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Fifteen-minute consultation: Diabulimia and disordered eating in childhood diabetes

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3 Box Figures

1 Table

ABSTRACT

Type 1 Diabetes (T1DM) is a common chronic disease in children and young people. Living with diabetes can pose many challenges both medical and psychological. Disordered eating behaviours, intentional insulin omission and recognised eating disorders are common amongst young people with diabetes and are associated with increased risk of short and long term complications and death. Recognition of these behaviours is important to ensure that relevant support is provided. Joint working between diabetes and mental health teams has challenges but is essential to ensure all needs are met during treatment and recovery.

THE PROBLEM

Living with diabetes, like many other chronic illnesses, can place a significant burden on the child and their family. Accepting that diabetes is lifelong, and has potential to disrupt activities of childhood can pose psychological difficulties for young people, and their families. Diabetes is associated, to varying degrees, with higher rates of a range of psychological difficulties including eating disorders(1) which has led the National Institute for Health and Care Excellence in the UK (NICE) to recommend that a Clinical Psychologist forms part of the diabetes multidisciplinary team(2), a requirement for receipt of the Best Practice Tariff (a system in England to financially incentivise the delivery of high quality care for children with diabetes by units demonstrating evidence of agreed care criteria)..

Box 1. Key definitions

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Eating Disorders: The term 'eating disorders' encompasses anorexia nervosa (AN), bulimia nervosa (BN) and atypical eating disorders (AED) or eating disorder not otherwise specific (EDNOS). The two classification systems for eating disorders (DSM IV TR and ICD-10) distinguish between AN (primarily characterised by weight loss) and BN (primarily characterised by bingeing and purging).

Disordered eating behaviours: Maladaptive eating behaviours including fasting and dieting; binge eating; self-induced vomiting; the abuse of laxatives, diet pills, and other medications though the behavior and psychopathology does not reach threshold for an diagnosis of an eating disorder as per DSM IV TR and ICD-10.

Diabulimia: An increasingly used term to describe intentional insulin omission or manipulation to induce weight loss.

A number of studies have identified high rates of disordered eating behaviours, issues with body image and intentional manipulation of insulin for weight loss amongst young people with diabetes(3)(4). A recent meta-analysis(5) showed a higher prevalence of disordered eating problems (39.3 v 32.5%) and eating disorders (7.0 v 2.8%) in adolescents with T1DM compared to peers without T1DM. 'Diabulimia' is an increasingly used term to describe intentional insulin

omission to induce weight loss (see box 1.). Disordered eating behaviours are thought to be more common amongst girls than boys, and more frequently identified in adolescents(6). Disordered eating is associated with higher HbA1c and increased risk of microvascular complications, particularly retinopathy(7). Insulin restriction leads to increased risks of ketoacidosis and long term complications including retinopathy, nephropathy, vascular disorders and premature death(8). Goebel-Fabbri and colleagues(8) reported more than three times the relative risk of death amongst those who intentionally restrict insulin, with a mean age of death of 44 years compared to 58 years compared to those who did not report intentional insulin restriction.

The management of T1DM includes a focus on healthy eating, carbohydrate counting and insulin timing. Young people are regularly weighed and their weight is openly discussed with often a noticeable increase in weight after diagnosis. This can lead to an over-focus on body weight and shape with adverse implications for blood glucose control. Living with T1DM is associated with higher anxiety and depression (1,2) which again can predispose to maladaptive eating behaviours. Sadness and struggles accepting the diagnosis can also contribute to these difficulties.

A framework for understanding the processes that lead to the development and maintenance of an eating disorder in children and young people with diabetes is shown in Figure 1.

Figure 1. Development and Maintenance of eating disorders in T1DM (Adapted from Fairburn(9))

Figure 2. The Case

This growth chart illustrates a common presentation in Paediatric Diabetes clinics. Focus is needed in the consultation to establish the underlying cause of the poor glycaemic control and weight loss which will shape subsequent management.

