

# **What is Diabulimia and what are the implications for patients with Type 1 Diabetes?**

## **Abstract**

Diabulimia has become a common term used to describe a condition when a person with type 1 diabetes has an eating disorder. The individual may omit or restrict their insulin dose to lose/control weight. Evidence suggests that as many as 20% of women with type 1 diabetes may have this condition. The serious acute and long-term complications of hyperglycaemia are well documented. Detection of this condition is challenging and health care professionals need to be vigilant assessing reasons for variable glycaemic control and weight changes. Management requires a collaborative response from both the specialist diabetes team in conjunction with the mental health team. Nurses must ensure that they are aware that the condition may be possible in all patients with Type 1 diabetes but especially younger female patients. These patients require timely intervention to prevent any severe acute or long-term complications.

## **Key phrases and key words**

- Increased incidence of eating disorders in type 1 diabetes
- Physical complications from diabetes and increased mortality are much more prevalent in people with eating disorders and diabetes
- Early detection and appropriate treatment for the eating disorder and management of diabetes is essential
- Nurses need to be able to identify eating disorders in this group and work with MDT and person to address and manage their care

## **MESH words/database search terms**

Diabetes Mellitus Type 1, Hyperglycaemia, Insulin, Feeding and Eating Disorders, Body Weight

## **Introduction**

Diabulimia is not an official diagnosis but a colloquial term used by the media to describe a condition where a person diagnosed with diabetes omits or restricts their insulin dose in order to lose/control their weight (Philpot, 2013, Allan, 2015, Falcão & Francisco, 2017). They may avoid fats and carbohydrates, restrict their dietary intake and eat a large amount of food which subsequently results in feelings of guilt and self-loathing. It is a weight loss strategy used predominantly by young females with type 1 diabetes (Shaban, 2013). However, the correct terminology is eating disorder with type 1 diabetes (ED- T1M) (Philpot, 2013).

Omitting insulin results in weight loss as glucose is not stored as fat but is excreted in the urine. A person then feels they have better control over their body, which is a major factor in eating disorders. However, when the individual returns to their correct

insulin regime, they regain the weight they had lost. This therefore reinforces the practice of omitting/restricting their insulin (Falcão & Francisco, 2017).

### Eating disorders

An eating disorder is defined as a preoccupation with food and/or weight and body shape. The person is generally unhappy with their body and appearance. Individuals frequently suffer from low self-esteem, guilt, shame and secrecy (Institute of Psychiatry, 2018). Therefore the person engages in very disordered eating behaviour. This may include severely restricting their dietary intake, eating large quantities of food rapidly (binge eating), excessive exercise and using laxatives and diuretics to eliminate food from the body in order to avoid weight gain (BEAT, 2017).

The main eating disorders are anorexia nervosa, bulimia nervosa, binge eating disorder and other specified eating and feeding disorders (OFSED) (BEAT, 2017, NICE 2017b). A person with anorexia nervosa will severely restrict their dietary intake and may also engage in excessive exercise. They will present as severely underweight, which may be masked by wearing oversized clothes (Institute of Psychiatry, 2018). In bulimia nervosa, a person will report a loss of control of their eating. They are usually of normal weight or slightly overweight, and have periods of self-imposed starvation punctuated by binge eating vast amounts of carbohydrate foods, secretly. These binges are followed by self-induced vomiting and/or laxative use to prevent weight gain (Institute of Psychiatry, 2018). Binge eating disorder consists of episodes of binge eating, as reported above, but it is not accompanied by purging and the person is usually obese. OFSED is diagnosed when a person has elements of the disorders above, but does not completely fulfil the diagnostic criteria for these disorders (MIND, 2017).

### Diabetes

In the United Kingdom 3.7million people are living with diabetes. Approximately 10% of this population have type 1 diabetes and insulin is a life-saving drug for these individuals (Diabetes UK, 2017). For people with type 1 diabetes their pancreas no longer produces insulin and without injections of exogenous insulin they would experience persistent hyperglycaemia. In an acute situation this could result in Diabetic ketoacidosis (DKA). DKA is a complex life threatening metabolic state combining hyperglycaemia, acidosis and ketonaemia (JBDS IP Group, 2010). The importance of maintaining optimal glycaemic control in the avoidance of long-term complications is very well documented (DCCT, 1993). NICE guidelines recommend the optimal HbA1c target is 48mmol/mol (6.5%) for children, young people and adults (NICE, 2017a). Patients with Type 1 diabetes have an enormous challenge managing their glycaemic control to meet this target, while maintaining busy lifestyles which can be especially difficult for adolescents (Borus & Laffel, 2010).

