Lived Experiences of Diabulimia: A Reflexive Thematic Analysis

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Abstract

Eating disorders (EDs) and disordered eating behaviours (DEBs) are significantly more prevalent among individuals with type 1 diabetes than the general population. Not currently recognised in the DSM-5-TR, diabulimia is a colloquial term for a diabetes-specific DEB characterised by the intentional reduction or omission of exogenous insulin to influence body shape or weight. Although it is a particularly dangerous and potentially wide-spread form of DEB, diabulimia remains understudied and there is limited qualitative literature on the experiences of individuals with diabulimia. Drawing on data generated in semi-structured interviews with 10 women recruited from online communities, I explored what the experience of diabulimia is like, what it means, and how it is understood. I analysed this data using reflexive thematic analysis through a lens of critical realism. Four key themes were developed: (1) diabetes distress and burnout; (2) perceptions of being in or out of control; (3) shared knowledge and understanding; and (4) a reason to recover. Findings indicate that diabulimic behaviour has a variety of complex motivations, and is about more than weight and shape. Individuals with diabulimia distinguish their diabulimic identity from other DEB subtypes, and articulate the need for improved knowledge and understanding among healthcare professionals. Motivations to engage in recovery varied, and recovery was often contingent on the acceptance of diabetes more broadly. These findings contribute to psychosocial theories of diabulimia, help healthcare professionals to better understand the experience of diabulimia, and have important implications for the support and treatment of individuals with diabulimia.

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Chapter 1 - Introduction

Diabulimia is a colloquial term for the intentional reduction or omission of exogenous insulin to influence body shape or weight (Falcão & Francisco, 2017). It is a uniquely available, diabetes-specific disordered eating behaviour. Recent studies suggest that diabulimia is a common weight-loss behaviour among individuals with type 1 diabetes (T1D), with prevalence rates reported between 5% and 40% (Bächle et al., 2014; De Paoli & Rogers, 2018; Doyle et al., 2017; Falcão & Francisco, 2017; Troncone et al., 2019). In New Zealand, one third of a sample of 300 young people with T1D in Auckland and Waikato reported engaging in diabulimia (Hatton, 2018).

The consequences of diabulimia are severe and dangerous, and individuals who engage in diabulimia have a reduced average life span of 45 years compared to 58 years among those who do not engage in diabulimia (Goebel-Fabbri et al., 2008). However, the effectiveness of existing treatments for diabulimia is currently disputed (Clery et al., 2017). Individuals with diabulimia frequently speak about negative interactions with healthcare professionals, and state that they do not feel understood or taken seriously by health professionals, often resulting in disengagement from support services (Goebel-Fabbri, 2017). Researchers highlight the importance of rapport between individuals and healthcare professionals in identifying and recovery from diabulimia. Research on the lived experiences of individuals with diabulimia is therefore essential to build rapport and understanding within the therapeutic context, and to develop insights into support, treatment and recovery.

Despite this, most research to date has used quantitative methods to examine aetiology, symptoms and prevalence, with little attention paid to experiential perspectives. There is only one known qualitative study of diabulimia that uses a New Zealand sample (Thomas et al., 2020), and there is room for additional research in this area.

In this research project, I used reflexive thematic analysis to explore lived experiences of diabulimia with the following objectives in mind. Firstly, I aimed to explore what it is like to engage

in diabulimia by providing a rich account of how it presents, how it feels, and how it affects different facets of participants' lives. Secondly, I aimed to explore what diabulimia means for participants and how they understand it. Thirdly, I wished to engage with peoples' experiences of diabulimia as shared in their own words. Finally, I had a goal of increasing awareness of and curiosity about diabulimia in order to encourage further research to improve available support. To fulfil these objectives, my research was guided by the question: What are the lived experiences of individuals who engage in diabulimia?

Chapter 2 – Literature Review

The following chapter explores the existing literature related to type 1 diabetes (T1D) and diabulimia. It begins with an overview of T1D before exploring eating problems among individuals with T1D. The chapter then discusses the literature around diabulimia specifically, before making a case for the research question.

2.1 Type 1 Diabetes

2.2.1 Defining Type 1 Diabetes

Diabetes Mellitus is a metabolic disease characterized by hyperglycaemia (elevated plasma glucose) that results from a deficiency in insulin production, insulin action, or both (Crimmins & Dolan, 2008). *Type 2 diabetes mellitus* (T2D) is the most common form of diabetes and is primarily characterized by a relative deficiency in the hormone insulin (Crimmins & Dolan, 2008). This occurs due to insulin resistance in bodily tissues and the failure of insulin-producing cells to compensate for this (Crimmins & Dolan, 2008). Individuals with T2D often make a considerable quantity of insulin, but the hormone is unable to move glucose from the bloodstream into bodily tissues. T2D is usually diagnosed in individuals over 40 years of age, may develop over many years, and is often unaccompanied by overt symptoms of disease (Crimmins & Dolan, 2008).

Type 1 – or Insulin Dependent - diabetes mellitus (T1D) is an autoimmune disease characterized by a severe or total reduction in insulin production. This is caused by immune-mediated destruction of pancreatic islet β-cells, specialized cells within the pancreas that release insulin to regulate plasma glucose levels (Ionescu-Tirgoviste et al., 2015). In T1D, β-cells are destroyed by autoimmune cells, leading to an absolute shortage of β-cells (Zhao & Mazzone, 2010) and an almost complete absence of effective insulin (Edmonds, 2002). The symptoms of T1D typically have an abrupt onset, and include excessive urination (polyurea), excessive thirst

(polydipsia), weight loss, headaches, and high levels of blood acids called ketones (ketoacidosis) (Craig et al., 2014).

2.2.2 Epidemiology and Aetiology

T1D makes up approximately 5-10% of all cases of diabetes globally (Atkinson et al., 2014). An estimated 26,000 individuals live with a diagnosis of T1D in New Zealand (Diabetes New Zealand, 2021), although the incidence of T1D is increasing both in New Zealand (Derraik et al., 2012) and worldwide (Mayer-Davis et al., 2017). From 1990 to 2009 the incidence of T1D diagnosis between those aged 0 to 14 increased from 10.9 to 22.5 per 100,000 New Zealanders (Derraik et al., 2012). T1 is more prevalent within western societies and among Caucasians (Miller et al., 2020), is usually diagnosed in childhood, and is most commonly diagnosed between 10 to 14 years of age (Patterson et al., 2014).

The development of T1D is believed to occur because of interactions between susceptible genes and epigenetic, physical, social, and environmental factors (Blanter et al., 2019; Bluestone et al. 2010; Zhao & Mazzone, 2010). To be diagnosed with T1D, doctors typically look for specific autoantibodies (antibodies that mistakenly attack the body's own cells) as evidence that pancreatic β-cells are being destroyed by the immune system (Crimmins & Dolan, 2008). At least one form of autoantibody is present at some level prior to the appearance of clinical disease (Riley et al., 1990).

2.2.3 Management

T1D is a chronic, incurable disease that requires daily management to prevent the development of acute and long-term health complications (Riddle & Herman, 2018). Individuals must adhere to an intensive daily regimen of insulin therapy and self-monitoring of blood glucose and dietary intake (e.g., counting carbohydrates) (Riddle & Herman, 2018). Insulin therapy requires the individual to administer synthetic insulin to regulate the level of glucose in their bloodstream, which is affected by a plethora of factors such as diet, activity, stress, hormones, and temperature

(McDonnell & Umpierrez, 2012). Too much insulin causes hypoglycaemia (low blood glucose levels), which can rapidly result in coma or death if left untreated (McDonnell & Umpierrez, 2012). Conversely, too little insulin means that glucose cannot be removed from the bloodstream to be used as fuel for the body and leads to hyperglycaemia (high blood glucose levels) (McDonnell & Umpierrez, 2012). In such circumstances, the body burns fat and muscle tissue for energy, resulting in rapid weight loss and, if insulin is not administered, a life-threatening condition called diabetic ketoacidosis (DKA) (McDonnell & Umpierrez, 2012).

2.2.4 The Burden of Type 1 Diabetes

Because unregulated blood glucose levels can have serious short- and long-term consequences, it is recommended that individuals with T1D adhere to a complex regimen of disease management (Hunter, 2016). These management demands, as well as the initial diagnosis of T1D, can have manifold social, emotional, and psychological implications for individuals and their families, which are explored below.

Social Implications

When diagnosed in childhood or adolescence, T1D impacts - and is affected by - the diagnosed individual's entire family (Moreira et al., 2013). The impact of T1D on family cohesion is not yet fully understood. Overstreet et al. (1995) found that families of children with T1D had lower levels of cohesion, while Hamlett et al. (1992) found no differences in family cohesion compared to control groups. However, family members of individuals with T1D often report making sacrifices in their own health, work life, and social needs in order to support their loved one (Vanstone et al., 2015). Usually, the parents of children or adolescents with T1D take primary responsibility for management of the condition, particularly during pre-adolescent years (Wysocki et al., 2009). Parents often experience significant stress because they must maintain their normal parenting duties while also caring for a child that has an intensive disease management regimen (Streisand et

al., 2010). This may lead to disturbed family functioning (Overstreet et al., 1995), and increases the parent's risk of psychological pathology (De Beaufort & Barnard, 2012).

Parents of children with T1D – and especially mothers - are more likely to develop symptoms of depression (Driscoll et al., 2010), symptoms of anxiety (Williams et al., 2009), and even post-traumatic stress disorder (Horsch et al., 2007). Parents may feel stretched by the financial burden and time demands associated with caring for a child with T1D, and have reported worrying over their child's future, long-term health complications, and who will manage their child's illness when they are outside the home (Moreira et al., 2013). Further, the difficulties and strain of living with T1D can create antagonism between individuals with T1D and their family members. Interpersonal conflict between partners, friends, and family members may occur due to fear and disagreement over diabetes management (Hortensius et al., 2012), and many individuals with T1D report feeling like a burden due to their family (Rankin et al., 2018). Hypoglycaemic episodes can also make individuals with T1D confused, irritable, or aggressive, which may be alarming for family members, and some have expressed feeling vulnerable to their family member's moods and aggressions (Trief et al., 2013).

Beyond the family sphere, individuals have reported that T1D affects their everyday relationships and social experiences. Many have described feeling alienated, embarrassed, stigmatized, and unable to participate in regular social activities. Individuals with T1D frequently report discrimination on the basis of their condition, most commonly at school but also from employers, work colleagues, friends, and healthcare teams (Mellerio et al., 2015). For example, young adults with T1D have spoken of being viewed negatively for engaging in diabetes management behaviours at work (Mellerio et al., 2015). Individuals with T1D have also described the widespread misunderstanding that T1D stems from lifestyle factors (e.g., an inactive lifestyle and poor diet), and that disclosing their T1D status can lead to unsolicited and unhelpful health advice (Chalmers et al., 2022). Diabetes stigma and misunderstanding may lead to individuals with T1D

feeling embarrassed and compelled to hide their condition and self-management activities, which can increase feelings of alienation from the general population (Nettleton et al., 2022) and lead to consciously skipping self-management behaviours (Davidson et al., 2004). Further, some individuals have described how needing to constantly monitor and regulate their diet and exercise has hampered their enjoyment of social activities and outings (Balfe et al., 2013). Others avoid normal social activities, driving, and work altogether, which significantly reduces their of quality of life (Vanstone et al., 2015).

Individuals with T1D have attributed limited engagement with employment and leisure activities to various reasons, including the high level of organisation required to manage T1D, absences related to illness and attending medical appointments, lower functioning during episodes of hyper- or hypoglycaemia, and the need for space and time to engage in self-management activities (Vanstone et al., 2015). For some, these challenges have resulted in a loss of wages and employment opportunities (Brod et al., 2013; Burda et al., 2012). Certain careers are also not available to individuals with T1D, such as those in the military or emergency services (Vanstone et al., 2015). All in all, it is evident that T1D has significant social implications for individuals with the condition and their families.

Emotional and Psychological Implications

Being diagnosed with T1D in childhood or adolescence can hinder an individual's developmental growth, which may impact emotional and psychological functioning (van Duinkerken et al., 2020). Meta-analyses and systematic reviews have shown that children, adolescents, and young adults with T1D experience elevated psychological distress compared to healthy peers (Buchberger et al., 2016; Johnson et al., 2013; Reynolds & Helgeson, 2011), of which an important component is *diabetes distress*. This term refers to the negative emotional impact of living with diabetes, which stems from the burden of self-management as well as living with diabetes-related health complications or the risk that they develop (van Duinkerken et al., 2020). Diabetes distress is

strongly correlated with symptoms of anxiety and depression, so those experiencing diabetes distress are very likely to have additional symptoms of anxiety or depression as well (van Duinkerken et al., 2020). One in three adults with T1D report diabetes distress to such an extent that they experience *diabetes burnout*, a cycle of frustration and "giving in" followed by a decline in glycaemic control and heightened emotional distress (Polonsky, 1999). Stress and the risk of demoralization and depression are further increased by repeated episodes of hyperglycaemia and hypoglycaemia, which negatively influence mood and cognitive performance (van Duinkerken et al., 2020).

Individuals with T1D experience psychological comorbidities at a higher rate than the general population (de Groot et al., 2016). Lifestyle changes and complex self-management behaviours impose a considerable burden on individuals with T1D, which may lead to an increased risk of diagnosed depression and subsyndromal depressive symptoms compared to the general population (Fisher et al., 2014; Nouwen et al., 2011). This increased risk is particularly pronounced for individuals who experience recurrent hypoglycaemic episodes and poor glycaemic control (Holt et al. 2014). People with T1D are also at increased risk of diagnosed anxiety disorders and subsyndromal anxiety symptoms compared to the general population (Smith et al., 2013). This risk is especially pronounced in women, young individuals, individuals with a longer duration of diabetes, and individuals with multiple medical conditions (Smith et al., 2013). In qualitative research that examined T1D-related fears, adolescents and young adults reported feeling anxious about how they are perceived by others, passing out or not waking up due to hypoglycaemia, developing long-term health complications, requiring surgery or other invasive procedures, and experiencing pregnancy complications due to T1D (Balfe et al., 2013; Beveridge et al., 2006; de Groot et al., 2016; Ersig et al., 2016; Overgaard et al., 2020).

Management of T1D also involves multiple elements that raise an individual's risk of disordered eating behaviours (DEBs) and eating disorders (EDs), such as close monitoring and/or restriction of dietary choices to assist in blood glucose control (de Groot et al., 2016). While the

estimated prevalence of DEBs and EDs in individuals with T1D varies by assessment methodology (e.g. diagnostic interviews vs. self-report questionnaires) and whether measures have been tailored to reflect diabetes-specific behaviours and treatments, the literature broadly agrees that individuals with T1D – particularly adolescent girls and young women – are at higher risk of experiencing DEBs and EDs than those without T1D (e.g. de Groot et al., 2016; Rodin et al., 2002; Young et al., 2013; Young-Hyman & Davis, 2010). Individuals with comorbid T1D and DEBs or EDs are also more likely to experience anxiety disorders (Papelbaum et al., 2005) and heightened symptoms of depression (Herpertz et al., 2001).

The psychological conditions described above are associated with decreased diabetes self-management behaviours in adults with T1D (de Groot et al. 2016). Depression and depressive symptoms are correlated with poorer adherence to treatment recommendations (e.g. dietary control, medication use, glucose monitoring, medical appointments, and foot care) (Buchberger et al., 2016; Gonzalez et al., 2008), and impaired problem solving skills linked to poor glycaemic control (Hill-Briggs & Gemmell, 2007). Similarly, symptoms of anxiety worsen diabetes self-care and reduce adherence to dietary recommendations (Janzen Claude et al., 2014), while DEBs and EDs decrease adherence to diabetes self-management behaviours, particularly insulin administration (de Groot et al., 2016).

Individuals with comorbid T1D and psychological conditions tend to have poorer diabetes outcomes than individuals with T1D alone. Each psychological condition described above is associated with poorer glycaemic control and poorer health outcomes among those with T1D (de Groot et al., 2016). Comorbid depression and T1D are correlated with greater disability (Egede, 2004), increased healthcare costs (Egede et al., 2002), and earlier mortality (Molosankwe et al., 2012) than T1D alone. Individuals with T1D who experience symptoms of anxiety tend to have poorer quality of life than those who do not experience anxiety (Hood et al., 2014; Klein-Gitelman & Curran, 2015). Cross-sectional and longitudinal investigations among T1D samples have shown that

DEBs and EDs are associated with hyperglycaemia and microvascular complications (e.g., diabetic retinopathy, peripheral neuropathy, and proteinuria) (Young et al., 2013) and increased rates of hospitalisations for DKA (Young-Hyman & Davis, 2010). In light of the reciprocal relationships between these psychological conditions and T1D, and the accompanying burdens, it is vital that we gain a deeper understanding of the complex interactions between T1D and psychological comorbidities.

2.3 Type 1 Diabetes, Eating Disorders, and Disordered Eating Behaviours

2.3.1 Overview

EDs are complicated psychological conditions related to disturbances in eating behaviours, thoughts and attitudes to food, and body weight or shape (Polivy & Herman, 2003). They are diagnosed according to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM); within the latest DSM (5th ed., text rev.) this includes anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant/restrictive food intake disorder (ARFID), and other specified feeding and eating disorder (OSFED) (American Psychiatric Association, 2022).

Despite the fact that many individuals with EDs require treatment, relatively few receive treatment compared to individuals with other types of psychological problems such as mood or anxiety disorders (Hart et al., 2011; Oakley Browne et al., 2006). Barriers to treatment are wide-ranging, and may include individual characteristics, socio-environmental factors, and systemic treatment factors (Innes et al., 2017). A recent systematic review by Innes and colleagues (2017) examined 11 studies investigating barriers to ED treatment and found that those most commonly reported were shame and stigma, financial cost, and service-related factors. EDs frequently go unrecognized in clinical settings, particularly for individuals with non-stereotypical presentations (Mond et al., 2007) and where health care providers have biases about individuals with EDs (Becker et al., 2003). For example, while significant weight loss is an obvious symptom of anorexia nervosa,

individuals with bulimia nervosa or OSFED may not display obvious physical symptoms and may go undiagnosed – and untreated - by health care professionals (Currin et al., 2009).

ED symptoms may also present at a frequency or severity below the level required for formal diagnosis. These are termed *disordered eating behaviours* (DEBs), and may include behaviours such as binge eating, dieting for weight loss, calorie purging through laxative/diuretic use, self-induced vomiting, and excessive physical activity (Olmsted et al., 2008). Among individuals with T1D, DEBs may include *diabulimia*, wherein the individual restricts their exogenous insulin to induce hyperglycaemia (high blood glucose levels) and glycosuria (excretion of glucose in the urine) for the purpose of calorie purging and weight loss (Weaver, 2012). In my research, including in this literature review, I will use the term *eating problems* to refer to EDs and DEBs collectively, in order to recognize the complexities of ED diagnosis and highlight the overlap between the two classifications.

