

# Eating disorders in young people with diabetes: Development, diagnosis and management

*Ursula Philpot*

**Citation:** Philpot U (2013) Eating disorders in young people: development, diagnosis and management. *Journal of Diabetes Nursing* 17: 228–32

## Article points

1. Eating disorders and disturbed eating behaviours are common in young people with diabetes, where manipulation of insulin or hypoglycaemic agents is used to manage body weight.
2. Diabetes teams should use a screening tool to identify affected individuals for early initiation of treatment.
3. Eating disorders in diabetes greatly increase mortality and morbidity (particularly retinopathy), and teams should be vigilant for indicative symptoms.
4. Management of young people with eating disorders and diabetes must be multidisciplinary in approach, with the individual and family at the centre of care.

## Key words

- Diagnosis
- Eating disorders
- Multidisciplinary treatment
- Young people

## Authors

Ursula Philpot is Senior Lecturer and Advanced Practice Dietitian, School of Wellbeing, Faculty of Health and Social Sciences, Leeds Metropolitan University.

**Eating disorders and disturbed eating behaviours are common in young people with diabetes, where manipulation of insulin or hypoglycaemic agents are often used to manage body weight. The ego-syntonic nature of eating disorders, where sufferers view the eating disorder as a solution to their problem, commonly delays diagnosis. Left untreated this dual diagnosis is a toxic mix, accelerating the incidence of retinopathy threefold (Nielsen, 2002). Diabetes teams should expect an incidence of approximately 20% in their adolescent population (Markowitz et al, 2010). Teams should be vigilant for symptoms, and the use of a validated screening tool can help with early recognition. Research into the efficacy of treatments for this population is lacking; best-practice guidance focuses on a multidisciplinary approach, with a psychological formulation of the problem that places the individual and family at the centre of treatment. Frequent whole-team contacts and enhanced communication between all professionals are essential for a successful outcome.**

Eating disorders affect up to 20% of females with diabetes (Markowitz et al, 2010). Most commonly they take the form of disturbed eating behaviour, characterised by food restriction, bingeing, excessive exercise or vomiting. Young people with type 1 or type 2 diabetes may also use an altered dose of insulin or hypoglycaemic agents to manage their body weight, which is known as eating disorder with type 1 diabetes (ED-T1DM) or termed “diabulimia” by the media. Most research to date has centred on type 1 diabetes and its prevalence and complications; in contrast, research is lacking on type 2 diabetes as well as effective treatment strategies for disturbed eating behaviour. As a result of the ego-syntonic nature of eating disorders, they present a great challenge to healthcare professionals in terms of their identification and treatment. Left untreated,

there is a high incidence of both morbidity and mortality.

## The development of eating disorders in young people with diabetes

Disordered eating is a well-recognised complication of type 1 diabetes, and is twice as likely to occur in teenage girls with type 1 diabetes than in those without the condition (Affenito and Adams, 2001; Grylli et al, 2005). However, these prevalence studies used self-reported questionnaires, and because of the secretive nature of eating disorders the real incidence may even be higher. Disordered eating is not exclusive to girls, with reports indicating that boys with diabetes are more likely to use vomiting for weight control and dieting than boys without chronic illness (Neumark-Sztainer

et al, 1995). Despite this commonality, the eating disorder presentation varies according to the type of diabetes:

- Anorexia and bulimia or diabulimia are more common in those with type 1 diabetes.
- Binge-eating disorder is more prevalent in those with type 2 diabetes (Pinhas-Hamiel and Levy-Shraga, 2013).

Various theories have particularly sought to explain the high prevalence of eating disorders found in people with type 1 diabetes (*Table 1*). The most common emerging themes centre on four central aspects of diabetes and their management.

### Weight loss associated with diagnosis

The presence of initial weight loss before diagnosis is considered to influence the development of eating disorders. Weight loss associated with diagnosis may often result in positive comments from family and peers. When rebound weight gain occurs with the initiation of insulin treatment, it may trigger behaviours that attempt to reverse weight gain.

### Higher BMI in females with diabetes

The trend towards a higher BMI in females with diabetes is thought to predispose to eating disorders. Overweight adolescents appear to be the most vulnerable, and a higher prevalence of unhealthy weight-control behaviours can be evidenced in this group (Neumark-Sztainer et al, 1995).

### Dietary restraint

Dietary restraint, which has traditionally been an essential part of diabetes management, has been postulated as a key causative factor of eating-disordered behaviour. Restraint in some individuals leads directly to overeating and can lead to cycles of restraint followed by binge eating, which may then lead on to the use of compensatory behaviours (Ouwens et al, 2003). Binge-eating disorders show increased prevalence among individuals with type 2 diabetes (Pinhas-Hamiel and Levy-Shraga, 2013).