Figure 1: Impact of excursions from optimal glycaemic levels

## Eating disorders and diabetes

Shaban (2013), states that the presence of eating disorders and diabetes was initially reported in 1970s. It is now well recognised that there is an increased incidence of eating disorders or disordered eating behaviours in people with Type 1 diabetes (Larrañaga et al, 2011, Allan, 2015, NICE, 2017a). Women with Type 1 diabetes are twice as likely to develop an eating disorder than those without diabetes and prevalence can range between 31 – 40% in females from 15 – 30 years (Doyle et al, 2017). Prevalence of eating disorders in men with type 1 diabetes has not been studied as widely due to decreased incidence of eating disorders in men generally. However, Doyle et al (2017) small pilot study using a specific validated measure (Diabetes Eating Problem Survey) to examine eating disorders in this group found 18% of their sample of men had disordered eating.

A person with an eating disorder and Type 1 diabetes is more likely to have impaired glycaemic control, experience more frequent episodes of diabetic ketoacidosis and a greater likelihood of developing complications from their diabetes, particularly retinopathy (Larrañaga et al, 2011). Worryingly this restriction of insulin has also been found to have a threefold risk increase in mortality for women (Goebel-Fabbri et al, 2008).

In essence, the presence of eating disorders in diabetes should not be surprising. Type 1 diabetes is most commonly diagnosed between the ages of 9-14 years, although people can be diagnosed as a younger child or as an adult. (Diabetes UK, 2017a) The age group at greatest risk of developing an eating disorder are those between the ages of 13-17 years (NICE, 2017a, Royal College of Psychiatrists 2018b). It is thought that 20% of females with diabetes also have an eating disorder (Markowitz et al, 2010) although other research suggests that a third of patients with diabetes admit insulin avoidance to lose weight (Hamiel et al, 2015).

During adolescence the body undergoes a number of physiological changes, many involving changes to body shape. Young people, particularly females are more concerned with their body shape and weight (Mintem, et al, 2015). Those living with type 1 diabetes face the additional challenge of requiring vigilance with their dietary intake, physical activities and the regular monitoring of their glycaemic levels. All of this can lead to increased stress (Borus & Laffel, 2010). In addition research has confirmed that child and adolescents with type 1 diabetes are more prone to becoming overweight or obese and females are the most at risk (Minges et al, 2017).

It is widely reported that chronic illnesses such as diabetes can have a detrimental effect on a person's mental health, in particular disordered eating (Larrañaga et al, 2011, Royal College of Psychiatrists, 2018a). An eating disorder may predate diabetes or diabetes may trigger an eating disorder. On initial diagnosis of diabetes, weight loss is often reported by the person and/or family members. This weight loss may have had a positive impact on the person including compliments on weight and

shape from friends. When treatment begins and weight gain occurs, this may cause disordered eating patterns and weight loss strategies such as insulin omission (Mathieu, 2008, Philpot, 2013).

### **Detection & Management of Eating Disorders in Diabetes**

It is unlikely that a person with an eating disorder will disclose this information. Eating disorders are shrouded in shame and secrecy (Candler et al, 2017). Individuals with an eating disorder will also find it distressing and difficult to discuss and it is often the health care professionals who detect that this may be a concern (Larrañaga et al, 2011). See Box 1 for signs of an eating disorder in diabetes.

It may also be helpful to use a screening tool to establish the presence of disordered eating specifically for individuals with diabetes, rather than a validated eating disorder questionnaire (Young, et al, 2013, Doyle et al, 2017). The rationale is that a generic eating disorder measure can overestimate and underestimate the prevalence of eating disorders in diabetes. Overestimation can occur because a person with diabetes has to be vigilant regarding their dietary intake and has limited ingestion of carbohydrates which on a generic eating disorder questionnaire may be interpreted as an eating disorder. However, such measures can also underestimate the prevalence as they will not include questions regarding insulin omission as a weight loss strategy (Young, et al, 2013, Doyle et, al, 2017). Awareness around this area has increased and there is a specific tool for use in diabetes known as Diabetes Eating Problem Survey, known as DEPS-R. It is a 16 item self-report measure and can be used to identify if there is the presence of disordered eating requiring further investigation (Markowitz et al, 2010). (Box 2). The NICE guidelines (2017a) fail to recommend this specific screening tool and also highlight that screening tools should not be used as the sole determinant for the assessment and diagnosis of an eating disorder.

It is essential to detect eating disorders in diabetes as soon as possible. It is widely reported that unstable glycaemic control caused by insulin omission/ restriction, has resulted in increased physical complications from diabetes and has the added risk of early mortality (Larrañaga et al, 2011). Results from the Diabetes Control and Complications Trial Research Group (DCCT) have consistently shown that maintenance of optimal glycaemic levels prevents complications from diabetes (DCCT, 1993)

A multi-disciplinary approach to working with people with diabetes and eating disorders is imperative. It is important to involve both the diabetes team; which should consist of an endocrinologist, specialist nurse, dietician and an eating disorder team including a psychiatrist, psychologist and nurses. (NICE, 2017b). NICE (2017b) stipulate that both teams should collaborate on managing both the mental health and physical health comorbidities. It is important to agree who has the

main responsibility for monitoring the physical health and in reality, this can be difficult to achieve (Allan 2017). Some diabetic teams include a psychologist or a member of the liaison mental health team. NICE (2017b) outlines a treatment care plan.

