

Experiences of Insulin Restriction or Omission in Type 1 Diabetes Mellitus: A Meta-Synthesis of Patient Experiences and Evidence-Based Guidance for Practice

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Declaration

This report contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this report contains no materials previously published except where due reference is made.

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Insulin Restriction or Omission in Type 1 Diabetes Mellitus ('Diabulimia'): Literature Review

Abstract

Diabetes mellitus is a significant health issue globally, contributing considerably to morbidity and mortality. Type 1 diabetes mellitus (T1DM), a specific type of diabetes mellitus, is a chronic endocrine disease characterised by insufficient insulin production which requires daily management. Research has shown that individuals with T1DM have increased rates of psychosocial issues, including disturbed eating behaviours compared to their nondiabetic peers. Unique to individuals with T1DM is a disordered eating behaviour whereby insulin is deliberately restricted or omitted, coined '*diabulimia*'. T1DM and its management present a unique set of biological, psychological and social eating disorder risk factors in addition to those imposed on the general population which may account for the higher prevalence of disordered eating behaviours observed. Disturbed eating behaviours and clinical eating disorders predispose individuals with T1DM to many complex medical risks and increased risks of morbidity and mortality, which highlights the importance of effective prevention strategies and interventions. As the empirical evidence surrounding this area of research continues to grow, it is evident that standard eating disorder treatments are ineffective among individuals with T1DM, and currently, there is a lack of consensus on best practice. For this reason, it is critical to increase understanding about the thoughts, beliefs and experiences associated with disordered eating behaviours and, specifically, the intentional restriction and omission of insulin within individuals with T1DM. This review aims to identify, analyse and synthesise existing knowledge about disordered eating behaviour among individuals with T1DM with a focus on the deliberate restriction and omission of insulin for weight loss.

Keywords: Type 1 diabetes mellitus; diabulimia; disordered eating behaviour; eating disorders; insulin restriction and omission

Diabetes Mellitus: Introduction, Definitions and Epidemiology

Diabetes Mellitus (DM) is a prominent health issue and a leading cause of morbidity and death within Australia (Australian Bureau of Statistics [ABS], 2019) and across the globe (World Health Organisation [WHO], 2018). DM refers to a group of endocrine diseases characterised by the body's inability to regulate blood sugar levels resulting from a lack of insulin production, resistance to insulin or both (WHO, 2019). Most cases of DM fall into two broad categories: Type 1 Diabetes Mellitus (T1DM) and Type 2 Diabetes Mellitus (T2DM). T1DM results from the destruction of pancreatic islet beta cells by an autoimmune response within the body, where the pancreas becomes unable to produce sufficient insulin to assimilate glucose and nutrients for healthy cell functioning (Atkinson et al., 2014). T2DM results primarily from skeletal muscle and liver cells becoming resistant to the insulin produced by the pancreas. The natural progression of T2DM can see a gradual decline in the pancreas' ability to produce sufficient insulin, as seen in T1DM, thus becoming insulin-dependent (WHO, 2019).

As of 2014, an estimated 422 million adults were living with DM worldwide (WHO, 2016), with this figure projected to increase to 642 million by 2040 (Atlas, 2015). Currently, distinct global estimates of DM types do not exist; however, T1DM is estimated to account for 5-10% of the total cases of DM (American Diabetes Association, 2013), and recent estimates within Australia indicate that in 2017-2018 1.2 million Australian adults had DM, with approximately 145,000 people having T1DM (ABS, 2018).

Diabetes Mellitus: Burden of Disease

Management of DM and DM-related complications bring about a significant economic burden to individuals and healthcare systems. Globally, direct medical costs of DM are estimated to be more than US\$ 827 billion annually (Seuring et al., 2015; Zhou et al.,

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2016), with DM accounting for 5%-20% of total health expenditure in most countries (Atlas, 2015).

The highest cost of DM, however, is its impact on morbidity and mortality. Individuals with DM are at a significantly higher risk of health complications, hospitalisations, disability and premature death than the general population due to fluctuations in blood glucose (Australian Institute of Health and Welfare [AIHW], 2017; Atlas, 2015). Slight fluctuations in blood glucose levels are normal, but complications can arise when blood glucose becomes too low (hypoglycaemia) or too high (hyperglycaemia).

Long-term diabetes-related complications primarily relate to chronic or recurrent hyperglycaemia (Daneman, 2006). Hyperglycaemia occurs when there is not enough insulin within the blood to assimilate glucose into cells for energy use, and blood glucose accumulates to dangerously high levels (Fowler, 2009). Deprived of glucose utilisation, the body turns to its stores for fuel (Fowler, 2009). The process of burning fat and tissue for energy produces ketones which can turn the blood acidic and can result in a life-threatening condition called diabetic ketoacidosis (DKA) (Fowler, 2009). As blood glucose levels exceed what the kidneys can filter, glucose is excreted through the urine, increasing urine output (polyuria) and increases the risk of dehydration and loss of electrolytes (Fowler, 2009). Long-term diabetes-related complications are divided into microvascular or macrovascular complications (Fowler, 2009). Microvascular complications refer to damage to small vessels, such as capillaries, and can lead to visual disability and blindness (retinopathy), diabetic kidney disease (nephropathy) and nerve damage (neuropathy). Macrovascular complications refer to damage to large vessels, such as arteries and veins, increasing the risk of cardiovascular disease, peripheral artery disease, and stroke (Atkinson et al., 2014; Bourne et al., 2013; Cade, 2008; Daneman, 2006).

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In 2012, DM accounted for approximately 1.5 million deaths across the globe, with hyperglycaemia causing an additional 2.2 million deaths by increasing the risks of cardiovascular and other diseases (WHO, 2016). Within Australia, DM contributes to approximately 10% of all deaths with age-adjusted death rates almost double for DM individuals compared to the general Australian population and highest in those aged under 45 years (AIHW, 2017; AIHW, 2018).

Management of Diabetes Mellitus

Optimal management of DM leading to good metabolic control and prevention of complications is therefore of significant social and economic importance. Although effective self-management of DM is possible, management of T1DM is a particularly demanding and daily, lifelong task. A strict insulin therapy regime and careful attention to blood glucose levels, dietary intake and physical activity are, therefore, the most integral components of T1DM management to prevent associated risks to health (Atkinson et al., 2014; Fowler, 2011). In order to replicate a normal baseline in the blood, individuals with T1DM must administer basal insulin daily and further bolus insulin to correct any changes in blood glucose from carbohydrate intake and achieve glycaemic control via manual injections or an insulin pump (Atkinson et al., 2014). T2DM is predominantly managed through a combination of lifestyle modifications and pharmacological treatment without the need for insulin therapy; however, disease progression can result in insulin dependence (Mosenzon et al., 2016). The focus of this current review is T1DM, so the remaining discussion will only refer to T1DM.

Disordered Eating Behaviours and T1DM

High rates of disordered eating behaviours among T1DM populations are becoming increasingly recognised (Pinhas-Hamiel et al., 2015). Disordered eating behaviours include a range of abnormal eating behaviours associated with clinically significant eating disorders in

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the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition (DSM-V; American Psychological Association [APA], 2013), namely anorexia nervosa, bulimia nervosa, other specified feeding and eating disorders (OSFED) and unspecified feeding or eating disorders that are not at a level of severity or frequency to be diagnosable (Olmsted et al., 2008). These behaviours are designed to control weight and shape and include extreme dieting behaviour, self-induced vomiting, binge eating episodes, the use of diuretics and laxatives, excessive exercising and other compensatory behaviours for weight control (APA, 2013).

The literature indicates that the incidence of disordered eating behaviours among those with T1DM is alarmingly high. In meta-analyses by Young et al. (2013) 39.3% of participants with T1DM displayed disordered eating behaviours, compared to 32.5% of controls, while clinical eating disorders were diagnosed in 7.0% of people with T1DM and only 2.8% of controls. Moreover, results of a 14-year longitudinal study in a cohort with T1DM reported a cumulative probability of experiencing a clinically significant eating disorder of 60% by the age of 25 years (Colton et al., 2015).

With regard to eating disorder subtypes in T1DM, a systematic review and meta-analysis by Nielsen (2002) demonstrated that while anorexia nervosa was not more prevalent in those with T1DM, there was a threefold increased risk of bulimia nervosa and a twofold increased risk of a subthreshold eating disorder and eating disorder not otherwise specified (EDNOS; now known as OSFED; APA, 2013). Similarly, a meta-analysis of controlled studies by Mannucci et al. (2005) found no significant difference in the prevalence of anorexia nervosa in females with T1DM when compared to non-diabetic peers; however, a significantly higher prevalence of bulimia nervosa and EDNOS was found for individuals with T1DM.

Insulin Restriction and Omission in T1DM ('Diabulimia')

Unique to individuals with insulin-treated diabetes, and a growing area of interest to researchers, is a purging behaviour whereby insulin is deliberately restricted or omitted (Affenito & Adams, 2001; Doyle et al., 2017; Falcão & Francisco, 2017; Mathieu, 2008). Insulin restriction refers to individuals deliberately taking less insulin than they need (Goebel-Fabbri et al., 2008), while insulin omission involves missing of insulin doses completely (Peyrot et al., 2010). The mechanism of 'diabulimia', as it has been coined, reflects the purging of calories via a process called glycosuria, in which hyperglycaemia is deliberately induced, and glucose is excreted through urine (Goebel-Fabbri et al., 2008; Hasken et al., 2010). Proteins and fats are broken down to be used as alternative energy sources further contributing to weight loss (Hasken et al., 2010). Insulin restriction or omission as a disordered eating behaviour is not yet an approved diagnosis recognised in the DSM-V (APA, 2013). Instead, the behaviour is recognised under the labels of an inappropriate compensatory purging behaviour, bulimia nervosa and OSFED (APA, 2013).

Among disordered eating behaviours observed in T1DM, insulin restriction and omission has been reported as the most common weight loss behaviour after dieting (Jones et al., 2000). Prevalence of insulin restriction and omission has varied significantly across the literature with a recent systematic review reporting rates of 4.1%-58% within T1DM populations without an eating disorder and 47.9%-90% in comorbid T1DM and eating disorder populations, with higher rates typically observed in females (De Paoli & Rogers, 2018). Insulin restriction and omission are often used in addition to other disordered eating behaviours. In one study, 75% of T1DM individuals with a comorbid eating disorder used insulin omission and restriction alone, while 19% used insulin omission with self-induced vomiting and 6% used insulin omission with excessive exercise (Takii et al., 1999). In a more recent study, 26% of those reporting insulin restriction and omission for weight loss used it

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exclusively while 74% used it in combination with other disordered eating behaviours (Powers et al., 2012).

Disordered Eating Behaviours in Males with T1DM

Most research has focused on females with T1DM. The paucity of research concerning disordered eating behaviours in males with T1DM may be attributed to the lower incidence of eating disorders reported in men generally (Galmiche et al, 2019). Although lower rates have been observed, disordered eating behaviours are still overrepresented in males with T1DM compared to their non-diabetic counterparts (Doyle et al., 2017). Neumark-Sztainer et al. (2002) found that 37.9% of adolescent females and 15.9% of adolescent males with T1DM used unhealthy weight management behaviours. Similarly, Doyle et al. (2017) found that 18% of males with T1DM had disordered eating behaviours. Furthermore, drive for thinness and body dissatisfaction in young men with T1DM has also been reported to be high (Araia et al., 2017; Neumark-Sztainer et al., 2002; Svensson et al., 2003). A recent Australian study found among adolescents with T1DM, 88% of females and 76% of males expressed body dissatisfaction (Araia et al., 2017). Furthermore, 39% of females and 25% of males expressed the belief that they would be at their ideal size or thinner than their ideal size (23% and 16%, respectively) if they did not have T1DM (Araia et al., 2017). Within the literature on insulin restriction and omission in T1DM, females have also been over-represented (De Paoli & Rogers, 2018). Therefore, very little is known about why males may misuse insulin.

