

Diabetes Distress:

Screening Tools and Intervention Strategies

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Diabetes self-management involves multiple, complex self-care recommendations, including taking medication, monitoring glucose levels, following a healthy diet, and engaging in regular physical activity.¹

However, integrating these behaviors into daily life can be challenging for many patients with diabetes. Frustration to meet recommended behavioral goals may be reflected in new or existing psychosocial concerns that further hamper patient's efforts to manage diabetes. The most common psychosocial concerns is diabetes distress. The purpose of this document is to define diabetes distress and familiarize primary care clinicians with screening tools and evidence-based interventions to help patients with diabetes distress.



What is Diabetes Distress?

Diabetes distress refers to the negative affective experience of living with diabetes. This includes frustrations with self-care behaviors, concerns about the future and possibility of developing complications, worries about the quality and cost of medical care, and perceived lack of support from family and/or friends.²⁻³ The constant behavioral demands, pressure to meet A1C goals, and disease progression are associated with diabetes distress.⁴ High levels of diabetes distress are common, with a prevalence of 22% to 36% in adults with type 2 diabetes.⁵

It is important to understand that diabetes distress is not a psychiatric condition. It also is not a proxy for major depression or anxiety.⁶

Why is This Significant?

Diabetes distress is associated with:4

- Decreased self-efficacy
- Decreased self-care behaviors
- Increased A1C levels (even at low levels of distress)
- Increased microvascular and macrovascular complications
- Decreased quality of life

Is Diabetes Distress Related to Disease Duration?

The evidence related to the timing of diabetes distress is unclear. A 2017 systematic review and meta-analysis of 55 studies involving nearly 37,000 subjects with type 2 diabetes found no significant association between diabetes distress and disease duration.⁵ Diabetes distress can occur at any time regardless of how long a patient has had diabetes.

What Are the Validated Measures for Screening for Diabetes Distress?

The Problem Areas in Diabetes (PAID) scale and the Diabetes Distress Scale (DDS) are short questionnaires that are used to screen for diabetes distress. These tools are free for health care professionals and non-profit organizations to use.

Problem Areas in Diabetes (PAID)

Short versions available: PAID-5 (5 questions) and PAID-1 (1 question).⁷⁻¹⁰

20-item measure assessing feelings related to living with diabetes, including guilt, anger, frustration, worry, and fear.

Diabetes Distress Scale (DDS)

Short version available: DDS-2 (2 questions).7-10

Feeling	Not a ing Problem		Moderate Problem		Serious Problem	
Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
Feeling that I am often failing with my diabetes regimen.	1	2	3	4	5	6

For those patients whose average of the two screening items is \ge 3, or whose sum is \ge 6, the 17-item DDS should be completed.

17-item measure assessing distress via four factors:

1. Emotional Burden, 2. Physician-Related Distress, 3. Regimen-Related Distress, and 4. Interpersonal Distress.

How Often Should Patients be Evaluated for Diabetes Distress?

It is recommended to routinely monitor patients with diabetes for diabetes distress. The American Diabetes Association recommends at least annual screening for diabetes distress, and more frequent monitoring when treatment targets are not met, during transition times, and/or in the presence of diabetes complications. Although there is not a gold standard for how often patients should be screened for diabetes distress, more frequent screenings should occur when patients experience comorbidities, diabetes-related complications, food insecurity, changes in life events, or changes in their diabetes treatment plan.^{4, 11-13}

What are the Implications for Care?

Primary care teams are well-positioned to screen and monitor patients for diabetes distress considering that they deliver more than 90% of the clinical care to patients with type 2 diabetes in the United States. ¹⁴ Interventions can be tailored to the sources of distress because diabetes distress is associated with the day-to-day experiences of living with the disease.

Start the conversation by doing the following:

- 1. Ask the patient if they are experiencing feelings of distress.
- 2. Avoid minimizing the patient's concerns.
- 3. Use Motivational Interviewing to elicit and understand concerns by asking open-ended questions, acknowledging their strengths, reflecting on what the patient says, and summarizing your understanding of what the person is experiencing.

For more information, access Cardi-OH's expanded resources on motivational interviewing, tools to reduce stigma, and the impact of diabetes distress on primary care.

The American Diabetes Association recommends the following interventions:



Routinely screen and monitor with validated measures.



If moderate or high diabetes distress identified, discuss sources of distress with patient.



Refer to diabetes education to address problems with self-care.*



If tailored diabetes education does not improve self-care, refer to behavioral health clinician.

*Research has shown significant reductions in diabetes distress at 6-months and 12-months post diabetes education. Referral to diabetes education is recommended at all points of diabetes care and is not limited to patients who are experiencing diabetes distress. Diabetes education is usually covered by insurance once a year.

Additional diabetes self-management interventions to consider:15

- Have the person focus on smaller goals for managing their diabetes to avoid feeling overwhelmed.
- Encourage the person to join a diabetes support group.
- Suggest the person visit with a diabetes educator, who can provide additional one-on-one insight and counseling to improve diabetes care.
- Include alerts in electronic health records to prompt clinicians to screen for diabetes distress.
- Coordinate with other members of the health care team, including diabetes educators, behavioral health care clinicians, and registered dietitians.

For more information, access Cardi-OH's resource on Diabetes Self-Management Education and Support.

Additional Resources

Diabetes Distress Scales and Scoring: Behavioral Diabetes Institute listing of self-report tools commonly used to assess diabetes distress.

behavioraldiabetes.org/scales-and-measures/#1448434304099-9078f27c-4106

10 Tips for Coping with Diabetes Distress: Centers for Disease Control and Prevention tips on how to cope with diabetes distress.

cdc.gov/diabetes/articles/10-tips-coping-diabetes-distress.html

Dealing with the Weight of Diabetes: Association of Diabetes Care & Education Specialists resource on healthy coping with diabetes.

diabeteseducator.org/docs/default-source/living-with-diabetes/tip-sheets/healthy-coping/distress_eng.pdf?sfvrsn=6

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