Eating problems are significantly more prevalent in individuals with T1D than in those without T1D (e.g., Colton et al., 2004; Rodin et al., 2002). Females with T1D are an estimated 2.5 times more likely to develop an ED than those without T1D (Coleman & Caswell, 2020; Goebel-Fabbri, 2017), although it can be difficult to measure the prevalence of eating problems in T1D populations because specific aspects of diabetes management can mimic those of eating problems (e.g., a focus on food portions and the types of food eaten) (Goebel-Fabbri, 2017).

Nielson (2002) conducted an early systematic review of controlled studies between 1986 and 2000 to investigate the prevalence of eating problems among T1D populations, concluding that anorexia nervosa was not more common in those with T1D but that individuals with T1D were three times more likely to engage in bulimia nervosa and twice as likely to engage in subthreshold DEBs and ED-NOS (a category similar to OSFED but from a prior iteration of the DSM). The author further concluded that deliberate insulin restriction was strongly related to weight loss, but that research examining this as a feature of eating problems was lacking. Mannucci et al. (2005) conducted a

similar meta-analysis of eight studies, excluding studies involving males. The authors similarly concluded that the prevalence of bulimia nervosa, but not anorexia nervosa, was significantly higher in girls and women with T1D than in those without. However, the study did not include ED-NOS, stating that it had an uncertain definition, nor did they investigate the role of insulin restriction, despite Nielson (2002) previously acknowledging the importance of such research.

More than a decade later, Allan (2019) undertook an extensive systematic review of 60 studies from 16 countries to investigate how eating disorders in T1D had been researched. The author concluded that there was a general consensus in the research that females with T1D are more susceptible to eating problems than their male counterparts, but that males were displaying higher levels of eating problems (including insulin omission) in more recent years compared to older studies. Studies using adult samples tended to report higher levels of insulin omission than those including children and adolescents, although there was significant variation in reported rates of insulin misuse (Allan, 2019). Studies using clinical samples reported rates of insulin omission as high as 90%, suggesting that insulin omission is a key feature for those diagnosed with an eating problem (Allan, 2019). However, the author noted a number of limitations to these findings. Of the 60 studies, the majority came from America (n=21) and Canada (n=8), and most used mixed gender or women-only samples with only one study focusing exclusively on males. Sample sizes were typically less than 30 participants, and mostly centred on young adults and adolescents. These factors indicated a lack of diversity within the literature and limited the generalizability of findings (Allan, 2019). The author further remarked that the current literature on eating problems among T1D populations was “messy” (p.97), and that little consensus existed as to diagnosis, prevalence, and measurement.

Eating problems among individuals with T1D are associated with adverse psychological and medical outcomes. Cross-sectional and longitudinal investigations of T1D samples have found eating problems to be associated with impaired glycaemic control (Young et al., 2013), earlier onset and

increased severity of diabetes-related health complications (Rydall et al., 1997), and more frequent hospitalisations (Young-Hyman & Davis, 2010). Taken together, these findings suggest that eating problems among individuals with T1D are associated with significant risks to health and are of major clinical importance.

2.2.2 Risk Factors for Eating Problems in Type 1 Diabetes

The aetiology of eating problems is not entirely understood, but is generally thought to involve interactions between genetic, environmental, cultural, and personality factors (Striegel-Moore & Bulik, 2007). Within the general population, risk factors include a history of dieting, dietary restraint, and higher BMI (Graber et al., 1994), depression and anxiety (Kaye et al., 2004), self-esteem (Striegel-Moore & Bulik, 2007), and perfectionistic traits (Fairburn et al., 2003). These risk factors are also relevant in the context of T1D, as discussed below.

A History of Dieting, Dietary Restraint, and Higher BMI

Dietary restraint describes the mental energy expended by a person to eat less than they desire (Lowe & Kral, 2006), while *dieting* refers to adhering to a particular way of eating to facilitate weight loss (Schaumberg et al., 2016). Both dietary restraint and dieting are empirically supported risk factors for eating problems within general and T1D populations (Goebel-Fabbri, 2009). Dieting and periods of caloric restriction are thought to biologically increase the reinforcing value of food, thereby precipitating binge-eating, purging, and unhealthy weight loss (Epstein et al., 2003; Lowe & Timko, 2004; Stice, 2001). Aetiological models of eating problems suggest that dietary restraint results in feelings of perceived deprivation, leading to episodes of disinhibited eating that are predictive of eating problems (Schaumberg et al., 2016).

Dietary restraint and a history of dieting are also associated with higher BMI in the general population, particularly among girls and women (Ramirez-Contreras et al., 2021; van Strien et al., 2020). Individuals with T1D are at increased risk for higher BMI and being overweight both before

T1D diagnosis (Verbeeten et al., 2011) and post-diagnosis (Goebel-Fabbri, 2009). In a systematic review and meta-analysis of 9 studies, Verbeeten et al. (2011) found that childhood obesity and higher BMI were associated with an increased risk of subsequent T1D. Intensive insulin therapy – now the normal standard for T1D management - is also associated with higher BMI and a greater risk of being overweight or obese in individuals with T1D (Goebel-Fabbri, 2009). Indeed, being overweight is more prevalent among adolescent girls with T1D relative to age-matched controls (Calella e al., 2020; Domargard et al., 1999; Ingberg et al., 2003), and adolescent girls with T1D have a significantly higher proportion of body fat than their non-diabetic peers (Ingberg et al., 2003). In light of these heightened risk factors for being overweight and contemporary Western society's pressure for thinness, it follows that individuals with T1D – and particularly females – may be more likely to engage in dietary restraint and dieting, leading to a increased risk of eating problems relative to the general population.

Depression and Anxiety

Numerous studies have established a connection between depression and anxiety and the development of eating problems in the general population (e.g., Kaye et al., 2004; Lewinsohn et al., 2000). Depression, anxiety, and T1D often present as comorbid conditions (Berge et al., 2013). Indeed, individuals with diabetes are twice as likely to experience clinically significant depression than those without diabetes (de Groot et al., 2016), and adults with diabetes have a 20% higher prevalence of clinically significant anxiety symptoms than their non-diabetic counterparts (Smith et al., 2013).

Brechan & Kvalem (2015) propose that depression can lead to body dissatisfaction, which may give rise to eating problems within both the general and T1D populations. For youth with pre-existing body image concerns, the weight gain associated with initiating insulin therapy may worsen depression (Peterson et al., 2015). Nouwen et al. (2011) suggest that the drastic lifestyle changes and self-management behaviours required by diabetes impose a significant burden on the individual,

which may lead to or exacerbate depressive symptoms. Holt et al. (2014) further suggest that this burden may be particularly heavy for individuals with T1D compared to those with T2D, as the use of insulin requires significantly more intensive self-management than non-insulin treatment regimens.

Researchers have found that feelings of depression and anxiety among individuals with T1D often lead to reported decreases in self-care, diabetes management, and glycaemic control (Barnard et al., 2006; Gonzalez et al., 2008; Janzen Claude et al., 2014; Maia et al., 2014). Depressive symptoms are also associated with impaired problem-solving skills, which are independently linked to poor glycaemic control in diabetic individuals (Hill-Briggs & Gemmell, 2007). On the other hand, Bächle et al. (2015) and Strandberg et al. (2014) found that higher levels of depression and anxiety were not correlated with poorer T1D management. Evidently, we cannot yet be confident about the role of depression and anxiety in the aetiology of eating problems among individuals with T1Ds. Further research is needed on the impact of T1D on anxiety, depression, and subsequent eating problems.

Self-Esteem

Self-esteem refers, broadly, to how much worth and value an individual finds in themselves (Hewitt, 2009). Low self-esteem has long been implicated in the development of EDs within the general population (e.g., Mora et al., 2017). Although researchers have investigated whether individuals with T1D have lower self-esteem than their non-diabetic peers, no consensus has yet been reached (Luyckx & Seiffge-Krenke, 2009; Mohn et al., 2018; Rassart et al., 2014; Vlachioti et al., 2010; Zoffman et al., 2014). Vlachioti et al. (2010) found no difference in self-esteem levels between individuals with or without T1D. By contrast, Luyckx and Seiffge-Krenke (2009) identified, in a 5-year longitudinal study, that Belgian men and women with T1D had lower levels of self-esteem than their non-diabetic peers. A cross-sectional study of 891 Belgian emerging adults similarly found that women with T1D reported lower self-esteem compared to non-diabetic controls, but that men with T1D reported higher self-esteem than non-diabetic controls (Rassart et al., 2014). Mohn et al. (2018)

found that women with T1D had lower self-esteem than men with T1D, consistent with research suggesting that women generally have lower self-esteem than men (Bleidorn et al., 2016). Taken together, these results suggest potential differences in the effects of gender on self-esteem for those with T1D, and highlight the gaps in our current understanding of the role of gender in the aetiology and maintenance of eating problems within T1D populations. Further research is needed in this area.

Perfectionism

According to Frost and Marten (1990), *perfectionism* is a multi-dimensional construct that includes high personal standards, self-criticism, fear of negative evaluation, and excessive concern over mistakes (Stairs et al., 2012). Perfectionism can be considered a cultural phenomenon, wherein the cultural norms of different time periods create generational variation in levels of perfectionism (Curran & Hill, 2019). In a recent study of 41,641 American, Canadian, and British university students, Curran and Hill (2019) found that perfectionism scores displayed linear increases between 1989 and 2016. This indicates that recent generations have higher expectations of themselves and consider perfection to be more important than previous generations have done. According to the authors, this phenomenon is can be attributed to various cultural changes that foster perfectionism, such as heightened competition, individualism, meritocracy, and overbearing and worrisome parenting styles (Curran & Hill, 2019). This rise in perfectionism across generations may be a contributing factor to the growing prevalence of psychopathology, including eating problems, that has been observed over the past few decades (Bloch, 2016; Paik & Sanchagrin, 2013).

Perfectionism can be a contributing factor to the onset and maintenance of eating problems in the general population (Bardone-Cone et al., 2010; Farstad et al., 2016) and in the T1D population (Treasure et al., 2015). Within the general population, eating problems are maintained when individuals apply perfectionistic standards to areas such as diet (e.g., eating to a perfect meal plan or caloric intake), exercise (e.g., completing a particular number of minutes of physical activity), and

appearance. In the context of T1D, Treasure et al. (2015) suggest that a perfectionistic personality may combine with the focus on weight and eating necessary within diabetes management to increase weight and shape concerns, triggering dieting behaviours and eating problems. De Paoli and Rogers (2018) suggest that perfectionism combines with low self-esteem to encourage dysfunctional self-evaluation and an unhealthy focus on eating, weight, and shape. People with T1D may also attempt to manage the insecurities associated with the condition by exerting strict control over certain behaviours, such as food consumption, which may develop into eating problems (De Paoli & Rogers, 2018).

Perfectionistic tendencies may also emerge in individuals with T1D as the result of diabetic treatment goals (Goebel-Fabbri, 2017; Young-Hyman & Davis, 2010). Goebel-Fabbri (2017) suggests that the standard T1D management regimen encourages perfectionism in glycaemic control, such that striving to achieve "perfect" blood sugar levels engenders maladaptive attention to food and control of eating and body weight or shape. An inability to achieve perfect glycaemic control may lead to individuals viewing themselves as failures, thereby impacting their self-esteem and promoting eating problems (Goebel-Fabbri, 2017).

Goebel-Fabbri (2017) further suggests that interventions offered by healthcare professionals to try to reduce the impact of T1D, which are often based upon recurrent monitoring of glucose numbers, may actually encourage maladaptive perfectionism in individuals with T1D. In this way, perfectionistic expectations are seemingly reinforced by the healthcare system, placing individuals with T1D at increased risk of eating problems. It is therefore imperative to further investigate this risk factor for eating problems in T1D populations.

2.3.3 Diabetes-Specific Risk Factors

As discussed, some risk factors for eating problems are shared by individuals with and without T1D. However, individuals with T1D are significantly more likely to develop eating problems than those without T1D (Colton et al., 2004), indicating that there are additional and unique T1D-

related risk factors that contribute to the aetiology of eating problems within the T1D population. These are explored below.

Initiation of Insulin

Directly prior to being diagnosed with T1D, individuals may experience significant weight loss as the body loses fluid and breaks down its own tissues for energy. This is typically regained at the commencement of insulin therapy, together with significant water retention in what is known as *insulin edema* (Hussien et al., 2022). This sudden weight restoration may trigger emotional distress, body image dissatisfaction, and fear of continued weight gain in newly diagnosed individuals (Goebel-Fabbri, 2017), particularly girls and women who frequently experience sociocultural pressure to be thin (Peterson et al., 2015). This may create a fear of exogenous insulin and increase the risk of eating problems (Goebel-Fabbri, 2017; Olmsted et al., 2008).

Dietary Management of Type 1 Diabetes

Managing T1D involves multiple elements that increase an individual's risk of eating problems, including close monitoring and/or restriction of dietary choices, prescribed physical activity, and a loss of autonomy in food choices (de Groot et al., 2016). Traditional meal plans for T1D (e.g., exchange type diets) often allocate specific numbers of carbohydrate grams per meal, which can be likened to meal plans that focus on calorie amounts (Goebel-Fabbri, 2017). Some individuals report a sense of dietary restraint even when using more flexible methods of meal planning, such as carbohydrate counting (Daneman et al., 2002). Goebel-Fabbri (2017) describes how the educational approach to food provided to individuals with T1D is often "restrictive and depriving – akin to a rigid diet" (p. 21). Such dietary restriction may, in combination with a heightened attention to food, contribute to the development of eating problems among those with T1D (Goebel-Fabbri et al., 2008; Nash & Skinner, 2005; Rancourt et al., 2019; Tse et al., 2012). Peterson et al. (2015) further posit that eating problems may be promoted by an individual's

inability to fully adhere to such strict dietary guidelines, by way of guilt and emotionally driven eating.

Rancourt et al. (2019) suggest that eating problems may be fostered when an individual repeatedly overrides their physical hunger cues to achieve glycaemic control. Individuals with T1D may avoid eating when hyperglycaemic and may overeat when experiencing extreme hunger associated with hypoglycaemia, leading to hunger-satiety disruption (Rancourt et al., 2019). Indeed, 98% of individuals with T1D report engaging in disinhibited eating during episodes of hypoglycaemia (Merwin et al., 2014). Merwin et al. (2014) suggest that this dysregulation and hunger-satiety disruption together promote guilt and foster eating problems.

The Role of Family and Friends

Families can significantly influence an individual's psychosocial adjustment to a chronic illness (Hauser et al., 1993; Warner & Hauser, 2009), and T1D management typically involves a complex management plan requiring a shared family effort (Markowitz et al., 2015). The demands of managing T1D can strain the capacity of individuals and their families to cope, placing vulnerable individuals at greater risk of psychiatric disturbances (Kovacs et al., 1997; Turin & Radobuljac, 2021). Indeed, eating disturbances among youth with T1D are associated with poor family communication, family conflict, insufficient support, and a lack of familial trust (Goebel-Fabbri, 2017; Maharaj et al., 1998).

For youth with T1D, successful management of diabetes tends to require high levels of parental involvement, and parents may struggle to balance the provision of parental support with the fostering of independence (Hauser et al., 1993; Lohman & Jarvis, 2000). As a consequence, adolescents with T1D may seek to gain self-mastery and control by controlling their weight or shape (Daneman et al., 2002). In the same way, young adults with T1D may manipulate their body weight or shape as a way of expressing independence, mastery, and individuality (Weaver, 2012).

Individuals with T1D may also be more prone to societal pressures regarding body composition and size. A significant body of research has demonstrated that body dissatisfaction, negative body image, and the pursuit of thinness are risk factors for eating problems in the general population (Jiotsa et al., 2021; Tiggermann & Pickering, 1996) and T1D population (Araia et al., 2017; Falcão & Francisco, 2017). However, individuals with T1D tend to score more highly in measures of negative body image (Troncone et al., 2022; Verbist & Condon, 2021) and have a higher drive for thinness (Svensson et al., 2003) than their non-diabetic counterparts. This may, at least in part, be attributable to family or peers. In a sample of adolescents and adults with T1D, Verbist and Condon (2019) found that body image dissatisfaction was predicted by social network use, and that participants who used social networks more frequently tended to have greater body image dissatisfaction. Among girls with T1D, body dissatisfaction is also associated with unfavourable views of family and peer communication, and it is theorized that body dissatisfaction may mediate the link between negative communication and eating problems (Kichler et al., 2008). Young women with T1D may experience more pressure from family to maintain a thin body than non-diabetic controls, related to meeting the goals of diabetic guidelines (Troncone et al., 2022). Body dissatisfaction among young women with T1D is also correlated with a mother's opinion that her daughter is heavier than she should be (O'Brien et al., 2011). Taken together, this suggests that individuals with T1D – and particularly girls and women – are at higher risk for body dissatisfaction and negative body image than the general population, placing them at increased risk of eating problems.

2.4 Diabulimia

Until now, the literature review has broadly addressed the concepts of T1D and eating problems. From here on, the focus narrows to diabulimia. The following section introduces diabulimia before exploring its prevalence, consequences, and current treatments. Following this, I explore prominent studies that research diabulimia from a qualitative perspective, before articulating the aims of this research project.

2.4.1 Defining Diabulimia

Diabulimia is a colloquial term used to describe the intentional reduction or omission of exogenous insulin to influence body shape or weight (Falcão & Francisco, 2017). It is a uniquely available, diabetes-specific DEB. Diabulimia does not currently have a separate diagnostic code within the latest DSM, although it may be incorporated within multiple diagnoses depending on the individual's eating disorder behaviours (APA, 2022). It may be coded as bulimia nervosa if the individual is binge-eating and then restricting insulin, as anorexia nervosa if the individual is restricting both food and insulin, or, finally, as OSFED when included as "misuse of medications to influence weight" (Coleman & Caswell, 2020).

The naming and labelling of diseases have implications for the ways in which we understand, communicate about, and attempt to treat them (Sims et al., 2021). Arguably, the use of DSM labels to describe diabulimia are problematic in that they fail to capture diabulimia's central dual diagnostic component – namely, that individuals with diabulimia necessarily have pre-existing T1D (Sharma, 2013). Further, the use of terms such as bulimia nervosa, anorexia nervosa, and OSFED risks obscuring the nuances between them and diabulimia, implying that the experiences, symptoms, and prognoses are the same. This fails to reflect the notion that eating problems can be caused, or at least exacerbated, by the dietary restraint necessitated by diabetes management (Goebel-Fabbri, 2008).