A Biopsychosocial Perspective of Risk and Maintaining Factors of Disordered Eating in T1DM

Within the literature, few models encompass the development and maintenance of disordered eating in T1DM (De Paoli & Rogers, 2018; Goebel-Fabbri et al., 2002; Peterson et al., 2015; Treasure et al., 2015). Existing models draw from the eating disorder literature and

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well-established models of disordered eating psychopathology including The Transdiagnostic Model of Eating Disorders (Fairburn et al., 2003), and The Dual-Pathway Model (Stice, 1994; Stice et al., 1998). While these models provide a promising foundation for understanding disordered eating in T1DM, they are yet to be empirically established.

The Biopsychosocial Model of health and illness, developed by Engel (1977), posits that psychological and social factors can influence biological functioning and play a role in the development and maintenance of health and illness. Engel (1977) proposed that to understand the determinants of disease and form appropriate treatments, the traditional Biomedical Model must also consider the individual, the social context in which he/she lives, and the broader sociocultural environment. The use of the Biopsychosocial Model within T1DM has been repeatedly advocated (Driscoll et al., 2017; Peyrot et al., 1999; Snoek & Skinner, 2002).

It could be argued that the Biopsychosocial Model (Engel, 1977) is the most comprehensive theoretical framework within which to broadly conceptualise and evaluate the pathogenesis of disordered eating within T1DM. The aetiology of eating disorders is generally accepted as multifactorial with many specific biological (e.g. genetic vulnerability), psychological (e.g. modelling of body image and eating disturbances, body dissatisfaction, negative affect, inadequate coping skills, low self-esteem, perfectionistic traits, dieting), and sociocultural risk factors (e.g. sociocultural pressure to be thin, low social support) associated with the development and maintenance of eating disorders identified within the literature (Jackson & Chen, 2014; Holton-Viesel & Allan, 2014; Rodgers et al., 2014; Stice et al., 2012). However, several factors associated uniquely with the diagnosis and treatment of T1DM help to explain why the diabetic population are at an increased risk for developing eating disturbances compared to the non-diabetic population (Figure 1).

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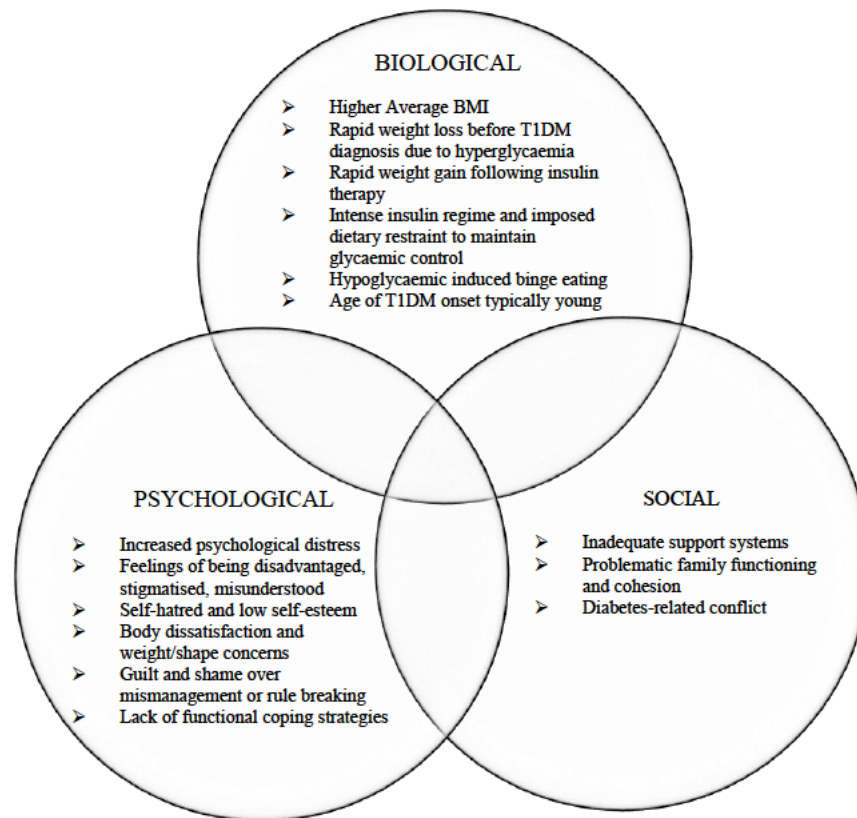


Figure 1. The Biopsychosocial Model (Engel, 1977) adapted to conceptualise T1DM associated risk factors for the development and maintenance of disordered eating.

Research has suggested a close relationship exists between T1DM and increased psychological distress, which has been theorised to relate to the complex and demanding nature of T1DM management (Buchberger et al., 2016; Butwicka et al., 2015; Cooper et al., 2017; Danne et al., 2014; Reynolds & Helgeson, 2011). The increased risk of significant comorbid anxiety (Smith et al., 2013) and significant depressive symptoms which has been found in adults with T1DM compared to their non-diabetic counterparts are examples of such an effect (Anderson et al., 2001; Dantzer et al., 2003). A meta-analysis by Reynolds and Helgeson (2011) found significantly more depressive symptoms and clinical depression were reported by adolescents with T1DM compared to non-diabetic peers. Moreover, a population-based case-cohort study found children with T1DM were at higher risk of psychiatric

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comorbidity compared with matched controls within six months of T1DM diagnosis, and suicide attempts were significantly more frequent (Butwicka et al., 2015). This increased susceptibility to depressive symptoms and psychiatric comorbidity has been theorised to increase the risk of developing disturbed eating behaviour in T1DM individuals. Indeed, among girls with T1DM, those diagnosed with depression reported higher disordered eating behaviours than those without depression (Colton et al., 2013). Although it is unclear if this is due to a shared vulnerability to disordered eating behaviours and mood problems, or that difficulties in one realm can confer risk in the other (Colton et al., 2013). Depression has also been linked explicitly to insulin restriction and omission in those with T1DM, with individuals with symptoms of depression more likely to omit insulin (Trief et al., 2014).

Individuals with T1DM have also reported feeling more disadvantaged than their non-diabetic peers, misunderstood, stigmatised, self-conscious and expressed hatred towards their bodies (Balfe et al., 2013; Kay et al., 2009; Marshall et al., 2009; Watts et al., 2010). Lower self-esteem has been associated with disordered eating behaviours in females with T1DM (Colton et al., 2007), and in a longitudinal study, the development of disordered eating behaviours in females with T1DM was predicted by lower self-esteem related to physical appearance, and also lower global self-esteem (Olmsted et al., 2008).

Furthermore, body dissatisfaction and negative body image are viewed as core clinical features of psychopathology in eating disorders generally (Neumark-Sztainer et al., 2006; Stice et al., 2017) and have been associated with disordered eating behaviours, including insulin restriction and omission, in T1DM populations (Ackard et al., 2008; Grylli et al., 2010). Before being diagnosed with T1DM, substantial weight loss due to unrecognised hyperglycaemia is common, and the commencement of an insulin regime is often then accompanied by rapid weight gain (Russell-Jones & Khan, 2007). Several authors have suggested this may trigger the development of weight and shape concerns and disordered

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eating behaviour (Goebel-Fabbri, 2009; Grylli et al., 2005; Hasken et al., 2010; Jones et al., 2000; Pinar, 2005; Russell-Jones & Khan, 2007; Svensson et al., 2003; Young-Hyman & Davis, 2010). Also due to insulin therapy, individuals with T1DM have on average a higher mean body mass index (BMI) than their age-matched counterparts (Jones et al., 2000), which may exacerbate body dissatisfaction and a preoccupation with weight and shape (Affenito & Adams, 2001; Goebel-Fabbri et al., 2008; Goebel-Fabbri, 2009; Grylli et al., 2010; Olmsted et al., 2008).

Furthermore, individuals with T1DM, unlike non-diabetic peers, must pay close attention to dietary rules, food restrictions, portion sizes, meal timing, exercise, and weight in addition to blood glucose levels. The strict insulin and dietary regimes necessary to maintain good glycaemic control exacerbate a preoccupation with food consumption and body size in T1DM individuals, which can ultimately lead to disordered eating behaviours (Colton et al., 2009; Daneman et al., 2002; Goebel-Fabbri et al., 2008; Jones et al., 2000; Olmsted et al., 2008; Pinar, 2005; Powers et al., 2012).

Individuals with T1DM may experience frequent hypoglycaemic episodes which can induce disinhibited eating and episodes of bingeing, which may lead to weight gain and feelings of guilt and shame and the need to compensate (Daneman et al., 2002; Goebel-Fabbri et al., 2008; Young-Hyman & Davis, 2010). Merwin et al. (2014) examining eating behaviours and insulin dosing in individuals with T1DM, found that disinhibited eating following low blood glucose was accompanied by guilt and shame and that the increased frequency of disinhibited eating was associated with increased insulin restriction and omission for weight control. Insulin restriction was also higher when individuals experienced anxiety, nervousness, guilt, and disgust with self before eating, or when a dietary rule was broken (Merwin et al., 2014).

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A further challenge posed by T1DM is that it is generally diagnosed in children and adolescents, a particularly risky period for the onset of disordered eating (Starkey & Wade, 2010). The addition of the complex management of T1DM on top of pre-existing developmental demands may contribute to the increased prevalence of psychological distress, and disordered eating behaviours observed (Colton et al., 2007; Danne et al., 2014; Grylli et al., 2005). Given societal pressure to obtain the perfect body ideal (Kaminsky & Dewey, 2013), adolescents especially seem to be at risk for developing disordered eating behaviours, as they are particularly vulnerable for body dissatisfaction (Gagnon et al., 2017). Takii et al. (2011) provide support to this, demonstrating that eating disorders were highest amongst individuals with a diabetes onset age between 7 to 18 years. Similarly, Baechle et al. (2014) found that frequent insulin restriction or omission was reported in individuals with later disease onset (mean age at onset between 8 and about 17 years).

Research has also shown that adolescents with T1DM and comorbid eating disorders are also more likely to use negative coping strategies (i.e. self-criticism, social withdrawal, avoidance) than their T1DM peers without eating disturbances (Grylli et al., 2005). Insulin restriction and omission have been suggested to represent another dysfunctional coping strategy aimed at managing stressful situations, taking back control and managing negative emotions (Mathieu, 2008; Yan, 2007). Similarly, Custal et al. (2014) hypothesised that insulin omission and restriction may be more closely connected to regulating emotion after observing individuals with T1DM and comorbid insulin misuse being significantly less likely to self-harm and have suicidal ideation and suicidal behaviour than non-diabetic controls.

Inadequate support systems and problematic family functioning have also been found to influence eating behaviours in adolescents with T1DM. Specifically, research has demonstrated that high levels of diabetes-related conflict and low levels of family cohesion are significantly associated with increased disordered eating behaviours in T1DM adolescents

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(Caccavale et al., 2015; Rodin et al., 2002; Wilson et al., 2015; Neumark-Sztainer et al., 2002). Furthermore, disordered eating behaviours are higher in T1DM families in which parents made negative comments about eating or weight (Maharaj et al., 2001). Maternal weight and shape concerns as well as impaired relationships between mothers and daughters also significantly predicted eating disturbances in females with T1DM (Maharaj et al., 2003).

Consequences of Comorbid T1DM and Disordered Eating Behaviours

The high occurrence of disordered eating behaviours in individuals with T1DM is especially concerning given the increased risks and poorer glycaemic control associated with comorbidity (Larrañaga et al., 2011; Rodin et al., 2002). Custal et al. (2014) found that apart from the manipulation of insulin, individuals with eating disorders and individuals with comorbid eating disorders and T1DM, do not differ greatly on psychopathological features. However, individuals with comorbid T1DM and eating disorders face a higher risk of serious diabetes-related complications and mortality than non-comorbid peers due to poorer glycaemic control (Affenito & Adams, 2001; Goebel-Fabbri et al., 2008; Hasken et al., 2010; Larrañaga et al., 2011; Mathieu, 2008; Pinar, 2005; Peveler et al., 2005; Scheuing, 2014; Takii et al., 2008; Young et al., 2013). Young et al.'s (2013) meta-analysis reported a significant association between disordered eating behaviours and poorer glycaemic control in adolescents with T1DM. Another study found those engaging in insulin restriction and omission were eight times more likely to have poorly controlled diabetes compared with those who denied omitting insulin (Bernstein et al., 2013). Takii et al. (2008) examined the physiological effects of pathological weight control behaviours in 109 females with T1DM with a diagnosed eating disorder; omitting insulin for weight control was associated with the highest rates of retinopathy and nephropathy. Similarly, Goebel-Fabbri et al. (2008) found that insulin restriction at baseline predicted several adverse outcomes, such as significantly higher rates of nephropathy and foot problems. Likewise, Peveler et al. (2005) found that of

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87 young women who developed serious microvascular complications, 21% had a probable eating disorder, 47% had a history of disordered eating behaviours, and 48% had a history of insulin misuse. Furthermore, rates of hypoglycaemia with coma, ketoacidosis and hospitalisations are significantly higher in individuals with comorbid T1DM and eating disorders (Scheuing et al., 2014).

