Middlesex University and Metanoia Institute

The lived experience of Diabulimia.
Individuals with Type 1 Diabetes using insulin for weight control

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Submitted in partial fulfilment of the degree of
Doctor of Counselling Psychology and Psychotherapy by Professional Studies

November 2020

Word Count: 43,885

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Abbreviations and Definitions

BMI	Body Mass Index
BPS	British Psychology Society
CBT	Cognitive Behavioural Therapy
COM-B	Capability, Opportunity, Motivation, Behaviour
CoP	Counselling Psychology
CoPs	Counselling Psychologists
DEPS/R	Diabetes Eating Problem Survey/Revised
DKA	Diabetic Ketoacidosis
DSM-V	Diagnostic and Statistical Manual of Mental Disorders Fifth Edition
ED	Eating Disorder
EDs	Eating Disorders
GP	General Practitioner
IPA	Interpretative Phenomenological Analysis
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
T1DM	Type 1 Diabetes Mellitus
T1ED	Type 1 Eating Disordered
UK	United Kingdom

Diabetic Ketoacidosis	Caused by a severe lack of insulin in the body. This means the body does not get enough energy from food, and starts to use energy from fat, muscle and organ tissue and excreting it through urine. When this happens ketones are released, which eventually will cause blood to become acidic.
Insulin restriction/omission	The intentional act of not taking as much insulin as needed or required. Terms are used interchangeably.
Kussmaul Breathing	Low, shallow, laboured, breathing caused by prolonged diabetic ketoacidosis

Acknowledgements

To begin, I would like to express my sincere gratitude to my research supervisor Dr Joel Vos for the continuous support and immense knowledge. Your insightful comments and encouragement kept me excited and passionate about my research, even when writing the most difficult sections.

My sincere thanks to all those involved with Diabetics with Eating Disorders, Diabulimia Helpline, and the Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust – Bournemouth Diabetes and Endocrine Centre. Collectively, you provided me with opportunities to recruit, present, share, explore, listen, and learn. The passion you all have for the field is limitless, and I thank you all for welcoming me into the research community and supporting me in your various ways.

To my mum and dad, this is for you. Thank for your endless support and love during this process which goes far beyond the writing of the thesis. To Daniel, thank you for the late-night calls and messages during my occasional crisis of confidence, and of course, for the endless tech support. Here’s to the power of two.

To Joe, I could not have done this without you. Thank you for all your patience, love, and care. For knowing when I needed to be left alone in the study and when what I really needed was for someone to tell me it would all be okay. For as long as you have known me, I have been studying, but I promise I will now take a break. You can use the computer and we can finally spend whole weekends together without me having to write. To my family and friends further afield, thank you. I have felt your encouragement and support from all corners of the world, from Australia, America, and Hong Kong.

To my participants, none of this would have been possible without you. Thank you for your honesty and trusting me to share your experiences. Each one of you taught me something that I will carry with me far beyond the boundaries of this thesis.

Abstract

Diabulimia is the term given to the intentional restriction of insulin for the purposes of weight loss in individuals with Type 1 Diabetes Mellites (T1DM). Diabulimia can be life-threatening, and prevalence rates in T1DM are high, yet there is a lack of research exploring how best to support individuals with this difficulty. Currently, individuals restricting their insulin appear in care and support pathways which do not always attend to specific psychological factors associated with T1DM. Recent literature has named the importance of understanding the physical and psychological issues related to insulin restriction to provide effective care.

Exploring the lived experience of diabulimia stands to provide much needed information to healthcare professionals working alongside this population. Which in turn, may inform psychological support, future research, and support pathways. Subsequently, this research aims to explore the lived experience of diabulimia.

Through Interpretative Phenomenological Analysis (IPA), five females and one male shared their subjective lived experience of using insulin for weight control through semi-structured interviews, which led to the identification of four superordinate themes: (1) Go count your carbs and take your jabs; (2) A deadly love; (3) It is so much deeper than just insulin, and (4) There is recovery. The analysis revealed the relational nature of diabulimia which encapsulated the participants longing for relational depth with healthcare professionals and peers.

Recommendations based on the research findings include incorporating an existential-phenomenological and relational psychoanalytic approach to therapeutic work, as well as utilising the participant's motivation to pursue recovery for the other. Future research would benefit from exploring the male experience of diabulimia, as well as enquiring into the construction of self-identity when using insulin for weight control.

CHAPTER ONE

Introduction

1.1. Setting the scene

Diabulimia is the colloquial term given to the intentional restriction of insulin for the purposes of weight loss in individuals Type 1 Diabetes Mellitus (T1DM). Up to 40% of women aged between 15-30 and 11% of men are estimated to have intentionally restricted their insulin to lose weight (Fairburn et al., 1991; Goebel-Fabbri, 2017; Hevelke, Albrecht & Busse-Widmann, 2016). The consequences of this practice are severe and lifechanging, as it can lead to nerve damage, kidney disease, retinopathy, heart attacks and strokes (Bryden et al., 1999; Goebel-Fabbri, 2017; Mathieu, 2008; Shaban, 2013). What is more, diabulimia stands to triple an individual's risk of mortality and reduce their life expectancy by up to thirteen years when compared to individuals with T1DM who do not restrict their insulin (Goebel-Fabbri et al., 2008; Shih, 2011).

Diabulimia is not currently recognised as a formal diagnosis. It does not feature in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) or the eleventh revision of the International Classification of Diseases (ICD-11) (American Psychiatric Association, 2013; World Health Organisation, 2018). The omission of diabulimia from these texts has led to a debate amongst healthcare professionals around whether the term is appropriate and whether it could help to generate recovery through facilitating awareness (Macdonald et al. 2018). A likely consequence of its contested status is that diabulimia to date remains under-researched. Darbar and Mokha remarked on the "extremely limited" (p.32) availability of research back in 2008, with Brookes (2016) raising the same concern recently through his reflection on the "scant" (p.8) literature available.

Studies investigating diabulimia have focused largely on population prevalence, aetiology, and practitioner accounts (Brookes, 2016; Mathieu, 2008; Sharma, 2013). Although valuable, such studies overlook an individual's lived experience. Consequently, the voices of individuals who have lived experience of diabulimia rarely feature in research or broader discussions surrounding the topic (Brookes, 2016). However, over the past three years, diabulimia has been increasingly recognised within medical and psychological communities. In 2017, Goebel-Fabbri published *Prevention and Recovery from Eating Disorders in Type 1 Diabetes,* which shared the voices and experiences of twenty-five women who restricted their insulin for weight control. Whilst in 2018 and 2019, researchers at The Royal Bournemouth and Christchurch Hospital and Kings College London respectively were awarded grants to design care and treatment programmes for diabulimia.

Despite the growing awareness of diabulimia, how best to support and care for the population is an area of ongoing research and inquiry. At present individuals restricting insulin for weight control are typically referred to their local Eating Disorder (ED) services. In such an environment, an individual’s difficulty is likely to be framed around food and eating, as opposed to one which also includes the numerous physical, behavioural, and psychological factors associated with having T1DM (Allan, 2015). Consequently, care and support pathways which do not address diabetes-related elements report high rates of individual drop out and low levels of recovery (Allan & Nash, 2014). More recently, studies have stressed the importance of person-centred and relational approaches to care and treatment (Coleman & Caswell, 2020; Goebel-Fabbri, 2017; Partridge et al., 2020). Yet research enquiring into an individual’s lived experience remains scarce and has seemingly never been explored from a phenomenological perspective.

This knowledge gap is not only cause for academic curiosity but could also assist the development of effective care and treatment pathways (Brookes, 2016). Coleman and Caswell (2020) state that to deliver effective psychological treatment, practitioners must understand the seriousness of diabulimia, as well as the ways and extent to which it impacts upon an individual’s life. Coleman and Caswell’s (2020) recommendation contributes to a larger body of academics and practitioners advocating research that explores diabulimia from the perspective of individuals who have first-hand lived experience (Brookes, 2016; Hasken et al., 2010; Shih, 2011).

1.2. Research aims and anticipated contributions

The aim of the study is to explore the lived experience of diabulimia. To do so, questions investigating specific areas of the phenomenon will be asked, for example, what was it like for individuals when they were using insulin for weight control, and what does diabulimia to mean to them. In this way, the study can be considered to have two main objectives. Firstly, to explore what it is like to use insulin for weight control, and secondly, to explore the meaning of diabulimia for participants. The aim and objectives of the study are discussed further in section 2.10.

Investigating the lived experience of diabulimia stands to contribute to the field of Counselling Psychology (CoP), and other allied professions in numerous ways. The provision of a rich and detailed account of the phenomenon may increase practitioners understanding and awareness of diabulimia. In turn, this may also assist practitioners working therapeutically with the population. Additionally, the findings of the study may also contribute to developing care and treatment pathways by offering an insight into what it is like to experience diabulimia, whilst also highlighting care and treatment experiences voiced by the participants.

More broadly, it is hoped that the research findings will also inform guidelines such as those produced by the National Institute for Health and Care Excellence (NICE), and training courses offered to practitioners and healthcare professionals working with the demographic. The provision of which have previously been described as scarce and limited (Balfe et al., 2013).

1.3. The language of diabulimia

As will be evident in my linguistic treatment so far, and in the subsequent chapters, I have elected to use diabulimia without quotations. Diabulimia is the term by which the natural standpoint currently knows the phenomenon. Consequently, whilst it may not capture the depths and complexities of the individual's experience entirely, it provides a means of communication and will be used in the research both in written form and when speaking to participants.

It is not the aim of the research to argue for or against the clinical or diagnostic status of diabulimia. Instead, it is to understand how individuals are articulating and making sense of their experience. To argue for the truth or certain existence of diabulimia would go against the phenomenological epistemological foundations of the research. From the phenomenological perspective, the study aims to understand the individual's experience and sense-making of the phenomenon, as opposed to making a claim for the objective truth of diabulimia (Langdridge, 2007; Willig, 2013).

1.4. Navigating the thesis

The thesis begins with a section on reflexivity, wherein I reflect upon my position in relation to the research, my initial understandings deriving from my natural standpoint, and how they came to be. Following this, the *Literature Review* presents the previous literature and research most relevant to the diabulimia phenomenon as well as the emerging connection between T1DM and eating disorders. The chapter highlights the necessity of the proposed research and ends by presenting the research aims and question.

The third chapter *Methodology* is divided into two broad segments. To begin, the chapter defines and justifies the use of a critical realist ontology and phenomenological epistemology while reflecting on these positions within the realm of CoP. From here, Interpretative Phenomenological Analysis (IPA) is outlined as the most suitable methodology. Within IPA choices were made around using Husserl (1913), Sartre (1956), and Merleau-Ponty (1962) to think about the self in relation to individual projects and the conceptualisation of the body. In addition, the methodology also reflects upon Heidegger (1978) with regard to the broader world and how meaning can be conceptualised in a world that is continuously changing. Heraclitus (2010) provides a way of linking Husserl (1913) and Heidegger (1978) by reflecting upon the flow of a river contained by its banks. A life flow akin to a river is forever changing but constrained by broader parameters. The second section, *Conducting the Research* demonstrates how I undertook the data collection, participant sampling and recruitment as well as the analytic strategy. The section further explores ethical considerations, and the specific steps taken to ensure the integrity of the research.

In the *Analysis* chapter, I explore the various facets that underpin the identified four superordinate themes, along with the inter-related subordinate themes. The identified superordinate themes were: Go and count your carbs and take your jabs, secondly; A deadly love, thirdly; It is so much deeper than just insulin, and finally; There is recovery. The final chapter, *Discussion* focuses upon what emerged within the analysis and how this connects back to the academic literature, as well as bringing forth new concepts which reshape what is currently known about diabulimia and how it is typically perceived. Towards the end of the chapter, the strengths, and challenges of the research are reflected upon, whilst also highlighting various recommendations for clinical practice, professional training, and support pathways. The chapter then outlines areas for future research and concludes with a final reflection.

1.5. Reflexivity

Reflexivity is a defining feature of CoP and phenomenological research (British Psychology Society, 2013; Husserl, 1913; Smith, Flowers & Larkin, 2009). The basis of reflexivity for Husserl (1913) is to work through what is currently known and understood within a natural standpoint to reach a deeper degree of understanding. It requires looking at what is usually taken for granted and engaging in a deep focus upon what it means, whilst also reflecting upon how this fits back into the wider world.

Berger (2015) notes that reflexivity is not just a skim upon the surfaces of everyday life but is a concentrated form of attaining insight, which involves connecting and taking responsibility for one’s own situatedness within the research, and the effect that this may have on the setting, the participants, the questions asked, the data collected and its interpretation. Finlay and Gough (2003) note the variations of reflexivity and encourage researchers to locate the most suitable reflexive form for their research project. Given the phenomenological positioning of the research, reflexivity as an intersubjective reflection was considered the most appropriate (Palaganas et al., 2017). From this position, I will be able to explore the mutual meanings involved within the research relationship, the situated, emergent, and negotiated nature of the research encounter. Furthermore, reflexivity offers an avenue through which reductionism can be lessened and the emotional connection I have towards the research explored.

Reflexive accounts will be embedded throughout the thesis and begin with my initial positioning in relation to the research topic. My reflections are not positioned as fixed truths, as this would go against my epistemological and ontological position that knowledge and meaning are variable and open to adjustment. Subsequently, the reflections capture my current understanding, wondering, and meaning-making at the time of writing.

1.6. Reflexivity (1)

I conceptualise my connection to the research topic as a tapestry. One made up of many strands and colours yet all interwoven and united. When growing up, I encountered T1DM and eating disorders as separate entities and viewed the impact of both on the people who existed around me. I became acutely aware of how numbers dictated their lives in different ways and the effect this had on their physical and mental wellbeing. Upon reflection, there were times when I struggled to connect to what was occurring before me. I experienced feelings of helplessness which turned into frustration. I longed for them to either eat more or to attend to their diabetes as I felt they were supposed to. I wanted to help but now realise that we were all trapped within our natural standpoints, and the ability to access or express deeper realms of emotional complexity was strained.

Another strand of my tapestry involves being a twenty-nine-year-old white British woman, born and raised in the South East of England in what can be considered a middle-class household. This compilation positioned me within certain cultural expectations, narratives, and privilege, which shaped who I came to be, and subsequently, my position within the research. My gender and age stand to place me in proximity with young women who may have felt pressurised by others or society to conform to specific conceptualisations of female beauty and ideals.

A documentary in 2017 titled *“Diabulimia: The world’s most dangerous eating disorder*” (BBC, 2017) highlighted how entities I had previously experienced as separate could come together to form a complex and potentially fatal combination. Discussions with various eating disorder professionals and individuals leading charities highlighted the dearth of literature and support available for this population. I entered the field of T1DM and eating disorders from a position of curiosity rather than an expert by experience. Through the ongoing process of thinking and reflecting, I developed a greater insight into diabulimia whilst also ensuring that the emerging processes and themes were a product of the participants and their experience as opposed to the imposition of my natural standpoint.

CHAPTER TWO

Literature Review

2.1. Chapter overview

The following chapter will explore the literature related to diabulimia whilst making a case for the proposed research question. The chapter begins with an overview of T1DM before exploring the existing literature on Eating Disorders (EDs) in individuals with T1DM. Diabulimia refers specifically to the act of insulin restriction for weight loss, whilst the acronym T1ED (Type-1-Eating-Disordered) encompasses broader eating difficulties such as purging by vomiting or restricting food. The chapter will attend to literature related to diabulimia and more broadly T1ED.

As the research is positioned at an intersection between T1DM and eating disorders, the parameters of T1DM are provided along with an overview of how eating disorders are frequently conceptualised (Maine, Davis & Shure, 2008). The wider specifics of T1DM and eating disorders are highlighted by Diabetes UK (2019) and Treasure (2003; 2007; 2013) respectively. The chapter concludes by justifying the value of researching the subjective experience of diabulimia, by naming the relevance to counselling psychology, as well as anticipated contributions to policy, support, and the advancement of professional practice.

The term healthcare professional is used throughout the literature review and refers to all personnel who may help support and care for an individual with T1DM. This includes but is not limited to, endocrinologists (diabetes specialist), general practitioner, psychologist, physiologist, dietitian, diabetes nurse, optometrist, and nephrologist (kidney specialist). The search strategy used for the literature review is located in appendix 1.

2.2. Type 1 Diabetes

Before reviewing the literature related to diabulimia and T1ED, the following section offers an overview of T1DM. The segment will discuss the aetiology and current treatments of T1DM, as well as the proposed social and psychological implications of the condition.

2.2.1. Defining Type 1 Diabetes

Type 1 diabetes is an autoimmune condition whereby the immune system attacks and destroys the insulin-producing cells of the pancreas, leaving the body unable to produce insulin and keep blood glucose levels under control (Juvenile Diabetes Research Foundation JDRF, 2020). The body breaks down carbohydrates into blood sugar which is used for energy. However, without insulin, the body cannot transport the glucose from the bloodstream into the cells of the body. Accumulating glucose in the bloodstream is fatal if left unattended (Allan, 2019).

Type 2 diabetes, by comparison, is a metabolic condition that results in high blood glucose levels due to the body being unable to produce enough insulin or being ineffective at using the insulin it has produced. The aetiology of type 2 diabetes is frequently associated with ethnicity, genetics, or lifestyle (JDRF, 2020). Managing type 2 diabetes often involves a combination of lifestyle changes such as diet and exercise, as well as oral medications. A proportion of individuals may also be prescribed insulin. Due to the differences in aetiology, nature and management of type 1 and type 2 diabetes, diabulimia literature focuses only on individuals with type 1 diabetes. This will also be the case for the current literature review and study.

2.2.2. Aetiology and epidemiology

There have been numerous attempts to explain the aetiology of T1DM. Research names the role of genetics, viruses, the environment, and even the season of birth (Allan, 2019; Filippi & von Herrath; Gale, 2002; Steck & Rewers, 2011; Maahs et al., 2010). In 2019, it was estimated that 3.8 million individuals in the UK were living with diabetes, of which 8% had T1DM with the rest having type 2 diabetes (Diabetes UK, 2019). T1DM is reportedly more prevalent within western societies and in Caucasians with the age of diagnosis, usually between 10 to 14 years old (Maahs et al., 2020; Patterson et al., 2014).

2.2.3. Treatment

As a result of being diagnosed with T1DM, individuals must mimic the pancreas by administering synthetic insulin to regulate blood glucose levels, which is affected by numerous factors such as food, temperature, illness, stress, hormones, and exercise (Kilpatrick, et al., 2007; McDonnell & Umpierrez, 2012). Too much insulin in the blood and therefore not enough glucose in the brain results in hypoglycaemia (low blood glucose levels), which if not treated rapidly can result in coma and death. Conversely, when there is not enough insulin, glucose cannot be removed from the blood resulting in hyperglycaemia (high blood glucose levels). In the absence of being able to access the energy from food due to a lack of insulin, the body then burns fat and tissue for fuel, resulting in rapid weight loss. This is the physiological process of diabulimia which is initiated when individuals restrict their insulin. However, if insulin is not administered, individuals will develop Diabetic Ketoacidosis (DKA), a life-threatening condition which can lead to multiple organ failure, coma, or death.

2.2.4. Psychological and social implications

The diagnoses of a chronic or life-threatening condition can impact many areas of an individual's life. Allan (2019) notes that T1DM is "disadvantageous in a multitude of ways" (p.30), citing how the condition can restrict access to particular careers such as those in the military (Choi & Cucura, 2018) and emergency services (Nafees et al., 2006; Ruston et al., 2013). Varying glucose levels have also been proposed to impact an individual's ability to concentrate, which may result in fewer professional opportunities and lower educational attainment (Balfe et al., 2013; Dahlquist & Källén, 2007).

Social relationships also appear to be affected by T1DM. Individuals with T1DM report low feelings of self-worth and high feelings of alienation and embarrassment towards their diabetes (Pera, 2011; Ridge et al., 2012). Likewise, Ritholz et al. (2014) note that T1DM increases feelings of estrangement from those without the condition. It seems then that because of T1DM an individual's way of being with others can be affected. For some, the cumulative effect of feeling isolated and different results in feelings of low mood (Ridge et al., 2012). A finding supported by Das-Munshi et al. (2007), who reported higher rates of anxiety and depression in individuals with T1DM in comparison to controls. However, despite the social implications and psychological difficulties suggested to be more prevalent in those with T1DM, one feature seems particularly prominent. It is estimated that by the age of 25, up to 60% of females with T1DM will have experienced an Eating Disorder (ED) (Colton et al., 2015). A discussion of the relationship between T1DM and EDs is offered in the following section.

2.3. Type 1 Diabetes and Eating Disorders (T1ED)

The following section explores the proposed prevalence of EDs in T1DM, whilst also addressing the difficulties in measuring this relationship. Within the literature, there appears to be a consensus that EDs are more prevalent in individuals with T1DM, with females with T1DM close to 2.5 times more likely to develop an ED than their non-diabetic peers (Coleman & Caswell, 2020; Goebel-Fabbri, 2017; Jones et al., 2000). For men, it was initially proposed that EDs were not more prevalent in those with T1DM (Rodin et al., 1991). However, this view is changing as Doyle et al. (2017), and before this Markowitz et al. (2009), note that up to 25% of their male participants had deliberately induced hyperglycaemia by not attending to rising glucose levels. Yet despite these high percentages, measuring the prevalence of EDs in individuals with T1DM has been problematic.

In 2002, Nielsen conducted a systematic review of the prevalence of EDs in individuals with T1DM. Through analysing studies that used interviews alongside self-reporting measures between 1986-2000, Nielsen made several conclusions. First, anorexia nervosa was not more prevalent in those with T1DM. Secondly, bulimia nervosa carried a threefold risk of occurrence, and thirdly, insulin restriction appeared directly connected to weight loss, yet there was a lack of research investigating this relationship. Mannucci et al. carried out a similar analysis in 2005, but only included eight papers in the analysis and excluded articles which included males (Allan, 2019). Mannucci et al. (2005) supported Nielsen's (2002) findings by concluding that bulimia nervosa had a higher prevalence in individuals with T1DM when compared to non T1DM controls. However, the review by Mannucci et al. (2005) has limitations. Firstly, the findings are restricted to the eight papers reviewed, meaning that results cannot be generalised or broader assumptions made, and secondly the role of insulin restriction is not included in the review despite Nielsen previously highlighting its importance when investigating EDs and T1DM. Taken together, Nielsen (2002) and Mannucci et al. (2005) offer an insight into the early reviews of studying EDs and T1DM. However, it took over a decade before an updated review of the relationship between EDs and T1DM to be published.

Allan (2019) conducted the most extensive systematic review to date on T1EDs. The review included 60 papers which spanned 16 countries. Of the 60 studies included, the majority focused on women, with only one paper focusing exclusively on males. This is concerning as more males are reporting higher levels of insulin omission in recent years (Doyle et al., 2017). The majority of the research came from America and Canada, with the UK only producing three articles included in the review. Sample sizes were typically less than 30 participants meaning the findings were not suitable for population assumptions. Furthermore, most participants were young adults and adolescents, which is notable given that EDs can reportedly appear later in life in individuals with T1DM (Goebel-Fabbri et al., 2011). Overall, the review concluded the current literature on T1EDs as "messy" (Allan, 2019, p.97) and noted little consensus on diagnosis, prevalence, and measurements. The latter point was the focus of an earlier systematic review by Young et al. (2013).

Young at al. (2013) stated that commonly used measures of eating difficulties, such as the Eating Disorder Inventory or the Eating Attitudes Test, may inflate the prevalence of eating problems in those with T1DM. In managing their T1DM individuals may spend more time thinking about food, reduce the intake of certain food groups, and eat when they are not hungry, meaning they may score highly on such items. To address specific diabetes-related factors within the context of EDs the Diabetes Eating Problem Survey (DEPS) was published in 2001 and revised in 2009 by Markowitz et al. (2009). However, whilst the survey includes diabetes-related factors, it does not allow an individual to express their subjectivity, nor does it provide insight of how to develop a treatment plan or think about recovery (Wisting et al., 2013). Thus, individuals with T1DM do not appear to be adequately catered for within the current research paradigm, which draws upon standardised models and questionnaires and leaves little room for a person's subjectivity and individuality. Having introduced the relationship between T1DM and EDs in this section, what follows is an exploration into why individuals with T1DM may be at a higher risk of developing an ED.

2.4. Aetiology of eating disorders in T1DM

T1DM is linked to various ED risk factors such as depression, anxiety, self-esteem, and perfectionism, in addition to specific diabetes elements such as diabetes management and stress which can then lead to family conflict (Goebel-Fabbri, 2017; Rodin et al., 2002). Given the expanse of the ED field, the current review focuses on how contemporary ED literature is relevant to the lives of those with T1DM. Treasure (2003; 2007; 2013) attends to the field of EDs outside the context of T1DM.

2.4.1. Depression and anxiety

A significant amount of literature notes the relationship between depression and anxiety in relation to the onset of EDs, connections which were highlighted by Kaye et al. (2004), along with Lewinsohn et al. (2000) and Grigsby et al. (2002). Several researchers have further argued that depression results in body dissatisfaction which can then give rise to ED behaviours (Brechan & Kvalem, 2015). This was also noted by De Groot, Golden and Wagner (2016), Gendelman et al. (2009), along with Grigsby et al. (2002). Furthermore, feelings of depression in individuals with T1DM are reported to lead to a decrease in self-care, diabetes management, and blood sugar control (Barnard, Skinner & Peveler, 2006; Maia et al., 2014). In contrast, Takii et al. (2008) cautioned that the links between anxiety, depression and T1DM require further research. Whilst Strandberg et al. (2014) and Bächle et al. (2015) stated that higher levels of depression and anxiety do not predict poorer T1DM management. Consequently, the literature offers several different perspectives and explanations when exploring the use of insulin for weight control. As well as depression and anxiety the literature also attends to the role of self-esteem in T1EDs.

2.4.2. Self-esteem

Self-esteem, according to Hewitt (2009), broadly relates to how much value and worth an individual finds in themselves. A characteristic, which noted by Mora et al. (2017) has become a significant concern for the development of EDs across individuals with and without T1DM. Nonetheless, Powers et al. (2012; 2013) and Vlachioti et al. (2010) claim that there is no difference in self-esteem between individuals with or without T1DM. These studies differ markedly from the results which appeared in the longitudinal studies and cross-sectional research by Luyckx and Seiffe-Krenke, (2009) and Zoffmann et al. (2014) who reported lower levels of self-esteem in women with T1DM compared to their non-diabetic counterparts.

The relationship between men restricting insulin for weight loss and self-esteem was not replicated in the literature, highlighting potential gender differences amongst those with T1DM and gaps in our current understanding on the role of gender in T1EDs (Rassart et al., 2014). Allan (2019) further states that a woman's weight and shape and the way she presents herself can be considered a "clinical red flag" (p.126) which becomes vital for noticing any emergent difficulties. However, another element related to self-esteem questions how self-esteem is attended to by practitioners. An important concept as the presence of low self-esteem appears to impact upon the ability to recover from an ED, as illustrated by La Mela et al. (2013). Self-esteem also appears to be influenced by perfectionism, which will be discussed in the following section.

2.4.3. Perfectionism

Fairburn, Cooper and Shafran's (2003) study highlighted how perfectionism is prevalent within EDs whereby individuals often pursue personal goals whilst being highly self-critical (Burns, 1990; Forbush et al., 2007; Rivière & Douilliez, 2017). In terms of gender, women are viewed as having higher perfectionistic tendencies than men as claimed by Downey et al., (2015) along with Shanmugam and Davis (2015). However, due to a lack of research, we cannot be confident about the role of gender between perfectionism and EDs in individuals with T1DM.

The literature positions perfectionism as a risk factor for the development of EDs in individuals with T1DM (Treasure et al., 2015), however, there is a growing body of research exploring whether the nature of T1DM inherently encourages perfectionistic tendencies which inevitably places individuals at risk of developing an ED. Young-Hyman and Davis (2010) as well as Goebel-Fabbri (2017), state that the perfectionist tendencies emerging in those with T1ED are primarily the result of interventions intended to help with T1DM management. Management strategies based upon continuous counting, checking, and keeping track of numbers, means the mind and body are reduced to mechanisms where the individual consciousness becomes lost. The forms of interaction based upon target setting and reaching milestones can lack compassion, which is viewed as one of the ways of generating recovery (Goebel-Fabbri, 2017). Perfectionism, then, is seemingly reinforced by the ways in which healthcare professionals offer support and try to reduce the impact of T1DM. As noted by Goebel-Fabbri (2017), the process of not being heard can lead to individuals "giving up" (p.21) and viewing themselves as failures which then impacts their self-esteem. This raises significant concerns around the implementation of interventions that do not engage with the subjectivity of individuals with T1DM.

