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Type 1 Diabetes and Disordered Eating (T1DE): The ComPASSION Project: Wessex: A Mini Review

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Abstract

It is widely recognised that type 1 diabetes can have a profound psychological impact on an individual, and mental health concerns often co-exist alongside the condition. Specific condition self-management requirements such as carbohydrate counting and insulin management can predispose an individual to difficult and often complex cognitions, emotions and behaviours related to food. Thus, the connection between type one diabetes and eating disorders is not surprising, yet this is currently poorly understood, with no clear definition and a limited evidence base for support and management. Though most diabetes professionals recognise the mental health concerns surrounding diabetes, there are very few areas where multidisciplinary teams work cohesively combining diabetes and mental health care. This is particularly relevant with regard to eating disorders, where both teams are likely insufficiently skilled in managing the combination of an eating disorder and type 1 diabetes. Thus, a strong multidisciplinary team approach with shared learning and a holistic ethos is paramount. This short commentary describes the NHS England funded pilot study whereby the diabetes team and eating disorder team in Wessex worked side by side to develop a service specifically for people with this unique, complex and challenging combination.

Keywords: Type 1 diabetes; Eating disorder; Diabulimia; T1DE; Mental health

Abbreviations

ED: Eating Disorder; PWD: Person with Diabetes; MDT: Multi Disciplinary Team; T1DE: Type 1 Diabetes and Disordered Eating; DDS2: Diabetes Distress Scale; CPA: Care Programme Approach; NICE: National Institute for Health and Care Excellence; MMD: Multidisciplinary Meeting; BMI: Body Mass Index; DKA: Diabetic Ketoacidosis; HCP: Health Care Professional

Introduction

There has been an increased recognition of the necessity of psychological support alongside medical support to ensure optimum management of type 1 diabetes, yet these intertwined aspects are often managed in silos, with very little link up between physical and mental health teams. Moreover, it has been suggested that virtually all mental health conditions likely coexist with physical disease, and this combination is associated with poorer outcomes and mortality [1]. One particular concern is the lack of support available for people living with type 1 diabetes and an ED. Eating disorders are twice as common in people living with type 1 diabetes than without, occurring in up to 30%, and the use of insulin omission/restriction as a purging behaviour gives rise to an increased rate of acute and chronic diabetes complications and a tripling of mortality risk [2-6].

The biological and psychological consequences of living with type 1 diabetes are fundamentally tied to an increased risk of the development and maintenance of an eating disorder for several reasons Figure 1.

Despite the acknowledgement of an increased risk of an eating disorder coexisting alongside type 1 diabetes, there is currently no clear consensus on diagnostic criteria nor nomenclature, with the term 'diabulimia' used colloquially but not recommended in medical literature. Type 1 Diabetes and Disordered Eating (T1DE) refers to a range of presentations in those with a diagnosis of type 1 diabetes whereby individuals use one or more of a range of behaviours to control their weight. These behaviours include omission of insulin, restriction of food, over exercise, self-induced vomiting and abuse of laxatives or diuretics. More than one of these compensatory behaviours may be present but of significant concern is insulin restriction, which puts patients at higher risk of the short- and long-term complications of diabetes.

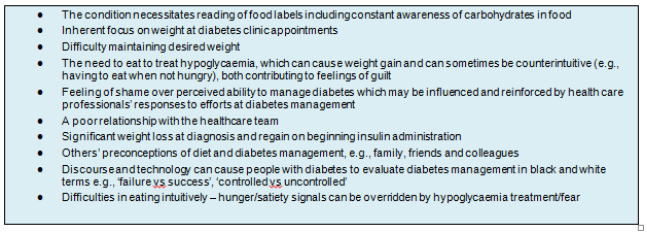

Figure 1: List of potential contributing triggers of disordered eating for individuals with type 1diabetes.

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In 2018, NHS England offered local NHS sites the opportunity to develop and test a one year funded project into pathways for a combined physical and psychological approach for the care of people with type 1 diabetes and eating disorders [7]. A working group was established 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. Figure 2 outlines the pilot T1DE care pathway.