2.4.2 The Prevalence of Diabulimia

While prevalence rates are challenging to ascertain due to potential under-reporting (Goebel-Fabbri, 2017), several studies suggest that diabulimia is a common weight-loss behaviour among individuals with T1D. Internationally, prevalence rates are reported between 5% and 40% of individuals with T1D (Bächle et al., 2014; De Paoli & Rogers, 2018; Doyle et al., 2017; Falcão & Francisco, 2017; Troncone et al., 2019), with these rates peaking in late adolescence and early adulthood (15-30 years) (Goebel-Fabbri, 2017). This variation in reported prevalence is likely due to

differences in assessment methodology. Generic ED questionnaires (e.g., the Eating Disorder Examination Questionnaire (Cooper & Fairburn, 1987); the SCOFF questionnaire (Morgan et al., 1999)) do not ask about insulin restriction, making detection of diabulimia difficult. By contrast, interviews in which the patient is asked "do you take less insulin than you should?" may more effectively identify diabulimia (Goebel-Fabbri et al., 2008). Another factor that may complicate the detection of diabulimia is that insulin omission may at times be unintentional or due to outside factors, such as an inability to pay for medication (Davidson, 2014).

In New Zealand, one third of a sample of 300 diabetic young people (aged 12-25 years) in Auckland and Waikato reported engaging in diabulimia (Hatton, 2018). Here, diabulimia was most common in young women, and among Pacific ethnic groups compared to Pakeha (European) and Māori ethnic groups (Hatton, 2018). While there is a general consensus in the literature that diabulimia is more prevalent among females than males (Morris, 2021), recent studies indicate that up to 25% of males with T1D have intentionally caused hyperglycaemia by deliberately failing to treat high glucose levels (Doyle et al., 2017; Markowitz et al., 2010). This suggests that diabulimia may be a common experience among all individuals with T1D.

2.4.3 Consequences of Diabulimia

The consequences of diabulimia are well-documented, and include both acute and chronic effects on the body. Acutely, insufficient insulin leads to hyperglycaemia (high blood glucose levels), resulting in rapid calorie loss through glycosuria (the excretion of glucose in urine) and catabolism (the breakdown of body tissues for alternative sources of energy). This quickly leads to diabetic ketoacidosis (DKA), a life-threatening condition caused by excess ketones (blood acids) in the blood, which can cause kidney failure, heart complications, cerebral edema, coma, or death (Goebel-Fabbri et al., 2008).

Long-term hyperglycaemia may result in microvascular and macrovascular complications such as retinopathy (vision loss), nephropathy (kidney damage), neuropathy (nerve damage),

cardiovascular disease, and strokes (Chawla et al., 2016; Gerstein & Werstuck, 2013). Individuals who engage in diabulimia report earlier onset of, and higher levels of, diabetic complications, and reduced quality of life, compared to individuals with T1D who do not misuse insulin (Wilson, 2012). Diabulimia also increases the risk of mortality among individuals with T1D (Goebel-Fabbri et al., 2008). An 11-year study of 234 women with T1D found that those who self-reported diabulimia at the start of the study had a 3.2-fold increased risk of death at follow-up, and an average life span of 45 years compared to 58 years for those who did not engage in diabulimia (Goebel-Fabbri et al., 2008). These severe consequences suggest that diabulimia is a particularly dangerous form of eating problem.

2.4.4 Treatment of Diabulimia

While the importance of early identification and treatment of diabulimia is frequently emphasized (Hoffman, 2019), there are no established guidelines or pathways for the treatment of diabulimia specifically. Most frequently, treatment strategies are those used for treating eating problems in the general population, such as psychotherapy, psychoeducation, pharmacological treatment, and in severe cases hospitalization (Callum & Lewis, 2014). Treatments within general ED facilities do not usually emphasize the patient's concurrent diabetes diagnosis (Roney, 2015), and patients with T1D frequently describe feelings of isolation and a lack of support as a result (Goddard, 2020). Treatment of diabulimia requires an initial goal of medical safety (Goebel-Fabbri et al., 2009), and patients must be stabilized and often treated for ketoacidosis in an acute setting before treatment of diabulimia can commence (Ruth-Sahd et al., 2009). An interdisciplinary team is fundamental to effective treatment (Juruć et al., 2016), and the team should ideally include an endocrinologist, a registered dietician with ED and/or diabetes training, a registered nurse, and possibly a psychiatrist (Roney, 2015).

The effectiveness of existing treatments for diabulimia is disputed (Clery et al., 2017), and qualitative literature frequently describes patients' dissatisfaction with treatment and support (e.g.,

Goddard & Oxlad, 2022; Morris, 2021; Thomas et al., 2020). Lack of provider knowledge is a consistent theme within the literature (Roney, 2015), and individuals with diabulimia often describe negative interactions with health care professionals in which they were dismissed, criticised, or infantilised (Goddard & Oxlad, 2022; Morris, 2020). This can generate feelings of alienation and isolation, creating a lack of engagement with healthcare services and a barrier to treatment (Goddard & Oxlad, 2022; Thomas et al., 2020). Individuals have noted that healthcare professionals seldom investigate the psychosocial impacts of T1D and diabulimia (Rankin et al., 2018), and that they need to be more educated and empathetic (Thomas et al., 2020). I suggest that further qualitative research is necessary to generate a deeper and more empathetic understanding of the lived experience of individuals with diabulimia.

2.4.5 Experiential Perspectives of Diabulimia

The aforementioned studies have primarily explored diabulimia from a quantitative perspective. These studies are helpful for establishing an understanding of the potential prevalence of diabulimia, as well as testing theories about diabulimia and contributing to theoretical development. There are also some studies that engage with participants using qualitative approaches, including thematic analysis and meta-aggregative techniques. I explore some of these here, to set the stage for how qualitative research can help to deepen understandings of diabulimia experiences.

Several qualitative researchers have explored risk and maintaining factors for diabulimia. These include fluctuations in weight before and after T1D diagnosis, body dissatisfaction, a desire for weight loss or fear of weight gain, low perceptions of control and perceived ineffectiveness, high levels of stress and negative emotions, and diabetes distress (Balfe et al., 2013; Coleman & Caswell, 2020; Goddard & Oxlad, 2022; Goebel-Fabbri, 2017; Macdonald et al., 2018; Staite et al., 2018). Participants often speak of ignoring the serious health risks associated with diabulimia in order to prioritize weight loss, despite understanding the importance of glycaemic control (Goddard & Oxlad,

2022; Goebel-Fabbri, 2017). Diabulimia usually begins as an intermittent behaviour, but tends to escalate into an entrenched habit that participants often liken to an addiction or trap (Goddard & Oxlad, 2022; Goebel-Fabbri, 2017; Staite et al., 2018).

Individuals with diabulimia frequently perceive support from healthcare professionals as unhelpful or even detrimental to recovery (Coleman & Caswell, 2020; Goddard & Oxlad, 2022; Goebel-Fabbri, 2017), and often speak of being dismissed or minimized when they disclose emotional issues relating to T1D and diabulimia (Goddard & Oxlad, 2022; Goebel-Fabbri, 2017). The need for healthcare professionals to be more educated about the psychosocial effects of T1D and diabulimia is a prominent theme throughout the literature (Balfe et al., 2013; Carlton et al., 2017; Goddard & Oxlad, 2022; Goebel-Fabbri, 2017). For example, Coleman and Caswell (2020), who used thematic analysis to explore the experiences and understandings of people who had engaged in diabulimia, concluded that clinicians needed to better understand the psychological issues associated with diabulimia in order to deliver effective psychological treatment.

In the absence of effective support from healthcare professionals, individuals frequently seek support from peers, either in person or online (Staite et al., 2018), and peer support is considered valuable to recovery (Goddard & Oxlad, 2022; Macdonald et al., 2018; Staite et al., 2018). For example, Goddard and Oxlad (2022), who used meta-aggregative techniques to generate synthesized findings from 12 qualitative studies about individuals' experiences and understandings of diabulimia, concluded that peer support was more conducive to recovery than other forms of support.

The importance of incorporating support from friends and family is also highlighted (Goddard & Oxlad, 2022; Macdonald et al., 2018; Thomas et al., 2020), although in some cases family members may contribute to or enable harmful eating behaviours (Goebel-Fabbri, 2017; Yahya et al., 2023). For example, Thomas et al. (2020), who used a general inductive approach to identify themes related to risk factors for diabulimia and participants' coping strategies, concluded that

diabulimia interventions should include family and community-based elements to address patients' specific needs, enhance social support, and assist patients in coping with stressful events.

Regarding treatment, participants frequently speak to the ineffectiveness of treatment in general ED services, while simultaneously emphasizing the lack of specialist care pathways (Goddard & Oxlad, 2022; Goebel-Fabbri, 2017). Researchers highlight the need for specialist care pathways based on expertise in both T1D and eating problems (Goddard & Oxlad, 2022; Goebel-Fabbri, 2017; Macdonald et al. 2018; Staite et al., 2018; Thomas et al., 2020). For example, Macdonald et al. (2018) used thematic analysis to explore the experiential perspectives of treatment and service provision of people living with diabulimia and the healthcare professionals working with them. The authors concluded that the overriding theme expressed by participants was the need for treatment to adopt a model of care that addresses both T1D and eating problems concurrently, and for treatment to include multidisciplinary teams. The authors also suggested that psychological therapies should be specifically designed for people with comorbid T1D and eating problems.

2.5 Research Aims

Individuals with diabulimia frequently state that they do not feel understood or taken seriously by healthcare professionals (e.g., Colton et al., 2015; Goebel-Fabbri, 2017), which often results in disengagement from support services. Banting and Randle-Phillips (2018) and Tollow and Ogden (2019) emphasize the necessity of a person-focused approach to treatment, and point out the value of rapport between patients and healthcare professionals in identifying and recovering from diabulimia. Research on the lived experiences of individuals with diabulimia is therefore essential to build rapport and understanding within this therapeutic context, and to develop insights into support, treatment, and recovery.

Despite this, diabulimia remains understudied. Most research to date has used quantitative methods to examine aetiology, symptoms, and prevalence, and given little attention to experiential perspectives. Studies using qualitative methods predominantly sample women from Western

cultures, often disregarding the experiences and understandings of males, non-Western cultures, health professionals, and family members. There is also only one known qualitative study of diabulimia that uses a New Zealand sample (Thomas et al., 2020), and there is room for additional research in this area.

In my research, I sought to explore lived experiences of diabulimia with the following objectives in mind. Firstly, I aimed to explore what it is like to engage in diabulimia by providing a rich account of how it presents, how it feels, and how it affects different facets of participants' lives. Secondly, I aimed to explore what diabulimia means for participants and how they understand it. Thirdly, I aimed to deeply engage with peoples' experiences of diabulimia, as shared in their own words. Finally, I hoped to increase awareness of and curiosity about diabulimia in order to encourage further research to improve the available support. To fulfil these objectives, my research was guided by the question: What are the lived experiences of individuals who engage in diabulimia?

Chapter 3 – Methodology

This chapter outlines the methodological approach employed in this research project, and provides an overview of the research design and analysis.

3.1 Research Design Overview

3.1.1 Qualitative Research Paradigm

The purpose of this research project was to explore lived experiences of diabulimia within a New Zealand and Australian context. To do this, I chose to use a qualitative approach, specifically reflexive thematic analysis (RTA). Broadly, qualitative research is commonly used to explore and understand the ways that individuals or groups experience, understand, think, and feel about a particular topic (Pietkiewicz & Smith, 2014). Qualitative researchers seek to explore how people understand their own experiences, rather than how outsiders view those experiences (Fiese & Bickham, 1998), and there is an emphasis on meaning, context, and complexity (Willig, 2001). Where quantitative researchers seek to identify prevalence or correlations, qualitative researchers instead emphasize the texture and quality of experience (Willig, 2001). Depth is prioritized over breadth, and qualitative researchers prefer to gather in-depth data from a smaller sample of participants than to collect more superficial data from a larger sample of the population of interest (Ambert et al., 1995).

Qualitative researchers often use open-ended questions to investigate the topic of interest, allowing for questions to be changed during the research process to reflect increased understanding (Creswell et al., 2007). This allows researchers to explore the subtleties of experiences in a way that quantitative research does not (Patton, 2015), facilitating a deeper and richer understanding. In this study I was interested in participants' subjective understandings and experiences of diabulimia, thus a qualitative approach to inquiry was the most appropriate for answering the research question.

Qualitative researchers tend to believe that knowledge is specific to its historical and cultural context (Burr, 2015). Because knowledge is context-bound, qualitative research does not seek

generalizations (Elshafie, 2013). In the case of my research, I was conscious that the way in which participants understood and experienced diabulimia were shaped by the particular social, cultural, and political systems that surround them.

Qualitative researchers acknowledge that they bring their own worldview and values to their research (Darlaston-Jones, 2007). The researcher cannot be removed from the research (Darlaston-Jones, 2007), and both the researcher and participants have a role in the creation of knowledge. It is thus essential for the qualitative researcher to engage in *reflexivity*, wherein they carefully contemplate the ways in which their background, assumptions, and values may impact the research process and findings (Levitt, 2016). In my research, I engaged in an ongoing process of reflexivity to connect with my own situatedness within the topic of interest and take accountability for the effect that this may have on the research project. In my reflections I sought to capture my understanding and questioning at the time of writing.

3.1.2 Reflexive Thematic Analysis (RTA)

Thematic analysis is an inclusive term for multiple approaches to analysing qualitative data that differ in philosophy and procedure, rather than a single analytical approach to qualitative research (Braun et al., 2019). Broadly speaking, thematic analysis involves identifying patterns or themes that emerge as important from the viewpoints of multiple participants (Nowell et al., 2017). In my research, I used *Reflexive Thematic Analysis* (RTA), which is often used within psychological research to analyze interview data (Clarke & Braun, 2018).

In undertaking RTA, the researcher generates themes from within the data that capture the shared meanings and experiences of the participants in relation to a topic of interest (Braun & Clarke., 2006; Braun et al., 2019). The focus of RTA is not reliability or replicability, as in quantitative methods, but rather deep comprehension and interpretation of the dataset to gain a rich understanding of the topic of interest (Braun & Clarke, 2019). The researcher's subjectivity is a core

component of the research process, and researchers using RTA need to be consistently reflexive and transparent when generating themes (Binder et al., 2012; Braun & Clarke, 2019).

Rationale for using RTA

I considered RTA to be the most appropriate method for this research project for several reasons. Firstly, it is described as an ideal method for beginner qualitative researchers, because it has fewer procedures and prescriptions than other qualitative approaches (e.g., discourse analysis), and thus can be learned relatively quickly (Braun & Clarke, 2014). Since this study represents my first foray into qualitative research, I considered this a significant benefit.

RTA also allows for a more in-depth exploration of a topic of interest than other thematic analysis approaches, such as coding reliability thematic analysis or codebook thematic analysis (Braun & Clarke, 2019). These approaches are grounded in quantitative philosophies and use structured coding processes to achieve statistical reliability. By contrast, RTA does not require a linear process, and is more flexible in nature. Researchers using RTA can reflect ongoingly on their process and themes, and can alter processes to generate more nuanced understanding of a phenomenon (Braun & Clarke, 2019). Since the aim of this project is a deep and nuanced understanding of lived experience, I considered RTA to be the most suitable methodology for this research project.

3.1.3 Theoretical Assumptions Underlying RTA

Braun and Clarke (2006) highlight how it is important to consider epistemological and theoretical assumptions before engaging in thematic analysis. This is to conceptualize theoretically how the researcher understands their data and the way in which the reader should interpret the findings (Braun & Clarke, 2013).

Critical Realist Perspective

Because the researcher necessarily brings their assumptions about how knowledge is created to the analysis (Braun & Clarke, 2006), RTA reflects particular theoretical assumptions based on philosophical theories and frameworks (Mauthner & Doucet, 2003). The analysis in this research project is informed by a *critical realist perspective*, which posits that an external (researchable) reality exists, but that our knowledge of reality is always shaped by our perspective and thus is always "partial, incomplete, and fallible" (Maxwell, 2008, as cited in Butler-Kisber, 2018, p.14). In adopting this perspective, I accepted that each participant's words, while accurately reflecting their own understanding and experience of diabulimia, represents only one of numerous simultaneous valid interpretations of the reality of diabulimia. Since this research seeks to explore participants' experiences and interpretations of their experiences, I considered this perspective well-suited.

Inductive Approach

Due to the lack of literature examining lived experiences of diabulimia, I chose to analyse the data using an exploratory and inductive approach wherein research findings could be generated from significant or dominant patterns within the data (Thomas, 2003). That is, codes are produced that reflect the content of the data, without a pre-conceived framework or codebook into which codes are intended to fit. I considered an inductive approach appropriate for this research project because I did not approach analysis with any pre-determined theories, and the research aim was to explore participants' experiences as expressed through their own words.

However, I acknowledge that in RTA "pure" induction is not possible because the researcher necessarily brings their own worldview and perspective to the research. My analysis was informed by a critical realist perspective as described above. As researcher, I also played an active role in data analysis as I coded and generated themes (Blaikie, 2007; Nowell et al., 2017). Since I had carried out a literature review before I engaged in analysis, which included exploring relevant theories, this may have affected my read of the data. To address this, I took a number of steps (detailed in the data

analysis section) to stay as close to participants' accounts as possible and to ensure that analysis remained rooted in participants' experiences.

3.2 Reflexivity

I began the iterative process of reflexivity prior to undertaking data analysis. *Reflexivity* describes a process of self-examination as both individual and researcher, in order to understand how our personal perspectives and assumptions may shape the research process and findings (Berger, 2015). It situates the researcher within the analytic process by considering social circumstances and positions, such as age, ethnicity, race, and gender (Thurairajah, 2018). It is an ongoing activity and should be carried out in all phases of the research project. Consequently, I examined my assumptions and biases with respect to the content matter of the interviews as well as the research and analytic process.

I have my own lived experience of diabulimia. When commencing this project, I saw myself as an "insider" – that is, "an individual who possesses intimate knowledge of the community and its members due to previous and ongoing association with that community and its members" (Labaree, 2002, p.100). However, as I explored this idea further and considered Deutsch's (1981) statement that "we are all multiple insiders and outsiders" (p.174), I reflected that I was in fact also an "outsider" to the community of people currently experiencing diabulimia because I approach this research project from a place of recovery. As a recovered diabulimic, I find it difficult to connect with my previous insulin misuse and the extreme beliefs underlying this behaviour. Further, since everyone's experience of diabulimia is unique, I also reflected that I am an "outsider" to the specific thoughts, behaviours, and experiences of the study participants.

While exploring the ramifications of my dual insider-outsider status, I became aware that an insider status conveyed a number of benefits (e.g., deeper understanding and clarity for the researcher, trust, shared experiences; Labaree, 2002) but also had potential costs. An insider risks failing to perceive either the familiar or the unique, risks feeling a sense of responsibility toward the

community of interest, and risks a lack of impartiality (Labaree, 2002). The methodological implications of an insider status are profound, as this group can either do the most harm or the most good (Haniff, 1985), thus I considered it important to use my insider status in a self-reflective manner to enhance this project.

