



Eating Disorders and Disordered Eating in Type 1 Diabetes: Prevalence, Screening, and Treatment Options

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Abstract

This review is focused on the prevalence of eating disorders and disordered eating behaviors in individuals with type 1 diabetes. Recent research indicates higher prevalence rates of eating disorders among people with type 1 diabetes, as compared to their peers without diabetes. Eating disorders and disordered eating behaviors – especially insulin omission – are associated with poorer glycemic control and serious risk for increased morbidity and mortality. Screening should begin in pre-adolescence and continue through early adulthood, as many disordered eating behaviors begin during the transition to adolescence and may persist for years. Available screening tools and treatment options are reviewed. Given the complexity of diabetes management in combination with eating disorder treatment, it is imperative to screen early and often, in order to identify those most vulnerable and begin appropriate treatment in a timely manner.

Keywords

adolescents; adolescence; type 1 diabetes; diabetes mellitus; eating disorder; disordered eating; anorexia nervosa; bulimia nervosa; disordered eating behavior; screening tool; treatment; glycemic control; insulin; prevalence

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Compliance with Ethics Guidelines

Conflict of Interest

Margo E. Hanlan, Julie Griffith, Niral Patel, and Sarah S. Jaser declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

Introduction

Given the detailed meal planning, precision in food portions, and constant monitoring of food intake (carbohydrates in particular) related to insulin doses recommended for diabetes management [1], people with diabetes may be inherently more prone to issues revolving around food [2]. The persistent focus on food that is intrinsic to diabetes management also lends itself to greater difficulty of detection of eating disorders and disordered eating in this susceptible population [3]. Thus, it is important for clinicians and researchers to understand risk factors, screening tools, and treatment options for eating disorders and disordered eating in people with diabetes.

The purpose of this paper is to synthesize the current literature on individuals with type 1 diabetes who engage in disordered eating and/or have an eating disorder. This paper will examine the prevalence of eating disorders and disordered eating behavior in the general population as compared to individuals with type 1 diabetes and provide clinicians with a resource to better understand the complexity of the situation when these conditions overlap. By educating providers on available screening tools and treatment options, people with type 1 diabetes who are at risk for developing disordered eating behaviors may be identified provided with the necessary support and treatment.

Eating Disorders Defined

Historically, studies on eating disorders have focused primarily on the psychiatric diagnoses of anorexia nervosa and bulimia nervosa. Essential diagnostic criteria in both disorders include a disturbed body image and weight. Additionally, anorexia nervosa is characterized by a refusal to maintain a minimally normal body weight accompanied by an intense fear of weight gain, whereas bulimia nervosa is distinguished by repeated episodes of binge eating followed by inappropriate compensatory behaviors [4], such as self-induced vomiting, misuse of laxative, diuretics, fasting or excessive exercise. In type 1 diabetes, insulin omission or restriction may be used as an additional means of weight control [5]. Individuals who do not meet criteria for either anorexia nervosa or bulimia nervosa may receive a diagnosis of Eating Disorder, not otherwise specified. The broader term “disordered eating” encompasses symptoms that are not yet at a level of severity or frequency to be quantified as the diagnosable eating disorders [5], and it includes such behaviors as dieting for weight loss, binge eating, or calorie purging through self-induced vomiting, laxative or diuretic use, and/or excessive exercise [5]. Both eating disorders and disordered eating may pose serious health consequences, especially for individuals with type 1 diabetes.

Prevalence in General Population and in those with Type 1 Diabetes Mellitus

According to national survey data, the prevalence of anorexia nervosa and bulimia nervosa across the lifetime is approximately 0.9 % and 1.5% in females and 0.3% and 0.5% in males, respectively [6]. The onset of most eating disorders is typically in adolescence or early adulthood, with a median age of onset ranging from 18-22 [6]. Thus, rates in adolescents are similar to those of adults; national data indicate that the prevalence of any eating disorder is

3.8% in adolescent girls and 1.5% in adolescent boys [7]. Prevalence rates, mortality rates and age of onset for anorexia nervosa, bulimia nervosa, any eating disorder, and disordered eating behaviors are summarized in Table 1.

