



DIABETES DISTRESS: A Common Occurrence in Patients Unable to Control Their Diabetes

ABSTRACT: Diabetes is one of the most difficult chronic diseases. Patients are faced with numerous psychological, emotional, social, and biological challenges. In many cases, multiple medications, finger sticks, dietary restrictions, and exercise are no longer an option. All of this coupled together can often make the patient feel defeated and drained. On the other side, the clinician is aware of the various complications of poor glucose control and is working to help the patient reach his or her goal. This article introduces the concept of diabetes distress and discusses methods to identify and treat the condition.



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Diabetes distress (DD) refers to the unique, often hidden, emotional burdens and worries that a patient experiences when they are managing a severe chronic disease, such as diabetes. Approximately 33% of patients with type 2 diabetes reportedly suffer from DD, which is distinctly different from clinical depression.¹

In DD, the patient is often overloaded with information (and misinformation) about medication, injections, dietary myths, nutritional content of foods, value of exercise, foot care, and other critical information. All of this is understood and filtered through each patient's educational background of education,

culture, and bias, as well as personal and family experience. Dealing with all these issues can create confusion and significant distress.

Primary care practitioners should suspect DD in any patient who is not achieving their goals for hemoglobin A1c (HbA1c), low-density lipoprotein (LDL), blood pressure, or has significant difficulty with self-management (eg, medication adherence, nutrition, or physical activity).

DD results from unsuccessful diabetes self-management over time. The distress leads to narrowing of attention span, limiting of creative solutions, and a spiral of poor management and coping.

This pattern hampers the ability to gain new knowledge and skills, as well as accelerates development of unrealistic goals and expectations, inaccurate personal beliefs, and perceptions that are self-defeating.²

Clinicians who recognize that diabetes is much more than metabolic defects can evaluate and treat for DD. This article will discuss how to use the 17-item Diabetes Distress Scale (DDS17) to identify and treat patients with this condition.

A CASE REPORT

A 43-year-old man presents with a 6-year history of diabetes, hypertension,



CLINICAL RESOURCES

For more information about diabetes distress, including a self-study guide, both the 2-question evaluation and 17-item Diabetes Distress Scale (also available in Spanish), and a DD certification program, please visit www.diabetesuniversitymcp.com/diabetes-distress-learning-center.html.

and dyslipidemia. His current medications for his diabetes include metformin and glimepiride. His HbA1c level is at 11.3%, blood pressure at 150/100 mm Hg, high-density lipoprotein (HDL) at 29 mg/dL, and triglycerides at 228 mg/dL. During the first few years of his diabetes, all of his measurements were at goal but over the course of the last 2 years, the numbers have become increasingly worse with each visit.

History. The patient is a truck driver and does not want to take insulin as that would most likely result in him losing his job. He lives with his sister and has no significant other. He does his own cooking and eating fast food is a frequent alternative. He admits that he often forgets to take his medication. The patient did not know how to correctly read food labels.

Physical examination. There were no abnormalities aside from his high blood pressure. His body mass index (BMI) was at 29.

Questionnaire. The patient was asked to complete the DDS17 questionnaire and the results revealed a total score of 64, with a mean score of 3.76. Note: A mean score ≥ 3 indicates severe distress. Subscores are also significant; in this case, the patient had an emotional burden mean score of 6 and regimen-related distress 5.4, both of which are indicative of major severe distress.

With this score, a patient may report feeling angry, scared, and or depressed when he thinks about living with diabetes, believes diabetes controls his life, and that friends and family do not appreciate how hard it is to live with diabetes.

After reviewing the DDS17 results, we reviewed the complications that may arise with uncontrolled diabetes and that if he was not able to achieve better control, he would develop comorbidi-

ties. Our patient said he has seen other family members with diabetes suffer from strokes, heart attacks, and other complications, and felt that regardless of what he did, he too would end up with a similar fate.

THE DIABETES DISTRESS SCALE

When attempting to screen for DD, start with an easy 2 questions evaluation (Table 1). If the scores are ≥ 3 for either question, complete the 17-item DDS17 questionnaire (Table 2).

DDS17 focuses on 4 distinct areas:

1. **Emotional burden.** Is the patient overwhelmed by personal emotions, such as fear, anger, or loss of control?
2. **Physician-related distress.** Is the patient feeling like the clinician is failing to give clear directions or address the patient's concerns adequately?
3. **Regimen-related distress.** Does the patient feel as if he or she cannot deal with the multiple medications, injections, finger sticks, and office visits, and/or does not confide in his or her ability to care the diabetes?
4. **Interpersonal distress.** Does the patient question whether friends and family appreciate how difficult it is to deal with diabetes and request additional support?

