What Is Diabulimia?

As many food and nutrition professionals know, working with a client who has an eating disorder can present many complex and difficult obstacles. These obstacles can grow exponentially when the client has type 1 diabetes and is deliberately injecting less insulin for the purpose of losing weight.

The practice, which has been termed *diabulimia*, has received recent coverage in the mainstream media by the Associated Press and other outlets (1,2). Experts interviewed for this article say it's important to note that the word diabulimia is not an official diagnosis but terminology generated by the popular press.

However, even though the word may be making current headlines, the practice itself is not new.

"The first case I saw was as a medical student in 1980," says John Buse, MD, PhD, president of the medicine and science division of the board of the American Diabetes Association. "It's the intersection of two diseases. It's a nasty cocktail."

While Buse says it's difficult to say how many individuals with type 1 diabetes have practiced this kind of behavior, he believes most, if not all, young women with type 1 diabetes are aware of this practice and "there's probably a substantial number" who have engaged in it to varying degrees, some to lose a few pounds before an important event, others who practice it so repeatedly they experience devastating medical consequences.

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The severity of these complications cannot be stressed enough, says Ann Goebel-Fabbri, PhD, a psychologist at Joslin Diabetes Center and instructor of psychiatry at Harvard Medical School. Goebel-Fabbri has focused her research on the relationship between diabetes and eating disorders.

"In a sense, it is shocking," says Goebel-Fabbri. "It is shocking that women would take such extreme measures and risks for the purpose of weight loss. What is not shocking is that the results can be catastrophic."

In research recently published in the journal *Diabetes Care*, Goebel-Fabbri and her colleagues found that women with type 1 diabetes who reported taking less insulin than prescribed had a threefold increase risk of death and higher rates of disease complications than those who did not skip their insulin shots (3). The 11-year follow-up study followed 234 women, and the frequency of the insulin skipping appeared to influence mortality risk (3). The study also found that insulin-restricting women who died had reported more frequent insulin restriction and more eating disorder symptoms at the study's outset than those who were still alive at the end of the study (3).

In addition to risking death, says Goebel-Fabbri and others interviewed for this article, patients who omit or reduce insulin run the risk of developing microvascular complications including eye disease, renal failure, nerve damage in the feet and hands, and macrovascular complications including heart attacks and strokes.

"No eating disorder is pretty," says Jessica Setnick, MS, RD, CSSD, the author of the *Eating Disorders Clinical Pocket Guide* and chair of the Behavioral Health Nutrition dietetic practice group (DPG). "But diabulimia can do damage much quicker than other disorders."

Diabulimia works when a patient omits insulin, therefore making it impossible for the body to process glucose, which is then excreted in the urine. Signs a patient may be diabulimic, say experts, include hyperglycemia, dramatic shifts in weight, low energy, unusual food patterns, binging on carbohydrates and sweets, obsession with food and body image, hiding food, and the smell of ketones on the breath and in urine. While those interviewed for this article have seen diabulimia mostly among teenage girls and young women, that is not to say that men and older women can't be susceptible.

"It is unusual in men, but that's not to say it can't happen," says Goebel-Fabbri.

Of course, not all persons with type 1 diabetes who mismanage their insulin are doing so for the purpose of weight loss.

"Some patients are not engaged with their diabetes; they're living in the here and now," says Buse. "They may have cognitive issues, or a thought or mood disorder. There may be social barriers, for example, not wanting to take a shot in public or wear a pump." Other experts noted those who are noncompliant may be in denial of their disease or depressed over the diagnosis.

Patients who are diabulimic may have elements of all of those issues, but what distinguishes them is that they are also focusing on weight loss.

"We've had [diabulimic] patients who have been seen by world-renowned endocrinologists," says Roberta Pearle Lamb, MPH, RD, director of nutrition services at Walden Behavioral Care, a treatment facility for patients with eating disorders, psychiatric disorders, addictions and co-occurring disorders in Waltham, MA, and member of several DPGs including the Behavioral Health Nutrition DPG. "They understand the risks, but it's hard for them to refrain from the behavior. They're not allowing themselves to lead full, productive lives because they're obsessed with thoughts of weight."

Like patients with eating disorders who do not have diabetes, those interviewed say diabulimics may experience an obsession with body image and other obsessive behaviors, a need for perfectionism, and self-loathing or a feeling of not being good enough, which can be exacerbated by the diagnosis of a life-threatening condition such as diabetes. There may also be dynamics within the family that contribute to the behavior.

The problem is complex and layered, say experts, and the onset of the disorder varies.

"Sometimes the eating disorder predates the diabetes," says Goebel-Fabbri. "I've also seen the opposite. They feel a vulnerability after diagnosis, and body image rears its ugly head."

Another trigger may be the initial weight gain that sometimes takes place when a diabetic is first diagnosed.

"Unexplained weight loss is often part of that primary diagnosis," says Setnick. "A young girl may have been thrilled that she lost 20 pounds." During the initial phase of treatment as weight begins to return to normal levels, the patient may want to stay underweight, triggering diabulimic behavior. Modest weight gain that can sometimes occur as doctors try to regulate a patient's insulin can also act as a catalyst.

"Patients notice when they're taking care of themselves, they tend to gain weight," says Buse.

Feeling different from peers, frustration over having to monitor diet and blood sugars, and the fact that initial diagnosis can often occur when a young girl or teenager is already at a vulnerable state of development can complicate matters, say experts.

"There are so many parallels between dealing with diabetes and the diabetes regimen and the grieving process," says Lamb. "When you dig deeper, you may find the diabulimic behavior is a way of acting out, or screaming for some kind of care and attention. We have to give them skills to find other ways of expressing their needs."

WHAT CAN FOOD AND NUTRITION PROFESSIONALS DO TO HELP?

According to Setnick, food and nutrition professionals need to educate themselves about eating disorders in all their forms.

"We must be vigilant," she says. "I'm thrilled we're bringing diabulimia to light. But eating disorders aren't limited to people with diabetes. For any population in our care, we should be looking out for signs." Lamb adds that diabulimia is a perfect example of why modern food and nutrition professionals must educate themselves across a wide spectrum of issues.

"The [registered dietitian] today has to have that breadth of understanding of the biological, behavioral, and emotional components," she says.

While there is no magic bullet to cure diabulimia, Goebel-Fabbri also urges food and nutrition professionals to educate themselves, ask questions, and embrace a multidisciplinary team approach that should include a doctor, a diabetes educator, a dietitian, and a mental health specialist. Family therapy, support groups, and the use of selective serotonin reuptake inhibitors (SSRIs) may also help.

If patients need to be hospitalized or spend time in an extended care facility, these facilities must be equipped to work with clients who have diabetes.

"Some eating disorder treatment centers are only for physically well people," reminds Setnick. "Not all are equipped with a staff that can manage diabetes."

Goebel-Fabbri also urges food and nutrition professionals to also take a realistic, flexible approach to working with diabetic clients.

"The old nutrition recommendations for diabetes almost mirrored an eating disorder mindset," says Goebel-Fabbri. "That is an antiquated approach, and we need a more flexible approach. The primary goal of the eating component is to try to regulate and normalize the eating pattern. Dietitians shouldn't reinforce a deprivation mindset."

Adds Lamb, "The goal is to empower the patient. They shouldn't feel like they are being scolded or forbidden from food. Freedom is there if they learn to use the systems in place. We have to build a foundation to help them believe they are deserving of that."

References

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