



Type 1 Diabetes Distress: Identifying and Managing It

Diabetes can be a difficult and demanding disease for individuals to manage. The behavioral and emotional burden of this chronic disease and its management often leads to significant diabetes distress, a common problem that affects one-third to nearly one-half of adults and adolescents with diabetes.¹⁻³ Fortunately, all clinicians can play an important role in identifying and managing diabetes distress in their patients.

? What is diabetes distress?

Diabetes distress is defined as a range of emotional responses to the specific health condition of diabetes.¹ Symptoms vary across individuals but typically include feeling ^{1,4,5}:

- Overwhelmed with the burden of managing a chronic health condition
- Afraid and anxious about complications and disease progression
- Defeated and discouraged when glycemic or behavioral targets, which may be unrealistic, are not met despite one's best efforts

With its cause focused specifically on diabetes, diabetes distress differs from major depressive disorder in many ways, but the two conditions often overlap and share some similar symptoms.^{1,4} Because of the similarities, diabetes distress can be misdiagnosed as depression, which can lead to individuals receiving inappropriate therapy.⁴ This misdiagnosis is also due, in part, to the similarity of common depressive symptoms with symptoms related to poor glycemic control (eg, lethargy, weight loss, insomnia).^{4,5} Distinguishing between diabetes distress and depression is crucial, as management strategies differ.^{4,5}

IMPORTANT

Compared with major depressive disorder, diabetes distress^{1,5,6}:

- Is defined within the context of a disease
- Is not considered to be a psychiatric disorder
- Is far more common
- Shares some similar symptoms but does not meet the criteria for major depressive disorder
- Is unlikely to respond to pharmacotherapy
- Is often directly linked to poor glycemic control and poor self-care (even at low levels of distress)

? What is the best way to assess diabetes distress?

The American Diabetes Association recommends screening for both diabetes distress and depression as part of overall care for individuals with diabetes.⁷ The most widely used tools for assessing diabetes distress are the Problem Areas in Diabetes (PAID) scale, the Diabetes Distress Scale (DDS), and the DDS for type 1 diabetes (T1D) (T1-DDS; [Table 1](#)).¹ Abbreviated versions of the first two instruments are available for initial screening of patients in busy practice settings.

The third instrument—the T1-DDS—is the only one that has been developed specifically for people with T1D. This tool differs from other tools in terms of its subscales, which focus on the following areas that have been identified as specific sources of distress for people with T1D⁸:

- Powerlessness (discouragement about the disease)

TABLE 1. Diabetes Distress Assessment and Screening Tools

| | NO. OF QUESTIONS | TIME TO COMPLETE (MIN.) |
|--------------------------------|------------------|-------------------------|
| Assessment Tools | | |
| PAID (Fisher, 2008) | 20 | 10-15 |
| DDS (Polonsky, 1995) | 17 | 10-15 |
| T1-DDS (Polonsky, 2005) | 28 | 10-15 |
| Brief Screening Tools | | |
| PAID-5 (McGuire, 2010) | 5 | 5 |
| PAID-1 (McGuire, 2010) | 1 | 1 |
| DDS2 (Fisher, 2008) | 2 | 1 |

Adapted from Beverly EA, et al. *J Family Pract.* 2017;66(1):9-14.

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Supported by Sanofi and Lexicon Pharmaceuticals.

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Developed by Med-IQ in collaboration with JDRF.

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- Negative social perceptions (concern about others' negative judgment)
- Physician distress (disappointment with healthcare providers)
- Friend/family distress (excess focus on the disease by friends and family)
- Hypoglycemia distress (concerns about severe hypoglycemic events)
- Management distress (disappointment with own self-care efforts)
- Eating distress (concerns about own excess thoughts of food and eating)

The T1-DDS is available online at <https://diabetesdistress.org/t1-dds-questions>. Patients can complete the tool on this website, have their responses automatically scored, and receive helpful visual feedback during their visit.

Quality of life and well-being are significantly affected by diabetes distress, so it is important to consider possible effects in these areas when assessing a patient. Those with high levels of distress have been shown to commonly experience⁹:

- Higher hemoglobin A1c (HbA1c) levels
- Greater frequency of hypoglycemia
- More missed insulin doses
- More episodes of diabetic ketoacidosis
- Less physical activity

Of note, several characteristics have been associated with higher levels of diabetes distress, including female sex, age younger than 40 years, and added complications.⁹

? What are some strategies to help reduce diabetes distress?

Strategies to address diabetes distress are crucial, as the condition may persist or worsen over time.¹ Clinicians are typically well positioned to open the conversation and develop management plans to address distress, if present. This approach helps normalize emotional reactions to diabetes and can help identify serious issues. As part of the conversation, clinicians should ask patients (or their parents) not just about diabetes-related issues, but also about socioeconomic changes that can exacerbate diabetes distress as well as life stress in general, such as changes in employment, insurance coverage, or living arrangements.¹

Once identified, a variety of interventions have been shown to be effective in reducing diabetes distress in individuals with T1D (Table 2).^{1,5,10-12} In addition, because the T1-DDS subscales identify critical sources of distress, interventions can be tailored to address specific issues.¹

TABLE 2. Strategies for Reducing Type 1 Diabetes Distress

| STRATEGY | COMPONENTS OF STRATEGY |
|--|--|
| Structured educational programs | Problem solving, goal setting, focus on motivational barriers |
| Education-/behavior-focused programs | Promotion of health behaviors and self-management education |
| Emotion-focused therapy | Scenarios and exercises to help individuals regulate emotions, coping strategies, personalized action plans to change behavior |
| Cognitive behavioral therapy | Ways to alter thinking and behavior, mindfulness |
| Support groups | Sharing of stories, coping mechanisms, and positive self-management behaviors |
| Introduction of appropriate diabetes technology | Continuous glucose monitoring, insulin pump therapy |

Derived from Beverly EA, et al. *J Family Pract.* 2017;66(1):9-14; Kreider KE. *Diabetes Ther.* 2017;8(1):1-7; Pallayova M, et al. *Diabetes Spectr.* 2014;27(2):143-149; Sturt J, et al. *Curr Diab Rep.* 2015;15(11):101; Polonsky WH, et al; DIAMOND Study Group. *Diabetes Care.* 2017;40(6):736-741.