2.5. Diabetes-specific risk factors

As outlined, there are links between T1DM and various researched ED risk factors. However, there are also specific diabetes factors which may contribute to the aetiology of T1ED. In this way, T1ED can be considered a unique field which is explored further below.

2.5.1. Receiving a diagnosis of T1DM

Prior to being diagnosed with T1DM, individuals may lose a significant amount of weight as the body burns fat and muscle for energy. The lost weight is typically regained when individuals receive insulin through pumps or injections. However, the reintroduction of insulin back into the body can also lead to water retention. Although the fluid retention is temporary, it is reported to be a frightening experience and one which can provoke a return to T1ED behaviours or contribute to its development by impacting on individual’s physical and mental wellbeing (Goebel-Fabbri, 2017).

The sudden regaining of weight through insulin treatment and water retention may inadvertently promote a fear of insulin which in turn can lead to ED behaviours (Goebel-Fabbri et al., 2008; Olmsted et al., 2008). Staite et al. (2018) strengthened this argument by noting that individuals associated taking insulin with injecting fat or lard when qualitatively analysing 11 blogs authored by people with T1DM. Similarity, Brookes’s (2016) discursive construction of diabulimia further revealed how insulin was named the “fat-storage hormone” (p.207). Staite et al., (2018) and Brookes (2016) show that taking insulin is not necessarily seen as beneficial to an individual’s health as it can be linked to weight gain, which is subsequently related to the psychology of each individual and the broader worlds they inhabit. Thus, the insulin treatment and individual’s relationship towards their insulin both present as risk factors to the development of T1ED. Individuals with T1DM are also required to attend to their diet. The way in which this may influence the development of T1ED is explored in the following section.

2.5.2. Dietary management in T1DM

Research has proposed that the attention on food inherent in the management of T1DM contributes to the development of T1ED (Criego, Crow & Goebel-Fabbri., 2009; Goebel-Fabbri et al., 2008; Nash & Skinner, 2005; Tse at al., 2012). Daneman et al. (2002) reported how focusing on food portions can reinforce and replicate rigid thinking about food, weight, and body image often reported in individuals with ED who do not have T1DM.

Goebel-Fabbri stated that the educational approach to food within T1DM is often “restrictive and depriving – akin to a rigid diet” (2017, p.21). In addition, Powers et al. (2012) wrote that the act of attending to hypoglycaemia, can be counterproductive and encourage insulin restriction, as hypoglycaemia can lead to individuals overeating, binging, and subsequently gaining weight. Furthermore, the stress of managing T1DM, fear of hypoglycaemia and anticipated stigma around injecting insulin and testing glucose levels (Goebel-Fabbri, 2008; Ismail & Treasure, 2010; Polonsky, 1999) were also identified as risk factors for the development of T1ED. As a result, individuals diagnosed with T1DM often experience resentment and denial of the condition and seek support from their family and friends (Ismail & Treasure, 2010).

2.5.3. The role of family and friends

A diagnosis of T1DM can be a significant family event (Allan, 2019). Blicke et al. (2015) highlighted that age-appropriate parental support, along with warmth, promotes healthy diabetes care whereby insulin is taken as required. Comparatively, conflict and restrictiveness may produce disagreements between parents and their child, which can lead to lower treatment adherence and blood glucose control (Grylli et al., 2010; Hawthorne et al., 2011; Hilliard et al., 2011). Another aspect which appears to shape an individual's eating habits is parental eating attitudes, most significantly the mother-daughter relationship and the mother's attitude to weight and shape (Colton et al., 2009; Daneman et al., 2012; Dickens & Ogden, 2014). The mother's perspective is also influenced by her upbringing and various cultural and societal pressures which in turn can influence her daughter's relationship towards insulin (Quick et al., 2012). Developmental milestones also appeared to influence the family system. Gress (2010) and Weaver (2012), stated that when adolescence or young adulthood is reached, individuals with T1DM may attempt to regulate their body weight and shape through their insulin, as a way of asserting their individuality, independence and control.

Alongside the family are peer groups where ruptures within friendship networks can generate an emotional loss. Peveler and Fairburn (1989) explained that in these instances, insulin restriction becomes a way of regulating and compensating for these feelings. Furthermore, individuals with T1DM are not immune to societal pressures with multiple researchers suggesting that cultural and societal issues regarding body composition are influential in the development of EDs and the use of insulin for weight control (Bulik, 2002; Kaminsky et al., 2013; Meltzer et al., 2001; Nielsen & Mølbak, 1998; Ogden et al., 2020; Pinar, 2005). As can be seen, several perspectives can be drawn upon to explain possible causes of diabulimia, but what is also important is how these perspectives can assist in generating recovery. This wondering has led to the development of treatment and theoretical models aiming to facilitate recovery and understanding. The most recent of which will be explored below.

2.6. Theoretical models for T1ED

In 2015 Treasure et al. proposed a theoretical maintenance model for disordered eating in T1DM. The model emerged from adopting the transdiagnostic maintenance model coupled with the dual-pathway model, both commonly used by clinicians when working with people experiencing bulimia nervosa (see Fairburn et al., 2003; Peterson, Fisher & Young-Hyman, 2015; Stice et al., 1998). The basis of the model is that individuals with vulnerability factors such as those discussed in the previous section, for example, low self-esteem and perfectionistic traits may find the uncertainty of T1DM management particularly difficult. Such factors coupled with environmental influences, for example, expectations around weight and shape can increase the likelihood of using insulin for weight control. Individuals who restrict insulin for weight control may then experience neurological changes, whereby an addictive pattern for high sugar foods and a cycle of disinhibited eating develops (Treasure et al., 2015). Staite et al., (2018) also noted the addictive quality of diabulimia and recalled a participant stating, "I could only imagine [it] would compare to what heroin addicts find so addictive" (p.315).

Building on the role of the environmental influence in T1EDs as highlighted by Treasure et al. (2015), Goebel-Fabbri (2017) emphasised the need for a compassionate, trusting relationship when working with individuals who may struggle to accept the necessity of taking insulin or may not have the skills required for dose adjustments. To help build rapport both Treasure et al. (2015) and Goebel-Fabbri (2017) cite the effectiveness of motivational interviewing, in particular an emphasis on affirmation and avoiding conflict (Channon et al., 2007; Miller & Rollnick 2013).

The models proposed by Treasure et al. (2015) and Goebel-Fabbri (2017) provide a useful template to guide interventions and support for individuals with T1ED, whilst also representing a growing awareness and appreciation of the complexity's individuals at the intersection of T1DM and EDs face, however, they are not without limitations. The models seemingly leave little room for the personal, unique experience of the individual and may be at risk of reducing an individual's complexity into categories around vulnerability and maintenance. Thus, little is known about what it is like to experience diabulimia or more broadly T1ED, resulting in an area which is currently considered as being "chronically under-investigated" (Allan, 2019, p.176).

2.7. Diabulimia

Up to this point, the literature review has attended broadly to concepts of T1DM and T1EDs. Studies investigating the aetiology of T1EDs have been explored, and current theoretical models discussed and critiqued. From here, the focus of the literature review will narrow to diabulimia. The following section will begin by discussing prominent studies researching diabulimia from a qualitative perspective. From here, the review will present different views on the treatment of diabulimia which will also include T1EDs. After this, the identified gap in the literature will be named, along with the rationale and contribution of the proposed research.

2.7.1. Experiential perspectives of diabulimia

In 2018, Macdonald et al. explored the perspective of individuals living with diabulimia and the healthcare professionals working alongside them through thematic analysis. The overriding conclusion of the study was the need to adopt a model of care based on shared expertise across diabetes and mental health practitioners. Furthermore, psychological therapies should be specifically designed for individuals with diabulimia and T1EDs. Such findings are valuable in informing future interventions and research; however, the emphasis of the analysis appeared to focus on treatment and service provision. This was the case for both the individual with T1ED and the healthcare professional. As such, what it is like to experience the phenomenon across different areas of the individual's life, such as socially or psychologically, received less attention.

Staite et al., (2018) also drew upon thematic analysis to undertake a qualitative review of online blogs authored by individuals self-identifying as having diabulimia. This study explored the experiences, thoughts, and feelings of the participants but was restricted to what was already publicly available through the blogs. A potential issue with blogs is that they rely upon a performance of the self within a social space. In contrast, face to face interviews rest upon building a rapport along with trust, meaning that experiences have the potential to be analysed at a greater depth. This limitation also seemed to apply to Brookes's (2016) investigation of the discursive construction of diabulimia, also through online blogs.

Coleman and Caswell (2020) attempted to explore the views and experiences of individuals experiencing diabulimia through online questionnaires. The study concludes that to deliver effective psychological treatment, practitioners must understand the complex issues associated with diabulimia. Whilst Coleman and Caswell (2020) go some way in illuminating these issues, for example, participants fear of weight gain, collecting data via questionnaires presents as a limitation. To illustrate, whilst online questionnaires may have improved the scope and accessibility of the study, the method arguably lacks depth. By comparison, interviewing from a phenomenological perspective would provide the participant space to tell their story in their own words whilst facilitating experiential depth and reflection in the moment. What is more, interviews allow for a degree of flexibility, meaning that areas can be expanded upon, whilst also attending to non-verbal communication.

2.7.2. Treatment pathways

One of the current challenges for clinicians or healthcare professionals working alongside individuals with diabulimia is that the treatment pathways are limited. Between 2017 and 2019, three systematic reviews exploring the treatment of EDs in T1DM were conducted (see Allan, 2019; Banting & Randle-Phillips, 2018; Clery et al., 2017). The following section utilises these systematic reviews to explore the current treatment pathways.

2.7.2.1. Inpatient support

Takii et al. (2002; 2003) and Dickens et al. (2015) published three studies looking at treatment interventions for T1ED. The treatments were described as integrated inpatient programmes which consisted of weekly therapy sessions, family sessions, as well as regular nutritional, and psychiatric appointments. Overall, the studies suggest that the inpatient support had a positive impact on self-care, improving blood glucose levels and halting insulin restriction. A three-year follow-up revealed that 70% of individuals no longer met the criteria for any ED. Building on the findings of Takii et al. (2002; 2003), Bermudez et al. (2009) argued that individuals should not be admitted to facilities that are not equipped to cope with the unique demands of T1ED. Further, insulin dosing should be the responsibility of healthcare professionals on inpatient wards, and that weight gain is not a primary function of the treatment intervention, as the diabetes-specific aspects of inpatient treatment should be prioritised.

2.7.2.2. Outpatient support

In 2009 Goebel-Fabbri published a paper on the outpatient treatment of diabulimia highlighting the need for a multidisciplinary approach based upon building rapport and drawing on a humanistic value base. A position which seemingly aligns with CoP’s emphasis on the importance of the therapeutic relationship and the prioritisation of the individual’s personal and subjective account of their experiences (Larsson et al., 2012). Goebel-Fabbri’s (2009) finding arguably presents itself as a common strand which could be present throughout all forms of care and support for this cohort.

2.7.2.3. Psychoeducation

Olmsted et al. (2002) promotes the idea of psychoeducation as the provision of information about an illness or problem and strategies for changing or coping with it. This is a position based on the notion that knowledge increases the understanding of the individual and allows them to make informed choices. However, the effectiveness of psychoeducational interventions has been disputed. In 2001, Alloway et al. found that a psychoeducational intervention was no more effective at reducing insulin restriction than a waiting list (Clery et al., 2017).

2.7.2.4. Systemic interventions

Moving away from psychoeducation, Olmsted et al. (2002) reported that treatment programmes involving an individual's family had a positive impact on reducing diabulimia and T1ED behaviours. Both Takii et al. (2002; 2003) and Dickens et al. (2015) appeared to build on the finding of Olmsted et al. (2002), by incorporating family therapy and workshops into the treatment programmes. Unfortunately, the papers do not provide any further details on the systemic elements of their programmes, which subsequently limits the generalisability and replicability of the findings (Banting & Randle-Phillips, 2018). Given that previous literature has suggested family functioning plays a role in the maintenance, development, and recovery from T1ED (Blicke et al., 2015; Colton et al., 2009), further research exploring this element within the T1ED population seems vital as it could provide further insight into what is deemed successful care and support pathways.

2.7.2.5. Cognitive Behavioural Therapy and Motivational Enhancement Therapy

One of the significant clinical interventions undertaken by the National Health Service (NHS) is the use of Cognitive Behavioural Therapy (CBT). In a study by Custal et al. (2014), sixteen CBT sessions were offered to individuals with T1ED, but many did not attend for all sixteen sessions, and the eventual treatment outcomes appeared limited. A Canadian study by Colton et al. (2015) again highlighted concerns around treatment outcomes for individuals with T1ED who attended a structured CBT-based treatment programme. Ismail and Treasure (2010) explored the possibility of combining CBT and Motivational Enhancement Therapy (MET) to improve glycaemic control. They found that whilst there was a positive change in behaviour in that insulin was administered more regularly, the intervention did not appear to improve many elements of an individual's psychological or emotional wellbeing.

Although CBT is widely used in non-diabetic ED populations and is often considered the "treatment of choice" (Murphy et al., 2010, p.611), there appears to be a paradigm shift towards interventions and treatment pathways which are designed by both clinicians and individuals with lived experience of the difficulty hoped to be treated. Examples of such programmes within the field of T1ED in the UK are the STEADY project (Safe management of people with Type 1 diabetes and Eating Disorder StudY) (Kings College London, 2019), and the ComPASSION project (NHS Southern Health Foundation Trust, 2020).

Reporting on the ComPASSION pilot study, Partridge et al. (2020) stressed the need for a holistic approach to care, which means in practice building upon the lived experiences of those on a recovery journey. The project was able to recognise the importance of incorporating the strengths, values, and goals of each individual and viewing them as being embedded within a wider set of relationships. In a tone resonating with Goebel-Fabbri (2017), Partridge et al. (2020) commented that "building a trusting and respectful therapeutic relationship through a focus on engagement is key in assisting people with T1ED to feel able to talk openly about their experiences and consider making changes" (p.4). Tollow and Ogden (2019) stated that the relationship between individuals and clinicians is an integral part of any treatment process and that it has the power to influence an individual's care and support experience substantially. The crucial role of relationships and the need for a person-centred, and collaborative approach to caring for and supporting individuals is becoming increasingly prominent in the field of diabulimia and more broadly T1ED.

2.8. Naming the gap in the literature

The literature review has discussed multiple studies attending to diabulimia and T1ED. The literature exploring the development of T1ED described how T1DM is associated with several elements considered to be aetiological of EDs, whilst also naming those specific to T1DM.

My research builds on the paradigm shift outlined by Partridge et al., (2020) and Goebel-Fabbri (2017), as I will look at the lived experiences of individuals with T1DM using insulin for weight control. Banting and Randle-Phillips (2018) as well as Tollow and Ogden (2019) outline the need for a person-centred approach to diabulimia, whilst also stressing the importance of building rapport between individuals and healthcare professionals. As the paradigm shifts, undertaking research looking at the lived experiences from a phenomenological perspective becomes essential for building and developing insights into care and recovery.

It is perhaps surprising then that despite the growing awareness, appreciation and significance assigned to the individual's experience, to date no research has explored the lived experience of diabulimia by exclusively speaking to individuals with this experience in person. This omission represents a gap in the current literature and understanding of those involved in the field. It is this gap which my research intends to address. The following sections highlight the value of pursuing this line of research by naming the anticipated contributions. After which, the aims and specific research question of the study are provided.

2.9. Contribution and rationale

Cooper (2009) claims that the distinctiveness of CoP resides in the application of humanistic values residing in a core that connects to Buber's I-Thou relationship (1958), whereby individuals relate with their whole selves without objectifying the other (Amari, 2019). As highlighted, studies on diabulimia are moving towards the position of attending to the individual and their subjectivities. A movement which Counselling Psychologists (CoPs) are well-positioned to facilitate given the humanistic philosophical foundations and values of the profession (Kirk, Schneider & Pierson, 2015). As calls for multidisciplinary teams increase within the field of T1ED, it seems crucial to consider the value and presence of CoPs in such contexts.

Overlooking the lived experiences of individuals in therapeutic encounters or adopting the position that the therapist knows best, risks de-valuing and de-humanising the individual (Rogers, 2004). This is a position which Cooper & McLeod (2011) propose can be detrimental to the wellbeing of clients. Consequently, insufficient awareness amongst CoPs and other practitioners, around the experiences related to diabulimia may impact psychological work due to a lack of understanding or recognition of the difficultly. This is a position supported by Colton et al. (2015) and Pinhas-Hamiel and Levy-Shagra, (2013), who reported that individuals identifying with diabulimia do not feel accepted or taken seriously by healthcare professionals. In turn, this impacted the ability to establish relationships with healthcare professionals and eventually resulted in individuals disengaging from support services.

The exploration of the lived experience of diabulimia could also have contributions beyond the realm of CoP. To illustrate, the 2017 NICE guidelines on Eating Disorders Recognition and Treatment, suggest "addressing insulin misuse as part of any psychological treatment for eating disorders in people with diabetes" (p.24 section 1.8.5). Consequently, the research findings may help future revisions of NICE guidelines to expand upon and clarify this point by highlighting the desired aims, nature, and characteristics of psychological interventions for this cohort.

Another area to be considered is how best to assist healthcare professionals working alongside individuals using insulin for weight control. Macdonald et al. (2018) and Tierney et al. (2009) highlight the lack of training and support available for healthcare professionals in the field of T1ED. The findings of the proposed research, therefore, may contribute to future teaching and training programmes by helping healthcare professionals understand the intricacies of experiencing diabulimia, which in turn may influence the relationships between healthcare professionals and their clients. A relationship which Goebel-Fabbri (2017) highlighted was essential for change and recovery.

Beyond healthcare professionals, the findings of the study may also help educate families in supporting someone using insulin for weight control. Although this would require careful consideration when thinking about which elements of the family network are supportive, the research findings may act as a useful information point for families. This information may help develop supportive and communicative aspects of the family system.

To overlook the named research avenue stands to reinforce the sense of ostracism voiced by individuals identifying with diabulimia, as they would be denied an open and explorative space in which their lived experiences would be heard and valued (Allan, 2015). Without this space, individuals may continue to be signposted to various unsuitable services where they may lose hope and recovery may feel out of reach. Additionally, the provision of appropriate and tailored support pathways becomes increasingly important when considering the extremely high mortality rate of this demographic (Goebel-Fabbri et al., 2008; Shih, 2011).

2.10. Research question and aims

The overall aim of the study is to explore the lived experience of diabulimia. By examining the lived experience of individuals who restrict insulin for weight control, I hope to achieve the following objectives.

Firstly, to explore what it is like to use insulin for weight control. It is hoped that this exploration will provide a rich and detailed account of diabulimia and how it may feature across different areas of the participant's lives. Secondly, to explore the meaning of diabulimia for participants, and thirdly, to contribute to the literature on diabulimia by offering a phenomenological analysis of the lived experience.

On a broader level, the study also hopes to provide a voice to the participants who are currently underrepresented in the literature, whilst at the same time acting as a springboard for curiosity and encourage further research into the area. To fulfil these objectives, the study will ask: What is the lived experience of individuals with type 1 diabetes who use insulin for weight control?

2.11. Reflexivity (2)

From my childhood, I have memories of a large yellow box filled with Lego. My brother and I would tip all the pieces out onto the floor and revel in the Lego mountain. Together we would sort out which pieces we needed to build our imagined construction, holding onto those that felt most valuable and integral whilst setting aside those that were not.

The process of writing the literature review reminded me of these memories. The initial searches resulted in a literature mountain, which I was then tasked to review and sort. At times it was challenging to hold in mind the direction and parameters of the literature review. At first, I was tempted to include as much literature as possible and to categorise the literature into fixed categories, before realising that this was against the rationale of the research. To undertake this research requires an openness and letting go of certainty, whilst also acknowledging the need for a sense of order that is essential to structure any new insights that emerge from the research. In this way, the sections presented in the literature review provided a loose structure, within which various ideas were explored. The different sections symbolised the riverbank, whilst the numerous perspectives and studies discussed captured the flow of the river.

The impact of my subjectivity emerged as I reflected upon my use of research terms. Initially, I had searched with the language I was most aligned and comfortable with, namely diabulimia. Yet after reading the literature, I realised that alternative terms such as insulin restriction or insulin omission were being used to describe the same phenomenon. The widening of search terms and moving away from my linguistic natural standpoint subsequently resulted in the discovery of valuable and relevant literature. I am mindful of the reality that someone else may have presented a different review based on the same literature, similar to how the same Lego pieces can be used in multiple ways. Yet, this review resonates with my methodological outlook. It offers an exploration and critique of the literature available whilst also drawing on the phenomenological standpoint.

CHAPTER THREE

Methodology

3.1. Chapter overview

Th first part of this chapter will present the ontological and epistemological positions of the research, as well as the general study design, the chosen methodology and alternative methodologies that were considered. After this, the second section *Conducting the research* provides details of how the study was conducted including data collection and recruitment methods. Ethical considerations, and matters pertaining to quality and analytic stages of the research will also be discussed.

3.2. Ontology and epistemology

Ontology is the philosophical basis for undertaking research and is often concerned with the nature of reality and what there is to know (Blaikie, 1993; Crotty, 2015). It is rooted in the study of being and addresses the question: what is the form and nature of reality and what can be known about that reality? (Ponterotto, 2005).

I hold a critical realist ontology which is associated with the early work of Bhaskar (1979, 2008) and its application and elaboration within the social sciences through the writings of Archer (1995), Sayer (2010) and Collier (1994). This position states that the universe is a stratified and open system comprised of three layers of reality: the empirical (what we perceive to be the case through human sensory experiences and perceptions); the actual (events that occur in space and time, which may be different to what we perceive); and the real (underlying mechanisms that generate events) (Bhaskar, 2008). From this perspective, reality is multiply determined with no single mechanism determining events. Reality may have an objective existence, but our knowledge of it is conceptually mediated, meaning that knowledge is fallible to varying degrees and open to adjustment (Fletcher, 2012).

The ontological position of the research accepts that events do occur within an objective (intransitive) world. Yet, it recognises that knowledge is a subjective, discursively bound and continuously changing social construction (Vincent & O'Mahoney, 2016). Subsequently, the ontological position relates to the tradition of Heraclitus (2010) who proposed that reality was in constant flux illustrated in his statement; "a man cannot step into the same river twice, for fresh waters emerge around him" (p.14). The Heraclitan tradition identifies a critical reality (water) but also allows room for a phenomenological perspective because, although the man chooses to step into the river, the water changes in ways he seemingly cannot control.

It could be proposed that the different body of water and the man's experience of it aligns with the phenomenological position that an individual is always embedded in a context and interprets reality (phenomena) through the filter of their consciousness, which results in a unique experiencing of the self and the world, that is the water (Langdridge, 2007). Heraclitus's proposition that reality is in flux suggests some common ground with Sartre's (1963) notion of reality as outlined in *Search for a method* and Husserl's (1913) concept of eidos. For Husserl (1913) truth is related to the eidos or the essence of what underpins consciousness. At the same time, the eidos is always connected to the intentions of each individual and is therefore changeable. Truth and essence from this perspective and that of this research exists, but they are always in flux and transformative.

Continuing with the position that a relationship between a critical realist ontology and phenomenology is possible, I embrace a phenomenological epistemology whereby, epistemology attends to what it means to know. A phenomenological epistemology, like a critical realist ontology, emphasises that reality is not bound or constrained by positivistic conceptions (Budd, Hill & Shannon, 2010). In the field of research, Budd et al. (2010) posit that critical realism and phenomenological epistemology align through insisting upon inquiry in an open-world. This ontological and epistemological combination allows me as a researcher to explore the subjective experience of individuals who use insulin for weight control within the objective reality of T1DM. My research aims to explore, rather than, to discover what is going on. I seek to generate knowledge about the quality and texture of the experiences whilst acknowledging the critical realist and phenomenological positions that a certain amount of interpretation is required to further the understanding of the named phenomenon. Furthermore, the idiographic commitment of the research highlights the phenomenological perspective of human individuality, as it recognises that diabulimia may be experienced differently by each participant (Young, 2019). In the same way that each person stepping into the changing waters of Heraclitus's river will have their own unique subjective experience.

3.3. Positioning counselling psychology

Counselling psychology in the UK is a discipline grounded in humanistic values, with influences from American CoP and European psychotherapy (Strawbridge & Woolfe, 2010). It owes much to humanistic and existential thinkers such as Maslow, Rogers, Fromm and May who argued the need to ground the practice of psychology in humanistic values (Strawbridge & Woolfe, 2010). These values stress the importance of prioritising the clients' subjective and intersubjective experience, whilst also emphasising the presence of individual choice and responsibility. The application of these values led Cooper (2009) to describe CoP as ethics-in-action whereby practitioners commit to conceptualising and engaging with individuals in a valuing and respectful way. Subsequently, individuals cannot be reduced to components and exist relationally (Orlans & van Scoyoc, 2008).

Counselling psychology values plurality in both therapeutic practice and research by adopting and acknowledging diverse therapeutic models, research methodologies and varying ontological and epistemological positions (Kasket & Gil-Rodriguez, 2011; Nielsen & Nicholas, 2016). By adhering to the scientist-practitioner model of professional practice, CoP acknowledges the role of the practitioner as producer and user of theoretical and research knowledge (Kasket, 2016). Alongside the scientist-practitioner foundation, the reflective practitioner model as conceptualised by Schon (1983) has provided CoPs with the means to develop their self-awareness concerning their role as practitioners, their values and beliefs, and how these can influence the individual on a personal and professional level (Lane & Corrie, 2006).

Counselling psychology’s caution against assuming one way of knowing relates well to the ontological and epistemological positions of my research, which values subjective experience and acknowledges that reality can only be imperfectly understood. Thus, knowledge and meaning are flexible entities and open to review (Parker, 1999). Within my research, all participants unite in their reality or given that is T1DM. Still, in line with the ethos of CoP, I do not intend to seek an objective truth, aiming instead to explore the subjective meaning-making and experiences of the participants. My participants are, in some way, influenced by their situational given of T1DM yet are ultimately free in how they respond to and make sense of it. As a result, my research is in line with the humanistic roots and values of CoP by considering the research participants as relationally embedded unique beings, while prioritising their subjective lived experience (Buber, 1958; Cooper, 2009).

3.4. Qualitative research

Kasket (2013) cautions against being method-led, and stresses that when considering research methodologies, the object of enquiry, the research question, should be considered first. Additionally, CoP’s commitment to methodological pluralism suggests that no form of research is better than any other, and thus no method of enquiry should be automatically rejected (Henton & Kasket, 2017). Given that this research aims to understand the lived experience of diabulimia there was a natural affinity towards qualitative methodologies. The research question was explorative and open and aligned with Willig's (2013) position that qualitative methodologies aim to produce detailed descriptions of experience that contain meaning.

The values of qualitative research and my ontological and epistemological foundations unite in considering observations as subjective, knowledge as contextual, phenomena as not being universal and believing that individuals have meaning in their lives (Kasket, 2013; Slife & Gantt, 1999). The nature of the research subsequently presented itself as a good fit within the realm of qualitative methodologies, which eventually led to IPA as the chosen methodology. Before elaborating on this decision-making process, the chapter will attend to the nature of phenomenology.

3.5. Phenomenology

Phenomenology can be defined as "the study that systematically describes how phenomena appear to our consciousness in the reality of our lived experiences" (Vos, 2018, p.38) and was primarily influenced by the writings of Husserl, Heidegger, Sartre, and Merleau-Ponty (Vos, 2018).

