Type 1 diabetes and disordered eating (T1DE): the ComPASSION Project – Wessex

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Abstract

The combination of type 1 diabetes and an eating disorder is ill understood with no clear nomenclature, definition or evidence base defined for management and support. It is well recognised that diabetes and mental health concerns often co-exist and type 1 diabetes *per se* is associated with specific self-management requirements which may predispose an individual to challenging cognitions and behaviours around food due to the nature of carbohydrate counting and insulin management.

While most diabetes teams recognise the mental health concerns around diabetes, there are few areas where multidisciplinary teams work cohesively combining diabetes care and mental health care. This is particularly relevant in the case of eating disorders where neither team are likely to be sufficiently skilled to manage the combination of type 1 diabetes and an eating disorder individually, and a strong multidisciplinary team approach with shared learning and a holistic ethos is paramount.

We describe here an NHS England funded pilot whereby the diabetes teams and eating disorders teams in Wessex work side by side developing a service specifically for people with this incredibly complex and challenging combination.
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Key words

type 1 diabetes; eating disorder; diabulimia; T1DE; mental health

Introduction

It is becoming increasingly recognised that optimum management of type 1 diabetes requires support for both physical and mental health and yet these are often managed in silos with little link up between physical and mental health teams. The Joint British Diabetes Societies in conjunction with the Royal College of Psychiatrists developed a consensus guideline in 2017 which recognises that virtually all mental health conditions may co-exist with physical disease and that this combination is associated with poorer outcomes and mortality.[1] One particular area of concern is the support available for people living with type 1 diabetes and an eating disorder. Eating disorders are twice as common in people with type 1 diabetes than without[2] occurring in up to 30% of people with type 1 diabetes,[3] and the use of insulin restriction as a purging behaviour gives rise to an increased rate of both acute and chronic diabetes complications[4,5] and a tripling of mortality risk.[6]

The biological and psychological consequences of living with type 1 diabetes are inherently tied to an increased risk of the development and maintenance of an eating disorder for several reasons (Box 1). Despite the recognition of an increased risk of an eating disorder co-existing alongside type 1 diabetes, there is currently no recognised consensus on diagnostic criteria nor nomenclature with the term 'diabulimia' used colloquially but not recommended in medical literature. Our collaborative partner pilot site in London developed the acronym T1DE (type 1 diabetes and disordered eating) to represent this specific cohort of people and is the term adopted by the ComPASSION project and used in this article.

Wessex pilot project

In 2018, NHS England offered the opportunity for local NHS sites to develop and test a one-year funded project into pathways for a combined physical and mental health approach for the support of people with type 1 diabetes and eating disorders.[7] A working group was set up between the diabetes team at Royal Bournemouth and Christchurch Hospital and the Dorset Eating Disorders Service to trial a multicentre, multidisciplinary hub and spoke model for Wessex (Box 2). Figure 1 outlines the ComPASSION pilot T1DE care pathway.

Box 1. Why is disordered eating common in type 1 diabetes?

- Need to carefully read food labels
- Focus on weight at diabetes clinic appointments
- Need to eat to treat hypoglycaemia, which can cause weight gain and can sometimes be counterintuitive (e.g. having to eat when not hungry), both contributing to feelings of guilt
- Constant awareness of carbohydrates or calories in food
- Feeling of shame over perceived ability to manage diabetes which may be influenced and reinforced by health care professionals' responses to efforts at diabetes management
- A poor relationship with the health care team
- Difficulty maintaining a desired weight
- Significant weight loss at diagnosis and regain on starting insulin
- Others' scrutiny of and assumptions about diet and diabetes management, e.g. family, friends and colleagues
- Language and technology can categorise people with diabetes into black and white thinking re diabetes management, e.g. 'failure vs success', 'controlled vs uncontrolled'
- Difficult to always eat intuitively – hunger/satiety signals overridden by hypoglycaemia treatment/fear