Most concerning about the comorbidity of eating disorders and DM is its effect on mortality. Individuals with comorbid T1DM and an eating disorder have been estimated to have three times higher mortality risk than individuals with T1DM alone (Larrañaga et al., 2011), with mortality rates per 1000 person-years estimated as high at 34.6 in females with both T1DM and an eating disorder, compared to 2.2 in females with T1DM and 7.3 in females with eating disorders (Nielsen et al., 2002). Goebel-Fabbri et al. (2008) similarly found that insulin restriction increased the risk of mortality by 3.2 times, even when controlling for BMI, age, and average level of diabetes control as determined by glycosylated hemoglobin, and decreased life span from an average of 58 to 44 years at 11-year follow up, highlighting the seriousness of this specific behaviour.

Current Treatments and Outcomes

Despite the high prevalence and clinical significance of disordered eating behaviour in T1DM, it remains a significantly understudied problem, and there is currently a lack of evidence about best practice treatment approaches for eating disorders generally in individuals with T1DM, with even less evidence for treating insulin restriction and omission. Most research investigating treatment for these individuals has concluded that standard eating disorder models do not work, and that relapse and attrition rates are high despite no significant differences in eating disorder psychopathology (other than insulin restriction) (Banting & Randle-Phillips 2018; Clery et al., 2017; Colton et al., 2015; Custal et al., 2014).

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Poor clinical outcomes have been suggested to result from low levels of motivation to change as well as a lack of understanding of the increased risks associated with comorbidity (Custal et al., 2014; Skinner et al., 2014). Furthermore, the nature of T1DM has been suggested to maintain unhealthy cognitions related to food, numbers and weight (Goebel-Fabbri et al., 2008; Goebel-Fabbri, 2009; Pinhas-Hamiel et al., 2015). Standard eating disorder treatments which focus on relaxing food rules and not counting calories are incompatible with successful T1DM management (Allan 2015; Hastings et al., 2016; Staite et al., 2018).

Clery et al. (2017) performed a meta-analysis to examine the effectiveness of interventions for comorbid eating disorders and T1DM. Overall, there was mixed support for the interventions examined with only some improvements in eating disorder symptoms and reduction in insulin restriction and omission reported in only four of the six included studies. Furthermore, improvements in glycaemic control post-intervention were observed in only three of the six included studies.

Of treatments that have shown promise for eating disorders in T1DM, Takii et al. (2002; 2003) compared the effectiveness of an “integrated inpatient therapy” (IIT) and outpatient treatment for bulimia nervosa in T1DM. Significant improvement in glycaemic control, depressive symptoms, anxiety and psychological/behavioural disturbances related to eating disorders was found among the IIT group, which continued at 3-year follow up, with 78% no longer meeting criteria for bulimia nervosa (Takii et al., 2003). Of the participants who received outpatient treatment, no significant improvement in measures was observed, and most still met criteria for bulimia nervosa at follow-up (Takii et al., 2003). Concerning insulin restriction and omission, there was a significant change in the percentage of participants restricting and omitting insulin in the inpatient treatment group, but not the comparison group, at first visit compared with follow-up (Takii et al., 2003). However, being

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a cohort-study, participants elected to be involved in the treatment, which may have reflected greater motivation to change (Takii et al., 2003).

Dickens et al. (2015) similarly explored the effectiveness of a multi-disciplinary residential treatment on eating disorder symptoms for women with T1DM. The treatment was Cognitive Behaviour Therapy based and focussed on the development of cognitive and emotional awareness to manage hunger and satiety cues as well as thoughts and urges. Participants attended two or three individual sessions per week and additional group sessions. A significant reduction in scores on drive for thinness, bulimia, body dissatisfaction, eating disorder risk, and general psychological maladjustment was found post-treatment (Dickens et al., 2015).

Psychoeducation interventions for eating disorders in T1DM have shown mixed results. Alloway et al. (2001) examined the effect of a six-week group psychoeducation program on eating disorder symptoms in T1DM compared to a waitlist control group but found no improvements. While Olmsted et al. (2002) evaluated a six-session psychoeducation program for young women with T1DM and disordered eating behaviours compared to treatment-as-usual and found that following psychoeducation, there were significant reductions in restraint and eating concerns, drive for thinness and body dissatisfaction. However, no improvement in the frequency of insulin omission or glycaemic control was evident.

Overall, inpatient treatment appears more effective than outpatient psychoeducation treatments for glycaemic control and eating disorder symptoms, which may reflect the greater intensity and length of inpatient treatments (Clery et al., 2017). Greater monitoring and less personal responsibility for insulin adherence during inpatient treatment may be responsible for the improvements in glycaemic control and insulin omission observed (Banting & Randle-Phillips, 2018; Takii et al., 2002 & 2003). Weak research designs and variation in

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methodology, however, make comparison across the literature difficult, and a lack of research explicitly evaluating treatment for insulin restriction or omission highlights the need for further investigation in this area.

Despite a lack of evidence for interventions, the literature generally emphasises the need for a multi-disciplinary team with experts in both T1DM and eating disorders to manage the unique features of the two conditions combined (Goebel-Fabbri, 2009; Macdonald et al., 2018).

Should ‘Diabulimia’ be a Separate Construct?

Currently disordered eating behaviours in T1DM fall into existing DSM-V diagnostic labels (APA, 2013), with insulin restriction and omission currently recognised under the labels of an inappropriate compensatory purging behaviour, bulimia nervosa and OSFED (APA, 2013). Research has, however, suggested the need to consider insulin restriction or omission for weight loss as a separate construct from current eating disorder labels (Allan, 2015; Allan & Nash, 2014; Custal et al., 2014; Nash, 2014; Tierney et al., 2009). The lack of a clear diagnostic term, and diagnostic criteria, has been suggested to contribute to the lack of understanding reported amongst health professionals, family members and friends, to a lack of tailored treatments (Hastings et al., 2016; Pinhas-Hamiel et al., 2015), and an inability to form connections with other comorbid peers (Colton et al., 2015). The term ‘diabulimia’ appears to have been adopted by the DM community (Allan, 2015; Hastings et al., 2016); however, individuals have reported rejection of the term ‘diabulimia’ by professionals in healthcare settings as being “made up on the internet” (Allan, 2015, p. 100). Similarly, controversy around the term exists within the literature with ‘diabulimia’ often used inconsistently between studies creating confusion regarding its meaning. Some authors use the term to describe insulin restriction and omission for weight control, while others use it to describe eating disorders comorbid with T1DM more generally (Wisting & Snoek, 2020). It

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has also been argued that the term is too narrow, predominantly represents bulimic symptomology and does not capture the broad spectrum of disturbed eating behaviour seen in DM (Colton et al., 2009; De Paoli & Rogers, 2018; Wisting & Snoek, 2020). Colton et al. (2009) proposed that the preferred nomenclature should be Eating Disorder – Diabetes Mellitus Type 1, while Wisting and Snoek (2020) propose that qualitative research seek the perspective of individuals with DM.

Clinical Practice

Given the similar nature of a healthy eating regime for optimal diabetes management, and disordered eating behaviours, disturbed behaviour among people with T1DM is a challenge in clinical practice (Hanlan et al., 2013). Indeed, disordered eating behaviours are also often well-hidden and denied, particularly ‘diabulimia’, and a high index of suspicion among health professionals working with DM individuals is needed (Pinhas-Hamiel et al., 2015). Furthermore, health professionals have reported difficulties in managing the care of individuals with comorbid eating disorders and T1DM, finding it a daunting task and have expressed often feeling unequipped to do so (Allan, 2015; Matthieu, 2008). Health professionals have similarly reported a lack of clarity about what constitutes “problematic” behaviour (Tierney et al., 2009). Individuals with T1DM and comorbid eating disorders have similarly expressed the need for health professionals to have increased knowledge and understanding of comorbid illnesses (Macdonald et al., 2018).

Conclusions and Implications for Research and Clinical Practice

Disordered eating behaviours are common and complex among individuals with T1DM, and the detrimental effects of comorbidity on health are alarmingly high. To date, research has predominantly focused on prevalence and symptoms rather than treatment approaches or individuals’ experiential perspectives. Furthermore, research has predominantly focused on disordered eating behaviours comorbid with T1DM, with a lack of

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research specifically examining the intentional restriction and omission of insulin for weight loss. Given this, very little is known about how individuals understand and experience this type of disordered eating behaviour. Qualitative methods are particularly suited to gain in-depth knowledge about individuals' perceptions of illness. Therefore, the future use of qualitative and mixed methods approaches within this unique population offers the potential for crucial knowledge and clinical practice development. Research examining disordered eating behaviours among males with T1DM appears to be scarce. Furthermore, research to develop empirically tested disordered eating behaviour and insulin misuse screening and assessment tools across all DM populations would be beneficial. Finally, further work is required to determine whether 'diabulimia' should be recognised as a separate diagnostic entity, and if so, what criteria would be required for such a diagnosis.

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**Insulin Restriction or Omission in Type 1 Diabetes Mellitus: A Meta-synthesis of Lived
Experience of Diabulimia**

Short title: Experiences of Diabulimia

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Author note: This article is intended for submission to the *British Journal of Health Psychology*. The journal adheres to the American Psychological Association (APA) referencing style (6th Ed.). The journal guidelines specify that the manuscript for qualitative research should be no longer than 6000 words including quotes, excluding the abstract, tables, figures and references. Tables and figures are required to be presented after the reference list, but for the ease of the examiners, at present they have been included within the main body of the article; this will be changed before submission for publication. The article has currently been written for the purpose of the thesis requirements of between 5,000 and 8,000 words.

Abstract

Purpose: Unique to the insulin-dependent diabetes mellitus (IDDM) population is a disordered eating behaviour whereby insulin is deliberately restricted or omitted. To date, research has predominantly focused on examining the prevalence of insulin restriction and omission and its' impact on morbidity and mortality, with individuals' experiential perspectives of this unique behaviour remaining an understudied area. Hence, the purpose of this meta-synthesis was to explore the lived experience of individuals with Type 1 Diabetes Mellitus (T1DM), the main form of IDDM, by identifying, analysing and synthesising existing knowledge concerning their experiences of insulin restriction or omission as a disordered eating behaviour. **Methods:** Meta-aggregative techniques were employed to identify key themes related to individuals' understanding and experience, physical and psychological impacts, support and treatment-related needs and experiences, noted in nine studies. **Results:** The analysis revealed a multifaceted relationship with insulin restriction and omission as a disordered eating behaviour, beyond having control of weight and shape. Many individuals experienced a wide range of diabetes-related complications from insulin restriction and omission alongside increased distress, loss of control and intense feelings of regret, guilt, and shame later in life. Almost all individuals valued peer support from those who shared a 'diabulimic' identity; peer support appeared more conducive to recovery than support from friends, family and formal support services which were not uniformly supportive. **Conclusions:** These findings have widespread interdisciplinary implications for health professionals working with individuals with T1DM and may provide useful guidance concerning the prevention and treatment of this unique behaviour.

Keywords: Type 1 diabetes mellitus; diabulimia; disorder eating behaviour; eating disorders; insulin restriction and omission

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Introduction

Diabetes Mellitus (DM) is one of the most significant health conditions across the globe (Atlas, 2015). Alongside the significant economic cost brought about by DM on individuals, their families, and to global healthcare systems (Atlas, 2015), DM is a leading cause of morbidity and mortality. In 2012, DM accounted for 1.5 million deaths, with higher-than-optimal blood glucose causing an additional 2.2 million deaths, by increasing the risks of cardiovascular and other diseases (World Health Organisation [WHO], 2018).