Husserl famously proposed that we should go back to things themselves, where the thing refers to the experiential content of consciousness, which is impeded by various obstacles such us our pre-existing categorisation system (Smith et al., 2009). Husserl's phenomenology involves stepping out of our everyday experience, the natural attitude, and adopting a phenomenological attitude by turning our gaze inwards towards our perception of objects. Without reflection, the natural attitude, is at risk of being embedded as a way of experiencing and understanding the world based upon a set of biases and assumptions. Husserl (1913) notes that the natural standpoint must be worked through via the phenomenological method so that we transcend what is merely being presented in appearance and move closer towards the essential qualities of an experience (Smith et al., 2009).

Husserl's phenomenology is intimately intertwined with the notion of intentionality, a concept first proposed by Scholasticism and later revived by Austrian philosopher Brentano (1995) in his book *Psychology from an empirical standpoint,* wherein he states that all mental phenomena hold the principle quality of being intentional. When we are conscious, we are conscious *of* something, when we are seeing, it is a seeing *of* something when we are remembering, it is a remembering *of* something, and so forth (Crotty, 2015; Smith et al., 2009). Brentano’s notion of intentionality claimed that when an individual experiences an object on a perceptual level, the object always exists (Moustakas, 1990; 1994). However, although aligning with Brentano in that the mind is directed *towards* something, Husserl differed slightly by stating that an object may exist not only in reality but may also be imaginary.

3.6. The phenomenological method

Four aspects are often identified in the phenomenological method developed by Husserl (1913). First, epoché, the act of suspending one's judgments and beliefs, also referred to as bracketing. Secondly, description, the act of careful examination over explanation. Thirdly, horizontalization, whereby all elements of experience are treated equally, without imposing a hierarchy of importance, and finally, verification, whereby any analysis is taken back to the text to ensure it makes sense in the context (Langdrige, 2017). Together the four aspects aim to identify the core structures and features of human experience.

From Husserl's position, hierarchies and similarities may emerge within and across individual narratives. Yet, for hierarchies of significance to arise, we must consider the consequences of our natural attitude and bracket or set aside the taken-for-granted world (Smith et al., 2009). Through reflection, we can become aware of our natural attitude and preconceived ideas, specifically what they mean to us and how they influence the way we habitually understand the world (van Deurzen & Adams, 2011). Bracketing is not about dissolving the external world nor trying to fully part with our assumptions about the world, as arguably this is not possible. Instead, it involves taking a critical attitude to what appears to be the norm and wondering how this came to be (Husserl, 2012). Hierarchies of importance will emerge naturally and will be attended to as patterns of experience as opposed to truths, meaning that the essential qualities of experience will arise through a dynamic journey of reflection and comprehension (Langdridge, 2007).

When progressing with the phenomenological method, the concept of horizontalization ensures that hierarchies of meaning are avoided. Additionally, verification acts as an essential concept to ensure individuals keep returning to the presented realities (Spinelli, 2005). Within the method, individuals use intuition and grasp of what is real to return to what is being observed and described. In short, it is an ongoing process of moving from our biases and assumptions to intuition through continuing epoché and reflection (Husserl, 2012; van Deurzen & Adams, 2011).

Heidegger, Merleau-Ponty and Sartre developed Husserl's phenomenological foundations further by perceiving individuals as embedded and immersed in a world of objects and relationships, language and culture, projects, and concerns (Larkin, 2006; Smith et al., 2009). The presence of Heidegger, Merleau-Ponty and Sartre within the research is discussed below, along with the theoretical foundations of, and decision to use IPA.

3.7. Interpretative Phenomenological Analysis

IPA is an interpretative phenomenological method that embraces the phenomenological contributions of Husserl, Heidegger, Merleau-Ponty and Sartre to understand individuals as relational embodied beings (Smith et al., 2009). Heidegger moves away from Husserl's pure phenomenology by proposing a phenomenology which is hermeneutic, existential, and interpretive.

According to Heidegger (1978), individuals are thrown into a pre-existing world of people, language, and objects. We are all people-in-context, an essence which Heidegger termed Dasein which translates as there-being or also being-in-the-world, which emphasises his position that people are contextual and relational (Husserl, 2012). The concept of intersubjectivity is central to Heidegger's phenomenology, as it is intersubjectivity which aims to describe this relatedness and to account for our ability and attempts to communicate with and understand each other (Smith et al., 2009).

According to Heidegger, our engagement with the world is always through interpretation, such that Heidegger was concerned with the way things appear. Appearance for Heidegger has a dual quality, as things can have both visible meanings as well as concealed or hidden meanings (Smith et al., 2009). Subsequently, phenomenology is concerned with examining something which may be disguised as it presents itself. However, Heidegger (1962) stresses that interpretation is inevitably intertwined with our fore conception, as we cannot help but interact with new material in the light of our previous experiences. A point echoed by Sartre (1956) and his position that reality is both unknowable and uncapturable in any essentialist and absolutist sense. For Sartre (1956), individuals are caught up in the world and always becoming. Projects, to Sartre, are how the ‘self' remains grounded and are motived by a desire of being, lying within the individual's consciousnesses. Subsequently, the 'self' is not a pre-existing unity to be discovered, instead an ongoing project to be unfolded which is informed by its surrounding environment.

Whilst Heidegger and Sartre emphasised the worldliness of human existence, Merleau-Ponty (1962) described the embodied nature of our relationship to the world and how this informs our situated perspective. In *Phenomenology of perception*, Merleau-Ponty states; "the body is no longer conceived as an object in the world, but as our means of communication with it" (1962, p.106). Subsequently, the body provides individuals with a point of view on the world, and the means of participating in the world, as well as a place for others to view and interact with them. By defining the contours of existence and creating a platform of interaction, the body can be considered like a riverbed as, without it, there would be no river nor individual.

3.7.1. Idiographic and Hermeneutic contributions

Two further influences on upon IPA are idiography and hermeneutics. Idiography is the commitment to a detailed, nuanced analysis of a particular instance of lived experience, whilst hermeneutics refers to the theory of interpretations. As discussed, Heidegger positions himself as a hermeneutic phenomenologist by stressing that our access to things is always via interpretation. In a similar tone, Gadamer (1996) acknowledges the relationship between interpretation and preconceptions but goes a step further by stating that our understanding is both enabled and limited by not only our fore-conception but also our horizons as all knowledge is contextually based. For Gadamer, mutual understanding is achieved through the fusion of horizons in which individuals acknowledge the properties of their worldviews (1996).

Building upon Gadamer's position, Ricoeur (1970) proposed a dialectical relationship between suspicious and empathic interpretation. The former refers to an attempt to reveal a hidden truth by going beneath the surface to establish what is 'really' going on, thus generating explanations through suspicion. While the latter captures the researchers attempt to get as close to the participant's experience as possible and try to understand it from within, thus generating knowledge through empathy (Willig, 2013). Negotiating these elements is something which Smith et al., (2009) propose can be achieved by adopting a centre-ground, position. Integrating this position into the research requires an attempt to understand, whilst also acknowledging IPA's double hermeneutic.

Within the research, I am making sense of the participants sense-making, within the experiential context of using insulin for weight control. In this way I am both like and unlike the participant, as similarly I draw upon my human resources to make sense of the world, yet I only have access to the experience through what the participant reports. In this way, the participant's sense-making is considered first-order, whilst mine as researcher is second order (Larkin et al., 2006). Subsequently, the participants and I engage in a collaborative exploration to articulate the experience and meaning of using insulin for weight control (Spinelli, 2005).

3.8. Alternative methodologies

Before deciding on IPA alternative methodologies were considered, namely, thematic analysis, descriptive phenomenology, grounded theory, foucauldian discourse analysis and narrative analysis. The following section discusses why IPA was considered the most suitable methodology for the proposed research.

3.8.1. Thematic analysis

Braun and Clarke (2006) propose that the main benefit of thematic analysis is its flexibility, as it is not tied to a particular theory or epistemology, and therefore has the advantage of being applicable across a range of theoretical and epistemological approaches (Braun & Clarke, 2006; Norwell et al., 2017). Although to some, this theoretical freedom may present as empowering, for me, it evoked an element of concern. In choosing thematic analysis, I would be alone in navigating the philosophical and epistemological pillars of my research with little guidance on how to do so. Additionally, the literature varies in its conception of thematic analysis with some positioning it as a tool or skill as opposed to a specific method (Boyatzis, 1998; Ryan & Bernard, 2000).

Although thematic analysis recognises the importance of reflexivity, it does not appear to discuss in detail, the intricacies of interpretation and the hermeneutic aspects of unravelling meaning and the ongoing process of sense-making (Braun & Clarke, 2006). Consequently, I did not feel confident that thematic analysis would attend to my research question in as much depth, rigour, or complexity as IPA. Nor would it place as much weight behind the acknowledgement and reflection on the researcher's natural attitude or the co-construction of knowledge between participant and researcher, elements which are fundamental to my phenomenological epistemology.

3.8.2. Grounded theory

Constructivist grounded theory often attends to matters of reflexivity and conceptualises the role of the researcher as someone who is actively constructing a particular understanding of the phenomenon under investigation (Charmaz, 2006). Subsequently, elements of a social constructivist grounded theory and my phenomenological epistemology appear to align. However, grounded theory aims to construct theories about the phenomenon in question by taking up a more conceptual explanatory position based on larger samples. In contrast, my research was concerned about the lived experience of individuals with T1DM using insulin for weight control. The aim was to produce a detailed and nuanced analysis of the lived experience, with an emphasis on the convergence and divergence between participants, as opposed to generating a theory. Additionally, a fundamental motivation for my research question was identifying the absence of literature and understanding regarding the lived experience of diabulimia. As such, it felt necessary to remain close to the motivation and aim of the research. Generating a theory around the use of insulin for weight control would be a valuable area of future research, however, for the research aim and question to hand, grounded theory was not considered suitable at this time.

3.8.3. Descriptive phenomenology

Descriptive phenomenology, like IPA, is a method rooted in a phenomenological epistemology. However, Giorgi's (1992; 2012) descriptive phenomenology attempts as close a translation of Husserl's phenomenological method as possible and seeks to reach the essence of an experience. To do so, descriptive phenomenology advocates the researcher to bracket all past knowledge and experience about the phenomenon under investigation, something which I do not feel is possible or desirable as it overlooks the co-constructed nature of knowledge and analysis. What is more, the proposed research makes room for the particular in that it welcomes convergences and divergences in individuals' experiences as opposed to pursuing the presence of a universal essence. For these reasons, descriptive phenomenology was not selected as the methodology.

3.8.4. Foucauldian discourse analysis and narrative analysis

Foucauldian discourse analysis was another consideration as both IPA and foucauldian discourse analysis appear concerned with how context is implicated in individual experiences. Yet whereas IPA focuses on an individual's involvement in the context, foucauldian discourse analysis offers a critical analysis of the context itself (Wilig, 2013). Foucauldian discourse analysis seeks to understand how discursive constructions and practises influence how individuals experience themselves and their world; however, this gives rise to tension with my phenomenological epistemology (Langdridge, 2004). From the phenomenological perspective, we do not think about or reflect on our experiences while we live them. Rather as soon as we reflect on a lived experience, the living moment has gone, meaning that we can only retrospectively try to recover the experience and then reflect on what the experience was like at that moment (van Manen, 2017; Young, 2019). The research aimed to understand my participants lived experience through their retrospective descriptions and reflections on the phenomena, it did not strive to know how their experiences were retrospectively constructed through language, thus foucauldian discourse analysis was discarded.

The final method to be considered was narrative analysis as it appears to have connections with IPA. IPA is concerned with meaning-making, and the construction of a narrative is seemingly one way of making meaning (Crossley, 2000; Reissman, 1993; Ricoeur, 1984). However, coming from a predominately social constructionist foundation, narrative analysis concerns itself with how people construct versions of reality including self-identity through the use of language as opposed to the quality of the experience itself (Hiles & Cermak, 2008). Whilst narrative analysis would allow for the diabulimia identity to be further understood and explored, thus making a useful contribution to the field. It would move the research away from its original question and aim and was subsequently not considered suitable for the current study.

3.9. Reflecting on IPA

Although IPA emerged as the most appropriate methodology for the proposed research based on the above discussion, it is not without its shortcomings. By seeking to understand the depth of participant's experiences, meanings and perception, IPA arguably makes a compromise between depth and width. Such that it not able to sufficiently comprehend or comment on the width of an individual's life namely, their interactional patterns, institutional affiliations, or cultural embedding, in addition to matters of power and discourse (Houston & Mullan-Jenson, 2011). This is an unfortunate deficit as it arguably restricts the interpretative potential of the method and risks an analysis shifting from the interpretive towards the descriptive (Houston & Mullan-Jenson, 2011).

Despite the shortcomings, IPA still presented as an accessible, flexible, and suitable approach to understand what it is like to use insulin as a means of weight control from the perspective of the participant who is trying to make sense of it. As a method, IPA stands to give voice to my participant demographic, who to date have had limited opportunities for their voices and experiences to be heard and recognised. In choosing IPA I acknowledge that that broad generalisation from the findings may not be possible. Yet, I align with the position of Reid et al., (2005) whereby commonalities across accounts and analytic commentary can lead to useful insights which have broader implications (Pringle et al., 2011). Subsequently, the dialogue resulting from IPA studies can contextualise the contribution of research to the more general literature, meaning that from gaining insight into an individual, insight into the whole can also be achieved (Pringle et al., 2011). In this respect, my research strived for theoretical transferability rather than empirical generalisability (Smith at al., 2009).

3.10. Conducting the research

3.10.1. Data collection

Semi-structured interviews and demographic questionnaires were chosen as methods of data collection. Semi-structured interviews enabled me to strike a balance between consistency and flexibility. While demographic data can help to situate the sample and enhance sensitivity to context, thereby adding a greater depth of meaning to the data (Yardley, 2000).

3.10.2. Interview schedule

The construction of the interview schedule was influenced by the phenomenological positions of Husserl (1913) and Heidegger (1978). In a tone similar to Husserl's (1913) reductive step, the first part of the interview consisted of a broad orientation statement. The rationale was to encourage the participants to remain close to their lived experience and sense-making of the phenomenon, whilst assisting me as the researcher to focus my attention on the subjective lived experience of the participant. As the interview progressed the aim was to go beyond the surface level of the phenomenon to the deeper and more concealed layers of experiencing. A process which Vos (2018) likens to unpeeling the phenomenological layers of experience, but without the assumption that there is a core essence to be discovered. To assist the revealing and attending to the phenomenon, prompts and follow up questions were used. These were non-directive and focused on clarification, explanation, observation (such as reflecting on non-verbal behaviour), and summarising to ensure I had accurately understood the participant. Empathic validation also featured through nodding, paraphrasing or verbal acknowledgments such as "mm," which stood to signify to the participants that what they had to say was being heard and valued, whilst gently encouraging them to continue with their narrative. The final interview schedule is located in appendix 2.

3.11. Participants

3.11.1. Sampling

Purposive sampling was used as the research prioritised gaining insight into the lived experience of a particular phenomenon. All participants were, therefore required to be individuals with T1DM who had the experience of restricting insulin for weight control.

3.11.2. Inclusion and exclusion criteria

The inclusion criteria stated that all participants needed to be over eighteen, living in the UK and fluent in English. Guided by the code of human research ethics (2014) and code of ethics and conduct (2018) published by the British Psychological Society (BPS), in particular the principle of *maximising benefit and minimising harm,* the inclusion criteria also required participants to feel well established in their insulin management for at least one year, which is line with previous research and inclusion recommendations when studying T1ED (see Allan, 2015; Macdonald et al., 2018), and have ongoing or previous contact with a service that offers psychological support.

The rationale was that in having ongoing or previous support of this kind, participants were more likely to have a history of processing, containing, making sense of, and managing their experiences. In turn, this reduces the possibility of participants reflecting on their experiences for the first time during the interview, which may cause higher levels of emotional distress and move the conversation away from a research frame and more towards a therapeutic one. Lastly, this criterion adds a level of support and safeguarding for participants who may feel they would benefit from more therapeutic work after the interview. They have established a relationship with services, which may facilitate the ease and speed at which they could return to psychological support should they choose. The counter side is that individuals who did not have a historical or current relationship with support services, who were not able to manage their insulin independently or who were currently in, or had been in residential treatment settings within the past year were unable to participate in the research.

3.11.3. Sample size

Given IPA's ideographic commitment and its emphasis on obtaining a detailed account of individual experience, IPA studies can benefit from a concentrated focus on smaller cases. Although there is no prescribed sample size for IPA studies, Smith et al., (2019) recommends between four and ten interviews for doctoral research. The sample size further depends on the accessibility to the participants, the richness of individual cases and any pragmatic restrictions the researcher is working under (Pietkiewicz & Smith, 2012).

Given that diabulimia is formally unrecognised and specialised support services and pathways are limited, it was anticipated that recruitment could be difficult. As a result of this, coupled with the privilege of a homogeneous sample within IPA it was expected that a participant pool between four and eight individuals would be most viable. The final number of participants was further influenced by the level of saturation achieved in the interviews. As the interviews progressed it became apparent that certain facets of the phenomenon were being repeated, whilst the emergence of new aspects decreased. At this point, a sample size of six appeared to have provided sufficient data for the development of meaningful points of similarity and difference between participants, and thus, recruitment ended.

3.11.4. Demographics

Given the ontological and epistemological stance of my research, meaning is always sensitive to context. The participants' backgrounds, therefore, stand to shape the meanings they attribute to their experience of using insulin for weight control (Holloway, 1989; Willig, 2013). Participants were asked to complete a demographic questionnaire before beginning the interview (appendix 3). The table below illustrates the participants' demographic information.

Table 1.1. Participant Demographic Information

Participant Number	1	2	3	4	5	6
Pseudonym	**Jen**	**David**	**Catherine**	**Peggy**	**Carly**	**Alex**
Gender	Female	Male	Female	Female	Female	Female
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian	Caucasian
Nationality	British	Welsh	British	British	British	British/Australian
Age (at interview)	38	40	34	25	26	38
Age of T1DM diagnosis	21	23	2	15	16	23
Age when first used insulin for weight control	21	25	19	16	17	23
Duration of using insulin for weight control	4 years	5 years	2 years	9years	8years	5 years
Interview duration (nearest minute)	1hr 06m	1hr 17m	1hr 15m	1hr 08m	1hr 36m	1hr 05m

3.12. Procedure

3.12.1. Recruitment

An online advert on callforparticipants.com was created, which is an online platform reaching individuals who have expressed a willingness to take part in academic research (see appendix 4). Once created the details of the study were shared on the social media platforms of Diabulimia Helpline and Diabetics with Eating Disorders (DWED), currently the only two charities in the UK and America specialising in T1ED.

I also contacted the organisers of the Diabetes and Eating Disorders Conference, organised by Bournemouth Diabetes and Endocrine Centre to ask permission to recruit for participants at the 2019 conference. Permission was granted, and on 4th July 2019, I set up a stand at the conference and spent the day sharing my research to those in attendance (appendix 5). Research flyers and a participant information sheet titled frequently asked questions were handed out for individuals interested in participating (appendix 6 & 7).

Following the conference, I was contacted by eleven individuals interested in participating. I did not hear back from two individuals after resending the information document, and one individual withdrew from the study two days before our arranged interview. A further two people were thanked for their interest, but they did not meet the inclusion criteria. The recruitment process lasted five months between June and October 2019. Five participants were recruited from the conference and one came via the online advert.

3.12.2. Initial contact

Individuals were all resent the frequently asked questions document. A telephone conversation was then arranged with those still interested, during which I provided information about the purpose of the study and what participation would involve. I ensured individuals met the inclusion criteria and answered any questions they had. Individuals were also made aware that they could contact my research supervisor, should they wish to speak to a third-party member about the research.

3.12.3. Interviews

The first participant to be interviewed represented the pilot interview, however it was explained that her data and interview may still be used in the research. After discussions with my supervisor, it was agreed that the pilot participant could be included as there were no significant changes that needed to be made to the interview schedule. My personal reflections from the pilot study were noted in my research journal (see appendix 8).

All interviews took place in person, with three taking place in private study rooms of local libraries, and three in hired meeting rooms within local centres. Arriving early to the interviews provided time for grounding and reflection. These practices helped me to focus on my experiencing in the present moment and were recorded in my research journal (see appendix 9).

Before the interview began, I asked participants to read the information sheet and the consent form and provided the opportunity to answer any questions. I reminded the participant of the limits of confidentiality (for example, if participants disclose that there is an imminent and severe risk of harm to themselves or others), and that they were able to pause, skip questions or terminate the interview at any point without reason or negative consequences. Once the participant verbally acknowledged they understood and agreed to these conditions, we signed two copies of the consent form, one for each of us to keep (appendix 10).

Participants were invited to read the interview schedule, but all declined. I explained that the interview would begin with a broad opening, followed by further questions. As a safeguarding measure, a distress protocol was put in place to help manage any emotional distress that may have emerged during the interview (appendix 11). The distress protocol was not utilised during any interviews and was adapted from a previously devised protocol by Cockling (2008) and Kasket (2009). One interview was paused so that a participant could attend to her decreasing glucose levels. Before resuming, I checked that she felt able and willing to do so.

As the interviews closed, the participants were thanked and invited to discuss their experience of being interviewed. All participants were verbally debriefed and given a list of support services whom they could contact, in addition to their past or current service, should they feel the need for additional support (appendix 12). All but one participant chose their pseudonym, and the conversation gradually returned to daily chat before we said our goodbyes. After the interview, I stayed behind and noted my initial reflections and experiences of the interview in my research journal (appendix 13). This practice also acted as a form of self-care by helping me to end and contain the interview experience before leaving the room.

All recordings and transcripts were stored on a password-protected computer and folder with all file names identifiable by participant number and pseudonym only. All potential identifiers within the transcripts and write-up were removed or changed. As the audio recording devices used were not password protected, the recordings were removed from the devices and transferred onto a password-protected laptop before leaving the interview location. My copies of the consent forms were stored in a personal locked cabinet at home.

3.13. Ethical considerations

Ethical approval for the research was granted by the Metanoia Research Ethics Committee in June 2019 and conformed to the code of human research ethics (2014) and code of ethics and conduct (2018) published by the BPS (see appendix 14 for ethical approval letter). As part of the approval process, a health and safety risk assessment was also completed (appendix 15). The research also complied with the legal requirements related to the storage and use of personal data as outlined in the Data Protection Act (1998), General Data Protection Regulation (2018) and other similar acts. Measures were implemented to ensure informed consent, participant anonymity and the personal safety of myself and participants across the stages of data collection and analysis (see section 3.12).

Throughout the research, sensitivity to the participant's' welfare took precedence. I anticipated negligible risks for the participants, as previous studies have noted that research interviews can be a positive experience as it allows individuals an opportunity to share their story in a welcoming and contained space (Vos, Craig, & Cooper, 2015). Nonetheless, I acknowledged that some individuals might find it challenging to reflect on their experiences. In the unlikely event that the research would cause distress to a participant, the protocol would be followed, which outlines numerous indicators of distress and appropriate interventions. Furthermore, all participants provided details of an emergency contact who would be contacted in the extreme event that the participant was considered to be in immediate danger. It was not necessary to contact any of the emergency contacts provided.

In terms of participant withdrawal, before or during the interview stage participants could withdraw from the study at any point without reason or negative consequences. After the interview, participants had six months from the date of our meeting to withdraw, or until the participant data had been aggregated into the analysis, depending on which event occurred first. After these points, the data could not be extracted from the research as it will be part of the overall themes and findings, whilst also presenting difficulties for me as the researcher to attempt to unknow something. With regards to my self-care throughout the research, my research supervisor, therapist, and research journal all provided spaces where I could explore and reflect on my processes. Additionally, my family, friends and partner also provided motivation and support, whilst regular exercise also helped regulate emotions and stress.

3.14. Transcription

Interviews were transcribed within a week of taking place. As IPA is primarily concerned with the content of an individual's narrative and their meaning-making of a phenomenon, a detailed transcription, including the length of pauses or all non-verbal communications for example, is not critical and a semantic transcription may suffice (Smith et al., 2009). In preparation for the analysis, dialogue references were included in the transcript, along with ample margins for ease of coding. Transcripts were initially organised into three columns as per the practical method outlined by Smith et al., (2009) descriptive comments, transcript, exploratory comments and emerging themes.

3.15. Reflexivity (3)

My phenomenological epistemology is evident in my research position which acknowledges that understandings are based upon our fore-understandings and pre-judgements, and without examination we run the risk of letting our unelucidated prejudices dominate research findings (Finlay & Gough, 2003). However, for a researcher holding a different epistemological or theoretical lens, the approach to the same field of research, could yield quite different findings. For example, a researcher adopting a feminist position within an existentialist lens may draw upon Simone de Beauvoir's text, *The Second Sex* (1997), as a way of illuminating the relationship between men and women. This position may influence a research avenue which enquires into the construction of myths created by man. One such myth from de Beauvoir's perspective is the ideal image of a woman, which may or may not then relate to the thinness ideal seemingly pursued by those using insulin for weight loss.

The influence of my subjectivity on the research process was further highlighted when formulating a research question. Early editions of my research question gave rise to biases and assumptions which to that point had remained out of my awareness and un-reflected. I became aware of my personal position towards the discussions around whether diabulimia should be officially recognised as a diagnosis, as well as a personal reaction towards those who use insulin for weight loss. An extract of my research journal (appendix 16) shares this reflexive process.

As the interviews progressed several participants disclosed their ongoing desire to be thin and the imagined successes that came with this body shape. It struck me that I was sitting opposite my participants as a slim young woman, and I questioned how this may have affected their interaction with me. What might this have brought up for them? Were they constructing a version of my reality based upon my physicality and academic position?

I also recall being met with a sense of not-knowing during the pilot interview with Jen. Although conceptually aware that I was there to find out about her experience, I noticed the re-emergence of a historic discomfort in relation to not-knowing. This is evident in my initial increased presence in the interview and tendency to reflect Jens narrative back to her or introduce new terms, as though to communicate my developing knowing and understanding. However, as the interview progressed, I contained this discomfort and reground myself into a phenomenological position of openness and curiosity. This was a valuable learning from the pilot interview which I was able to hold in mind for the reminder of Jen's interview and those of subsequent participants.

3.16. Analytic strategy

IPA does not prescribe a single way of working with data. Instead, it emphasises the need for analytic attention to be directed towards the participants attempts at making sense of their experiences (Smith et al., 2009). Subsequently, IPA can be characterised by a set of conventional processes within which there is flexibility. I used the analytic steps outlined by

Smith et al., (2009) and Gee (2011) to guide the analysis, as they are considered to encapsulate many of the processes, principles and strategies typically employed by IPA researchers (Reid et al., 2005). In viewing the analytic steps phenomenologically, they presented as useful analytic contact points to ensure researcher immersion as opposed to a fixed and manualised approach. How I approached the analysis is outlined below.

3.16.1. Reading and re-reading

I sought to re-familiarise and immerse myself in the original data. I read the transcript multiple times and listened to the audio recording simultaneously during the first reading. By engaging with the data in a slow and thorough manner, I increased my awareness of the overall structure of the interview, including changes or patterns in the participant's narrative. My initial observations and responses were also noted in my research journal, for example, a self-critical narrative that emerged for me whilst transcribing the interviews (see appendix 17). This acknowledgement and containment of my responses helped me to remain fully immersed with the data.

3.16.2. Initial coding

I aimed to keep an open mind and produce a comprehensive and detailed set of notes and comments on the data. In line with Smith et al., (2009) and Gee's (2011) recommendations, I noted descriptive, linguistic, and conceptual comments in the right-hand column in different colours (appendix 18). Descriptive comments focusing on the content were made in blue, linguistic comments attending to the participants use of language, for example, repetition and metaphor were made in red, and conceptual comments which focused on engaging with the data at a more interrogative and conceptual level were made in green (appendix 18).

3.16.3. Emerging themes

Looking for emergent themes represented an analytic shift whereby I worked primarily with my provisional notes and codes rather than the transcript itself. Emerging themes were identified chronologically in a separate right-hand column and marked in purple (appendix 18). Themes stayed close to the original transcript and attempted to map interrelationships, connections, and patterns between exploratory comments (Smith et al., 2009).