Screening

Routine screening tools for eating disorders are not valid in the context of type 1 diabetes due to the inherent focus on food that having type 1 diabetes entails. These tools may therefore overestimate the frequency of eating disorders in this cohort.[8] Despite NICE guidance for treatment of eating disorders[9] recommending routine screening for eating disorders in people with type 1 diabetes, there is no consensus on what measures should be used. Some screening tools specifically looking at eating disorders in type 1 diabetes do exist[10–12] but these remain challenging to incorporate into routine clinical care in busy diabetes consultations, and diabetes clinicians can feel concerned about whether they have the necessary skills to open up this area of conversation.

We therefore set to trial a new clinic proforma giving ownership of the diabetes consultation to the person with diabetes (PWD) allowing them to raise questions around weight concerns and body image while pairing this with measures of diabetes distress (DDS-2).[13] We introduced a short guide to using the proforma to health care professionals (HCPs) with support around language and communication skills. The guide helps to establish a therapeutic relationship in which the PWD feels able to share their thoughts, emotions and behaviours without fear of judgement, embarrassment and shame.

Assessment

Initial assessments are jointly conducted by two members of the team, usually one from each specialty, to allow the assessment of both psychological and physical health. The occurrence of comorbid pathologies is important to establish early. Suicide is over represented in eating disorders and most people presenting with an eating disorder will have a comorbid psychiatric disorder such as anxiety or depression, which can be associated with poorer outcomes. From our experience, the majority of our cohort meet the criteria for a depressive episode and suffer from a high degree of diabetes distress. Additionally, physical comorbidities such as gastroparesis or retinopathy can greatly influence the treatment pathway.

Minuted multidisciplinary team (MDT) clinical meetings are held at each of the sites fortnightly to discuss referrals, assessments and suitability for the pathway as well as to follow progress, address individual concerns and clinical needs and review care plans. Physical and mental health risk, along with patient engagement is considered, with escalation plans for assertive outreach agreed, if indicated.

Diagnosis

Using the phenotypic and assessment data derived from the project thus far, we have been able to devise a working diagnostic definition for people living with T1DE combining assessment of both physical and mental health (Box 3). Ongoing use and development of this definition will continue throughout the pilot as will recognition of phenotypes as we learn more about the variety of behaviours that individuals utilise to manage their weight and insulin usage.

Box 2. Hub and spoke model for Wessex

Hub multidisciplinary team
Royal Bournemouth Hospital and Dorset Eating Disorders Service

- Consultant diabetologist and consultant psychiatrist
- Diabetes nurse specialist
- Specialist dietitian
- Diabetes clinical psychologist
- Eating disorders specialist practitioner
- Persons with lived experience

Spoke multidisciplinary teams
Poole Hospital, Dorset County Hospital – Dorchester, Queen Alexandra Hospital – Portsmouth, Dorset Eating Disorders Service, Southern Health Specialist Eating Disorders Service

- Consultant diabetologist
- Eating disorders specialist practitioner
- Specialist diabetes nurse/dietitian

Treatment

Approach. We have adopted the Care Programme Approach (CPA) to patient management for both physical and mental health needs. CPA was introduced by the Department of Health in 1991 to provide a framework for effective mental health care.[14] It is widely used in secondary mental health to assess, plan, review and coordinate care, and guide treatment and support for people with complex mental health needs. The role of the nominated Care Coordinator is paramount as having a single point of contact is containing for the patient and allows for effective communication between the patient and the rest of the treating MDT.

The approach is influenced by the strengths, values and goals of the individual as well as the PWD's personal preferences for intervention (where possible) and the therapeutic fit with team members.

