Chapter 25

Type 1 Diabetes and Disordered Eating Behavior

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Abstract

Type 1 diabetes mellitus (T1DM) is a chronic disease characterized by chronic hyperglycemia. Its treatment typically requires the administration of insulin, and weight gain is a common side effect as glycemic control improves. Thus, patients with T1DM are at heightened risk for developing comorbid disordered eating behaviors (DEBs) or eating disorders (EDs), primarily due to mandatory food monitoring and other aspects related to the treatment of T1DM. In this chapter, we discuss the specific characteristics related to DEBs and EDs in children, adolescents, and adults with T1DM, especially intentional insulin omission, and some important aspects related to the screening and assessment of DEBs and EDs related to diabetes. Because of the higher dropout rates from therapy in individuals with T1DM and EDs, we also discuss the implications for treatment and recovery of these patients since joint work between diabetes and mental health teams is essential to ensure the best management of these specific situations.

Keywords: Type 1 diabetes mellitus, body image dissatisfaction, dietary regimen, disordered eating behaviors, eating disorders, insulin restriction, diabulimia.

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1. Introduction

Type 1 diabetes mellitus (T1DM) is a chronic condition in which the pancreas produces little or no insulin, and most cases of T1DM are diagnosed in childhood. The prevalence estimates indicate almost 500,000 children under 15 years of age suffer from T1DM worldwide (1). Access to affordable treatment, including insulin, is critical to the survival of individuals living with diabetes. According to the World Health Organization (2), data on global trends in T1DM prevalence and incidence are not available, but many high-income countries have reported an annual increase in the incidence of T1DM in childhood of between 3% and 4%. T1DM is characterized by chronic hyperglycemia, which leads to macrovascular and microvascular complications (3) that may be prevented or delayed with current treatment recommendations. However, the risk of complications of T1DM (e.g., eye disease, kidney disease, nerve damage) and mortality increase when diabetes is comorbid with disordered eating behaviors (DEBs) or eating disorders (EDs) (4,5) because EDs have the highest mortality rate of any mental illness (6).

Patients with T1DM are at heightened risk for developing comorbid DEBs or EDs, primarily due to daily disease management, which requires mandatory food monitoring and surveillance of the insulin-to-carbohydrate ratio (7–9), and other psychological difficulties, including depression, anxiety symptoms, or psychological distress (10–13). A longitudinal study of girls with T1DM for 14 years (with a mean age of 11.8 years at time 1) revealed a probability of developing DEBs or an ED over this period of 79% and 60%, respectively (14). Diverse studies reported a higher risk of 2–3 times in individuals with T1DM compared to healthy controls (e.g., 15,16). The estimated prevalence of DEBs in T1DM individuals is 25–50% in women and 9–27% in men, with variations depending on the sample, age range and measures

used (13,17–20). Despite males and females are equally affected by T1DM, the highest occurrence of DEBs and EDs is observed in females and young adults (13). A meta-analysis of controlled studies on the prevalence of EDs in T1DM revealed no increased prevalence of anorexia nervosa compared to the general population, but there was an increase in the prevalence for bulimia nervosa and eating disorder not otherwise specified (EDNOS) in this group of patients (21).

2. Disordered Eating and Eating Disorders Among Type 1 Diabetes Patients

Living with T1DM requires major lifestyle changes and demanding daily disease management from an early age, including insulin administration and dietary intake monitoring (e.g., carbohydrate counting), exercise, and the frequent monitoring of blood glucose levels, to reduce the risk of short- and long-term complications (22). Weight gain is a common side effect as glycemic control improves, which leads to frequent weight concerns and body dissatisfaction (4) that may increase the risk of restrictive and overeating DEBs. Previous studies demonstrated that poor metabolic control, as measured by HbA1c as an indicator of long-term blood glucose levels, especially in females (16,18,23), and high body mass index (22,24) are strongly associated with DEBs. In addition to the typical behaviors associated with DEBs in the general population (e.g., excessive dieting, excessive exercise, binge eating, purging behaviors), a common and serious DEB in individuals with T1DM is intentional insulin restriction or omission, which is not currently appropriately reflected in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (4). This specific condition – when prescribed insulin doses are omitted or altered with the sole goal of achieving weight loss and the purging of calories occurs via glucosuria (glucose excreted through the urine) – have been referred to as “diabulimia” (25–27). Diverse

studies reported that a significant percentage of people with T1DM intentionally omit insulin, from 7.3% of young adults (8) to approximately 30% in women who participated in longitudinal studies (5,14). Deliberate insulin omission is a widely recognized cause of recurrent diabetic ketoacidosis in adolescents and young adults with T1DM (12,24), which is a life-threatening emergency in which the body is unable to use glucose as an energy source and breaks down fatty acids as an alternative energy source (25). T1DM patients who omit insulin exhibit significantly increased rates of diabetes complications (e.g., nephropathy and foot problems) and earlier death than those who use insulin appropriately (5).

It is of particular importance to reflect in a systemic and integrated way on the process of the development of DEBs and EDs in patients with T1DM. The development of T1DM in preadolescence or adolescence seems to place girls at risk for the subsequent development of DEBs or EDs because of the hormonal changes and gains in weight and fat mass associated with the transition from childhood to adolescence (28). In addition to dealing with the typical demands of adolescence (e.g., accepting body changes, integration in peer groups, becoming more independent of the family), patients with T1DM must also cope with the demands of this chronic metabolic disease (e.g., hospital stays, blood glucose self-control, injections, maintaining a strict diet) and the emotional and social demands of adjustment. All of these aspects are a constant challenge to the well-being of the adolescent and may trigger DEBs and/or EDs (22,29).