Providers must pay special attention to disordered eating behaviors, even those that are sub-threshold for diagnostic criteria [8]. According to the Center for Disease Control's Youth Risk Behavior Surveillance, a national survey of risk behaviors of high school students, 45% of high school students reported trying to lose weight. In an effort to lose weight or keep from gaining weight, 10.6% of students reported not eating for a 24-hour period or more, 5% reported taking diet pills without a doctor's consultation, and 4% reportedly took a laxative or vomited to keep from gaining weight [9]. These results suggest that disordered eating behavior is fairly common in the general adolescent population. There is limited research looking at rates of disordered eating in adult populations, but rates of binge eating and diet pill use appear to increase from adolescence to young adulthood [10].

Research has begun to establish the prevalence of eating disorders among people with type 1 diabetes. A recent meta-analysis of six studies reported a medium effect size for eating disorders ($d = 0.46$, 95% CI 0.10-0.81), indicating that the prevalence of eating disorders in adolescents and young adults with type 1 diabetes was higher than in their peers without diabetes [11]. For example, Jones and colleagues found that 10% of adolescent females aged 12-19 with type 1 diabetes met diagnostic criteria for eating disorders as compared to 4% of an age-matched control group without diabetes [12]. Similarly, the meta-analysis of eight studies on disordered eating behavior in adolescents and young adults reported a medium effect size ($d = .052$, 95% CI 0.10-0.94), showing that prevalence of disordered eating behavior was also higher in individuals with type 1 diabetes as compared with peers [11]. For example, Neumark-Sztainer and colleagues reported elevated rates of disordered eating behaviors among adolescents and young adults (age 12-21) with type 1 diabetes: 37.9% of females and 15.9% of males [13]. Although studies in adults with type 1 diabetes are limited, it is likely that many cases of eating disorders are going undiagnosed in this population. Taken together, these results indicate that both eating disorders and disordered eating behaviors may be more prevalent in individuals with type 1 diabetes as compared to their peers without diabetes.

Studies also suggest that disordered eating behaviors tend to start in adolescent years and persist into adulthood, especially if left untreated; over an 8 – 12 year time span, Peveler et al. found 26% of subjects with type 1 diabetes to have some form of disordered eating or weight control management such as self-induced vomiting, and/or laxative misuse [14]. In addition, 61% of the 23 participants in this study with a history of disordered eating reported insulin misuse, as compared to 26% of those without any history of disordered eating [14]. These findings highlight the trend toward manipulating insulin administration as an additional means of weight management. Results from these studies also suggest that eating disorders and disordered eating behaviors do not usually resolve without treatment.

Implications of Disordered Eating for People with Diabetes

Eating disorders are associated with serious medical risks, including increased mortality; a recent meta-analysis reported mortality rates (deaths per 1000 person-years) of 5.1 for anorexia nervosa, 1.7 for bulimia nervosa, and 3.3 for eating disorder, not otherwise specified [15] (Table 1). In addition, even well-controlled diabetes puts stress on the body's organs, and research demonstrates that microvascular complications begin at a younger age in people with diabetes than those without diabetes [1]. Engaging in disordered eating patterns or insulin manipulation further stresses the body, and insulin restriction has been shown to increase mortality risk [16]. The presence of eating disorders has also been correlated with higher levels of hemoglobin A1C levels in adolescents, indicating poorer glycemic control [13]. In a recent meta-analysis, there was a medium effect size for disordered eating behavior and eating disorders on glycemic control ($d = 0.40$, 95% CI = 0.17-0.64). These findings emphasize the increased risk of disordered eating behaviors for individuals with diabetes, exacerbated by poor glycemic control [17].