3.16.4. Searching for connections across emerging themes

Emerging themes identified in the transcript were then transferred and listed in a separate document titled emerging themes table. Within each table, the theme number, name of the emerging theme, key text and corresponding transcript location was detailed in separate columns (see appendix 19). I began with a large number of emerging themes per transcript and attempted to cluster the emerging themes together to help facilitate the process of producing a structure which would allow me to capture and identify the most significant aspects of the participant's account.

To help look for patterns and connections between emergent themes I made use of Smith et al. 's (2009) techniques of abstraction (putting like with like and generating a new name for the cluster), subsumption (where an emerging theme becomes a super-ordinate theme by bringing together other related themes), polarisation (searching for differences between themes rather than similarities), contextualisation (identifying the contextual and narrative elements within the analysis), numeration (accounting for the frequency with which a theme is supported) and function (examining a theme's specific function in the transcript). Themes were discarded at this stage if they were too vague or if other themes better captured the participant's description.

Once I was comfortable that my theme clusters best appeared to represent the meanings within the participant's account, I complied a graphic representation of them (see appendix 20). Under each super-ordinate theme, supporting themes were listed and annotated with a brief participant quote and corresponding transcript location.

3.16.5. Moving to the next case

The processes described were repeated for each participant in chronological order. In line with IPA's idiographic commitment, I made every attempt to monitor and set aside ideas and reflections evoked by the analysis of previous transcripts, thus allowing for the development of new themes.

3.16.6. Patterns across participant cases

I conceptualised this part of the analysis like a jigsaw and lined up each participant's graphic representation of super-ordinate themes on the floor. Although themes varied amongst participants, commonalities aided the process of identifying connections as did the ongoing use application of abstraction, subsumption, and polarisation as previously described. This analytic process eventually resulted in an overall table of superordinate and subordinate themes for the group (see appendix 21). Themes were renamed as phrases which aimed to highlight the psychological nature of the theme, whilst containing enough particularly to be grounded and enough abstraction to the conception (Smith et al., 2009). Once this part of the analysis was complete, I started to writeup the findings. This helped keep momentum and allowed for the analysis to continue into the writing phase, meaning that as I started to write up a particular theme my interpretation of it could develop.

3.17. Reflexivity (4)

The peak of COVID-19 and my writing of the analysis coincided. On one hand I was attempting to enter the experiential worlds of the participants and immerse myself in their meaning-making, yet all external narratives were advocating distance from and the potential danger of getting too close to the other. This marked a notable tension where I was both trying to be close and distant to the other at the same time. Furthermore, I became concerned for the wellbeing of the participants as those with diabetes were considered a vulnerable population. This evoked an additional sense of responsibility and commitment towards my participants and the research.

As I moved deeper into the analysis, I found myself at risk of becoming overwhelmed with the volume of data and the number of emerging themes. Themes which appeared to be characterised by different elements, dimensions, polarities, antinomies, and contradictions. At the time I longed for a simple analytic route to present itself, yet upon reflection the experience of being overwhelmed and at times confused arguably paralleled my participants' process. Their sense making of diabulimia was complex, non-linear, and layered. Thus, my attempts at making sense of their sense making, if I were remaining true to the hermeneutic effort of IPA, would arguably mirror this process to a degree (Smith et al., 2009).

An important part of developing my understanding of the data was allowing my preconceptions to be challenged. The most significant of which was my assumption that individuals would be entirely positive in their movement away from using insulin as a means of weight control. Yet, the participants' reality was far more layered and complicated than anticipated. The duality of the relationship was captured in Alex's statement when she shared that diabulimia was *"great, I loved it. I loved it until I didn't, until it started killing me" (A3).*

3.18. Quality in qualitative research

Various sets of criteria, recommendations and guidelines have been developed to evaluate the quality of qualitative research (see Elliot, Fischer & Rennie, 1999; Finlay & Evans, 2009; Henwood & Pidgeon, 1992; Madill et al., 2000; Yardley, 2000, 2017).

The guidelines proposed by Yardley (2000, 2017) and Elliot et al. (1999) are of the most frequently used, and have been endorsed by Smith et al. (2009) in assessing quality within phenomenological research due to their sophisticated, pluralistic, and accessible stance. Due to the methodological and epistemological alignment with my research, I have elected to apply Yardley's (2000, 2017) criteria to the study, which also overlap with the guidelines proposed by Elliot et al. (1999), to establish the quality, trustworthiness, and reliability of the research. Yardley's criteria names four core principles to qualitative research, *sensitivity to context; commitment and rigour, transparency and coherence,* and *impact and importance* (2000, 2017). The application and presence of each criterion within the current study is discussed below.

3.18.1. Sensitivity to context

The study demonstrates the fulfilment of Yardley's (2000) *sensitivity to context* as well as Elliot et al. (1999) *situating the sample and grounding in examples* guidelines in numerous ways. Firstly, there is the context of the theory addressed in the literature review. Here, the understanding based upon previous research, as well as current limitations to knowledge on the research topic was discussed. Secondly, the study provides a firm grounding in the philosophy of the approach adopted, phenomenology. Sensitivity to context was again demonstrated by sensitivity to the data itself in the context of data collection and analysis. For instance, within the interviews, I asked participants what specific terms, such as magic, meant to them as opposed to assuming a meaning.

During interviews, I was also aware of the presence of power and strived for a balance between participant and researcher. To support this aim, I reminded participants that they were the expert of their own experience. Additionally, I reflected and clarified my understanding of their narratives, and welcomed the participants to share anything about their experience that we had not covered during the interview that they felt was meaningful. The use of semi-structured interviews and my therapeutic skills facilitated this process by helping to construct an empathic, flexible, attuned and contained environment. Meetings took place at a time and location which was convenient to the participant. The consideration of ethical issues (see section 3.13.), the provision of primary demographic data, as well as using considerable extracts from the participants material to support the emerging interpretations within the analysis, all further support the position that the research has considered and remained grounded within the participant's perspectives.

3.18.2. Commitment and rigour

Commitment was demonstrated through prolonged engagement with the topic. Before researching the subject, I had experienced T1DM and EDs in friends and contacted two specialised charities (DWED and Diabulimia Helpline) to further my understanding of the complex combination. As a researcher, I read extensively around the research topic and IPA, whilst also attending numerous conferences addressing T1ED, such as *Diabetes and eating disorders: a complex combination* run by Bournemouth Diabetes and Endocrine Centre and Royal Bournemouth Hospital in July 2018 and 2019.

In February 2020, I presented the preliminary findings of my research at the international Diabulimia Helpline conference in San Diego. In addition, I sat on the panel *Debunking diabulimia* alongside healthcare professionals and individuals with previous lived experience. Furthermore, I am scheduled to speak at the next East Anglia Eating Disorder Network Annual Training Conference, which has been postponed at the time of writing due to the COVID-19 pandemic. Commitment is further shown by the degree of attentiveness to the participant during data collection and the care with which the analysis was carried out.

Rigour according to Yardley (2000) relates to the completeness of the data collection, analysis, and interpretation. To this point, the participants were recruited via purposive sampling to ensure participants all had experienced the named phenomenon within the inclusion and exclusion criteria outlined (see section 3.11.2). The sample aimed at homogeny in line with the principles of IPA research and could, therefore, be considered appropriate to the research question. The analysis demonstrates commitment and rigour by a lengthy contemplative and empathic exploration of the topic in a thorough and systematic way, as an attempt to transcend superficial and overly descriptive understandings (Yardley, 2000). Themes are supported with quotes from several participants, and participants accounts are drawn upon as evenly as possible.

3.18.3. Transparency and coherence

To attend to the element of coherence I asked myself questions suggested by Smith et al., (2009). Does my research present a coherent argument? Do themes come together logically and rationally? Are contradictions recognised and attended to? I believe the research has strength in a narrative and account, which is attentive, consistent, and accessible. I have also attempted to bring the participants experience to life through the writing and subsequently fulfil Elliot et al. (1999) aim of *resonating with readers*. Coherence is further demonstrated by the claim of the research in being an IPA study and the underlying theoretical assumptions, such that the research is consistent with the underlying principles of IPA as opposed to adhering to the expectations of a different qualitative approach (Smith et al., 2009).

Transparency as a principle is present throughout the research in various ways. Firstly, the stages of the research process have been detailed, from participant recruitment, the construction of the interview schedule and conducting the interviews. The analysis followed the steps suggested by Smith et al. (2009) and Gee (2011), with annotated transcripts, tables of themes, coding patterns at different stages of analysis, interview schedule and all participant materials used included as appendices. The inclusion of these materials would enable a reader to follow the progression of the research from the initial documentation and research proposal (appendix 22) through to the final report. This provides an additional element of strengthening the quality and trustworthiness of the data by acting as an independent audit as advocated by Smith et al. (2009), and Yin (1989), and meeting the guidelines of a credibility check as outlined by Elliot et al. (1999).

Reflexivity acts as another strand of transparency which has been interweaved throughout the research and aligns with Elliot et al. (1999) *owning one's perspective.* In line with my research foundations that our experience of the world is influenced by our assumptions, context, intentions, and actions, I have openly reflected on how my positioning in the world, such as my socio-cultural position and previous experience may have influenced the research. To aide self-reflection and reflexivity, a journal has been kept since the early stages of research conceptualisation. The journal acted as a space to name and reflect upon my feelings, thoughts, and responses throughout the research journey, extracts of which have been shared. At times, poetry featured in my journal as an additional reflective space (see appendix 23). Heidegger stated that “our existence is fundamentally poetic” (1949, p.283), as it can provide a clearing where being is illuminated. In this way, poetry supports phenomenology by acting as another form of the hermeneutic circle, which Caputo (1982) defines as a circling process between being and beings.

3.18.4. Impact and importance

This final principle echo’s Elliot et al. (1999) position of *accomplishing the research task* and *resonating with the reader*. It means that however well or sensitively a piece of research is conducted, the most decisive way it may be evaluated is concerning impact, utility, and usefulness. That is assessing the value of the study in relation to the objectives, the applications it was intended for and the community for whom the findings were deemed relevant (Yardley, 2000). To this end, the impact, importance, and usefulness of this study are considered in the *Discussion* (see section 5.7.5).

CHAPTER FOUR

Analysis

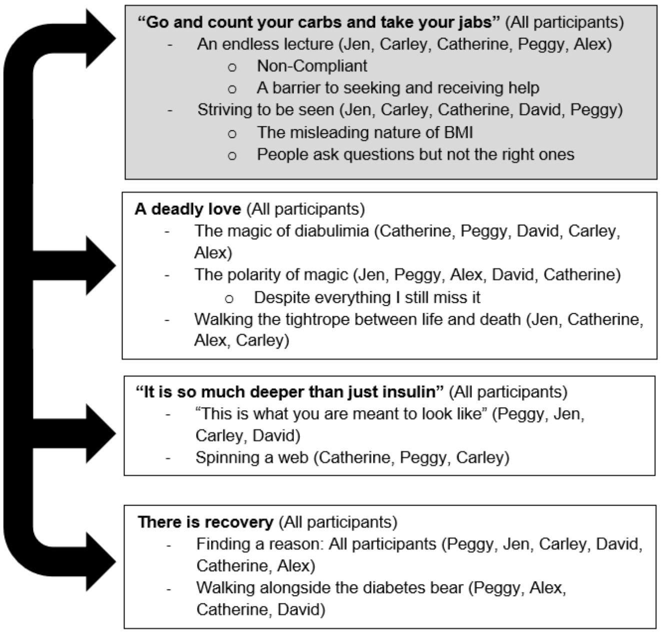
4.1. Chapter overview

The analysis resulted in four superordinate themes which represent the lived experiences of the participants, with each theme attending to specific aspects of diabulimia. The following chapter will discuss each superordinate theme chronologically, using direct quotes from participants to expand the analysis.

Where clarification is needed in participant quotes, additional explanations are marked by italicised text in parentheses, for instance *(being thin)* (see appendix 24 for further information regarding extract formats). In addition, whilst most themes were named using extracts from the participants, there are some exceptions, for example, striving to be seen, a deadly love, and walking the tightrope between life and death. In these cases, it proved difficult to find an exact phrase which encapsulated the emerging theme. Subsequently, the theme name was created as close to the participant narratives as possible. In addition, only the more salient of participant quotations have been used, appendices 19-21 encapsulate a broader range of citations that were considered for the analysis.

Within the analysis, the term lifeworld is used to refer to the different dimensions of human existence, which from an existential perspective can be broadly considered to be; the physical, the social, the personal and the spiritual (van Deurzen & Adams, 2011). The concept of the lifeworld is not applied overtly or rigidity, rather it is a way of communicating the multifaceted nature of humanity. Figure 2.1. illustrates the superordinate themes, subordinate themes, and prevalence amongst participants, and will feature throughout the analysis to help guide and orientate the reader.

4.2. Superordinate theme 1: “Go count your carbs and take your jabs”



“Go and count your carbs and take your jabs” (All participants)
- An endless lecture (Jen, Carley, Catherine, Peggy, Alex)
    - Non-Compliant
    - A barrier to seeking and receiving help
- Striving to be seen (Jen, Carley, Catherine, David, Peggy)
    - The misleading nature of BMI
    - People ask questions but not the right ones

A deadly love (All participants)
- The magic of diabulimia (Catherine, Peggy, David, Carley, Alex)
- The polarity of magic (Jen, Peggy, Alex, David, Catherine)
    - Despite everything I still miss it
- Walking the tightrope between life and death (Jen, Catherine, Alex, Carley)

“It is so much deeper than just insulin” (All participants)
- “This is what you are meant to look like” (Peggy, Jen, Carley, David)
- Spinning a web (Catherine, Peggy, Carley)

There is recovery (All participants)
- Finding a reason: All participants (Peggy, Jen, Carley, David, Catherine, Alex)
- Walking alongside the diabetes bear (Peggy, Alex, Catherine, David)

Figure 2.1. Representation of themes and prevalence amongst participants

This superordinate theme encapsulates the participants experiences with healthcare professionals, which is further attended to within two subordinate themes. To begin, an endless lecture, explores the participant’s being-with the healthcare professionals. Participants describe being scolded and infantilised, which consequently results in the shutting down of the participants narrative and an exploration of their being-in-the-world.

The second subordinate theme, striving to be seen, addresses the longing of participants to be interacted with (seen) on dimensions deeper than that of their physical and objective forms, namely numbers and medical notetaking. Emerging from the superordinate theme is the sense that participants and healthcare professionals are distant and adrift from each other, which from the perspective of the participants influences the duration and severity of their difficulties.

4.2.1. Subordinate theme: An endless lecture

This theme explores the self-with-other relationship between participants and healthcare professionals, and the resulting impact on the participant’s thoughts, feelings, and behaviours. For many of the participants there a sense of being infantilised in the presence of a powerful other. The excerpt from Jen below describes this experience in terms of being encouraged to be a “good girl.”

> I’ve only ever had one female consultant, so they've all been men, they've all actually been quite old and for them it’s simple. Little girl why aren't you taking your insulin, do

> as you are told now run along (*makes a* sweeping *away hand gesture)*, just go and count your carbs and take your jabs be a good girl (Jen: J19)

By taking on the voice of an older male consultant (“them”) Jen appears to project herself into the mind of the consultant by voicing how she believes they perceive her from her experience; as a child who needs to be instructed. Jen feels infantilised by the older male consultants, while her emphasis on their demographic highlights a perceived lack of connection because of the difference in age and gender. Jen’s use of language is reminiscent of a past era where women and children were expected to be seen and not heard. In being positioned as a “little girl,” Jen is stripped of her adult development, complexity, voice, and identity. She is encouraged to be a “good girl” through obeying commands and “doing as she is told.”

An emerging power imbalance between healthcare professionals and Jen is strengthened by her hand gesture which gives rise to a sense of being dismissed by the other. There is a simplification of Jen’s experience captured by the statement “just go and count your carbs and take your jabs,” thus denying any depth, difficulty, or complexity that Jen may be holding. The sweeping gesture further creates an image of annoyance and impatience that seems symbolic of a desire to drive someone away, akin to a bothersome fruit fly. From this perspective the inherent complexity of Jen’s being appears to be questioned in the gaze of the consultant which gives rise to a negative interpersonal experience. A feeling amplified by Carley as she shares:

> When you go to clinic you are always made to think that you are a piece of shit for having high levels. I come out feeling worse. (Carley: CAR9)

Carley’s excerpt emphasises how her experiences with healthcare professionals influence her thoughts and self-with-self relationship, which negatively impacts her self-worth and self-esteem. Carley and Jen’s excerpts raise questions around the nature of health consultations, as both voice negative interpersonal interactions peppered with essences of being shamed and patronised. In a similar tone, Catherine shares her experiences of being infantilised and scolded by the other:

> I used to see the diabetes team every three or four months and I can remember feeling like I was about to go in for an exam or to see the headmaster and like taking your book in and giving them your book and they would be like “oh why was it high on this day” and “I was like I don’t know it was three weeks ago”, “what did you do then”, “I didn't do anything” (Catherine: C69).

The image of going into an exam or visiting the headmaster portrays Catherine in a younger self-state, similar to Jen’s feelings of infantilization and imbalance of power. Catherine appears to be a schoolgirl within an educational hierarchy about to face assessment or judgement. A position which does not give rise to feelings of empowerment or equality. It seems plausible then to deduct that Catherine would feel anxious ahead of her diabetes meetings ("exams") or powerless in the gaze of the diabetes team ("the headmaster"). A position support by her statement "I didn't do anything" as though she is having to actively justify and defend herself against a questioning tone from the diabetes team. Akin to Jen, Catherine takes on the voice of the healthcare professionals to highlight a quizzical and questioning relational experience. A dynamic which seemingly places narratives of the participants and healthcare professionals within an us-and-them dynamic, giving rise to distance, difference, and disconnection.

4.2.1.1. "Non-compliant"

Another element within the experience of being lectured, is related to the term non-compliant, which Catherine, Jen, and Carley all have experience of being labelled as. As Carley explains:

> They made me feel like I was being naughty or defiant although they call it "non-compliant" *(makes quotation marks with hands)* and that's the key term cos that suggests that you're breaking the rules and yet this is something you have to manage yourself day to day, and they're *(medical/healthcare professionals)* suggesting that you are breaking a regime or you're breaking some sort of law and that's a big problem I think they're judging me straightway, and unless they are diabetic, and they've been through it who are you to sit and say (Carley: CAR 26)

To be compliant is usually referred to the process of following instructions, which in this context are set and delivered by the healthcare professionals to the participants. Subsequently, this suggests that non-compliant refers to those who are unable to follow the designated instructions. This gives rise to a transactional and impersonal relationship between healthcare professionals and participants, whereby the former is the instructor and the latter the instructed.

Carley's use of quotation marks implies a sense of sarcasm and contempt towards the term. A sentiment which continues as she positions the term in relation to laws and regimes, thus making her insulin omission criminal. Carley offers another experience of being infantilised by sharing she was made to feel "'naughty," yet quickly enters a more adult world of law and crime. Analogous to the distance provoking narratives of Jen and Catherine, Carley also seems to seek distance from the healthcare professionals by asserting that only someone who has had a similar lived experience to her would be able to comment on her decisions and relationship with insulin. Thus, the qualified healthcare professionals are not qualified to scold or judge her lived experience. The term non-compliant also struck participants as critical and oversimplified:

> Every healthcare professional I came across, would initially say well just take your insulin and like labelled me as non-compliant. It kind of implies to me that you’re not looking after your diabetes on purpose that you're kind of not caring about the consequences and just kind of yeah, because you can't be bothered or whatever but for me I really did want to did want to erm like start taking my insulin again but the psychological barrier I had toward it, I was genuinely really frightened to (Catherine: C16)

Catherine’s excerpt highlights the absence of openness and exploration associated with the label non-compliant. It refers to her behaviour of not taking insulin as instructed, yet seemingly overlooks the position that behaviour can be considered a form of communication. For Catherine, this is the communication of fear. Despite Catherine naming the psychological component of her insulin restriction, it appears to be overlooked by healthcare professionals who remain in the shallow waters of what is being presented on the surface. This gives rise to a wondering as to whether healthcare professionals are aware of, able to, or willing to venture into the deeper water of that which is beyond the physical presentation, namely the psychological aspect of insulin restriction.

It may be that healthcare professionals hope that lectures or warnings will be effective in changing an individual’s behaviour and motivate them into being compliant. Yet, as Peggy shares, she was fully aware of what she should or should not do when it came to her diabetes care and the associated consequences.

> I mean obviously rightfully so you are warned of the complications of not taking your insulin by your doctor, and you do need to be aware of what might happen. But it makes it into this terrifying thing that it doesn’t necessarily mean to be. Also, my insulin omission had nothing to do with a lack of awareness of the consequences, so it really didn’t matter how many times they told me I would lose my legs or my eyesight (Peggy: P29)

For all the participants, the nature of their difficulties was not associated with a lack of information or intellectual understanding of the risks of insulin omission. However, the communication and relational styles experienced by the participants from healthcare professionals, did not seem to promote open or collaborative discussions to help understand the nature of their difficulties. This element coupled with the label of non-compliant stands to drive participants difficulties as it shuts down their narratives and life worlds and does not allow room for conversations beyond adherence. Which, as addressed in the following section appeared to act as a barrier for participants in seeking and receiving help.

4.2.1.2. A barrier to seeking and receiving help

The sense of being lectured appeared to have consequences for the seeking of support and duration of using insulin for weight control. For Peggy, her previous and anticipated experiences with healthcare professionals acted as a barrier to seeking help. As she explains:

> I went to A&E a couple of times and you know just the response I got from Doctors there was you know quite patronising and not understanding, you know why aren't you taking it (..). So I didn't feel like I could then go to the doctor or the diabetes clinic and be like help you know, I'm doing this but I really don't want to be doing this but I can't figure my own way of getting out of this situation, you know (…) Obviously, you know I did go and do it after a while, but for a long time I was terrified of being told off by a doctor or by the diabetes team. (Peggy: P8).

Peggy sought help multiple times, but in her time of need she was refuted, patronised, and misunderstood by the A&E Doctors. Ultimately, this left Peggy feeling trapped in her own difficulties as she needed support, asked for it, yet it was not received. The communication style experienced by Peggy led her to a feeling of terror which resulted in further delay of seeking and receiving help. It appears for Peggy that the medical other acted as a perpetuating factor for her use of insulin for weight control, something which Catherine also experienced:

> I remember because I was I went in as a day patient initially erm but then I was getting worse and worse so they admitted me as an inpatient and after I had been in for like almost 3 days, they realised that I wasn't taking my insulin erm and told me off, and said that you just need to take it. I think it would have made a lot of difference early on if the eating disorders team talked to my diabetes team because the eating disorder was so linked in to the diabetes that you can't really separate the two, but the eating disorder team would look at me and see eating disorder oh we should treat that and then then diabetes team would look at me and see diabetes and want to treat that (Catherine: C10)

Catherine's narrative echoes elements previously highlighted by participants, namely feeling lectured or told off, with her experience being oversimplified and not enquired about. Yet, within a facility of care Catherine's health deteriorated, something which she feels may have been lessened if communication between healthcare professionals had been present. Up to this point, the emphasis has been on the communication between participant and healthcare professionals, yet Catherine's experience highlights the importance of effective communication between healthcare professionals, and the need to integrate not separate the different components of Catherine's difficulties. The consequence of these omissions for Catherine resulted in her becoming more unwell.

The participants' experiences of their difficulties being minimised and misunderstood left several feeling that they were the only one with the difficulty, that it could not be understood, it was minor, and that help would not be available, as highlighted by Peggy below:

> I really felt that no one else was doing this, no one else understands what this is like, it is only me and because it's only me I can't talk to anyone else about it. It made me feel like I had to keep doing it because I can't stop because no one understands (Peggy: P4)

These experiences gave rise to a sense of isolation and reinforced Peggy's belief that it was not worth talking about her difficulties as it would not help. Over time this evoked a since of rebellion and nihilism for Peggy, which was also shared by Carley.

> It gets to that point you know where people have said that I need to do it *(take the insulin)* for so long that you have this almost type of rebellion like you know what screw you, no one seems to genuinely want to help me so what the fuck what's the point then. (Carley: CAR20)

> I was like oh fuck it if I'm going to die what is the point of looking after myself, if I'm going to have this, if this is going to happen to me one day then what's the point (Peggy: P18)

Both Peggy and Carley ask, "what is the point," as though they are questioning the value of existing in a world where their diabetes is inevitable, yet the help they need with it is unavailable. Peggy's expression of "oh fuck it" represents a sense of emptying and the discarding of any meaning, purpose or opportunity for change that may have been present at the time. Conversely, Carley appears to directly talk to the healthcare professionals "screw you." Whilst there is a sense of anger in Carley's language and tone, there appears to be an undercurrent of despair captured by her reflection that no one seems to genuinely want to help her, in a way that is perhaps not lecturing or labelling. Rebellion and nihilism were not the only responses to being met with incomprehension or minimisation by healthcare professionals. For Alex and Jen this experience evoked a desire to "shut down" and "disappear."

> I think I went into a shut-down and a denial mode erm you know if they don't want to talk about it or hear about it, then I'm making a big deal out of nothing (Jen: J24)

Jen's shutting down and denial appears reminiscent to a mode of avoidance which allowed her to control the discourse, such that she could pretend the relational experience was not happening. In turn Jen attempts to ignore her underlying experience, which is that the healthcare professionals do not want to discuss or hear about her difficulties. For Alex incomprehension and minimisation of her experience resulted in wanting to "disappear:"

> All I wanted was support with it and it wasn't there which made me feel like I wanted to disappear (…) this is why other diabulimics saved me because I was like it's not just me (Alex: A81)

The nature of disappearing in Alex's statement remains ambiguous, it could be perceived as disappearing in terms of her body in that it is getting smaller, or the disappearing from the world through death. Equally, there is the possibility that it refers to wanting to disappear in response to being shamed. Despite the multiple meanings which could be assigned to the nature of disappearing, what is clear in Alex's narrative, is that she wanted and needed support from the healthcare professionals, the traditional life savers, yet was unable to elicit this desired response. Consequently, the life-saving remedy for Alex appears to be relational connection with peers and the end of her perceived isolation.

The subordinate theme, an endless lecture, has highlighted participant's experiences of engaging with healthcare professionals. What emerged was a sense of being lectured, labelled, and minimised in their difficulties. The effect was that the participants' difficulties appeared to remain recurrent, prolonged, and concealed, as the help and support they desired was not available or accessible. To conclude this subordinate theme and as a segue into the next, I revert to Carley who simply stated:

> I've had enough of being told off, no one asks how are things? (Carley: CAR13)

4.2.1.3. Reflexivity (5)

Whilst writing this subordinate theme I wondered how the participants positioned me, how I positioned myself against the term healthcare professional, and how this may have influenced the way I made sense of and interpreted the participants narratives. I questioned whether being a woman within the field of CoP influenced how much participants felt willing and able to share. It felt likely that my therapeutic skills helped to create a comfortable and relational interview setting, whilst my gender and psychological positioning may have been perceived as safe to the participants thus helping to elicit rich and powerful descriptions of their experiences.

I reminded vigilant as to how my psychological and psychotherapeutic lenses stood to colour my sense making of the participants sense making. For instance, when detecting shame or nihilism in the participants experiences, I quickly went to the writings of DeYoung (2015). In these moments, it felt important to regain a connection with the participants and set aside my theoretical preferences. I found writing the participant names and visualising our interview setting helped with this grounding. Where did we meet, what was the room like, what did the participant look like, how did they sound?

4.2.2. Subordinate theme: Striving to be seen

Striving to be seen is a metaphor capturing what participants feel is happening to them in their life world. Whilst they can be seen physically and objectively participants voiced that the undercurrents of their being, that is everything beneath the physical presentation felt out of sight and unnoticed.

This subordinate theme highlights the nature of these unseen undercurrents, and the emerging complexity. There is a longing for healthcare professionals to ask the right questions to gain access to and see the undercurrents of their being, which once attended to is described by one participant as being a lifesaving experience.

