Diabulimia: Psychological perspectives on management

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Although diabulimia has been known about for forty years, and despite its increasing prevalence, knowledge of the condition is often limited in primary care. Definitions of diabulimia vary and continue to evolve, but broadly it is the dangerous practice in people with diabetes who are insulin-dependent of omitting insulin to promote weight loss. This article provides an overview of our understanding of this complex condition and its presentations, as well as offering insights into its effects and risk factors. It also provides recommendations into its detection and management, and outlines the barriers to its treatment, with an emphasis on the requirement for better professional education in order to support people with diabulimia more effectively.

"A crust eaten in peace is better than a banquet eaten in anxiety." Aesop

The term "eating disorder" has historically focused on anorexia, bulimia and binge eating. More recently, descriptions of ARFID (avoidant/restrictive food intake disorder), orthorexia and OSFED (other specified feeding and eating disorders) have arisen as a result of the awareness of the complexity of presentation of eating disorders in contexts outside of the "traditional" settings (NICE, 2019). It is important to note that eating disorders can change form over time and also coexist as combinations of the above (Lazenby, 2022).

We know that eating disorders are not about food *per se*. Rather, food is used as a means of control for individuals attempting to manage their anxieties. This means that not all people living with eating disorders have a "typical" disordered eating presentation (Lazenby, 2022).

For patients living with long-term conditions (LTCs) such as diabetes, there is a significant emphasis placed on diet, weight and health. Indeed, temporary weight gain is part of the outcome of successful insulin therapy. Unfortunately, this means that the diagnosis itself can result in increased vulnerability to disordered eating, by both further contributing to pre-existing disordered eating or by triggering disordered eating as a result of the fear of physical harm of not managing diabetes. This is likely to occur without suspicion or detection, as treatment plans may reinforce the importance of supporting a specific dietary regimen.

The term diabulimia has emerged around the awareness of the interface between the often life-threatening impact of (poor) diet in people with diabetes and the resultant effect this has on their relationship with food, any pre-existing anxieties, related coping strategies and their vulnerability to disordered eating.

Described by Torjesen (2019) as "the world's most dangerous eating disorder," diabulimia is by no means a new discovery, with clinicians raising alerts to the condition for nearly four decades.

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Article points

1. Defining diabulimia is difficult, but it is a complex psycho-medical condition that involves the practice of omitting insulin to promote weight loss.
2. The effects of diabulimia arise from both the impact of having an eating disorder and from the restriction of insulin.
3. Awareness of the condition needs to be raised in health professionals so that its psycho-medical aspects can be addressed effectively.
4. Acute medicine and mental health services need to share information to properly address the care needs of an individual with diabulimia.

Key words

- Diabulimia
- Eating disorders
- Health psychology
- Long-term conditions

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"The term diabulimia is difficult to define, as it necessarily needs to assume the complexity of eating disorders and of diabetes."

Unfortunately, initial incidences were neither reported nor recorded, with little attention being given to a growing national problem. Well known to endocrinologists, it is largely unrecognised by primary healthcare providers or by family members and caregivers. Where healthcare professionals do have concerns, management appears to be sporadic, relying heavily on individual staff members to identify and draw attention to specific patient presentations (Ruth-Sahd and Haagen, 2009; Shaban, 2013; Callum, 2014; Ribeiro et al 2014; Chandran et al, 2018; Van Heynigen and Manoharan, 2018; Torjesen, 2019).

This article presents a general overview of our understanding of diabulimia and considerations of patient presentation, as well as referencing existing management strategies. It aims to build on existing information and offer considerations on how to improve both detection and management of symptoms, borrowing from the wider context of eating disorders. Whilst the focus is on diabulimia, the information is of relevance to any of those LTCs where regulation of diet has a significant impact on deterioration of health.

What we know

Definitions of diabulimia

These may vary not only due to the emergence of increased information about disease trajectories of both eating disorders and diabetes, but also because of the impact of dietary regimens on fatalities and health deterioration (in turn increasing the pressure on patients to conform and adhere to dietary and exercise regimens). These influencing factors have meant that definitions focus on a range of associated relationships.

Also known as ED-DMT1 (eating disorder-diabetes mellitus type 1), the term initially referred to any type of eating disorder comorbid with type 1 diabetes. The generality of the description allowed for the accommodation of all of the pre-existing categories, especially OSFED, creating a helpful benchmark (Davidson, 2014).

Kinik et al (2017) defined diabulimia in terms of the relationship between diet management and insulin treatment, which are both withheld owing to body and social acceptance issues, especially in individuals whose disease is diagnosed during adolescence. Again, this borrowed from the more traditional understanding of eating disorders to be sourced largely in body image.

Kinik et al (2017) also highlighted the relevance of the focus of diabetes treatment on diet and weight control. This leads to the context of the relationships between health deterioration, mortality and adherence to dietary regimen, with threat or fear as the moderating factor. This may increase risk and a person's vulnerability to disordered eating.

This does not imply treatment causes disordered eating, but highlights how an emphasis on symptom management may trigger or feed into pre-existing additional vulnerabilities (Shaban, 2013).

