Understanding poor outcomes in women with type 1 diabetes and eating disorders

Jacqueline Anne Allan

Although it has been debated for many years, there is now a general consensus that there is an increased incidence of eating disorders in people with type 1 diabetes. With the addition of insulin omission as a clinical symptom in both anorexia nervosa and bulimia nervosa in the DSM-V (*Diagnostic and Statistical Manual of Mental Disorders, fifth edition*), incidence rates may increase even further. People with eating disorders and diabetes develop debilitating complications at a younger age, show a higher rate of disengagement with healthcare teams, are harder to treat and have a significantly higher mortality rate. Little is known, however, about why eating disorders are more common in this demographic or why people with eating disorders are much more difficult to treat. Using an online questionnaire, 98 people with type 1 diabetes and an eating disorder were surveyed in order to determine if they have comorbid psychiatric diagnoses and which terminology they use to describe their eating disorder. This article describes the findings of this survey and discusses the importance of having correct diagnostic terms for eating disorders in people with diabetes.

The onset of physical illness is a well-known risk factor for the development of mental conditions. There are reportedly higher rates of depression (Anderson et al, 2001), anxiety (Grigsby et al, 2002) and emotional instability (Rassart et al, 2014) among people with type 1 diabetes. Eating disorders are also associated with high rates of comorbid mental pathology and substance abuse (Striegel-Moore and Bulik, 2007).

The comorbidity of eating disorders with type 1 diabetes represents a notoriously difficult combination to treat effectively, which may be further complicated by the presence of other psychiatric diagnoses. It has been reported that this demographic does not respond well to standard treatment for eating disorders, and even when there appears to be an improvement in psychological well-being, this does not relate to an improvement in glucose management (Olmsted et al, 2002). Any treatment model that does not allow for comorbidities, as well as diabetes-specific factors, may be ineffective.

An additional barrier to effective treatment may be the way these individuals categorise themselves. The colloquial nomenclature for using insulin omission for weight control is "diabulimia", although this is not an academic or clinical term. Regardless, it has been adopted by the diabetes community and it is how they refer to this practice. The issue of

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Article points

1. The comorbidity of eating disorders with type 1 diabetes represents a notoriously difficult combination to treat effectively, which may be further complicated by the presence of other psychiatric diagnoses.
2. This article describes a study that was carried out to ascertain the psychiatric characteristics of those with type 1 diabetes who are recovering from an eating disorder and to investigate their attributions in regard to diagnosis.
3. This small study shows that those with type 1 diabetes and an eating disorder (or those who deliberately omit insulin for weight control) are likely to have multiple psychiatric morbidities that can further complicate treatment.

Key words

- Diabulimia
- Eating disorders
- Insulin omission

Authors

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Page points

1. The term "diabulimia" may be problematic as many healthcare professionals do not recognise it but the action of insulin omission for weight loss purposes is very common and very serious.
2. Those who omit insulin have significantly higher rates of diabetes complications, such as retinopathy and nephropathy, and a much higher mortality rate.
3. This study involved 98 participants with diabetes who answered questions relating to eating disorders and other mental health difficulties.

different terminology may partially account for treatment difficulties within this demographic. People have reported approaching healthcare professionals with this self-diagnosis only to be told that diabulimia "doesn't exist" or was "made up on the Internet" (www.dwed.org.uk). The term may be problematic but the action of insulin omission for weight loss purposes is very common, with researchers reporting an incidence of up to 40% of 15–30-year-old females with type 1 diabetes using this mechanism to facilitate weight loss (Fairburn et al, 1991). Regardless of the diagnostic term, or lack thereof, the practice is incredibly dangerous. Those who omit insulin have significantly higher rates of diabetes complications, such as retinopathy and nephropathy (Rydall et al, 1997) and, therefore, cost the NHS considerably more than people with diabetes but without eating disorders. Furthermore they have a much higher mortality rate (Goebel-Fabbri et al, 2008).

This article describes a study that was carried out to ascertain the psychiatric characteristics of those with type 1 diabetes who are recovering from an eating disorder and to investigate their attributions in regard to diagnosis.

Method

Ethical approval was obtained from Birkbeck College (University of London). Participants were recruited for the study via the registered charity, Diabetics with Eating Disorders (DWED), with use of their social media pages. The study recruited 95 females and 3 respondents who did not wish to state their gender. All participants had been in recovery for at least 2 years, which is a recommendation of the eating disorder charity, B-eat, for inclusion in research.

