Diabetes and eating disorders: Update to the NICE guideline

Jacqueline Allan

The latest NICE guidance on the management of type 1 diabetes acknowledges the increased risk of eating disorders in this population. The updated guideline on eating disorders, due to be published in May 2017, is expected to follow suit, with subsections on type 1 diabetes added for all categories of eating disorder. In this article, the author reviews the diabetes-related advice that has been added in the draft guideline. While these updates are welcome, some concerns remain. This critique aims to stimulate further thought about these issues, both for practitioners and prior to publication of the final guidance.

It is well established that eating disorders are more common in people with type 1 diabetes. Despite increasing awareness of the prevalence of eating disorders and the importance of considering insulin omission when diagnosing them, there has been a distinct lack of advice for healthcare professionals on how to deal with these complicated dual diagnoses. This has been partly addressed by updates to NICE guidelines and quality standards for type 1 diabetes, both in children and young people and in adults. The guidelines feature psychological support more than ever before, and they specifically note the increased prevalence of eating disorders and the potential for insulin omission in people with type 1 diabetes.

In addition to the diabetes guidelines, updated guidance on eating disorders is due for release in May 2017. The new guideline follows suit, with whole sections on diabetes added for the first time. While these updates are welcome and validate the unique issues faced by this demographic, it is still necessary to critically evaluate the guideline and make recommendations for the future. The latest draft has been shared with stakeholders and, while there are likely to be substantial changes before the final publication, there are a number of issues that deserve comment.

Diagnosis

Diabetes first appears in the guideline in the statement that people with type 1 diabetes are a high-risk population, mostly because they are more prone to serious complications as a result of eating disorders. As such, risk management should be the first priority. The guideline then suggests that screening for eating disorders in those with particular risk factors, such as type 1 diabetes, should be considered as a matter of course. This raises a problem, however, as there is no current consensus on appropriate screening tools for eating disorders in people with type 1 diabetes. Hopefully, the inclusion of this advice in the guideline will encourage future research into screening measures, or at least a general agreement on how current instruments should be adapted to account for issues such as insulin omission.

Management and treatment

Type 1 diabetes as a comorbidity has specific sections under treatment for all categories of eating disorder: anorexia, bulimia, binge eating disorder

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Article points

1. The NICE guideline on the management of eating disorders is due to be published in May 2017.
2. The draft guideline features, for the first time, specific sections on eating disorders in the context of diabetes.
3. Recognition of the risks associated with insulin omission and recommendations for collaborative care between the diabetes and eating disorder teams are welcome.
4. However, some issues remain, and it could be argued that diabetes-related eating disorders belong in a category of their own.

Key words

- Clinical guidelines
- Eating disorders
- NICE
- Type 1 diabetes

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1. The new draft NICE guideline on eating disorders now has subsections on diabetes for all categories of eating disorder.
2. Diabetes and eating disorder teams are advised to work in collaboration to treat both conditions, and to use outcome measures such as HbA_{1c}, not just BMI, to monitor the effectiveness of treatment.
3. A specific treatment plan, including structured diabetes education, is outlined for people who are misusing insulin.

and eating disorders not otherwise specified (EDNOS). The guidelines under all are identical:

1. Eating disorder specialists and other care teams should collaborate when caring for people with physical or mental health comorbidities that may be affected by their eating disorder.
2. When collaborating, teams should use outcome measures for both the eating disorder and the physical and mental health comorbidities, to monitor the effectiveness of treatments for each condition and the potential impact they have on each other.
3. Eating disorder teams and diabetes teams should collaborate to explain the importance of physical health monitoring to people with an eating disorder and diabetes.
4. Consider involving family members and carers (as appropriate) in the treatment programme to help the person with blood glucose control.
5. Agree between the eating disorder and diabetes teams who has responsibility for monitoring the physical health of people with an eating disorder and diabetes.
6. Explain to the person and their diabetes team that they may need to monitor their blood glucose control more closely during the treatment for the eating disorder.
7. Address insulin misuse as part of any psychological treatments for eating disorders in people with diabetes.
8. Offer people with an eating disorder who are misusing insulin the following treatment plan:
   - A low-carbohydrate diet, so that insulin can be started at a low level.
   - Gradually increasing insulin doses to reduce blood glucose levels.
   - Adjusted total glycaemic load and carbohydrate distribution to meet their individual needs and prevent rapid weight gain.
   - Carbohydrate counting when adjusting their insulin dose (including via pumps).
   - A diabetes educational intervention, such as Dose Adjustment for Normal Eating (DAFNE).
   - Education about the problems caused by misuse of diabetes medication.
9. For more guidance on managing diabetes, refer to the NICE guidelines on type 1 and type 2 diabetes in children and young people, type 1 diabetes in adults and type 2 diabetes in adults.