3.2.1 Personal History and Situatedness

I am a middle-class, New Zealand born, white, heterosexual female master's student in my early thirties. I was diagnosed with T1D at 20 years old while attending law school in a city far from my hometown. With a history of bulimia nervosa, I had been preoccupied with my weight and appearance since the age of 17. In the weeks preceding my T1D diagnosis, I had made a concerted effort to reduce my caloric intake to lose weight before returning home for the end-of-year holidays. I attributed my rapid reduction in body fat to this caloric restriction, and recall feeling proud of my self-control and euphoric at the results. I simultaneously felt guilt and shame at my inability to concentrate or stay awake, and would berate myself for regularly falling asleep while studying for exams. Symptoms of T1D were explained away as manifestations of exam stress and even joked about with my housemates. Upon returning home, my mother (a general practitioner) quickly diagnosed T1D, bringing with it a slew of mixed emotions.

My situatedness within society - and within a highly medical family - created certain expectations, narratives, and privileges around caring for my T1D, most particularly that I could and would manage my diabetes at an optimal level. When others expressed dismay or sympathy at my diagnosis, I recall replying "If it had to happen to someone, it's lucky it was me because I can handle it well and have everything I need to look after myself". This echoed my family's no-nonsense approach, but in hindsight left little room for my own feelings of grief or loss. I continued to feel society's pressure to conform to female beauty ideals of thinness, but viewed T1D and eating disorders as separate entities. For me, T1D was a purely physical disorder and EDs purely mental.

My experience with diabulimia began several years later, once the initial gratification of being able to manage my T1D to an excellent level had long worn off. At the time, I would have attributed my motivation for diabulimia to a desire to eat whatever I wanted without gaining weight, and completely separate from any psychosocial difficulties. Upon reflection, the time directly preceding my diabulimia was extremely turbulent and unhappy. I felt completely out of my depth as I began my first job, unable to live up to expectations imposed by others and myself. I was also deeply miserable at my living situation, and felt isolated and distressed. I sought comfort in food and my bulimia resurfaced, closely followed by diabulimia once I discovered this much easier method of purging calories. It seems obvious now that diabulimia represented a way for me to narrow the focus of my world down to something that I could successfully control.

My recovery happened almost spontaneously - I cannot recall a conscious decision to stop restricting insulin. In fact, when I think back to my time with diabulimia all I recall is a desperate thirst and exhaustion, an inability to properly work or really do anything other than lie in bed eating ice cream, and the odd appearance-based compliment from friends. I don't even recall feeling particularly happy at being thin. It is only in light of this research project that I have begun to deeply reflect upon my experience, and come to realise just how much my diabulimia was a manifestation of my mental distress.

3.2.2 Assumptions and Presuppositions About Diabulimia

Given the memories of my own experiences, I felt compelled to recognize and remain cognisant of my assumptions and expectations about T1D and diabulimia. I reflected that:

1. I often felt that the only people who truly understood me were others with T1D, and that I was living in an "us" (people with T1D) and "them" (people without T1D) world.
2. Engaging in diabulimia was associated with secrecy, shame, and guilt, thus uncovering knowledge about participants' experiences could only be helpful in preventing and treating the condition.

3. Disclosing my own experience of diabulimia to participants would help to form the basis for building trust and rapport, indicating to participants that I had knowledge and understanding in this area, and lead to richer and more nuanced data.

3.2.3 Potential Impact

Positioning myself as an insider led me to assume that I knew what participants were saying, or that I had a deep understanding of their experience. Although I tried to be mindful of this during interviews, I realized during transcription that there were some comments that I had failed to seek clarification about or follow up on. For example, one participant stated that she began to engage in diabulimia because she was having a hard time adjusting to life after university. I did not ask for details of what she had difficulty adjusting to, as I remembered feeling the same way and had similarly begun to engage in diabulimia at that time. In failing to ask for clarification or elaboration, I may have missed an opportunity to obtain more nuanced information about the participant's experience.

I considered whether I would disclose my own history of diabulimia to participants. There are no formal ethical guidelines as to whether to make such disclosures, although some researchers do recommend disclosure (e.g., Reinharz, 1992). I reflected that participants could assume, in light of my history, that I possessed knowledge or understanding that I lack, and as a result might provide less thorough descriptions of their own experiences or understandings. Ultimately, I did disclose my own history of diabulimia at the beginning of each interview, as I wanted to be honest with participants and recalled my own reluctance to discuss the condition with outsiders due to the associated shame and guilt. I hoped that this disclosure would help to create a safe space for participants so that they could more deeply explore their own experiences. Upon reflection, I believe that this was achieved, as a number of participants stated that their interview was the first time that they had talked to anyone about their experience of diabulimia.

3.2.4 Reflexivity Regarding the Literature Review

When conducting the literature review, I found it challenging to keep the parameters of the research project in mind. I was inclined to incorporate as much literature as I could, much of it quantitative, before recognizing that this was beyond the scope of this study. While the existing research is interesting and valuable in grounding the current project, I realized that it had limited value due to the exploratory nature of this study and risked overshadowing the participants' voices. Incorporating significant literature on non-diabetes related EDs also risked downplaying the unique nature of participants' experiences as individuals with T1D, perhaps reflecting my own positioning of T1D as just a physical disease that "you just get on with". To avoid this and to emphasize the uniqueness of living with T1D, the literature review focuses on EDs as experienced by people with T1D only and attempts to emphasize literature from qualitative rather than quantitative studies.

3.3 Participants

3.3.1 Recruitment

Participants were recruited between May and August in 2022. I shared an invitation to participate in the form of a digital poster image (see Appendix A) to various New Zealand and Australian T1D-related Facebook groups and a Massey University research student Facebook group. I sought to gather ten to 12 participants, as this number would provide a sizable amount of qualitative data to capture rich experiential diversity without exceeding the project's logistical and pragmatic limits. This number accords with Guest et al.'s (2006) suggestion that research aiming to explore the experiences of participants rather than to acquire statistical generalizability may use data from as few as 12 interviews.

3.3.2 Eligibility Criteria

Eligibility criteria for potential participants included:

- 18 years or older

- Currently living within New Zealand or Australia
- Has received a diagnosis of type 1 diabetes
- Has lived experience of restricting insulin in order to lose or control weight
- Available for a 60-90 minute interview via Zoom

Potential participants did not require an official diagnosis of diabulimia, as diabulimia is not yet a diagnosable mental disorder within the DSM-V-TR. Instead, participants were those who self-identified as having lived experience of insulin restriction for the purpose of losing or controlling their weight. The study's minimum age cut-off of 18 years was guided by the existing literature regarding T1D and disordered eating, which to date has primarily focused on children and adolescent populations. The intention behind this decision was address a gap in the literature regarding T1D and disordered eating within the adult population. Participants were required to reside in either Aotearoa New Zealand or Australia at the time of interview, based on the dearth of existing literature within the New Zealand population regarding T1D and disordered eating. Residency in Australia was included to ensure a sufficient number of respondents, as well as similarity to New Zealand in terms of demographics, culture, and healthcare.

3.4 Procedure

3.4.1 Prior to the Interview

Participants who had seen the recruitment poster and were interested in taking part or obtaining more information contacted me by email or Facebook Messenger. An information sheet (see Appendix B) was then provided to each prospective participant, together with any additional information requested. The information sheet contained information regarding privacy, confidentiality, the recording of interviews, data management procedures, and how findings will be disseminated. After reading the provided information sheet and agreeing to take part, written informed consent was obtained from each participant via a secure online survey software called Qualtrics. Zoom interview meetings were subsequently scheduled at each participant's convenience.

3.4.2 Covid-19 and Online Data Collection

Covid-19-related lock-down periods and social distancing stipulations prevented interviews from being held face-to-face. Zoom, a cloud-based real-time video conferencing platform (Zoom Video Communications Inc., 2021), was used as an alternative platform to collect interview data. This yielded a number of notable advantages. Firstly, interviews could be scheduled with increased convenience and greater flexibility for both participants and myself, as interviews could be attended from almost any location using a phone, laptop, or tablet (Archibald et al., 2019). Secondly, the use of Zoom removed any travel required to attend in-person interviews, minimizing the time and cost involved for all parties (Hanna & Mwale, 2017). Finally, Zoom minimized risks to safety for all parties by avoiding unfamiliar interview locations and maximizing privacy. Since real-time online video communication tools produce comparable levels of connection and data quality as in-person interviews (Deakin & Wakefield, 2014), I considered Zoom an optimal alternative to in-person interviewing.

I envisaged a number of possible Zoom-related disadvantages prior to commencing interviews. Firstly, a possible pitfall of online data collection is a delayed or disrupted internet connection. This is particularly disadvantageous if the participant is interrupted while disclosing a distressing part of their experience, as it may require them to repeat themselves and potentially increase the risk of psychological distress. Fortunately, no technical or connectivity issues were experienced during the participant interviews and the quality of the interview experience was not reduced.

Secondly, conducting participant interviews via Zoom eliminates the possibility of rapport-building gestures such as hand-shaking, as well as each person's ability to observe the other's body language since Zoom generally displays only the top half of each individual. I sought to mitigate these challenges by establishing rapport with each participant at the start of the interview, with an overview of my background and why I chose to research lived experiences of diabulimia. All

interviews flowed well with good participation, and participants appeared calm and comfortable during most of each interview.

3.4.3 Data Collection

Data collection occurred between 10 June 2022 and 15 July 2022. All interviews were recorded directly to my password-protected laptop using Zoom video recording software. Interview duration ranged from 28 minutes to 1 hour 27 minutes, with an average length of 58 minutes. I chose to use individual interviews because this method of data collection offers privacy and allows the interviewer to be responsive to the interviewee, making individual interviews a preferred method for researching sensitive topics (Roulston et al., 2003). A semi-structured approach ensures sufficient structure to ensure that the research questions is answered, while holding space for participants to engage in personal narratives or speak of unexpected or additional topics (Galletta, 2013). This format also allows the interviewer to probe and use active listening skills (e.g., nodding encouragement to continue) to obtain information and ask participants to expand upon their answers where desired (Given, 2012).

Building trust and rapport with participants is crucial for creating an environment of safety and respect, which is necessary for open, honest, and in-depth dialogue (Legard et al., 2003). Consequently, I began each interview by thanking the participant for their participation before briefly describing my background and why I chose to research lived experiences of diabulimia. I then initiated an informal conversation to establish a comfortable atmosphere. I reminded participants that any identifiable information would be removed before publication and that this was an opportunity for them to talk about their experiences, so it would be open to them to take the conversation in the direction that they wished.

The interview schedule (see Appendix C) was made up of open-ended questions with a series of prompts within each question that I could use, if required, to probe for further information. I also asked unscripted spontaneous questions in response to the participants' narratives, while

avoiding leading questions. I used active listening cues such as nodding and smiling to indicate interest and encourage participants to expand on their narratives. Moments of silence were welcomed as a chance for participants to think more deeply about their lived experiences, in order to provide the richest insights.

A few participants became visibly upset and tearful during the interview process, which had been foreseen as a possibility. I gave these participants time to express their emotions rather than rushing to the next question. Each participant resumed their narrative after a few moments, and none expressed or exhibited signs of distress at the end of their interview. A number of participants remarked that they found sharing their experience to be helpful, with the majority stating that their interview was the first time that they had discussed their experience of diabulimia with another person.

As recommended by Braun and Clarke (2013), a "clean up question" was asked toward the end of each interview, such as "is there anything else that we haven't spoken about that you think is important to include in the study?". This ensured that participants were not constrained to topics that were asked about directly. As each interview concluded, I thanked each participant for their time and involvement, and advised them of the next steps in the research project.

3.4.4 Transcription

I transcribed each interview verbatim and re-read each completed transcript alongside the recording to ensure accuracy and data integrity. I removed identifiable information (e.g., names, locations, job titles) and substituted it with a general note of what the data described, in order to keep the meaning clear. Each participant was emailed a copy of their transcript to review, and given two weeks to provide feedback, clarify, or amend the transcript. Two participants requested minor amendments, such as a number or date. I considered all subsequent transcripts final and approved for analysis. I then assigned each transcript a pseudonym using an online random name generator.

3.5 Ethical Considerations

I designed and carried out this research project with regard to the ethical principles laid out by the Massey University Code of Ethical Conduct for Research, Teaching and Evaluation Involving Human Participants (2017). After discussion with my supervisor, it was decided that this project was high risk and a high-risk notification was made to the Massey University Human Ethics Committee. Ethics approval was granted by the Massey University Human Ethics Northern Committee on 31 March 2022 (NOR22/10) (see Appendix D).

3.5.1 Informed Consent

To ensure informed consent, participants were provided with an information sheet as described above. At the commencement of each interview, I ensured that the participant understood the potential benefits and risks of participation. I reiterated that they are free to not answer any of the questions, and are free to stop participating at any time up until two weeks after they receive a copy of the interview transcript from me. I also advised participants of how their data would be securely stored and how the research findings would be disseminated, before confirming that they wished to proceed with participation.

3.5.2 Participant Confidentiality

Each participant was given the opportunity to select a pseudonym to protect their privacy. All participants but one were happy to have their real name used. However, to ensure that ethical standards of confidentiality and privacy were maintained, I subsequently allocated a pseudonym to each participant using an online random name generator. I advised participants of this, and told them that this was intended to limit the potential for retrospective harm if they felt uncomfortable with how they or their experiences were portrayed in the research. In such circumstances, their stories and experiences could then remain anonymous.

3.5.3 Data Management

I kept participant names and contact details confidential. Zoom interview recordings were saved onto a local password-protected computer only, and not to the cloud. Zoom recordings were transcribed by myself, and transcriptions were saved to the local password-protected computer using pseudonyms. Interview recordings were deleted immediately after transcription. Upon completion of the project, the remaining data will be stored securely for five years, then deleted.

3.6 Data Analysis

Data were analysed using Braun and Clarke's six-phase approach to RTA (Braun & Clarke, 2021):

1. Data Familiarisation And Writing Familiarisation Notes

Braun and Clarke (2013) recommend reading the data repeatedly to develop a critical view and generate initial thoughts that may eventually evolve into codes and themes. During this stage I read and re-read the interview transcripts, highlighting extracts of potential interest and noting down initial observations, thoughts, emotions, and reflections in an electronic document. I also documented my thoughts and feelings relating to both the data and to the analytical process in a research journal.

2. Systematic Data Coding

A *code* is a word or phrase used to label a piece of data that captures the core concept of that data and how it relates to the research question (De Santis & Ugarriza, 2000). Since qualitative researchers accept that that there is no single best way to code data (Saldana, 2009), I used a data-driven "bottom up" method wherein codes were derived from the dataset itself and without consideration of the existing literature. Coding was carried out using NVivo, a computer assisted data analysis software package. It was a recursive process, and I returned to the dataset and revised

codes numerous times. Multiple codes were used when data extracts related to several topics. This process generated 23 codes, which can be found in Appendix E.

3. Generating Initial Themes from Coded and Collated Data

Codes (and their corresponding data extracts) that had similar, related, or overlapping ideas or concepts were grouped together to generate initial themes. A *theme* is made up of codes that share a "central organizing concept" (Braun & Clarke, 2013, p.226). I repeated this process several times, resulting in the reshuffling of some groupings. Some initial themes were expanded into subthemes. A few codes did not fit within any of the proposed themes and did not appear relevant to the research question, but were retained within a "miscellaneous" theme category in case they became relevant in later analysis.

Reflexivity was important during this phase to identify and acknowledge how my preconceived ideas and assumptions that could impact the way in which I read and interpreted the data. For example, the initial theme "consequences of diabulimia" only included codes and extracts relating to negative consequences, echoing my view of diabulimia as a solely negative behaviour. Upon reflection, I realized that diabulimia could in fact have positive consequences for participants as well.

4. Developing and Reviewing Themes

I explored whether the initial themes worked in relation to each other and were appropriately aligned with the selected extracts of data. This resulted in the reorganization of the initial themes and the collapse of some, to ensure that each theme addressed the research question and was distinct from each other but still related (Willig & Rogers, 2017).

5. Refining, Defining, and Naming Themes

A definition was written for each theme to outline the theme's scope, boundaries and core concept. In conjunction with my supervisor, I reviewed the working theme names to ensure they

were both meaningful and remained close to the meaning of the data (Terry et al., 2017), as well as informative, concise, and catchy (Braun & Clarke, 2022). Some theme names had initially used quotations from the data, which I reassessed to capture the theme effectively. I also created a mindmap to visually depict the relationships between themes (Willig & Stainton Rogers, 2017) (see Appendix F).

While these stages of data analysis are organized sequentially, Braun and Clarke (2006) emphasize that analysis is recursive and iterative, and may require the researcher to move back and forth between the stages. Throughout analysis, I remained cognizant that I needed to make judgments about when to move between each stage of analysis (Braun & Clarke, 2019), and that coding and deeper analysis do not have a clear endpoint (Lowe et al., 2018). However, the time allocated to analysis and exploration of the dataset was necessarily constrained by the time frame of the study. I was also conscious that my interpretations represented just one version of "reality", and that other researchers with differing perspectives and experiences may reach different interpretations (Vaismoradi et al., 2013).

6. Writing the Report

Within RTA, writing is embedded in the analytic process as a process of refinement (Braun & Clarke, 2022). In this phase, I attempted to combine the analysis and existing literature into an illustrative and analytic "story" (Terry et al., 2017). I sought to extend the narrative past mere description of the data to make a cogent argument that addressed the research question.

Chapter 4 – Findings

Participants spoke about a range of different experiences in relation to diabetes and diabulimia. While there were variations in their experiences and feelings towards both, there were also some distinct similarities. Using RTA, I identified four themes that reflected participants' experiences of diabulimia: (1) diabetes distress and burnout; (2) perceptions of being in or out of control; (3) shared knowledge and understanding; and (4) a reason to recover. I broke each theme down into subthemes to illustrate similarities and differences within participants' experiences.

In the next sections, each theme is elaborated on and illustrated using direct quotes from participants. The themes are not presented in order of significance or frequency, and I did not consider any theme to be more dominant than the others. Each of these themes and subthemes are illustrated in Appendix F.

4.1 Theme 1: Diabetes Distress and Burnout

A prominent theme within participants' stories were feelings of diabetes distress and burnout, and the use of diabulimia as a coping mechanism. Nearly all participants spoke of the overwhelmingness of lifelong diabetes management and how the moral imperative to achieve optimal glycaemic control contributed to diabetes distress. Some described a perfectionistic approach to glycaemic control, and discussed where these expectations derived from and how they exacerbated diabetes distress. For most, diabetes distress resulted in a cascade of negative consequences that contributed to diabetes burnout in the form of diabulimia.