Alarming high rates of disordered eating behaviours and clinically significant eating disorders are being increasingly recognised amongst DM populations. These high rates of disordered eating are especially concerning given the significantly higher risk of mortality associated with such comorbidity, secondary to developing serious acute diabetes-related complications and microvascular and macrovascular complications (Goebel-Fabbri et al., 2008; Larrañaga et al., 2011; Takii et al., 2008; Young et al., 2013).

Unique to insulin-treated DM (mainly Type 1 Diabetes Mellitus [T1DM]), and a growing area of interest to researchers, is a disordered eating behaviour whereby insulin is deliberately restricted or omitted, with prevalence rates reported between 2% and 40% among individuals with T1DM (Affenito & Adams, 2001; Davidson, 2014; Doyle et al., 2017; Mathieu, 2008). Coined '*Diabulimia*', the process of restricting or omitting insulin reflects the purging of calories via a process called glycosuria, in which hyperglycaemia is deliberately induced (Frayn, 2010; Hasken et al., 2010).

Deliberately inducing hyperglycaemia for weight control places individuals at a significantly higher risk of developing serious diabetes-related complications, with the behaviour leading to the highest rates of retinopathy (eye disease) and nephropathy (kidney disease) when compared to other weight control behaviours (Goebel-Fabbri et al., 2008; Takii et al., 2008). Most concerning is its effect on mortality, with the risk of mortality 3.2 times

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higher than non-comorbid peers and a decreased life span from an average of 58 years to 44 years at 11-year follow up, highlighting the seriousness of this behaviour (Goebel-Fabbri et al., 2008).

Given the extremely high persistence and recurrence of disordered eating behaviours, prevention and treatment of diabulimia within this population is of high importance (Colton et al., 2015; Hanlan et al., 2013). To date, however, there is a lack of evidence and consensus on the best treatment approaches for comorbid T1DM and eating disorders. The vast majority of research investigating treatment for these individuals has concluded that standard eating disorder models do not work, and that relapse and attrition rates are high despite no significant differences in eating disorder psychopathology (other than insulin restriction and omission) (Banting & Randle-Phillips, 2018; Clery et al., 2017; Colton et al., 2015; Custal et al., 2014; Peveler & Fairburn, 1992).

Despite its growing interest to researchers and its clinical significance, diabulimia remains a significantly understudied problem, and the vast majority of studies have relied on quantitative methods to examine prevalence, aetiology and symptoms with minimal attention to individuals' experiential perspectives. As a result, little is known about how individuals understand and experience this emerging health phenomenon, including their treatment and support needs. Accordingly, researchers have advocated for the use of qualitative research that is focused more holistically, values experience and seeks understanding which incorporates social context, to address the gaps created by quantitative research (Chamberlain et al., 1997; Wisting and Snoek, 2020). Qualitative research emphasises "meaning over measurement" (Chamberlain et al., 1997, p. 695) by encompassing the subjective viewpoints of individuals. To date, no synthesis of qualitative research examining the lived experience of diabulimia has been undertaken. Synthesising such research has significant implications for knowledge development and clinical practice.

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The current study, a meta-synthesis of qualitative studies employing meta-aggregative techniques, aims to better understand the lived experience of individuals by identifying, analysing and synthesising existing knowledge concerning individuals' experiences of insulin restriction and/or omission as a disordered eating behaviour (diabulimia) and perceptions of support and treatment. With this overarching aim guiding the research, the following research questions will be addressed:

- 1) What are individuals' subjective understanding and experiences of diabulimia?
- 2) What physical, psychological and social impacts do individuals who experience diabulimia describe?
- 3) How do individuals who experience diabulimia describe their support and treatment needs and the level of support received?

Method

Design

There are many available methods to incorporate and synthesise findings from qualitative research (Barnett-Page & Thomas, 2009). One such approach, meta-aggregation, was adopted in the current study. Meta-aggregative approaches aim to synthesise the meaning of human experience captured in independent but related primary research studies (Pearson et al., 2011). Meta-aggregation is not interested in reinterpreting data for the generation of new or different meaning. Instead, it aims to accurately interpret the combination of findings from across the included studies (Pearson et al., 2011).

A particular strength of a meta-aggregative approach is how it gives researchers the ability to synthesise qualitative research in a way that reflects the rigorous process applied to systematic reviews and meta-analysis of randomised control trials and other quantitative research while maintaining sensitivity to the contextual nature of qualitative research (Pearson et al., 2011). Also inherent in its development is recognition of the valuable role

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qualitative research synthesis can play in informing evidence-based healthcare (Hannes & Lockwood, 2011b). Meta-aggregation is aligned with pragmatism in that it is particularly sensitive to the practicality and usability of its findings. It seeks to enable generalisable statements, in the form of recommendations or ‘lines of action’, on individual and community levels to guide health practitioners and policymakers (Hannes & Lockwood, 2011a). The meta-aggregative approach, in contrast to other methods of qualitative synthesis, is particularly useful in attempting to address questions about healthcare practice or summarising views regarding interventions or health issues (Noyes & Lewin, 2011). The present study sought to summarise common findings among homogeneous studies, aiming to provide cross-study generalisations which can inform healthcare and decision-making practice (Hannes & Pearson 2012; Lockwood et al., 2015). This meta-synthesis was preregistered (CRD42020171223).

Search Strategy

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines were followed throughout the review process (Liberati et al., 2009). Six electronic databases (CINAHL, Embase, PsychINFO, PubMed, Scopus, and Web of Science) were systematically searched from database inception until 01 January 2020 to identify qualitative studies that have examined individuals’ lived experience of diabulimia. In addition, alerts were created to ensure any studies published after the initial search were also identified and examined for possible inclusion. A search strategy combining controlled vocabulary and free-text search terms was customised as appropriate for each database, including terms such as “diabetes mellitus type 1”, “insulin-dependent diabetes mellitus”, “eating disorder”, “insulin omission”, “qualitative research”, “lived experience” and appropriate variants. A research librarian was also consulted to improve search term

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relevance and accuracy. Additionally, a manual search of the reference lists of included papers was completed to identify any relevant studies that did not emerge in the initial search.

Eligibility Criteria and Study Selection

Studies were selected for inclusion if they (i) investigated the lived experience of individuals with diabulimia, that is investigated the deliberate restriction or omission of insulin in individuals with T1DM (ii) reported primary data, (iii) presented an analysis of qualitative data (mixed methods papers were eligible for inclusion if qualitative data were reported separately and in detail), and (iv) were published in English in a peer-reviewed journal. Data were considered qualitative if obtained by qualitative data collection methods or analysed using qualitative methods. Studies investigating eating disorders and disordered eating behaviours broadly in individuals with T1DM were eligible for inclusion if data on insulin restriction and omission for weight control was reported separately and could be extracted. Quantitative studies, those that did not report primary data, or were not full articles, along with editorials, book reviews and conference abstracts were excluded. Studies on individuals with type 2 diabetes mellitus were also excluded.

As noted previously, PRISMA guidelines were followed for this meta-synthesis (Figure 2; Liberati et al., 2009). The initial search resulted in 2777 identified studies. A total of 978 duplicates were removed, leaving 1799 records to be screened by title and abstract. After applying inclusion and exclusion criteria, 1663 studies were excluded. The author (GG) and a second researcher (MO) co-screened a randomly selected sample of 450 potentially eligible articles (25% of title and abstract screening) to limit data-selection bias. Interrater agreement was high (99%, $K=.95$, $p<.05$) with any discrepancies resolved by consensus discussion. The full texts of 136 studies were then considered according to the inclusion criteria; 122 studies were excluded as they did not meet the inclusion criteria ($n = 119$), or the

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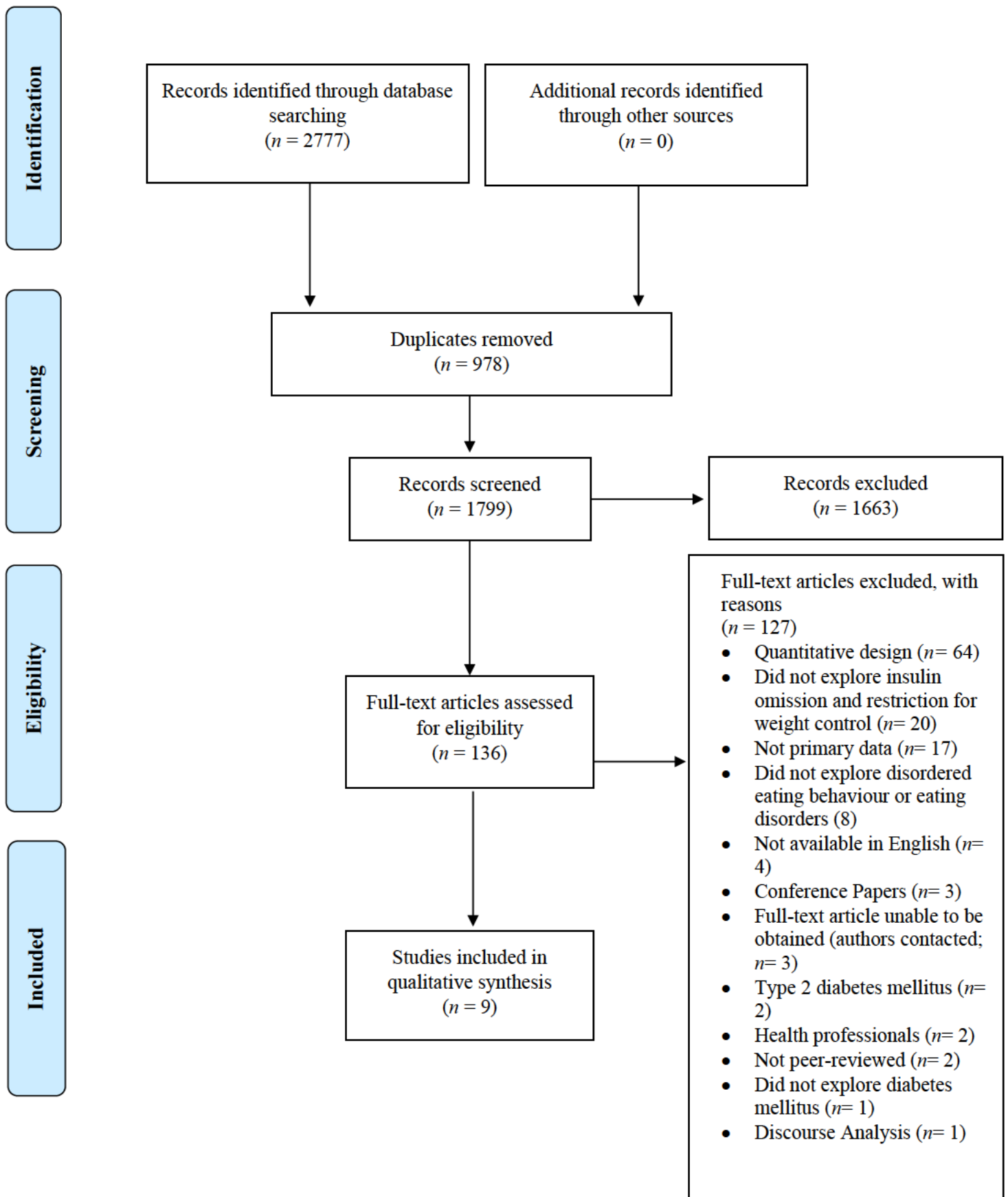


Figure 2. PRISMA flow diagram (Liberati et al., 2009) demonstrating the article selection and screening process.

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full text could not be retrieved ($n = 3$; emails were sent to three authors for whom contact details were available, but no responses were received). Therefore, the final search and screening processes resulted in nine studies eligible for inclusion that were subsequently assessed for methodological quality. After methodological appraisal, all nine studies were of sufficient quality to be included in the meta-synthesis.