If possible, individuals with moderate-to-high diabetes distress should be referred to a mental health professional trained in cognitive behavioral or problem-solving therapy who is also knowledgeable about diabetes. Diabetes educators can also be called on to help patients focus on self-management strategies that can help reduce diabetes distress.⁷

New diabetes technology, such as continuous glucose monitors (CGMs), have also been associated with decreases in diabetes distress (compared with self-monitoring).¹² This decrease is related primarily to reducing fears of hypoglycemia and enhancing sense of control.¹² The association between such devices and diabetes distress is complex, however, as studies have been conflicting on the benefits.¹³

CASE SCENARIOS To help understand the challenges that diabetes distress can cause in individuals with T1D, as well as potential strategies to manage diabetes distress, consider the following case scenarios.



CASE 1 **Mary**

Mary is a 42-year-old woman who received a diagnosis of T1D more than 20 years ago. Her current HbA1c is 7.2%, and she has had no episodes of severe hypoglycemia in the last 10 years. However, she has a history of being overwhelmed with diabetes self-management, especially as family and work demands have increased. She has become increasingly discouraged and frustrated with fluctuating glucose levels and tells you, “I’m trying to keep everything under control, but it doesn’t matter what I do. I just feel like giving up.” Also, she is worrying excessively about having a severe hypoglycemic episode, especially when driving, and it is beginning to affect her ability to function well in her life. Her scores on the T1-DDS, which she completed before today’s visit, confirm what she’s told you—her primary sources of distress are powerlessness and fear of hypoglycemia.

You acknowledge Mary’s concerns, explain that diabetes is tough to manage for almost everyone and that feeling discouraged and frustrated is common, and reassure her that her observed fluctuations in glucose levels don’t mean that she is “failing” with her diabetes. Indeed, her current HbA1c of 7.2% points to her ongoing success and indicates that her efforts are, in fact, making a difference. You also recommend that Mary consider a CGM device. Being able to view her glucose levels throughout the day and take action if needed may help her to feel more in control of her diabetes, ease her fears about hypoglycemia, and help her feel less overwhelmed about self-management. You acknowledge her time constraints because of family and work responsibilities but recommend that she attend a support group when she has time.



CASE 2 **James**

James is a 16-year-old who received a diagnosis of T1D when he was 14. His current HbA1c is 8.5%. At his routine diabetes check-in, he seems sullen. You ask him how he is feeling and how he is coping with self-managing diabetes. He tells you, “I feel fine. I try to do the right things, but my parents are constantly on my case about what I eat and what my glucose levels are. I can’t stand it.” He also says that he tries to hide his diabetes at school because he just wants to be a “regular kid.”

You first congratulate James on how well he has done, learning how to manage his diabetes over the past 2 years, and acknowledge that self-managing diabetes is a challenge. You also empathize with his desire to fit in but explain that he needs to find a better balance between ignoring his diabetes versus paying enough attention to his diabetes so that he can be safe, in control, and feel okay. You also discuss the possibility of using a CGM device. He seems a bit reluctant, so you stress that it does not have to be a lifelong commitment and that it is merely a powerful tool that he may want to consider—a tool that can help him keep an eye on his blood glucose levels, be more successful with his diabetes management, and show his parents that he is doing his best.

You also suggest asking one or both parents to join him at your next visit so they can negotiate reasonable diabetes goals. In addition, you suggest that he might want to attend a diabetes camp over the summer to meet other teens with T1D.

TIPS FOR ADDRESSING TYPE 1 DIABETES DISTRESS IN PRACTICE

- ▶ **ACKNOWLEDGE** diabetes distress as part of the common experience, and start a conversation about how to manage it
- ▶ **ENCOURAGE** patients to express their concerns and ask open-ended questions
- ▶ **SCREEN** periodically for diabetes distress (and major depressive disorder) as part of comprehensive diabetes care, at least annually
- ▶ **EMPOWER** patients to play an active role in diabetes self-management
- ▶ **ENGAGE** your multidisciplinary clinical team in addressing diabetes distress (eg, nurses, nurse practitioners, physician assistants, dietitians, pharmacists)
- ▶ **BE ALERT** to patients' (or parents') socioeconomic changes (eg, job, insurance coverage, living situations)
- ▶ **RECOMMEND** support groups
- ▶ **SUPPORT** shared decision making, showing respect for patients' values and preferences
- ▶ **REFER** patients with moderate-to-high diabetes distress to a therapist trained in cognitive behavioral therapy or problem-solving therapy who is knowledgeable about diabetes
- ▶ **PROVIDE "etiquette" cards** to all patients, so that they can help their friends and family gain a better perspective about T1D and learn how to be appropriately supportive (<https://behavioraldiabetes.org/xwp/wp-content/uploads/2015/12/BDITeenEtiquette.pdf> and <https://behavioraldiabetes.org/xwp/wp-content/uploads/2015/12/BDIAdultEtiquetteCard.pdf>)

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