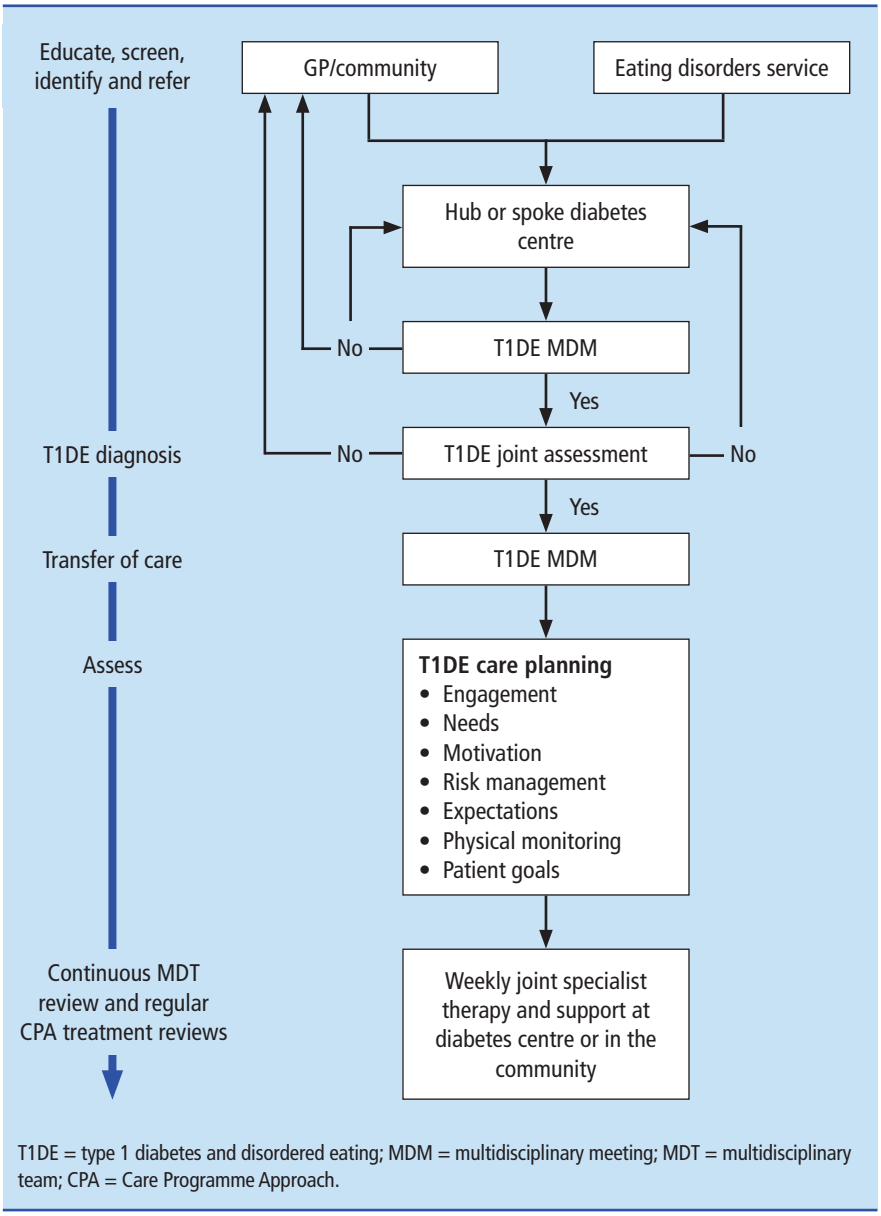
Psychological interventions. There is an emerging but limited evidence base regarding the psychological

interventions effective in treating eating disorders in type 1 diabetes. NICE guidance proposes that further research is needed regarding treatments for eating disorder in people with a comorbidity. Specifically, it notes the potential to investigate the effectiveness of a modified eating disorder therapy for those with a long-term health condition that addresses both conditions and avoids the need for offering two different interventions (in parallel or one after the other).

In this pragmatic project the psychological interventions delivered draw upon the evidence base and recommendations for eating disorders[15] as well as for the psychological difficulties associated with living with diabetes, including diabetes distress[16] and fear of hypoglycaemia. Key elements of the psychological treatments offered are summarised in Box 4. Treatment sessions have been delivered weekly and complement the other interventions offered to address nutrition and diabetes management. The team has sought to develop the skills of psychological practitioners from both specialties by delivering some aspects of therapies together where practical.

