Case: A 16yo female with type 1 diabetes presents to Adolescent Clinic for her annual sports physical. She most recently saw her endocrinologist two months ago where her hemoglobin A1C was noted to be 10.2%. Since the last well child check, she has had 3 urinary tract infections, two hospitalizations for DKA, and has had infrequent menses. At today’s visit, you notice that she has lost approximately 10lbs in one year. You question her about diet and exercise, and she tells you that she occasionally has forgotten to take her insulin after meals, and does not like to inject insulin in front of other people. She works out every day for 1 hour and is trying to eat a lot of “healthy” food. Vital signs include HR 60, BP 110/60, and SpO2 96%. On physical exam, the patient is thin yet well appearing, has dry skin, and dull hair. All other systems are normal. She is cleared for participation in sports. Three weeks later, you are notified that your patient is admitted to the hospital for DKA.

Diabulimia is a unique condition characterized by patients with diabetes, usually type 1, who use insulin restriction or omission for the purpose of losing weight. This specific type of eating disorder is especially dangerous given the comorbidity of diabetes. In fact, women with type 1 diabetes are 2.4 times more likely to develop an eater disorder compared to their non-diabetic peers, and 30% of women with type 1 diabetes admit to omitting insulin to lose weight. Diabulimia can take many forms, but the overall theme in each patient’s disease is insulin reduction or complete omission. While there is no DSM-5 classification for diabulimia, the act of omitting insulin is considered a purging behavior and as such can be coded as any of the following: 1) anorexia nervosa – restricting food intake as well as insulin, 2) bulimia nervosa – binge eating and restricting insulin, or 3) purging disorder – eating normally and restricting insulin.

The cause of diabulimia is often attributed to two main causes. The first is described as a new diagnosis of type 1 diabetes and the co-occurring weight loss due to hyperglycemia and catabolic processes. Once insulin is introduced, the result is often weight gain as the body is able to function normally again, and therefore the thought of “insulin makes me fat” can be developed. This thought process then leads to patients omitting insulin as a way to control their weight, despite the detrimental effects on type 1 diabetes management. The second cause of diabulimia is attributed to diabetes burnout. With this cycle, an already diagnosed type 1 diabetic patient neglects their disease management by missing insulin doses, not counting carbohydrates, and/or not testing BG due to the incredible mental burden they experience. This driving force causes a similar cycle to that of the newly diagnosed patient, and insulin is omitted to lose weight.

Just as in any eating disorder, diabulimia has both emotional/behavioral and physical signs and symptoms. These signs can include secrecy about diabetes management, extreme anxiety regarding body image, overly strict food rules, excessive and/or rigid exercise, depression and/or anxiety, multiple DKA episodes, hemoglobin A1C greater than 9.0%, frequent UTI or yeast infections, irregular or lack of menstruation, fatigue, lethargy, and dry hair and skin. Complications for untreated diabulimia not only encompass typical eating disorder complications, but also longstanding uncontrolled diabetes complications. Research has shown that microvascular complications, such as retinopathy, nephropathy, and neuropathy, are 2.4-
3.5 times more likely in patients with diabulimia. Left untreated, diabulimia can lead to increased risk of stroke, heart disease, coma, and death.

Treatment for diabulimia is aimed at not only treating the eating disorder mindset, but also minimizing injurious consequences that occur from uncontrolled hyperglycemia. Ideally, a multidisciplinary team-based approach is best, including an endocrinologist, nutritionist (preferably with diabetes training), and a mental health professional (social worker, psychologist or psychiatrist). The early stages of treatment is geared toward medical stabilization and safety. Patients should, at the minimum, commit to taking a basal rate of insulin for DKA prevention. Intensive glycemic control is not an early treatment goal. Aiming for near-normal glycemia too quickly can increase a patient’s risk of developing retinopathy or worsening a preexisting condition and exacerbate neuropathy pain. Unfortunately, compared to individuals with eating disorders but without diabetes, this cohort shows lower partial and full recovery rates, and the patients are more likely to drop out of treatment at an earlier stage.

Diabulimia can be a fatal condition if not recognized and treated. Both healthcare professionals and patients need to remember that “good enough” diabetes management is the goal, not “perfect” control. The quest for perfection can lead to an increase in diabetes burnout and enhance all-or-nothing thinking which in turn can boost the eating disorder.

For more information or patient support, please contact the Diabulimia Helpline, a non-profit organization founded and run by a type 1 diabetic who suffers with diabulimia.

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