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Dying to be Skinny: Eating Disorders and Type 1 Diabetes (ED-DMT1)
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Disclosures

- Notice of Requirements For Successful Completion
  - Please refer to learning goals and objectives
  - Learners must attend the full activity and complete the evaluation in order to claim continuing education credit/hours

- Conflict of Interest (COI) and Financial Relationship Disclosures:
  - Presenter: Susan Weiner: Advisor for Livongo, Consultant Abbott Nutrition
  - Presenter: Asha Brown, No COI/Financial Relationship to disclose

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Learning Outcomes

- After attending this session, participants will be able to actively identify the warning signs of insulin restriction and other eating disorder symptoms in type 1 diabetes.
- After attending this session, participants will be able to lead the healthcare team on discussions of the prevalence of eating disorders in type 1 diabetes, medical risks and treatment outcomes.
- After attending this session, participants will be able to actively explain how eating disorder treatments (psychological and nutritional) can be adapted for the person with type 1 diabetes.
And then, in 2009, my world fell apart ...

*explosion sounds*

My reality had become ...

- Food Restriction
- Over Exercising
  - Trying to hide “extra exercise” from family and friends.
- Bingeing
  - Binges triggered even more severe calorie cutting and exercise.
- Exhaustion
  - The combination of both calorie restriction and over-exercise triggered binges.
More reality ...

- Insulin omission
- No one knew
- No one asked

The Turning Point

- Accepting treatment.
- Surrendering to change.
- Embracing recovery.
- Long-term commitment to recovery.
What is Type 1 Diabetes?

- An auto-immune disease in which the immune system attacks itself, destroying the insulin secreting beta cells of the pancreas until they produce little to no insulin
- Treatment requires a fine balance of 24/7 monitoring of blood glucose and insulin (plus carb counting and a million other things!)
- Less than one-third of people living with Type 1 in the U.S. achieve target blood glucose levels (1)
- There is CURRENTLY no cure, just the lifeline of insulin

22 Factors That Affect Blood Glucose

- Adam Brown, diaTribe.org
Does Insulin Cause Weight Gain?

- Myth “Insulin makes me fat”
- Excess energy intake causes weight gain
- Synthetic insulin is more efficient than natural insulin which means people with Type 1 tend to be heavier than their non-diabetic peers by 4 to 13 lbs.²

What Happens Without Insulin?

- DKA (diabetic ketoacidosis) - the body can’t use sugar for fuel so it turns to alternative sources, like fat and muscle.
- As fat is broken down, acids called ketones begin building up in the blood and urine.
- High levels of ketones are poisonous and if left untreated can lead to coma or death.

Insulin and Attitude

- Increased attention to numbers: Carb counting, blood glucose levels
- No access to a dietitian, CDE or health care professional
- Satiety cues compromised
- Understanding hunger cues
- Label reading, menu planning, feeling deprived
- Insulin attitude
- Not listen to: Judgment from health care professionals
What Constitutes an Eating Disorder?

• Anorexia Nervosa – Severe restriction of energy intake leading to excessive weight loss; fear of insulin can cause a person to limit or reduce eating to avoid needing insulin.
• Bulimia Nervosa – Recurrent episodes of binge eating with inappropriate compensatory behavior such as vomiting, excessive exercise and insulin omission.
• Binge Eating Disorder – Recurrent episodes of binge eating; though less common some will intentionally overdose insulin to justify binge eating.
• Purging Disorder – Normal eating patterns with recurrent inappropriate compensatory behavior, including insulin omission.

Overeating vs Binge Eating Disorder (BED)

• Three or more of the following symptoms must also occur for BED diagnosis:
  – Eating until feeling uncomfortably full
  – Eating more rapidly than normal (i.e. two hour period)
  – Feeling depressed, guilty, or disgusted with oneself after overeating
  – Eating alone because of embarrassment associated with how much one is eating
  – Eating large amounts of food when not feeling physically hungry

Overeating vs Binge Eating Disorder (BED)

Everyone occasionally overeats

People with Binge Eating Disorder

Often feel guilty or shame after eating.

Marked distress over bingeing episodes.

Loss of control over amount of eating.

AN, BN, BED, Other Specified Feeding or Eating Disorder, Avoidant/Restrictive Food Intake DSM-5, Diagnostic Statistical Manual for Mental Disorders, May 2013

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ED-DMT1 ("diabulimia")

• Dual dx of eating disorder and type 1 diabetes
• Restricting insulin for weight loss
• Not listed in DSM-5

ED-DMT1 is ...

