Recognizing Disordered Eating in People with T1D

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Eating disorders (EDs) are a common problem in the general population, and they occur even more frequently among individuals with type 1 diabetes (T1D).[1] In adolescents and young adults with T1D, EDs or disordered eating behaviors affect at least 40% of women and 16% of men.[2] This e-brief will explore the recognition, screening, and treatment of EDs in individuals with T1D, with a focus on strategies for talking to patients and their families about this important topic.

THE FACES OF EATING DISORDERS AND T1D

Disordered eating can range from subclinical behaviors (eg, being overly focused on body image, diet, and exercise) to life-threatening EDs, such as anorexia nervosa and bulimia.[1] Intentional insulin reduction or omission as a symptom of calorie purging—frequently called "diabulimia" in popular references—is a phenomenon unique to T1D.[3] However, not everyone with T1D and disordered eating engages in this practice.

WARNING SIGNS OF EATING DISORDERS IN T1D

- Poor school or work performance
- Trouble with interpersonal relationships
- Poor adherence to blood glucose monitoring, insulin administration
- Depressive symptoms
- Frequent dieting
- Laxative/diuretic use
- Self-induced vomiting
- Extreme focus on body size or shape
- Excessive exercise
- Recurrent exercise-related hypoglycemia
- Unexplained increase in hemoglobin A1c (HbA1c) levels
- Repeated episodes of diabetic ketoacidosis (DKA)
- Amenorrhea

Aaliyah is a 17-year-old girl who was diagnosed with T1D at 8 years of age. She has always had a low body mass index (between 18 and 20). Over the last 2 years, she has maintained a "perfect" HbA1c between 6.5% and 7%. However, when her physician asks to see her glucose meter data, insulin logs, or food records at visits, Aaliyah always replies that she forgot to bring them. She does not want her physician and parents to know that she has only been eating 1,000 to 1,200 calories a day to prevent weight gain, which has greatly reduced the amount of mealtime insulin she needs.

Corrina is a 37-year-old woman with T1D who became overly concerned about maintaining her current weight after her son was born 2 years ago. She notes that she occasionally "goes overboard" with junk food about once a month when she feels stressed. She then skips her insulin for a few days to help prevent weight gain, going back to her insulin treatment plan when she feels like she has adequately compensated for the binge. Her HbA1c is 9%.

Josh is a 25-year-old man with T1D. He has become depressed over substantial weight gain that began when his insulin regimen was intensified. He read online that insulin restriction could help him lose weight, so he has been cutting his insulin dose for the last 3 months. At his next checkup, he complains of feeling tired throughout the day, having difficulty concentrating, and waking up several times most nights to go to the bathroom. He's lost 15 pounds, but his HbA1c has increased from 7.5% to 10%.

Developed in collaboration

EDs AND T1D: COMPLICATIONS

Studies have found that EDs in individuals with T1D can lead to significant morbidity and mortality, including the following issues[4-8]:

- Patients with T1D and EDs have a higher risk of DKA and hospitalization
- Insulin restriction is associated with recurrent DKA and increased mortality
- Individuals with T1D and anorexia nervosa have a crude 10-year mortality rate of approximately 35%—a rate that is 5 times higher than that of those with T1D alone
- Those with T1D and bulimia have a 2.5-fold higher risk of retinopathy
- EDs predispose individuals with T1D to hypoglycemia

Given these potential complications, it is critically important that providers be mindful of the warning signs of EDs in their patients with T1D. To this end, the American Diabetes Association suggests that age-appropriate assessment and management of psychosocial issues (eg, diabetes-related distress, fear of hypo- or hyperglycemia, EDs, insulin omission, mood disorders) be carried out at most diabetes visits.[8,9] Formalized ED screening should be considered when unexplained hyperglycemia, weight loss, or other risk factors are present.[8] Screening can take the form of an open-ended discussion or a questionnaire, but a comprehensive evaluation by a mental health professional is also recommended to make a definitive diagnosis.[8]

SCREENING FOR EDs

T1D-Specific Screening Tools

The modified SCOFF tool (mSCOFF, provided to the right) is a diabetes-specific, 5-question screening questionnaire that can be quickly administered during a routine clinical visit.[10]

The 16-question, revised Diabetes Eating Problem Survey (DEPS-R) was designed specifically for use in children and adolescents with T1D and has also demonstrated good psychometric properties among adults with T1D.[11,12] However, this tool is primarily used in research.[11]

Focus on Language Used in Screening Conversations

Choose your words carefully when discussing ED-related behaviors. Avoid language that may be perceived as critical or shaming by patients. Aim for more supportive communication.[13]

mSCOFF TOOL

1. Do you make yourself **S**ick because you feel uncomfortably full?
2. Do you worry you have lost **C**ontrol over how much you eat?
3. Have you recently lost at least 14 lbs (**O**ne stone) in a 3-month period?
4. Do you believe yourself to be **F**at when others say you are too thin?
5. Do you ever take less insulin than you should?*

Reprinted with permission from Zuijdwijk CS, Pardy SA, Dowden JJ, Dominic AM, Bridger T, Newhook LA. The mSCOFF for screening disordered eating in pediatric type 1 diabetes. *Diabetes Care*. 201 ;37(2):e26-e27.

*The authors modified this question to be diabetes specific.