Participants were asked to follow a link to the questionnaire, read a study brief and provide their consent to the briefing. They were then advised to allow 10–20 minutes in a quiet environment to fully complete an online questionnaire. This questionnaire was developed using an online survey tool (www.questionpro.com) and consisted of 17 items, which were designed specifically for this survey.

For each question, the participants were able to select a "prefer not to say" option. Participants were asked to respond to the following open-ended questions:

- How old are you?
- What gender are you?
- At what age were you diagnosed with type 1 diabetes?
- What nationality are you?
- Do any other family members have type 1 diabetes?
- If so, what is their relationship to you?
- Have you ever received an official eating disorder diagnosis?
- If so, what was the diagnosis?
- Have you ever received another mental health diagnosis?
- If so, what was the diagnosis?
- How long after your diabetes diagnosis did you develop an eating disorder?
- Did you manipulate or omit insulin?
- Do you think that you had any of the following?:
  - Anorexia.
  - Bulimia.
  - Diabulimia.
  - A combination of bulimia and diabulimia.
  - A combination of anorexia and diabulimia.
  - A combination of anorexia and bulimia.
  - A combination of all three conditions.
  - Eating disorder not otherwise specified (EDNOS).
- In the time that you had your eating disorder, did you seek professional help?
- If so, which of the following did you approach?:
  - GP.
  - DSN.
  - Diabetic consultant.
  - Dietitian.
  - Eating disorder specialist.
  - Other health professional (please state).
- Have you experienced bullying because of your weight?
- Have you experienced bullying because of your diabetes?

Results

Demographics

In total, 98 participants responded to the advert and completed the questionnaire. As

mentioned, three of the respondents did not wish to state their gender and 95 were female. Respondent age ranged from 18 to 65 years, with a mean age of 28.49 (standard deviation [SD]=9.66).

Age of onset

The age at which respondents were diagnosed with type 1 diabetes ranged from 0–45 years old, with a mean age of 11.9 (SD=8.98). The age at which they felt they were developing an eating disorder ranged from 7–45 years, with a mean age of 16.96 (SD=7.06). The average time between diagnosis of type 1 diabetes and onset of an eating disorder was 4.76 years (SD=4.7), but ranged from 0–19 years.

Insulin manipulation, diabulimia and eating disorder diagnosis

Ninety-four of the 98 respondents (95.9%) had omitted or manipulated insulin during their eating disorder. Four believed they had anorexia (4.1%); 27 believed they had diabulimia (27.5%); 19 believed they had a combination of bulimia and diabulimia (19.4%); 18 believed they had a combination of anorexia and diabulimia (18.4%); and 28 believed that they had a combination of all three conditions (28.6%). None reported a diagnosis of bulimia or "eating disorder not otherwise specified" (EDNOS). Two participants did not respond (2.04%). Data are shown in *Figure 1*.

Despite all of the respondents feeling that they did have an eating disorder, 38 participants had never been diagnosed with one (38.8%). Of those who had been diagnosed, 22 had been given a diagnosis of bulimia nervosa (22.4%), nine had been given an diagnosis of anorexia nervosa (9.2%), 13 had received an EDNOS diagnosis (13.3%), 10 had been given dual anorexia and bulimia nervosa diagnoses (10.2%), four had dual diagnoses of bulimia and EDNOS (4.1%) and two had been given a triple diagnosis of bulimia, anorexia and EDNOS (2%).

Other diagnoses

A total of 76 (77.6%) of the participants had been diagnosed with a mental health illness. Of these, 58 (59.18%) had been diagnosed with depression; 20 (20.34%) with anxiety; 19 (19.5%) with personality disorders; three (3.06%) with bipolar disorder; one (1.02%) with