### Drug manipulation

The ease with which insulin or hypoglycaemic drug doses can be deliberately omitted or

**Table 1. The development of eating disorders in young people with diabetes.**

General risk factors	Aspects of diabetes management that may increase the risk of ED-T1DM
Female	Higher BMI
History of dieting	Dietary restraint
Low self-esteem	Effect of diabetes on self-image and family interaction
Depression	Difficulties in coping with long-term condition
Disturbed family functioning or parental eating attitudes	Family interaction involving autonomy or independence of diabetes management
Perfectionism	

ED-T1DM=eating disorder with type 1 diabetes.

manipulated as a weight-loss strategy links chronic disease with eating disorders (Pinhas-Hamiel and Levy-Shraga, 2013); the disturbed eating behaviours are used as a way to gain control over a life that individuals perceive is out of their control. The number of young people who admit to insulin restriction or omission is variable and appears to be dependent on age; reports suggest that prevalence increases from 15% of girls in their mid-teens (Jones et al, 2000) to 30% of older teenagers (Peveler et al, 2005; Ackard et al, 2008).

### Recognising eating disorders in diabetes

Eating disorders should be suspected in patients with recurrent diabetic ketoacidosis or poor glycaemic control with weight loss, despite the appearance of compliance; however, a sole focus on weight loss is misleading and insufficient. As shown in *Table 2*, there are a wide range of signs and symptoms to look out for. These may be missed by clinical teams who spend just a short time with each individual, and are more likely to be reported by parents or teachers. Young people may comment on some of the symptoms of disordered eating that they find distressing, such as hair loss or thinning, fainting episodes or abdominal pain and constipation, but are unlikely to proffer information about dieting or omitting insulin or hypoglycaemic agents.

**Table 2. Recognising eating disorders in diabetes.**

<b>Psychosocial influences</b>	<ul style="list-style-type: none"> <li>• Deterioration in psychosocial functioning, e.g. relationship with peers, school and academic work</li> <li>• Avoiding eating with family and peers</li> </ul>
<b>Diabetes management</b>	<ul style="list-style-type: none"> <li>• Self-critical thoughts</li> <li>• Preoccupation with food or meal planning</li> <li>• Low mood, irritability or anxiety</li> <li>• Obsessive calorie and carbohydrate counting</li> </ul>
<b>Cognitive factors</b>	<ul style="list-style-type: none"> <li>• Poor attendance at clinic</li> <li>• Increased concern about shape or weight</li> <li>• Poor metabolic control despite the appearance of compliance</li> </ul>
<b>Physical factors</b>	<ul style="list-style-type: none"> <li>• Weight loss/gain</li> <li>• Thin hair</li> <li>• Pale, dry skin</li> <li>• Feeling cold, especially hands and feet, e.g. wearing a coat despite it being warm in clinic</li> <li>• Diabetic ketoacidosis</li> <li>• Puffy face or drawn</li> <li>• Electrolyte abnormalities, especially potassium abnormalities</li> <li>• Tachycardia and hypotension</li> <li>• Abdominal pain, irritable bowel syndrome or constipation</li> <li>• Dizziness and fainting</li> </ul>
<b>Behavioural factors</b>	<ul style="list-style-type: none"> <li>• Going to the bathroom after eating</li> <li>• Avoiding eating with others</li> <li>• Cooking for others but not eating</li> <li>• Reading diet magazines and articles and watching food-related programmes</li> </ul>

Eating disorders are ego-syntonic in nature and are seen by the sufferer as a solution to the problem of poor self-esteem or body image, which often leads to concealing the disorder from families and the diabetes team. According to prevalence data, a diabetes team should expect that approximately 20% of their teenagers have disordered eating (Markowitz et al, 2010), and should be prepared to implement further training in identification and screening for eating disorders if this is not the case.

Healthcare professionals can initiate dialogue in an empathic, non-blaming way to open up conversations with young people whom they feel

may be struggling with eating issues:

*“From some of the results we have and some of the things we have discussed today I’m wondering if you might be struggling with your eating. It’s common for young people with diabetes to struggle with their eating – for example, wanting to restrict what they eat or skip their insulin – in fact, most people have at least thought about it at some point. I wonder what you think?”*

*“We know that lots of young people try skipping insulin or food to help them to lose weight, but the down side is that you usually end up getting stuck doing it more and more over time – I wonder if you feel like that?”*

Symptoms to be vigilant for include low mood, irritability, anxiety and critical cognitions around self-image; commonly these may often be dismissed as part of a normal teenage presentation. Clinicians with a special interest in eating disorders and diabetes have adapted the DSM-IV (*Diagnostic and Statistical Manual of Mental Disorders*, fourth edition; American Psychiatric Association, 1994) criteria for bulimia to include insulin misuse and the term diabulimia or ED-T1DM (Criego et al, 2009). One of the core constructs of the diagnosis is “inappropriate compensatory behaviours”; this compensatory behaviour might manifest itself as purging or misuse of laxatives. In individuals with diabetes, it also takes the form of a reduction in insulin dose or omission of hypoglycaemic agents for the purpose of weight loss.