In addition to the more formal 1:1 psychological therapies offered, there is an overarching psychological approach to all contacts the PWD has with the team that include a focus on:

- Building engagement (where we seek to understand the difficulties from the person's perspective and to come alongside them to envisage what change might look like and build hope for change).
- To hold empathy and validate the emotions of the PWD, believing the person is doing the best they can, while also holding hope, offering encouragement and assisting the person to take the next steps that are needed.
- Developing realistic expectations and working at the individual's pace (while supporting each other to contain our own anxieties about this) and conceptualising slips back as just that (rather than indicating failure).
- Noticing progress and celebrating effort.



T1DE = type 1 diabetes and disordered eating; MDM = multidisciplinary meeting; MDT = multidisciplinary team; CPA = Care Programme Approach.

Figure 1. ComPASSION pilot T1DE care pathway

- Keeping the person connected with their values and why they (not us) feel it is important for them to make a change.
- Building a life beyond eating disorder with a space for diabetes within it.

Risks. Each treatment plan is personalised and based on the processes that appear to be maintaining the eating problem and taking into account the identified risks. Physical health risks include diabetes parameters (HbA1c, ketosis), biochemical parameters and the risk of refeeding syndrome (in the context of starvation and the inability to utilise macronutrients in the absence of physiologic insulin). Mental health risks centre around harm to self or others, self-neglect, vulnerability and disengagement from services.

Family. There has been significant work in the field of eating disorders looking at the role of the family. Historically, the family was seen as the potential cause of the disorder. Current thinking sees the family as having a crucial role in supporting recovery. This would seem to be no less true in those with both type 1 diabetes and eating disorders.

Accommodating and supporting someone who is working on challenging their eating disorder alongside managing their diabetes requires

insight, understanding, empathy and patience. It is invaluable to have this support.

Educating family members about the challenges can create an environment which is conducive and enabling for the individual.

The team is drawing heavily on the work of Janet Treasure (*et al.*) in developing such education and training.[17,18]

Peer support. Peer support has an important place in the recovery journey of someone with T1DE. There are online communities for PWD and those with eating disorder already in existence nationally and internationally.[19,20]

Insulin management. Personalised, documented, insulin reintroduction algorithms are developed collaboratively between the PWD and the team with a discussion around speed of insulin increase as well as appropriate sick day rules.

Protocols have been developed for both outpatient and inpatient care with emphasis around supporting the emotional needs of the PWD as insulin is reintroduced and the corresponding deterioration in mental health that may accompany the improvement in physical health and weight restoration. Special attention is paid to the risk of insulin oedema, distress linked to pseudohypoglycaemia (symptoms of hypoglycaemia at higher blood glucose levels), refeeding syndrome and the emergence of alternative compensatory behaviours such as excessive exercise, vomiting, and laxative and diuretic abuse.

Some overarching principles guide the reintroduction of insulin which have an overall focus on safety and preventing diabetic ketoacidosis (DKA):

- An immediate focus on ideals of near normal glycaemic management are unreasonable and unsafe.
- Instead there is an emphasis on small incremental steps that are attainable, and in line with a harm reduction approach that prioritises reducing the risk of DKA.
- While it may feel uncomfortable for the HCP to accept high blood glucose and ketone levels, it is a temporary measure with the aim of working with the person at their own pace to gradually increase the regularity and amount of insulin dosing and monitoring, moving towards recommended targets.