Quality Appraisal

Critical appraisal is a pivotal part of meta-aggregation and the qualitative systematic review process (Pearson, 2004). The critical appraisal of each of the primary studies and their subsequent inclusion or exclusion directly impacts the quality of the resultant synthesis. The quality of each eligible paper was appraised independently by the author (GG) and a second researcher (MO) using QualSyst Quality Assessment Checklist (Kmet et al., 2004). For qualitative studies, this method of appraisal considers the methodological rigour and quality of studies across ten elements considered central to internal study validity. Each study was appraised on the extent to which it met 10 items specific criteria (“yes” = 2, “partial” = 1, “no” = 0). A summary score was calculated for each study by summing the total score obtained across relevant items and dividing by 20 (the total possible score), giving a possible score of (0-1), with a higher score indicating better quality. Variation in quality assessment was resolved through reviewer discussion. Kmet et al. (2004) report a liberal cut-off score of .55, and a conservative score of .75. In the current meta-synthesis, given all studies received a quality score of more than .55, with the lowest being .65, to avoid presenting an overly restricted picture of this modest research, all studies were included for subsequent synthesis.

Data Extraction and Synthesis

In following PRISMA guidelines, a study-specific data extraction form was developed to gather study characteristics and relevant findings from included studies. Data extracted from each study included (i) sample characteristics (e.g., sample size, gender, age),

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(ii) T1DM characteristics (e.g., age at diagnosis, time since diagnosis), (iii) disordered eating and eating disorder characteristics, (iv) study characteristics (e.g., aims, design, inclusion/exclusion criteria, recruitment source), and (v) lived experience.

Following extraction, findings from each of the primary studies, in the form of categories or themes, were extracted verbatim. In addition, accompanying illustrative extracts and quotations were also extracted. Where it was not possible to extract author-identified themes, findings, in the form of definitive statements made by authors, were extracted from the narrative by the author (GG) and discussed with a second researcher (MO).

Each finding was assigned a level of evidence of credibility; unequivocal (U) - evidence beyond reasonable doubt, such as directly reported or observed findings clearly derived from qualitative data and not open to challenge; credible (C) – findings that were plausible interpretations, given the presented data and theoretical framework; and unsupported (Un) – findings that were not supported by the presented data (Pearson, 2004). Unsupported findings were not included in the meta-synthesis. Findings were then summarised, using a meta-aggregative approach, based on similarity in meaning across all primary studies included to produce a set of synthesised findings.

Results

Study Characteristics

The key characteristics of the nine included studies are provided in Table 1. The studies were published between 2008 and 2018 and originated from a diverse range of countries, with most studies originating from the United Kingdom ($N_{studies} = 5$). Single studies were conducted in the United States of America, Australia, Portugal and Ireland. Qualitative data were collected via interviews ($N_{studies} = 4$), focus groups ($N_{studies} = 2$; 1 online), personal online blogs ($N_{studies} = 1$) and a self-report questionnaire which included open response

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Table 1: *Characteristics of Included Studies* ($N_{studies} = 9$)

Lead Author (Date)	Country	Sample Size ($n = 133$)	Recruitment Source	Methodology	
				Data Collection	Data Analysis
Balfe (2013)	Ireland	6	Young adult diabetes clinic. Advertisements on Facebook page of Diabetes Ireland and different diabetes centres	Interviews	Thematic Analysis
Falcão (2017)	Portugal	55	Study link posted on social networks specific to diabetes populations	20-item self-report questionnaire with open response questions	Content Analysis
Hastings (2016)	UK	13	Advert posted on a 'Diabulimia' online support group	Focus groups via an online chat room	Thematic Analysis
Hillege (2008)	Australia	4	Recruited from self-help/support groups i.e. The Juvenile Diabetes Foundation and Diabetes Australia	In depth semi-structured interviews	Content Analysis
Kay (2009)	UK	9	City wide specialist diabetes service	Semi-structured interviews	Phenomenological Analysis
Macdonald (2018)	UK	9	National Charity (Diabetes with Eating Disorders) and professional networking	Semi-structured interviews	Thematic Analysis
Powers (2016)	USA	16	Letters of invitation from attendance of the Park Nicollet Health Services (PNHS) specialised dual diagnosis treatment program	Focus Groups	Thematic Analysis
Staite (2018)	UK	11	Blogs identified through the search engine Google using search terms	Written Content from Personal Online Blogs	Thematic Analysis
Wilson (2012)	UK	10	Diabetes meeting following the Insulin Pump Therapy group (INPUT)survey	Focus Group	Thematic Analysis

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questions ($N_{studies} = 1$). Most data were analysed using thematic analysis ($N_{studies} = 6$); however, authors also employed content analysis (including framework approaches $N_{studies} = 2$) and phenomenological analysis ($N_{studies} = 1$).

Participant Characteristics

The sample consisted of 133 individuals with T1DM ($N_{studies} = 9$). Participants were aged between 16 years and 62 years, based on 78 participants ($N_{studies} = 8$), with a mean age of 25.64 years ($SD = 6.55$), based on 71 participants ($N_{studies} = 2$). One hundred and fifteen participants (86.5%) were female, and 18 participants (13.5%) were male. Of eating disorders and disordered eating behaviour, 47 participants (35.3%) deliberately restricted or omitted insulin, and 26 participants (19.5%) had unspecified disordered eating behaviours and eating disorders. The status of disordered eating behaviour and eating disorders for 60 participants (45.1%) was unknown. Information about participant demographic characteristics is reported in Table 2.

Quality Appraisal

The nine included studies were of moderate to high quality and possessed scores ranging from 0.65 to 0.95 ($M = 0.81$, $SD = 0.09$) on the QualSyst Quality Assessment Checklist (see Table 3; Kmet et al., 2004). Seven papers (77%) also did not explicitly comment on the impact of the researcher on the study. Two papers (22%) did not comment on verification procedures. Two papers (22%) partially justified sampling strategy. Two papers (22%) partially commented on the data analysis used. One paper (11%) partially described the context/setting for the study. One paper (11%) partially described the theoretical framework or wider body of knowledge. One paper (11%) partially commented on data collection procedures. One paper (11%) partially commented on the impact of the researcher on the study.

Table 2: *Characteristics of Participants in Included Studies**

<i>Variable</i>	<i>N_{studies}</i>	<i>N_{participants}</i>	<i>M (SD)</i>	<i>Range</i>
T1DM Participants	9	133		
<i>Age of T1DM Onset</i>	2	71	13.97 (5.03)	
<i>Duration of T1DM</i>	2	71	11.67 (7.24)	
Age				
	2	71	25.54 (6.55)	
	8	78		16-62
Gender				
<i>Male</i>	1	18		
<i>Female</i>	9	115		
Ethnicity				
<i>European/Caucasian</i>	5	47		
<i>Unknown</i>	3	6		
<i>Not supplied</i>	4	80		
ED, DEB Type				
<i>Unspecified DEB or ED</i>	4	19		
<i>Insulin Restriction/Omission</i>	5	49		
<i>Unknown</i>	2	65		

Note. $N_{studies}$ = number of studies; $N_{participants}$ = number of participants; M = Mean; SD = standard deviation; T1DM = type 1 diabetes mellitus; DEB = disordered eating behaviour; ED = eating disorder; * not all studies provided this data for their participants.

Table 3: *Evaluation of Methodological Quality of Included Studies* ($N_{studies} = 9$)

Lead Author (Date)	QualSyst Criteria										Summary Score
	Question/ Objective	Study Design	Context	Theoretical Framework	Sampling Strategy	Data Collection	Data Analysis	Verification Procedure	Conclusion	Reflexivity	
Balfe (2013)	●	●	●	●	●	◐	●	●	●	○	0.80
Falcão (2017)	●	●	●	●	◐	●	●	●	●	○	0.80
Hastings (2016)	●	●	●	●	●	●	●	●	●	○	0.85
Hillege (2008)	●	●	●	●	◐	●	◐	○	●	○	0.65
Kay (2009)	●	●	●	●	●	●	●	●	●	●	0.95
Macdonald (2018)	●	●	●	●	●	●	●	●	●	○	0.85
Powers (2016)	●	●	●	●	●	●	●	●	●	○	0.85
Staite (2018)	●	●	●	●	●	●	●	●	●	◐	0.90
Wilson (2012)	●	●	◐	◐	●	●	◐	○	●	○	0.65

Note. ● = yes, ◐ = partial, ○ = no

Synthesised Findings

Individuals’ understanding and experience of diabulimia. The meta-synthesis of individuals’ understanding and experience of diabulimia was derived from six studies that were grouped into three categories and five subcategories (Table 4), to provide the overall synthesised finding: *“Type 1 Diabetes Mellitus may lead to a multifaceted relationship with insulin, where weight is prioritised over health, and occasional restriction or omission of insulin may escalate to chronic behaviour”*.

Across the included studies, individuals’ relationship with their use (and restriction or omission) of insulin was complex and multifaceted. A variety of thoughts, emotions and behaviours related to the deliberate restriction and omission of insulin were described. While some individuals’ stumbled across insulin restriction or omission as a way to lose weight by accident, discovering the method through media, friends or other informal sources, or through losing weight after stopping injections because they were painful (Balfe et al., 2013), others appeared to be aware of weight loss as a consequence of hyperglycaemia and made a conscious decision when they first started intentionally restricting or omitting insulin for weight loss (Staite et al., 2018); *“At sixteen years old, feeling the pressures of being around other girls in sixth form, I first made the conscious decision to cut out my insulin in order to lose weight”* (Staite, et al., 2018, p. 1332).

Regardless of how individuals initially learned about insulin restriction and omission and its effect on weight, a spectrum of triggers driving insulin restriction or omission was shared by individuals across the included studies. Body dissatisfaction and the desire to lose weight were strong drivers of insulin misuse (Balfe et al., 2013; Falcão & Francisco, 2017; Staite et al., 2018). Insulin restriction or omission was an attempt to conform to socially prescribed body ideals, particularly during adolescence and early adulthood (Balfe et al.,

Table 4: *Synthesised Findings and Component Categories of Experiences of Diabulimia Among Individuals with T1DM*

Individuals' understanding and experience of diabulimia: Type 1 Diabetes Mellitus may lead to a multifaceted relationship with insulin, where weight is prioritised over health, and occasional restriction or omission of insulin may escalate to chronic behaviour

- Multifaceted relationship with insulin
 - Discovery of insulin restriction or omission as a method of weight control versus a process of conscious decision-making
 - Complex spectrum of triggers driving insulin restriction or omission including socially prescribed ideals, body dissatisfaction and fear of weight gain from insulin therapy
 - A positive experience where weight loss was quick, effortless, and provided a sense of control and empowerment
 - A way of coping with painful emotions
 - Insulin restriction or omission as a form of self-destruction and harm
- Weight control a sufficient motivator to omit insulin and ignore the serious risks to health
- Intermittent insulin restriction or omission often escalates to chronic insulin manipulation

Physical and psychological impacts: Diabulimia: Initial feelings of mastery may lead to an eventual loss of control, and alien way of thinking, whereby individuals become increasingly distressed, experience widespread acute and chronic complications and are subject to intense feelings of regret, guilt and shame from deliberately inducing hyperglycaemia.

- Physical consequences
 - Experiencing and living with acute diabetes-related complications
 - Development of extensive microvascular and macrovascular complications
- Psychological impacts
 - Experiencing a loss of control over behaviour, development of an alien way of thinking, continual struggle
 - Increasingly distressed
 - Experiencing regret, guilt and shame later in life
 - Reduced quality of life

Support and Treatment Needs and the Level of Support Received: Avenues of informal and formal support are not uniformly supportive and individuals' restricting or omitting insulin considered peer support from others who shared the same distinct diabulimic identity most helpful and conducive to recovery.

- Perceived distinct diabulimic identity separate from other eating disorder and diabetic populations
 - Peer support from others who share the same diabulimic identity most conducive to recovery
 - Support from family and friends valued but not uniformly supportive
 - Barriers to formal support
 - Need for health professionals to have increased knowledge and understanding of diabulimia
 - Negative experiences with health professionals
 - Lack of formal recognition of diabulimia and lack of empathy are barriers to engagement in treatment
-

2013; Staite et al., 2018). Individuals wanted to look better, and events triggered the desire to alter insulin to lose weight as quickly as possible (Balfe et al., 2013): *“If like there was an event coming up I’d be prone to letting my bloods run high and fit into my dress”* (Balfe et al., 2013, p. 2033).

Individuals also became increasingly dissatisfied with their bodies and worried and fearful of weight gain following the initiation of insulin therapy (Falcão & Francisco, 2017; Staite et al., 2018). Individuals reported that using the prescribed amount of insulin immediately led to rapid weight gain and was described by one individual as being *“psychologically crippling”* (Staite, 2018, p. 1331). Others noted that they began to make an association between insulin and fat (Falcão & Francisco, 2017; Staite et al., 2018).

