Diabetes & Eating Disorders: A Complicated Relationship

Quinn Nystrom, M.S.
Speaker, Author & Diabetes Advocate
National Diabetes Ambassador – Center for Change
• Blood glucose meter
• Blood glucose test strips
• Blood ketone meter and blood ketone strips OR urine ketone strips
• Lancing device
• Lancets
• Continuous Glucose Monitor & Sensor
• Alcohol swabs
• Syringes
• Insulin pump supplies
• Batteries
• Glucose tablets or other quick acting source of sugar
• Glucagon kit
• Waterproof tape
• Adhesive remover
• Frio cooling wallet
• Snacks
Camp Needlepoint

Hudson, WI

National Youth Advocate
Other reality...
"Make sure you pour some out for your dead homies." — Greg Glassman #CrossFit
#Sugarkills @CrossFitCEO

White House says diabetics don’t deserve health insurance

Mueller wants to leave the 28 million Americans living with diabetes out in the cold, because he doesn’t deem them worthy of treatment.

CUSTOM FOOTWEAR

For that special uncontrolled diabetic in your life
Veronica M. Landry

I'm prepping for my first figure competition at age 45 on ketof! I have done a lot of research on keto. It is very safe and effective. I have major health conditions and this has literally saved me, along with good supplementation and essential oils. It kills inflammation, which is key to fighting heart disease, diabetes, etc. Do yourself a favor and try keto!

1 hour ago · Edited · Like · Reply

Jeanette Chapman Hulett

Is it something you do constantly or do you get a “cheat” meal every so often?

1 hour ago · Like · Reply

Chandra Sommerfeld Abill

Write a comment...

Kelly McConkey

It was a very controversial film and with those I often believe half...
Consequences of Poor Diabetes Management

- Diabetes is leading cause of new cases of blindness for 20-74
- Stroke and heart attack – 38%
- Blood pressure – 75%
- ESRD – 44% of new cases are with diabetes
- Loss of sensation in hand and feet – 60-70%
- 12-15% with diabetic foot ulcer

This is diabetes.

This is NOT.
What is ED-DMT1?

• The dual diagnosis of an eating disorder and type 1 diabetes is often referred to as “diabulimia,” however this is not a medically recognized term and it is not an accurate description.

• “Among some academics, the nomenclature eating disorders in diabetes mellitus type 1 (ED-DMT1) is used to denote the spectrum of disturbed eating behavior found within this specific demographic.”

  –Jacqueline Allen, Birkbeck University

Prevalence of Eating Disorders

75% of American women are dissatisfied with their appearance.

50% of 9 year old girls and 80% of 10 year old girls have dieted.

At least 4% of teenage girls and college-age women become anorexic or bulimic.

Eating Disorders + Diabetes

- ED behaviors seen in 8% of T1DM vs 1% of peers without DM.
- Increased risk of disturbed eating behavior in girls with T1DM as young as 9.
- 32.4% of females with type 1 diabetes have some form of disordered eating or weight control behavior.
- 36% reported intentional omission of insulin.
- Strong association between type 2 diabetes and clinically significant binge eating.

Peveler RC. Type 1 Diabetes & Eating Disorders, Diabetes Care 2005
Colton P. et al. Disturbed eating behavior and eating disorders in preteen and early teenage girls with type 1 diabetes; a case-controlled study Diabetes Care 27:1654-1659, 2004
Udo et al. Menopause and metabolic syndrome in obese individuals with binge eating disorder. Eat Behav 2014;15

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Why higher risk?

- Feels betrayed by body with diagnosis of diabetes.
- Emphasis on food and dietary restraint.
- Society setting “food rules” for people with diabetes.
- Diabetes management focuses on numbers. Patient judges self being “good” or “bad” based on eating patterns or blood glucose level.
- Belief that you “ate your way into diabetes”.
- Easy availability of deliberate insulin omission to control weight.
- Weight gain/higher BMI, result from intensive insulin therapy.
- Effect of diabetes on self-concept, body image, and family interactions.
- Temptation factor
- Family dynamics involving autonomy and independence concerning diabetes self-management.
ED Screening Tools for Diabetes Patients

Diabetes and Eating Problem Survey – Revised (DEPS-R)  

SCOFF

DEPS-R

16 questions 0-5 Likert scale, can complete in <10 min

Some examples of questions specifically related to diabetes:

- I feel fat when I take all of my insulin.
- Other people tell me to take better care of my diabetes.
- After I overeat, I skip my next insulin dose.