Box 3. Working diagnosis of T1DE

People with type 1 diabetes who present *with all three criteria:*

1. Disturbance in the way in which one's body weight or shape is experienced or intense fear of gaining weight or of becoming overweight
2. Recurrent inappropriate direct or indirect* restriction of insulin (and/or other compensatory behaviour**) in order to prevent weight gain
3. Person must present with a degree of insulin restriction, eating or compensatory behaviours that cause at least one of the following:
   - Harm to health
   - Clinically significant diabetes distress
   - Impairment in areas of functioning

*Note: indirect restriction of insulin refers to reduced insulin need/use due to dietary restriction.
**Self-induced vomiting, laxative use, dietary restriction, excessive exercise.

Box 4. Key components of psychological interventions

- Developing a picture of how the problems have developed and are being maintained (capturing the interplay between the eating disorder and psychological difficulties of living with diabetes)
- Psychoeducation
- Enhancing self-efficacy
- Building sense of importance and confidence around making changes
- Cognitive restructuring (e.g. body image and diabetes management)
- Mood regulation, including understanding and coping with strong emotions
- Developing compassion for oneself
- Building acceptance (e.g. of diabetes as a long-term health condition)
- Identifying and living in line with personal values
- Understanding and planning for high risk situations as part of relapse prevention work

Nutrition. Dietetic assessment may highlight a range of compensatory dietary strategies, for example:

- Restriction of total energy intake.
- Selective restriction of carbohydrate intake.
- Unrestricted eating of carbohydrate in a deliberate attempt to keep blood glucose and ketones raised to achieve weight loss.

Once any risks associated with refeeding have been managed, dietary counselling should aim to work with the PWD to gradually move towards a normalised pattern of balanced eating in line with mainstream nutrition recommendations for type 1 diabetes. As with changes to insulin doses, a gradual stepped approach to change should be supported. In our experience there may be benefit for some people with T1DE in temporarily leaving to one side carbohydrate counting, instead taking a more generalised dietary approach alongside fixed doses of insulin.

Awareness, education and staff development

Education. The Wessex hub is developing a suite of educational tools for use by any HCP involved in the care of people with T1DE in the form of presentations, online resources and downloadable educational resources which will be freely available. These are being developed in conjunction with people with lived experience of T1DE. The aim is to use these resources to increase awareness, knowledge and skills in the identification and management of this cohort of patients within a range of staff groups including: A&E staff; inpatient and outpatient teams in both diabetes and eating disorder services; GPs and practice nurses.

In addition to staff training, the Wessex hub has identified the need for regular peer supervision to discuss issues arising from working

with this cohort that are beyond case management discussions in MDT meetings. Sessions provide a setting to discuss the more emotional reactions and dilemmas that might occur. A safe reflective space helps to make sense of feelings and concerns and find ways to move forward that serves to maintain wellbeing and the integrity of the treatment being offered.

What have we learned?

During the initial six months of the Wessex pilot 11 people were referred into the Bournemouth hub. Of these, nine people were diagnosed on clinical assessment as having T1DE. Demographics of eight of our cohort are detailed in Table 1.

Age (years)	Gender	Duration of diabetes (years)	HbA1c (mmol/mol)	Weight (kg)	BMI	DDS score
37	F	6	86	55.4	21	10
69	F	63	50	54.1	22.8	8
17	F	3	98	49	18.8	12
28	F	18	112	–	–	–
29	M	5	92	86	24.6	12
59	F	13	106	63.4	23.2	12
19	F	4	100	56.5	21	7
20	F	8	113	62.6	24.8	10

DDS = Diabetes Distress Scale.

Table 1. Demographics of people referred to T1DE Wessex

Identification. Neither HbA1c nor BMI have proved consistently useful in making a diagnosis of T1DE. The majority of people presented with a BMI within the healthy weight range. Different phenotypic groups can be identified exhibiting different cognitions and behaviours. Those with restrictive eating patterns but appropriate insulin dosing have a preserved HbA1c whereas those primarily restricting insulin have a significantly elevated HbA1c. A change in HbA1c or BMI seems to represent more clinical significance and may reflect a change in the status of the person's mental health with relapses and remissions.