In addition, insulin restriction places an individual at an increased risk for the development of diabetic ketoacidosis (DKA). The frequent presence of ketones in the body is dangerous and can lead to heart complications, kidney failure, cerebral edema, coma or death [1]. Other long-term medical complications of diabetes include retinopathy, nephropathy, and neuropathy [16], which may be aggravated by disordered eating behavior. For example, one study found some degree of retinopathy was found in 84% of those with highly disordered eating as compared to 24% of those without any disordered eating [18]. Similarly, a recent study of women with type 1 diabetes diagnosed with eating disorders found that insulin omission was significantly associated with retinopathy and nephropathy [19]. It is likely that poor glycemic control associated with disordered eating behaviors and eating disorders increases risk for diabetes-related complications [14], but more research is needed to determine the mechanisms of risk. Taken together, these studies highlight the increased medical risks associated with eating disorders and disordered eating behavior – especially insulin omission – in individuals with type 1 diabetes. Table 2 lists the various implications and risk factors associated with disordered eating for people with diabetes.

Risk Factors

The etiology of eating disorders is still not well understood, but it appears to involve a combination of genetic, biological, and temperamental factors [20]. We review the most widely studied risk factors below (Table 2).

Adolescence

Adolescence is a time characterized by numerous cognitive and physical changes, as well as increased independence, with more time spent with peers than with family. Adolescence is also a developmental stage of increased risk behaviors, such as tobacco and alcohol use, unsafe sexual behaviors [21], and unhealthy dietary behaviors [9]. Research supports that behaviors such as disordered eating are strongly influenced by peer groups, especially among adolescent females [22]. Adolescents' frequent use of social media may also increase their risk for disordered eating behavior, as it places importance on appearance and

facilitates social comparisons [20]. In addition, one study found that females diagnosed with type 1 diabetes between the ages of 7 and 18 years were at a significantly higher risk for developing an eating disorder than those who were diagnosed with diabetes in either young childhood or early adulthood [8]. Thus, it is imperative that health care providers are aware of the increased risk of eating disorder in this age group.

Gender

It is well established that females are at higher risk for eating disorders; the National Comorbidity Survey indicated that girls are twice as likely to develop an eating disorder as compared to boys (3.8% and 1.5%, respectively), and girls are more likely than boys to engage in disordered eating behavior [9]. This gender difference is apparent in studies of individuals with type 1 diabetes as well. For example, research indicates that 12-58% of young women with type 1 diabetes overeat [23] and 37% omit or restrict their insulin in order to control their weight [24]. Similarly, a study of adolescents ages 12-21 found that 10.3% of girls in their sample reported skipping insulin and 7.4% reported taking less insulin to lose weight, as compared to only 1.4% of boys [25].

While research is generally conclusive that females – both with and without diabetes – are more likely to have eating disorders or engage in disordered eating than males [2], it is important that providers do not dismiss the possibility of disordered eating behaviors in males. One study showed males with type 1 diabetes to have a higher drive for thinness as compared to males without diabetes [26], which may be a risk factor for further development of disordered eating. Further, research from Ricciardelli and McCabe suggests that boys may be more likely to exercise than to diet for weight loss, and boys who participate in sports that emphasize weight or leanness, such as wrestling or diving, may be at higher risk for disordered eating behaviors [27]. These findings are consistent with previous research and emphasize the importance of screening both male and female adolescents with type 1 diabetes [28][12][29]. Because more research is needed on eating disorders in males, it is important for healthcare providers to be aware of the potential for such problems in both genders.

BMI

Higher Body Mass Index (BMI) has been hypothesized to lead to increased drive for thinness, which may result in dieting, negative affect, and disordered eating [20]. The research of Colton and colleagues on adolescent females with type 1 diabetes, for example, showed disordered eating behavior to be associated with higher BMI [30]. Further, adolescents who scored lower on self-worth scales and showed more symptoms of depression had a greater incidence of disordered eating [30]. Similarly, Tse and colleagues found that adolescents with diabetes classified as at-risk for disordered eating had higher BMI [31]. These adolescents also had poorer self-reported diabetes management, less frequent blood glucose monitoring, and higher A1C than those not at risk. Thus, providers may take note of BMI as a potential risk factor for disordered eating.

