Is Diabetes Distress on Your Radar Screen?

Diabetes distress, which affects almost half of those with diabetes, contributes to worsening glycemic control. Recognizing and responding to it is essential.

Elizabeth A. Beverly, PhD, Nedyalko N. Ivanov, BS, Autumn B. Court, BS, Todd R. Fredricks, DO

PRACTICE RECOMMENDATIONS
Educate patients about diabetes distress, explaining that diabetes is manageable and that neither complications nor diabetes distress is inevitable. 
Empower patients to take an active role in self-management of diabetes, encouraging them to express their concerns and ask open-ended questions.
Support shared decision-making by inquiring about patients’ values and treatment preferences, presenting options, and reviewing the risks and benefits of each.

STRENGTH OF RECOMMENDATION
A Good-quality patient-oriented evidence
B Inconsistent or limited-quality patient-oriented evidence
C Consensus, usual practice, opinion, disease-oriented evidence, case series

Managing diabetes is a complex undertaking, with an extensive regimen of self-care—including regular exercise, meal planning, blood glucose monitoring, medication scheduling, and multiple visits—that is critically linked to glycemic control and the prevention of complications. Incorporating all of these elements into daily life can be daunting.

In fact, nearly half of US adults with diabetes fail to meet the recommended targets. This leads to frustration, which often manifests in psychosocial problems that further hamper efforts to manage the disease. The most notable is a psychosocial disorder known as diabetes distress, which affects close to 45% of persons with diabetes.

It is important to note that diabetes distress is not a psychiatric disorder; rather, it is a broad affective reaction to the stress of living with this chronic and complex disease. By negatively affecting adherence to a self-care regimen, diabetes distress contributes to worsening glycemic control and increasing morbidity.

Recognizing that about 80% of those with diabetes are treated in primary care settings, this review is intended to call your attention to diabetes distress, alert you to brief screening tools that can easily be incorporated into clinic visits, and offer guidance in matching proposed interventions to the aspects of diabetes self-management that cause patients the greatest distress.

DIABETES DISTRESS: WHAT IT IS, WHAT IT’S NOT

For patients with type 2 diabetes, diabetes distress centers around four main issues:

- Frustration with the demands of self-care
- Apprehension about the future and the possibility of developing serious complications
- Concern about both the quality and the cost of required medical care
- Perceived lack of support from family and/or friends

As mentioned earlier, diabetes distress is not a psychiatric condition and should not
be confused with major depressive disorder (MDD). Here’s help in telling the difference.

For starters, a diagnosis of depression is symptom-based. MDD requires the presence of at least five of the nine symptoms defined by the Diagnostic and Statistical Manual of Mental Disorders, Fifth ed. (DSM-5)—eg, persistent feelings of worthlessness or guilt, sleep disturbances, lack of interest in normal activities—for at least two weeks. What’s more, the diagnostic criteria for MDD do not specify a cause or disease process. Nor do they distinguish between a pathological response and an expected reaction to a stressful life event. Further, depression measures reflect symptoms (eg, hyperglycemia), as well as stressful experiences resulting from diabetes self-care, which may contribute to the high rate of false positives or incorrect diagnoses of MDD and missed diagnoses of diabetes distress.

Unlike MDD, diabetes distress has a specific cause—diabetes—and can best be understood as an emotional response to a demanding health condition. And, because the source of the problem is identified, diabetes distress can be treated with specific interventions targeting the areas causing the highest levels of stress.