THE CONSULTATION

It is important to guide history taking and examination to exclude organic causes of weight loss including hyperthyroidism and coeliac disease as well as other systemic illnesses. An assessment of the patient's current insulin regime together with a review of serial blood glucose measurements may suggest a deficiency of prescribed insulin.

There are many psychosocial issues that impact on glycaemic control. At times, young people struggle to engage with their diabetes, leading to a reluctance to adhere to their insulin regime or monitoring of blood glucose. There are many reasons for this and it is important to take a wider psychosocial history (for example exploring home, school, friendship, activities, risk taking behaviours) to explore potential risks and resilience.

Assessment of disordered eating and diabulimia

Identifying diabulimia and disordered eating can be difficult in practice. Young people are often reluctant to disclose a history of disordered eating. By their very nature eating disorders are secretive and young people may feel ashamed of their struggle (10). It can be very difficult to get them to talk about or recognise that they have a problem. It is important to involve other members of the multidisciplinary team whose expertise and relationship with the young person may elucidate crucial information that points towards a diagnosis of intentional insulin omission and/or disordered eating behaviours. An empathetic, accepting, non-blaming and curious stance helps enable honesty in young people. The context in which consultations take place (i.e. privacy, presence of parents, known or unknown staff members) should be carefully considered. Strong links with schools facilitates sharing of concerns(11) regarding eating behaviours and helps to build a thorough understanding.

The clinical features suggestive of disordered eating and diabulimia are shown in Box 2. Rising HbA1c and/or changing weight may be the only initial sign of concern.

Box 2. Clinical features of diabulimia and disordered eating in diabetes

Box 2. Clinical features of diabulimia and disordered eating in diabetes

- Change in eating habits
- Low mood, poor self esteem
- Distorted body image
- Weight loss or weight gain
- Purging behaviours (vomiting, excessive exercise, use of laxatives)
- Binge eating behaviours
- Hoarding food
- Worsening glycaemic and metabolic control (rise in HbA1c, hyper and hypoglycaemia)
- Missed or cancelled appointments
- Change in school attendance
- Admission for diabetic ketoacidosis
- Secretive behaviour
- Evidence of accessing internet sites which focus on weight loss

Many centres use screening questionnaires to identify mood disturbances and psychological difficulties in children and young people with diabetes, e.g. Strengths and Difficulties Questionnaire (12). Screening tools used for detection of eating disorders in young people with diabetes often have developed from tools used in the general population and include mSCOFF(13), mEDI (Eating Disorder Inventory)(14) and DEPS (Diabetes Eating Problem Survey)(15). mSCOFF (see Box 3.) and DEPS offer a concise, self-report survey to detect disordered eating behaviours in young people with diabetes and can be utilised in clinical settings to identify these behaviours.

Box 3. Modified SCOFF questionnaire

Box 3. Modified SCOFF questionnaire

- 1 . Do you make yourself **Sick** because you feel uncomfortably full?
- 2 . Do you worry you have lost **C**ontrol over how much you eat?
- 3 . Have you recently lost >14 lbs **O**ne stone in a 3-month period?
- 4 . Do you believe yourself to be **F**at when others say you are too thin?
- 5 . Do you ever take less **I**nsulin than you should?

Positive score of 2 or more is suggestive of an eating disorder

MANAGEMENT

Prevention

There are several risk factors associated with developing disordered eating or diabulimia (Box 4.). Specific targeting of at risk children with diabetes may prove advantageous. There is evidence from other areas of high eating disorder prevalence (e.g. weight specific sports) that prevention programmes focused on positive body image and anti-restrictive behaviours significantly reduce the incidence of eating disorder development(16).

