

Diabulimia: mental health condition or media hyperbole?

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Type 1 diabetes demands optimal control of a variety of metabolic parameters, most notably blood glucose. This is achieved through attention to food choice, portion size, insulin dose adjustment, exercise and other contributors to a healthy lifestyle. The consequences of long-term poor glycaemic control are wide ranging and potentially devastating. For some individuals this attention to food results in perceived restraint and restriction of choice, weight gain associated with insulin use and a sense of loss of control. The first reports of eating disorders (EDs) and diabetes emerged in the 1970s. Almost 50 years later it is now well established that when compared with their non-diabetic peers, individuals with type 1 diabetes are at increased risk of developing disordered eating behaviours (DEBs) and EDs which are associated with poor glycaemic control.¹ Poor glycaemic control and its potentially life threatening impact on health, make it essential that diabetes health care teams are aware of the potential for disordered eating in conjunction with a preoccupation with weight and negative body image so that it can be recognised and treated early.

Eating disorders and diabetes

There are three main diagnoses of eating disorder: anorexia characterised by an obsessive fear of weight gain and severe restriction of dietary intake; bulimia characterised by binge eating followed by purging, usually vomiting or laxative abuse; and eating disorders not otherwise specified (EDNOS) characterised by the above symptoms but which do not meet the criteria for a diagnosis of a specific eating disorder. Although EDs occur in males (1 per 400)² they are most prevalent in teenage girls and young adult females (1 per 50).² The prevalence of atypical EDs is even more common and may not receive treatment. The interpretation of the reported prevalence of DEB and diabetes is difficult because there are no standardised diabetes-specific measures; however, it has been suggested that between 11.5% and 27.5% of adolescents with type 1 diabetes meet the diagnostic criteria for an ED, most commonly bulimia nervosa or binge eating disorder.^{1,3} Up to 30% mismanage insulin to avoid weight gain or lose weight.⁴

The most common risk factors for the development of an ED in the general population include young female, a history of dietary restraint and dieting, weight gain, low self-esteem, and family dysfunction. These risks are intensified by type 1 diabetes because the foundation stone for successful management of the condition is a focus on food. Diagnosis of type 1 diabetes frequently occurs around puberty when weight and body image concerns are very prominent and the individual is likely to have negative emotional reactions to the diagnosis and the tendency to weight gain following the initiation of insulin therapy. The core symptom dimension is a negative self-evaluation influenced by weight and perceived body

shape. Mild eating disturbances can compromise metabolic control, and longitudinal studies report that these tend to be persistent rather than transient.⁴⁻⁶

What is diabulimia?

Diabulimia is not a medically recognised condition, but the term has been used in the media⁷⁻⁹ and academic literature to describe the deliberate omission or underuse of insulin to control weight. It relates specifically to insulin restriction and does not include all types of disordered eating. Insulin omission results in the purging of calories through glycosuria and is used predominantly by teenage girls and young women with type 1 diabetes. It is included in the purging behaviours listed for a diagnosis of bulimia and EDNOS.¹⁰ A recent study¹¹ reaffirmed earlier findings¹²⁻¹⁵ that deliberate insulin omission is the most favoured means of weight control in people with type 1 diabetes. Prevalence data for those who report insulin misuse to control weight range from 14–36%.^{4,11,16,17} As an aspect of an eating disorder it often goes unrecognised and is not addressed.¹⁸

The deliberate omission of insulin results in severe hyperglycaemia, frequent hospital admissions with diabetic ketoacidosis (DKA), earlier onset of complications, and at worst premature death. An 11-year follow-up study indicated mortality associated with insulin restriction appeared to occur in the context of eating disorder symptoms rather than other psychological distress such as anxiety, depression, fear of hypoglycaemia, and diabetes distress.⁴

Recognising the problem

Diabetes-specific clinical characteristics associated with the presence of disordered eating and diagnosable ED include unexplained fluctuations in blood glucose, frequent DKA, improved control only when in hospital, refusal to let others observe injections, and anxiety about being overweight.^{19,20} Diabulimia is associated with feelings of shame and embarrassment, negative body image, low self-esteem, depression and anxiety.²¹ People are reluctant to disclose the problem so it is particularly important to have a high index of suspicion in the context of the above symptoms.

In view of the prevalence of approximately one-third of people (predominantly teenage girls and young women) with type 1 diabetes who restrict or omit insulin for weight control,¹⁷ together with a significant proportion who adopt additional purging and disordered eating practices, regular screening should be an integral part of diabetes care. Although there are self-report questionnaires and standardised assessments for eating disorders in the general population there are no validated screening tools for people with type 1 diabetes. Aspects of diabetes management require attention to diet, a focus on carbohydrate and the need to eat without feeling hungry (to treat hypoglycaemia). Consequently, the scores may be inflated relative to those from a sample without

diabetes and generic measures do not assess the unique behaviour of insulin omission. The Revised 16-item Diabetes Eating Problem Survey²² is a new self-report measure that has been demonstrated to have appropriate psychometric properties. It is a diabetes-specific measure of disordered eating incorporating questions about weight concerns, eating patterns, control and purging, including self-induced vomiting and maladaptive insulin use. Such a screening tool can alert the health care team to issues for further discussion during a sensitive non-judgemental consultation.