4.1.1 Subtheme: "A Life Sentence"

Participants spoke about diabetes distress and diabetes burnout as motivating factors for engaging in diabulimia. They described the heavy mental and emotional toll of managing both the constant behavioural demands of diabetes self-management and the potentiality of disease complications and progression. For example, Nicole shared:

> "It definitely feels like much more of a life sentence. The whole "why me". Like, you do everything that you should do – you exercise, you eat reasonably well, all that sort of stuff, and yet we're stuck with this thing that's constantly on your mind. I think it's understanding that it's not just a physical disease. It's a mental and emotional one." (Nicole)

Nicole described the relentless nature of managing T1D, reflecting on how this can feel unfair ("why me") and like a constant physical, mental, and emotional presence in her life. Nicole's narrative suggests that her experience as an individual with T1D has been misunderstood and oversimplified as "just a physical disease" by others – or possibly even herself when first diagnosed. Nicole's use of the terms "everything", "all" and "constantly" emphasize that T1D negatively impacts all areas of her life unremittingly, while "life sentence" invokes feelings of inescapability and being imprisoned. Other participants similarly used metaphors to describe their experience of living with T1D, often likening it to a battle or fight, which emphasizes the non-volitional nature of their experiences as well as their desire to be rid of the condition. Many used the metaphor of drowning to emphasize the overwhelmingness of T1D and diabetes management, often reflecting that they had felt particularly overwhelmed immediately prior to the onset of diabulimia. For example, Jen said:

> "I think it [diabulimia] was a lot to do with like mental health and the overwhelmingness of the diagnosis of diabetes, and I think it's more common than people think. It's just such an overwhelming thing to have diabetes. It's [diabulimia's] probably part of the coping mechanism." (Jen)

Here Jen described her diagnosis with T1D as an "overwhelming" stressor that challenged her mental health and coping abilities, directly attributing the onset of her diabulimia to difficulties in being diagnosed and living with T1D. For individuals newly diagnosed with T1D, the complexity of adjusting to a complicated new lifestyle combined with psychological adjustment to living with a chronic health condition can be an intensely stressful and emotional experience (Thoft et al., 2022).

This was evident in the narratives of several participants, who described the period following initial diagnosis as “traumatic”, “stressful”, “harrowing” and “just too hard”. Such emotional dysregulation may lead individuals to engage in maladaptive behaviours to self-soothe and regulate their emotions (Carson, 2016), as suggested by Jen when she described diabulimia as a “coping mechanism”. The notion of diabulimia as a coping strategy references the relationship between control and diabulimia, which is discussed in greater detail in the theme entitled *Perceptions of Being In or Out of Control*.

Participants described feelings of diabetes burnout in response to an inability to consistently achieve optimal blood glucose levels despite their best endeavors, as shared by Ashley:

> “The thing with diabetes is that you can try 110% all of the time, and your blood sugar will still go high or low for no reason at all. That’s just one of the things about being diabetic. It’s just something that happens. It could be that the weather’s hot outside, or hormones… No matter what you do, there’s always an issue… and then you get the guilt, because you think ‘my blood sugar’s a bit high and it’s all my fault, and I can’t do this’. That makes you feel bad.” (Ashley)

Ashley described how she continued to feel let down by unpredictable blood glucose levels despite her best efforts at self-management. Individualised health practices are located within dominant health discourses that emphasize individual responsibility and control for maintaining health (Crawford, 1977; Crawshaw, 2013). This approach risks bringing health and health-related behaviours into the moral domain, such that health and ill health are indicative of moral value and disvalue respectively (Brown, 2018). The quote from Ashley illustrates how blood glucose levels outside of the recommended levels may be understood as reflective of a personal moral failing (“it’s all my fault”), despite her acknowledgement that a multitude of other factors – such as the weather or hormones – also impact blood glucose levels. Such discourses of individual responsibility and morality were evident in many participants’ descriptions of their blood glucose levels and diabetes

management, which often included terms such as “good” and “bad”, as well as “guilt”, “blame” and “my fault”. The use of this terminology signals an uptake of dominant discourses around health and individual control. Participants described how sometimes healthcare professionals would align with these dominant discourses as well, which had significant consequences for the participants as patients. Nicole shared that “my doctors would always sing my praises about how good I was at managing it and being really independent and checking my sugars regularly”, while Liz described leaving appointments with her diabetes specialist “feeling like a bad person and the worst diabetic every single time”. For some participants, the moral imperative to achieve optimal blood glucose levels contributed to feelings of overwhelm and burnout when these goals remained unachievable, ultimately culminating in diabulimia.

4.1.2 Subtheme: Perfectionism and Failure: An All-Or-Nothing Mindset

Some participants linked their diabetes distress or burnout to a perfectionistic personality and an “all-or-nothing” mindset, explaining that the failure to consistently achieve “perfect” glycaemic control often led to feelings of frustration or despair. These participants attributed their expectations of “perfect” diabetes management to inherent perfectionistic character traits, rather than externally imposed expectations such as those described in the subtheme above. For example, Amanda described herself as “a very Type A personality”, while Sarah shared that she had “very black and white thinking” and was “very much an all-or-nothing type of personality – if it’s not perfect, it’s not good enough”.

Participants described a cascade of negative consequences resulting from the unsuccessful pursuit of perfect glycaemic control in their stories. Perfectionism is common when people experience high levels of distress around their diabetes (Powers et al., 2016). Participants engaged in a variety of avoidant coping strategies related to this perfectionism, deliberately disengaging from emotions, thoughts and behaviours related to the problem of suboptimal glucose control. Participants’ descriptions of disengagement and avoidant behaviours were analogous to those of

diabetes burnout, such as “giving up”, “quitting diabetes”, “I stopped caring”, “I stopped trying”, and “I decided ‘why bother?’”. On a practical level, participants spoke of less frequent (or discontinuing) blood glucose monitoring, reduced self-care behaviours, avoiding healthcare appointments, and engaging in diabulimia. Nicole shared:

> “For most of the time, I think it [diabulimia] starts off as unintentional. I get busy, I get distracted, so I’ll have some food and keep going, and not give myself insulin for it. Then it becomes ‘oh, I’m not going to test my sugars because I know they’re going to show high and I don’t want to see a high number’. Because that just mentally makes me feel like shit. And then if I’m high already, I might as well stay high for a little bit longer and have a little benefit from this. You’re just like ‘I’ve failed anyway, so why even try?’… And then you’re like ‘oh, my pants fit a bit better’.” (Nicole)

Here Nicole, who described herself as “quite an extreme sort of person” who holds herself to “really high standards”, explained how even a single instance of non-adherence to her diabetes management regime could trigger an episode of diabetes avoidance and diabulimia. The extract shows how Nicole’s perfectionism is strongly entwined with the tendency to be harshly self-critical and unkind to herself (“I’ve failed”), even as she acknowledged that the initial missed insulin dose was unintentional. Self-criticism and lack of self-compassion are predictors of diabetes distress and glycaemic control (Tanenbaum et al., 2018), and are associated with increased use of negative emotion regulation strategies such as avoidance (Kane et al., 2018). This is evident in Nicole’s description of harsh self-criticism and diabetes distress (“I’ve failed”) swiftly followed by diabetes-related avoidance (“I’m not going to test my sugars”) and diabulimia (“I might as well stay high for a bit longer… why even try?”) to avoiding feeling “like shit”. The excerpt speaks to Nicole’s use of diabetes-related avoidance and diabulimia as coping strategies to manage the distress associated with failing to achieve perfectionistic standards of glycaemic control, and emphasizes the

importance of understanding the internal coping processes that contribute to engagement in diabulimia.

Although perfectionistic participants often took ownership of their uncompromising expectations regarding diabetes management, individuals' narratives about health and ill health are inextricably intertwined with societal influences (Cheshire et al., 2020). As individuals with a chronic illness who regularly attend healthcare appointments, it is perhaps unsurprising that participants' narratives often seemed to reflect the self-management and treatment goals conveyed to them by healthcare professionals. Many participants appeared to have internalized unrealistic, perfectionistic ideas about diabetes management and glycaemic control from their healthcare team, leading to self-criticism and feelings of being judged by their healthcare team when perfect glycaemic control proved unattainable. Melissa said:

> "I stopped going to clinics and things like that, because I knew they'd say my control was rubbish and I guess I just didn't want to get a lecture about how bad I was. So yeah, I didn't see a clinician for quite a long time and just kind of gave up on looking after myself and my diabetes. I couldn't control it well enough no matter what I did, so I just didn't bother." (Melissa)

Here Melissa projected herself into the mind of her clinicians by anticipating how they would perceive her based on her own previous experiences: as a "bad" person with "rubbish" self-control. The phrase "I couldn't control it well enough" suggests that she is comparing her diabetes management to an unrealistically high goal set by her clinicians, which she finds impossible to attain. The excerpt shows how Melissa's healthcare professionals influenced her thoughts and feelings about herself as well as her diabetes management, negatively impacting her self-esteem to the point that she "just kind of gave up" on looking after herself and her diabetes. For Melissa, as with Nicole above, these feelings of personal failure and diabetes burnout resulted in the avoidance of diabetes self-management altogether, culminating in diabulimia.

4.2 Theme 2: Perceptions of Being In or Out of Control

Perceived levels of control were central to participants' narratives, although significant variation was evident within this theme. Some participants spoke of diabulimia as something that signaled a lack of control on their part, while others described diabulimia as a way to increase their perceived level of control over their lives generally or over diabetes-related areas specifically. Some participants associated diabulimia with heightened feelings of self-efficacy, while others described a loss of control over their diabulimia and the feelings of powerlessness that this engendered. Although insulin was related to power and control for many participants, this theme highlights the polarity of participants' experiences wherein diabulimia may either give or take away their perception of being in control.

4.2.1 Subtheme: Diabulimia as an Auxiliary Control Mechanism

Participants' stories spoke to the ways in which diabulimia provided a way to feel at least temporarily in control of their otherwise chaotic lives. For some participants, diabulimia was related to larger issues of freedom and control within their daily existence. They described feeling a loss of control over various circumstances in their lives, often around times of transition such as moving from high school to university. Amanda shared:

> "I was like 'no, I'm never going to skip my insulin' kind of thing. I was very adamant it was never going to happen. But then it was more like once I went to Uni and went away from home, I guess it was harder for me to control everything in my life. I was trying to study at university, and have a job, and have a social life, and other stuff as well. So then I was like 'maybe this will be an easier way to control my weight'. That was such a big thing for me in my twenties. I'm so glad I've got that out of my way now, and that I don't have to worry about that for the rest of my life. It (being slim) consumed me for a long time." (Amanda)

Amanda spoke of using insulin restriction to gain a sense of power and control in response to feeling out of control in other areas of her life. She listed the various areas in which she felt a lack of control ("trying to study at university, and have a job, and have a social life, and other stuff as well"), invoking feelings of overwhelm and giving the impression that she could go on reciting endless examples. Individuals affected by eating problems often look for control, and this sense of control is often obtained by the continuous monitoring of a certain parameter such as body weight or shape (Fairburn & Harrison, 2003). In the excerpt, Amanda shared how she constructed a world in which controlling her body weight was at the center ("it consumed me"), such that she could ignore her lack of control in other areas. This suggests that, recognizing that there were circumstances beyond her control, Amanda chose to exercise her limited situated freedom through the choice to take or restrict her insulin, thereby using her body to express her self-autonomy. For Amanda and other participants, diabulimia was a form of resistance against feelings of overwhelming powerlessness in her life. However, the excerpt moves from the past to the present tense, suggesting that Amanda has experienced change and movement since this time. There is a sense of learning and growth in her narrative as she reflected back on her past with relief that she is no longer "consumed" by the need to be thin.

4.2.2 Subtheme: Diabulimia as a "Warped Sense of Control" Over Diabetes and Diabetes-Related Components

While some participants spoke of using diabulimia to gain a perception of control over life events or circumstances, others spoke of using diabulimia to gain a sense of control over diabetes itself. Nicole shared:

> "Just reflecting on all of that, my diabulimia does feel like it was trying to take some control. It's nice to feel that your clothes aren't as snug and things like that, but that happens at different times of the month anyway, and it depends on how much water you've drunk and all of that. So for me, I don't actually think a huge part of it is looks. I thought it was, but I

> don't actually think that now. I think it is the control. Or it's essentially going "fuck you" to the diabetes, and trying to have some control even though it's a very warped sense of control." (Nicole)

In this excerpt, Nicole externalized her diabetes as an adversary against which diabulimia is being used to gain control. She called it "the" diabetes rather than "my" diabetes, linguistically separating herself from diabetes while at the same time creating an affiliation with diabulimia by terming it "my" diabulimia. Given that our use of language has significant implications on how we understand and locate problems (Kristensen & Køster, 2014), this external separation of diabetes locates diabetes – and a lack of control over diabetes – as Nicole's problem. By contrast, diabulimia becomes an expression of Nicole's self-autonomy and identity, and the solution to her problem. This is common among individuals with other eating problems, who often positively identify with their eating problem and experience eating problem-related beliefs as ego-syntonic (Griffiths et al., 2015). Despite suggesting that a lack of control over diabetes was a motive for the development of diabulimia, Nicole seemed to acknowledge that the practice is deviant and disordered ("even though it's a very warped sense of control"). The interview allowed Nicole to reflect upon her experience with diabulimia, resulting in a self-discovery ("I don't actually think a huge part of it is looks. I thought it was, but I don't actually think that now"). During the course of the interview she seemed to move from a surface position, wherein her diabulimia was all about looks, to one of more depth, acknowledging it was actually about trying to have some control over her diabetes. This reflects the power of phenomenological research, wherein Nicole was able to come to new understandings and meanings about herself and her subjective experience.

While some participants, such as Nicole, framed diabetes more broadly as the problem, others identified particular diabetes-related components as the problem that causes a perceived lack of control. Prominent among these were fluctuating glucose levels, insulin, the weight gain associated with beginning insulin therapy, and dietary restriction. For example, Sarah said:

> "When I was diagnosed, I dead-set refused to accept the diagnosis. I went through a stage where I totally rebelled and refused to do insulin, because I knew it would put weight on… I've had body image issues all my life, I won't deny that. But I never really paid much attention to it until I began insulin and started stacking the weight on." (Sarah)

For Sarah, as with other participants, insulin is inextricably linked with weight gain, with insulin restriction in turn presented as helping to control her body weight. In using the phrase "started stacking the weight on," Sarah framed continued weight gain as inevitable and beyond her control without the assistance of diabulimia. This narrative locates diabulimia as an ally in the "rebellion" against insulin and insulin-related weight gain, and insulin and insulin-related weight gain as the problem, helping Sarah to rationalize her practice of insulin restriction for weight loss.

Participants' narratives around the acquisition of control via diabulimia are tied to self-efficacy, in that they report improved feelings of mastery when an intended outcome is achieved. Key to this is the predictability that diabulimia provides, which participants spoke of using phrases like "I knew it [diabulimia] worked", "it [diabulimia] was like an old reliable friend", "it always did the job", and "I knew I could do it [lose weight] successfully". Since the day-to-day reality of diabetes often includes inexplicable or uncontrollable blood glucose levels, the certainty that diabulimia provided in regard to hyperglycaemia, hyperglycaemic symptoms, and weight loss can engender feelings of mastery and agency that may be otherwise missing. As Amanda stated: "at least you're in charge of what your sugars are doing and how you feel. It's nice when your results actually reflect your actions for a change, even if it's not necessarily in a good way". This improved sense of self-efficacy even allowed some participants to reframe the negative features diabulimia into positive attributes, as shared by Ashley:

> "There were lots of physical things, but they almost turned into positive feelings for me because with each physical aspect of hyperglycaemia I knew it was doing the trick. It was

> working. They were positive instead of me thinking of them as negative things. They were positive because that was what was meant to happen." (Ashley)

Ashley revealed how the feelings of mastery associated with diabulimia and the assurance of controlling weight through diabulimia were sufficient motivations to continue restricting insulin, even as her health deteriorated ("there were lots of physical things"). Ashley's use of the term "trick" suggests that diabulimia has a magical and transformative element. It is unclear whether she was referring to the ability of diabulimia to transform otherwise negative physical symptoms into positive features, or to the improved sense of control and self-efficacy that engaging in diabulimia "magically" provides ("that was what was meant to happen"), or possibly both. The magic nature of diabulimia was similarly described by other participants who used terms like "superpower", "secret power", "this amazing ability" and "a strength", which also emphasize the empowering nature of diabulimia.

4.2.3 Subtheme: A Downward Spiral

Participants spoke of initially regarding diabulimia in a positive light, as they lost weight quickly without depriving themselves of food. However, some participants described diabulimia as becoming increasingly out of their control, and no longer associated with initial feelings of empowerment and mastery. Liz shared:

> "Your brain is like 'you're not skinny, you're still fat. Keep going…' Once I realized I could control my weight with insulin, it was a downward spiral from there. I lost all control over it. Your mind can just manipulate you." (Liz)

In this extract, Liz reflected in hindsight on her disturbed thinking as diabulimia became more entrenched. She spoke of developing, and battling with, a disordered mindset that helped to maintain her diabulimia, explaining that diabulimia was now associated with a loss of control rather than self-autonomy and empowerment. Liz's story reflects a common trajectory within narratives

around eating problems, wherein eating problems begin as a tool for control but gradually assume control over the individual instead (e.g., Walters et al., 2016). Participants like Liz who spoke of a loss of control over diabulimia frequently incorporated themes of manipulation and coercion, anthropomorphizing diabulimia as an oppressive agent that strips them of control. Nicole described her journey with diabulimia as "getting suckered down that path that leads nowhere", while Amanda shared: "it got into my head and I couldn't stop, even when I wanted to". Here, Amanda described becoming locked into her diabulimic behaviour, emphasizing the acute sense of powerlessness caused by diabulimia. This can be contrasted with the previous theme wherein participants described diabulimia as conferring power and control, highlighting that, despite sharing the condition of diabulimia, an individual's phenomenological reality is as unique and distinct as the individual themselves.

4.3 Theme 3: Shared Knowledge and Understanding

This theme explores the impacts of shared knowledge and understanding of diabulimia and T1D on participants. Participants described the importance of a shared diabulimic identity and its recognition in the literature for combatting loneliness and supporting connections with similar others. For those participants who were able to engage with similar others, the positive impacts of peer relationships were powerful and ranged across multiple life domains. However, some participants also described a variety of negative consequences associated with shared experiences and knowledge, ranging from risky peer-conformity behaviour to implied encouragement of diabulimia. Participants spoke of the relationship between themselves as patients and healthcare professionals, who were perceived as lacking knowledge and understanding of both T1D and diabulimia. This had negative impacts on participants' health, recovery, and self-with-self relationships.