Note: Regimen-related distress is the most common challenge for patients.²

THE PATIENT PERSPECTIVE

For some individuals, a diagnosis of diabetes translates to a significant change in lifestyle. This starts with dietary choices, where foods that used to be go-to favorites may now have to be restricted. Physical activity is no longer an option, but rather a requirement. A

health regimen may now include multiple medications to sustain life, finger sticks to guide treatment, and frequent visits to the healthcare provider.

All of this sudden change is coupled with the sobering reality that if the disease is not controlled, the patient may face loss of vision, heart attack, stroke, amputation, and kidney failure.

While self-management is the key to longterm success, it is the patient's reaction to this self-management that will determine whether or not he or she is capable of doing so. It is not unusual for patients with diabetes to feel overwhelmed with the demands of self-management. Common feelings include frustration, fatigue, anger, burnout, a poor mood, and depression. The care for diabetes is complicated before you factor in all of these additional challenges; if self-management is not properly incorporated into the new lifestyle, diabetes distress may lead to worsening diabetes.

THE SUPPORTER PERSPECTIVE

Friends and families of patients with diabetes may or may not understand all of these issues and their lack of understanding may place an additional burden on the patient. For example, family meals may pose a new challenge. If appropriate options are not readily available, the patient may not want to inconvenience other family members.

Teach your patient how poor nutritional choices and eating patterns may have played a significant role in the development of diabetes. Conveying this message to friends and family will go a long way in creating a supportive environment for your patient.

Note: Your patient may be reluctant to talk about diabetes with their friends, family, or even a spouse for a variety of

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INSTRUCTIONS FOR SCORING:

The DDS17 yields a total diabetes distress scale score plus 4 sub scale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. The letter in the far right margin corresponds to that item's subscale as listed below. **We consider a mean item score of 3 or higher (moderate distress) as a level of distress worthy of clinical attention.** Place a check on the line to the far right if the mean item score is ≥ 3 to highlight an above-range value.

We also suggest reviewing the patient's responses across all items, regardless of mean item scores. It may be helpful to inquire further or to begin a conversation about any single item scored 3 or higher.

Total DDS Score:

- a. Sum of 17 item scores. _____
 b. Divide by: 17
 c. Mean item score: _____ ≥ 3 _____

A. Emotional Burden:

- a. Sum of 5 items (1, 3, 8, 11, 14) _____
 b. Divide by: 5
 c. Mean item score: _____ ≥ 3 _____

B. Physician-related Distress:

- a. Sum of 4 items (2, 4, 9, 15) _____
 b. Divide by: 4
 c. Mean item score: _____ ≥ 3 _____

C. Regimen-related Distress:

- a. Sum of 5 items (5, 6, 10, 12, 16) _____
 b. Divide by: 5
 c. Mean item score: _____ ≥ 3 _____

D. Interpersonal Distress:

- a. Sum of 3 items (7, 13, 17) _____
 b. Divide by: 3
 c. Mean item score: _____ ≥ 3 _____

TABLE 1. DIABETES DISTRESS SCREENING TEST

Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you during the past month and circle the appropriate number. If the scores are 3 or greater for either question, complete the 17-question Diabetes Distress Scale (**Table 2**).

	NOT A PROBLEM	A SLIGHT PROBLEM	A MODERATE PROBLEM	SOMEWHAT SERIOUS PROBLEM	A SERIOUS PROBLEM	A VERY SERIOUS PROBLEM
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6

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TABLE 2. 17-QUESTION DIABETES DISTRESS SCALE

Listed below are potential problem areas that people with diabetes may experience. Consider the degree to which each of the items may have distressed or bothered you during the past month and circle the appropriate number.

	NOT A PROBLEM	A SLIGHT PROBLEM	A MODERATE PROBLEM	SOMEWHAT SERIOUS PROBLEM	A SERIOUS PROBLEM	A VERY SERIOUS PROBLEM
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6
3. Feeling angry, scared, and/or depressed when I think about living with diabetes.	1	2	3	4	5	6
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6
6. Feeling that I am often failing with my diabetes routine.	1	2	3	4	5	6
7. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6
8. Feeling that diabetes controls my life.	1	2	3	4	5	6
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes.	1	2	3	4	5	6
16. Not feeling motivated to keep up my diabetes self-management.	1	2	3	4	5	6
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6

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reasons, including simply being embarrassed. Encourage your patient to discuss his fears and concerns with individuals or groups he can trust.