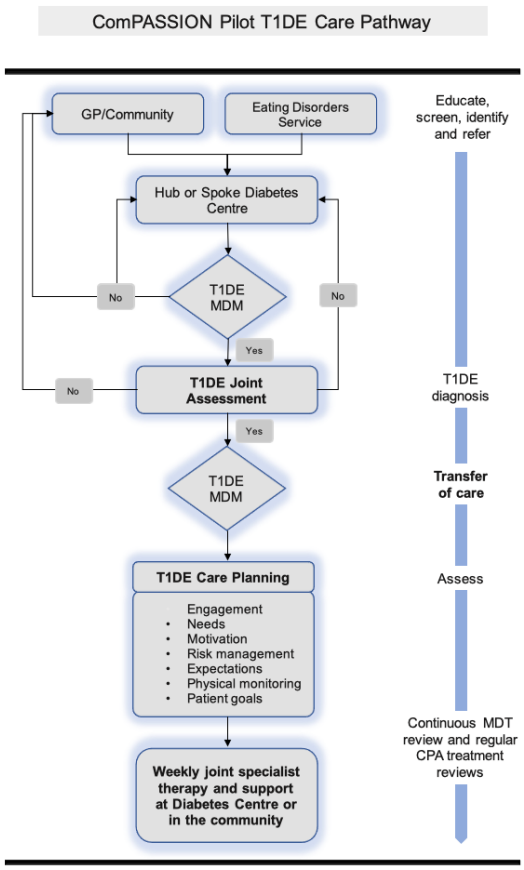

Figure 2: ComPASSION pilot T1DE care pathway.

Screening, assessment and diagnosis

Standard ED screening tools are neither applicable nor valid in the context of type 1 diabetes, as a result of the focus on food necessitated by the condition. Therefore, standard measures often overestimate the frequency of EDs for this cohort [8]. Although NICE guidance for treatment of eating disorders recommends routine screening for such in people with type 1 diabetes, there is no consensus on what measures should be used [9]. Despite the development of unique screening tools for eating disorders in people with type 1 diabetes, this remains a challenging topic for clinicians to navigate, as many doubt whether they possess the necessary skills to begin this conversation nor indeed the accessibility of necessary psychological support [10-13].

It is crucial for the person living with these 2 conditions that the health care team have experience in managing both conditions. It proved important therefore to develop a multidisciplinary team approach with initial consultations offered from both the physical and mental health teams. The MDT consists of a consultant diabetologist and consultant psychiatrist, diabetes nurse specialist, specialist dietician, diabetes clinical psychologist and eating disorders specialist practitioner. This enables thorough assessment of both the type 1 diabetes and eating disorder concerns, alongside a medical assessment for diabetes related complications and comorbid mental health concerns. Most people in the cohort exhibited very high levels of diabetes distress as measured by Diabetes Distress Scale (DDS2) and high levels of depression and anxiety often requiring additional pharmacological therapy [14].

Fortnightly, minuted team clinical meetings are held to ensure the collaborative approach to referrals, assessments and care pathways, alongside progress-tracking and individual concerns, clinical needs, and review care plans. Physical and mental health risk assessments are also discussed, with escalation plans for assertive outreach agreed, if necessary.

There is yet to be an agreed consensus on how best to define this patient group. In our experience the majority of patients are normal weight, with a BMI of 18-25. Whilst some patients omit or reduce the recommended insulin dose, others restrict their dietary intake of carbohydrates but use insulin doses appropriately for the carbohydrate intake. As a result, BMI and HbA1c cannot be used exclusively in the identification or diagnosis of patients with T1DE. It is important to recognise the contribution of other diabetes specific psychopathologies that may contribute to a difficulty engaging with diabetes self-management such as diabetes distress, needle phobia, fear of hyperglycaemia/ hypoglycaemia and acceptance of diabetes diagnosis. Using phenotypic and assessment data from our project, we developed a working diagnostic definition for people living with T1DE as shown in Figure 3. Ongoing use and development of the definition is anticipated, reflecting new and emerging evidence.

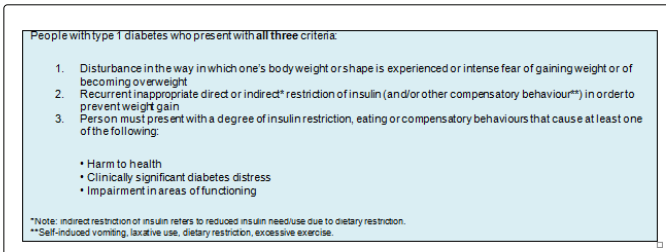

Figure 3: Proposed working diagnosis of T1DE.

Therapeutic and risk considerations

After confirmation of the diagnosis, treatment options are discussed within the team with the patient concerned. Adopting the Care Programme Approach (CPA), the PWDs strengths, values, goals and personal preference for intervention are regarded as great influencers of treatment [15].