Often individuals’ physical appearance can trigger a need for further investigations; typically symptoms include a pale appearance, dry lips and cold extremities with signs of poor nutrition, such as dull hair, a swollen or sunken face and lethargy. Urgent care should be considered if abnormal electrolytes, dehydration or rapid weight loss (over 0.5 kg/week) are present alongside poor diabetic control.

Markowitz et al (2010) developed the first validated brief screening tool for disturbed eating behaviour in diabetes; the Diabetes Eating Problem Survey–Revised (DEPS-R) tool is a 16-item, diabetes-specific, self-report measure of disordered eating that can be completed in less than

10 minutes (*Box 1*). It demonstrated excellent internal consistency, construct validity and external validity in a contemporary sample of young people with type 1 diabetes; a screening tool such as the DEPS-R can help the clinician to determine whether a more extensive assessment is necessary.

In their study of 772 participants aged between 11 and 19 years (Markowitz et al, 2010), approximately 25% of females had disturbed eating behaviours and one-third of females restricted their insulin dose. In addition, participants who were classified as missing or restricting insulin who also scored  $\geq 20$  on the DEPS-R had the highest glycosylated haemoglobin (HbA<sub>1c</sub>) value of all participants.

### The consequences of eating disorders in young people with diabetes

The consequences of eating disorders in diabetes have been well researched (Rydall et al, 1997; Jones et al, 2000). Young people who use insulin dose manipulation to achieve weight loss often suffer serious consequences to their health, in the form of early onset of diabetes complications: typically, higher HbA<sub>1c</sub> levels as a result of poor metabolic control, hypoglycaemia caused by not eating or not eating enough, and diabetic ketoacidosis brought on by deliberately reducing or omitting insulin.

The most common complication is retinopathy; Japanese investigators (Nielsen, 2002) reported that a cohort of individuals with type 1 diabetes took an average of 11.5 years to develop retinopathy, compared with just 3.4 years in individuals with diabulimia. Young people with the most severe eating disorders had the most damage, with 86% of those with eating disorders showing evidence of retina damage, compared with 24% for those with diabetes alone.

Left untreated, insulin manipulation and disordered eating can result in increased morbidity and mortality. Goebel-Fabbri et al (2008) published a retrospective follow-up study, which showed that self-reported insulin restriction at baseline resulted in a 3.2-fold increased risk of death during the 11 years of follow-up.

#### Box 1. The 16-item Diabetes Eating Problem Survey-Revised self-report measure can help determine disordered eating behaviour in young people with diabetes.\*

Respondents answer the following statements:

- Losing weight is an important goal to me
- I skip meals and/or snacks
- Other people have told me that my eating is out of control
- When I overeat, I don't take enough insulin to cover the food
- I eat more when I am alone than when I am with others
- I feel that it's difficult to lose weight and control my diabetes at the same time
- I avoid checking my blood sugar when I feel like it is out of range
- I make myself vomit
- I try to keep my blood sugar high so that I will lose weight
- I try to eat to the point of spilling ketones in my urine
- I feel fat when I take all of my insulin
- Other people tell me to take better care of my diabetes
- After I overeat, I skip my next insulin dose
- I feel that my eating is out of control
- I alternate between eating very little and eating huge amounts
- I would rather be thin than to have good control of my diabetes

Items are answered on a 6-point Likert scale: 0=never; 1=rarely; 2=sometimes; 3=often; 4=usually; 5=always. \*From Markowitz et al (2010).

### Treatments

Early treatment is important because the longer an eating disorder continues, the harder it is to treat. Treatment includes decreasing dietary restraint, promoting healthy eating and psychological interventions to address underlying psychopathology. The treatment of choice for eating disorders in children and young people is family therapy (NICE, 2004); for individuals with coexisting diabetes, the approach must also be multidisciplinary in nature. Minimally this should include a psychologist, a specialist eating disorders dietitian, a DSN and a physician. Care should be coordinated and overseen by a consultant diabetologist and consultant psychiatrist working together. Families and carers are essential members of the treatment team, and including family members in treatment interventions will enhance treatment compliance and increase shared understanding of the difficulties experienced by the individual.