Meal Structure

Another risk factor for the development of disordered eating relates to family meal structure. For example, one study found that adolescent girls with type 1 diabetes in families who had infrequent family meals were more likely to report disordered eating behaviors [32]. Additionally, adolescent females who experienced weight-related teasing by parents report a higher prevalence of disordered eating [33]. This combination of low family meal structure and high family attention to weight and weight loss was nearly twice as common in families with girls with disordered eating as compared to families with teenage girls without disordered eating [32]. Therefore, providers may find it useful to investigate familial eating patterns and thoughts on weight control/loss as a way to see if this is a potential risk factor.

Body Dissatisfaction

Finally, dissatisfaction with one's body and drive for thinness have been identified as risk factors for disordered eating behavior, and these factors may be especially relevant for individuals with diabetes. For example, one study found that adolescents who reported body dissatisfaction were more likely to restrict insulin, suggesting that this may be a particularly important risk factor for people with diabetes [34]. Similarly, Hegelson and colleagues' research revealed an increase in drive for thinness in adolescents with diabetes as compared to their peers without diabetes [35]. Another study found that adolescent females with type 1 diabetes reported higher scores of negative body image, which were, in turn, associated with disordered eating behaviors [36]. Collectively, these results support that body dissatisfaction and drive for thinness are important to consider when screening individuals with type 1 diabetes for eating disorders.

Diabetes Technology/Treatment and Eating Disorders

While advances in diabetes technology, such as continuous glucose monitoring (CGM) and insulin pumps, provide greater flexibility, clinical observation suggests that they also have potential for misuse by individuals with body dissatisfaction. For example, pumps allow easy titration of insulin doses and may enable individuals to keep blood sugars high. Similarly, CGM provides constant glucose data, so individuals may believe they can more "safely" keep blood glucose elevated. Data presented in CGMs around mealtimes may cause individuals to restrict food intake to prevent blood glucose excursions. For adolescents, there may be less parental (or outside) involvement/knowledge of diabetes management with pump therapy, allowing for more privacy and freedom to alter insulin doses. Further, food databases and focus on carbohydrate intake when using insulin pumps/CGMs may cause individuals to be overly aware of nutritional aspects of food and restrict or obsess about food intake. Finally, patients may ask for the hormone amylin (Symlin™), a medication prescribed to reduce postprandial hyperglycemia. A known side effect of amylin is reduced appetite, and it could therefore be misused/abused for weight loss. Thus, providers need to be aware of the risks for misuse of diabetes technology and medications in individuals seeking to lose weight.

Available Screening Tools

As noted above, people with type 1 diabetes may be more susceptible to the development of EDs and disordered eating behaviors than people without diabetes. Further, longitudinal studies of disordered eating behaviors in patients with type 1 diabetes indicate that these behaviors are likely to persist and become more severe in young adulthood [14]. Eating disorders often go untreated; national survey data indicate that only 17% of girls and 1.8% of boys receive mental health services for eating disorders [37]. These data support that screening for disordered eating should begin in pre-adolescence and continue through early adulthood to obtain treatment as early as possible. It is important for providers to look for any signs of disordered eating behavior and probe for additional information if an individual appears to be at risk. Providers can ask about eating attitudes, or the patient's thoughts, feelings, and behaviors toward food as a way to screen for disordered eating [3]. Thoughts about food and meal planning are a normal part of life, and people with type 1 diabetes have an increased focus on nutrition for diabetes management. Labeling foods as “good” or “bad,” however, may lead to guilt and anxiety around eating, which in turn may result in disordered eating behaviors [3]. The goal for early prevention and treatment is to help patients remain healthy and avoid the deleterious effects of disordered eating and eating disorders.