* ADD the total score = greater than 20 is clinically significant.

SCOFF

- Do you make yourself sick because you feel uncomfortably full?
- Do you worry you have lost control over how much you eat?
- Have you recently lost more than one stone (7.7 kg, about 15 lbs) in a 3 month period?
- Do you believe yourself to be fat when others say you are too thin?
- Would you say that food dominates your life?

*One point for every "yes;" a score of ≥2 indicates a likely case of anorexia nervosa or bulimia

PURPOSE/METHODS

- Reviewed charts of the past 27 patients with type 1 diabetes who have been admitted into 24-hour care at Center for Change.
- Analyze Diabetes and Eating Problem Survey -Revised (DEPS-R) scores to determine frequency of insulin omission.
- Analyze HbA1c levels according to reports of insulin omission. This analysis will help determine percentage of patients with diabetes and eating disorders who omit insulin for weight loss.
- There in theory may be many patients with diabetes and eating disorders who go unrecognized since they do not omit insulin for weight loss or have a high HbA1c.
Eating Disorder Diagnosis

DEPS-R Scores of Patients

- DEPS-R Scores for Keeping BG High to Lose Weight
- Faced Pat when Take All of Insulin

52 Total Patients
ED-DMT1

Diagnosis

Treatment

“Owning our story can be hard but not nearly as difficult as spending our lives running from it. Embracing our vulnerabilities is risky but not nearly as dangerous as giving up on love and belonging and joy—the experiences that make us the most vulnerable. Only when we are brave enough to explore the darkness will we discover the infinite power of our light.”

-Brene Brown
Treatment and Recovery: it’s a process


Graduate School Research

Diabetes Daze: How Adolescent Patients are Affected by Messaging
- Illness Perception
- Social Learning Theory
- Peer, Media, Medical Professional & Parental Messages
Results

- Not all adolescents had optimum control of their diabetes currently (45 percent were at 8.1 percent or higher for their A1c).
- Nearly 97% agreed that better diabetes management would allow them to live longer.
- Adolescents place their greatest information source with diabetes medical professionals.
- Negative messages came from multiple sources.

- 75% told of a person having misinformation.
- 40.6 % reported that they had a negative experience where they were called overweight.
- 71% say a motivating factor in improving self-management is curability/controllability.
Most Helpful Communication Practice & Least Helpful Communication Practice by a Healthcare Professional

J. (non-DMT1)

- Most Helpful: reminding me that I can use my voice instead of my body to communicate.

- Least Helpful: invalidation! I had a therapist tell me that I was exaggerating my ED symptoms because my labs were fine (and therefore I was fine). ED specialists should know that lab values (or weight) does not determine how sick someone is.
J.V. (T1D)

- Most helpful: Since I was in such denial of how sick I was it was important for my providers to have clear communication about my ED diagnosis as well as how they recognized the ED taking away my energy, joy, and personality. I will always be grateful for the honesty of my therapist who told me "well your diagnosis is anorexia, don't you know that?" I had no clue! The words and direct approach and challenges to my thoughts were what helped me realize where I needed to be to be in recovery.

- Least helpful: When they questioned if I was a type 1 diabetic since I was diagnosed at 27. As someone who was struggling with an ED at the time it was the worst thing someone could ask. It’s like they were saying I’m fat by asking if I’m sure I am a type 1.

E.S. (T1D)

- Most Helpful: Helped me explore the functions that the eating disorder served in my life and helped me find healthier ways to address those same needs without using the eating disorder to do so. Helped me learn to trust my intuition and validate my own feelings.

- Least Helpful: Being treated as though I am not the expert on myself. Of course the professionals are going to know more about the medical and technical aspects of the disease. But I am the only one who knows what it feels like to live in my body with my brain. It’s important to allow the patient to be the expert on themselves, because without learning to trust themselves, they will not achieve true recovery. Doing the behaviors of a healthy, recovered person is only half the battle.
M.G. (non-dmT1)

• Most Helpful: just sit and listen to me talk about what I experience without trying to diagnose me. After we got done talking she called my therapist and asked her what the diagnosis was (so it could be accurately reflected in my medical chart) instead of trying to use purely medical standards for the diagnosis. For me this felt very validating and like she understood that the things I was experiencing may not have fit one particular diagnosis perfectly and that was okay.