4.3.1 Subtheme: The Importance of Shared Identity and Experience: "It's Nice to Know I'm Not Alone"

This subtheme explores the relationships between participants and similar others. All participants expressed that they felt isolated and alone in their experience of diabulimia, and that this loneliness heightened the distress associated with the condition. Amanda shared:

> "I just felt really alone, because I didn't know anybody else like me. Like, I had no… I guess if you have bulimia or anorexia, at least there's a lot of information online about that type of stuff, so you can sort of find other people to relate to. I would find like little things and studies and stuff online about it [diabulimia], but it was really hard to find any information on it. So yeah, I think I felt quite alone in that respect, and because you couldn't tell your friends about it or anything." (Amanda)

From Amanda's statement "anybody else like me" it is clear that she had incorporated her diabulimic behaviour into her identity, rather than externalizing it. By differentiating other eating disorders (bulimia nervosa and anorexia nervosa) from her own, it is evident that Amanda perceived her diabulimic identity as uniquely distinct from other eating disorder subtypes. She described an absence of identity recognition in the academic literature, making it difficult to form connections with others who share the same diabulimic identity. Connections with similar others online can support recovery in individuals with eating problems (McNamara & Parsons, 2016). Amanda's excerpt suggests that the lack of recognition of a distinct diabulimic identity in the literature may act as a significant barrier to finding this kind of support. Amanda, like most participants, wanted to share her experience of diabulimia to help others, and expressed that this was a prime motivator for participation in the study. This suggests that participants recognized the importance of a shared social identity for support and recovery, and sought to counteract the absence of identity recognition within the academic literature.

For many participants, feelings of loneliness pre-dated diabulimia and were attributed to not knowing others with T1D. Liz expressed her need for relationships with those who are able to understand the full experience of living with T1D as a young person:

> "That was one thing I really struggled with, with not knowing anyone else who had it [diabetes]. Yeah, and especially someone like your own age. Well, not necessarily your own age, but someone… Like, the other day someone said 'oh, I know another diabetic, it's my Uncle's old grandad' or something, and you're like 'cool'. [laughs] And more often than not they're type two anyway." (Liz)

Here, Liz distinguished her own lived experience from those of older individuals and those with type 2 diabetes, suggesting that she considered a T1D diagnosis and youthfulness to be key elements of her identity and vital for fostering a sense of connection with others. The excerpt exemplifies the difficulties expressed by many participants in finding such similar others, while highlighting the importance of peer relationships based on shared experience. Indeed, for individuals with T1D, the value of peer relationships extends beyond combatting social isolation. Peer relationships allow for the creation of *patient knowledge*, a term describing practical knowledge that translates biomedical knowledge into something with practical utility (Kingod, 2020). Participants spoke of peer relationships as a trusted source of information and practical advice about navigating life with T1D, as shared by Jessica:

> "As soon as I turned 16, I started volunteering there [at a diabetes camp] and my whole social network over there was my diabetic friends… And it was great because we all tested out technology and supported each other when it was difficult, and tested all the boundaries as teenagers. Like, when we all wanted to start drinking or someone wanted to try a drug, we all did it together. There would always be somebody who was sober and testing blood sugars and treating lows and giving insulin." (Jessica)

It is evident from Jessica's story how powerful the impact of peer support was for her in multiple life domains, extending beyond the sharing of technology to emotional support during difficult periods, and testing the limits of diabetes and adolescence itself. For individuals with T1D, experimentation with alcohol and illicit substances, such as that which frequently occurs during adolescence and early adulthood, compounds the risk of short-term complications like hypoglycaemia and diabetic ketoacidosis (Barnard et al., 2012). However, Jessica's excerpt suggests that she felt both physically and emotionally safe as a result of her diabetic peer group, to the point that she felt free to explore new experiences in both the diabetic and non-diabetic domains of her world.

4.3.2 Subtheme: Sharing Experiences and Knowledge Can Be Unsafe

While most participants expressed a desire for more widely shared knowledge of both T1D and diabulimia, some revealed that shared knowledge actually led them to engage in high-risk behaviours, including diabulimia. For example, despite a narrative that consistently positioned her diabetic peer group as supportive and helpful during adolescence, Jessica acknowledged that her diabetes management was suboptimal during this time:

> "There have been heaps of ups and down in my control when I was a teenager. It was awful, even with all those people that I knew. But diabulimia was one of those things that me and all my diabetic friends tried out together, as terrible as that is… It was just one of those things that my friends and I were like 'oh, if we can lose some weight just by taking less insulin that's, like, next level'." (Jessica)

In stark contrast with previous research suggesting that peer support improves treatment adherence in individuals with T1D (e.g., Due-Christensen et al., 2016), Jessica reflected that she initially began engaging in diabulimia as a form of group experimentation with her diabetic peers. Her statement that "it was just one of those things" illustrates how normalized risk-taking behaviours had become within her peer group environment, although years later she is able to

recognize the danger in what she later described as “egging each other on”. It seems evident that, for Jessica, these shared experiences generated a sense of belonging that outweighed the sense of danger associated with engaging in these risky behaviours. She further reflected that “if everyone’s doing it, you don’t want to be the odd one out”, suggesting that the bond within her peer group implicitly rested on assumptions of behavioural conformity. The phenomenon of peer pressure is not by any means unique to adolescents with T1D. Most adolescents are thought to engage in peer-conformity behaviour to ensure group membership and foster a sense of social identity (Clasen & Brown, 1985). However, vulnerability to peer pressure within diabetic peer groups may be exacerbated by a fear of isolation, which is often experienced by this cohort as a result of feeling different to their non-diabetic peers (Castensoe-Seidenfaden et al., 2016). Indeed, this narrative was expressed by a number of participants, who described themselves as “an outcast”, “a pariah”, “rejected”, “bullied”, and “different from” their non-diabetic peers.

Whereas Jessica learned of diabulimia from her diabetic peers, other participants spoke of first learning about diabulimia from their healthcare providers. Melissa shared:

> “I think when I was around thirteen they started asking those questions about like ‘how do you feel about your weight?’, and I didn’t really know how to respond. But then it was at the back of my mind. Then in my later teenage years social media was coming in, and yeah… I didn’t like what I saw, and I remembered that the clinician had said that some people are missing their insulin to lose weight, so I thought ‘wow, maybe I’ll give that a try’… It was fine that they said ‘how do you feel about your weight?’, but that was it. There were no other questions around it.” (Melissa)

Melissa described how early experiences with her clinicians left her feeling confused about her weight and provoked disconnection with her healthcare providers. When combined with societal expectations of thinness, this isolated confusion perpetuated further thoughts of weight loss and culminated in diabulimia. Melissa’s narrative highlights her clinician’s lack of exploration around her

weight-related beliefs, giving rise to the question of whether healthcare professionals are aware of – or perhaps simply do not wish to dig into – the complexities surrounding T1D and eating problems. This accords with research examining the experiences of healthcare providers, which found that healthcare professionals often feel ill-equipped and are reluctant to discuss the issue of eating problems with their T1D patients (Tierney et al., 2009). However, Melissa's excerpt emphasized the importance of effective communication and the sharing of knowledge between healthcare professionals and patients that extends beyond a cursory inquiry or comment.

Despite most participants taking part in the study for the purpose of generating more knowledge and understanding of diabulimia, some expressed concern that having more knowledge about diabulimia in the world would actually lead to more individuals with T1D developing the condition. Ashley described coming across the concept of diabulimia accidentally through her own research, which first led her to engage in the behaviour:

> "I'd looked it [diabulimia] up on Google and that kind of thing. There are articles written about it and stuff like that, so that's when I realised that people did this type of thing… I guess the only flip side of having diabulimia more 'out there' and known about is that more people might do it. Because like I say, I didn't know it existed until I stumbled across it and then started doing it. Whereas if somebody who was newly diagnosed type one finds out about it, they're going to go 'oh, okay, I can now do this'." (Ashley)

Individuals with T1D who lack an in-person diabetic peer group often look to online resources to understand the behavioural expectations associated with a diabetic social identity (Chalmers et al., 2022). Ashley's statement that "I realised that people did this type of thing" suggested that she conceived of diabulimia as something widespread - an almost "normal" behaviour for individuals with T1D. Her suggestion that newly diagnosed diabetics will think "I can now do this" implies that knowing others engage in diabulimia offers a permission of sorts for an

individual to engage in the disordered behaviour themselves. This speaks to notions of peer-led behavioural conformity, as previously expressed by Jessica. However, despite the majority of participants accessing information about diabulimia online, Ashley was the only participant to suggest that online research brought about her diabulimia and so it is unclear whether more widespread knowledge of diabulimia will encourage the behaviour among individuals with T1D.

4.3.3 Subtheme: Being Misunderstood Compounded My Distress

This subtheme explores the relationship between participants and healthcare professionals, and how this impacted their thoughts, feelings, and behaviours. Participants frequently described misconceptions that they believed healthcare professionals held about individuals with T1D and individuals with eating problems. For many, these misconceptions impacted their willingness to seek support and engage in treatment for diabulimia, thereby prolonging and compounding their distress.

Experiences with health professionals were predominantly described as negative, with most participants expressing frustration with the lack of knowledge healthcare providers had regarding T1D and diabulimia. Participants spoke of being met with insensitive or critical statements when they brought up their struggle with diabulimia. Amanda described an early attempt to seek support from her healthcare practitioner, and being met with a reaction of impatient confusion:

> "It would have been helpful if doctors and staff were more aware of it [diabulimia]. I felt like at that time especially, no one even really knew about what diabulimia was. I remember one time when I was back in New Zealand, when I was like 22 or 23, I tried to explain it to the endocrinologist and I was in tears and I didn't know what was happening. I didn't know how to stop it. And they were just like 'what the heck? What's wrong with her? Like, why don't you just control your diabetes?'… I just felt really alone." (Amanda)

In this excerpt, there was a simplification of Amanda's experience in the endocrinologist's phrase "why don't you just control your diabetes?", which denies any complexity or depth that Amanda might be experiencing. The excerpt highlights the absence of exploration and openness in the interaction, where the endocrinologist is unwilling to venture beyond Amanda's physical behaviour and into the psychological aspect of insulin restriction. In Amanda's case, she was left feeling trapped in her own difficulties and like she was the only one struggling with this difficulty. This sentiment was expressed by other participants, such as Liz:

> "I felt guilty for struggling. Everyone in the healthcare system was very nonchalant about it all, like it was no big deal. It made me feel incredibly embarrassed and ashamed for struggling. Angry also, that it felt so permanent and that I didn't get help sooner." (Liz)

For Liz, being met with minimisation by healthcare professionals evoked feelings of shame and anger simultaneously. She described feeling judged while at the same time sensing an absence of concern around her mental health ("the healthcare system was very nonchalant"). While she expressed anger at not receiving help sooner, there was an undercurrent of despair in Liz's reflection that no one seemed to recognise her difficulties or care about her mental wellbeing. This reinforced Liz's belief that it was not worth talking about her difficulties as she would not receive the support that she needed, thereby delaying treatment-seeking and recovery.

A number of participants spoke of receiving misguided and judgmental reactions from healthcare professionals in which they were considered "rebellious" or "non-compliant". This resulted in negative consequences to participants' physical and mental health, as described by Sarah:

> "They thought it was just rebellion for a good two years, maybe three, and then it was actually diagnosed as diabulimia. It wasn't picked up early enough, otherwise I probably

> wouldn't have ended up in the position I was in. In a coma… I blame myself majorly now for the complications that I've got, because had I not restricted that insulin I may not have the complications." (Sarah)

Sarah described how her behaviour was initially labelled as "just rebellion", evoking the idea of non-compliance. Because compliance in the context refers to the process of following instructions given by healthcare professionals, this gives rise to a sense of imbalanced power in the relationships between Sarah and her healthcare professionals. Such relationships do not give rise to feelings of empowerment or trust on the part of the patient, nor do they promote positive interpersonal experiences. Rather, they create an us-versus-them dynamic that leads to disconnection, distance, and indifference. Sarah described the negative consequences stemming from this dynamic, which included both health consequences ("a coma" and "the complications") and feelings of self-blame ("I blame myself"). The excerpt emphasizes how the influence of participants' experiences with disconnected health professionals extends beyond the realms of their physical health to negatively impact their mental health and self-with-self relationship.

4.4 Theme 4: A Reason to Recover

Participants tended to frame recovery as a process, and almost all participants explored this process of recovery in their stories. Motivations to recover from diabulimia varied. For some, engagement in recovery was motivated by a change in attitude ascribed to a particular event or change in life circumstances, particularly those related to health complications. For others, motivation to recover arose in the context of social relationships or relationships with health professionals. Others described the process of recovery as contingent on the acceptance of T1D more broadly, and as more than just the absence of diabulimic symptoms.

4.4.1 Subtheme: An Event Or Change That Motivated Recovery

Some participants spoke about a particular event or change in life circumstances that served as a turning point in changing their attitude toward diabulimia, providing the impetus to engage in recovery. This concept has been previously described as a "the tipping point of change", at which point pursuing recovery outweighs the need to continue with the maladaptive behaviour (Dawson et al., 2014). For several participants, this turning point occurred after a specific event prompted realization of the risk of losing something meaningful in their lives. For Sarah, an acute diabulimia-related medical event generated a realization of the risk that diabulimia posed to her health and life:

> "I ended up in a coma and she said to me 'this is why I've been trying to warn you'. I was like 'okay, I should have listened'. As I said, it made me realise that it's a serious illness. Or serious disease, I should say. You can't just play around with your health. It's not worth it." (Sarah)

Sarah described how realization of the potential health consequences of diabulimia led to re-evaluation of her priorities, such that her potential loss of health or life was too high a price to pay for engaging in diabulimia. For most participants, knowledge of hyperglycaemia-related health complications was not new. Participants frequently explained that their insulin restriction was not related to a lack of awareness or intellectual understanding of the associated health consequences. As Sarah stated, "I was fully aware of what I was doing to my body and what could happen". However, participants' narratives suggested a difference between abstractly knowing about health complications and understanding them from experience, wherein the latter appears significantly more successful in driving behaviour change. It may also be that individuals have their own view of when the potential loss of heath or life is too much, and change is needed.

While Sarah's understanding of the health consequences of diabulimia was catalyzed by a one-off event, other participants described a gradual dawning of this understanding. For Ashley, use

of the Libre Freestyle Continuous Glucose Monitor ("the Libre") pushed her to gradually comprehend the extent to which her deliberate hyperglycaemia was endangering her health:

> "The only thing that made me stop was when I started on the Libre Freestyle monitor. I'd moved down here from [town] and the new diabetes nurse talked to me a few times about the Libre. With pricking your fingers, if you didn't do it then you didn't know what your blood sugar was and you could just push that aside… But eventually I did go on the Libre, and I fully think now that the Libre saved my life. When you're on the Libre, your blood sugar is being monitored all the time, so it's not like when you're pricking your fingers and you just choose not to prick your finger. With the Libre it was there all the time, and it was just that visual thing of seeing all those high blood sugars getting really high. It just unconsciously flipped my mind into giving me just a real good shake-up, as if to say 'what the hell are you doing? Look at these high blood sugars, look at what they're doing to you'. I mean, it wasn't instant, but over a matter of time of just constantly seeing these blood sugars… It was just that visual, instead of me being able to just forget and not think about it. I couldn't, because it was like Big Brother's always watching. And just slowly over time, it turned my mind into realizing what I was doing to myself." (Ashley)

Here, Ashley explained how she previously engaged in diabetes avoidance-related behaviours by refusing to prick her fingers, a deliberate strategy to prevent contemplation of current and future damage to her health. Since using the Libre, the visual image of her chronically high blood glucose levels meant she could no longer avoid thinking about the damage she was causing herself. Ashley's description of feeling "like Big Brother's always watching" evokes feelings of powerless due to constant prying surveillance, where, as in George Orwell's "1984", a punitive power seeks to stomp out her individual freedom. This metaphor equates the act of engaging in diabulimia as ego-syntonic, an expression of Ashley's free will that she was reluctant and fearful to relinquish. Indeed, she later stated: "I didn't realise it would change everything. I guess maybe then I wouldn't have

done it, I wouldn't have gone over to the Libre". For Ashley, her change in attitude toward diabulimia – and orientation toward recovery - was elicited by circumstances that she could not predict and that were beyond her own control. This is reflected in the narratives of other participants, such as Jen who credits the onset of the Covid-19 pandemic as "sparking" her own journey of recovery:

> "It wasn't until Covid that my sugars started really worrying me, because I was told 'don't leave the house, don't do this', that sort of thing. It really played on me. I thought 'if I leave the house, I'm going to die because I haven't been looking after myself'. And that was sort of it. It kind of sparked my whole recovery. Once the Covid restrictions lifted, I was straight into finding a new GP and just ticking all the boxes of the things I was not doing for my health. I worked really hard on my A1c. I think Covid scared me into where I needed to go." (Jen)

In this excerpt, Jen explained how the pandemic generated a realization of the risk of losing her life if she continued to engage in diabulimia, providing the motivation to actively pursue recovery. Fear-based motivation was similarly evident in the narratives of Sarah and Ashley above, although Jen's motivation was based on the possible future loss of something valuable rather than the damage that she was currently inflicting upon herself and her health. Jen suggested that her motivation is grounded in fear ("Covid scared me into where I needed to go"), but her sense of strength and empowered self-discovery is also evident in the excerpt. The term "sparked" conjures imagery of bringing light to Jen's hidden, secretive world of diabulimia, while at the same time bringing a sense of hope and the possibility of a life beyond diabulimia. The phrase "and that was sort of it" evokes the idea of a turning point: a sense that Jen has let go of her former life with diabulimia and embarked on a new life of freedom and health. The sense that pursuing recovery has created new-found freedom for Jen is further heightened by being juxtaposed with a description of Covid-19 restrictions ("don't leave the house, don't do this") and associated with the lifting of these restrictions ("once the Covid restrictions lifted").