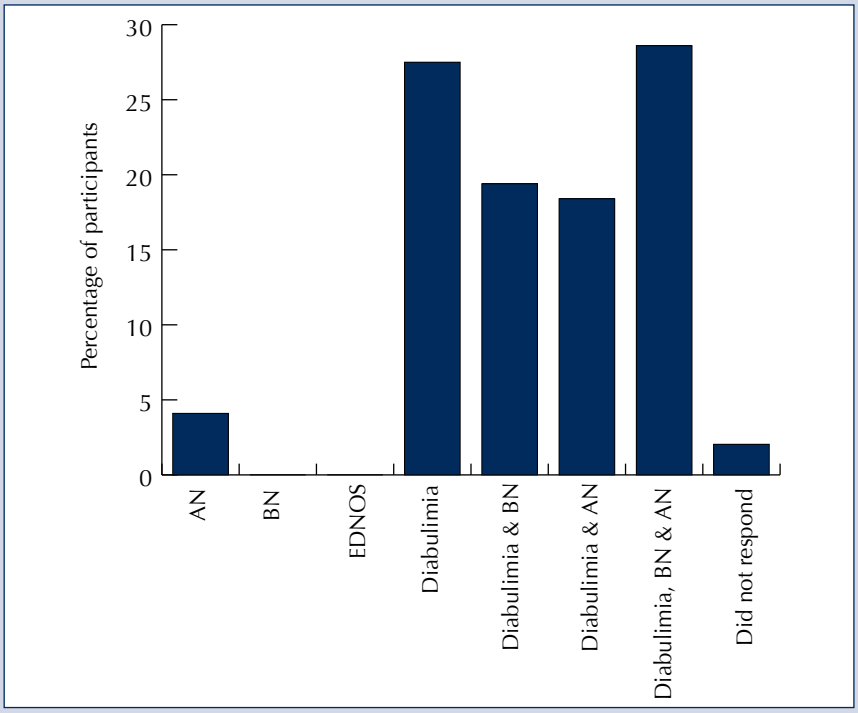

Figure 1. Participant reported beliefs about eating disorder (AN=anorexia nervosa; BN=bulimia nervosa; EDNOS=eating disorder not otherwise specified).

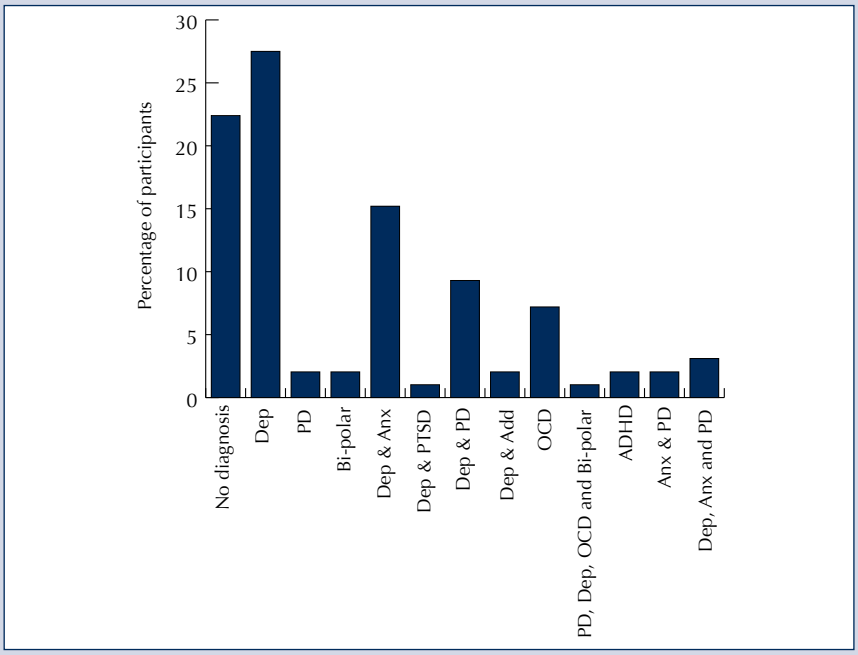

Figure 2. Percentage of participants diagnosed with mental health disorder (Dep=depression; PD=personality disorder; Anx=anxiety; PTSD=post-traumatic stress disorder; Add=addiction; OCD=obsessive compulsive disorder; ADHD=attention deficit and hyperactivity disorder).

Page points

1. This study found that other mental health diagnoses were more common in people with diabetes and eating disorders.
2. Diabetes clinicians tend to find it harder to manage those with type 1 diabetes and an eating disorder and feel that they lack training in the area. Individuals with many comorbidities present an even more significant challenge.
3. Binge-eating disorder has its own classification in the DSM-V and it could be argued that, on this basis, diabulimia, or another formal diagnostic term relating to the deliberate manipulation of insulin for weight control purposes, may also warrant its own diagnostic criteria.

post-traumatic stress disorder; two (2.04%) with an addiction; eight (8.30%) with obsessive compulsive disorder and two (2.04%) with attention deficit hyperactivity disorder.