• Least Helpful: tell me I could not have a restrictive ED because of my size and then go on to give me weight loss and diet/exercise tips after explicitly asking that others not.

E.C. (T1D)

• Most Helpful: Listening and not judging! I know I can go to an appointment and my provider will let me talk and kindly direct me back on topic if necessary. She celebrates my successes and encourages me to do my best.

• Least Helpful: Being too quiet or talking at me. I know it is their job to listen and give me information to help my recovery journey, but there is a fine line of appearing like they are uninterested when we are discussing the same topic or goal every visit.
• Most Helpful: The acts of genuine empathy (non-verbal communication). When the torturous screams of the eating disorder become too fierce to battle, and you find yourself collapsed on the floor blinded by wretched tears, the empathetic act of simply sitting by your side. The simple presence of someone enduring moments of true Hell with you. Knowing that you are not alone in the battle.

• Least Helpful: Not separating the eating disorder from the True You (your authentic self). When others pair the True You with the eating disorder.
MOST HELPFUL

- Strengthening Voice
- Clearly Communicate
- Validate
- Trust Intuition
- Listen
- Understand
- Non-Judgmental
- Celebrate Successes
- Encourage
- Empathetic

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<th>Instead of...</th>
<th>Try saying...</th>
<th>Explanation</th>
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| A diabetic | Person living with diabetes | There is much more to a person than their 
diabetes, so it is preferable to avoid 
labeling someone as a disease. |
| Control (as a verb or adjective) | Manage | Control is not a verb. It is the ability or 
the condition of being able to control 
something. It is preferable to focus 
on what the person is doing well and 
what needs improvement. |
| Control (as a noun): glucose control, good control, bad control, etc. | ACG: blood glucose levels, targets, goals, variability | Focusing on neutral words and the biopsy 
removes judgment, shame, or blame. |
| Lifestyle disease | Diabetes | Saying "diabetes" instead of "lifestyle 
disease" removes any implied judgment. |
| Cheating, sneaking | Good/dishonest | Moving away from value judgments to 
neutral language removes any implied judgment. |
| Non-diabetic, normal | Person without diabetes | The opposite of "normal" is "abnormal". |
| Test (blood sugar) | Check blood sugar | A test implies good or bad. 
Checking blood sugar is simply a way to 
gather information to make decisions. |
| Prevent, prevention | Reduce risk | There is no guarantee of preventions (disease 
or complications) therefore, focusing on what 
the person can do to reduce the risk if the person 
does develop diabetes or complications. |
| Compliant/compliance | Engagement | Compliance and adherence imply doing 
what someone else wants. In diabetes care, 
people make decisions and form self-management. |
| Shaming | Lives with diabetes, Has diabetes, Diagnosed with diabetes | Assuming that someone is suffering puts 
them in victim mode rather than 
empowering them. |

AADE, ADA, 2018
## For Mental Health Providers
### Practical Applications

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<th>Gather</th>
<th>Adapt</th>
<th>Comfort</th>
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| Gather diabetes history  
- Diagnosis, family’s response, relationship with providers  
- Expectations, targets for glucose and approach to food. | Adapt your standard approach to eating disorders  
- Diabetes specific concerns need to be integrated into treatment  
- Perfectionism: diabetes management, food, weight | Comfort level - burnout |

- Create a nonjudgmental treatment relationship.
- Language:
  - Management vs. control
  - check/value vs. test (glucose or A1c)  
    - Like a compass not a report card
  - High/low or in target vs. good/bad
  - Avoid labeling food as good or bad
  - Avoid suggestions or comments that diminish the complexity and difficulty of having both DM and ED  
    - “just eat”
    - “Just take your insulin”
  - Avoid labels “non-compliant”

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Ann Goebel-Fabbri 2017 Injecting Hope  
Prevention and Recovery from Eating Disorders in Type 1 Diabetes
Diabetes Providers Practical Applications

Take the fear of weight gain seriously

Help cope with edema

Teach symptoms of DKA

Gradual decreases in A1c

Focus on when the patient feels ready

For Family and Friends Practical Applications

KNOW WARNING SIGNS OF ED AND SYMPTOMS OF DKA

REFRAIN FROM FEAR TACTICS OR SHAMING

END “BODY TALK”

ENCOURAGE FLEXIBLE EATING