Treatment

Early identification of insulin restriction or omission and any additional eating disturbances will enhance the treatment outcome. Weight concern is one reason for insulin restriction. It may also occur as a method of coping with diabetes-specific distress, fear of hypoglycaemia, needle anxiety, and generic psychological problems, so it is important to do a full assessment of eating behaviours, health beliefs, and predisposing and perpetuating factors before embarking on any intervention. Insulin omission to avoid hypoglycaemia will require different treatment to that of insulin omission linked to body image concerns and weight control.

Evidence-based psychological therapies in the context of a multidisciplinary team are the broad recommendation for the treatment of eating disorders.² There are no specific guidelines for the treatment of diabetes and disordered eating; however, the default position for the treatment of people presenting with two complex conditions has to be a multidisciplinary team approach integrating knowledge of both diabetes and eating disorders. The initial priorities of treatment are to stabilise eating and eliminate any purging behaviour, which in the case of diabulimia is insulin omission or restriction. The weight gain consequent upon improved glycaemic control is a risk for relapse and needs to be anticipated early in therapy. Assessment and formulation shape treatment plans and, until there is a robust evidence base specific to people with diabetes that suggests otherwise, there is a choice of psychological therapies available to accredited practitioners.

Is diabulimia a mental health condition?

Diabulimia is only one aspect, albeit extremely serious, of disordered eating in people with type 1 diabetes and it has been suggested that up to 30% of people with type 1 diabetes omit or restrict their insulin as a consequence of weight and body image concerns.¹⁷ Treatment of the dual presentation of diabetes and eating disturbance requires an additional dimension because the management of diabetes has to be integrated into the treatment of the disordered eating. A condition for which food and exercise are the central tenets of management presents inherent conflicts for the sufferer of the eating disorder where food issues, weight gain and body image are core themes. The consequences of not recognising and so not treating this presentation can have serious long-term health consequences. It is therefore appropriate to consider eating disorders presenting with diabetes as a mental health condition deserving recognition and treatment. As people with type 1 diabetes can present with any eating disorder, not exclusively insulin omission, it

has been suggested that this concurrent presentation is described as ED-DMT1.¹⁸ Diabetes education alone is an inadequate response to these problems; these individuals also need appropriate treatment for complex psychological problems as identified in The King's Fund report²³ which emphasised the need for integrated rather than 'tacked on' mental health provision.

NHS National Diabetes Audit

The most recent (2011) NHS National Diabetes Audit^{24,25} reported 8472 hospital admissions with DKA. The highest incidence in England and Wales was young people between the age of 10–19 years, who were predominantly female and from areas of England and Wales with higher indices of deprivation. Over a similar time period, eating disorder admissions demonstrated a 16% rise compared to the previous year, more than half of which (55%) were accounted for by those aged 10–19 years.²⁶ The cause for DKA was not coded; however, it is likely that a proportion of these admissions were a consequence of 'diabulimia'. The NICE quality standard for diabetes²⁷ states that 'people admitted to hospital with DKA receive educational and psychological support prior to discharge...'. The incidence of DKA admissions reinforces the need both to raise awareness of insulin omission as a means of weight control and to have access to specialist psychological intervention. The old saying 'a stitch in time saves nine' is more than slightly relevant. If these people are identified early and treated appropriately they will benefit from improved glycaemic control, and fewer and less severe diabetes health complications and improved quality of life which will be cost effective in the long term.

Summary

Disturbed eating patterns and weight concerns are prevalent in people with type 1 diabetes and strike at the heart of problematic glycaemic control with potentially devastating health consequences. The diagnosis of type 1 diabetes increases the risk of developing DEB in the vulnerable, who are predominantly young females. Eating disorders can be treated successfully and diabetes managed optimally with an integrated multidisciplinary approach. Diabetes teams need to have a high index of suspicion for the presence of eating disturbance and feel confident to ask questions pertaining to thoughts, feelings and food choice, weight concerns and the impact on diabetes management. The team should have access to a specialised diabetes mental health professional qualified to deliver psychological therapies so that difficulties can be addressed as an integral aspect of the diabetes management. However, in more severe circumstances a referral to an eating disorder service may be necessary.

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Declaration of interests

There are no conflicts of interest declared.

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References are available at www.practicaldiabetes.com.

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