• Restricting
• Restricting with purging
• Restricting with bingeing and purging
• Bingeing
• Self induced vomiting
• Laxative abuse
• Diuretic abuse
• Compulsive exercising

What's the Secret?

• Studies show 30-40% of Type 1 young women engage in this life threatening behavior, as high as 50%.
• You may have innocently/accidentally discovered it for yourself and never recognized it for what it is.
• It can happen to anyone.
• It will kill you.

AADE, 2013. Other Specified Feeding or Eating Disorders. American Association of Diabetes Educators. #AADE.
T1Ds have an increased risk of developing an Eating Disorder

- Ongoing close monitoring of nutrition, exercise, blood glucose levels and insulin dosages may lead to obsessive thinking and unhealthy preoccupation with food and weight.
- Fear of going low, eating to prevent or correct, then feeling guilty about eating and fear that eating will lead to weight gain.
- “Insulin treatment often leads to increased hunger and weight gain.”
- Role of parents or others (diabetes police) in managing diabetes (control).

Increased risk for T1Ds (cont’d)

- Need for control (over food and/or weight when one can’t control emotions or external situations).
- Use as a coping mechanism (emotional disassociation).
- Psychological issues associated with diagnosis and management of long-term illness (anger at diabetes).
- Onset of diabetes is often associated with weight loss that person with diabetes does not want to give up.
- Routine focus on weight at every hcp visit.

ED Thought Process can be Exacerbated with Type 1 Diabetes Management

- Pressure of perfect BG readings = perfect body, perfect weight, perfect blood sugars, approval from MD, family and educators.
- High focus on numbers = obsession on weight, A1C, blood sugars, minutes of exercise, calories, grams of carbohydrates.
- High focus on food = “good” and “bad” foods, fear of eating anything sweet or “bad” in front of others.
- Hypoglycemia (low BGs) may trigger bingeing.
“Eating disorders coupled with diabetes represent some of the most complex patient problems to treat – both medically and psychologically.”

--- Dr. Ann Goebel-Fabbri

"Tight Control" = Perfectionism = Eating Disorder

Contributing Factors

- Biology – genetics, metabolic disruption, neurochemical imbalance
- Psychology – co-morbid mental health disorders
- Social – trauma, social pressure, troubled relationships, media, diabetes history and education
Ask the Right Questions

- How much of the day do you think about weight, body shape or size?
- What have you used to try to lose weight? (if first question affirmative)
- Do you ever feel you have out of control eating?
- Do you ever feel guilty about what you have eaten?
- Do you have a hard time figuring out how much insulin you need for your carbohydrates?
- Is it hard to give your insulin sometimes? Why?
- Do you give “partial” insulin doses because it is hard to give the full amount?

Ask the Right Questions

- Do you give “partial” insulin doses because it is hard to give the full amount?
- Do you ever purposely skip insulin injections? How often?
- How often do you check your BG’s? Do you ever skip the tests because you don’t want to see the number?
- Do you check for ketones? When?
- Are there certain foods or food groups that you avoid? What are they?
- What are your thoughts when you have eaten “forbidden foods”?
- What do you do after you have eaten “forbidden foods”?

Signs and symptoms

- Changes in eating habits (typically eating more but still losing weight).
- Rapid weight loss or weight gain.
- Low self-esteem or preoccupation with body image, weight or food intake.
- Frequent urination, excessive thirst or high glucose.
**Signs and symptoms**
- Discomfort with eating or taking insulin in front of other people.
- Hoarding food.
- Unwillingness to follow through with medical appointments.
- Recurrent diabetic ketoacidosis (DKA).
- Low energy, fatigue, shakiness, irritability, confusion, anxiety or even fainting.

**What PWDs aren't telling you!**
- "The more I eat, the higher my blood sugar will go, the more weight I will lose."
- "I know exactly how high I can bring my blood sugar levels without going into DKA or needing to be hospitalized."
- "I can function at blood sugar levels that others would normally be hospitalized for. I am invincible!"

**What PWDs aren't telling you!**
- "Eating carbs before or after exercising defeats the purpose of the exercise."
- "If I'm following all of the rules that a 'good' person with diabetes follows, I'm also following all the rules that my eating disorder dictates."
- "My endocrinologist picked up on the fact that I was purposefully skipping my insulin, so I went to a different endocrinologist."
So How Do We Effectively Manage ED-DMT1?