4.2.2.1. The misleading nature of Body Mass Index (BMI)

Participants reacted strongly to the emphasis of BMI in healthcare appointments, indicating that a focus on weight in this way was not representative of their difficulties, and in some cases appeared to reinforce participants beliefs and thoughts around the need for ongoing weight loss:

> On my last admission I was told that I had malnutrition, so I literally had nothing in my body, but I wasn't technically underweight, so my BMI was about 21-22. (Jen: J55)

Jen’s excerpt highlights a paradoxical element to her existence. Internally, her body was empty, hollow and malnourished, yet to the external world was presented as healthy through the numerical value of her BMI. Jen’s body was considered both malnourished and healthy at the same time, which gives rise to wonderings around the potential discrepancy between her external presentation and internal reality when restricting insulin through the lens of BMI.

Jen’s experience indicates a technical and statistical approach towards her being, where numerical benchmarks were used by healthcare professionals to signify whether her weight could be considered healthy. An approach which for Catherine and Carley appeared to contribute to and exasperate body-image concerns and thoughts around weight loss.

> I have always been on the larger side, like even at my worst my BMI was only just inside the normal bracket, erm and so it kind of I guess confirmed to me that I needed to lose weight so it kind of reinforced that thought. (Catherine: C43)

> Don't focus on BMI, don't focus on those numbers because my BMI tells me that I am obese and I know that I have body image issues I think I'm fat but I don't think I'm obese, and when you do some elements of CBT it's all evidence, so when people are doing evidence based stuff you know the thought being "I think I'm fat" and trying to find evidence for it well I go to clinic and my BMI is this, it tells me I'm obese, evidence. (Carley: CAR10)

For both Catherine and Carley, the use of BMI as a numerical representation of their wellbeing seemed to act as a motivational factor for further weight loss. Catherine shares how BMI "confirmed" her thought around the necessity of further weight loss, such that BMI appeared to become a source of support and motivation for the longevity of Catherine's use of insulin for weight control. A similar experience was named by Carley, however for Carley BMI seemed to worsen her self-image illustrated by her comment "I think I'm fat, but I don't think I'm obese." Additionally, Carley shares how an emphasis on BMI undermined her attempts at recovery and change by acting as "evidence" in support of her self-perception. The experiences of Catherine and Carley highlight how BMI could be a perpetuating factor when using insulin for weight control. This in turn raises concerns around the potential of recovery and change, if the participant's experiences of care and support appear to strengthen their thoughts and beliefs around the necessity of further weight loss.

4.2.2.2. "People ask questions but not the right ones"

Continuing with the essence of wanting to be seen, participants voiced the questions they hoped healthcare professionals would ask them and shared their experiences of what it was like when they did. In short, the multidimensional nature of their being felt valued and visible. An important element of individuals being seen by healthcare professionals appeared to lie in their acknowledgment of their patients as fellow people, as Jen explains:

> I think a lot of it with Doctors is trying to understand their patients as human beings, as a whole entity you know not just a name or a hospital number on a page with a condition. (Jen: J148)

Jen suggests that individuals are reduced to separated fragments of name, number, and condition. With this procedural approach, human consciousness and complexity is erased, and the acknowledgement of the inter-relational aspect of human existence denied. From Jens description it can be deduced that she was not able to develop her own identity and relationship with the healthcare professionals, and she was not seen as an individual who is situated within the world in a wider meaningful context of people, ideas, places and events. In a similar tone to Jen, Carley shares her experience of being interacted with on a numbers first basis.

> People are asking questions but not the right questions, when you go into the A&E there isn't those questions of the mental health side of it, there isn't, it's we've got to fix the numbers we've got to get the numbers sorted, it's always the numbers. (Carley: CAR59)

Carley's statement that people are not asking the right questions, stresses that there is more to Carley's humanity and difficulties than numerical presentation. She indicates that there is an absence of concern around her mental health, as though this element of her being is invisible. Her desire for people to ask the "right questions," suggests that she is longing for someone to access the backstage, to look beyond the numerical foreground that appears to dominate her existence and relational interactions with others. The passages from Carley and Jen highlight how the body can be positioned as an object. Something which needs to be calibrated, and therefore almost machine-like. This sense is highlighted in David's narrative as he shares:

> I've built a mathematical model and spreadsheet. When I eat, I enter in carbs of what I eat and what time it is and what my blood sugar is, and it tells me what my dose so should be and how long I should leave it before taking it. (David: D118)

David's spreadsheet appears to be an externalisation of his bodily functions and needs. It is numerical, black and white and removes the complexities of humanity in a way similar to that of the healthcare professionals. Yet, whilst David shares this is how he currently interacts with his body, he is quick to name how he would like to relate to healthcare professionals, which is strikingly less machine-like:

> When you walk into a consultants office the first thing he should say to you is 'how are you, really how are you doing, have you got anything you want to discuss with me at all first, I'm here to listen' and to keep on saying it even if it doesn't work first time keep on saying it ten times and eventually maybe they'll say 'actually there was something that I would like to discuss with you for the last few meetings but I've not been brave enough to but I think I might do now' erm and yet I think the most important this is seeing the person and hearing the person first. (David: D153)

There is a paradox in David's existence, in that he is existing within a machine-like paradigm of BMI and numbers, yet akin to Carley and Jen stresses that the most important part is to see and hear the person first. In a statement almost matching David's, Carley shares the right questions that are needed to gain access to an individual's backstage:

> Ask them how are things, what's going on and they might not say anything, they might turn around and say nothing is fine because they might not want to talk, people have

> to be ready to talk but if that's the question that then allows them to say well actually I'm having a really tough time with it all (…) but none of them are just asking what's going, how are things at the moment. (Carley: CAR60)

It is notable that both David and Carley stress the importance of continual questioning and opening a space for dialogue. A possible plea for healthcare professionals not to give up on their expressions of curiosity, care, and attempts to see the person beyond the numbers. As well as sharing the hoped-for relational interactions with healthcare professionals, Carley and Peggy were able to describe what it was like to experience such relationships.

> I mean the GP before I really liked him, I was able to talk to him and there was no judgemental air about him at all there was genuine care. One time I missed an appointment and he called me because he just wanted to make sure I was okay. I've never sort of experienced it so when he did that I was like oh that's really nice and I really liked him and I am really sad that I don't have him as my doctor anymore because he was really good and he would see me regularly and I knew I could go and talk about the mental health stuff and he would say I'm not an expert but we can try. (Carley: CAR46)

Carley stresses how she was able to openly discuss her difficulties with her GP, in a relationship where she knew she would receive, non-judgemental genuine care. The loss of this relationships evokes sadness for Carley and arguably represents the loss of a collaborative and compassionate space. She is no longer able to be seen and the complexities of her humanity are once again invisible in the backstage. Interestingly, Carley does not appear to be deterred by her GP's lack of expertise, which is contrary to her early position where she stated "unless they are diabetic, and they've been through it who are you to sit and say" (Carley: CAR26). Carley appears to move away from a requirement of expertise or parallel experience in the wake of being with a containing and caring other. Thus, it seems that the sense of not being alone with her difficulties outweighed the importance of an omniscient other. Comparably, Peggy reflects on her experience of asking for help:

> I did go and do it *(ask for help)* after a while and no one told me off you know the level of care and support I've received from the NHS has been unbelievable (…) I owe them a lot, I think I owe them my life which is true (Peggy: P9)

Peggy shares that she was met with care and support as opposed to the anticipated telling off. Being supported and interacted with in this way, was a life saving experience for Peggy who feels she is indebted to the NHS for giving her back her life. The presence of care and support seemingly distanced Peggy from her demise and helped her to revisit the meaning and value ascribed to her life.

4.2.2.3. Reflexivity (6)

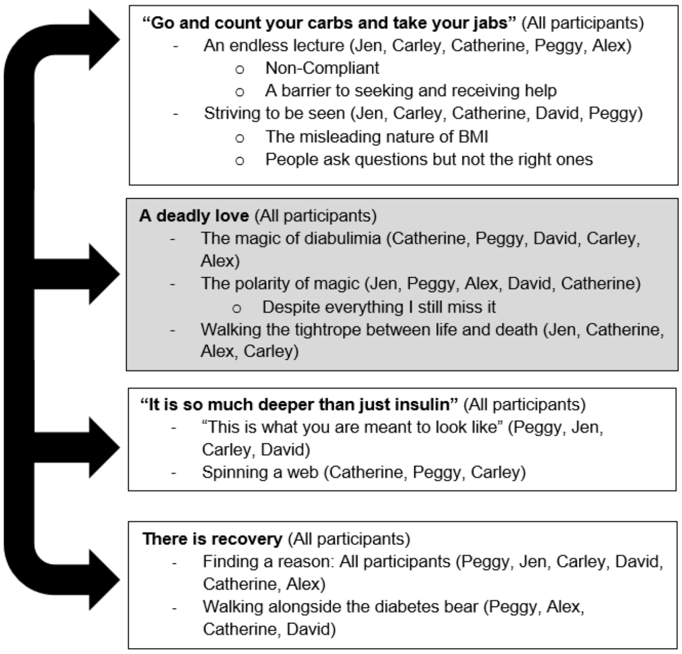
Can you see me, do you know that I am there?
Do you know my name, or the pain I cannot share?
You look at my numbers, but these are the black and white,
they do not capture my thoughts in the night.
The black and white is limited, they do not represent me,
whilst they are important, so is my complexity.
We need some colour in our communication, so you can truly understand
I need more than just the black and white,
so please extend your hand.

This poem captures my attempt at stepping into the world of the participants and give voice to the experience of striving to be seen. Poetry has always been a route to expressing that which I found difficult to name or felt there was no room for in other areas of my life. My personal experiences of not having room for emotional expressions or when only certain emotions were allowed, may have increased my sensitivity to something similar occurring in the participants, such that not all colours or elements of their being were allowed or seen.

4.2.3. Summary: "Go and count your carbs and take your jabs"

The first superordinate theme emphasised the interpersonal relationships and experiences between participants and healthcare professionals; identifying experiences of being lectured, labelled, simplified, infantilised, dismissed, and misunderstood. These encounters appeared to have negative consequences around the seeking and receiving of support, and ultimately the duration of the participants difficulties. Participants vocalised their desire to be seen and connected to as a person with complexities and layers, as opposed to being reduced to numerical or physical presentation.

The absence of such relationships and emphasis on numbers as an indication of health and wellbeing, appeared to perpetuate thoughts on further weight loss and for Carley seemingly undermined an attempt at change and recovery. Conversely, for Peggy who had a positive interpersonal relationship with healthcare professionals, the experience was named as lifesaving. The importance of communication extended beyond the participant-practitioner dynamic, as the superordinate theme noted how the absence of practitioner-practitioner relations and ongoing segmentation of difficulties led to the deterioration of Catherine's wellbeing within a setting aimed at care and recovery. This theme has attended to the relational dynamics of healthcare professionals, yet questions remain around the relationship between participants and the phenomenon of using insulin for weight control itself. An element which is explored in the second superordinate theme; a deadly love.



"Go and count your carbs and take your jabs" (All participants)

- An endless lecture (Jen, Carley, Catherine, Peggy, Alex)
    - Non-Compliant
    - A barrier to seeking and receiving help
- Striving to be seen (Jen, Carley, Catherine, David, Peggy)
    - The misleading nature of BMI
    - People ask questions but not the right ones

A deadly love (All participants)

- The magic of diabulimia (Catherine, Peggy, David, Carley, Alex)
- The polarity of magic (Jen, Peggy, Alex, David, Catherine)
    - Despite everything I still miss it
- Walking the tightrope between life and death (Jen, Catherine, Alex, Carley)

"It is so much deeper than just insulin" (All participants)

- "This is what you are meant to look like" (Peggy, Jen, Carley, David)
- Spinning a web (Catherine, Peggy, Carley)

There is recovery (All participants)

- Finding a reason: All participants (Peggy, Jen, Carley, David, Catherine, Alex)
- Walking alongside the diabetes bear (Peggy, Alex, Catherine, David)

4.3. Superordinate theme 2: A deadly love

This superordinate theme captures the participants paradoxical relationship towards diabulimia across three subordinate themes; the first, the magic of diabulimia shares how participants experienced diabulimia as "magic," stating that it was a "gift from God," or a "magic tool" which they "loved." However, as highlighted in the second subtheme, the polarity of magic, the cost of using insulin for weight control is in stark contrast to the uplifting sense which emerged in the first subordinate theme. Participants appear to be continuously balancing different elements of their experience, which extends to the balancing of their mortality in the third subtheme, walking the tightrope of life and death. Here, participants reflect on their mortality and that of others as they name their experiences of and attempts to manage their anxieties around death and its inevitability.

4.3.1. Subordinate theme: The magic of diabulimia

For all the participants there was a magic element to diabulimia. Participants initially spoke fondly of the experience, often using adjectives which positioned diabulimia as being positive, beneficial and something which made the impossible seem possible in relation to the body and pursuing an idealised shape, as Catherine explains:

> I was really elated by it *(weight loss)* because like although the eating disorder was not primarily about weight loss that was the outcome I was wanting. So, I needed to keep

> doing it *(losing weight)* and this *(insulin omission/restriction)* was the magic tool that I needed. (Catherine: C43)

Catherine's account shows that she was "elated" by her discovery of the "magic tool" that would enable her to lose weight. She seems to have been searching for a way to access the hoped-for weight loss, despite her acknowledgement that her ED was not primarily about losing weight. What was driving Catherine's ED is missing in this excerpt, and questions around what drove her insulin restriction, and subsequently what was gained from it remain unanswered at this point.

Catherine's use of the world "tool" implies an element of objectification. On one hand Catherine appears to have objectified diabulimia as an abstract instrument separate to her being that she could use to carry out a particular function, namely losing weight. Yet she also stands to have objected herself such that the "tool" or diabulimia is done to her in a disconnected and mechanistic way. Additionally, Catherine's repetition of the statement "I needed" suggests the necessity of losing weight and the value of the "tool" to facilitate this. Consequently, the magic tool of diabulimia appears to give Catherine access to a weight loss reality, something shared by Peggy as she notes:

> If I stop taking my insulin, I'm going to lose weight and it's like it's magic because you can eat what you like, and you lose weight and it's fantastic. (Peggy: P19)

Catherine and Peggy capture the magic nature of diabulimia through their expressions of being "elated" and considering it "fantastic," as it facilitated the desired goal of weight loss through the usually incompatible route of being able to eat whatever they desire. Here lies a polarity, in that the more the participants eat the more weightless they become. Although the bodies of Catherine and Peggy may be starved of nutrients, they have not had to starve or restrict their desires, something which Peggy names as being "fantastic" and Jen describes as being a "win-win" (Jen: J94). David also refers to the magic of diabulimia but through the metaphor of a magic pill.

> Imagine I said to you right here's a magic pill, continue eating what you want. In fact, the more you eat the better it's going to work continue eating what you want, the more you eat the better it will work erm and the weight will just drop off you and all you've got to do is take this magic pill. There is some small print though, but no one reads them do they. You might go blind, you mind damage your kidney's, you might bla bla bla all the complications, but do you want to do live for now or live for the long term. If you gave that option to a number of people without diabetes, I actually think more than 40% would say 'yeah I'll take it' It's the magic pill with the horrible small print. (David: D142)

Here, David attempts to rationalise the decision to restrict insulin to a non-diabetic audience through the image of a magic pill. The magic pill captures the temptation that those with T1DM face daily, in that they are confronted with an easily accessible route to pursue an idealised body shape through weight loss. David names the polarity inherent in diabulimia. He shares the somewhat idealistic option of losing weight by eating more, while noting how the "small print" that is the consequences of the "magic pill," are usually overlooked by a preference for hedonistic living.

David's analogy of the magic pill resonates with the myth of Doctor Faustus, a tragedy which sees Faustus strike a deal with Lucifer in exchange to move beyond the usual limits of humanity. Such that, the participants could be seen to enter into an arrangement with diabulimia and thus move beyond the usual human limitation of having to eat less to lose weight. Yet, over time Lucifer, akin to the consequences of diabulimia reappear with the reminder that no individual is able to escape the limits, givens or mortality of humanity.

Participants are clear in perceiving diabulimia as magic, yet up to this point have not shared what it is about losing weight or what they gain from it that is valuable, meaningful, purposeful, or worth pursuing. In a performative sense magic often refers to the transformation or disappearance of something or someone. Elements which are similar to the disappearing and transformation of the participants through the physical shrinking of their bodies. Furthermore, there is often an element of illusion required in magic, and an ability to allow individuals to temporarily escape their daily life. In this way, the restriction of insulin could represent a temporary escape or a denial of having T1DM. A position illustrated by Carley:

> I hate it, its stereotypical I didn't ask for this, I don't want it, I don't want to take the insulin, it makes me different I can't take a break there's no pause on it. (Carley: CAR39)

Here Carley shares her relationship towards her diabetes, it is something she hates, did not ask for, does not want, and makes her different. What is more, the absence of the "pause" button makes diabetes unrelenting, such that it can take a toll on daily life and requires an individual to make ongoing decisions about their care. From this position, Carley's insulin restriction presents her with a temporary gateway to feeling and being normal that is non-diabetic and take a pause from the demands of the condition. As well as providing Carley with a sense of diabetic respite, Alex positions diabulimia as a "gift from God:"

> I loved my diabulimia like I felt when I first got type 1 diabetes and I realised I could do this, I thought it was a gift from God. (Alex: A81)

Here the experience of diabulimia transcends magic and moves into the spiritual domain of Alex's lifeworld. By being experienced as gift it may be deduced that Alex did not seek or ask for this phenomenon, but nonetheless she regards it as precious and responds with gratitude and love. However, the use of her past tense suggests that she has moved away from this position and is sharing a reflection of how she felt at the time.

Up to this point participants have all spoken highly of diabulimia as their thoughts and feelings reflect positive associations and experiences of the phenomenon. Nevertheless, the participants experiences are multifaceted, and analogous to the nature of humanity, are characterised by tensions, complexities, and polarities. For alongside the magic nature of diabulimia there is another experiential realm which has not yet been articulated.

4.3.1.1 Reflexivity (7)

At first, I questioned why individuals would pursue weight loss through insulin restriction given the severe health consequences. In this way, I was aligned with those taking a simplistic position to the phenomenon, yet David's analogy of the magic pill provoked considerable reflection; would I take the magic pill, and would my answer to this question remain the same if it was asked multiple times a day for the rest of my life?

There was great reflection on the inclusion of Dr Faustus. I wondered whether such elements belonged in the analysis and how did this fit with the phenomenological process of bracketing. Perhaps because I am aware of the myth, I saw the participants through this lens, or perhaps the participants narratives continued to lead the analysis and my reflection on Dr Faustus came secondary. It is the latter position which feels more authentic, such that Dr Faustus surfaced as a way of articulating and making sense of the participants narrative, as opposed to fitting the participants narratives into the myth.

4.3.2. Subordinate theme: The polarity of magic

Continuing with David's metaphor it seems that once participants have taken the magic pill, that is started to restrict insulin for weight control, other properties become increasingly prominent. The following subordinate theme, the polarity of magic, attends to these elements and their impact on the participants. Participants all named similar physical sensations in response to restricting insulin namely, exhaustion, a continuous need to urinate and an unquenchable thirst.

> You can't run up a flight of stairs, you feel faint your chest gets tight you're out of breath, you know I would cry in despair sometimes if I had got downstairs and I had left

> something upstairs. I would be in tears because I would have to go back up again. I was getting up every twenty minutes to half an hour through the night to pee, and drink and pee some more. I likened it, I had never had kids, but it must have been like having a new-born baby, cos you're literally constantly up. (Jen: J67)

Jen's experience of crying in despair reveals feelings of hopelessness and desperation. There is emotional anguish at the thought of further physical exertion, whilst her anthropomorphism of diabulimia into a new-born baby presents itself as a way of articulating and making sense of her experience both for herself and the other. By assigning the more known and familiar human qualities of a new-born to her experience, Jen appears to convey diabulimia as being demanding, disrupting and in constant need of her attention. Additionally, the comparison to a new-born may provide Jen with a means of connecting with the other. Through the more culturally familiar and accessible experience of new-borns, Jen may have her experience understood, recognised, and empathised with. A dynamic which reinforces the first superordinate theme, and the participants desire to be seen and acquire deeper relationships. Continuing with physical experiences inherent in the polarity Peggy shares:

> I felt awful. I felt tired all the time and I'd you know I'd be going to the loo like twice an hour you know all the classic symptoms awful horrible breath, weeing all the time no energy, super tired, super weak you know that clouded mind I ended up dropping out of uni (…) *(Pause 3 seconds)* actually, omitting insulin omitted every part of my life. (Peggy: P27)

Peggy itemises her experiences, giving an impression of distance towards her narrative and that she could go on reciting examples which appear readily accessible. Her repetition of the words "awful" and "super" stress the intensity and severity of her lived experience, which resulted in her hoped-for-future of completing university being lost. The pause represents a shift in Peggy's proximity towards her past experiences. It interrupts her listing narrative, and she moves into a position of reflection and awareness, highlighted by the realisation that "actually" omitting insulin omitted every part of her life. Several participants echoed the experiences of Jen and Peggy, sharing the physical toll of diabulimia and how this impacted their present or future hopes and ambitions:

> I would get up in the morning and I would be shattered because I would not have slept through the night because I would be up peeing through the night (..) and I couldn't breathe properly, so it's caused Kussmaul breathing and it's actually a thing and you get fluid in your lungs as a by-product of Ketoacidosis. (Alex: A10)

> I had so little energy that I had to prioritise my energy for what went on in the classroom, talking to, teaching the kids you know. I loved the teaching but that wore me out to a point where I didn't have energy for it. (David: D36)

The extracts above present a reality in stark contrast to that voiced in the previous subordinate theme, thus highlighting the presence of a polarity. Participants have moved away from feelings of elation to feeling worn out, as though their weightlessness has become heavy with the consequences of diabulimia. Participants also shared how using insulin for weight control impacted their relationships and way of being with others, as Catherine explains:

> I made a couple of friends at university but not many and most of that was because I didn't have the energy to kind of invest in friendships and when you're spending such a large part of your day so exhausted and feeling so unwell erm yeah it's hard, like I didn't go out in the evenings or anything. (Catherine: C33)

Catherine's excerpt highlights how insulin restriction left her with no energy to invest in building or maintaining friendships, which in turn gives rise to a sense of isolation and distance from the other. This concept of distance is also shared by Peggy, but through the medium of anger as opposed to exhaustion:

> You know relationships with other people, I was so angry all the time, I would fly off the handle into a rage. I made friendships really difficult and I really regret that you know because I have some really kind, loyal and understanding friends because they're all still here but I look back and I understand the way I jeopardized my friendships and the way I was with my parents and my family. I was a really horrible difficult person but somehow I was able to ignore all of those things and that side of my life and think well it doesn't matter because you are skinny and that's all that matters which is it's such a bonkers irrational way to think but it was truly what I believed for a really long time. (Peggy: P27)

Peggy shares how she had constructed a reality in which being thin was at the centre. She held a firm belief that being thin was all that mattered, which in turn suggests the absence of meaning and value in other areas of her life. The presence of this belief and acting upon it affected Peggy's emotions and behaviours towards others. This is highlighted by her feelings of anger and rage, and that despite being aware of disintegrating relationships she was able to set this aside in favour of being "skinny." In this way, the power of Peggy's belief and idealisation of being "skinny" was so prominent it acted as a strategy of avoidance or disconnection, such that she was able to "ignore" all that which may deter or interfere with the pursuit of her thinness ideal.

Peggy also names a belief that she was a “horrible difficult person,” yet the details and reasoning behind this remains unsaid. Peggy’s use of the past tense further suggests that she no longer holds the same values or beliefs as she once did. There is a sense of learning and growth in her narrative as she is able to reflect back on the past and make sense of herself. Peggy voices a different emotional response to the same phenomenon at a different time in her life, thus highlighting a process of change as her once rigidly held beliefs appear less powerful and prominent as she has become open to alternative ways of being-in-the-world. Yet despite her progression and reflection there is also an air of regret in Peggy’s narrative, which is also shared by David as he states:

> I was being half the person, half the teacher, half the family man, half of everything I could have and should have been. (David: D30)

David’s reflection illustrates that whilst using insulin for weight control, he felt he was living a reduced and diminished existence. That he was not reaching his potential as a person, teacher or family man. David’s past tense modal “could have and should have been” expresses his present feelings about the past. David has moved through a period of difficulty to a position of reflection, where he has been able to make sense of himself and name the misleading nature of his previous existence, in that he was effectively living a half-life. From all angles in David’s except there is a sense of lost opportunities and a wondering around what might have been.

Up to this point in the subordinate theme there is an emerging sense of loss, such that the experience of diabulimia eliminates or diminishes areas of the participants lives; be that physical capabilities and relationships, as well as hopes and ambitions for the future. Yet the experience of loss is not limited to these domains, as some participants feel a sense of loss in relation to the phenomenon itself, thus highlighting another strand of the complexities and tensions that exist for the participants using insulin for weight control.

4.3.2.1. “Despite everything I miss it”

> I miss it, despite everything I've done since I actually think if you said to me right now we'll take away all of your achievements but you'll be a size 6 for life I would take that. In fact if they said we'll kill everyone that you've ever loved but you’ll be a size 6 for life I would struggle with that, I would struggle with that if I’m being really brutally honest about it. (Alex: A32)

Previously Alex shared how using insulin for weight control impacted her sleep and breathing, yet despite this appears to reminisce the loss of diabulimia thus indicating a polarity in her own narrative. For Alex, the ideation of being thin for the rest of her life continues to be incredibly powerful, such that it is equal to all those she has ever loved as she would struggle to choose between them. Alex's use of the present tense "I miss it" and "right now," suggests that although she may have experienced movement and change, a psychological tension between the past and present can remain. Echoing the reminiscent tone of Alex, Peggy shares:

> I found the greatest, you know it is magic, diabulimia omitting your insulin you get to eat what you like and you eat more and more because your body is crying out for energy and nutrients and whatever, so you eat more and more (…) everyone was like wow your metabolism is like so fast and you're so skinny and you're so active and I don't know it's *(breaks out into a large smile)*, I'm kind of smiling about it now thinking about it, just how great it was but yeah it was just yeah it was just so easy once I started it was so easy, you know the weight dropped off, I could eat anything I liked yeah it was great. (Peggy: P49)

Peggy's narrative differs to Alex's in that although they both feature the other, Alex is prepared to use her relational currency in exchange for being a permanent size 6, whereas Peggy appeared to pursue the phenomenon as a means of gaining something from the other. For Peggy there was a sense of gaining acceptance, admiration, and praise from other which seemed inaccessible if she were not "skinny." Peggy's tone and language takes on a reminiscent air, as though she is indulging in enjoyable memories of past events. She is reminded of the magic of diabulimia and all that she gained from it. A pleasurable moment manifesting as a smile and ending with a sense of loss that those times have passed.

4.3.3. Subordinate theme: Walking the tightrope between life and death

In having T1DM, participants are constantly aware and reminded of their own mortality, in a way that individuals living without a chronic illness are not. The presence and inevitability of death infused the participants narratives in various ways, demonstrating how individuals can differ in their relation towards an event which we never fully experience personally but remain aware and in anticipation of. There was a sense of tightrope walking whereby participants would vary in their proximity to death, yet there is a duality, as irrespective of the participants influence all of humanity is united in its being-towards-death.

> I know from my own experiences that there were times when I thought I was going to die, this was it and that was when I had to give myself an injection because it was like a choice, I was lucky I had that choice. (Jen: J18)

Here Jen shares her experience of approaching her own death then seeking distance from it, in a way that suggests she felt in control of her own mortality. Through the omission or administration of her insulin she was able to exercise her agency and determine her fate, something which she felt “lucky” to have. In a similar tone, Catherine also feels “lucky” upon reflecting on the proximity of her own demise.