Diabetes is a genetic and lifestyle-related disease and other family members may already be diagnosed with or are at risk for developing the disease. Remind your patient that open discussions about the challenges and psychological burdens he faces benefits both himself, as well as his family.

THE PROVIDER PERSPECTIVE

Diabetes creates significant challenges for all healthcare providers who are driven by the fear of diabetes-related comorbidities and the knowledge that achieving goals for HbA1c, LDL, blood pressure, and BMI lowers the odds of such complications. The practitioner's reaction may consequently interfere with diabetes self-management. It is not uncommon for the practitioner to feel guilty if a patient is not achieving diabetes goals. That guilt may lead to a culture of blame—where someone has to be blamed, and in this case, the patient is usually the target. The patient is now labeled as non-compliant.

Instead, it is more productive to replace the idea of compliance with the concept of barriers to adherence. These include:

- Ineffective coping skills
- Lack of support from family and friends
- Misconceptions about the disease and its treatment
- Inability to understand, purchase, and use medications
- Poor nutritional choices
- Lack of availability of better food options
- An environment that is not conducive to physical activity
- Poor self-efficacy (ie, the confidence that they can achieve longterm behavioral change)

Addressing these barriers leads to better outcomes and less distress for both the patient and the healthcare provider. Primary care practitioners need to pay

attention to how they react to their patients and how their patients react to them. The DDS17 tool can help gauge how patients perceive their physicians, which in turn can be used to better interact with your patient.

DIABETES DISTRESS VS DEPRESSION

It is difficult to clearly classify whether a patient is suffering from diabetes distress or depression. Research suggests that the structured clinical interview, considered the gold standard to diagnose depression, often finds no relationship between depression and diabetes self-management.³ Furthermore, interventions that successfully lower depression in patients with diabetes do not demonstrate a corresponding improvement in glycemic control or self-management.^{1,4}

Major depression is one of the few diagnoses in medicine that is defined exclusively by symptoms, and not by the cause or disease process. Major depression does not distinguish what may be an expected reaction to a significant life stressor, such as diabetes. On the other hand, diabetes distress encapsulates the worries, concerns, and fears among individuals who struggle with a progressive and demanding chronic disease. Distress is an expected response to perceptions of health threats balanced against available coping resources.^{3,4}

Many patients with diabetes are depressed and depression is associated with poorer outcomes. A study of 506 patients with type 2 diabetes found no association between improvement in major depressive disorder and better glycemic control.⁵ However, a correlation was found between incidence of diabetes distress and improvement of A1c levels. Could we be using the wrong terminology? What was previously been labeled as depression among patients with type 2 diabetes may really be 2 conditions—depression and diabetes distress. Depressive symptoms may be a reflection of distress. Treatment of the depression is important, but to change the A1c, treatment of the diabetes distress is vital.

TREATING DIABETES DISTRESS

The AASAP (anticipate, acknowledge, standardize, accept plan)⁶ protocol was developed from research that showed a unique constellation of clinically meaningful distress associated with diabetes and its management. Fisher and colleagues² found that diabetes programs that only focused on behavior change and ignored emotional distress had higher dropout rates due to unaddressed feelings of hopelessness, fear, and being overwhelmed.

The Reducing Distress and Enhancing Effective Management (REDEEM) study compared a diabetes self-management program that helps establish behavioral goals, address barriers, and monitor progress with an intervention that combined the same self-management program with a distress-reduction program. Note: Traditional interventions for depression or anxiety are not likely pharmacological because diabetes distress is specifically caused by overwhelming treatment regimens. The treatment, therefore, is highly malleable and focused on reducing the emotional burden of having diabetes.² Reducing distress and improving diabetes outcomes may have less to do with behavior change and far more to do with the healthcare provider listening to, acknowledging, and normalizing patients distress so that their internal resources can be fortified.

Here is the intervention model to operationally reduce diabetes distress, which requires developing accurate empathy and building emotional intelligence.