Healthcare Provider Communication When Inquiring About ED-Related Behaviors

DON'T Say	DO Say
"You lost a lot of weight, and your HbA1c is up since your last visit. Are you taking your insulin as recommended?"	*"I noticed that your weight is lower and your HbA1c is higher since your last visit. Have you been doing something differently since then?"*
"You keep forgetting to bring your glucose meter data to your visits. Are you hiding something from me?"	*"I noticed that you forgot to bring your glucose meter data for your last 2 visits. I really need to see your blood glucose patterns to help tailor your insulin plan. What do you think is making it hard to remember to bring it in?"*
"Your HbA1c is higher each time I see you. Are you skipping insulin to lose weight?"	*"Your HbA1c keeps getting higher. I'm guessing you're having trouble taking the insulin. There are a lot of different reasons why people might have trouble with insulin. What's making it hard for you right now?"*

Adapted from expert faculty opinion and Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. *Diabetes Care*. 2017;40(12):1790-1799.

TREATMENT OF EDs

For patients with T1D and an ED, a multidisciplinary team approach is required and should include the following providers[6]:

- Endocrinologist
- Certified diabetes care and education specialist
- Primary care physician
- Registered dietitian with expertise in EDs and/or T1D
- Psychiatrist and/or mental health professional

Identifying mental health professionals with expertise in both EDs and T1D can be challenging. For individuals who can be cared for in the outpatient setting, the best approach is to refer the patient to an ED expert who is willing to learn about specific T1D-related issues from the healthcare team. Sources for locating mental health providers include:

- The ADA's Mental Health Provider Directory (https://professional.diabetes.org/mhp_listing)
- The National Eating Disorders Association (https://map.nationaleatingdisorders.org/)

For those who cannot be safely treated in an outpatient setting (eg, patients who exhibit psychiatric and/or medical instability), admission to an inpatient treatment center is required for a comprehensive medical and psychiatric assessment.[14] A general psychiatric unit may be more appropriate if the patient's suicide risk outweighs medical urgency, whereas a specialized ED inpatient unit is better suited for individuals whose EDs have caused medical and psychiatric instability without suicidality. After the individual's acute needs are addressed, a medical management plan should be developed to reestablish insulin therapy and regular eating patterns during the inpatient stay. Behavioral psychosocial interventions are also needed to address the underlying issues associated with EDs.[14]

CHANGE THE CONVERSATION

Choosing our words carefully when screening for EDs is important, but it is equally important when thinking about ED prevention. Word choice also plays an important role in enhancing health outcomes when discussing T1D, weight, and EDs with patients in a more general way.[13] Language should be nonjudgmental and free from stigma while imparting hope and conveying a sense of collaboration.[13] Consider the following tips[6,13]:

- **Focus less on numbers.** Encourage patients to focus less on specific scale or meter results and more on how they feel when at a healthy weight and blood glucose range.

Use words like "check" instead of "test," "manage" instead of "control," and "higher" or "lower" instead of "good" or "bad."

- **Educate patients about weight gain and insulin.** Patients may not fully grasp that weight gain associated with effective insulin treatment indicates a reversal of the adverse effects of diabetes.

Without insulin, your body was eating away at itself, but now your body is healing, getting stronger, and rebuilding itself with insulin.

- **Explain why rapid weight gain might occur after hospitalization.** Patients hospitalized for DKA may experience weight gain due to fluid replacement resulting in fluid retention (also called insulin edema).

DKA results in severe dehydration, so when the body gets appropriate fluids, it hangs onto that fluid. This is water weight, not true weight gain. It will resolve over time. It's healthiest to keep providing your body with the fluids it needs.

- **Talk with parents.** Beginning in a child's preteen years, clinicians should discuss with parents the potential risk of disordered eating. Clinicians can encourage children, siblings, and parents to be less focused on weight and appearance in their conversations in order to create a "no body talk" rule of thumb at home. They can also encourage healthy behaviors, such as balanced, flexible eating, and de-emphasize restrictive dieting and extreme approaches to exercise.

Healthcare Provider Communication Regarding Weight	
Don'ts/Critical	**Do's/Supportive**
"Your weight is creeping up. You need to lose at least 10 lbs."	*"May I ask about your weight? Would you be interested in a referral to a dietitian to learn more about balanced eating?"*
"You have to increase your exercise to 45 minutes every day if you want to get control of your weight."	*"Have you tried upping your physical activity? Can I tell you about some exercise choices that have worked for my other patients?"*
Family Member Communication Regarding Weight	
Don'ts/Critical	**Do's/Supportive**
"I know you need to lose weight, so I've decided we better start a diet."	*"I know you want to lose weight. Let's find some ways to make healthier meals as a family."*
"You just sit around after school. You need to join the gym."	*"Tell me about some fun stuff you'd like to try to get moving. Would you like me to go visit that new gym with you?"*

Adapted from expert faculty opinion and Dickinson JK, Guzman SJ, Maryniuk MD, et al. The use of language in diabetes care and education. *Diabetes Care*. 2017;40(12):1790-1799.

ADDITIONAL RESOURCES

We hope you found this to be a useful summary of information to help you manage EDs in individuals with T1D. The following additional organizations provide support and awareness for individuals with T1D who struggle with disordered eating and might be helpful for your patients and their families:

- Diabulimia Help Line (www.diabulimiahelpline.org)
- We Are Diabetes (www.wearediabetes.org)

In addition, this book is a helpful guide for healthcare providers as well as for patients and their loved ones: Goebel-Fabbri, AE. *Prevention and Recovery from Eating Disorders in Type 1 Diabetes: Injecting Hope*. New York, NY: Routledge Press; 2017.

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