<table>
<thead>
<tr>
<th>Measure</th>
<th>No of items (time to complete)</th>
<th>Scoring</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes Distress Scale (DDS)</td>
<td>17 (10-15 min)</td>
<td>2.0-2.9 = moderate distress; ≥ 3 = high distress (items rated as “serious” or “very serious” warrant clinical attention)</td>
<td>diabetesed.net/page/..files/diabetes-distress.pdf</td>
</tr>
<tr>
<td>DDS-2</td>
<td>2 (1 min)</td>
<td>Average ≥ 3 or total ≥ 6 = moderate to high distress*</td>
<td><a href="http://www.annfammed.org/content/suppl/2008/05/08/6.3.246.DC1/Fisher_Apps1-5_new.pdf">www.annfammed.org/content/suppl/2008/05/08/6.3.246.DC1/Fisher_Apps1-5_new.pdf</a></td>
</tr>
<tr>
<td>Type-1 DDS†</td>
<td>28 (10-15 min)</td>
<td>1.5-1.9 = low distress; 2.0-2.9 = moderate distress; ≥ 3 = high distress (items rated “serious” or “very serious” warrant clinical attention)</td>
<td>N/A</td>
</tr>
<tr>
<td>Problem Areas in Diabetes (PAID)</td>
<td>20 (10-15 min)</td>
<td>Score 0-100; ≥ 40 indicates high distress (items rated “serious” warrant clinical attention even if score &lt; 40)</td>
<td><a href="http://www.dawnstudy.com/content/dam/Dawnstudy/AF">www.dawnstudy.com/content/dam/Dawnstudy/AF</a></td>
</tr>
<tr>
<td>PAID-5</td>
<td>5 (5 min)</td>
<td>Score 0-20; ≥ 8 indicates high distress (items rated “serious” warrant clinical attention even if score &lt; 8)</td>
<td>N/A</td>
</tr>
<tr>
<td>PAID-1</td>
<td>1 (1 min)</td>
<td>≥ 3 indicates high distress</td>
<td>N/A</td>
</tr>
</tbody>
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Abbreviation: N/A, not available.
*Each of the items on the DDS-2 is scored on a 1-6 range, with 1 or 2 indicating “not a problem” and 5 or 6 indicating a “serious problem.” The responses to the two items are then averaged and added; an average score ≥ 3 and/or a total ≥ 6 indicates moderate to high distress.
† Validated only for patients with type 1 diabetes; all others are validated for those with type 1 and type 2 diabetes, but recommended for patients with type 2 diabetes.
When a psychiatric condition and diabetes distress overlap

MDD, anxiety disorders, and diabetes distress are all common in patients with diabetes, and the co-occurrence of a psychiatric disorder and diabetes distress is high. Thus, it is important not only to identify cases of diabetes distress but also to consider comorbid depression and/or anxiety in patients with diabetes distress.

More often, though, it is the other way around, according to the Distress and Depression in Diabetes (3D) study. The researchers recently found that 84% of patients with moderate or high diabetes distress did not fulfill the criteria for MDD, but that 67% of diabetes patients with MDD also had moderate or high diabetes distress.

The data highlight the importance of screening patients with a dual diagnosis of diabetes and MDD for diabetes distress. Keep in mind that persons diagnosed with diabetes distress and a comorbid psychiatric condition may require more complex and intensive treatment than those with either diabetes distress or MDD alone.

SCREENING FOR DIABETES DISTRESS

Diabetes distress can be easily assessed using one of several patient-reported outcome measures. Six validated measures, ranging in length from one to 28 questions, are designed for use in primary care (see Table, page 31). Some of the measures are easily accessible online; others require a subscription to MEDLINE.

**Problem Areas in Diabetes (PAID).** There are three versions of PAID—a 20-item screen assessing a broad range of feelings related to living with diabetes and its treatment, a five-item version (PAID-5) with high rates of sensitivity (95%) and specificity (89%), and a single-item test (PAID-1) that is highly correlated with the longer version.

**Diabetes Distress Scale (DDS).** This tool is available in a 17-item screen assessing diabetes distress as it relates to the emotional burden, physician-related distress, regimen-related distress, and interpersonal distress. DDS is also available in a short form (DDS-2) with two items and a 28-item scale specifically for patients with type 1 diabetes. The only diabetes distress measure focused on this particular patient population, assesses the seven sources of distress found to be common among adults with type 1 diabetes: powerlessness, negative social perceptions, physician distress, friend/family distress, hypoglycemia distress, management distress, and eating distress.