Initially, insulin restriction or omission was regarded as a positive experience by individuals across the studies. Individuals lost weight quickly without much effort or food deprivation, and without experiencing any noticeable side effects (Balfe et al., 2013; Falcão & Francisco, 2017; Kay et al., 2009); as one individual explained: *“I could just see these ketones as like little maggots...eating at my stomach fat and thinking, this is working”* (Kay et al., 2009, p. 245). Furthermore, individuals were able to manipulate their insulin without others knowing. The secretive nature of restricting or omitting insulin, combined with perceptions of control over their body, was associated with feelings of mastery and empowerment (Balfe et al., 2013; Staite et al., 2018) As highlighted by one individual: *“I felt as if it was my secret tool that nobody knew about and nobody else could do”* (Staite et al., 2018, p. 1332). For others, manipulation of insulin appeared to be a way of coping with other painful issues: *“The reason I stopped taking my injections ... I didn’t have to think about other things that were going on. And I didn’t have to think about what other people thought of me because I was ... feeling ill”* (Kay et al., 2009, p. 245). Individuals, similarly, acknowledged insulin restriction and omission as a self-destructive, self-harming behaviour

(Hillege et al., 2008; Staite et al., 2018), ranging from not caring for one's health to the extreme of referring to insulin restriction as 'slow suicide' hidden from everyone else: *"I know in my heart that the worst consequence from this slow suicide is the deceit"* (Staite et al., 2018, p. 1333).

Some individuals appeared to be unaware of the consequences of restricting and omitting insulin (Balfe et al., 2013; Wilson, 2012). However, most individuals were aware of the consequences but tended to make a conscious choice to ignore them (Balfe et al., 2013; Falcão & Francisco, 2017; Kay et al., 2009). Individuals placed greater importance on their desire to lose weight over maintaining good glycaemic control. The assurance of controlling weight through restricting or omitting insulin was sufficient motivation to continue despite the potential consequences. One individual expressed this prioritisation of weight over health as follows: *"I don't think about it.. I know all [the consequences] but I think that what matters to me is to be thin (...) I don't feel good being fat"* (Falcão & Francisco, 2017, p. 679). Similarly, another individual reflected on allowing her blood sugar levels to run high: *"It was just something that happened... to be honest I didn't care, as long as I was losing weight"* (Kay et al., 2009, p. 245). Even as health noticeably deteriorated, individuals remained committed to manipulating their insulin for weight loss (Balfe et al., 2013; Staite et al., 2018).

For many individuals, insulin restriction and omission initially occurred on an intermittent basis and was cyclical. Individuals experimented with the behaviour to achieve short-term weight loss goals but would often return to correct insulin use (Balfe et al., 2013; Falcão & Francisco, 2017; Staite et al., 2018). Over time, however, the nature of insulin manipulation seemed to gradually escalate (Balfe et al., 2013; Falcão & Francisco, 2017; Staite et al., 2018). The initial experimentation with insulin gradually turned into chronic restriction or omission behaviour, with some individuals taking less and less until they were

taking none at all: *“I would omit my insulin to get the extra few pounds off and then would stop. Anybody with diabetes and an eating disorder will know that this is never the case. Once becomes twice, twice becomes three times and so the cycle continues”* (Staite et al., 2018, p. 1333).

Physical and psychological impacts described by individuals who experience diabulimia. The meta-synthesis of the physical and psychological impacts of diabulimia was derived from five studies that were grouped into two categories and six subcategories (Table 4), to provide the overall synthesised finding: *“Initial feelings of mastery may lead to an eventual loss of control and alien way of thinking, whereby individuals become increasingly distressed, experience widespread acute and chronic complications and are subject to intense feelings of regret, guilt and shame from deliberately inducing hyperglycaemia”*.

Weight loss came to assume a greater role in individuals’ lives. Moving away from initial feelings of mastery and empowerment, individuals began to feel more out of control, conflicted between insulin restriction or omission and wanting good diabetes control, and unable to alter their behaviour (Balfe et al., 2013; Kay et al., 2009; Staite et al., 2018). As one individual described: *“Small patches I might be like, I’m going to do this, I have to take care of my diabetes. But it wouldn’t last”* (Balfe, 2013, p. 2033). While some individuals explained becoming locked into their behaviour, realising that if they started retaking insulin properly, they would regain the weight they had lost (Balfe et al., 2013), others related their behaviour to the addictive nature of gambling and substance use (Staite et al., 2018): *“[...] alike to a stupor I could only imagine would compare to what heroin addicts find so addictive”* (Staite et al., 2018, p. 1332).

As insulin restriction and omission became more out of individuals’ control, individuals also became increasingly distressed by the behaviour, with depressive episodes becoming common and some experiencing suicidal thoughts. One individual shared: *“When I*

was a teenager 15–16 I suffered with bulimia and then that led to depression. I remember sitting there after trying to slit my wrists and not taking insulin for a week, about to jump out the window. If I had to die from it I had to die from it and that was OK” (Balfe et al., 2013, p. 2033).

As insulin restriction and omission became more entrenched in their lives along with the effects of high blood glucose, individuals felt as if their minds had shifted into an alien way of thinking that they could reflect on in hindsight: *“I only realise it now... I just thought it was normal. I wasn’t in a good head space at all”* (Balfe et al., 2013, p. 2033), and *“I had high blood sugars for 10 years. I couldn’t tell you the last time I had a reasonable thought from beginning to end, and finally the blood sugars came down and things were different”* (Powers et al., 2016, p. 2973). Individuals who wanted to desist from insulin manipulation continued to struggle with cognitive patterns and weight loss impulses (Balfe et al., 2013); one individual described it taking a long time to return to normality: *“It took a long time to get it where it should be. It took about 3–3½ years. I suppose it was just being conscious of what you’re doing. I would actually start questioning; I’m getting an urge not to take my insulin. Why am I getting it? I found it very difficult to force myself to think about it. It took a long time of conscious effort”* (Balfe et al., 2013, p. 2034). Individuals described a constant battle with impulses to restrict or omit insulin even following “recovery”, particularly during stressful experiences such as becoming unemployed or experiencing relationship difficulties (Balfe et al., 2013), as two individuals explained, *“[...] it’s not something you get rid of”* and *“it would be a constant battle”* (Balfe et al., 2013, p. 2034).

The experience of chronic complications from deliberately and frequently mismanaging blood glucose was accompanied by intense feelings of regret, guilt and shame later in life (Staite et al., 2018; Wilson, 2012). As one individual explained: *“I feel so ashamed and guilty about the stupid things I used to do as a youngster. I would drink*

Lucozade and not have my insulin because I wanted to lose weight. God knows what my blood glucose levels were like! It wasn't long before I started developing eye problems and I cried because they said I would lose my sight. Then, when I was in my 30s, I began fainting for no reason, and feeling dizzy when I got up. They diagnosed difficulties with blood pressure regulation and heart problems. I realised I'd brought it all on myself" (Wilson, 2012, p. 22).

Alongside this, the development of chronic diabetes-related complications reduced the overall quality of life of individuals reflecting on past insulin misuse: *"Life is hard with diabetes and complications. I am often depressed by what has happened and wish that life had an undo button! I often get a pounding in my head and ears when my blood pressure is too high, and have had several terrible nosebleeds. My feet prickle constantly, and it is much worse at night [peripheral nerve damage], meaning I often can't sleep. And all because of diabetes"* (Wilson, 2012, p. 22).

Insulin restriction and omission led to a variety of acute and chronic diabetes-related complications. Frequent and repetitive diabetic ketoacidosis (DKA) was the most cited acute complication and commonly required hospitalisation and admission into intensive care units (Powers et al., 2016; Staite et al., 2018; Wilson, 2012). Chronically elevated blood sugars also impaired concentration, led to blurred vision, dry skin, frequent urination, hair loss, and generally feeling ill (Powers et al., 2016; Staite et al., 2018). Individuals persisted with alterations in their insulin despite experiencing serious symptoms of acute diabetes complications, accepting them as a normal consequence of reducing their insulin. As one individual articulated: *"[...] was walking to and from work every day in severe ketoacidosis but I kept at it"* (Staite et al., 2018, p. 1333).

Severe chronic complications due to insulin restriction and omission were also frequently cited by individuals (Staite et al., 2018; Wilson, 2012). The descriptions of chronic

complications differed between individuals but were consistently described as being extensive and reflected the damage high blood sugar poses across all systems of the body (Staite et al., 2018; Wilson, 2012). The extensive damage is illustrated in one individual's description of her current diabetic health status from past insulin restriction and omission: *"Thanks to the decade of damage I did to my body, I am now also the proud recipient of peripheral neuropathy, vasovagal syncope, and gastroparesis – which caused three ulcers and cyclical vomiting syndrome"* (Staite et al., 2018, p. 1333). Predominantly microvascular damage, rather than macrovascular damage, was described by individuals across the studies and included hypertension, cardiomyopathy, dyslipidaemia, retinopathy (eye disease), gastroparesis (delayed stomach emptying), neuropathy (nerve damage characterised by pain and/or numbness), neuropathic osteoarthropathy (destructive joint disorder) and nephropathy (kidney disease).

Support and treatment needs and the level of support received. The meta-synthesis of individuals' support and treatment needs and level of support received was derived from four studies that were grouped into four categories and three subcategories (Table 4), to provide the overall synthesised finding: *"Avenues of informal and formal support are not uniformly supportive and individuals restricting or omitting insulin considered peer support from others who shared the same distinct diabulimic identity most helpful and conducive to recovery"*.

Importantly, individuals with diabulimia considered themselves as having a distinct identity separate from other eating disorder and diabetic populations, and a lack of identity recognition by others was a significant barrier to accessing support (Hastings et al., 2016). Insulin restriction and omission was viewed as a unique and defining feature of their eating disorder that separated them from people with other eating disorders, making current treatment protocols, whereby illnesses are seen as comorbid and are treated separately,

unhelpful. One individual emphasised this separation: “[...]the other patients did fail to grasp the effect diabetes had to play in my situation, they didn't understand the complexity of it, so it was easy to feel alone even when surrounded by support, as through no fault of their own, they could not fully understand” (Hastings et al., 2016, p. 81).

Accordingly, peer support from others who share the same diabulimic identity appeared most helpful and more conducive to recovery than support from those who did not share this identity (Hastings et al., 2016; Macdonald et al., 2017). The support offered by other ‘diabulimics’, was perceived as qualitatively different from that received from other sources of support. Individuals felt a sense of community helped to combat feelings of isolation, provide emotional support, develop strong social connections and provide a space to share experiences without being judged: *“I think the chance to really say all on my mind, to rant and just get it all out because a lot of the time healthcare professionals don't provide that space, or don't know where you're coming from. Also, you bond with people online, and strike up friendships, so the mutual support is really valuable. you can say your most honest shit but it's not the unbalanced relationship of a healthcare professional and client”* (Hastings et al., 2016, p. 82). Furthermore, this peer support was also instrumental in learning to manage their insulin restriction and omission and face the challenges of recovery (Hastings et al., 2016; Macdonald et al., 2017). The community served as a valuable information source about the illness *“because no one knows more about Diabulimia than Diabulimics”* (Hastings et al., 2016, p. 82). Individuals had a strong willingness to share their experience of recovery in order to help others (Staite et al., 2018), and connections with others appeared to assist individuals to appreciate the adverse consequences of insulin restriction and omission from a trusted source of information as well as finding comfort in the encouragement and motivation of others (Hastings et al., 2016). Peer support was also instrumental in encouraging people to

connect with friends and family, either through providing other avenues of support or by providing a means of validating diabulimia to others (Hastings et al., 2016).

Support from trusted friends and family in recovery from insulin restriction and omission was particularly valued (Falcão et al., 2017). However, these were described as imperfect supports and not uniformly supportive (Balfe et al., 2013; Hastings et al., 2016). Individuals found it difficult to confide in family and friends about their illness (Hastings et al., 2016) as they were often not understanding or lacked knowledge about the potential risks of the behaviour (Balfe et al., 2012; Hastings et al., 2016). This lack of knowledge was highlighted by one individual whose mother encouraged the behaviour: *“I said it to my mum, look, I’m not taking my insulin and I’m losing loads of weight. She was like, that’s brilliant, I wish I could do that”* (Balfe et al., 2013, p. 2033).