> I would go 3 or 4 days not taking insulin and I would get to the point where I felt that I was about to collapse and at that point I would take a massive dose of insulin and then kind of hope for the best, I mean I think I’m really lucky that I didn't end up killing myself doing that. (Catherine: C25)

Catherine’s sentiment of “hoping for the best,” implies wanting a favourable outcome of survival coupled with an awareness that this was not guaranteed, such that in hoping for the best she was also preparing for the possibility of the worst. Not all participants shared Catherine and Jens sense of feeling lucky to have survived, as for Alex this gave rise to feelings of guilt and punishment:

> There are so many people that aren’t here, I made it and I really shouldn’t have, erm yeah I’ve lost so many friends. When I think I just can't do this, I think well you know I'm sure Sean would have loved the opportunity to it for another day or Eve or Charlotte or Elise or Katie and that's kind of like you know pick yourself up bitch and let's get going because it's not right for you to have thoughts when actually they're not even here so yeah I think a lot of my coping comes from guilt (…) survivors guilt, it is absolutely survivors guilt yeah. (Alex: A62)

By speaking the names of those that have died Alex keeps lost friends alive. Through verbalising her take on their internal narratives her friends symbolically guide Alex in her life and support her in managing and moving through difficult thoughts or emotions. Alex’s excerpt highlights the amount of loss she has experienced coupled with a wondering around her own survival. The comment “I really shouldn’t have” suggests a belief of evading death, something which Alex feels guilty about. By not dying, Alex appears heavy with the memories of lost ones and burdened with guilt by the undeserving nature of her survival. This felt sense underlines her thoughts, feelings, behaviours, and attempts to cope with in her daily life. As well as feeling guilty for surviving, Alex also feels punished for escaping or evading death, in that she did not die how she was “supposed to.”

> I felt like I was being punished (..) for trying to escape who I really am which is this twig androgynous twig that’s who you really are and you're going to get punished because that is how you were supposed to die like that, that's how you were supposed to die rather than some fat old person. (Alex: A86)

Alex’s excerpt starts in the past tense yet quickly moves into the present, suggesting that this element of her experience is something which she continues to feel. It is though Alex had an expectation of how to die, in that she was supposed to live, and die based on the image of an "androgynous twig." By not dying as her 'true self' she is trapped in a form of remorse and feels she is punished by having to live the rest of her life in a large and aging body, opposite to that of her 'true self,' thus condemning her to a 'false existence.' Alex's self-identity has moved from an "androgynous twig" to "some fat old person," who she regards with an air of criticality, distance, and distain. Nonetheless, not all participants spoke about loss and death in such clear and direct ways. As for Carley death featured in a more elusive and oblique form.

> I always make the joke that I'm not going to live until I'm fifty cos of damage that I've done so (…) and you know you make that joke of oh yeah I'm probably not going to live until I'm fifty and you know you joke about it but a lot of the time the things people actually joke about are things that are effecting them. (Carley: CAR26)

Carley's use of joking initially presents itself as a form of avoidance and a way of coping with the flows of anxiety around death. To begin, Carley takes ownership of her use of humour in relation to her anticipated early mortality through the use of "I", yet by the end of excerpt she appears to have partially dissociated from her own lived experience by referring to the collective "people." Carley voices her imagined future of dying before she is fifty and appears to seek reassurance from the other through her repeated use and questioning of "you know."

Towards the end of the excerpt, Carley names that her jokes around her own mortality are not really jokes, such that they offer her a way of indirectly naming an area of uncertainty and anxiety. In this way, Carley seems to be attempting to come to terms with the fact that she does not believe she will live beyond fifty, something with could be a realistic assessment of her situation or an ideation. Irrespectively, Carley seems to attempt to both confront her own mortality and distance herself from it through the medium of humour.

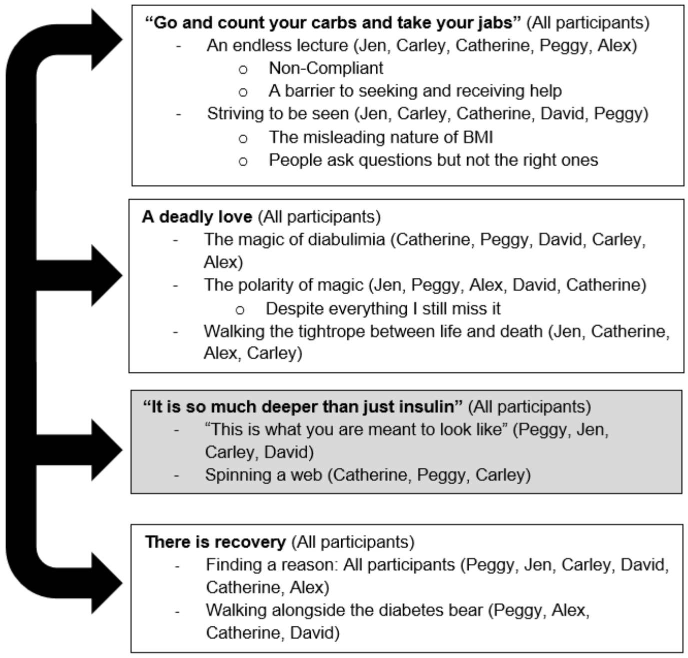
4.3.3.1. Reflexivity (8)

Death and dying do not feature prominently in my lens towards the world. I do not hold beliefs around an afterlife and to date have only interacted with death and dying as it presents itself. I wondered how the absence of reflection in my own world on death and mortality influenced my interaction with it in the analysis. It may have been that due to my own lighter involvement with this given of existence, that I did not view it or immense myself to the same depths as someone who, for instance, may hold beliefs around religion and an afterlife.

4.3.4. Summary: A deadly love

The second superordinate theme, a deadly love, builds on the first superordinate theme, in that it continues with a relational nature but from the position of the participants relationship towards the phenomenon and their own mortality. What emerged was the inherently complex and polarising nature of participants experiences, where elements were gained and lost in their lifeworld's.

As participants reflected on the impact of the phenomenon on their physical, social, and future-orientated lifeworld's, the intricacy of diabulimia was once again highlighted as two participants shared that they continue to miss this element of their being despite its cost on other areas of their life. Participants reflected upon their past and present relationship towards using insulin for weight control, yet questions around what drove participants' insulin restriction and what they gained from it remained unanswered. These elements are addressed in the following superordinate theme; "it is so much deeper than just insulin."



"Go and count your carbs and take your jabs" (All participants)
- An endless lecture (Jen, Carley, Catherine, Peggy, Alex)
  - Non-Compliant
  - A barrier to seeking and receiving help
- Striving to be seen (Jen, Carley, Catherine, David, Peggy)
  - The misleading nature of BMI
  - People ask questions but not the right ones

A deadly love (All participants)
- The magic of diabulimia (Catherine, Peggy, David, Carley, Alex)
- The polarity of magic (Jen, Peggy, Alex, David, Catherine)
  - Despite everything I still miss it
- Walking the tightrope between life and death (Jen, Catherine, Alex, Carley)

"It is so much deeper than just insulin" (All participants)
- "This is what you are meant to look like" (Peggy, Jen, Carley, David)
- Spinning a web (Catherine, Peggy, Carley)

There is recovery (All participants)
- Finding a reason: All participants (Peggy, Jen, Carley, David, Catherine, Alex)
- Walking alongside the diabetes bear (Peggy, Alex, Catherine, David)

4.4. Superordinate theme 3: "It is so much deeper than just insulin"

The third superordinate theme, it is so much deeper than just insulin, attends to the participants self-with-self relationship whilst acknowledging their position in wider societal and cultural systems. There is a sense of participants pursuing a particular way of being-in-the-world, through which using insulin for weight control seemingly acts as vehicle towards this idealised position of the self in relation to the body. Through two subordinate themes, "this is what you are meant to look like," and spinning a web, the function, driving forces and hoped-for gains of the phenomenon are illuminated beyond the behavioural domain of restricting insulin.

4.4.1. Subordinate theme: “This is what you are meant to look like”

The participants use of insulin for weight control existed in a wider social and historical context. Participants were born into a pre-existing culture and were tasked to make sense of themselves within it where one factor appeared to relate to being considered as healthy through thinness. A social norm which the female participants appeared to internalise. Nonetheless, there was a performative sense of self emerging in all participants, whereby individuals constructed a forestage and kept the backstage of their lives hidden.

Although subjective experiences within the context may differ, all participants were Caucasian and had lived in the UK for the majority, if not all their lives. Whilst the influence of peer and family teachings and experiences were mentioned intermittently by the participants, there appeared to be an emphasis assigned to the perceived societal and cultural messages which gave rise to participants evaluating their personal and physical traits and abilities against the supposed ideals of their context, as illustrated by Peggy:

> I always thought you know once I was skinny or once I was a certain weight then everything would be fine and just fall into place. You know I would be able to be better at uni, my friendships would be better and I would feel more confident and you know later when I had a job, you know I would just do better at work, you know I will find the man of my dreams. (Peggy: P7)
>
> Once I’m skinny then everything will be fine because everyone will find me attractive (..) I think that's the image that in society we are taught, this is what you are meant to look like, this is what being great looks like (Peggy: P20 -21)

Peggy’s citations name the ‘truths’ she previously held based on her experiences and perception of the messages that are broadcast in society. For Peggy, the external presentation of her body is positioned akin to a key, whereby if it is a certain shape, elements of her life will slot together like a jigsaw. From this position Peggy appears to have internalised and brought into a myth that suggests all can be resolved based upon her external appearance. Being “meant” to look a certain way suggests that there is a prescribed, intended, and preferred way of appearing, such that anyone not adhering to the physical expectation of being skinny is seemingly outside of the norm and at risk of being perceived negatively or ostracised.

The value of obeying the societal requirement of being skinny seemed crucial for Peggy as it equated to educational, occupational, and relational success. In fact, it transcended these worldly domains and stood to make her ‘dreams come true,’ by allowing her access to the ideal man she longed for. In this way, Peggy stood to get the man of her dreams through her body once it reached an idealised shape. A stance which further supports the performative element of the self and highlights the power and currency associated with being thin, elements which were echoed by Jen as she commented “if you are thin in society then you can be successful, you can marry someone quite easily” (Jen: J109).

Jens comment suggests that success is related to the ease at which you can get married, which taken together with Peggy’s belief that being skinny would give her access to the man of her dreams, gives rise to a sense of being wanted, accepted or desired by the other. Subsequently, a function of using insulin for weight control appeared to relate to being desired and wanted by the other, coupled with the belief that the only way to obtain this was through being thin. The notion of being desired further emerges in Carley’s narrative as she shares:

> I don’t fit the stereotype of what people want, and then they say you don’t know what people want, but it’s like in my mind if you’re not a skinny person with a flat stomach who looks good in bikini’s and stuff then you’re shit. The peer pressure from everywhere, you know that you need to look like this or you’re just ugly, fat, and worthless piece of crap, and you know I’ve been battling these feelings of feeling you know not normal and like I don’t fit in for a very very long time. (Carley: CAR47)

Carley talks about herself in relation to an idealisation, a stereotype that she does not “fit,” characterised by the image of having a flat stomach and looking good in bikini’s, whilst positioning those who are not in line with the thinness ideal as being “worthless.” The perception and internalisation of messages around how she should look, has impacted Carley’s self-worth and value to the point that she considers herself worthless and a societal outsider, which is highlighted by positioning herself as “not normal” and her repetition of “don’t fit.” Carley appears to pursue belonging, acceptance, and desirability, which she equates to a certain body shape, through the medium of her diabetes. A paradox given that she is pursuing ‘normality’ through the very element which she previously noted “hating” as it “makes her different” (Carley: CAR39).

Peggy, Jen, Carley, and Alex all position thinness as an idealised body shape and name what can be accessed if one achieves the idealised external presentation, namely success, belonging, safety and desirability. However, there does not appear to be a connection between the participants surface presentation and that underneath, that is the forestage and the backstage. This disconnection or sense that participants are performing theatrical presentations of the ‘self’ based upon their perceived societal messages is highlighted by

Carley when she acknowledged “you should be who you are, but in a really cliché sense of it I don’t know who I am” (Carley: CAR27).

4.4.1.1. “It was literally like a switch”

The gaining of safety, belonging, and desirability through insulin restriction as identified in all the female participants was not shared by David, which gave rise to a difference between feminine and masculine driving forces and hoped-for gains of the phenomenon within the context of the research. David shares his rational for using insulin for weight control below:

> It became a conscious decision, to right (…) so (…) even though my diabetes was a mess anyway (…) it was like let’s make it even more of a mess because that is going to make me lose weight and I’ll get round the fitness test better. (David: D11)

David’s quote suggests that his diabetes was chaotic and tumultuous, something which he was aware of and used to inform a “conscious decision.” In making a conscious decision to make his diabetes “even more of a mess,” there is a sense of nihilistic pursuit in David’s being-in-the-world. By acknowledging the decision, David demonstrates an awareness that other options may have been available to him, yet he chose to set aside his diabetes care in pursuit of the immediate goal of losing weight. Paradoxically, by doing so David compromises his actual health to pursue a ‘false’ external presentation of health, through becoming slimmer and passing a fitness test quicker. In this way David’s performative forestage is based upon the external image of losing weight and running quicker, while his backstage and other elements of his being remain unknown.

Linguistically there was a difference between David and the female participants who spoke of finding the man of their dreams and looking good in bikini’s in an almost magical or theatrical tone. In comparison David spoke in a rationalist, cognitive discourse conceptualising his experience as “objective based” and akin to a “switch” as he explains:

> Mine was objective, my objective was to lose a couple of stone for that fitness test (David: D134)
>
> It was not an ongoing thing; it was like a switch that I would turn off and turn back on (David: D20)

David appears to perceive himself as robotic. An unfeeling, mechanical existence moving towards goals and objectives. There is an absence of David’s humanity and sense of self, as though there is a safety in his mechanical way of being-in-the-world. A speculation supported by his own reflection on being perceived as vulnerable by the other:

> I'm processing this for the first time actually how erm was my anxiety over hypo’s at school was it related to how I felt or was it related to how I think they would feel about it. It was obviously a bit of both, but to what extent was it, did I think I would lose respect if they saw me vulnerable (David: D56/57)

The interview allowed David to reflect upon his experience from multiple positions for the first time. David acknowledges that he may have been concerned with how he would be perceived which in turn suggests an ability to project himself into the mind of the other. David speaks of the interdependent relationship between respect and vulnerability, whereby respect is lost if vulnerability is shown on the forestage. A belief and way of being which for David may represent a version of the masculine ideal. David’s internal questioning “to what extent was it” suggests that part of his process was to connect with his humanity and the inevitable fallibilities that make up our existence. In doing so, David moves away from a calibrated one-dimensional robotic existence and towards one which embraces the messiness and many colours of humanity.

Diabulimia, subsequently appears to act as a mode of transport towards an idealised version of the self for all participants, which appears to have at least been partially constructed by implicit and explicit messages. Yet in pursuit of their physical ideals and whilst performing their idealised selves the participants bodies are eroding and breaking down. Thus, in the pursuit of idealisation comes a path of self-destruction.

4.4.2. Subordinate theme: Spinning a web

In addition to facilitating the pursuit of certain occupational and relational successes, the use of insulin for weight control also appeared to have regulatory and empowering properties for the participants, elements which started to emerge in the previous subordinate theme through David’s avoidance of vulnerability. Of significance was the sense of control emerging in the participant narratives, whereby control primarily related to whether insulin was taken. However, there were also depths to the concept of control, with participants sharing how they made sense of it and what it meant to them, as demonstrated by Catherine below:

> It's a sense of I guess a sense of sense autonomy and I guess me being able to influence things rather than other things having a major impact on me when I don't want them to to or being done to me. I suppose being diagnosed with diabetes when I was so little means I don't remember not being diabetic (…) My regime as a child was always quite strict (…) so I guess part of the control thing is around that and yeah there were quite a few things that made me feel like I wasn't in charge of my life or I didn't have a voice or a say so I guess for me control is more about me having a say in stuff and the self-autonomy stuff. (Catherine: C67)

Catherine's excerpt paints a picture in which she is objectified and dehumanised by her diabetes. It is though Catherine is the diabetic, as opposed to an individual in her own right. The strict regime of her childhood gives a sense of regulation and rules, elements which seem partially aligned to David's mechanistic and robotic self-perception. Catherine speaks of wanting to gain control in her life whereby for a significant part she has not been in control. Instead, Catherine has been done to which stands to have shut down the recognition of her humanity and her voice. Despite Catherine not naming the experiences that led to these feelings, there is a sense that she was a passenger in her life, whereby decisions and actions may have been taken on her behalf, which she may or may not have consented to. Irrespectively, Catherine found a way of articulating and exercising her self-autonomy, possibly for the first time, through insulin restriction. In this way Catherine uses her body to express that which is not expressed verbally, yet once again there appears to be little space for Catherine's voice as there is an absence of the other enquiring into Catherine's being and reasons behind her insulin restriction.

Peggy shared Catherine's sentiment, stating that in response to feeling out of control in other areas of her life insulin restriction provided her with a sense of power and command. Peggy and Catherine appear to recognise that there are circumstances which they cannot and do not control, however they both exercised their situated freedom through the freedom to choose. Namely the choice to take or restrict their insulin. Over time, Peggy and Catherine appeared to have become overpowered by the initially appealing concept of control, with Catherine stating "it was so out of control, it controlled me" (C32) and Peggy using the comparison of being trapped in a self-created web.

> I don't know it was hard to get out of that kind of web that I had created for myself, I felt very really trapped by my own decisions and my own kind of weird sense of control, it was weird. (Peggy: P7)

Peggy's use of the word "web" alludes to a complex network of interconnected pieces which she created. Comparable to a spider's web it is though Peggy as spider has woven and created a web, whose primary function is usually to entice and catch pray. However, in searching for control and power it appears that Peggy lost her way, and trapped herself, positioning her as both predator and prey in her own narrative. Peggy's repetition of the word "weird," suggests she may be struggling to make sense of this paradoxical element of her experience. It seems that both Peggy and Catherine became 'caught' in their own pursuits of control and self-autonomy.

The acquisition of control was not the only way control featured in the participants narratives, as for Carley her insulin restriction was partially driven by a desire to relinquish control.

> I contemplated deliberately putting myself into (…) hospital (…) because when you're in hospital you're not dealing with it, you're not doing your blood sugar you're not making decisions, you are a passenger they are giving you the insulin and yes I know insulin is fat and all of that but it's out of my control and someone else can deal with it because I really don’t want to deal with it. (Carley: CAR42)

Carley’s excerpt represents the opposite polarity of Peggy and Catherine’s experience, to the degree that the term “passenger” is used in a positive way for Carley to represent a sense of being looked after, as opposed to Catherine’s experience which symbolised being led in her own life. Carley’s envisioned hospitalisation allows her respite from her diabetes reality, something which she appears to struggle with. As Carley names all the elements of her care she would be temporality be freed from and no longer having to “deal with,” she oscillates between the use of “you” and “I.” It is not initially clear why Carley uses different pronouns, yet there is a sense of fluctuating distance that emerges. Perhaps Carley does not feel comfortable being the subject of her own narrative and seeks a comforting distance in “you.” What is more, as Carley’s narrative progresses the weight of being in control presents itself. As an individual with T1DM, Carley arguably has a higher degree of control over her body on daily basis in comparison to someone without T1DM, as she takes on the role and responsibilities of an organ. Carley’s desire to relinquish control of her diabetes care and related decisions seemingly outweighs the possibility of weight gain through taking insulin, a stance captured through her comment “yes I know insulin is fat and all that.” Carley’s comment is almost dismissive, as though weight loss and her previously held position of not fitting the stereotype of what people want (see CAR47) becomes secondary in the face of being presented with help, care, and support from the other.

4.4.2.1. Reflexivity (9)

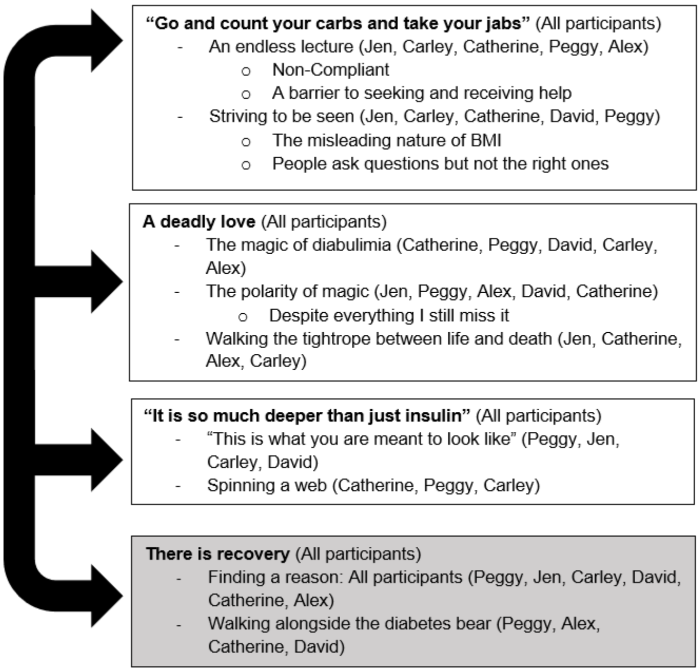
At this point in the analysis I had numerous thoughts about participants feeling out of control because of their T1DM and relational experiences. It was a conscious effort to set these aside and stay connected to what was emerging from the participants narratives as opposed to my ideas. Writing my assumptions on post-it notes then placing them out of sight, helped to contain my personal thoughts and maintain an openness to what may emerge when attending to the participants narratives whilst lessening the distraction of my assumptions.

In this way my practicing of epoché involved physically placing my ideas to one side and coming back to the post-it notes at a later stage to reflect upon how my thinking was changing. The post-it notes helped to create a baseline for seeing how I was moving into a greater sense of depth through questioning and reflection. My starting position was somewhat academic and cognitive, with rules around what can be included and a naive questioning around why an individual would seek control through such a dangerous means. Yet through this reflective process, I started to move into a more phenomenological position where different forms and conceptualisation of control emerged and ideas from deeper depths generated.

4.4.3. Summary: It is so much deeper than just insulin

The third superordinate theme looked beyond the surface presentation of diabulimia and questioned what this phenomenon meant for the participants. Across the two subordinate themes it appeared that the use of insulin for weight control assisted in pursuing specific and idealised ways of being-in-the-world, however what made up the idealised 'self' varied amongst participants. For Peggy, Carley, and Jen there was a longing for desirability, belonging and acceptance which they believed would be obtained if they reached the thinness ideal. Comparatively, for David omitting his insulin acted as a means to an end which enabled him to occupy a position of being perceived as "fit" and "respected" by the other.

Insulin restriction further acted a means to obtain power and control, yet once again not in uniform ways. Catherine spoke of restricting insulin as a way of acquiring autonomy whereas control for Carley represented the handing over of her autonomy. The element of gender again emerged as David's experience differed significantly to that of the female participants. While generalisations will not be made what arose were further polarities, antinomies, and paradoxes within the same phenomenon. Thus, despite participants sharing the condition of T1DM, the superordinate theme demonstrates the importance of attending to an individual's phenomenological reality from inside their systems or self 'created webs' as these are as unique and distinct as the individuals themselves.



"Go and count your carbs and take your jabs" (All participants)
- An endless lecture (Jen, Carley, Catherine, Peggy, Alex)
    - Non-Compliant
    - A barrier to seeking and receiving help
- Striving to be seen (Jen, Carley, Catherine, David, Peggy)
    - The misleading nature of BMI
    - People ask questions but not the right ones

A deadly love (All participants)
- The magic of diabulimia (Catherine, Peggy, David, Carley, Alex)
- The polarity of magic (Jen, Peggy, Alex, David, Catherine)
    - Despite everything I still miss it
- Walking the tightrope between life and death (Jen, Catherine, Alex, Carley)

"It is so much deeper than just insulin" (All participants)
- "This is what you are meant to look like" (Peggy, Jen, Carley, David)
- Spinning a web (Catherine, Peggy, Carley)

There is recovery (All participants)
- Finding a reason: All participants (Peggy, Jen, Carley, David, Catherine, Alex)
- Walking alongside the diabetes bear (Peggy, Alex, Catherine, David)

4.5. Superordinate theme 4: There is recovery

The process of recovery and change featured in all participant narratives and will be attended to through two subordinate themes. First, finding a reason and second, walking alongside the diabetes bear. The former attends to the nature of recovery within the context of the phenomenon and highlights the importance of finding a reason and way of accessing recovery. As will become evident motivations to recovery varied amongst participants, with elements related to the reality of health complications and the role of the other emerging as particularly significant. In the second subordinate theme additional elements related to recovery and change emerge. Participants speak of integrating and accepting their diabetes, as well as sharing the dynamic and ongoing nature of their recovery.

4.5.1. Subordinate theme: Finding a reason

One way of conceptualising recovery is to view it as a process of overcoming an illness or shortcoming, whereby an individual reaches a state of health and wellness. Yet this description raises questions around the nature of the participants recovery, as T1DM is not something individuals are currently able to overcome or be rid of. As will become evident, recovery for the participants in this context represents an acknowledgement and acceptance of their diabetes and the need to manage it in a certain way for longevity. To this end, recovery involves moving towards a position of self-care and the creation of meaning from their lived experience of diabulimia.

When speaking about their experiences of change and recovery, participants did not identify a single light-bulb moment consisting of clarity and realisation, rather motivation for recovery appeared to develop as something or someone helped them access an envisioned and hoped-for-future. For Peggy and David, envisioning a future with significant health complications appeared particularly influential:

> The medical side effects of not taking my insulin they have really kind of forced me to be better, the problems that I have with my eyes you know even though they're not severe I know they could be and they are probably likely to get worse (…) you know being skinny yeah you might think it's great, but you know your eyes are also fantastic and they're super helpful and so are your feet and you know your heart and your kidneys and all the things. (Peggy: P18)

By naming the problems with her eyes Peggy appears to acknowledge and face a reality of the external world. Her phrase "probably likely," suggests that she may be struggling with the impact of her insulin restriction and its emerging reality yet is attempting to come to terms with it. As Peggy continues, she names her appearance of "being skinny" and its value in comparison to her internal features of heart and kidneys. There is a sense of Peggy valuing the internal aspects of her being not just the external, which seems to suggest that she may not have always been connected to her internal state. This sense of being disconnected or distanced is also present in David's narrative:

> I don't think I ever got to that point where I had to take stock and reflect on it *(insulin restriction)* until my eyesight started going downhill so for the last three years since my eyesight started to go, I really made a decision to get back on board with it, to be better and erm as I am now. (David: D84)

David's 'having to taking stock,' implies that he was existing in a state of denial or avoidance, which was disrupted by his deteriorating eyesight and in turn required him to face a reality. It seems that David's worsening eyesight influenced his decision making to get "back on board" with his self-care, a position which he remains in and takes ownership of.

Earlier in the analysis (see section 4.2.1.1.) it was noted that participant's insulin restriction was not related to a lack of intellectual understanding or awareness of the health consequences, yet the narratives above suggest that there may be a difference between abstractly knowing and experiencing health complications. For both Peggy and David there is a sense of realisation provoked by the manifestation of complications, which in turn encouraged a choice and the re-evaluation of other aspects of their being. Whilst significant for Peggy and David, the onset of health complications did not motivate change for all participants or individuals as Alex shares:

> I must be the only person stupid enough to have a stroke and not stop do you know what I mean and then you meet girls and they have gone blind and not stopped, they've lost limbs and they've not stopped. (Alex: A68)

Alex highlights that even when her health deteriorated and she had a stroke, there was still an ability to assert a denial and continue restricting insulin. What is more, Alex talks about a shared experience of numerous others mostly “girls.” Alex’s narrative stresses that severe health consequences are not always enough to provoke change or recovery. A way of being that she reflects on and considers herself “stupid” for.

Motivation for recovery and change was also generated beyond the realm of health complications and often stemmed from the presence of significant others namely, friends, family, intimate relationships, and other individuals in diabulimia communities both online and in person. Several of the participants shared that it was these meaningful external relationships that prompted recovery and change, in the absence of feeling able to or wanting to pursue this for themselves.

> The thought has just come into my head, if someone was holding a gun to my best friends head and said if you don't take your insulin right now I'm going to shoot her, I wouldn't think twice I would take my insulin (….). That suddenly sprung to my head but that's a powerful kind of image really, it shouldn't be that way you know I should want to do it for myself but I would move heaven and earth for them because I want to see them happy but yet I seem to not care about seeing myself happy. That is something I just literally just thought about, that is almost like a self-discovery like I just had today. (Carley: CAR82)

Carley’s impactful statement shows how powerful the presence of the other is for her, as she feels able to quickly set aside her challenges around taking her insulin (“wouldn’t think twice”) for the wellbeing (“life”) of her best friend. Carley’s excerpt gives rise to a sense of being-for-the-other, such that difficult avenues feel accessible when positioned in relation to caring about or making another happy. In turn, this suggests Carley has an absence of love, care, or value towards herself, a position illustrated by her reflection “I seem to not care about seeing myself happy.”