Torjesen (2019) describes diabulimia as a process where people diagnosed with type 1 diabetes restrict their insulin intake to lose weight, and involves a complex interaction of influences (e.g. insulin and blood glucose levels, emotions and body image) that cut across diabetes care and mental health.

Coleman and Caswell (2020) stressed the significance of the intentional aspect, specifying that the decision is made with intention (and not from a point of naivety, ignorance or misunderstanding of the treatment regimen [e.g. a fear of injecting]).

The term itself is difficult to define, as it necessarily needs to assume the complexity of eating disorders and of diabetes. However, ongoing review and redefining of the term has increased our understanding of the contexts in which the problem exists, including those of both generic disordered eating behaviours and of those specific to diabulimia.

Prevalence rates

Whilst eating disorders are acknowledged as a major problem, diabulimia has not been formally recognised either as a medical or psychiatric diagnosis and, as such, is often overlooked and under-reported (Nezami et al, 2018). As a consequence, there are few statistics on prevalence, patient profiles and demographics, onset or types of related eating disorders. The general understanding is that approximately 20% of women with type 1 diabetes may have this condition in the UK (Chelvanayagam and James, 2018; Chandran et al, 2018; van Heynigen, 2018).

It is important to note that there is often significant weight loss in people diagnosed with

diabetes, and since successful treatment necessitates a recovery of weight loss or temporary weight gain, the diagnosis itself becomes a potential trigger for disordered eating (particularly for those with a pre-existing vulnerability to or existing eating disorder). This may further contribute to its under-reported or unknown prevalence, and must be considered as part of any management strategy (see **Detection of symptoms**).

American diabulimia websites suggest that of the 26 million people in the US diagnosed with diabetes, at least 30% of females and about 17% of males have had an eating disorder at some point. Studies have reported people between the ages of 13 and 60 years affected by diabulimia. Regardless of sex, approximately 30% of adolescents with type 1 diabetes will present with symptoms, and young people who have negative attitudes towards their medical conditions are more likely to exhibit disordered eating behaviours in general. Further, adolescents experiencing diabetes burnout (the frustration with and subsequent negligence in managing type 1 diabetes) are also far more likely to develop diabulimia.

As with all eating disorders, females are more likely to develop diabulimia than males. Nearly 40% of females with type 1 diabetes exhibit diabulimia behaviours, while about 17% of males do (Hull, 2022; Hunnicutt, 2022).

The effects of diabulimia

The effects of diabulimia result from the impact of having an eating disorder and from the restriction of insulin in the management of diabetes.

They include micro- and macrovascular complications, dehydration, high blood glucose levels, electrolyte imbalance, heart attack, stroke, vision problems, kidney disease, nervous system dysfunction and infertility. Evidence suggests that people with diabulimia have a reduction in life expectancy of 13 years compared to those with diabetes only (Nezami, 2017; Chelvanayagam and James, 2018; Hull, 2022).

Solely regarding the restriction of insulin, people may be affected by a loss of muscle tissue, reduced immune system function, frequent bacterial or yeast infections, temporary or permanent eye damage, and pain, tingling or numbness of the limbs (Hunnicutt, 2022).

Risk factors

There are a number of risk factors associated with the development of diabulimia (Hoffman, 2019; NEDA, 2019). These include:

- **Biological**. Having a close relative with an eating disorder or a mental health condition; a history of dieting; burning more calories than are being taken in; and a diagnosis of type 1 diabetes.
- **Psychological**. Perfectionism; body image dissatisfaction; a personal history of trauma, neglect or abuse; a history of anxiety disorder; and behavioural inflexibility.
- **Social**. Weight stigma; teasing or bullying; internalisation of the appearance ideal; acculturation; limited social networks; and historical trauma.

This list is not comprehensive, and the problems may or may not exist co-dependently with other eating disorders. The diagnosis of diabetes and its related weight changes create an underlying additional challenge for people, which may serve to fuel any pre-existing disordered eating.

Symptom management recommendations

Screening

Whilst a wider management plan necessitates screening, due to the absence of a formalised diagnosis there are no directly relevant screening tools (Shaban, 2013).

Research studies developing an evidence base have used a range of criteria (such as anxiety and depression, mood disorders, obsessive thinking, eating disorders, diet and diabetes, and body image) to capture aspects of the problem (Ruth-Saad and Haagen, 2009; Mafi et al, 2016; Falcoa and Francisco, 2017; Sahir-Bodur, 2021).

In the absence of a formal definition and with varying treatment plans, accurate screening for diabulimia is not possible. However, the ongoing and evolving evidence base will provide clarity to both.

Management recommendations

Research has concluded that the core elements of management are training staff to raise their awareness of the condition, and to address its psycho-medical aspects in the wider context of

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public awareness. A collaborative response from mental and physical health services is advocated.

The training should focus on symptom detection and recognition, exploring and assessing reasons for variable glycaemic control and weight changes as well as low mood (depression or flat affect), and awareness on the specific issues facing patients with diabulimia, allowing for wider socio-cultural influences (Ruth-Sahd and Haagen, 2009; Dieana et al, 2016; Hastings et al, 2016; Nezami et al 2018; Brookes, 2018; Chelvanayagam and James, 2018; Coleman and Caswell, 2020; Goddard and Oxlade, 2022).

