 countries, including the United States, documented the negative feelings that are common in patients with diabetes. About two thirds of patients in this study reported negative emotional reactions on learning that they had diabetes. These included feelings of guilt for having developed the disease. They also described feeling angry about having a chronic condition, fearful of its many complications, and frustrated that their best self-management efforts did not always yield the desired results. The DAWN study also demonstrated that psychosocial problems can influence a patient's adherence to treatment. Study participants from the United States, who reported more self-blame for their
disease than did participants from other countries, also had less confidence in the effectiveness of insulin therapy. This diminished confidence in insulin delayed its introduction and prolonged inadequate control of these patients' diabetes.

**Diabetes and depression.** Negative emotions often lead to depression, which is twice as common in persons with diabetes as it is in those who do not have a chronic disease. Up to 30% of patients with diabetes have depression. Hemoglobin A\textsubscript{1c} levels are 2% to 3% higher in patients with comorbid depression and diabetes than in patients with diabetes who are not depressed. The risk of death is also significantly higher in patients with both conditions than it is in those who have either one alone.

**When insulin is used as a threat.** Too often, health care providers add to the guilt and other negative emotions experienced by patients with type 2 diabetes by making remarks such as "If you do not stick to your diet and exercise program, we will have to start you on insulin." The result of such threats is that patients usually blame themselves once they need to start insulin therapy, especially if they are not managing the disease well or have diabetic complications. Between 50% and 55% of primary care nurses and physicians in the DAWN study reported that they delayed insulin therapy until absolutely necessary. Patients are less likely to feel guilty if they are told at the time of the initial diagnosis that the natural course of the disease involves progressive -cell deterioration that eventually results in a need for insulin replacement.

**HOW YOU CAN HELP**

There are numerous psychological barriers to overcome in caring for patients with diabetes, especially those in whom the disease must be controlled with insulin. An initial assessment of the patient's concerns and fears can help overcome most of these barriers.

**Ask about the patient's emotional state.** Good diabetes care consists of more than ensuring glycemic control and monitoring blood pressure and lipid levels. It also includes asking "How do you feel?" and determining whether patients are depressed or overwhelmed by their diabetes, whether they are worried and frustrated by having a chronic and progressively worsening disease, and whether they feel guilty about not exercising adequately or following their meal plan. Ask patients what is bothering them the most or what is the most difficult part of caring for their diabetes. Question even those patients with good metabolic control. It is easy to assume that such patients are doing well psychologically, but this is not necessarily true. Depression and anxiety disorders often go undiagnosed and untreated even in patients with good control.

**Listen empathetically.** Effective communication involves listening to patients in a way that ensures that they feel understood, respected, and cared for. Reassure them that attempts are being made to help them cope with their disease.

**Teach patients to use their numbers as tools.** Educate patients about the practical value of such critical measurements as blood glucose and hemoglobin A\textsubscript{1c} levels, blood pressure, and weight. Patients tend to view these measurements as judgments of past performance. Help them instead to understand their numbers and encourage them to use these values as analytical tools for modifying self-management efforts and guiding future behavior. Such an approach can alleviate the performance guilt that often impedes patients' efforts and leads to other psychological consequences.

**Enlist the help of other health care professionals.** Every practitioner who cares for patients with diabetes—including podiatrists, ophthalmologists, and others—needs to understand the anger, fear, and frustration that these patients and their families may have about the disease. Take advantage of opportunities to raise awareness of this issue in the specialists to whom you frequently refer your patients with diabetes.

**THE PATIENT EDUCATION DILEMMA**

Patient education is an essential part of managing diabetes. Unfortunately, it takes time, and primary care physicians are poorly reimbursed for this time. Moreover, the amount of time spent on education that is reimbursed at all is significantly restricted. Despite legislative mandates in 46 states, coverage for patient education varies significantly from one insurance plan to another, especially for education about lifestyle changes. Clearly, most insurers undervalue patient education. Still, primary care physicians must take the initiative, since they provide 90% of diabetes care. It is essential to identify patients' psychosocial needs and provide emotional support.

A similar approach, in which the health care provider inquires about the patient's feelings and listens with empathy, is also effective in caring for those with other chronic diseases, such as arthritis and chronic obstructive pulmonary disease.
Diabetes Care: Are We Asking the Right Questions?

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