Comments

Collaborative care

A multidisciplinary approach to dealing with eating disorders in people with type 1 diabetes has been advocated in the research literature both historically and more recently (Peveler and Fairburn, 1989; Colton et al, 2015). Practically, however, patients have complained that this type of professional collaboration is rare (Hastings et al, 2016). This is particularly important as advice for standard eating disorders (such as employing a more relaxed attitude to food, being less focused on nutritional labels and being less rigid around timings) may be in direct contradiction with advice for managing blood glucose. If specialists in one condition do not understand the ramifications of the other, then advice could be confusing and hinder, rather than help, the recovery process.

The recommendation for multidisciplinary teams to use specific health outcomes for both the eating disorder and diabetes is another welcome addition as, historically, HbA_{1c} has not been considered as important as BMI. Indeed, in most research papers on the issue, HbA_{1c} has been absent entirely as an outcome measure, as stated in the draft guidelines themselves:

> *"No data was available on HbA_{1c} scores, remission, weight, all-cause mortality, adverse events, quality of life, resource use, relapse, general psychopathology, general functioning, family functioning or service user experience."* (page 411)

Taking HbA_{1c} outcomes into account will also, hopefully, widen treatment access to this demographic, who are often denied support by merit of a "normal" BMI, regardless of often dangerously high HbA_{1c} levels.

The recommendation that the importance of physical health monitoring should be "explained" to patients is potentially problematic, and similar issues arise with "explaining" to patients that they may need to monitor their blood glucose control more closely during the treatment for the eating disorder. People with type 1 diabetes can usually be considered "expert patients", and to repeat the consequences of mismanagement

and the need for monitoring may seem condescending or patronising, as these people know the consequences of their actions more than most (Diabetics with Eating Disorders, 2010). Given that this group often feels marginalised by healthcare professionals, highlighting such issues may widen the divide between patient and professional (Hastings et al, 2016). It also should be apparent that anyone involved in eating disorder behaviours who also has type 1 diabetes should be cared for by a specialist clinic, whereby such issues are discussed as a matter of course. The obvious exception to this are patients who have disengaged with their diabetes teams and may be seen only and sporadically in primary care, if at all. Under these circumstances, highlighting the importance of physical health monitoring may be appropriate.

Involving family members in treatment for both eating disorders and type 1 diabetes is fairly standard, but it should be considered that family problems are a risk factor for the development of eating disorders (Striegel-Moore and Bulik, 2007), and conflict over the management of type 1 diabetes and related poor glycaemic control is common (Anderson et al, 2002). Therefore, in some cases, familial involvement could ignite further issues.

Further issues arise when deciding who between the eating disorder and diabetes teams should have responsibility for monitoring the physical health of people with type 1 diabetes and eating disorders. Given that so much of each area is highly specialised, it is understandable that one team should take the lead. That said, there is so much in type 1 diabetes that diverges from the standard physical monitoring in people with eating disorders – not just blood glucose, ketones and HbA_{1c}, but also cerebral oedema, rapid onset of complications and glucose toxicity, to name a few – that it seems most appropriate to have the diabetes team take the lead.

Insulin misuse

Including insulin omission as part of any psychological treatment may appear to be an obvious addition, but issues arise again when there is no suggestion of how to implement or evaluate this. Given that insulin omission is incredibly common in people with type 1 diabetes, with an estimated prevalence of around 40% in women in particular, and new evidence suggesting that 11% of adolescent males are affected (Fairburn et al, 1991; Hevelke et al, 2016), treatment recommendations are now imperative. That said, the fact that insulin omission is mentioned at all is potentially life-changing for those people for whom insulin omission comprises their primary eating disorder behaviour but who are treated as if this is not the case. The inclusion of this in the guideline should hopefully bring attention to the lack of research and, thus, treatment options. Similarly, the addition of a treatment plan that focuses on insulin omission will no doubt have a significant impact for patients.