Box 4. Risk Factors for development of disordered eating and diabulimia

Box 4. Risk Factors for development of disordered eating and diabulimia

- Female gender
- Higher BMI pre diagnosis
- Low self esteem or history of depression
- Body dissatisfaction
- Diabetes diagnosis between 7-18 years
- Family history of dieting or eating disorders

Multidisciplinary approach

- Early intervention is essential in the management of any eating disorder, but particularly in those with T1DM.
- A multidisciplinary approach between the diabetes team, child and adolescent mental health teams and other agencies (e.g. school, youth worker) is essential with agreement needed for individual treatment plans. Close communication and support between teams is important as adolescent mental health teams may have little experience of managing diabetes nor paediatric diabetes teams of eating disorders.

Insulin management and medical approach

- The associated weight gain with insulin treatment may reinforce the perceived benefits of insulin restriction as an effective weight loss tool.
- There may need to be a relaxation of glycaemic targets to try and achieve small incremental goals with regard to their disordered eating and prevent rapid weight gain which can be counterproductive to their overall care.

- The timing of insulin (usually advised premeal) may have to be delayed to prevent hypoglycaemia if the young person does not complete meals.
- Insulin regimes may be revised accordingly with some evidence that pump therapy (with lower insulin requirements which minimises weight gain) leads to reduced disordered eating behaviours(17) and better HbA1c in those with T1DM and eating disorders(18).
- Medical or parental supervision of meal-times is often needed.
- The importance of appropriate insulin dosing to restore weight and nutritional status of the individual may not always be appreciated by mental health services, though is important for diabetes care.

Dietetic approach

- Dietetic treatment should encourage flexible and non-restrictive approaches to eating, whilst still focusing on regular meal patterns and carbohydrate counting.
- Encouraging intuitive and flexible approaches to food by the young person and their family should underpin dietetic treatment recommendations.
- Weighing all sources of carbohydrate may need to be relaxed, and estimation encouraged.
- A whole diet approach towards normalisation and stabilisation of eating patterns is recommended.
- Concurrent stabilising of meal patterns (combined with insulin adherence) is necessary to promote glycaemic control and restore weight changes, decision making and reduce food anxieties.
- It is important to appreciate concerns over body shape and weight, particularly when re-engaging with insulin treatment.

Psychological approach

- Psychological therapy for eating disorders may take various forms depending on the individual and condition e.g. Cognitive Behavioural Therapy (CBT) and family therapy.
- It is important that the Clinical Psychologists between both teams work together to ensure that both the eating disorder and impact of diabetes on daily living are understood and discussed. This helps to ensure that interventions are effective, and a cohesive message is given across both teams.

NICE guidance (4) advises awareness of diabetic complications which may prevent recovery (e.g. gastroparesis) and encourages joint working with mental health practitioners. The details of these guidelines are not explicit and the practicalities of application are challenging (see Table 1.). The availability of diabetes specific inpatient eating disorder support is likely not to be available. Therefore, regular reviews and discussions between diabetes and mental health teams are crucial. When working with a young person with an eating disorder, 'splitting' is common (11), for example where one party is seen as 'good' and the other 'bad'. These processes are unconscious and relate to the inner conflicts and overwhelming emotions the young person is facing. This can cause problems within and between teams, meaning that efforts to maintain joint working, peer education and effective communication are especially important.

Table 1. National Guidelines of Eating disorders and diabetes care

Guideline	Recommendation	Challenges in Diabetes Care	Application in Practice
NICE CG9. Eating Disorders in the over-8's: management (19)	Young people with T1DM and poor treatment adherence should be screened and assessed for the presence of an eating disorder.	Diabetes care occurs in a paediatric setting, where clinicians may not be experienced in screening for eating disorders	Paediatric Diabetes teams should consider specific screening for all adolescents with poor treatment adherence.
	Treatment of both sub-threshold and clinical cases of an eating disorder in people with diabetes is essential	High prevalence of sub-threshold eating disorders or disordered eating patterns in T1DM Challenge for mental health teams to provide service.	Increase staff awareness of both eating disorders and sub-threshold eating disorders in young people with T1DM Communication with mental health services to support those with greatest needs.
RCPsych. Summary of Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa(20)	Re-establish regular meal pattern based on 3 meals + 2-3 snacks per day, without any macro-nutrient avoidance or self-restriction	Restriction or avoidance of carbohydrate based between meals is often encouraged or advised to patients who do not wish to give themselves additional insulin between meals.	Individualised meal plans with contribution or input from both an Eating Disorder and Diabetes Dietitian are essential in the re-establishing of meal pattern.
	For patients requiring specialist eating disorder beds, safe re-feeding including access to dietetic advice is essential	Diabetes nursing and dietetic staff will rarely have the skills, experience or access to support to identify and monitor re-feeding risk	Individualised re-feeding insulin regimens should be developed jointly with experienced eating disorder teams, particularly if NG feeding is required.