The NICE guidelines recommend that with the treatment of eating disorders in people with type 1 diabetes, outcome measures for both conditions must be considered when monitoring the effectiveness of any treatments. Essentially HbA1c and BMI must both be considered (NICE, 2017b). The usual treatments for eating disorders which encourage a relaxed manner with food may be in conflict with what many patients with type 1 diabetes have been taught about their diet. The potential physical risks for these patients can be significant, so the best management is often where the specialist diabetes team takes responsibility for care with support from the mental health team (Allan, 2017)

It is imperative that the person with diabetes and an eating disorder is fully involved in all the decisions surrounding their care and managing their diabetes. The maintenance of control is fundamental to a person with an eating disorder. Therefore if they feel excluded from the decision making process and their control is threatened their disordered eating behaviour may accelerate. Also with the person's agreement and if appropriate, involvement of a family member or carer can provide both practical help and emotional support (NICE, 2017b).

### Case study

*Grace was a 21-year university student who was seen by her practice nurse following an urgent request for an insulin prescription. It was clear to the practice nurse that Grace's visits to the surgery for her insulin prescription were sporadic. She had also not attended her annual review and correspondence from the secondary care team was missing, indicating her lack of engagement.*

*On further questioning Grace appeared to be symptomatic with polyuria, polydipsia and lethargy. She stated that she could guess her blood sugar levels and didn't feel the need to test regularly. Grace admitted that she only attended that day because she was feeling really unwell and thought her levels were raised. and knew she needed insulin. Grace regularly took her basal insulin but indicated that she was less inclined to take her meal-time bolus insulin. In clinic her blood sugar was 15mmols, with no ketones. On further questioning Grace admitted she felt under pressure to lose weight and missing her insulin was the easiest way to do this.*

*Grace was at high risk of developing DKA and further long term complications of diabetes. In the short term, it is essential to reduce her acute risk and lower her blood sugars. It is really important to develop a relationship with Grace where she feels she is able to be honest and seek support. It is essential that Grace leave the clinic with her insulin prescription, updated blood glucose monitoring equipment and ketones stix. (advised to check for ketones, if her blood sugars are ever above 14mmols). Grace requires intensive education and-urgent collaborative interventions with both the secondary care diabetes team working with her primary care team and in conjunction with the mental health team.*

### **Awareness of misdiagnosis**

It is important to be aware that misdiagnosis of an eating disorder is possible. Insulin doses may be forgotten, rather than omitted and people with hectic lifestyles report difficulties incorporating regular meals each day (Davidson, 2014). Individuals may also have brittle diabetes, where glycaemic control is very difficult to achieve (Wilson, 2012). Nurses and the MDT need to explore thoroughly why this may be occurring as well as ensuring that other organic causes have been excluded (Candler et al, 2017).

## **Implications for practice**

Nurses, particularly those working in medical settings or diabetic teams need to be aware that there is an increased incidence of eating disorders in people with diabetes. The short term consequences include DKA which is a life threatening condition. Due to omission of insulin and abnormal eating patterns, DKA is much likely to occur in this population (Candler et al, 2017). Identification of symptoms or concerns regarding physical health requires further investigation, ensuring that the person with diabetes is actively involved with all discussions and decisions (Falcão & Francisco, 2017). If an eating disorder is suspected, use of Eating Problem Survey, known as DEPS-R will help to identify eating issues and whether further investigation by a mental health practitioner is required (Candler et al, 2017). Approximately 10% of patient with type 1 diabetes are managed in primary care often through their own choice (James, 2013). It is important that primary care teams are aware of the risk of eating disorders in association with diabetes and seek support from secondary care.

Healthcare practitioners report difficulties managing the care of people with Type 1 diabetes and eating disorders and feel that they do not possess the skills required (Mathieu, 2008). Therefore support and collaboration by MDT including education from eating disorder/mental health services is extremely beneficial (Allan, 2015)

## **Conclusion**

Nurses need to be cognisant that there is an increased incidence of eating disorders in people with diabetes, particularly younger people. Therefore if there is an indication from their symptoms such as unstable glycaemic control and fluctuating weight; discussion regarding their eating behaviour is required as well as assessment using specific assessment tool such as DEPS-R. A multi- disciplinary approach which includes a mental health professional such as a mental health nurse or psychologist with excellent communication channels and full involvement of the person with diabetes is imperative to ensure optimal care.

## **Useful websites**

**BEAT** For up to date information about eating disorders

<https://www.beateatingdisorders.org.uk>

**Diabetes UK** Up to date information about diabetes and also discusses eating disorders <https://www.diabetes.org.uk>

**DWED – Diabetics with Eating Disorders** <http://dwed.org.uk/> a charity organisation that supports and advocates for people with both type 1 diabetes and an eating disorder.

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