There are limited data on effective screening tools in this specific population, so it is important for providers to be vigilant and detect any suspicion a patient may give that he/she engages in disordered eating. The Yale-Brown-Cornell Eating Disorder Scale [38] is an eight-item scale to assess the severity of disordered eating behaviors. It has shown good reliability and validity in adolescents, but, to our knowledge, it has not been used in people with type 1 diabetes. It is important to note that eating disorder screening tools developed for the general population may overestimate problems in people with type 1 diabetes. In a recent study, a panel of experts determined that two widely used measures of eating disorders (The Eating Disorders Examination Questionnaire [39] and the Eating Disorders Inventory-3 [40]) may result in false positives, since many of the questions regarding attention to diet (e.g., monitoring food) reflect appropriate behaviors in individuals with type 1 diabetes [41]. A lengthier tool that may be useful is the Diabetes Eating Problem Survey (DEPS). It has traditionally been used in adults, but new research is working to validate it in the pediatric population as well. The revised version (DEPS-R) has 16 items and has demonstrated excellent internal consistency (Cronbach's α of 0.86) [42] and specificity; adolescents who scored greater than 1 standard deviation above the mean were found to be at risk for disordered eating [31]. This tool takes less than 10 minutes to complete and may be a useful resource for providers who are concerned about the possibility of disordered eating in their youth with type 1 diabetes. Finally, one study investigated the use of a single question, “Have you ever been overweight?” to screen for the presence of disordered eating in adolescents with type 1 diabetes [42]; this one question yielded 83% sensitivity and 94% negative predictive value, so it may be an excellent screening question when time is limited.

Detection of eating disorders and disordered eating may be aided by these screening tools as well as a clinical interview. For adolescents, the presence of family members in the clinic visit may affect a teen's honest response to basic screening questions; it may be beneficial to

ask the family member to step out for a moment. When family members are present, however, inquiring about family meals and caregiver weight concerns may also be of use. As previously described, fewer family meals are a risk factor for disordered eating [32], and mealtimes may be the only time caregivers/significant others can observe eating patterns. These suggestions may aid providers who prefer to use a clinical interview rather than a more formal screening tool.

Brief Review of Eating Disorder Treatments

When an eating disorder or disordered eating behavior in an individual with type 1 diabetes is suspected, further investigation is necessary. Consultation and referral to mental health services is an appropriate first step for screening and treatment. Various treatments exist for eating disorders, including family therapy, cognitive-behavioral therapy and interpersonal psychotherapy. Nutritional counseling is also recommended as a component of successful therapy [43]. Eating disorder treatment is a complex, lengthy, and sometimes life-long process.

Traditionally, individual psychodynamic therapy was used to treat eating disorders, but family therapy and cognitive behavioral therapy have become more widely used methods in the treatment of individuals with eating disorders. A treatment that has recently gained support is the Maudsley approach, developed for adolescents with anorexia [44]. This approach focuses on the dangers of severe malnutrition associated with anorexia and enlists the help of parents as the primary support system for the adolescent. Gradually, the adolescent gains control of his/her eating, thereby leading to an increase in feelings of independence. The family-based, Maudsley approach is a relatively short-term treatment option, and it has been shown better long-term success than individual therapy; a randomized controlled trial found remission rates of 40% at six months and 49% at 12 months for the family-based treatment, as compared to 18% and 23% for individual therapy [44]. Similarly, bulimia nervosa has been effectively treated with individual cognitive-behavioral therapy to identify and change the maladaptive cognitions and behaviors associated with the disorder. A multicenter randomized trial found that 29% of patients who received cognitive-behavioral therapy recovered, as compared to only 6% for interpersonal psychotherapy [45].

Few treatments for eating disorders have been tested specifically in patients with type 1 diabetes. One successful trial found that inpatient therapy for women with type 1 diabetes and bulimia nervosa in Japan improved HbA1c and reduced frequency of binge eating and purging behaviors [46]. A psycho-educational program for young women with type 1 diabetes was also shown to improve areas related to eating concern, drive for thinness, and body dissatisfaction, but it did not have an impact on insulin omission or A1C levels [47]. Cognitive-behavioral therapy is also likely to be effective for insulin omission or dosage modification, which may be considered a compensatory behavior related to the eating disorder [48]. It is unknown, however, which treatments are most effective for men or minority populations [20].

It is also important to note that psychotherapy is not the only treatment option for eating disorders. Currently, no medications have Food and Drug Administration approval for the treatment of anorexia nervosa, and fluoxetine is the only medication approved for treatment of bulimia nervosa [49]. Nutrition counseling with a RD, CDE includes assessment of eating patterns and attitudes regarding weight, shape, and eating, determine the nutrient intake needed to establish health goals [43]. Dietitians can also monitor nutrient intake and make adjustments as necessary (e.g., adjust food intake once weight is restored) [43]. More recently, treatment approaches including alternative therapies, such as yoga, stress management, and spirituality have been used to manage disordered eating. Mindfulness has also shown promise in the treatment of binge eating [50].