4.4.2 Subtheme: Meaningful Relationships and Connections with Others

Several participants identified meaningful relationships as a prominent motivator for engaging in recovery from diabulimia. For some, these relationships led them to self-identify as a role model, provoking feelings of responsibility and the compulsion to look after their own health in order to care for the other. Jen described how her relationship with her daughter inspired her to engage in recovery:

> "Now I have a reason and a purpose, and that's my daughter. I want to be a good role model. I need to be looking after myself so I can look after her. No one's perfect, and you don't have to be. Be real and be open about what you're going through, because there's help. There is help out there to get to the other side. You can feel better for others and for yourself, and that's an amazing feeling when you get there." (Jen)

Jen's statement that "I need to be looking after myself so I can look after her" indicates that she needed someone else – her daughter – to encourage change, suggesting she was initially able to access recovery only through her relationship with another and not for her own value. The extract contains a sense of being-for-the-other, and an absence of value or care toward herself at the time of accessing recovery. Perceptions of low self-worth are implicated in the development and maintenance of eating problems (Warren, 2015), so recovery may be more accessible for some individuals when initially undertaken for other people. However, Jen's subsequent reflection that "you can feel better for others and for yourself" indicates that feeling worthy of recovery for herself came later in the recovery process. This increase in self-value and self-compassion is further evident in Jen's statement that "no one's perfect, and you don't have to be", and in the following quote by Jen which suggests that improved self-worth was a key element of her recovery:

> "In the hierarchy of things I just didn't value myself as highly as I should have, or give myself respect. I genuinely thought that was how it should be. Like, take care of all these things and of others to make their lives easy, but if they were going to give me that help it's all 'no,

> don't worry about me, I'm useless'… My self-worth was so low. The smallest amount of money spent on me was too much. That was really sad… Before it seemed like what I was doing was almost a suicide thing. Not that I wanted to not live or anything; I just didn't value my worth enough to push through that to get to the other better side. Until my daughter came along, that is… But where I am now, and how I feel, and how I can potentially support my daughter with self-esteem and self-awareness, I've got this." (Jen)

Participants also spoke of meaningful relationships outside of the familial context. For Jessica, volunteering as a camp counsellor at a diabetes camp and babysitting children with T1D placed her in a position of responsibility and authority over younger diabetics, wherein she felt obliged to role-model exemplary diabetes self-management. She describes how this generated a change in mindset that ultimately led her to seek support to recover from diabulimia:

> "I had also started volunteering at camp, and I was looking after diabetic kids outside of camp. The young ones that were coming to camp that lived close to me, I'd look after them. I had girls that I was kind of a mentor figure for as well. So I think I probably started to make that shift of 'if kids are going to look up to me and I'm going to be responsible for them, I need to be taking better care of myself'. I think that was probably a big factor in getting help and getting better." (Jessica)

Here Jessica indicates that caring for diabetic children activated cognitive dissonance-based mechanisms of change, wherein she found it difficult to reconcile caring for the health of others while not caring for her own. This sentiment was echoed by other participants, such as Melissa who described the cognitive shift that she experienced upon starting work in a diabetes ward:

> "I guess it was once I got into a diabetes ward. I guess I just realized that I have to look after myself first, and I can't be telling people or encouraging them to take their insulin if I'm not doing the same thing. So I guess that was my turning point." (Melissa)

As with Jessica, Melissa indicated that that assuming responsibility for other diabetics created awareness of the dissonance between her actions in caring for the health of others and failing to care for her own health. For both participants, this tension motivated an attitudinal and then behavioural change wherein they began to care for their health and seek recovery from diabulimia. This enabled consistency in their actions when caring for others and for themselves.

4.4.3 Subtheme: Feeling Understood and "Called Out" By a Healthcare Professional

Participants frequently spoke of negative interactions with healthcare professionals, in which they were criticized or dismissed as "willfully non-compliant" diabetics. Others, however, described their healthcare professionals as key motivators in their journey towards recovery from diabulimia. Within these participants' narratives, two key features stand out. Firstly, participants were helped toward recovery by healthcare professionals who demonstrated both an empathic and practical understanding of their experience as individuals with T1D and diabulimia, as explained by Sarah:

> "I didn't see any counsellors until I was 16 years old, so it was three years after my diagnosis. And the only reason I was sent to a counsellor then is because I tried to do myself in… But they weren't diabetic-trained. They focused more on my emotional state rather than my diabetic diagnosis, and it didn't work… Then I went to hospital one day, feeling sick, and that's when I got linked with [diabetes specialist], and I swear that's what saved me… It was just that they understood. I linked in with her when I was close to 18, and she knew a lot about diabetes. She understood the constant, like, ups and downs and that sort of stuff. The turmoil. She'd even trialed the pump on saline and she'd trialed the CMG, so she knew what it was all about. It was just really good to actually know someone out there has trialed it and gone through it, whether they were diabetic or not. Gone through what a diabetic would go through." (Sarah)

In this extract, Sarah explained that standard mental health support was ineffective in assisting her to recover from diabulimia. She emphasizes the importance of feeling understood by health professionals within her diabetic identity, which requires an empathetic awareness of the complex mix of biological, social, and psychological effects of T1D and insulin on individuals. For Sarah, this required an understanding on both an emotional level ("she understood the constant, like, ups and downs and that sort of stuff. The turmoil.") and practical level ("it was good to actually know someone out there has trialed it and gone through it, whether they were diabetic or not.").

The second element that participants spoke of is being "called out" on engaging in diabulimia – that is, having their deliberate insulin restriction recognized and acknowledged by a health professional. Ashley describes her experience of being directly queried about diabulimia by a dietician:

> "It took a dietician at X Hospital who just out of the blue said to me 'have you ever heard of diabulimia?'. I was so mad at her. I was like 'how dare you find out what I'm doing? This is my secret'… Obviously this dietician was a bit more savvy than some of them, and she cottoned on to what I was doing… She was straight out with it, and there was no pussyfooting around. I think that helped. For me, anyway… I guess just the fact that the clinician actually makes the person know that they know what you're doing and what's going on, and they say 'look, maybe we can't help you and maybe you don't want to be helped, but I know what you're doing and we are here for you if you do want to talk about it, or if you do want help'… It was exciting and good when it was my secret. I think when the dietician found out about it then I felt ashamed and guilty and embarrassed and a bad person." (Ashley)

Ashley described how having her diabulimia identified by a health professional changed her view of diabulimia as something positive ("exciting and good") to something negative ("then I felt ashamed and guilty and embarrassed and a bad person"), which ultimately provided the impetus to

engage in recovery. Liz described a similarly positive experience with being called out by a psychologist:

> "I had an appointment with a psychologist, and yeah, after about a 2-hour appointment she diagnosed it pretty much straight away… And then she called me back the next day and was like 'based on this information…', and she was the one who changed my life. Honestly, I owe everything to her. She was great, and I feel like that's been my only good experience with the healthcare system. She actually saw it, and it felt like she saw me. Because by not telling anyone, it was easier to lie to myself." (Liz)

For both Ashley and Liz, having a health professional bring their secretive diabulimic behaviour to light forced them to confront the realities of engaging in a dangerous behaviour. Where they had previously avoided reflecting on, or deceived themselves about, the consequences of their actions, Ashley and Liz now felt compelled to consider their diabulimia from a more honest perspective. In this way, being "called out" by a health professional facilitated a process of self-discovery for some participants, which ultimately motivated their journey toward recovery.

4.4.4 Subtheme: Recovery as Acceptance of Diabetes Itself

During the interviews, most participants spoke from a place of recovery. They explained that their relationship with diabetes had changed in various ways since engaging with diabulimia. While many expressed that they still hated having T1D, they described a sense of coming to terms with it being part of their lives. Several participants used the terms "peace" and "inner peace" to describe this mental transition from avoidance or rebellion against diabetes to acceptance. For Ashley, this acceptance was necessary for her to begin her journey of recovery:

> "I was able to find some kind of inner peace with myself to be able to turn it around. Whereas before I couldn't have done that. There was no way I wanted to do that… I really do believe that all of the help could have been thrown at me and I really don't think it would've

> helped. So maybe it's just that realisation you have yourself. Maybe it does come with maturity… I found that peace with myself and my diabetes... Yes, your blood sugar may well go up a little bit, but then you manage it and it comes back down again. It's fine and that's okay to do that." (Ashley)

In this excerpt, Ashley described how accepting that everything, including herself and her diabetes, does not have to be constantly perfect allowed her to engage in recovery. Self-acceptance and self-compassion have been cited as central factors impacting recovery from eating problems (Bowlby et al., 2015), suggesting that behavioural and physical changes are a necessary but insufficient foundation for recovery. This was reflected in participants' narratives; they often described recovery in terms of accepting themselves and their diabetes rather than in terms of remission of external symptoms such as insulin misuse. In the following quotation, Sarah reflects on her recovery as a "road to acceptance" rather than normal insulin use:

> "It's been a rough road for me, and I'm finally on the road to acceptance and getting somewhere… I think the main thing that helped me accept diabetes in my life was having an understanding… You just need to be understanding with people that everyone's different. No two diabetics are exactly the same, and no one's perfect." (Sarah)

A self-described "control freak", Sarah had previously used diabulimia to achieve a sense of control over fluctuating glucose levels and her diabetes. Like Ashley, she described how surrendering this need for perfect control over her diabetes allowed her to accept diabetes as part of her life and gain mastery of her diabetes in a realistic but not perfect manner. Sarah's use of the term "on the road" highlights the ongoing nature of her recovery, while at the same time "getting somewhere" implies that she has already significantly improved in relation to both diabetes acceptance and discontinuing diabulimia. It suggests that acceptance and recovery take ongoing effort, and that recovery is a continuous process of resisting triggers to fall back into familiar patterns of insulin restriction. This is reflected in the narratives of other participants, such as Liz:

> "Realising that, like, everybody else's bodies produce insulin, so to have a functioning body you need to give yourself that insulin. So I was like 'you're just doing what everybody else is doing, but manually', and really tried to keep with that sort of mentality… I try to look at myself, my eating and my diabetes objectively now." (Liz)

Here, Liz's switch from the past tense ("I was") to the present tense ("I try") captures the ongoing effort of her recovery. This suggests that for Liz, as with Sarah, recovery is a perpetual process of resisting old patterns and striving for a more positive approach toward herself, her eating, and her diabetes. In the same way that T1D and its requirements do not go away, neither does the psychological struggle around taking insulin. The quotation further suggests that Liz's recovery involved the removal of moralistic judgments about herself, her eating, and her diabetes. The passage is free from value-laden descriptors such as "good" and "bad", and instead uses more objective medicalized terminology such as "functioning" and "manually". This detaches the emotional significance of insulin use and diabetes, allowing Liz to view her diabetes in a more level-headed objective manner. By comparing her manual insulin use to that of non-diabetics and framing it as a "need" rather than a choice, Liz positions the use of synthetic insulin as normal and scientifically logical. This helps her to rationalize her diabetes management where she had previously imbued it with emotional significance, paving the pathway to diabetes acceptance and recovery.

Chapter 5 – Discussion/Conclusions

This study explored the lived experiences of individuals who engage in diabulimia, the manipulation of exogenous insulin by individuals with T1D for the purpose of weight loss. Participant experiences were analysed using RTA to explore what it is like to engage in diabulimia, how diabulimia is understood and what it means for participants, and to engage with participants as they reflected on their experiences with diabulimia. Participants' stories illustrated how diabulimia is about much more than controlling weight or shape. They highlight the importance – and current lack – of understanding of their unique diabulimic identity and describe a variety of motivations for recovery. I explore these points in more detail below, alongside implications. I also comment on limitations and future research directions.

5.1 It's Not Just About Weight and Shape

Participants' stories spoke to the complex nature of diabulimia, consistent with research about the complicated nature of eating problems generally (Rodgers et al., 2014). Diabulimia has previously been linked to a desire for weight loss, a high BMI, fluctuations in weight after T1D diagnosis or during adolescence, and body dissatisfaction (Pinna et al., 2022; Takii et al., 2011; Young-Hyman & Davis, 2010). Participants in this study initially spoke of weight loss or weight control as their primary motivations for engaging in diabulimia. However, as each participant reflected on their experience throughout the course of their interview, they articulated a variety of more complex motivations for their diabulimic behaviour. Diabulimia was variously described as empowering, helping to manage painful emotions, and increasing perceptions of control over diabetes and life more generally. Participants commented specifically on control as a core part of the onset of their diabulimia. Many spoke about a heightened need to feel in control and described themselves as a "Type A personality". Researchers have previously theorized that individuals engage in diabulimia to regain a perception of control and compensate for ineffectiveness (Custal et al., 2014; Goddard & Oxlad, 2022), and to cope with stress and regulate mood (Peyrot et al., 2012).

However, participants also spoke of control in another polarity: diabulimia as the relinquishing of control. This relates to the unrelenting pressure placed upon individuals with T1D to manage the condition with perfect control, such that choosing to restrict insulin represents the relinquishment of this emotional burden.

Further elaborating on the complexities of control in diabulimia, participants frequently spoke of a psychological shift as their diabulimia became more entrenched, from initial improved perceptions of control to feeling as if the diabulimia was in fact controlling them. They described the development of a disordered mentality that helped to maintain their diabulimia, which they could only in hindsight identify as irrational. This echoes previous research in which individuals used terminology such as “crazy thinking” or “negative mind” to describe their thinking while battling eating problems (D’Abundo & Chally, 2004, p.1098).

For participants, these motivations and distorted cognitions outweighed the importance of achieving optimal glucose control. Although participants were adamant that they understood the serious health risks posed by prolonged hyperglycaemia, many spoke of how during their diabulimia they prioritized weight loss and focused on the short-term, resolving to deal with complications later. This echoes previous findings that diabulimic individuals may ignore long-term health consequences due to the importance that weight loss has in their lives (Falcão & Francisco, 2009). Inducing guilt and anxiety by emphasizing the health complications associated with diabulimia not only adds to the emotional burden carried by individuals with diabulimia, but may induce “defensive avoidance”, wherein individuals avoid exposure to the content of the message itself (Loewenstein et al., 2001). This was evident in participants’ descriptions of avoiding blood sugar checks, injections, and healthcare appointments, which resulted in information avoidance and delayed treatment.

These findings have implications for the support and treatment of individuals with diabulimia. Firstly, because participants shared that entrenched diabulimia results in a worsening cycle of powerlessness, early and routine screening using empirically validated instruments is vital.

Open and collaborative communication, and a comprehensive understanding of the individual in a holistic sense, are important for healthcare professionals to identify early risk factors and dangerous behaviours (Goddard & Oxlad, 2022).

Secondly, the findings reinforce the importance of attending to feelings of control and self-efficacy in any potential intervention to support recovery and change. It seems important to avoid unattainable goals, as this may contribute to feelings of incompetency and powerlessness (Goebel-Fabbri, 2009), thereby maintaining diabulimic behaviour. More easily achievable initial treatment goals can lead to a greater sense of self-efficacy, such as the patient committing to complete basal insulin doses in order to prevent future episodes of DKA (Goebel-Fabbri, 2009). An all-or-nothing mindset is unhelpful when positive health-related behaviours are being consolidated (Hillege, 2005), and it can be helpful to regularly assess what is achievable for patients at the present time. Treatment goals can gradually build toward increasing insulin and lowering blood glucose levels. This may also help to maintain motivation and reduce the chances of burnout, relapse, and disengagement with treatment services (Wolpert & Anderson, 2001).

The findings suggest that it can be counter-productive to emphasize the health consequences of prolonged hyperglycaemia. It may be more helpful to explore the psychosocial effects of living with T1D and diabulimia (Rankin et al., 2014). A common complaint among participants was that healthcare professionals failed to explore the psychosocial effects of either T1D or diabulimia, or were dismissive when they disclosed emotional issues relating to either condition. This suggests a biomedical model of care, wherein professional care is only focused on the physical element of health. Sandelowski (1999) suggests that this dehumanizes health care and constitutes a form of salient control over patients. To improve patients' perceptions of control and provide support to recover from diabulimia, healthcare professionals should move toward a more holistic and empathetic style of treatment. Due-Christensen et al. (2018) emphasize that it is

important to recognize that patients function in more than one domain, and to attempt to work towards meeting their unique needs in each area.

5.2 A Lack of Understanding, and The Importance of Being Understood

Participants spoke about their interpersonal experiences with similar others and healthcare professionals, and how this impacted their thoughts, feelings, and behaviours. Although there were some notable exceptions, experiences with healthcare professionals were typically described as negative and unhelpful, and most participants expressed frustration with healthcare professionals' lack of knowledge about T1D and diabulimia. Communication between participants and healthcare professionals was characterized by a lack of openness and exploration, and participants felt that their clinicians were unwilling to venture beyond the physical elements into the psychological aspects of T1D and diabulimia. This may reflect the dominant Western scientific model of health, which seeks to see, measure, and catalogue as a means of increasing knowledge (Wills & Naidoo, 2016). This approach necessarily focuses on the physical human body as the mind cannot be observed, and risks overlooking the broader sociocultural contexts in which illness takes place (Petersen, 2006). Participants reported being met with minimization and an absence of concern around their mental and emotional health when they brought up their struggle with diabulimia. Sociocultural reasons for engaging in insulin restriction were overlooked, and they were instead labelled "non-compliant" or "rebellious". This label implies a lack of rationality on the part of the patient and rationality on the part of the healthcare provider (Nakata et al., 2016), entrenching the power imbalance inherent in the relationship. For participants, this lack of understanding led to feelings of self-blame and a disconnected dynamic with their healthcare professionals, often followed by healthcare avoidance and exacerbated health complications.

In the absence of understanding and support from healthcare professionals, many participants sought support from others with diabulimia or T1D, either in person or online. Participants perceived their diabulimic identity as a unique identity distinct from other eating

disorder subtypes, echoing previous research (Goddard & Oxlad, 2022; Hastings et al., 2016). Establishing connections with similar others can be important in recovering from diabulimia (Hastings et al., 2016); however, participants noted that the diabulimic identity was not always recognized or understood. Most participants sought connections based on shared experience, although some warned of normalized risk-taking in a peer environment or thoughtless sharing of knowledge about diabulimia. In these ways, connections with similar others could either help or hinder recovery (Hastings et al., 2016).

These findings have implications for the support and treatment of diabulimic individuals. Firstly, healthcare providers who adopt a purely prescriptive biomedical approach based on physiological parameters may risk alienating and disempowering their patients, echoing previous research (Goebel-Fabbri, 2017; Thorne & Paterson, 2001). As previously stated, it is important to take a holistic approach to treatment with reference to the patient's unique needs and resources within each domain of their lifeworld (Goldman & Maclean, 1998). Since participants described authoritarian interactions as disempowering and alienating, a more collaborative relationship may be useful in empowering the patient to take control of diabetes management and diabulimia treatment. Michie et al. (2003) suggest that collaboration requires individualized care with a focus on patient beliefs and goals rather than numerical indicators of health. Since health behaviours are situated in and dynamically affected by stressors and resources encountered in daily life (Nakata et al., 2019), it may also be useful for healthcare providers to explore the patient's personal resources and life challenges.

Secondly, since participants described a strong diabulimic identity distinct from other eating disorder subtypes, specialist treatment services with a concurrent focus on diabulimia and T1D may be indicated. This echoes previous suggestions that a multidisciplinary approach incorporating specialist knowledge of both conditions is necessary (Goebel-Fabbri et al., 2009; Tierney & Fox, 2009), and may help to explain why individuals with diabulimia treated within generalized ED

services tend to show little improvement (Macdonald et al., 2018). Participants asserted that a lack of recognition of diabulimia in the literature acted as a barrier to accessing support from similar others. This barrier may stem from a lack of recognition of diabulimia in the Diagnostic and Statistical Manual of Mental Disorders, which may also contribute to a lack of understanding and recognition of diabulimia within healthcare services and society more broadly (Allan, 2019). Given the unique diabulimic identity expressed by participants, it may be useful for healthcare professionals to categorize and treat diabulimic individuals differently. Diabulimia may also warrant distinct diagnostic criteria in order to remove barriers to accessing peer support, which is associated with improved rates of recovery among individuals with eating problems (McNamara & Parsons, 2016).

