Healthcare professional awareness of eating disorders in people with type 1 diabetes: a staff survey

SARAH BREWSTER,1 HELEN PARTRIDGE,2 CAROLINE CROSS,3 HERMIONE PRICE1

Abstract
Background: People with type 1 diabetes are at increased risk of eating disorders. ‘Diabulimia’ is a term used in academic literature and social media to describe insulin omission/restriction in type 1 diabetes for fear of weight gain. The condition is associated with a significant increase in morbidity and mortality.

Aim: To determine healthcare professional awareness and knowledge of eating disorders in type 1 diabetes.

Method: A short, cross-sectional, online healthcare professional survey across primary, secondary and community settings.

Results: The study will report in 2020.

Discussion and Conclusion: Results from the survey will establish the awareness and knowledge of diabulimia amongst healthcare professionals, helping to inform the requirement for subsequent healthcare professional training on the identification, sign posting and referring of vulnerable individuals to specialist care as appropriate. These data are important in the subsequent development of services to support people with eating disorders in the context of type 1 diabetes.

Key words: type 1 diabetes, eating disorders, diabulimia, insulin omission, healthcare professionals

Introduction
The careful attention to diet and lifestyle that is required to manage type 1 diabetes puts these individuals at increased risk of developing eating disorders.1 ‘Diabulimia’, ‘Syndrome of Insulin Omission’ (SIO) and ‘Type 1 Diabetes and Eating Disorder’ (T1DE) are all used to describe the practice of insulin restriction or omission for fear of weight gain in people with type 1 diabetes. ‘Diabulimia’ is the term that has been most widely adopted and increasingly used both in academic literature and social media, but is not currently a recognised medical or psychiatric disorder. Nonetheless, those affected by the presentation identify with the term, and some find the identity important to the validation of their struggles.2

The prevalence of diabulimia is difficult to quantify, but studies have demonstrated an increasing prevalence with age rising from 1% in pre-adolescence3 to 27–39% in late adolescence and early adulthood.4-6 Most screening tools suited to the general population are unable to accurately detect the presence of eating disorders in people with type 1 diabetes.7 They typically focus on behaviours that are inherent to diabetes management such as monitoring the intake of macronutrients. Screening tools specific to type 1 diabetes that have been used in the context of research are typically lengthy and not practical for use outside of this setting. The Diabetes Eating Problem Survey Revised (DEPS-R) attempted to address these barriers and takes approximately 5 minutes to complete.8 When assessing its clinical utility, however, although the DEPS-R was good at identifying those with type 1 diabetes who may be at risk of an eating disorder, it had a low positive predictive value.8

Despite the uncertainty surrounding its prevalence, diabulimia is associated with significant morbidity and mortality.8 Prolonged periods of high blood glucose resulting from insufficient insulin puts these individuals at profound risk of irreversible microvascular complications including retinopathy, peripheral neuropathy, renal disease and autonomic dysfunction.5,6 There are also the short-term consequences including electrolyte imbalance, volume depletion, increased risk of yeast and bacterial infections, muscle atrophy and diabetic ketoacidosis. Over an 11-year study period, women with type 1 diabetes who restricted their insulin for fear of weight gain were 3.2 times more likely to die over the study period.9 They also died on average 13 years younger than those who did not restrict insulin.

In light of the severity of diabulimia and the impact it has on those affected, designing care pathways and services to help support these individuals is of great importance. One of the challenges in this process is in the identification of those struggling with the condition. Healthcare professionals likely to encounter...
people with diabulimia need to recognise the condition, understand the increased risk prevalence, have confidence to engage in early detection and in supporting, sign-posting and/or referring on to appropriate services. To understand the requirement for training amongst healthcare professionals in identifying, sign posting and referring individuals with diabulimia or who may be at risk of it, we designed a cross-sectional staff survey. Data from this will highlight what learning needs there are across settings (e.g., primary care, secondary care and community pharmacy), across the different healthcare professional groups, and how healthcare professionals would like training to be delivered.

**Aims**

- To establish the awareness of diabulimia amongst healthcare professionals across primary, community and acute healthcare settings who may come into contact with individuals affected by the condition.
- To determine the awareness, confidence and competencies of healthcare professionals in:
  - being able to identify individuals with diabulimia
  - supporting people with diabulimia
  - knowing where to refer to for further support in managing diabulimia.

**Methods**

**Study design**

A cross-sectional, self-report, online survey has been designed to gain data from a large cohort of healthcare professionals. The online survey platform used is Survey Monkey. Informed consent is recorded at the beginning of the electronically completed questionnaire. All responses are anonymous, but participants are able to provide their e-mail address to be contacted again at a later date for further studies. The study has been approved by the Health Research Authority and Health and Care Research Wales REC reference 19-HRA/4284; IRAS number 269186.