Structured education

The fact that the draft guidance takes into account issues around carbohydrates, carbohydrate counting and weight gain further validates assertions that people with type 1 diabetes require a highly individualised approach that takes their diabetes-specific needs into account. However, there are issues with the treatment plan, particularly the recommendation that patients attend a DAFNE course. DAFNE improves outcomes in many people with type 1 diabetes; however, its efficacy in those with an eating disorder has no evidence base. This recommendation may be appropriate at some stages of recovery, but there is no research to support it as part of an initial plan. Given that DAFNE takes place in groups and involves activities such as group dosing and group eating, this course of action may be inappropriate and cause further problems, not least of which may be complications associated with rapid tightening of control.

Looking ahead

The guideline review committee members ask the question "Does any intervention for an eating disorder need to be modified in the presence of common long-term health conditions?". They go on to consider evidence from a number of studies but conclude that none of the research is appropriate to draw any conclusion from. It is notable that this assumption is made for all categories of eating disorder with comorbid diabetes. Therefore, it could be argued that, as we are aware that standard treatments rarely show

Page points

1. A number of issues in the draft guidance have been identified, including the recommendations to "explain" the need for additional blood glucose monitoring, involve the patient's family in management and refer patients to structured diabetes education. This may not be appropriate for all people.
2. The issue of insulin omission in the guidance is a welcome addition; however, it also highlights the lack of an evidence base for treatment recommendations.

Page points

1. It could be argued that diabetes-specific eating disorders require their own categorisation.
2. "Diabulimia" is a term that, although not recognised as a diagnosis, appears to resonate with patients and may be appropriate to include in the guideline.

efficacy, especially in regard to HbA_{1c} levels, a new paradigm is warranted. The panel conclude that:

> *"The ideal study design to answer the question of whether a treatment for eating disorders needs to be modified in the presence of a long-term health problem would be to randomise people with an eating disorder and diabetes to two different treatment groups: one modified to address both the eating disorder and diabetes and one non-modified eating disorder treatment."* (page 411)

Inclusion of this discussion in the guidelines will hopefully ignite interest among researchers and funders, especially as the committee also highlights that the resource needs of people with type 1 diabetes and eating disorders increase as issues go unaddressed.

The new guideline demonstrates positive progression towards recognition that eating disorders in people with type 1 diabetes, and insulin omission specifically, pose a unique problem. Although a few particular concerns remain, the guideline constitutes a new framework from which further advancements can be made. One may ask, however, why type 1 diabetes-related eating disorders are not in a category of their own. The advice for each category of eating disorder (anorexia, bulimia, binge eating disorder and EDNOS) is modified in exactly the same way for people with type 1 diabetes, including the addition of advice on insulin omission. This suggests that eating disorders in people with type 1 diabetes are fundamentally distinct from eating disorders in the general population. Further support for this view comes from the drastic alterations to standard physical monitoring that are needed in this population.

Another potential problem is the omission of the term "diabulimia". This term is problematic for a number of reasons, not least of which is the fact that diabulimia is not a clinical diagnosis and there is no consensus on the term's use. Patients, however, identify with it. In a recent study in which women with type 1 diabetes who were in recovery from an eating disorder were asked "what type of eating disorder do you think you had?", 27.5% believed they had diabulimia, 19.4% believed they had a combination of bulimia and diabulimia, 18.4% believed they had a combination of anorexia and diabulimia, and 28.6% believed that they had a combination of all three conditions (*Figure 1*; Allan, 2015). Only 4.1% believed they had anorexia nervosa and none reported singular bulimia or EDNOS. This suggests that the patients themselves view the act of insulin omission as behaviourally distinct from binging and purging or restricting. As such, they identify with the term diabulimia and, whether or not clinicians or researchers feel the term is appropriate, this is how patients may present in clinic or at the GP. At the very least, healthcare professionals dealing with eating disorders and type 1 diabetes should be aware and prepared. The inclusion of the term diabulimia in the guidelines would facilitate such awareness and should, therefore, be encouraged.

Alternatively, perhaps it is time that there was some consensus around how we screen, diagnose and treat eating disorders in this population that acknowledges the specific biological and psychological ramifications of type 1 diabetes which are so inherently tied to the