Further analysis showed that 27 were diagnosed with depression only (27.5%), two had personality disorder only (2.04%) and two had bipolar disorder only (2.04%). Fifteen participants had both depression and anxiety (15.2%); one had depression and post-traumatic stress disorder (1.02%); nine had depression and personality disorder (9.3%); two had depression and addiction (2.04%); seven had obsessive compulsive disorder alone (7.2%) and one had personality disorder, depression, obsessive compulsive disorder and bipolar disorder (1.02%). Two people had attention deficit hyperactivity disorder (2.04%), two had anxiety and personality disorder (2.04%) and three had depression, anxiety and personality disorder (3.1%). See *Figure 2* (previous page).

Discussion

As found in the non-diabetic population of those with eating disorders (Hudson et al, 2007), this study showed there were comorbidities with most of the core DSM-V (*Diagnostic and Statistical Manual of Mental Disorders, fifth edition*) mood, anxiety and personality disorders. The results showed that the majority (77.6%) were formally diagnosed with another psychiatric condition and the majority of the sample had been diagnosed with multiple disorders. This may make treatment for this demographic even more difficult. It has long been understood that emotional issues mediate blood glucose control (Simonds et al, 1981). For the person with an eating disorder and borderline personality disorder, for example, insulin misuse not only facilitates weight loss but is also a self-destructive behaviour. Combine that with the tendency to form unstable relationships and clinically these individuals represent a very challenging treatment prospect that diabetes teams may not be skilled in (Leichter and Dreelin, 2005). Furthermore, there is the issue of practitioner engagement; clinicians find those with type 1 diabetes and an eating disorder harder to manage and feel that they lack training in the area (Tierney et al, 2009). Individuals with many comorbidities present an even more significant challenge.

A very interesting finding of this small study is that, when asked to indicate which eating disorder they had, all but four of the participants replied "diabulimia". What may be even more important is that a number of participants thought they had a combination of eating disorders including diabulimia, showing that there is a distinction between the act of insulin omission and that of dietary restriction or classical binge/purging. None of the participants felt that they had EDNOS or bulimia, which are terms that have been used to describe the act of insulin omission frequently in academic research (Nielsen 2002; Takii 2002; Young-Hyman and Davis, 2010). There is an obvious disconnect between what an individual feels they have and what they are actually being diagnosed with, which may further explain why these individuals are resistant to standard eating disorder treatment.

It is also notable that all participants who identified their gender were female. It may be that the other three participants were, in fact, male and that this is further illustrative of the increased stigma around men with eating disorders. Alternatively it could be because recruitment was largely from online social networks that are predominantly female occupied. Further research focusing on males should be a priority.

Binge-eating disorder has its own classification in the DSM-V and it could be argued that, on this basis, diabulimia, or another formal diagnostic term relating to the deliberate manipulation of insulin for weight control purposes, may also warrant its own diagnostic criteria.

Diabulimia may have diabetes-specific roots separating it etiologically from anorexia and bulimia, and this may explain some of the problems in treating it within those paradigms. To judge severity using weight or episodic frequency criterion rather than HbA_{1c} is problematic (Allan and Nash, 2014), further justifying the need for a distinct classification. To treat insulin omission in the same way as

other clinical features is potentially dangerous.

Conclusion

Those with type 1 diabetes and an eating disorder (or those who deliberately omit insulin for weight control) are likely to have multiple psychiatric morbidities that can further complicate treatment. These individuals also attribute their illness, or at least the practice of insulin omission, to "diabulimia". These aspects must be taken into consideration when both diagnosing and treating eating disorders in people with type 1 diabetes.

NICE clinical guidelines state that healthcare professionals dealing with those with type 1 diabetes should maintain a high index of suspicion for eating disorders. Furthermore, they recommend immediate referral to psychological services. In practice, there seems to be an issue as to where to refer these people. Although resources exist via charities such as DWED, there appears to be no consensus on how to treat these individuals, which is made even more complicated by the high rates of multiple comorbidities.

The charity DWED recommends that DSNs become part of a multidisciplinary team and liaise with psychological services frequently. It may be that their patients are attending programmes that do not understand the mechanisms of insulin omission. Good communication between everyone involved may lessen the risk of these people being treated inappropriately.

Healthcare professionals working with people with diabetes and eating disorders can direct patients to the DWED website (www.dwed.org.uk). Both healthcare professionals and people with eating disorders may benefit from reading the book, *Skills-based Learning for Caring for a Loved One with an Eating Disorder* (Treasure et al, 2007). ■

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