5.3 Motivations for Recovery

Participants spoke of recovery as a process situated within the reality of T1D, expressing various motivations for engaging in recovery. Motivation for recovery was frequently linked to growing awareness of the extent to which they were risking their health and lives, echoing Goebel-Fabbri (2017). Such awareness was often prompted by an internal or external event (e.g., acute health complications or the COVID-19 pandemic) that led to a "tipping point" (Dawson et al., 2014), where pursuing recovery outweighed the need to continue restricting insulin. Meaningful relationships were another prominent motivator, and participants spoke of recovering for another person after initially feeling unable or unwilling to pursue recovery for themselves. This may speak to low self-worth, which is thought to contribute to the development and maintenance of eating problems (Warren, 2015). Healthcare professionals could facilitate participants' recovery by "calling out" diabulimia behaviour, as long as they also demonstrate an empathic and practical understanding of both T1D and diabulimia. This reiterates the importance of specialist treatment described by Goebel-Fabbri (2017). Another key finding was that recovery from diabulimia tended to correspond with positive changes in participants' relationships to their T1D, with participants voicing

that they had transitioned from avoidance or rebellion of diabetes to tolerance and acceptance. This supports research suggesting that the difficulty of living with T1D is a core factor in the emergence and maintenance of diabulimia (Coleman & Caswell, 2020).

These findings have implications for the support and treatment of individuals with diabulimia. Firstly, the concept of recovery for the other may be a valuable avenue for engagement, at least until a more positive sense of self has been built, and it may be useful for healthcare professionals to explore this with patients. Secondly, the importance of a therapeutic alliance is underscored, since empathetic, non-judgmental, and knowledgeable healthcare professionals promoted motivation to recover. Venturo-Conerly et al. (2020) suggest that a blend of supportiveness and directivity may be most useful in motivational and treatment interventions, although the authors caution that forcing treatment risks making patients feel less autonomous. To facilitate a therapeutic relationship between healthcare professionals and individuals with diabulimia, further education about insulin restriction and the challenges of life with T1D may be required. Finally, the findings suggest that it may be important to assist individuals with diabulimia to develop a more accepting relationship with T1D, since participants linked their recovery with increased acceptance of living with T1D. EDs may represent a maladaptive coping mechanism for emotional issues relating to having T1D (Larranaga et al., 2011), so individual therapy to develop more healthy coping strategies may be indicated. From a systems perspective, family therapy may also help families struggling with the diagnosis of a family member to address issues that may contribute to diabulimia (Sartor & Cosma, 2017).

5.4 Strengths and Limitations

This research project offers an analysis of the lived experiences of individuals with diabulimia. There are a number of strengths to the current study. In light of the paucity of qualitative research into diabulimia, this research aids in furthering the understanding of a complex topic. It contributes to psychosocial theories of diabulimia by demonstrating that insulin restriction has a

variety of psychological and social causal factors. It highlights important elements of treatment and recovery, such as the necessity of considering diabulimia holistically and in light of diabetes distress. Further, recognizing the importance of understanding for support and treatment, this study may help healthcare professionals to better understand the experiences of both diabulimia and T1D.

However, the study has some limitations. Firstly, while the goal was to gather a diverse group of participants, the sample size was small and included Caucasian women only, echoing samples in most existing qualitative literature about diabulimia. This homogeneity may be because diabulimia is more prevalent in females than males (Goebel-Fabbri, 2017), or because boys and men are less likely to disclose eating problems due to facing greater stigma in light of traditional male gender roles (Staite et al., 2018). Ethnic minority individuals are also less likely to disclose eating problems due to social barriers, such as perceived stigma and social stereotyping (Becker et al., 2010). Future research could seek to replicate these findings in a more diverse sample that includes male and gender diverse individuals, non-heterosexual individuals, individuals of various ethnicities and socioeconomic statuses, and international participants. This would help to increase the generalizability of findings and address the gaps in our knowledge regarding lived experiences of diabulimia.

Secondly, individuals self-selected into this study by self-identifying as having lived experience of diabulimia. Since diabulimia is not yet recognized in the DSM, it was not possible to select individuals who had received a formal diagnosis. However, it is possible that insulin restriction varied greatly in frequency and severity between participants. Further, this means of recruitment may have created a self-selection bias in recruiting people who spoke from a position of recovery, as individuals presently engaging in diabulimia may be more reluctant to engage with research about a current struggle.

5.5 Reflexivity

Berger (2013) proposes that having a shared experience with research participants confers three particular benefits to researchers: easier entrée, increased knowledge of the topic, and greater understanding of the nuanced reactions of participants. I agree with this position, and found that my knowledge of the technicalities of diabulimia and T1D allowed interviews to flow seamlessly and without diversions for participants to explain the intricacies of these phenomena. However, during the interviews I was conscious of the danger of positioning myself as expert and imposing my own understandings or experiences on participants. The participant should always be considered the expert (Raheim et al., 2016), and I tried to frame my research through a lens of curiosity and exploration. Where the meaning of certain responses was unclear or ambiguous, I made sure to gently probe for clarification instead of making assumptions based on my own experience. I also chose an inductive data-driven approach to coding in an attempt to stay true to participants' meanings and to eliminate any preconceived ideas about what might be important. Upon reflection, I believe that participants were able to articulate their own experiences and understandings of diabulimia, and that this resulted in a nuanced and valuable addition to the literature.

5.6 Conclusions

This study represents an exploration into lived experiences of diabulimia in New Zealand and Australia. The findings revealed a complex and multidimensional relationship with insulin restriction beyond control of weight and shape. Individuals engaged in diabulimia as a response to diabetes distress or burnout and feeling out of control; conversely, diabulimia often led to a gradual loss of control. Individuals highlighted the importance of sharing a diabulimic identity, experience, and knowledge, although some spoke of associated risks. Recovery was framed as a process, and motivations to recover included growing awareness of the extent to which individuals were risking their health or lives, meaningful relationships, being "called out" by health professionals in an empathetic and understanding manner, and acceptance of T1D itself.

These findings provide valuable knowledge about lived experiences of diabulimia to researchers and health professionals working with individuals with T1D and/or diabulimia. They highlight the need for early, routine, and thorough screening using empirically validated instruments, and open inquiry by healthcare professionals who have a comprehensive and empathic understanding of the individual in a holistic sense. It may be useful for healthcare professionals to explore the concept of recovery for another person, as well as the patient's personal resources and life challenges, including those associated with living with T1D. The findings also highlight the importance of a collaborative and individualized approach to treatment within specialist treatment services that are informed by knowledge of both diabulimia and T1D. Healthcare professionals may also require further training on the psychosocial challenges of living with T1D to assist individuals to develop a more accepting relationship with T1D.

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Appendices

Appendix 1. Digital graphic invitation to participate

Appendix 2. Information sheet

Appendix 3. Interview schedule

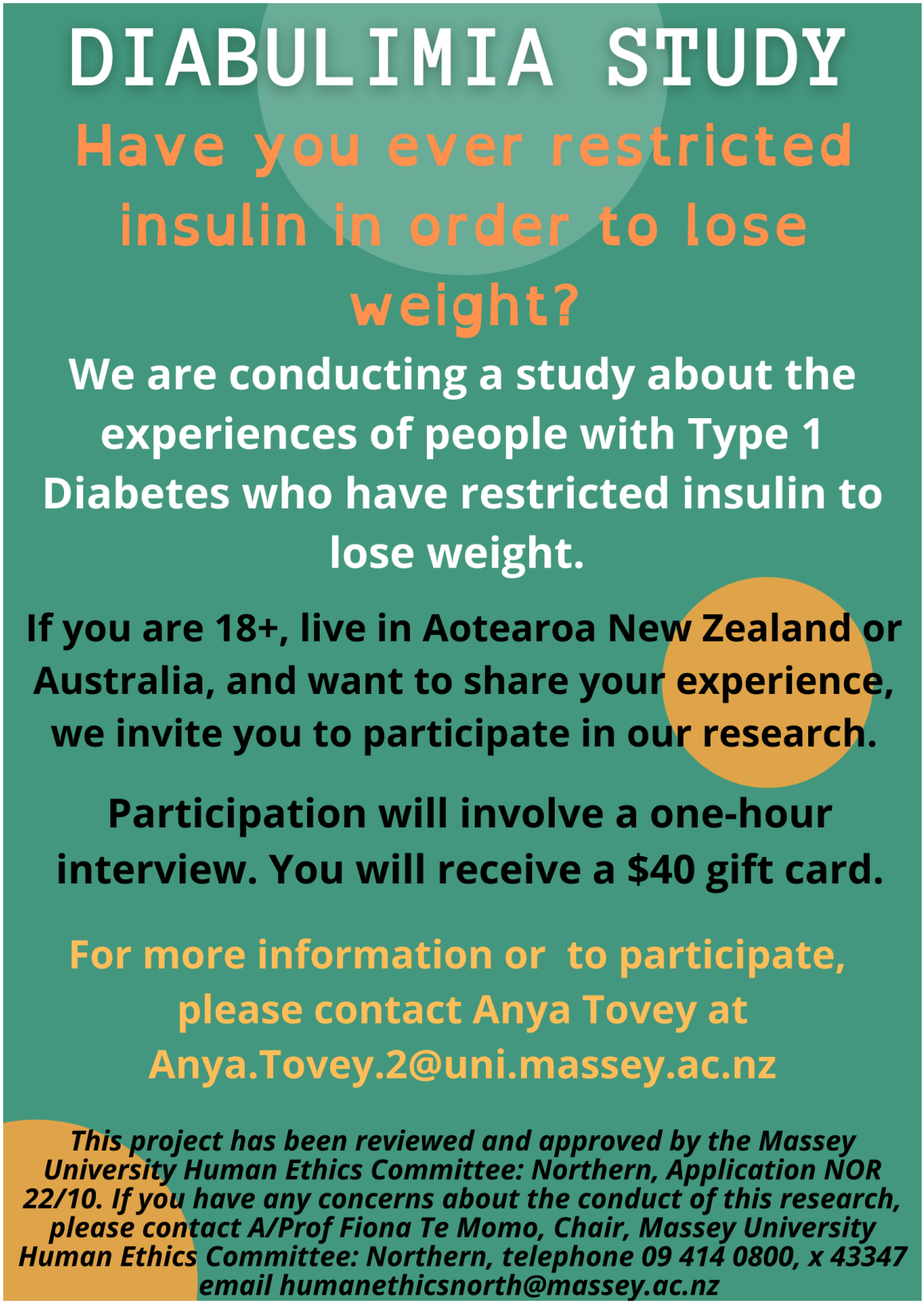
Appendix 4. Ethical approval letter

Appendix 5. Initial codes

Appendix 6. Themes and subthemes

Appendix A

Digital Poster Invitation to Participate



Appendix B

Information Sheet

Lived Experience of Diabulimia (Insulin Restriction for Weight Loss)

INFORMATION SHEET

Kia ora and greetings from our research team. My name is Anya Tovey, and this project is part of my Masters research. My supervisor is Dr Andrea LaMarre. We are conducting a study on the lived experience of diabulimia (insulin restriction for weight loss). This research will help us to better understand the common themes among peoples' experience of diabulimia, which may assist future researchers in the development of an effective intervention.

Inclusion criteria

You are eligible to take part in the study if you fulfill the following criteria:

- Are 18 years or older;
- Have type 1 diabetes mellitus;
- Have lived experience of engaging in insulin restriction for the purpose of weight loss; and
- Live in New Zealand or Australia.

What will participation look like?

If you decide to participate, we will schedule an interview on Zoom. Before the interview, we will invite you to complete a consent form. Please feel free to ask us any questions about the project and/or to consult with people you trust before you decide to participate.

Participation is ***completely voluntary*** – if you do not want to participate, you do not have to. You can also choose to:

- Stop participating at any time before or during the interview/data collection phase.
- Withdraw your data up until two weeks after you have received your transcript for review.

What are the benefits of participating?

You may enjoy or find meaning in talking about your experiences. This project will also help us to learn more about people's experiences of diabulimia.

You will also receive a $40 gift card to thank you for your time.

What are the risks of participating and how are they being managed?

Risks to participation are minimal – you are welcome to share as much or as little as you want in response to questions, and to not answer questions that make you feel uncomfortable. There is the potential for you to feel upset discussing your experiences if they were challenging for you. Should any distress arise for you, there is also a list of resources at the end of this form.

What will be done with my information?

Interviews will be recorded and transcribed. Recordings will be stored on password protected computers. If any identifiable data is shared within the research team, we will use secure (password protected) means to do this. If any printouts are made, they will be kept in a locked cabinet in my supervisor's office on the Massey University Albany campus.

Recordings and transcripts will be securely deleted 5 years after the close of the research project.

Analysed data may be used in any of the following ways:

- My Masters thesis
- Academic publications
- Academic and/or community presentations
- Policy briefings
- Knowledge translation outputs – e.g. blog posts, infographics, webinars, etc.

You will be invited to choose a pseudonym (fake name) that will be used to identify you in any outputs from the research. If you do not have a preferred pseudonym, we will select one for you.

Participant's rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question;
- Withdraw from the study at any time until two weeks after you have received your transcript for review;
- Ask any questions about the study at any time during participation;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Ask for the recorder to be turned off at any time during the interview;
- Be given access to a summary of the project findings when it is concluded.

Project contacts

If you have any questions about the research, please contact:

Student Investigator: Anya Tovey
Phone +64 27 207 7972, Email: Anya.Tovey.2@uni.massey.ac.nz

Supervisor: Dr Andrea LaMarre, Lecturer, School of Psychology, College of Humanities & Social Sciences, Massey University, Albany Campus.
Phone +64 6 356-9099 ext. 43106, Email a.lamarre@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Northern, Application NOR 22/10. If you have any concerns about the conduct of this research, please contact A/Prof Fiona Te Momo, Chair, Massey University Human Ethics Committee: Northern, telephone 09 414 0800 ext. 43347, email humanethicsnorth@massey.ac.nz.

Support resources

For a full list of mental health crisis teams
www.health.govt.nz/your-health/services-and-support/health-care-services/mental-health-services/crisis-assessment-teams

Lifeline
0800 543 354 (0800 LIFELINE)
or free text 4357

1737 Need to Talk?
Free call or text 1737 for support from a trained counsellor

Depression Helpline
0800 111 757 or text 4202

Anxiety Helpline
0800 269 4389 (0800 ANXIETY)

Healthline
0800 611 166

Centre for Psychology
Level 3
North Shore Library Building (off Kell Drive)
229 Dairy Flat Highway
Albany Village, Auckland
Tel: (09) 213 6095
Fax: (09) 414 7328
Email: Centreforpsychology@massey.ac.nz

Massey Health and Counselling Centre
(For Massey Students only)
09 213 6700
Email: studenthealth@massey.ac.nz
www.massey.ac.nz/massey/student-life/services-and-resources/health-counselling-services/counselling/counselling_home.cfm

Diabetes NZ Helpline
0800 342 238 (0800 DIABETES)
Email: admin@diabetes.org.nz
www.diabetes.org/nz
www.facebook.com/diabetesnz

Appendix C

Interview Schedule

Prior to asking questions, I will spend some time explaining the research project and building rapport with participants.

1. Why did you want to take part in this study?
2. Can you tell me a bit about your experiences with diabetes, and how it has impacted your life?
    a. Possible prompts:
        i. When were you diagnosed?
        ii. What was that experience like?
        iii. How did you integrate diabetes management into your life?
3. Did getting diabetes change the way you felt about, or saw, yourself?
4. Before getting diabetes, did you ever try any strategies to lose weight or change your body shape?
    a. If so, what were these?
5. As you know, this study is about peoples' experiences of restricting insulin to lose weight. When did you first start restricting insulin?
6. What did restricting your insulin look like for you?
7. Why do you think you started restricting insulin?
    a. Was there a particular trigger?
        i. If weight loss: Were there any other reasons?
        ii. If weight loss: Did you use any other strategies at the same time as restricting insulin to lose weight or change your body shape?
        iii. If so, what were these?
8. How did you feel physically after you started restricting insulin?
9. How did you feel emotionally after you started restricting insulin?
10. Did anyone else know that you were restricting insulin?
    a. If so, what were their reactions?
    b. How did you feel about these reactions?
11. Did restricting insulin have any effects on your life in general?
    a. Prompts: on your social life? On your health?
12. How long did you restrict insulin for?
    a. *Note: Use this to determine whether currently restricting insulin and so to decide which of the next 2 sets of questions to ask.*

If not currently restricting insulin:

13. Why do you think you stopped restricting insulin?
14. What strategies did you use to stop restricting insulin?
15. Did you ever try to get support to stop restricting insulin?
    a. If so, did you receive support?
        i. If so, what form did this support take, and who was it from?
        ii. How did that support affect you?

    b. If you did not seek support, why do you think that was?
16. If you reflect on that time in the past when you restricted insulin, how do you feel about it now?
17. How do you feel about your health now?
18. Do you have any thoughts around what might be helpful for you and your life with diabetes going forward?

If currently restricting insulin:

19. What is your experience of restricting insulin like these days?
20. How do you feel about restricting insulin to lose weight or change your body shape?
21. How do you feel about insulin generally?
22. Have you ever tried to get support to stop restricting insulin?
    a. If so, did you receive support?
        i. If so, what form did this support take, and who was it from?
        ii. How did that support affect you?
    b. If not, why do you think you did not try to get support?
23. What do you think are the main barriers to stopping insulin restriction?
24. Do you have any thoughts around what might be helpful for you and your life with diabetes going forward?

After asking questions, I will ask participants if they have anything else that they would like to add, whether they have any questions, reiterate our next steps, and thank them for their time.

Appendix D

Ethical Approval Letter

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

13/05/2022

Dear: Anya Tovey

Re: Ethics Application - NOR 22/10 - The lived experience of diabulimia: A thematic analysis.

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Human Ethics Northern Committee at their meeting held on **Thursday, 31 March 2022**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics Office, Research and Enterprise
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand T 06 951 6841; 06 95106840
E humanethics@massey.ac.nz; animalethics@massey.ac.nz; gtc@massey.ac.nz

Appendix E

Initial Codes Generated Using NVivo

1. Caring for myself and my diabetes felt selfish.
2. Diabetes is a mental health struggle or weakness.
3. Diabetes defined me.
4. Diabetes is unrelenting and exhausting.
5. I had a diabetes network (friends and family).
6. Diabulimia as control, power, or advantage.
7. Diabetes was part of becoming independent.
8. Diabulimia to avoid or have a break from diabetes.
9. Diabulimia impacted my social life.
10. Having diabetes is unfair.
11. I resent my body for failing me.
12. Knowledge about complications.
13. Medical experiences.
14. Healthcare professionals don't understand the experience.
15. Money and costs.
16. Other eating disorder(s).
17. People don't like to talk about diabetes or diabulimia.
18. Perfection, high standards, and all-or-nothing approach.
19. Body image and pressure to be thin.
20. Public perception of diabetes.
21. Role models and mentors.
22. Technology.
23. Acceptance, empowerment, and overcoming diabulimia.

Appendix F

Themes and Subthemes