Currently there is an emerging yet limited evidence base for psychological interventions in the treatment of T1DE. There is certainly recognition that there is a need to investigate the effectiveness of programmes designed to offer parallel interventions of physical and mental health [9]. Taking these recommendations into account, our pilot study encompassed standard psychological interventions from the evidence base and recommendations for EDs alongside specific psychological concepts associated with living with diabetes, such as diabetes distress or fear of hypoglycaemic events [16,17]. The weekly clinical sessions aim to target interventions on the interrelated thinking patterns, emotions and behaviours that maintain the ED and diabetes distress, with consideration of nutritional needs and acute health

concerns with reference to hyperglycaemia and ketosis with adapted sick day rules which can be tolerated by someone struggling to manage regular insulin doses. These sessions are supported by the skills and experiences of the specialist teams working collaboratively and jointly where appropriate (Figure 4).

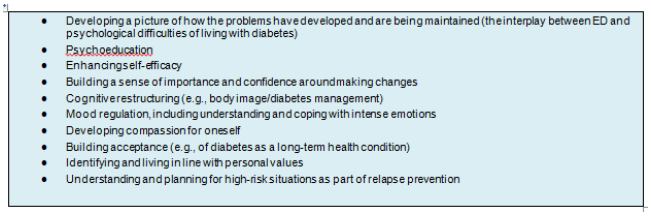

Figure 4: Key components of psychological interventions.

In particular it is vital for the eating disorders team to learn from the diabetes teams the nuances and complexities of life with type 1 diabetes and for the diabetes teams to understand the nature and presentation of eating disorders. In addition, and perhaps more importantly, is the need to develop skills around the language used in reference to both conditions so as to avoid being stigmatising or undermining of self-care which could have a detrimental effect on clinical outcomes [18]. Figure 5 outlines advice for future HCPs engaging with people with T1DE.

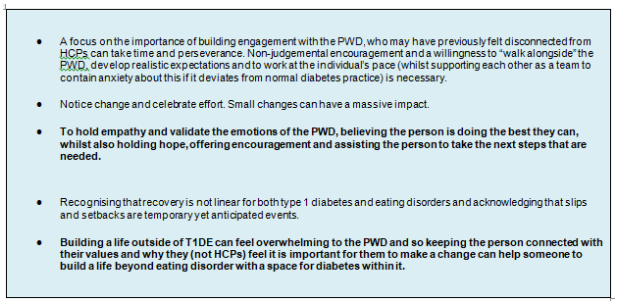

Figure 5: Advice for future teams approaching the topic of T1DE.

Family

There has been significant research in the field of eating disorders looking at the role of the family. Historically, the family has been viewed as a potential contributor to the disorder. Despite this, current thinking places the family at the centre of recovery support. We have found this to be true in those with T1DE. Supporting an individual challenging their eating disorder alongside managing their diabetes requires insight, understanding, empathy and patience. Educating family members about challenges an individual with T1DE faces, can create an environment which is conducive and enabling for the individual. Our team has drawn upon the work of Janet Treasure, et al. in developing such education and training [17,18].

Peer support

Peer support plays an essential role in the recovery journey of someone with T1DE. There are online communities for PWD and those with eating disorder nationally and internationally [19,20].

Insulin management

Insulin reintroduction algorithms must be developed collaboratively between the PWD and the team with a focus around rate of insulin increase, as well as appropriate sick-day rules. Individual protocols need to be 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 should be 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.

Overarching principles guiding the reintroduction of insulin have an overall focus on safety and preventing Diabetic Ketoacidosis (DKA)

• An immediate focus on ideals of near normal glycaemic management is unreasonable and unsafe.

• Emphasis on small incremental steps that are attainable and prioritise reducing the risk of DKA.

• While potentially uncomfortable for the HCP, accepting high blood glucose and ketone levels 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.

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 carbohydrates in a deliberate attempt to keep blood glucose and ketones raised to cause weight loss.

Once any risks associated with refeeding have been managed, dietary counseling should aim to work with the PWD to gradually move towards a normalized pattern of balanced eating, in line with common 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 to temporarily avoid carbohydrate counting, instead taking a more generalized dietary approach with fixed insulin doses.

Conclusion

T1DE is seen in people with type 1 diabetes who live with a comorbid ED 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 T1DE. A better understanding of the clinical manifestations, specialist education and promotion of multispecialty working are likely to improve clinical outcomes. 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 who are willing to think outside the box, as it is essential 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. Use of an individualized supportive, non-judgmental approach allows the person with T1DE to recognize their want for a future and to develop skills to move forward within a secure holistic team.

Declaration of Interests

None.

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