Carley’s expression of making a “self-discovery” suggests that through the interview she was able to learn something about herself which she previously did not know. Carley moved from a surface position to one of more depth where an element of her being became illuminated. This emphasises the value of the interview for Carley and the power of phenomenological research, such that there is a dynamic of exploration taking place throughout the interview. The interview was not only a space for data collection, rather it provided Carley with a space where she was able to reflect, process and come to new understandings and meanings about herself and her subjective experience. Continuing with the role of significant others for motivating recovery and change, Catherine shares:

> I know a lot of people say that recovery has to be for yourself (..) they say like you have to find something for yourself to live for, but for me I disagree with that. I think it is okay to do it for somebody else because at that point in my life like I hated myself so much and didn't see anything good about myself so I couldn’t do it for me because that felt pointless, but doing it, recovering for other people who were important to me and who I knew loved me and who I knew would be really distraught if I died, that's what kept me going and the thought of okay if I did kill myself, or accidently kill myself through DKA or whatever how would those people feel erm yeah for me that was part of the reason those relationships were so important. It took me a long time into recovery before I started to feel better about myself and could see that me as a person in my own right was worthwhile. (Catherine: C58)

Earlier in Carley’s extract the notion of needing someone, a best friend, to encourage change was introduced. Catherine holds a similar position and elaborates upon this, making a significant point that she was only able to access recovery through her relationships with other people. Catherine situated herself into the minds of those she loved and reflected on how they would feel should she die. It was through the process of inhabiting their perception and feeling their remorse that she began to see her value, and realised that she meant something to other people and that there could be another meaning to her existence.

Catherine’s quotation indicates that recovery may be more accessible when initially done for others, as this could allow individuals to understand that others care about them. It is through the care that the other emits, or the individuals relate to through inhabiting the others perception, that aids the realisation that the individual matters and has value. Over time, this value can become owned and integrated as beliefs around self-worth and self-esteem may take longer to change. A position echoed by Catherine’s reflection that feeling “worthy” of recovery in her “own right” came later into the process.

As well as pursing recovery for the other, participants also described a tension between envisioning a future that they wanted to build for themselves whilst realising it would not be possible to obtain without recovery or change.

> You have to start thinking, well I have this other relationship in my life and it's quite a long term thing, not very healthy, but this relationship doesn't want me to have this relationship erm it sounds a bit nuts but then well which one do I want, and that was a

> big change for me, because I think at that point I felt I deserved a future, and I wanted a future. (Jen: J116)

Jen appears to personify diabulimia as a “long-term relationship” which is “not very healthy” as a way of making sense of an experience which otherwise may be abstract and difficult. Diabulimia appears to be positioned as a jealous partner, one of the suitors she needs to choose between. Personifying her difficulty appears to help Jen in making a change, from which she realised that she not only deserved a future but that she wanted one too. Arriving at a position of choice was a “big change” for Jen as it seemingly represented the opening of opportunities and prospects of an alternative way of being and living. Jen’s future hope was to be alive and in-relation to others, a stark contrast to her earlier position of anticipating death on numerous occasions (Jen: J18). For Catherine and Jen, recovery was also pursued by wanting to have a child, coupled with the realisation that continuing to restrict insulin could take that option away.

> Ever since I was little really wanted to have children and it was like well if I continue doing this then I'm not going to be able to have children so that was a big motivating factor for me, that big long-term goal (Catherine: C51)

> When you want to have children which I did, you think well actually this isn’t sustainable, I can’t keep doing this so I need to sort my life out. (Jen: J33)

The notion of pursuing recovery for the other or being-with-others appeared to extend into the envisioned or hoped-for other of a baby. Jen and Catherine both positioned motherhood as a hoped-for future self, an image which they were able to work towards and in turn moved away from pursuing a thinness ideal where the body was malnourished and disappearing. In pursuing pregnancy and motherhood, Jen and Catherine pursued a different representation and function of the body. Thus, the body was no longer life depleting or shrinking and instead became representative of a life-baring entity that was able to nourish, hold, support and grow another.

4.5.1.1. Reflexivity (10)

As a practitioner I believe that a primary motivation for humans is to be in relation with others, such that our emotional and physical wellbeing depends on it. In turn, I hold a relational lens when working with clients often exploring their relational templates and self-with-other relationships. When recovery for the other started to emerge from the participants narratives, I was cautious not to move into a theoretical domain and lead with my knowledge of relational psychotherapy and associated theories. Whilst it could be argued that this sense emerged because of my theoretical interest, I believe the quotations used are sufficient in demonstrating that this was an emerging piece in and of its own right.

4.5.2. Subordinate theme: Walking alongside the diabetes bear

Recovery and change did not result in an omnipresent love for living with T1DM, yet several of the participants named a sense of coming to terms with it being one aspect of their lives as opposed to a defining feature. Participants learned to live side by side with T1DM, a process Peggy shares through the metaphor of a diabetes bear.

> I realised I needed to stop fighting this monster that is diabetes you know, I just need to talk to the monster and then we can walk side by side I know it's a stupid analogy but the way I kind of like to visualise things like that and I see it as this stupid horrible bear that you think is going to kill you but then you calm down and the bear calms down and you're side by side and it's totally fine and you get on with one another that’s my kind of diabetes analogy, that's how I think of it. (Peggy: P28)

By personifying her diabetes as a bear Peggy transforms her experience into an image which in turn appears to help her to manage and respond to her difficulties, a position which is similar to Jen and her two relationships. Both Peggy and Jen created a phenomenological image that they used to motivate and support themselves through change and recovery, thus indicating a potential value of imagery in change and recovery for some individuals. Peggy’s citation highlights her journey of coming to terms with her diabetes, something which she initially feared, fought, and considered to be a threat to her existence. Talking to “the monster” and calming down, suggests a movement away from resistance or avoidance and towards one characterised by openness, integration, connection, and expression, a position illustrated by her comment “you’re side by side and it’s totally fine.”

In relation to the behavioural act of taking insulin participants considered themselves to be improving. However, body image concerns remained and became pronounced when participants felt stressed or anxious. Alex, Carley, and Peggy, all described ongoing body-image concerns and challenging relationships with their body, despite no longer using insulin for weight control.

> I still do think like I just can’t do this today and I'm really anxious and I've got all this stuff going on and you know what would made me feel better, being half a stone lighter by this time tomorrow. I still struggle to take care of my diabetes a lot you know and if it hadn't have been for my partner I think I would have probably relapsed happily I might add. (Alex: A58)

Alex highlights the incessant nature of diabetes and the necessity of making daily health orientated decisions, whilst at the same time suggesting that it is through her diabetes that she can make herself “feel better.” In this way, Alex’s diabetes appears to have a defensive function as it enables her to displace her feelings and “feel better” by omitting insulin, which in turn leads to weight loss and a reduction of anxiety. Losing weight therefore appears to hold a sense of emotional regulation and coping for Alex. There is also a duality in that to “feel better” she makes herself physically unwell by restricting her insulin.

Although Alex voices her temptation to restrict her insulin in the face of daily stressors and anxieties she resists because of the presence of her partner. This adds a layer to the value of relationships in motivating recovery and change, by suggesting that at least for Alex a significant other helps her to maintain recovery. “Happily” relapsing without her partner suggests that Alex may not view herself as worthy of recovery in her own right, a piece which shared by Catherine can take time to acquire, and once achieved does not diminish the ongoing battle around taking insulin:

> Even after treatment and stuff it was still it's a really conscious decision that I have to make every single time. The psychological battle with it and how difficult that can be erm and although and it's not something that ever completely goes away I don't think. (Catherine: C71)

By switching from the past tense “it was” to the present “it is,” Catherine captures the ongoing effort of her recovery. In the same way that Catherine’s diabetes and its requirements do not go away, nor does her “psychological battle” around taking her insulin. There is a sense of realism and honesty emerging from Catherine’s narrative as she speaks from a position of recovery, but not one which portrays recovery as idealistic and ‘happily ever after.’ Indeed, Catherine does not strive to abolish triggering thoughts or situations, rather she uses them as “signs” to indicate a need to increase efforts and motivation to maintain her recovery, as she explains:

> I mean on a good day (..) I don't have to like battle with taking my insulin or what I'm eating it’s good. The days when I feel like I struggle to decide what to eat because I start thinking about what will that do to my weight, how many carbs has this got, how much fat has that got and they are like my warning signs (..) and I'm very aware that it's when I’m tired, stressed or upset, they are the times when I'm more likely to resort to disordered patterns of thinking and old behaviours and stuff (Catherine: C72)

As participants reflected on their journey of change and recovery, a newfound appreciation of their inner strength and ability to have got through a difficult time emerged.

> I feel proud of myself, proud of getting through it and getting on with it. I feel like I'm quite a resilient person and I feel quite good about that. I can acknowledge the inner strength that I have, it's a nice feeling I am proud about being able to make it through this journey and being on the other side. (Peggy: P33)

> It was a painful and dark time for me but also it also really encourages me as well about how far I've come and just thinking about like what life was like then and what is like now and the progress I've made because I don't think I often give myself credit for that but when I sit here and like talk about it for that length of time, I'm like oh yeah that was pretty massive, it's good. (Catherine: C73)

The interviews enabled Peggy and Catherine to reflect upon how they emerged through a difficult time. There is a sense of realisation and achievement in their narratives as they acknowledge the difficulties they have overcome and take ownership of their own attributes. Neither Peggy or Catherine minimise their own positive characteristics or qualities, which in turn suggests a change in their self-perception and self-esteem. Through recovery and change, Peggy and Catherine seemed to have developed confidence in their own ability and worth, and no longer associate their value or measure of worth on thinness. Both have moved towards a healthier self-with-self relationship whereby they are able to recognise, acknowledge and celebrate their strengths and successes.

4.5.2.1. Reflexivity (11)

The concepts of recovery and change are used frequently throughout the superordinate theme, but I wondered how my position in the world influenced my understanding of and meaning assigned to these concepts. My experience of Western culture is that it is weighted heavily towards an individualistic position as opposed to a collective. As such, recovery and change often extend themselves to being individual pursuits. Yet, the narratives of the participants are emphasising the need for something more than an individual emphasis, they call out for the other and stress their value. At this point, I realised that I had made sense of and approached the research through the lens of growing up in a Western, individualistic culture. In response, I questioned why I feel there is a tendency to view recovery as something for the individual, as though a problem or difficulty is located within them. I wondered whether there could be room for a collective experience of change with the significant others. More so, if the same phenomenon was to emerge within a more collectivist way of living, such as that traditionally assigned to Asian cultures, would the approach to recovery and change be different?

4.5.3. Summary: There is recovery

The final superordinate theme emphasized a different element of the participants' experiences. Previously, the superordinate themes have attended to the sense of being *in* the phenomenon, whereby participants shared what it was like to be in relation to others, themselves, and the phenomenon itself. In contrast, this superordinate theme focused on what it was like for participants to *come through* the phenomenon via change and recovery. In this way, there is a sense of time passing and transition captured through the analysis and the participants lives.

Overall, the superordinate theme stressed the importance of participants being able to access an envisioned or hoped-for-future as a gateway to change and recovery. For Peggy and David, this was obtained through something, namely facing the reality, of health complications. An element which raised questions around the potential difference between knowing about and experiencing difficulties. Additionally, participants spoke of recovering and staying well for the other, which extended to family, loved ones, best friends and hoped-for children. What emerged was the need to consider the value of recovering for the other, at least initially, as this avenue often felt more accessible and meaningful in the absence of valuing the self as worthy for recovery.

4.6. Chapter summary

Over the course of the four superordinate themes various aspects of the participants experience of using insulin for weight control have been explored. To begin the analysis attended to relational experiences between participants and healthcare professionals. Broadly speaking, participants were scolded and infantilised by the medical other, who adopted a common sense approach towards participants and their insulin restriction. In doing so, the participants consciousness and emotional beings were not considered, and their voices and narratives were shut down and erased. For the most part, healthcare professionals and participants existed in a transactional relationship, which contributed to participants sense of isolation and in some cases acted as a barrier to seeking and receiving help. Where participants and healthcare professionals were able to establish positive relationships, genuine care and life saving support was experienced. Yet even in the absence of connection with healthcare professionals, participants found meaning and validation of their experiences through connecting with peers.

When exploring the relationship towards the phenomenon itself, a significant paradox emerged. On the one hand diabulimia was positioned as magic as it enabled participants access to a weight loss reality that usually does not exist. However, this reality was not without its consequences as participants shared the detrimental impact of the phenomenon across all areas of their lives. Participants appeared to be balancing different realms of their experience, which extended into the realm of life and death. Here, participants shared coming to terms with their own mortality and that of close friends. Reflections of feeling lucky and guilty emerged when reflecting on their survival, and in some cases the acknowledgment of an approaching yet unknow arrival of their demise.

As the analysis attended to questions around the function and hoped-for-gains of diabulimia meanings related to desirability, acceptance, safety, power, and control started to emerge. In this way, it appeared the use of insulin for weight control was a vehicle to move towards an idealised self, which once obtained would result in relational, personal, or academic success and autonomy. It started to become clear that the use of insulin for weight control was the participants 'vehicle of choice,' partially in response to the internalisation of implicit and explicit societal messages for the female participants. However, akin to a role reversal, participants named feeling out of control and trapped by the very element they hoped would help them feel better via the acquisition of the successes. It was here that possible differences between masculine and feminine experience of diabulimia emerged, with David describing his insulin restriction as “objective-based” and like a “switch.” Nonetheless, all participants appeared to have a performative element of the self, whereby the foreground was prioritised yet for the process of recovery and change, access to the backstage and relational depth was required.

Participants voiced a longing to be desired in the third superordinate theme, yet when reflecting on their journey of change and recovery in the final superordinate theme the importance and value of relational depth emerged. In this way, participants experienced being valued beyond their physical presentation, such that their worth was not equated to their thinness in the minds of the other. Recovery was subjective to each participant with several naming its ongoing and non-linear nature. Recovery and change were aided by the envisioning of hoped-for-future, and in several cases was motivated by initially recovering for the other, namely loved ones and hoped-for children. How these findings are located within and contribute to existing literature is addressed in the following chapter, along with reflections on how the research adds to the field of CoP and wider contexts.

CHAPTER FIVE

Discussion

5.1. Chapter overview

This chapter begins by elaborating on the research findings and locating them within the existing literature, theory, and wider societal context. The discussion will be organised by the four central themes that emerged from the analysis. Throughout this section, consideration will be given to which findings appear to extend, support, and differ from the literature. After this, the strengths of the research are considered, and clinical recommendations based on the research findings are made. The chapter concludes by naming possible future research avenues and a final reflexivity statement.

5.2. “Go and count your carbs and take your jabs”

Within the first superordinate theme, participants shared their interpersonal experiences with healthcare professionals. Although there were some exceptions, communication between healthcare professionals and the participants was described as patronising and judgemental, with connections to the lifeworld of the participant not being made. In *Foundations for Health Promotion* Wills and Nadioo (2016) name the dominance of the Western scientific model of health which prioritises observation, classification, and calculation for the means of increasing understanding. Within this model, the human body appears to become an object for the pursuit of scientific knowledge and overlooks how difficulties and illness take place in a social context. Wills and Naidoo (2016) stress that individuals working within this model risk bracketing the lifeworld of the individual and overlooking how the stressors of their context may shape the nature of illness. Supporting this proposition, the research highlighted how diabulimia was not solely about insulin. Instead, it appeared to be about the participants mind and the body, interaction with families and peers and positioning within a wider social-cultural world.

An endless lecture revealed the presence of one-way conversations between healthcare professionals and participants, whereby healthcare professionals assumed a position of power seemingly embedded within a natural standpoint of common-sense. A position highlighted by the participant’s experiences of being told by healthcare professionals to just take their insulin. By doing so, the healthcare professionals impose what appear to be fixed and absolute commands at the expense of trying to see the world from the participant’s perspective. The healthcare professionals common-sense position holds a tone similar to that of the Rational Choice Theory proposed by Cornish and Clark (1987). Here, behaviour is viewed through the lens of rational choice and assumes that there is inherent rationality in making decisions whereby the costs and benefits are evaluated. Within this study, it appears that healthcare professionals interacted with the participants from a position of rational choice, yet as Peggy reminds us “my insulin omission had nothing to do with a lack of awareness of the consequences, so it really didn’t matter how many times they told me I would lose my legs or my eyesight” (Peggy: P29). By adopting a rational choice position the consciousness, emotional complexities and the broader context of the individual are overlooked, with the voice of the individual erased as questions around their choices and feelings remain unasked (Laing, 1954). What emerged was a dynamic of transactional analysis between healthcare professionals and individuals (Berne, 1964). Healthcare professionals appeared to take on the role of a parent relaying a series of barbs and warnings to the participant, who in turn became relationally infantilised, which led to them feeling misunderstood and isolated.

Participants not aligning with the rational behaviour of taking insulin as required were frequently assigned the label of being non-compliant. A title which participants felt implied they were naughty, breaking a rule, and intentionally overlooking the health consequences of insulin restriction. This finding supported an element of Goebel-Fabbri’s (2017) study, wherein participants spoke of hating the label non-compliant as it felt critical and oversimplified. Becker’s (1963) labelling theory posits that as members of society begin to treat individuals based on an assigned label, the individual beings to accept this position and behave in accordance with the expectations given to the label. A process that was evident as Carley voiced her descent into rebellion and nihilism in the absence of genuine care and support from the other (Carley: CAR20), and as Peggy questioned the point of looking after herself in the face of seemingly inevitable diabetes complications and her mortality (Peggy: P18). Subsequently, there appears to be a cyclical pattern emerging whereby healthcare professionals continuously advocate compliance, yet in response, Carley and Peggy rebelled and further entrenched themselves into their insulin restriction. This sense of a cyclical power struggle appears to be partially dissolved through building rapport.

Participant accounts of being made to feel that they were the only one experiencing their difficulties resonate with the notion of symbolic violence by Bourdieu (1989). Symbolic violence in this sense represents the participants not being heard or understood, with their narratives being closed down or framed within a concept which means the individual and their experiences are erased or constrained within certain preconceived assumptions. Symbolic violence also appears present in previous studies on diabulimia as Allan (2015) reported that individuals were frequently told the phenomenon was “made up on the internet,” (p.100) thus invalidating the individual’s expression and experience of reality. The closing down of the participant’s narratives is further problematised when considering Woods’ (2012) claim that narrative is pivotal to (re)humanising medicine. Narrative facilitates insight into the subjective experience of illness, enhances communications skills, and facilities the individual’s exploration and articulation of changes in their being. Moreover, Charon (2008) and Frank (1995) stress that opening an individual’s narrative helps healthcare professionals to grasp the complexity of the illness experience and understand its relationship to and impact upon other aspects of an individual’s world.

In the absence of support and understanding from healthcare professionals, participants benefitted from connecting with peer groups and sharing the identity of diabulimia. Alex stated that “other diabulimic’s saved me because I was like it’s not just me” (Alex: A81) whilst Jen reflects on her moment of discovering an American based community as a “lightbulb moment when you’re like I’m not the only one” (Jen: J6). This finding supports that of Hastings et al. (2016) who reported that the diabulimia group identity provided individuals protection from the isolation of their difficulties and enabled members to share experiences without being judged. Additionally, individuals could receive emotional support and encouragement from group members that were absent from other networks. Staite et al. (2018) reported similar themes by positing that groups also validated the feelings of members and may encourage an identify change from suffering to supporter. A sentiment which was echoed by all participants in the current study when voicing their reasons for participating in the research.

Through connecting with peers, the lifeworld of the participants stand to have been acknowledged and welcomed, a position which David advocates healthcare professionals to adopt through his statement “when you walk into a consultants office the first thing he should say to you is, how are you, really how are you doing, have you got anything you want to discuss with me at all first, I’m here to listen” (David: D153). David’s account encapsulates the need for healthcare professionals to move away from a simplistic and reductive position of stating that individuals should just take their insulin and to enquire into the person beneath the T1DM presentation. David stresses the need for improving interpersonal relationships which if achieved, appear to result in feelings of support and care. A position that was highlighted by Carley’s reflection that through a non-judgemental GP she experienced genuine care, whilst Peggy received “unbelievable” support from an NHS service and feels that she “owes them” her life (Peggy: P9). Peggy’s experience is of particular significance as previous negative experiences from healthcare professionals resulted in Peggy becoming “terrified” of being told off for restricting her insulin, which consequently prevented her from seeking help and support until she was gravely unwell (Peggy: P8).

The findings from the first superordinate theme support the notion proposed by The Care Quality Commission (2014), Findley et al. (2015) and Lowes et al. (2015) that clinical environments can influence an individual’s relationship with their diabetes. Additionally, the findings also mirror the current call by Partridge et al. (2020) to move towards a humanistic and person-centred approach to caring for and supporting individuals with T1DM who restrict their insulin to aid weight loss. Emerging from the first superordinate theme is a sense of being-with analogous to that which Buber (1958) termed I-It. Participants and healthcare professionals are placed within a subject-object relationship. One which is distant, detached, lacking in reciprocity and appears to be categorised by healthcare professionals regarding participants as an entity that can be categorised, analysed, and fixed. When the participant's body is understood as being a malfunctioning biological object by the healthcare professional, it is, according to Sartre (1956) objectified through the gaze of the other. A fundamentally alienating experience as the participants' 'self' is separated and becomes a thing (Svenaeus, 2009). Nevertheless, Laing (1954) reminds us that relationships always exist in the world; thus, when individuals face difficulties around insulin restriction the relationship between them and healthcare professionals does not cease to exist; instead, it becomes more critical than ever.

5.3. A deadly love

Participants engaged in a complicated, paradoxical relationship towards their use of insulin for weight control. In the magic of diabulimia, there is a sense of love towards the magical and mysterious phenomenon. Participants spoke of the uniqueness of the diabulimia and the realisation of how much weight could be lost through insulin restriction, which Alex considered a "gift from God" (Alex: A81). The sense of uniqueness and effectiveness of insulin restriction for weight loss voiced by the participants is also noted in previous research investigating the motivations for insulin restriction. Several studies suggested that the uniqueness of the phenomenon, coupled with the realisation of how much weight can be lost appears to be a driving factor towards the behaviour of insulin restriction (Ackard et al., 2008; Daneman et al., 2002; Goebel-Fabbri et al., 2008; Ismail & Treasure, 2010).

The description of magic appeared to indicate a sense of hedonistic living, whereby the participants took pleasure in the immediate weight loss from insulin restriction without any explicit concern of the future consequences. Sartre (1956) reminds us that humans, above all, are beings of projects. The project for all participants was to lose weight through insulin restriction, yet by doing so, they set aside their yet-to-come existence with diabetes. This position points to the matter of authentic and inauthentic living, as proposed by Heidegger (1978). Participants conceptually understood their yet-to-come existence could bring severe complications, yet at the same time denied this reality. A sense which David captured through his analogy of taking a magic pill and overlooking the "small print" (David: D142).

Building on the notion of hedonism, the magic property of diabulimia appeared to extend into diabetes denial, and subsequently supports Ismail and Treasure's (2010) finding that once diagnosed individuals often experience resentment or rejection of their T1DM. Within the current study, the restriction of insulin removed a reminder of having diabetes, as evidenced by Carley when she shared “I don’t want to take the insulin, it makes me different” (Carley: CAR39). Carley also reflected on the unrelenting nature of diabetes, noting that she “can’t take a break, there’s no pause on it” (Carley: CAR39). This latter statement appears to allude to the potential or presence of diabetes burnout, whereby the ongoing management of the condition can lead to a lapse in self-care. In this way, the research supports and contributes to previous literature highlighting the relationship between the aetiology of T1EDs and diabetes burnout or stress (Colton et al., 2009; Macdonald et al., 2018; Smith et al., 2008).

Whilst experiencing the magic nature of the phenomenon, participants were also experiencing the polarity of magic marked by physical distress and restricted interactions in their social and personal worlds. Participants were reminded of their fallibilities, mortality, and the givens of humanity as the impact of diabulimia was felt across all areas of their lives from the physical to the social, and even the spiritual. Building upon the latter, Moss (2008) and Bachhuber (2011) focused on the existential and spiritual concerns related to living with T1DM, concluding that there is an inherent tension in living with T1DM. Each time an individual carries out an act of health, such as administering insulin it is also a reminder that illness and death are present, and further that health and illness are inseparable (Dossey, 1991). The research participants arguably face their mortality daily through the knowledge that without insulin, they would die. A way of being which holds both life and death in equal illumination, and subsequently acts as an example of Heraclitus’ (2010) union of opposites.

In the third subordinate theme, walking the tightrope between life and death, Jen and Catherine speak of pushing their bodies to the limits of existence, where is there is an ambivalence towards living and dying. Through controlling their insulin intake, Jen, and Catherine attempt to control their fate, a form of empowerment over life and death. In a similar tone, Carley, and Alex, refer to how they envisioned their future corpses, namely within an idealised frame of the ‘self’, such as an androgynous twig and someone younger than fifty. This imagined goal and anticipated future resonate with Adler’s (1999) fictional finalism. Here, the described imagined state operates as a powerful image which then stands to influence both Alex and Carley’s behaviour. Within their fictional goals, participants have a subjective experience in which they choose what is meaningful, purposeful, and how to understand and perceive events. Whilst it remains unknown how Carley’s fictional finalism will manifest, Alex voices a tension in her continued existence as she did not die in line with her fictional finalism as she was “supposed to” (Alex: A63).

5.4. “It is so much deeper than just insulin”

Within the third superordinate theme, the participants use of insulin for weight control within a broader societal, cultural, and historical context became apparent. Participants were thrown into a pre-existing culture, meaning that part of their existence was to make sense of themselves within this cultural given (Heidegger, 1978). One of the givens identified and internalised by the female participants within the subordinate theme “this is what you are meant to look like,” was the perception of being healthy or desirable through thinness. As discussed in the literature review, Meltzer et al. (2001) and Pinar (2005) highlight how cultural and societal norms are influential in the development of using insulin for weight control. A finding echoed by the current study as participants appeared to compare themselves against an idealised position which in turn influenced their self-with-self relationship. As Peggy and Carley highlight respectively “that’s the image in society, we are taught” (Peggy: P7) and “if you’re not a skinny person with a flat stomach who looks good in bikini’s and stuff, then you’re shit” (Carley: CAR47).

In *Bodies* Susie Orbach (2009) discusses how bodies have become sites of display and manufacture as opposed to a place from which to participant in and understand the world (Merleau-Ponty, 1962). For Orbach (2009) the female body is a place for transformation, performance and marketisation, harbouring hope that if one could have, own, inhabit or display the thin ideal then you become a person who lives within a wanted body, and with this comes the acquisition of certain cultural markers of success. Furthermore, Fikkan and Rothblum (2011) claim that women who conform to the thinness ideal, have considerable advantages in employment, education, romantic relationships, and positive portrayals in media. Jen’s comment that “if you are thin in society then you can be successful, (and) marry someone quite easily”(Jen: J109), Carley’s reflection that she does not fit the stereotype of what people want (Carley: CAR47), and Peggy’s (Peggy: P7) belief that everything in her life would fall into place once she was skinny or reached a certain weight, are poignant examples of such embedded and internalised societal ideals. Principles which appear associated with the attainment of belonging and acceptance, based upon the external surface presentation of the body. Nonetheless, Heraclitus (2010) offers a reminder that the idealised position is always changing and in flux. Thus, the quest to reach the thinness ideal seems to be nothing more than a myth or mirage but one which can be fatal.

The participants attempt to guide the impression that others may make of them through losing weight resonates with Goffman’s (1956) *The presentation of self in everyday life.* Participants assign positive aspects of the self, namely being thin, to the forestage whilst that which may be considered undesirable or detrimental to the intended impression remains in the backstage.

Carley's (CAR27) reflection that she does not know herself further suggests that an existence defined by a theatrical performance of the 'self' can result in what Sartre (1956) would term bad faith. In the stance of bad faith, the participant's beliefs around weight loss dominate their existence resulting in a fragmentation of their being, automation-like behaviour, and a one-dimensional 'self' made up of only the external presentation (Spinelli, 2005).