Once the treatment team has been established, it is essential that all members meet frequently and maintain good communication channels to share information concerning the individual's

**“Eating disorders commonly coexist with diabetes, and if not identified early they can lead to serious and accelerated complications, particularly retinopathy.”**

treatment goals, interventions and progress. The intensity and frequency of contact with the team will depend on the severity of the eating disorder. Close physical monitoring should be maintained alongside intensive therapeutic support for changing thoughts and behaviours. Safety of the young person is paramount, and must be the initial treatment focus. Reducing physical risks by implementing incremental goals that aim to re-establish regular insulin and reduce episodes of diet restriction should be the early focus; longer-term treatments should focus on helping individuals accept the distress caused by living with a long-term condition, its treatment and the disease course.

It is unlikely that treatment will be effective if the young person perceives that the diabetes team work in isolation from the eating disorders treatment team; thus integrated and coordinated care is essential. A phenomenon known as “splitting” is common, where individuals with eating disorders promote polarisation and splitting of healthcare staffs’ attitudes and beliefs, often holding one team or team member in high esteem, while others are rubbished. Joint consultations and therapy sessions between cross-team members will prevent this, and will enhance shared care and understanding between healthcare professionals and young people, their families and carers.

### Conclusion

Eating disorders commonly coexist with diabetes, and if not identified early they can lead to serious and accelerated complications, particularly retinopathy. Research has focused on the prevalence of eating disorders, its consequences and prevalence of complications, but a greater emphasis is now needed to evaluate whether early identification can improve outcomes in addition to developing and measuring more effective treatments. ■

*The author wishes to thank Alison Middleton, Affiliate of the Open University, who contributed to the literature search and review of the data for this article.*

Ackard DM, Vik N, Neumark-Sztainer D et al (2008) Disordered eating and body dissatisfaction in adolescents with type 1 diabetes and a population-based comparison sample: Comparative prevalence and clinical implications. *Paediatr Diabetes* 9: 312–9

Affenito SG, Adams CH (2001) Are eating disorders more prevalent in females with type 1 diabetes mellitus when the impact of insulin omission is considered? *Nutr Rev* 59: 179–82

American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders*. 4th edn. APA, Washington DC

Criego A, Crow S, Goebel-Fabbri A et al (2009) Eating disorders and diabetes: Screening and detection. *Diabetes Spectrum* 22: 143–6

Goebel-Fabbri AE, Fikkan J, Franko DL et al (2008) Insulin restriction and associated morbidity and mortality in women with type 1 diabetes. *Diabetes Care* 31: 415–9

Grylli V, Hafferl-Gattermayer A, Wagner G et al (2005) Eating disorders and eating problems among adolescents with type 1 diabetes: exploring relationships with temperament and character. *J Pediatr Psychol* 30: 197–206

Jones G, Colton J, Lawson M et al (2000) Eating disorders in adolescent females with and without type 1 diabetes. *BMJ* 320: 1563–6

Markowitz J, Butler DA, Volkening LK et al (2010) Brief screening tool for disordered eating in diabetes. Internal consistency and external validity in a contemporary sample of paediatric patients with type 1 diabetes. *Diabetes Care* 33: 495–500

NICE (2004) Eating disorders: Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. Clinical Guideline 9. Available at: <http://www.nice.org.uk/CG009> (accessed 10.6.13)

Neumark-Sztainer D, Story M, Resnick MD et al (1995) Body dissatisfaction and unhealthy weight-control practices among adolescents with and without chronic illness. *Arch Pediatr Adolesc Med* 149: 1330–5

Nielsen S (2002) Eating disorders in females with type 1 diabetes: an update of a meta-analysis. *Eur Eat Disord Rev* 10: 241–54

Ouwens MA, van Strien T, van der Staak CP (2003) Tendency toward overeating and restraint as predictors of food consumption. *Appetite* 40: 291–8

Peveler RC, Bryden KS, Neil HA et al (2005) The relationship of disordered eating habits and attitudes to clinical outcomes in young adult females with type 1 diabetes. *Diabetes Care* 28: 84–8

Pinhas-Hamiel O, Levy-Shraga Y (2013) Eating disorders in adolescents with type 2 and type 1 diabetes. *Curr Diab Rep* 13: 289–97

Rydall AC, Rodin GM, Olmsted MP et al (1997) Disordered eating behaviour and microvascular complications in young women with insulin-dependent diabetes mellitus. *N Engl J Med* 336: 1849–54

### Useful information

#### Beat – Beating Eating Disorders

Beat provides helplines, online support and a network of UK-wide self-help groups to help adults and young people in the UK beat their eating disorders.

[www.b-eat.co.uk](http://www.b-eat.co.uk)  
 Helpline 0845 634 1414  
 Youthline 0845 634 7650

#### Diabetics with Eating Disorders

A charity that provides support to individuals with diabetes and training for healthcare professionals.

[www.dwed.org.uk](http://www.dwed.org.uk)