Engagement. We have found that building a trusting and respectful therapeutic relationship through a focus on engagement is key in assisting people with T1DE to feel able to talk openly about their experiences and consider making changes. Most eating disorders are deeply rooted in shame, low self-esteem and secrecy. It was not uncommon that prior to entering this project, and even during it, our cohort had episodic engagement with the team. Some key aspects of our approach to building and maintaining engagement have included being welcoming, trying to understand what it is like to be in the person's position, to offer hope of change and a willingness to work at the pace of the individual.

Order of treatments. It is important where possible not to separate out the psychological treatments for diabetes and eating disorder. These two areas of difficulty reside within the same person. Both treatments need to be included in a joint formulation that captures the interplay between the two conditions to guide a treatment plan moving forward. We have learned that it does not work well for the individual to be only receiving psychological treatment while not seeing the rest of the team regularly; the other aspects of T1DE multidisciplinary care are crucial to effective treatment.

Cognitive functioning. Starvation impacts an individual physiologically, psychologically, cognitively and socially. This has the potential to interfere with utilisation of therapeutic sessions with the MDT because of impaired concentration, retention and processing as well as emotional numbness and disconnection. This possible impact of starved brain may well be additive to the impact of high blood glucose on cognitive functioning also. Cox *et al.* found hyperglycaemia (>15mmol/L) associated with slowing of all cognitive performance tests and errors made.[21] We have considered these factors on the effective use of sessions and made adaptations where necessary, such as the use of repetition, summarising and written plans.

Specialist education. It is essential that health care teams each need to have a firm knowledge of both specialist areas. People living with type 1 diabetes are specialist in their own self-management skills and struggle to engage if their HCP is not conversant with a reasonable depth of knowledge of diabetes. This also holds true in terms of eating disorders and understanding the cognitions and emotions firmly held which drive behaviours. It is essential therefore that specialist educational opportunities are made available to each respective team. This is particularly important for inpatient teams supporting someone with T1DE. Other HCPs from both primary and secondary care, who may support people with type 1 diabetes, would also benefit from T1DE educational opportunities. Accident and emergency and acute medical units may be first-line services to see people with recurrent DKA which may be a manifestation of T1DE insulin omission.

Summary

T1DE is seen in people with type 1 diabetes who live with a comorbid eating disorder and is associated with a high mortality rate. It can go undetected due to the nature of both illnesses and the lack of HCP knowledge and awareness of this condition. A better understanding of the clinical manifestations, specialist education and promotion of

multi-specialty working are likely to improve clinical outcomes. It is important to consider both the physical and mental health risks when formulating management plans. From our experience, enabling PWD to start talking about their distress, body image concerns and the behaviours they employ to manage their fear of weight gain, seems to be a powerful intervention to effect change and the first step to recovery.

We have learned that it is possible to deliver safe, coordinated and holistic care to people with complex physical and mental health needs, by drawing on the expertise and experience of two specialist MDTs that are based at separate locations and do not share an electronic patient record system. The skill sets of the individual members of the team complement each other and should be recognised as being equally relevant and contributory. The experience has been enriching and rewarding and an excellent opportunity for continuing professional development. The same approach could be considered in all aspects of diabetes management and indeed other areas of medicine associated with high levels of psychiatric comorbidity.

Declaration of interests

There are no conflicts of interest declared.

KEY POINTS

- Support for people with type 1 diabetes and an eating disorder requires a multidisciplinary team comprising diabetes teams and mental health teams each up-skilled and cognisant of the complexities of this combination of pathologies
- Increased awareness and skills in raising concerns with patients in a clinical scenario require widespread education and support for diabetes health care professionals to develop confidence in communication and motivational interviewing
- The non-judgemental therapeutic relationship is fundamental in allowing someone with T1DE to develop trust in the support of their health care professional and to start to take tiny steps forward in addressing cognitions and behaviours
- Recognising and celebrating small changes allows confidence to build along with acceptance that significant changes take time and require intensive support

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