In regards to service provision, many individuals expressed the need for health professionals to be more informed about diabulimia as an eating disorder (Hastings et al., 2016). Individuals felt misunderstood, invalidated and frustrated by lack of empathy from health professionals (Hastings et al., 2016; Macdonald et al., 2017). Individuals were often met with insensitive or critical statements or had other negative experiences with health professionals, which often made them feel alienated and alone in their struggle. For example, one individual had particularly negative experiences with hospital staff: *“Then there were incidents with things like them forgetting to give me my insulin, forgetting to do blood tests ... I was in there to be treated for my eating disorder and part of that is struggling with taking it so for me to have to remind them that I needed to do it or that they needed to test my blood, was just ridiculous”* (Macdonald et al., 2017, p. 226). Another individual noted: *“[...] all that happened is that the nurse scolded me for not improving my BGs [blood glucose levels] in a week, and THAT set me off to the point where I wouldn’t go back”* (Hastings et al., 2016, p. 81). These types of interactions combined with no formal recognition of diabulimia created

barriers to receiving appropriate care, despite individuals' efforts to engage with support services: *"I've tried counseling and therapy (for eating disorders) but none of them had a clue what Diabulimia was so weren't much help whatsoever. Everyone I tried to explain to they'd just ignore me and talk about other eating disorders that I may have"* (Hastings et al., 2016, p. 81). Even if they strongly wanted to recover, individuals felt that recovery was not possible without support from others who shared the same diabulimic identity and properly educated health professionals (Hastings et al., 2016).

Discussion

Diabulimia is a unique health phenomenon occurring among individuals with T1DM that involves a complex interplay between biological, psychological and social factors. To the author's knowledge, this is the first meta-synthesis to explore the lived experience of individuals with T1DM who deliberately restrict or omit insulin for weight control. Findings from the included studies were aggregated into nine categories, fourteen subcategories and three synthesised findings related to individuals' understanding and experience of diabulimia, the physical and psychological impacts of diabulimia and finally, individuals' support and treatment needs and the level of support received (Table 4). Guidelines for health professionals, such as psychologists, nurses, doctors and endocrinologists, caring for individuals with T1DM restricting and omitting insulin as a disordered eating behaviour are provided in Table 5.

Individuals' understanding and experience of diabulimia. The complex nature of the restriction and omission of insulin described by individuals in the current study appears consistent with other published research about the complex nature of eating disorders generally (Collier & Treasure, 2004; Ghaderi & Scott, 2001; Ricciardelli et al., 2003; Rodgers et al., 2014). Individuals in the current study described a range of risk and maintaining factors involved in their deliberate misuse of insulin.

Table 5: *Guidelines for Healthcare Professionals Caring for Individuals with T1DM who Restrict or Omit Insulin as a Disordered Eating*

Behaviour

Individual's Subjective Experience.

Health professionals should:

- Demonstrate awareness of, and empathy for, the biological, psychological and social impacts of T1DM on individuals
- Demonstrate understanding of, and empathy for, specific diabetes-related risk factors for disordered eating behaviours including diabulimia
- Use sensitive, open-ended questions about current levels of satisfaction with weight and shape to identify individuals with T1DM at risk of developing, or those on the cusp of emerging, disturbed eating behaviours such as diabulimia
- Address poor body image and weight and shape concerns early, and continually as appropriate, in individuals with T1DM
- Try to understand individuals' patterns of insulin use and non-use without the risk of unintentionally "educating" individuals about diabulimia
- Be highly alert to the possibility of, and proactive in identifying, disordered eating behaviours including diabulimia amongst individuals with T1DM
- Be suspicious of quick and/or unexplained weight loss as a potential consequence of disordered eating behaviours such as diabulimia
- Provide information on acute and chronic diabetes-related complications that can arise from hyperglycaemia to individuals with T1DM
- Be proactive in identifying and addressing maintaining factors contributing to diabulimia
- Provide information on adaptive means of coping and self-care practices to individuals with T1DM
- Aim to increase the self-efficacy of and sense of control for individuals with T1DM

Biopsychosocial Impacts.

Health professionals should:

- Be highly suspicious of acute and chronic symptoms of hyperglycaemia as a consequence of disordered eating behaviours such as diabulimia
 - Thoroughly investigate acute and chronic symptoms of, and reasons for, hyperglycaemia
 - Routinely assess and monitor the physical and psychological health of individuals with T1DM
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- Be proactive in managing poor psychological functioning and distress in individuals with T1DM and comorbid disordered eating behaviours including diabulimia
 - Be proactive in identifying and addressing co-morbid psychiatric conditions that may further contribute to, and/or be exacerbated or caused by, disordered eating behaviours such as diabulimia
 - Prioritise medical and psychiatric safety in the management of disordered eating behaviours such as diabulimia in individuals with T1DM (i.e., admission to hospital may be required if the individual is at imminent risk of serious medical complications or suicide)
-

Support and Treatment Needs.

Health professionals should:

- Consider diabulimia as a valid construct, separate from current eating disorder diagnostic labels
- Enlist peer support for individuals with T1DM who have comorbid disordered eating behaviours such as diabulimia from similar others where appropriate
- Provide carers and families with education about comorbid T1DM and disordered eating behaviours including diabulimia and the associated risks to health
- Address carer needs and provide families with the resources necessary to enable caregiving and to create a familial environment which is conducive to the prevention and treatment of disordered eating behaviours such as diabulimia
- Enlist carers and families as partners in the assessment and treatment process of disordered eating behaviours in T1DM where appropriate
- Develop an emotionally open, accepting, warm, and collaborative relationship with all individuals with T1DM
- Ensure warm, genuine and supportive communication in all interactions
- When working within a multidisciplinary team frequently and openly communicate with one another to maintain congruent treatment approaches, messages, and goals
- Seek supervision from skilled peers and mentors trained in how to respond to disordered eating behaviours such as diabulimia

Additional support and treatment need recommendations:

- All diabetes educators, nurses, endocrinologists, doctors and psychosocial clinicians should be trained in how to sensitively and respectfully respond to the biopsychosocial challenges experienced by individuals with T1DM
 - Current evidence-based treatment options should be explicitly tailored to individuals with T1DM and disordered eating behaviours including diabulimia
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- Hospitals and clinics should have multidisciplinary teams trained in best practice responses to T1DM and should include an endocrinologist/diabetologist, a nurse educator, a nutritionist with eating disorder and/or diabetes training, and a psychologist or social worker
 - Hospitals and clinics should have established referral pathways for psychologists experienced in supporting those with comorbid T1DM and disordered eating behaviours such as diabulimia
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Note. T1DM = Type 1 Diabetes Mellitus

Many individuals appeared to accidentally discover insulin restriction and omission as a method of weight control through media, peers or other informal sources. These stories highlight the need for particular caution when discussing insulin restriction with individuals diagnosed with T1DM, parents, in media coverage, or on social media. The Diabetes Eating Problem Survey – Revised (DEPS-R) and similar screening instruments for disordered eating behaviour such as the modified SCOFF questionnaire (Zuijdwijk et al., 2014) have also been criticised for directly inquiring about dangerous behaviours (i.e. insulin restriction/omission), which could be construed as ‘suggestive’ to vulnerable individuals with T1DM (Powers et al., 2016). Health professionals have also expressed concern that enquiring about deliberate insulin restriction and omission for weight loss may be detrimental to the patient and actually cause or increase insulin misuse (Tierney et al., 2009).

The desire for weight loss and body dissatisfaction appeared central to understanding individuals’ restriction or omission of insulin in the current study, and alongside fluctuating weight before and after diagnosis, such factors have previously been identified as a reason for insulin misuse (Biggs et al., 1994; Grylli et al., 2005; Hasken et al., 2010; Jones et al., 2000; Pinar, 2005; Polonsky et al., 1994; Smith et al., 2008; Takii et al., 2011; Young-Hyman & Davis, 2010). Interventions that have effectively decreased body dissatisfaction among individuals with T1DM, however, have failed to improve DM management and glycaemic control (Goebel-Fabbri, 2009; Olmsted et al., 2002; Rodin et al., 2002), suggesting other factors also influence the decision to withhold insulin.

In this study, individuals described deeper-seated motives behind the restriction and omission and of insulin in addition to body dissatisfaction. Restricting and omitting insulin was commonly described as providing a sense of empowerment and mastery, increasing perceptions of control and as helping to manage painful emotions. Authors have previously theorised the behaviour as a desperate attempt to compensate for an underlying sense of

ineffectiveness and lack of control in the rest of an individual's life (Custal et al., 2014; Farsaei et al., 2014; Mathieu, 2008; Yan, 2007), as well as a means to manage stress and emotional problems (Peyrot et al., 2012). Similarly, individuals with eating disorders who do not have T1DM have often described their eating disorder as being particularly meaningful. For some, this is related to a distraction from life stressors, feelings of achievement and self-mastery as well as a means of coping and a response to feelings of lack of control, ineffectiveness and worthlessness (Higbed & Fox, 2010; Jeppson et al., 2003; Mathieu, 2008; Pettersen et al., 2013; Polivy & Herman, 2002; Wade et al., 2015; Waller et al., 2007).

Individuals in the current study appeared to ignore the serious risks restricting and omitting insulin posed to their health, instead choosing to prioritise weight loss. Similarly, Hasken et al. (2010) previously postulated those who have diabulimia are so focused on weight control that they do not think about the serious long-term consequences of consistently elevated blood sugars. Other authors have also suggested increased knowledge about risky behaviours does not necessarily deter young individuals (Schechter & Francis, 2010). This paradox may be underpinned by a belief that while their behaviours may be risky, they are not at risk and has been identified in the theoretical maintenance model for disordered eating in T1DM proposed by Treasure et al. (2015). Wolpert and Anderson (2001) explain that, while individuals with T1DM may understand the importance of achieving optimal blood-glucose levels, achieving this is often competing with other important concerns, for example, meeting the thin ideal. Hillege (2005) also notes that many young individuals trying to manage a chronic illness such as T1DM, focus on the short-term and deal with any complications later.

Like most gateway behaviours for eating disorders, such as dieting and exercise, insulin restriction and omission appeared to be practised initially intermittently before crossing a threshold into a compulsion. Longitudinal studies suggest that early and relatively

mild eating disturbances, like initial experimentation with insulin identified in this study, are likely to persist, become more frequent and worsen, both in individuals with T1DM (Bryden et al., 1999; Colton et al., 2015; Daneman et al., 2002; Rydall et al., 1997) and in the general population (Attie & Brooks-Gunn, 1989; Gardner et al., 2000). In a longitudinal study of women with T1DM, of those considered to have highly or moderately disordered eating behaviour at the baseline assessment, 60% of individuals continued to exhibit the same behaviours four years later (Daneman et al., 2002). Disordered eating behaviours also tended to increase in frequency as women moved into late adolescence and young adulthood (Daneman et al., 2002). Similarly, according to a longitudinal study of 126 young T1DM girls, 92% of those who reported any disordered eating behaviours, including insulin misuse, continued those behaviours after a 5-year follow up (Colton et al., 2015).

Physical and psychological impacts described by individuals who experience diabulimia. Deliberately induced hyperglycaemia from restricting and omitting insulin had a widespread impact on individuals in the current study with a range of acute and chronic diabetes-related complications described. Feelings of lethargy, impaired concentration and generally feeling unwell have previously been reported as unpleasant early complications from hyperglycaemia (Balfe et al., 2013; Rogers et al., 2012; Ruth-Sahd et al., 2009; Savage et al., 2012), and in the current study, individuals described similar repetitive and uncomfortable symptoms of high blood glucose. It is not surprising that individuals described hospitalisation following DKA, as insulin restriction and omission attributable to diabulimia increases DKA risk significantly and is a life-threatening condition (Goebel-Fabbri et al., 2008). The development of long-term diabetes-related complications cited by individuals in the current study was also consistent with quantitative data. Previous literature has consistently demonstrated a strong correlation between the restriction and omission of insulin for weight control and the development of serious and widespread microvascular and

macrovascular complications (Colton et al., 2009; Goebel-Fabbri et al., 2008; Jones et al., 2000; Peveler et al., 2005; Smith et al., 2008; Takii et al., 2008; Young-Hyman & Davis 2010).