CONCLUSIONS

Identifying disordered eating behaviours, eating disorders and diabulimia can be difficult in practice. Raising awareness amongst the multidisciplinary team is crucial to ensure these problems are considered in consultations. Screening tools can be effective and should be used when clinically suspected and considered as part of annual diabetes review. The management of comorbid eating disorders and diabetes is challenging and conventional approaches to diabetes care may need to be adapted to fit the individual. Effective joint working with mental health teams forms a key part of treatment and recovery with early liaison encouraged.

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QUESTIONS

1. Those children and young people with diabetes at higher risk of developing disordered eating/diabulimia include

- a. Boys
- b. Adolescents
- c. A family history of dieting or eating disorders
- d. Diagnosed with diabetes between 7-18 years
- e. Higher BMI pre diabetes diagnosis

Answers: BCDE

2. Signs or symptoms of disordered eating/diabulimia include

- a. High HbA1c
- b. Low mood
- c. Weight change
- d. Diabetic ketoacidosis
- e. Secretive behaviour

Answers: ABCDE

3. Screening tools used to identify disordered eating/diabulimia include

- a. DEPS
- b. mEDI
- c. mSCOFF
- d. Skills and Difficulties Questionnaire
- e. Conners' questionnaire

Answers: ABC

4. Management of disordered eating/diabulimia may include

- a. Diabetes multidisciplinary team – doctors, dietitians, clinical psychologist and paediatric diabetes nurse specialist
- b. Youth worker
- c. Child and adolescent mental health teams (CAMHS) only if the child or young person reaches threshold for eating disorder (e.g. anorexia nervosa)
- d. Inpatient eating disorder facility
- e. Liaison with CAMHS team