Finally, preventive interventions may reduce the risk of developing eating disorders in high-risk populations. For example, a dissonance-based prevention program (Body Project) asks young women who are at risk for eating disorders to engage in verbal, written, and behavioral exercises in which they critique the thin ideal (e.g., writing an essay about airbrushing models in magazines). This program has been proven efficacious; 3 one-hour sessions resulted in a 60% reduction in risk for developing eating disorders over 3 years [51]. Research is needed to determine if such a program would be similarly effective for young women with type 1 diabetes.

Regardless of treatment approach, the cornerstone of standard of care for eating disorders in patients with type 1 diabetes involves a multidisciplinary approach. Health care providers, including endocrinologists, nurse educators, dietitians, and mental health providers all play essential roles in treatment [2]. Both in-patient and out-patient options are available, and an appropriate treatment plan should be decided upon by the patient, family, and healthcare team. Setting realistic, attainable goals, with family involvement and support, is imperative for treatment to be successful [2]. Diabetes goals should be more flexible in order to keep the individual safe [48]. Treatment is highly individualized and can often be a long, tenuous process. Because of the complexities of treating people with type 1 diabetes who experience eating disorders, early detection and intervention are essential to improving quality of life for those at risk.

Conclusion

Individuals with type 1 diabetes, especially females, appear to be at greater risk for the development of eating disorders and disordered eating as compared to their peers without diabetes. Additionally, adolescents who develop diabetes in the pre-adolescent and adolescent years may be more likely to develop eating disorders as compared to those diagnosed at earlier or older ages. Simple screening tools, such as asking patients during routine clinic visits “Have you ever been overweight?” or inquiry into use of insulin may be useful initial questions to detect eating disorders. Given the complexity of diabetes management in combination with eating disorder treatment, it is imperative to screen and detect those most at risk as early as possible. Early intervention is critical in this population in order to maintain optimum health status and decrease the chances of complications such as retinopathy, neuropathy, or DKA. Evidence shows a growing success of family therapy, and additional treatments are available for eating disorders in people with type 1 diabetes.

With consistent and early screening, those most vulnerable to develop eating disorders or disordered eating behaviors may receive timely and appropriate treatment.

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Table 1
Prevalence Rates, Mortality Rates and Age of Onset for Anorexia Nervosa, Bulimia Nervosa, Any Eating Disorder, and Disordered Eating Behaviors

	Anorexia Nervosa		Bulimia Nervosa		Any Eating Disorder		Disordered Eating Behaviors	
	Males	Females	Males	Females	Males	Females	Males	Females
Prevalence in General Population	0.3%	0.9%	0.5%	1.5%	1.5%*	3.8%*	--	--
Prevalence in Type 1 Diabetes Population	--	--	--	--	--	10%	15.9%	37.9%
Median Age of Onset (years)	18.0 (16.0 – 22.0)		18.0 (14.0 – 22.0)		21.0 (17.0 – 32.0)		20.0 (16.0 – 27.0)	
Mortality Rate**	5.1		1.7		--		3.3	

* Population: Adolescents

** Weighted Mortality Rate (deaths/1000 person-years) [15].

Table 2
Risk Factors and Complications for Disordered Eating in People with Diabetes

Risk Factors	Explanation
Adolescences	Increased risk taking behavior, peer influence
Gender	Females are more likely to engage in disordered eating behavior
BMI	Higher BMI may lead to dieting, negative affect
Body Dissatisfaction	Drive for Thinness
Meal Structure	Infrequent family meals
Type 1 Diabetes Complications	
	Poor Glycemic Control
	Frequent Diabetic Ketoacidosis (DKA)
	Retinopathy
	Nephropathy
	Neuropathy
	Cerebral Edema
	Kidney Failure
	Heart Problems (e.g., arrhythmia, bradycardia)
	Death