Studies have shown that not only do...
those with type 1 diabetes experience different stressors compared with their type 2 counterparts, but also that they tend to experience distress differently. For patients with type 1 diabetes, for example, powerlessness ranked as the highest source of distress, followed by eating distress and hypoglycemia distress. These sources of distress differ from the regimen distress, emotional burden, interpersonal distress, and physician distress identified by those with type 2 diabetes.30

**HOW TO RESPOND TO DIABETES DISTRESS**

Diabetes distress is easier to identify than to successfully treat. Few validated treatments for diabetes distress exist and, to our knowledge, only two studies have assessed interventions aimed at reduction of such distress.31,32

The REDEEM trial recruited adults with type 2 diabetes and diabetes distress to participate in a 12-month randomized controlled trial (RCT).31 The trial had three arms, comparing the effectiveness of a computer-assisted self-management (CASM) program alone, a CASM program plus in-person diabetes distress-specific problem-solving therapy, and a computer-assisted minimally supportive intervention. The main outcomes included diabetes distress (using the DDS scale and subscales), self-management behaviors, and A1C.

Participants in all three arms showed significant reductions in total diabetes distress and improvements in self-management behaviors, with no significant differences among the groups. No differences in A1C were found. However, those in the CASM program plus distress-specific therapy arm showed a larger reduction in regimen distress compared with the other two groups.31

The DIAMOS trial recruited adults who had type 1 or type 2 diabetes, diabetes distress, and subclinical depressive symptoms for a two-arm RCT.32 One group underwent cognitive behavioral interventions, while the controls had standard group-based diabetes education. The main outcomes included diabetes distress (measured via the PAID scale), depressive symptoms, well-being, diabetes self-care, diabetes acceptance, satisfaction with diabetes treatment, A1C, and subclinical inflammation.

The intervention group showed greater
improvement in diabetes distress and depressive symptoms compared with the control group, but no differences in well-being, self-care, treatment satisfaction, A1C, or subclinical inflammation were observed.32

Both studies support the use of problem-solving therapy and cognitive behavioral interventions for patients with diabetes distress. Future research should evaluate the effectiveness of these interventions in the primary care setting.

What else to offer when challenges mount?

Diabetes is a progressive disease, and most patients experience multiple challenges over time. These typically include complications and comorbidities, physical limitations, polypharmacy, hypoglycemia, and cognitive impairment, as well as changes in everything from medication and lifestyle to insurance coverage and social support.33,34 All increase the risk for diabetes distress, as well as related psychiatric conditions.

Aging and diabetes are independent risk factors for cognitive impairment, for example, and the presence of both increases this risk.35 What’s more, diabetes alone is associated with poorer executive function, the higher-level cognitive processes that allow individuals to engage in independent, purposeful, and flexible goal-related behaviors.36-38 Both poor cognitive function and impaired executive function interfere with the ability to perform self-care behaviors such as adjusting insulin doses, drawing insulin into a syringe, or dialing an insulin dose with an insulin pen.39 This in turn can lead to frustration and increase the likelihood of moderate to high diabetes distress.

Assessing diabetes distress in patients with cognitive impairment, poor executive functioning, or other psychological limitations is particularly difficult, however, as no diabetes distress measures take such deficits into account. Thus, primary care providers without expertise in neuropsychology should consider referring patients with such problems to specialists for assessment.

The progressive nature of diabetes also highlights the need for primary care providers to periodically screen for diabetes distress and engage in ongoing discussions about what type of care is best for individual patients, and why. When developing or updating treatment plans and making recommendations, it is crucial to consider the impact the treatment would likely have on the patient’s physical and mental health and to explicitly inquire about and acknowledge his or her values and preferences for care.40-44

It is also important to remain aware of socioeconomic changes—in employment, insurance coverage, and living situations, for example—which are not addressed in the screening tools.

Moderate to high diabetes distress scores, as well as individual items patients identify as “very serious” problems, represent clinical red flags that should be the focus of careful discussion during a medical visit. Patients with moderate to high distress should be referred to a therapist trained in cognitive behavioral therapy or problem-solving therapy. Clinicians who lack access to such resources can incorporate cognitive behavioral and problem-solving techniques into patient discussions. (See “Directing Help Where It’s Most Needed,” pages 34-35.) All patients should be referred to a certified diabetes educator—a key component of diabetes care.45,46

REFERENCES