ANTICIPATE THE PATIENT'S FEELINGS

Healthcare providers should anticipate the patient's feelings and show accurate empathy, which in turn lays the groundwork to build a trusting, therapeutic relationship and engages patients. Guessing how a patient is feeling is an individualized skill that tells the patient that you are listening intensely to the meaning of their words and showing interest. This does not mean that the healthcare provider must have the same experience. While the healthcare providers may have cognitive empathy,

demonstrating emotional empathy is a different skill that builds a therapeutic alliance as the patient feels understood by the provider. Rogers described this as the healthcare provider's ability to be an "accurate reader" and is a necessary step to be in tune with the client's needs and perspectives in order for them to move forward and grow⁷ It is not pity, it is understanding.

Examples of such conversations may be:

- "I am guessing you must be overwhelmed and frustrated to have to do all of these things day after day. Is that accurate?"
- "My intuition tells me you feel defeated. Does that seem true?"
- "You seem to feel you like can't get this diabetes under control. Is that right?"

Acknowledge their feelings (subhead)

Patients feel distress in different ways; it can present as discouragement, feeling overwhelmed, guilt, hopelessness, or self-pity. The good news is that once the patient accurately describes how they feel, these emotions can lose some of the power. Unidentified and unexpressed feelings cannot be managed.

Empathically acknowledging the patients true feelings allows them to gain clarity and can illicit change talk. Often, patients may respond ambivalently, which should also be acknowledged.

For example, a conversation may start with, "On the one hand, you feel like you really want to lose weight, change your diet, and exercise more, but on the other hand, you feel like you may fail again."

Identify both feelings. It is important to remember that to refrain from giving advice when ambivalence is present as those feeling can be counterproductive and drive the individual into resistance.⁸

STANDARDIZE AND NORMALIZE FEELINGS

Many patients with a chronic progressive illness feel very alone. Normalizing their feelings is a technique that can reduce their distress. Tell them that many patients with diabetes feel the same

way—this is typical, common, and even expected. Further, standardize their ambivalence by normalizing their desire to improve and the roadblocks that are preventing improvement.

For example, try saying, "Most people with diabetes feel this way. They want to improve but they often feel that [relate to the patient's feelings]."

The first 3 steps—anticipate, acknowledge, and standardize—form the basis of the program and are used most frequently during clinical encounters. Refer to the next steps when the patient is in distress and requires further attention.

ACCEPT AND UNDERSTAND

This skill requires holding unconditional positive regard for the patient and complete acceptance of where they are emotionally and physically. It is important to understand the origin of the distress, which is an emotional struggle experienced when change is not successful. Change is hard and distress occurs when goals that were anticipated are not achieved or turn out to be harder than expected. Once the distress is fully accepted, then it becomes something to attend to as another goal. Accept it—do not fight it, react blindly, give advice, discount or diminish it as not important.

For example, an interaction may be, "I understand how if must feel to have to constantly monitor your blood sugar, give yourself injections, and change almost every aspect of your life, and the hopelessness you feel about all of this."

PLAN YOUR RESPONSE

One approach is to have the patient identify what is most challenging aspect for them (above all the reasons) and to begin to unpack their concerns at each visit. Goal-setting research has found that goals that are most meaningful to people are more likely to be attained.⁹ Once that goal is established, have the patient name the obstacles and collectively develop a strategy for each obstacle. Small attainable goals lead to success and success breeds more success.⁹

Designing highly specific "where and when" strategies in their plan is also

linked to higher success with implementation.¹⁰ For example, if your patient identifies parties as a trigger for them to eat highly-processed, sugary foods, help them develop a specific action plan to avoid exposure to the toxic food.

Incorporate how to react to distress as part of the plan for behavioral change. If distress is experienced by discouragement with meal planning or exercise, and this blocks performance, use anticipatory problem solving. Plan an alternative activity (eg, look at yourself in the mirror and stick your tongue out) to break the pattern. Then reframe or redefine the distress as something that can be controlled.

Although the DDS17 test can be self-administered, it may be helpful if the clinician or staff member administers it to the patients. This provides an opportunity for the patient to offer expanded answers and engage in a conversation about his or her feelings. The interaction with the healthcare provider also creates trust and strengthens the bond with the patient, while creating an opportunity to start treatment.

All patients with diabetes, even those with minimal distress, profit from education and support that considers distress an expected part of diabetes. Incorporate distress education at critical times, such as when starting insulin or with the onset of complications. Minimal inexpensive interventions lower distress levels and improve disease management. With moderate and higher levels of distress, referrals to other health professionals may be beneficial. ■



For more, please visit our Diabetes Medical Resource Center at www.consultant360.com.

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Additional references at www.consultant360.com.