Regarding specific interventions, the core components should include psychoeducation to communicate information about the dangers of diabulimia; medical evaluation to identify serious physical ailments; motivational interviewing; and CBT in the context of the individual, group and family (Hunnicutt, 2022).

Shaban (2013) states that diabetes teams require not only heightened awareness of diabulimia, but also the confidence to ask relevant questions. She suggests that teams require in-house specialist psychological services to manage issues specific to diabetes, ensuring that difficulties can be addressed as an integral part of diabetes management. Only severe cases would be referred to an external eating disorder service.

The situation remains complex and with no easy solutions. Management strategies continue to evolve alongside our understanding of the condition, to which ongoing awareness and patient-centred conversation is key.

Detection of symptoms of disordered eating in people with diabetes

In considering the following suggestions, it is important to note the physiological impact of weight changes for people with diabetes. Given that prior to diagnosis there is often significant weight loss, insulin therapy will necessarily restore health and involve the restoration of weight loss or temporary weight gain. Staff must contextualise this information and inform patients of it in a positive way (i.e. the treatment is working). In and of itself, this may open up a discussion for patients to share concerns or beliefs around their weight.

Patient psychological and behavioural clues

Hull (2022) highlights a number of verbal and psychological pointers that may support healthcare staff in identifying the potential development of diabulimic thinking and behaviour. These include:

- Praising the appearance of people who are underweight.
- Focusing conversations on food, weight or calories.
- Expressing concerns about weight or appearance.
- Talking about insulin's effects on weight.
- Exhibiting signs of depression or anxiety.
- Isolating and avoiding social activities.
- Being secretive about insulin use.
- Avoiding medical appointments.
- Refusing to eat in front of others.

Staff psychological and behavioural triggers

People with eating disorders may be alerted to the responses they get to critical comments about others' weight or appearance, thereby reinforcing their internal narratives about how other people judge them based on their weight (Hull, 2022). This is a stark reminder for healthcare professionals to be mindful about trivialising changes in weight. Staff should be aware of :

- Comments or actions that invalidate or overlook the seriousness of disordered eating or distress, thereby normalising the problem.
- Judging severity and need for support solely on medical measures (e.g. weight or blood tests), thereby trivialising or missing the point of diabulimia.
- A lack of compassion, leading patients to refer to unhealthy existing coping strategies.
- Weight stigma encouraging a limited picture of healthy body shape.
- Making assumptions about what is or isn't distressing or challenging, thereby missing the link between eating and coping with distress (be it primary or secondary consequences of an emotional or practical trigger).

Considerations when responding to concerns

Lazenby (2022) offers us specific guidance on responses to avoid when concerned about disordered eating in our patients:

- Weight or appearance comparisons: "It's not that bad"; "You don't look like you have an eating

disorder"; "Have you lost/gained weight?"; "You look XYZ!"

- Comments about your own diet or exercise in the context of empathy: "I know what you mean – I'm watching my weight"; "I had a big takeaway last night, so I need to go to the gym today"; "I've been eating lots of biscuits recently"; "I've been naughty...".
- Judgemental or loaded comments about food, eating, weight or exercise: "Sugar is bad"; "You've been 'good' [when weight or calories are reduced]".
- Intrusive comments about behaviours asked insensitively and loaded with assumption: "So, do you make yourself sick?"; "So, do you not eat anything at all?"
- Comments that invalidate the distress caused by the eating disorder or fail to understand how hard it can be to recover: "Why don't you just eat?"; "Wow! You ate that much?"; "Didn't you feel full?"

These recommendations are significant in guiding staff away from barriers to a progressive discussion and towards more constructive dialogue (i.e. turning the focus of patient interaction to strengthening the relationship between health, dietary regimens and effective coping strategies).

Barriers to treatment

People with diagnoses of disordered eating and of diabetes are often involved with two different services. Given that one may be part of acute services and the other part of mental health, there is potential for important information to be missed. As acute and mental health services work within different systems, and access to shared notes is not always possible, there is an onus on staff to reach out actively across services to ensure consistency of information that may be impacting on either, or both, diagnoses.

This may be further complicated if a patient is moved between services for young people and adults. The result can be increased vulnerability or risk, and the need for the individual to regain or increase control of their situation, thereby further increasing disordered eating behaviours. Accepting the already highly pressured environments in which healthcare professionals are working, staff may be unable to access relevant information, or may require extra time to gather information to fill any gaps between services.

Conclusion

Diabulimia is a growing problem. With little formal recognition of the diagnosis, the onus is upon healthcare professionals to address issues at a local level with individual patients. Central to actioning changes in practice is the reality of competing clinical priorities in the wider context of treating a diagnosis that has not been clinically formalised, thus potentially marginalising the impact of diabulimia-specific patient needs. The situation is unlikely to change until diabulimia is given greater attention, and national clinical guidance is offered on diagnosis and treatment processes in conjunction with an active psychoeducational teaching and training programme. ■

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