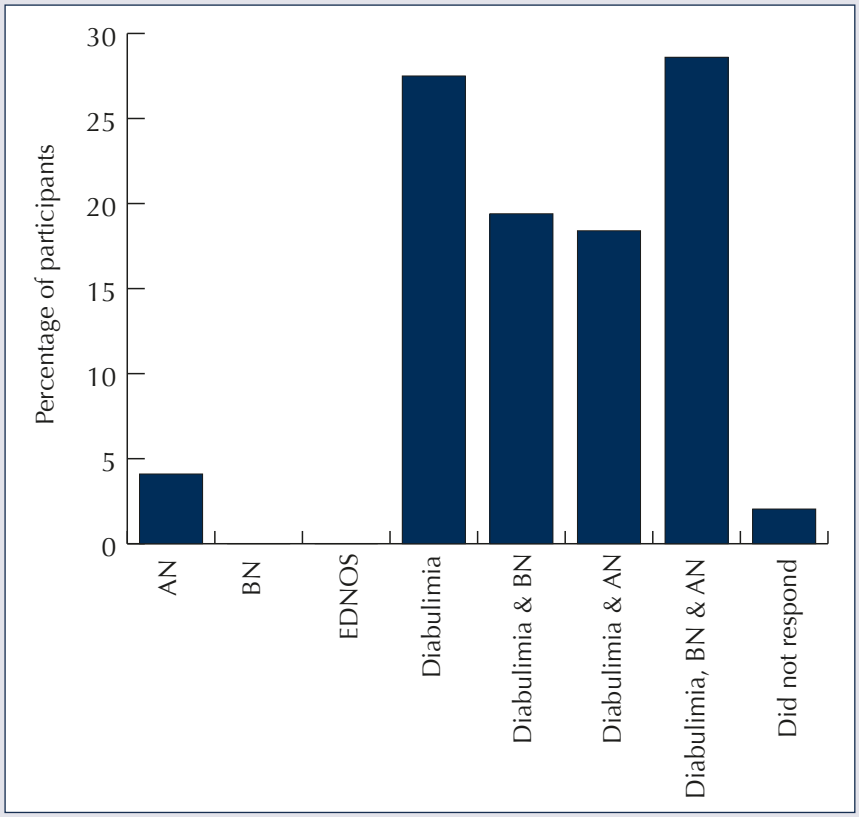

Figure 1. Participants' self-labelling of their eating disorder (n=98; Allan, 2015). *AN=anorexia nervosa; BN=bulimia nervosa; EDNOS=eating disorder not otherwise specified).*

development and maintenance of the disorders. Such a nomenclature could then separate this demographic into their own criteria and specify the type of eating disorder by behaviour (e.g. restricting, binging/purging, insulin omission, etc.). This would provide further clarification as to what is needed in terms of treatment and validate patient opinion, while avoiding the problematic term of diabulimia.

Concluding remarks

The addition of type 1 diabetes and insulin omission in such a comprehensive manner to the NICE eating disorder guideline is representative of a cultural shift towards recognising the magnitude of this problem. Mounting political pressure from MPs such as George Howarth and MSPs such as Dennis Robertson, the continued efforts of the charity Diabetics with Eating Disorders, spearheading clinicians such as Professor Janet Treasure and Professor Khalida Ismail, and the emerging support of the larger charities such as Diabetes UK and Beat indicate that we are moving towards a more specialised approach to type 1 diabetes-related eating disorders. ■

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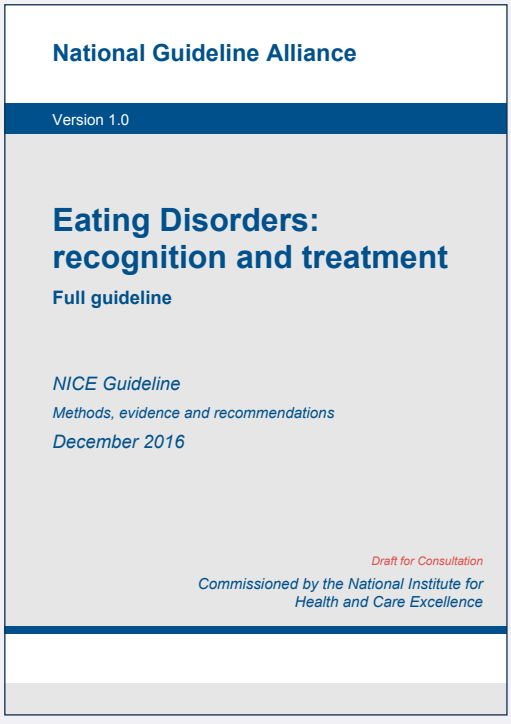

About the guideline

This article is based on the draft guideline presented for consultation in December 2016. Based on comments from stakeholders, the final guidance, due to be published in May 2017, may differ from the draft.

The full draft guidance can be accessed at: **https://www.nice.org.uk/guidance/GID-CGWAVE0703/documents/draft-guideline**