Effective treatment of ED-DMT1 involves...

• Finding a balance between appropriate insulin intake and slow, gradual weight gain (if necessary).
• Closely monitoring the individual’s progress and adjusting basal-to-carb and insulin-to-carb ratios as needed!
• Discuss POSITIVE approaches to thinking about your body.
• Continued therapy, potential medication for mood disorders.

Challenges in Treatment of ED-DMT1

Rollercoaster BGs
High A1c
Constipation
Gastroparesis
Neuropathy
Chronic Pain
Depression
Anxiety
Fatigue
Distrust in Providers
Lack of Quality Support
Lack of Positive Example
Recognizing Signs in a Loved One

- Not wanting to eat out or not wanting to eat with the family
- Eating in secrecy - finding empty bottles, wrappers, containers stashed or thrown away
- Noticeable change in how much a person is eating
- Eating a lot of junk food or food high in sugar
- Increased or new secrecy around their diabetes management
- Increased or new concern over their body size, shape or weight
- Excessive exercising, severe anxiety/panic if they cannot exercise
- Increased moodiness/depression

"Key Factors" for ED-DMT1 Treatment

- Medical
  - Consistent diabetes care (testing schedule or CGM, plan for slow insulin reintroduction).
  - Control insulin edema by slow increase of insulin versus aiming for immediate in-range BGs.
  - Pain control.
  - Complications may increase with better diabetes care (specialist MDs for treatment).

"Key Factors" (cont'd)

- Diabetes Education
  - Review, confront and change old diabetes "rules."
  - BG management before/during/after exercise.

- Nutrition
  - Practice carb counting with "real meals."
  - Meal plan based on treatment goals (adjustments made as often as needed).
  - Conquer the "good food" and "bad food" way of thinking.
"Key Factors" (cont'd)

- Psychological
  - Struggles with diabetes acceptance.
  - Attempt to decrease/eliminate ED behaviors and symptom use.
  - DBT skills.
  - Consider checking BGs before each therapy session.
  - Stress management.
  - Medication management for co-occurring mood disorders.

Ultimate Goals for Treatment

- PWDs find a balanced, healthy weight they can be happy with, without feeling compelled to abuse insulin.
  - Restore hunger scale to normal range.
  - Develop the ability to appropriately interpret and respond to physiological hunger.
- Decrease urges to restrict and/or binge.
- Help PWDs recognize when they are wanting to eat for reasons other than hunger.

Ultimate Goals for Treatment (cont'd)

- Equip PWD with tools and strategies including introduction to coping skills.
- Diabetes Online Community (DOC)
  - Diabetes Sisters
  - Beyond Type 1
- In-person meetings & gatherings.
  - Local JDRF "Adults with T1D" meetings.
Final Thoughts

• This is a TEAM effort! Multiple providers are needed for the successful treatment of an individual with ED-DMT1.
• Trying to treat the diabetes without treating the eating disorder is like putting a band-aid on a bullet wound.
• Eating disorder treatment for PWD is a balancing act.

Final Thoughts (cont'd)

• Eating disorders can occur at any age.
• It’s okay to NOT have all the answers. Referring to other specialists is a much better solution than trying to manage or treat a condition outside of your realm of expertise.
• Don’t assume the PWD needs more insulin if numbers are high. Ask more questions!
• Don’t put so much focus on weight; focus more on overall health.
Practice Applications

1. If a person with type 1 diabetes exhibits signs of Diabetic Ketoacidosis (DKA possibly due to insulin omission), immediately contact their physician or direct for hospitalization.
2. If a person with type 1 diabetes is missing necessary blood glucose data without a reasonable explanation, politely ask them to check their blood glucose before leaving your office. (Keep blood glucose checking supplies on-hand).
3. If a person with type 1 diabetes is eating in secret, or exhibits behaviors associated with disordered eating, ask them about these changes. Offer a referral to a mental health professional who is familiar with eating disorders and type 1 diabetes.
References 1

1. Type 1 Diabetes Facts, JDRF
2. Emotional Eating and Diabetes by Ginger Vieira
3. Prevention and Recovery from Eating Disorders in Type 1 Diabetes by Ann Goebel-Fabbri

Questions

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