Answers: ABDE

REFERENCES

1. Reynolds KA HV. Children with Diabetes Compared to Peers: Depressed? Distressed?: A Meta-Analytic Review. *Ann Behav Med*. 2011;42(1):29–41.
2. NICE. Diabetes (type 1 and type 2) in children and young people : diagnosis and management. 2015;(August):1–92.
3. Bryden KS, Neil A, Mayou RA, Peveler RC, Fairburn CG, Dunger DB. Eating habits, body weight, and insulin misuse: A longitudinal study of teenagers and young adults with type 1 diabetes. *Diabetes Care*. 1999;22(12):1956–60.
4. Bächle C, Stahl-Pehe A, Rosenbauer J. Disordered eating and insulin restriction in youths receiving intensified insulin treatment: Results from a nationwide population-based study. *Int J Eat Disord*. 2016;49(2):193–8.
5. Young V, Eiser C, Johnson B, Brierley S, Epton T, Elliott J, et al. Eating problems in adolescents with Type1 diabetes: A systematic review with meta-analysis. *Diabet Med*. 2013;30(2):189–98.
6. Neumark-Sztainer D, Patterson J, Mellin A, Ackard DM, Utter J, Story M, et al. Weight control practices and disordered eating behaviors among adolescent females and males with type 1 diabetes: Associations with sociodemographics, weight concerns, familial factors, and metabolic outcomes. *Diabetes Care*. 2002;25(8):1289–96.
7. Rydall AC, Rodin GM, Olmsted MP, Devenyi RG, Daneman D. Disordered Eating Behavior and Microvascular Complications in Young Women with Insulin-Dependent Diabetes Mellitus. *N Engl J Med [Internet]*. 1997 Jun 26;336(26):1849–54. Available from: <http://dx.doi.org/10.1056/NEJM199706263362601>
8. Goebel-Fabbri AE, Fikkan J, Franko DL, Pearson K, Anderson BJ, Weinger K. Insulin Restriction and Associated Morbidity and Mortality in Women with Type 1 Diabetes. *Diabetes Care [Internet]*. 2008 Feb 27;31(3):415 LP-419. Available from: <http://care.diabetesjournals.org/content/31/3/415.abstract>
9. Fairburn CG. Cognitive behavior therapy and eating disorders [Internet]. *Cognitive behavior therapy and eating disorders*. 2008. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=psyc5&NEWS=N&AN=2008-07785-000>
10. Goebel-Fabbri AE, Uplinger N, Gerken S, Mangham D, Criego A, Parkin C. Outpatient Management of Eating Disorders in Type 1 Diabetes. *Diabetes Spectr [Internet]*. 2009 Aug 28;22(3):147 LP-152. Available from: <http://spectrum.diabetesjournals.org/content/22/3/147.abstract>
11. Philpot U. Eating disorders in young people with diabetes: Development, diagnosis and management. *J Diabetes Nurs [Internet]*. 2013;17(6):228–32. Available from:

- <http://www.scopus.com/inward/record.url?eid=2-s2.0-84879950844&partnerID=tZOtx3y1>
12. Zenlea IS, Mednick L, Rein J, Quinn M, Wolfsdorf J, Rhodes ET. Routine Behavioral and Mental Health Screening in Young Children with Type 1 Diabetes Mellitus. *Pediatr Diabetes* [Internet]. 2014 Aug 26;15(5):384–8. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4033709/>
 13. Zuijdwijk CS, Pardy SA, Dowden JJ, Dominic AM, Bridger T, Newhook LA. The mSCOFF for Screening Disordered Eating in Pediatric Type 1 Diabetes. *Diabetes Care* [Internet]. 2014 Jan 23;37(2):e26 LP-e27. Available from: <http://care.diabetesjournals.org/content/37/2/e26.abstract>
 14. Jones JM, Lawson ML, Daneman D, Olmsted MP, Rodin G. Eating disorders in adolescent females with and without type 1 diabetes: cross sectional study. *BMJ*. 2000;320(7249):1563–6.
 15. Markowitz JT, Butler DA, Volkening LK, Antisdell JE, Anderson BJ, Laffel LMB. Brief Screening Tool for Disordered Eating in Diabetes. *Diabetes Care* [Internet]. 2010 Feb 27;33(3):495 LP-500. Available from: <http://care.diabetesjournals.org/content/33/3/495.abstract>
 16. Bar RJ, Cassin SE, Dionne MM. Eating disorder prevention initiatives for athletes: A review. *Eur J Sport Sci*. 2015;1391(March):1–11.
 17. Battaglia MR, Alemzadeh R, Katte H, Hall PL, Perlmutter LC. Brief report: disordered eating and psychosocial factors in adolescent females with type 1 diabetes mellitus. *J Pediatr Psychol*. 2006;31(6):552–6.
 18. Pinhas-Hamiel O, Graph-Barel C, Boyko V, Tzadok M, Lerner-Geva L, Reichman B. Long-term insulin pump treatment in girls with type 1 diabetes and eating disorders--is it feasible? *Diabetes Technol Ther*. 2010 Nov;12(11):873–8.
 19. National Institute for Health and Care Excellence. Eating disorders in over 8s : management. NICE Guidel. 2004;(January).
 20. Psychiatrists RC of. Summary of Junior MARSIPAN : Management of Really Sick Patients under 18 with Anorexia Nervosa. Coll Rep 168s. 2015;