In the current study, individuals restricting and omitting insulin for weight control experienced an assortment of psychological outcomes in addition to the experience of diabetes-related complications. The psychological outcomes described in the studies included in this meta-synthesis appear consistent with other published research examining eating disorders within the general population, particularly regarding a shift from increased feelings of control initially to feeling as if the eating disorder was controlling them. Other authors have described diabulimia having such a strong hold on individuals that they were unable to stop manipulating insulin doses, despite knowledge of the potential health complications (Ruth-Sahd et al., 2009). Goebel-Fabbri (2009) described insulin restriction and omission as having the potential to become a pattern of frequent and habitual insulin restriction that becomes entrenched, complex and difficult to treat (Goebel-Fabbri, 2009). Fairburn and Cooper (2011) note that individuals are often able to assert control over their disordered eating in the early stages; however, this control often begins to reduce as time goes on. Qualitative research with anorexia nervosa similarly has described an unwelcome power “taking over” and described a loss of control and loss of self (Higbed & Fox, 2010). Alongside this, individuals described the development of an ‘alien’ mindset that helped to maintain the disordered behaviour once established. Qualitative research has similarly described irrational thinking among individuals with eating disorders. Individuals used language such as “irrational” or “crazy thinking” as a way of describing their state of mind amid disordered eating behaviours (D’Abundo & Chally, 2004). Individuals also reported a constant battle with weight loss impulses, a finding that has previously been reported among eating disorder populations (Garrett, 1997; Goebel-Fabbri, 2017; Woods, 2004). “Disordered

thinking” has been described as remaining a constant and challenging aspect of individuals daily lives, with some expressing the belief that they will always grapple with their disorder (Garrett, 1997; Goebel-Fabbri, 2017; Woods, 2004).

Just as symptoms of depression and anxiety have been reported as risk factors for disordered eating behaviours (Buchberger et al., 2016; Butwicka et al., 2015; Cooper et al., 2017; Danne et al., 2014; Johnson et al., 2013; Reynolds & Helgeson, 2011), insulin restriction and omission as a disordered eating behaviour can also lead to reduced psychological functioning, increased distress and reduced quality of life, which has been reported in the current study. Individuals reported the challenges posed by long term diabetes-related complications and described a significant impact on their overall quality of life as well as intense feelings of regret and shame over past insulin restriction and omission. This finding is not unexpected given the association not only between eating disorders with notable quality of life impairment generally (Mitchison et al., 2012; Mond et al., 2014) but also between both acute and chronic diabetes-related complications and impairments in health-related quality of life within the literature (De Groot et al., 2001; Fenwick et al., 2012; Goebel-Fabbri, 2017; Smith et al., 2016; Solli et al., 2010; Vanstone et al., 2015). Furthermore, many studies have also proposed a bi-directional relationship between disordered eating behaviours and symptoms of depression and reduced quality of life in T1DM populations whereby hyperglycaemia is provoked by depressive symptoms and independently contributes to the exacerbation of depressive symptoms (De Groot et al., 2001; Colton et al., 2013; Lustman et al., 2000; Nip et al., 2019; Wisting et al., 2018). This evidence, taken together, strongly highlights the importance of directing attention and resources towards the prevention and treatment of disordered eating behaviours and psychological comorbidities concurrently in individuals with T1DM.

Support and treatment needs and the level of support received. In the present study, individuals viewed themselves as having a strong diabulimic identity that distinguished them from other current eating disorder labels and was a significant barrier to support. Previous research has similarly found individuals who restrict or omit insulin as defining their eating disorder as diabulimia or a combination of eating disorders including diabulimia, demonstrating a distinction between the act of insulin omission and that of dietary restriction or classical binge/purging (Allan, 2015). Diabulimia is not yet an approved diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2013). It is frequently described among academic research under existing diagnostic labels such as “eating disorder not otherwise specified” (EDNOS) or “bulimia nervosa” and has been theorised to contribute to a lack of understanding and recognition of the specific use of insulin restriction or omission as a disordered eating behaviour in T1DM individuals (Allan, 2015; Nielsen 2002; Takii 2002; Young-Hyman & Davis, 2010). Given the apparent differences emerging in relation to diabulimia, it could be argued that the deliberate restriction or omission of insulin for weight control purposes, may warrant its own diagnostic criteria. Given the unique context and complexity of insulin restriction and omission in T1DM individuals, it may be useful for clinicians and researchers to categorise such individuals differently.

Individuals, in the current study, felt that peer support was most conducive to recovery. Recovery from eating disorders is often assisted by the support and understanding of similar others (Ison & Kent, 2010), and face-to-face support groups have been recommended and are commonly used by individuals with eating disorders to improve their ability to cope with stress and share personal stories (Baskind-White & White, 2000; Kendal et al., 2017; Winzelberg, 1997). Qualitative research has demonstrated connecting to people that understood the eating disorder recovery process not only demonstrated that recovery was

possible but also decreased isolation (Linville, et al. 2012). Other research examining individuals with T1DM has found that engaging with similar others and sharing stories made them feel empowered, less alone, led to new supportive friendships, and a lower likelihood of high levels of depressive and anxiety symptoms (Hilliard et al., 2015; Saylor et al., 2018; Vallis et al., 2017).

As a result of a lack of understanding, individuals in the current study described a lack of services that specialise in insulin restriction and omission in T1DM. Currently, individuals with diabulimia are most frequently treated within eating disorder facilities, where the emphasis is not placed on the concurrent T1DM diagnosis. Healthcare professionals working with individuals with T1DM and disordered eating behaviours have reported perceiving that not only do they not have the skills to treat comorbid T1DM and disordered eating behaviour, and lack the support, there is currently no specialist care pathway to do so (Macdonald et al., 2018; Tierney et al., 2009). Together, this suggests specific pathways and multidisciplinary approaches delivering specialised care in T1DM and eating disorders or disordered eating behaviours, are considered essential for effective intervention, by both individuals with lived experience and healthcare professionals. Studies have previously noted the need for interventions to be led by those with expertise in both T1DM and eating disorders or mental health (Alloway et al., 2001; Olmsted et al., 2001; Romi & Kowen, 2006; Snoek, 2006; Tierney et al., 2009).

Support from others, such as family and friends, was not viewed as being uniformly supportive in the current study. Though some participants reported having positive experiences with their family and feeling supported and encouraged during recovery, others reported difficulty speaking to family and friends and felt misunderstood. Qualitative research has previously described individuals with eating disorders experiencing their family members on a continuum of disconnected to supportive, and reported that their experiences

with their family directly impacted their overall recovery (Linville et al., 2012). Family factors have previously been shown to influence eating behaviours in adolescents with T1DM (Caccavale et al., 2015; Gottesman et al., 2015; Neumark-Sztainer et al., 2002) and specifically, diabetes-related conflict and low levels of family cohesion in T1DM families have been significantly associated with increased rates of disordered eating behaviour in adolescents (Caccavale et al., 2015; Neumark-Sztainer et al., 2002). Among eating disorders more generally, research has demonstrated that family and other key social supports in an individual's life significantly influence the trajectory of and recovery from an eating disorder (Meno et al., 2008; Marcos & Cantero, 2009; Shomaker & Furman, 2009). Regular family meals have also been found to protect against disordered eating behaviours (Neumark-Sztainer et al., 2010).

Individuals perceived support from health professionals as unhelpful and sometimes detrimental to recovery. They often described negative experiences with health professionals and lack of provider knowledge and compassion. This need for health professionals to be more supportive, educated, and understanding, has been previously reported by individuals with diabulimia and other non-comorbid T1DM individuals (Carlton et al., 2017; Goebel-Fabbri, 2017). Individuals have previously reported that health professionals often fail to explore the emotional aspects or psychosocial effects of living with T1DM and how to seek support (Balfe et al., 2013; Rankin et al., 2014). Some individuals have disclosed emotional issues related to living with T1DM and have stated that health professionals did not take this seriously, instead, acting dismissively when the issue was raised (Clarke et al., 2018). Consistent with this, research examining the experiential perspective of healthcare providers working with T1DM with disordered eating behaviours, reported health professionals feeling unequipped to do so, hesitant to bring up the issue with their patients and lacking appropriate training (Tierney et al., 2009). It is of utmost important health professionals working with this

unique population are provided additional education and training to address the needs of T1DM populations with disordered eating behaviours.

Methodological Considerations

The methodological rigour of qualitative meta-syntheses, in terms of consistency, reliability, and generalisability, is comparable to that found in systematic reviews of quantitative data (Pearson et al., 2011). Pre-defined eligibility criteria were used, and PRISMA guidelines (Liberati et al., 2009) were followed, which contributed to the robustness of the meta-synthesis. In this meta-synthesis, the key experiences, impacts and support needs of people with T1DM who engaged in insulin restriction or omission were found consistently across studies suggesting that the findings are reliable. The current meta-synthesis, however, was limited by a relatively small number of qualitative studies examining insulin restriction and omission as a disordered eating behaviour that were available and that could be retrieved. The majority of the sample were women limiting the generalisability of findings to males with T1DM. Furthermore, for those studies who reported demographic information, the sample was drawn from western cultures further limiting the generalisability of findings to broader populations. The articles included in the current study also relied on self-reported data on insulin restriction and omission. Furthermore, the current study only reviewed articles available in the English language, for practical reasons, therefore, relevant studies may have been excluded from this review. Only those that were published after peer-review were included; 'grey literature' and articles currently in press were not actively sought out. While some authors have argued for the inclusion of 'grey literature', the focus of qualitative synthesis is on the development of themes and data saturation, rather than on exhaustive summary of all data (Booth, 2016; Dixon-Woods et al., 2006).

Future Directions

It is encouraging that there is a growing awareness of disordered eating behaviours and clinical eating disorders in populations with T1DM. There remain key gaps in our knowledge which are impeding our options to support individuals with T1DM who restrict or omit insulin as a disordered eating behaviour. Such gaps include insufficient qualitative research examining individuals' experiential perspectives, research examining health providers experiential perspectives as well as that of families and other social supports, knowledge about how males with T1DM use or deliberate misuse of insulin for weight control and support and treatment approaches. Future research should aim to address these gaps in order to better characterise the different (and potentially aetiologically distinct) features of diabulimia, improve the identification of these in clinical settings, and develop and implement evidence-based, effective interventions to prevent and treat this serious health condition.

Implications for Clinical Practice

The results from this meta-synthesis contribute knowledge regarding the lived experience of diabulimia for individuals with T1DM. Insulin restriction and omission is a dangerous method of controlling weight. Prevention and early identification of diabulimia are critical, given the persistence of the behaviour and the associated psychological impacts and increased risks to morbidity and mortality. The complexity of insulin restriction and omission observed in individuals in the current study reflects the need for treatments for this population to be equally multifaceted. This meta-synthesis is also relevant to health professionals working with individuals with T1DM and researchers interested in the restriction and omission of insulin as a disordered eating behaviour. A broad recommendation is for the treatment of eating disorders, and disordered eating behaviours in T1DM to employ evidence-based psychological therapies in the context of a multidisciplinary team. In practice,

however, there is a lack of consensus on how to treat insulin restriction or omission and a general lack of understanding and empathy among health professionals. The findings of this study may provide useful and timely guidance for health professionals as they attempt to identify and understand individuals restricting and omitting insulin for weight control, develop appropriate prevention and treatment support and increase engagement in treatment programs (Table 5). Likewise, this study's findings also highlight potential barriers to engagement in treatment that should be considered.

Conclusion

Three synthesised findings were identified from nine studies in this meta-synthesis. The extracted themes related to individuals' experiences of insulin restriction and omission as a disordered eating behaviour. The analysis revealed a multifaceted relationship with insulin restriction and omission as a disordered eating behaviour, beyond enabling control of weight and shape. Many individuals experienced a wide range of diabetes-related complications from insulin restriction and omission alongside increased distress, loss of control and intense feelings of regret, guilt, and shame later in life. Almost all individuals valued peer support from those who shared a 'diabulimic' identity, which appeared more conducive to recovery than support from friends, family and formal support services which were not uniformly supportive.

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* *Denotes studies included in this meta-synthesis*

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