**Table 1 Survey questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Which county do you work in?</td>
<td>Dorset, Hampshire, Isle of Wight, Other</td>
</tr>
<tr>
<td>(2) What type of team do you currently work in?</td>
<td>Community mental health, eating disorders service, diabetes specialist services, primary care, community pharmacy, acute setting, other</td>
</tr>
<tr>
<td>(3) What type of role do you currently work in?</td>
<td>Psychiatrist, psychologist, mental health nurse, diabetes specialist doctor, diabetes specialist nurse, general practitioner, pharmacist, pharmacy technician, dietitian, other</td>
</tr>
<tr>
<td>(4) What gender do you identify as?</td>
<td>Male, female, prefer not to say</td>
</tr>
<tr>
<td>(5) How confident do you feel recognising the combination of type 1 diabetes and an eating disorder?</td>
<td>Not confident, some confidence, fairly confident, very confident, not sure</td>
</tr>
<tr>
<td>(6) What would make/has made you consider a diagnosis of an eating disorder in type 1 diabetes? (Please tick all that apply)</td>
<td>Elevated or rising HbA1c, recurrent diabetic ketoacidosis (DKA), weight loss, restriction of insulin, not collecting prescriptions for insulin, not attending appointments, the individual has disclosed it, other___________</td>
</tr>
<tr>
<td>(7a) Have you ever managed or been involved in the care of someone with type 1 diabetes and an eating disorder before?</td>
<td>Never, a couple of times, a handful of times</td>
</tr>
<tr>
<td>(7b) If yes please provide details on what you felt went well or not so well.</td>
<td></td>
</tr>
<tr>
<td>(8) How confident do you feel talking to someone you think may have an eating disorder and type 1 diabetes?</td>
<td>Not confident, some confidence, fairly confident, very confident, not sure</td>
</tr>
<tr>
<td>(9) How confident do you feel about offering advice and support around insulin/diabetes/weight management for someone with type 1 diabetes and an eating disorder?</td>
<td>Not confident, some confidence, fairly confident, very confident, not sure</td>
</tr>
<tr>
<td>(10a) Have you ever had any education on type 1 diabetes and eating disorders?</td>
<td>No, Some, Yes</td>
</tr>
<tr>
<td>(10b) If ‘some’ or ‘yes,’ how was it delivered?</td>
<td>Talk/presentation, informal teaching, information leaflet/booklets, as part of speciality/training curriculum, online learning module, other</td>
</tr>
<tr>
<td>(11) How confident do you feel about knowing where to turn for additional help/support?</td>
<td>Not confident, some confidence, fairly confident, very confident, not sure</td>
</tr>
<tr>
<td>(12) Where would you go for additional support?</td>
<td>Eating disorders services, mental health services, diabetes services, patient’s GP, online, other</td>
</tr>
<tr>
<td>(13a) Would you be interested in participating in further education on eating disorders in type 1 diabetes and the services available locally?</td>
<td>Yes/No</td>
</tr>
<tr>
<td>(13b) If ‘yes’, how would you like this to be delivered?</td>
<td>Face-to-face, information pack, online webinar or module, other</td>
</tr>
<tr>
<td>(14) Please provide any additional comments below:</td>
<td></td>
</tr>
</tbody>
</table>
Study participants
Study participants will include healthcare professionals in the geographical area of Wessex (Hampshire, Dorset and the Isle of Wight) working in acute trusts, primary care, community pharmacies, specialist diabetes services or specialist mental health settings including, but not limited to, eating disorder services. Participants will be in roles where they may encounter individuals with type 1 diabetes and/or eating disorders as part of their day-to-day clinical practice.

Inclusion criteria
- Male or female, aged 18 years or above.
- Working as a healthcare professional in the geographical area of Wessex.
- Working in a patient-facing role where they may encounter people with type 1 diabetes and/or an eating disorder.

Exclusion criteria
- Those unwilling to participate.

Recruitment
Potential participants are being recruited through advertisement of the study within hospital trusts through their intranets, newsletters and e-mails. The study is also being advertised through existing clinical networks such as the Clinical Research Network for Wessex and the Local Pharmaceutical Committees who are advertising to general practitioners and community pharmacists respectively. The recruitment period will be open for approximately 12 weeks.

Survey questions
Questions in the survey are shown in Table 1.

Discussion
The results of this study will allow us to understand more about the awareness of diabulimia and the differing levels of knowledge and skills across healthcare professional groups. It will facilitate the development of initiatives to raise awareness of diabulimia and to improve the knowledge and skills set of those working in settings where they are likely to encounter individuals with the condition. Depending on the results, these initiatives may be generic or specifically tailored to meet the needs of differing staff groups and/or settings.

There is a possibility that the awareness and/or knowledge and skills of healthcare professionals are high, but that there is an impression or concern that limited services are available to support people with diabulimia. To address this potential issue, the responses from the survey will help inform the development of services in the geographical area of Wessex for people with eating disorders in the context of type 1 diabetes.

Conclusion
Diabulimia is associated with significant increased morbidity and mortality. This survey will help determine the level of healthcare professional knowledge and awareness of the condition so that relevant training can be designed and delivered as appropriate.

Conflict of interest
There are no conflicts of interest.

Funding
No funding was received.

References