Qualitative studies using the "voices" of patients provided rich insights into why people with T1DM are at increased risk for disordered eating. For example, adolescents with T1DM identified some main causative factors for their eating problems, such as body image dissatisfaction (because "it is more important to be beautiful than to take care of diabetes"), low compliance with insulin intake and food control, or fear of

weight gain and judgment by family and friends (30). Young adults also referred to the greater difficulty in losing weight since their diagnosis with diabetes, which contributes to higher body dissatisfaction and the tendency to stop taking insulin in order to lose weight (8).

Some models have been developed to encompass the development and maintenance of disordered eating in T1DM (e.g., 22,31). Recently, De Paoli and Rogers (4) proposed a transdiagnostic model of disordered eating in T1DM based on a systematic literature review and previous models. According to these authors, perfectionism and low self-esteem (complicated by feeling different due to diabetes) predispose an individual to dysfunctional self-evaluation (such as overconcern with eating, weight, and shape), as in the general population. The pressure of disease management exacerbates the body concerns of an individual with T1DM, because of the learned importance of eating, exercise, and the effects of insulin (including weight gain). If strict behaviors (e.g., dieting) are used to cope with the uncertainties and frustration of T1DM, these behaviors may develop into DEBs, such as restricting, binging, and/or purging (including insulin restriction). Poor affect regulation, perceived low blood glucose, and disinhibited eating contribute to the maintenance of insulin restriction. Besides the health complications related to ED (e.g., loss of bone density, hypotension), patients with T1DM suffer additional health effects, such as the effects arising from hypo- or hyperglycemia, which may be very deleterious. The confrontation with these short- and medium-term diabetes-related complications, including the fear of weight gain and poor glycemic control, feeds back into the overevaluation of shape, weight, and eating, and the cycle continues (4).

Given the frequency and severity of comorbid T1DM and DEBs and EDs, as well as their strong association with long-term medical complications in patients with

T1DM, significant attention must be given to screening, early detection, and subsequent treatment efforts (e.g., 5,14).

3. Screening and Assessment

The identification of DEBs and the diagnosis of an ED in the general population and patients with T1DM are difficult. Different screening methods produce different results for DEBs in this population because these patients present specific DEBs related to their disease (e.g., insulin omission), which are not reflected in traditional measures of EDs, such as EAT-26, EDE-Q, or SCOFF. However, the special focus on healthy eating, carbohydrate counting, and insulin timing required for the management of T1DM can lead to an overfocus on body weight and shape, implying a risk of false positives when these questionnaires are used (32,33). Therefore, the Diabetes Eating Problem Survey – Revised (DEPS-R) was developed as a disordered eating screening tool specifically for people with diabetes and presents good psychometric properties in children, adolescents, and adults with T1DM (e.g., 32,34). The DEPS-R is a 16-item diabetes-specific self-report measure for DEBs organized into three factors: maladaptive eating, preoccupation with thinness, and concept of maintaining high blood glucose values to lose weight. It may be completed in less than 10 minutes during a routine clinical encounter (34).

Evidence exists that patients with DEBs or EDs frequently hide or avoid exposing their disordered eating behaviors and attitudes, and this tendency is especially true for adolescents. Therefore, an adequate strategy for performing an accurate evaluation of adolescents with T1DM who may exhibit DEBs is to also consider a parent-report evaluation, who may contribute to the prompt detection of DEBs and timely intervention (15).

4. Treatment and Recovery

T1DM patients with EDs show worse outcomes with conventional outpatient treatment for EDs and have a higher likelihood of dropping out of treatment, and their EDs are more likely to relapse after recovery (14,27). Some specific aspects of the T1DM treatment itself may conflict with ED treatment. On the one hand, T1DM requires learning how to control glucose levels through the monitoring of weight, shape and eating and insulin administration. On the other hand, in order to recover from an ED, patients are encouraged to stop calorie counting, be flexible in their eating behaviors, and moderate their high standards and perfectionism (22). It is essential to ensure that all needs, including adherence to insulin administration and normalization of eating behaviors, are met during treatment and recovery. Multidisciplinary teams and joint work between diabetes and mental health teams are needed from childhood (9,22,28,33,35,36). Family members and other agencies, such as school or youth workers, should also be considered when defining individual treatment plans because of the importance of communication and collaboration between the systems involved and support from all sources (33). A recent systematic review of the efficacy of interventions for people with T1DM and DEBs found that inpatient therapy with multiple components (e.g., cognitive-behavioral therapy, psychoeducation, and family therapy) was the most effective treatment because of the intensity and complexity of treating this dual diagnosis (36).

Some authors consider the lack of motivation for changing the principle obstacle in treating these patients, possibly related to the low levels of consciousness of the illness (27,28). However, it is important to note that “recovery is built on the triad of struggle, strength, and support,” as stated by Goebel-Fabbri (9) based on interviews

with 25 women who recovered from insulin restriction for weight control. For this reason, using a motivational interview with emphasis on affirmations and avoiding conflict are particularly valuable when treating patients with T1DM and EDs (22). On the other hand, empathetic and non-judgmental support from family and friends, mental health providers, and diabetes clinicians positively impacts treatment and recovery (8,9,37).

5. Conclusion

The diagnosis of T1DM results in major lifestyle changes and a demanding daily disease management beginning in an early period of development. Emotional issues related to having this illness and disease management are characterized by some routines that may favor potentially unhealthy eating patterns, which leaves these individuals at risk for the development of eating disorders. Intentional insulin omission for the purpose of reducing or preventing weight gain is a disordered eating behavior unique to this population with serious health consequences. Disordered eating screening tools specifically developed for people with diabetes are essential for accurate evaluation, prompt detection, and timely intervention, which require multidisciplinary teams and joint work between diabetes and mental health teams.

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