In contrast to the female participants, David's relationship with his body and the use of insulin for weight control features somewhat differently. He does not explicitly speak of cultural pressures and instead, uses rational, technological language to describe his use of insulin for weight control such as it being a "switch" (D20) and "objective-based" (D134). David's speech resonates with Seidler's masculinity and social theory, in which he posits that men come to see the world through systems and the denial of emotions (Cole, 1999). Subsequently, it seems that through his mechanical language, David's 'self' takes on a robotic and automatic form whilst also engaging in a degree of self-performance resonant with the female participants. A difference, however, is that David spoke of pursuing weight-loss for sporting objectives, as well as a desire to gain respect and not to be seen as vulnerable. Vulnerability for David was associated with hypoglycaemia (low glucose levels), and in turn, may indicate his interpretation of societal and cultural expectations of men. From this perspective, avoidance of hypoglycaemia may contribute to T1ED through the reduction of insulin and the maintenance of high glucose levels, wonderings which have previously been noted in studies by Ismail and Treasure (2010) and Goebel-Fabbri et al. (2008) but without a specific gendered lens.

In *Phenomenology of Perception* Merleau-Ponty reminds us that "it is the body which speaks" (1962: p.197), whilst Treasure et al., (2010) stress that EDs are not about food; instead, they relate to feelings and act as a form of tacit communication to others. Within the subordinate theme, spinning a web, Catherine explains that insulin restriction provided her with a sense of control. A voice through which she was able to have a say in her own life and exercise her self-autonomy (Catherine: C67). In this way, Catherine's sense of self became defined by her insulin restriction while her body was an expressive and intentional source of meaning (Merleau-Ponty, 1962; Tierney & Fox, 2009).

Research on the adaptive functions of EDs has noted several purposes which can be broadly explained as helping individuals to avoid or regulate negative emotions, reinforce their identity, and express their distress (Nordbø et al., 2006; Skårderud, 2007; Wildes & Marcus, 2011). Purposes which were also noted within the current study, for example, Catherine's proclamation that her insulin restriction was not primarily about weight loss, which appeared to be the common-sense understanding (Catherine: C43) and Alex's reflection that insulin omission made everything “simple.” Notably, whilst convergences between T1ED and ED in non-diabetic populations can be identified, the current study also highlighted differences.

A large proportion of ED literature attends to the acquisition of control through EDs and whilst this featured in the present study, so did another polarity, the relinquishing of control. Carley’s (CAR42) statement that she deliberately thought about putting herself into the hospital so that she would not have to make diabetes-related decisions stresses her desire to relinquish control. A feeling which may be explained by the relenting pressure placed upon individuals with T1DM to manage the condition. It represents another example of the emerging relationship between the emotional burden of T1DM and insulin restriction. Whilst also reinforcing the importance of attending to specific T1DM related aspects in any potential intervention to support recovery and change, thus echoing the points previously raised by Bermudez et al. (2009); Young et al. (2013) and Allan and Nash (2014) within the literature review.

5.5. There is recovery

Recovery took place within the reality of having T1DM. Whilst this was shared by all participants, their psychological responses and sense-making of diabetes as a given condition of their existence differed (Heidegger, 1978). The final superordinate theme attended to the participant’s journeys of change and recovery, which were broadly characterised by envisioning and accessing a hoped-for-future and moving towards a position of acceptance and acknowledgement of having T1DM.

There are many cases in the literature of how individuals can be motivated to change health behaviours (see Llewellyn et al., 2019). One such example is proposed by Vos (2016) and hypothesises that individuals will change behaviours, such as taking insulin when they realise how this can help move towards a more significant meaning in life. Whilst this resonated with four of the participants, Peggy and David offered another insight by pursuing recovery in response to experiencing health complications caused by insulin restriction. Therefore, recovery as the hoped-for future state appeared to be influenced by positive and negative dynamics occurring in the present.

This finding implies that change and recovery can be motivated from the physical aspect of an individual’s existence, whilst also suggesting that there could be a difference between a surface level knowing and a more in-depth experiencing of health complications. However, this alone was not always enough to motivate recovery or change, as Alex and Jen spoke about numerous friends who had died because of insulin restriction. As such, this supports questions initially raised by Alloway et al. (2001) and Clery et al. (2017) into the effectiveness of continued health warnings or psychoeducational interventions from healthcare professionals to individuals restricting insulin after initial information has been shared. The consensus for most of the participants was that physical consequences alone were not enough to motivate recovery or change.

The study identified an additional avenue for change and recovery. Within the subordinate theme, finding a reason, participants spoke of recovering for the other, in the absence of feeling able or wanting to pursue this for themselves. Participants did not seem to have a positive concept of the self on which to build recovery form, thus if a positive sense of self from which to build recovery from is absent, then change and recovery for the self, as illustrated in the study, may be problematic. Subsequently, another conduit is needed, and the idea of recovering for the other allows for a sense of self to eventually form. This idea of recovery for the other draws upon the phenomenological relational nature of humanity as voiced by Heidegger (1978). From this perspective, a sense of self re-emerges through a connection with people. Recovery for the other, therefore, can be viewed as an empowering position and should not be set aside.

As illustrated by La Mela et al. (2013), low self-esteem in individuals with EDs appeared to impact on recovery. As such, one of the challenges for healthcare professionals may be establishing self-esteem and self-worth within individuals using insulin for weight loss and how this can be achieved to generate a sense of recovery. Within the current study recovery from an individual perspective appeared problematic as participants named self-hate, disgust, and ambivalence towards their own happiness. Nonetheless, despite experiencing low self-esteem and worth Carley, Jen, Alex, Peggy, and Catherine were able to access recovery and change through generating a final fictionalism of the other (Adler, 1999). Recovery for the other within the study involved participants projecting themselves into the minds of the other and empathising with their being-in-the-world. To illustrate, participants reflected on the emotional impact of friends and family if they continued to restrict insulin or died from doing so, whilst also envisioning how relationships with partners may be affected. For Jen and Catherine, the other also involved the hoped-for future of baring a child, and how their continued use of insulin for weight loss may move them away from this idealised position.

This finding raises potentially important questions around how to engage individuals in recovery and support pathways, when they view themselves negatively or as being unworthy of recovery. As developing care pathways start to adopt a humanistic and person-centred approach such as those proposed by Treasure et al. (2010) and Partridge et al. (2020), recovery for the other presents itself as a valuable engagement avenue. It may be that for individuals using insulin for weight loss, conceptualising recovery or change for the other, at least initially may assist in building engagement and recovery capital, in the absence of a positive sense of self. From this perspective, individuals may be more willing or feel more able to move towards positions of change and recovery for the other, and thus presents itself as an important concept to explore with individuals entering care and support pathways.

As well as being central in motivating change and recovery, the other also acted as a protective factor against returning to insulin restriction for several of the participants. Indeed, Alex claimed that she would have “happily relapsed” if it were not for her partner (A58). A reflection which raises several issues around the role of partners within the recovery process. From Alex’s perspective, it appears a significant responsibility is placed upon her partner, and should the relationship undergo stress, then this may impact her recovery process. It would, therefore, appear valuable for healthcare professionals to be mindful of the role of significant relationships in an individual’s life and involve such individuals in care planning and support, a position currently advocated in ED treatment (Treasure et al., 2010) and previously emphasised by Peveler and Fairburn (1998). It must be considered then, that if the presence of significant relationships acts as a motivational and protective element, their loss or rupture could be risk factors for the reuse of insulin for weight control. Consequently, a return to insulin restriction would need to be reflected upon with this element of the individual’s lifeworld in mind.

A second element identified by the study relating to change and recovery was the role of integration and tolerance. In the subordinate theme, walking alongside the diabetes bear, Peggy describes moving from a position of “fighting” her diabetes bear to being “alongside it,” metaphorical language which captures her transition from resistance to a tolerance of having T1DM (Peggy: P28). The presence of diabetes denial and avoidance has been referred to previously, as though participants rejected this part of the self. In *the illusion of personal individuality,* Stack-Sullivan (1964) argued that individuals have many different selves, all of which would ideally be integrated across the lifespan. Aspects of the self, which are segregated as opposed to integrated, are termed dissociated within the writings of attachment researchers and relational theorists (DeYoung, 2015; Wallin, 2007). Through this lens it appears that the participants initially dissociated their diabetic self, thus defensively modifying their sense of reality, but through recovery moved towards integration whereby diabetes was positioned as just one part of their multiplicity of selves (Wallin, 2007).

Akin to the perpetual nature of their diabetes participants positioned their recovery as an ongoing project and one often in flux. Nonetheless, as Peggy and Catherine reflected upon their journey of recovery and change, they spoke of their newfound appreciation of their inner strength and self-with-self relationship. Peggy’s comment that she is proud of herself and Catherine’s acknowledgement of her improvement suggest that both participants are working towards a position of self-love (P33; C73). Self-love, according to Fromm (1956) in *the art of loving* is vital for living a flourishing life but cannot be assumed from the outset to exist. Fromm (1956) advocates that love of the self is as an active art as opposed to a passive position into which an individual falls. Often within the natural standpoint, there is an assumption that people love or feel good about themselves, but as the six participants of the study have shown, this is not always the case. Instead, love-of-the-self is a skill that is developed through care, responsibility, respect, and knowledge. To this end, Peggy and Catherine demonstrate Fromm's (1956) view that one does not fall into love with oneself; instead, they have developed a love of the self in response to the opposite polarity, which is only loving diabulimia.

5.6. Strengths and challenges

One strength of this research project is that it is grounded in the lived experiences of the participants whilst being methodologically consistent. In this way, the research used phenomenology to move beyond the natural standpoint and towards dynamics that existed beneath the surface. This is highlighted by attending to the various polarities, antinomies, and inconsistencies that the participants, through a reflexive turn, have been working through. These characteristics of the research act as additional support for the trustworthiness and reliability of the findings as per Yardley's (2000) criteria discussed in section 3.18.

Participants shared how I had made them feel comfortable and communicated my attempts to understand them, for example, through asking prompt questions or inquiring into the meaning of certain words and statements, so that I did not assume meaning based upon my own experiences. This seemed particularly significant as participants spoke of their experiences of being misunderstood and dismissed. Carpenter (2009) highlights how the participant's perception of the research situation influences what they feel able to share. Consequently, the participant's feedback, as well as David and Carley's voiced self-discoveries, indicate that the interview environment contributed to their ability and willingness to share and gain insights into their experiences (D56/57; CAR82).

The challenges for the research are that it used a small sample and was undertaken with five women and one man who each have their own complex individual narratives. As such, it is difficult to make claims that encompass individuals outside of the study. That said, without undertaking these small-scale studies into a phenomenon, these complexities remain buried. Initially, I questioned how David's participation would be positioned within IPA's requirement for homogeneity. Yet Smith et al. (2009) note that the definition of homogeneity depends on each study. Subsequently, homogeneity was claimed through other means, namely, the shared experience of the research phenomenon, a diagnosis of T1DM, and residence within the UK. Additionally, findings that insulin restriction is more prevalent in females than males seem likely explanations for the uneven gender of participants (Goebel-Fabbri, 2017; Goebel-Fabbri et al., 2008), as well as studies noting that boys and men are less likely to seek help for insulin restriction because they face greater stigma as a result of traditional male gender roles (Griffiths et al., 2015; Peate, 2001; Staite et al., 2018). Furthermore, T1DM is reportedly more common in western society and in Caucasians, which could further explain the lack of diversity in participant nationality and ethnicity (Patterson et al., 2014).

As indicated by the shared superordinate themes across all six participants, David's experiences seemed to converge at a broader level with the female participants, with divergences noted within the subordinate themes. Whilst a formal comparison of gender difference is not possible, nor was it the aim of the research, David's participation is notable as previous qualitative studies on T1ED and diabulimia to date, such as those by Goebel-Fabbri, (2017), Hastings et al., (2016), Macdonald et al., (2018) and Staite et al., (2018) have included only female participants. Thus, David's contribution to this research is a pivotal step in understanding a masculine experience of using insulin for weight loss.

A further challenge to the study relates to my lack of familiarity with specific elements of the phenomenon. During two interviews, participants temporality moved away from their lived experience to explain some aspects of diabetes, namely Kussmaul breathing and the normal range for ketones. Padgett (2008), and Kacen and Chaitin (2006) claim that having a shared experience with research participants offers three advantages: more natural entrée, knowing more about the topic and understanding nuanced reactions of the participants (Berger, 2015). However, I would counter this position by stating that even if I did have personal experience of diabulimia, the participant would always be considered the expert and further, the methodological foundations of the research advocates for the setting aside and working through the natural standpoint. A broader knowledge of the technicalities of the phenomenon may have prevented such diversions. However, as my research was framed through a lens of phenomenological curiosity and exploration, the deviation did not appear to compromise the nature of the interview. Instead, it was a necessary context so that a phenomenological enquiry could take place.

5.7. Implications and recommendations

The research findings presented in the previous section have useful implications for CoPs and practitioners who may work therapeutically with this demographic, as well as professionals involved in broader discussions related to policy and training. The following section will name the clinical and professional suggestions based upon the research findings, whilst also considering how the findings relate to wider concepts in health psychology. Ogden (2019) attends to theoretical models of health psychology in considerable depth and with a reach beyond that of the current study. Equally, whilst clinical recommendations within certain therapeutic frameworks are made, an exhaustive list is not claimed to be presented.

5.7.1. Relational psychotherapy

Throughout the research, the concept of integration, that is the bringing together of different strands of being was emphasised. Participants voiced their desire for various facets of their difficulties to be considered equally within the broader contexts in which they lived, whilst also sharing how coming to terms with their T1DM was necessary for change and recovery. Consequently, a therapeutic approach which advocates a holistic view of the individual and their difficulties appears well-positioned to support individuals using insulin for weight control.

By drawing upon relational psychoanalytic theories such as those by DeYoung (2015) or Mitchell (2000), coupled with person-centred and humanistic values, an individual's difficulties can be viewed as being in-relation. For example, self-with-self and self-with-other as opposed to something being inherently wrong with the individual. This approach, whilst acknowledging the context and diabetes reality of the individual, would emphasise the importance and presence of intrapersonal and interpersonal relationships. Such elements were present throughout the research in various forms, namely, the longing of participants to reach relational depths with healthcare professionals and peers, as well the importance of relational connections within the processes of change and recovery.

In this way, it seems crucial for therapeutic work to attend to the relational wants and needs of the participants, thus reducing the sense of isolation and being misunderstood, which appear characteristic of the diabulimia experience. Furthermore, an enduring sense of connection and interconnection between client and therapist has been repeatedly linked to positive therapeutic change and outcomes (Mearns & Cooper, 2005; House & Lowenthal, 2008; Mitchell, 2000). Based upon the findings of this research, CoPs or allied professionals working therapeutically with this cohort are advised to strive for relational depth, as it through this process that a transformative connection with another may be experienced (DeYoung, 2015). Consequently, revised self-with-self and self-with-other narratives can emerge, which would then allow for a change in the way individuals experience and relate to themselves (Hubble, Duncan & Miller, 1999).

Therapeutic interventions should also note that different ways of relating to self and others may not always feel good. Less constriction means more opportunities to feel disappointment, sadness, or anger, emotions which may have been inaccessible or suppressed when restricting insulin. Nonetheless, by helping individuals to reflect on their emotional and relational patterns with greater insight, whilst also providing new experiences of relational empathy and regulation, the therapeutic relationship acts as a fundamental feature to change.

The therapeutic relationship is subsequently a crucial asset when working alongside individuals restricting insulin for weight loss, as it through this relational framework that all aspects of an individual can be heard, validated, and seen.

5.7.2. Embodied relating

A further clinical recommendation based upon the relational nature of the phenomenon is related to Totton's (2015) concept of embodied relating. Here, Totton proposes that embodiment is a relational resource, whilst Barad (2007) advocates for the body to be welcomed into the therapeutic space, not to the exclusion of discourse but rather to bring the discursive and material together. Furthermore, Shilling (2012) shares how the body itself both shapes and is shaped by society; thus, one cannot access the body in a pure form unaffected by culture.

Mindful of how the participants positioned their bodies as entities which needed to conform to the thinness ideal, or as sites for weight, measurement, intervention and assessment, the literature on embodiment and embodied relating appears valuable. The incorporation of this framework into therapeutic interventions may help individuals restricting insulin to build a different relationship towards their body. Actively incorporating embodiment as part of the therapeutic process and forging links between an individual's bodily sensations, their feelings, and the meanings ascribed could subsequently help an individual to be present in an integrated way with both their bodies and their minds. A position which would present the alternative polarity of living in a mechanistic or numerically dominated body which participants of the research frequently expressed a longing to move away from (Merleau-Ponty, 1962; Ogden et al., 2006; Wallin, 2007).

5.7.3. Existential-Phenomenological Therapy

An existential-phenomenological approach to therapy may provide this cohort with space within which they would be able to wrestle with the dilemmas, paradoxes, and finitude of existence (Iacovou & Weixel-Dixon, 2015). It became apparent that the participants were facing this finitude daily and were not able to bracket this reality as easily as individuals without a chronic health condition. Consequently, therapeutic interventions with this cohort need to move into the lifeworld of the participant as opposed to remaining external to their worlds through instruction or commands.

An existential approach may have additional value by assisting individuals in acknowledging that there are aspects of life that we have not chosen nor can we control, such as having T1DM. Instead, we have some choice as to how we respond to these elements, which Jaspers (1986) terms boundary-situations. Although existential therapies can differ in their influences and practice, they share an aim of helping clients become more authentic (Young, 2019), an important concept given the performative element of the ‘self’ identified in the participants. Furthermore, existential therapies may assist individuals to identify a new source of meaning. That is, to discover a why worth living for, for example, Jen’s longing to be a mother (Frankl, 2004). In doing so, individuals may move away from what they previously held as central to their way of being in the world, namely diabulimia, and towards an alternative source of meaning such as relationships and family (Iacovou & Weixel-Dixon, 2015; Ovideo & Boemer, 2009).

5.7.4. Recommendations for health psychology

Within the field of health psychology, there are many theories and models used to inform research and develop interventions aimed at changing health behaviours. In Ogden’s 2019 publication *Health Psychology*, the author outlines how health behaviours, such as restricting insulin, can be changed by drawing upon several theoretical perspectives, such as learning theory and cognitive theory. Continuing with the sense of integration models such the COM-B which stands for; Capability, Opportunity, Motivation and Behaviour, and the theoretical domains framework reflect an integration of various theories of behavioural change. As such, they will be focused upon in the following discussion (see Atkins et al., 2017 for a full review on both models).

The COM-B and the theoretical domains framework strive for behavioural change and consider several factors which may influence the process of change, for example, social influences, environmental contexts, physical skills, health knowledge, and beliefs about health consequences. What is notable, however, is the omission of the role of emotion in the case of the COM-B, and its limited frame as proposed in the theoretical domain’s framework. Within the latter Ogden (2019) notes that emotions are used to support behavioural change through fear, visual images, and self-affirmation. However, the findings of the current study highlighted how the behavioural component of insulin restriction related to deeper emotional and relational concerns. Consequently, although individuals may unite in their behavioural presentations, the psychological and emotional experience in relation to the behaviour is subjective.

Emotional responses, according to Iacovou and Weixel-Dixon (2015), are concomitant with cognitive and physiological responses and reveal an individual’s experience and perspective of the world. To not attend fully to this element of being, risks individuals being interacted based on their surface behaviours, such that their complexities are reduced and minimised. A possible consequence of this form of interaction, as highlighted within this research, is that individuals can become further entrenched within their difficulties. In response, the research findings advocate for emotions to be further incorporated within the COM-B and the theoretical domains framework as well as within newly developed models aiming to change health-related behaviours. The current study highlighted how a behavioural act of insulin restriction was associated with various emotions, such as powerlessness and self-loathing. Subsequently, future research may benefit from exploring the role of emotions and their expression in relation to diabulimia. Slatcher and Pennebaker (2007) noted the effectiveness of expressive writing in diabetes; however, an investigation into expressive writing and diabulimia or T1EDs more broadly has not been conducted.

5.7.5. Recommendations for guidelines and training

Beyond therapeutic interventions, the research findings may also contribute to guidelines and policies around T1DM and EDs. In 2017, NICE ED guidelines included a separate section on diabetes (Allan, 2017). Whilst this represents a shift towards the recognition of T1EDs, the guidelines stress the importance of educational interventions and physical health monitoring, with only one point noting the inclusion of insulin omission within psychological interventions. The current study highlights concerns with this approach, which although on the surface appears worthy has the potential to minimise and overlook the individual's complexity. Through highlighting the subjective experience of diabulimia and the relational needs of the participants, future editions of policies and guidelines may incorporate these findings by further specifying the role of practitioners as well as the nature and focus of psychological interventions.

To facilitate the hoped-for-relationship between healthcare professionals and individuals with T1ED, further training for healthcare professionals on insulin restriction in T1DM may be needed. This study offers an in-depth account of what it was like for six individuals to live with diabulimia. These accounts may assist healthcare professionals to be aware of the multiple dynamics and complexities of diabulimia and to recall the importance of responding with empathy and compassion to connect to the individual beyond their T1DM surface presentation.

This study seems to fulfil Yardley’s (2000) criteria of *impact and importance* by generating in-depth experiential knowledge on the lived experience of diabulimia. As discussed, the findings add to conversations around how best to support individuals restricting insulin therapeutically, whilst also highlighting possible additions to developing care and treatment pathways, for example, accessing recovery for the other. More broadly, the findings may also contribute to the development and revision of guidelines. As such, the research findings offer an original contribution to the field of counselling psychology and more broadly T1EDs by expanding the current understanding of diabulimia.

5.8. Dissemination and future research avenues

The research and preliminary findings were presented at the international Diabulimia Helpline conference, San Diego in February 2019, which was received with interest and support from healthcare professionals and individuals with lived experience. Consequently, Diabulimia Helpline invited me to speak at their 2020 conference. I also received invitations to present at the East Anglia Eating Disorder Network Annual Training Conference and the Diabetes and Eating Disorder. Unfortunately, due to COVID-19 these conferences have been postponed. My research was further disseminated through presentations at my training institute, which included presenting to my peer group and those in preceding years. The thesis will also be publicly available via the Middlesex University and British Library repositories. As for longer-term projects I am interested in exploring publication opportunities within journals such as the J*ournal of Diabetes Nursing, Journal of Counselling Psychology, International Journal of Eating Disorders* and *Journal of Diabetes Management* and would welcome the opportunity to help construct workshops and deliver training on diabulimia to healthcare professionals, including CoPs.

This study was an initial exploration into the field of diabulimia and has subsequently revealed other facets that need further investigation. David was the only male participant to share his experience of the phenomenon. Emotional discourses for David were mostly absent, and he appeared to hold a different concept of the body and experience of the self in comparison to the female participants. Future research would benefit from focusing solely on the masculine experience through, for example, further IPA or case studies. Such research could help to understand any potential gender differences in relation to the phenomenon and whether support and care pathways would need specialising as a result.

Another aspect of the research was the construction of a performative self, akin to Sartre’s (1956) idea of bad faith, and that underneath this social presentation, there was a series of dynamics. This finding, coupled with literature noting that individuals adopting the term diabulimia as part of their identity, suggests future research into the construction of self-identity when using insulin for weight loss could be valuable (Tierney at al., 2009). Narrative analysis would enable future researchers to explore how individuals construct versions of reality, including self-identity through language.

Relational experiences with peers and family members were briefly touched upon in several participant interviews, but this was not consistent or enquired about further, for example, David and Alex’s experience of bullying. This is an avenue for further research as the literature notes how early relational experiences with parents and peers can influence attachment styles and subsequently eating behaviours (Dickens & Ogden, 2014; Eleanor & Ogden, 2017). Research explicitly exploring these relational avenues may contribute to understandings regarding aetiology of diabulimia and T1ED. These suggestions are not exhaustive but offer a brief overview of further research avenues based upon the current study. Diabulimia is an area where further research is warranted, and the voices of the individuals at this complicated intersection ought to be heard.

5.9. Final reflections

The reflexive accounts embedded throughout the thesis aimed to demonstrate an awareness of my experiences, reasoning, and overall impact on the research. When reflecting on my role as researcher, I noticed the emergence of several processes. Namely, the relationship between myself as researcher, the participants, the notion of power, and ethical considerations.

Ethics-in-action

At the beginning of the research process, I had conceptualised research ethics as a predominately stagnant process made up of forms, criteria's, reports and approvals. Which whilst essential only represent one domain of ethical awareness. My research recruited individuals with a chronic health condition, and although my inclusion criteria aimed at ensuring individuals were as stable as possible before participating, I was not able to eliminate the potential of T1DM influencing the interview process. Indeed, on several occasions T1DM made its presence known.

For one participant the interview had to be paused while she attended to her decreasing glucose levels. The participant had to leave the interview, find a shop nearby, return to the room and wait for her glucose levels to return to a more balanced range. During this time, I wondered many things, should I go to the shop for her, do I go to the shop with her, what do I do if she is unable to stabilise her glucose levels? In this moment, I felt a large amount of unknowing, coupled with a desire to respect the participant in her own health management. I chose to ask the participant whether there was anything I could do to assist and allowed her the space and time needed before asking whether she felt able and willing to continue the interview. This experience was notable as it was a live insight into living with T1DM. Up to this point participants had explained this verbally to me, yet in this instance, I was witnessing an in-the-moment snapshot of what it was like to live with T1DM and the impact this can have on an individual's daily life. The participant likened this process to "life admin," yet for me, it added a layer of depth and richness to the lived experience and provoked a significant personal reflection around the complexities of having T1DM.

The presence of power

The role of researcher places me in a privileged and arguably more powerful position than that of the participants, particularly within the interview and when writing the analysis. As researcher I was able to set the agenda and define the parameters of conversation through the research question and interview schedule. I was asking the participants to share experiences which they may not typically share with others, whilst not revealing much about myself. Yet at the same time, I was dependant on my participants willingness to not only take part in the study, but also to share their experiences and thoughts about the phenomena in question.

Several attempts to acknowledge and balance the power differential between myself and the participants were made throughout the interviews and analysis, for example offering participants the opportunity to read the interview schedule, reminding the participants that they were the expert of their own experience, and encouraging them to choose their own pseudo-name. Attending to the presence of power became increasingly important in light of the power imbalances the participants encountered with health professionals. I was mindful that participants may be positioning me as a health professional and questioned the impact this may have on their willingness to share and discuss their experiences.

In an attempt to address this potential process, I aimed to come across as genuinely open and curious. I was not at the interview to impose my position or perspective, and before the interview ended, I ensured all participants had the opportunity to share anything else which they felt was important for me know. On several occasions, participants had to clarify diabetes related terms or conditions which were beyond my understanding. I believe these moments highlighted the expertise of the participants and my attitude of openness and curiosity to genuinely understand their experiences.

During the analysis, I was aware of the interpretive strand of IPA and how this would inherently take me beyond the participants transcripts. Again, the process of power emerged as I became responsible for what narratives were included and how they were interpreted. In these moments, it was important to treat the narratives with respect and sensitivity. I ensured that I used the participants narratives as much as possible and as evenly as I could when supporting an interpretive point or naming a theme. What is more, I included a large amount of the participants transcripts in the appendices to reduce the likelihood of participants feeling that their narrative had been “discarded” or considered “not good enough.” My own personal process came into play as I noticed a longing to want to include all the participants narratives as a sign of thanks and respect for their honesty and bravery. My role as researcher further extends to how I interpreted the participants narratives and made sense of their sense making. My subjectivity was inherent in this process as another individual interacting with the participant transcripts may have produced different findings and understanding. It is likely, for example, that my positioning as a young woman made me more sensitive to the emergence of female beauty ideals in the participants narratives.

Whilst writing, I also became aware of how I felt at different stages of the research process. The analysis, whilst emotionally taxing at times, felt expressive and colourful. I felt connected to the participants and over time, gained confidence in my ability to communicate the emerging experiential themes. In contrast, the literature review generated feelings of anxiety and dread, which were mirrored in a rigid and depersonalised writing style in early drafts. Conversations with my supervisor led me to identify the anxiety as being a product of getting lost in the literature. I learnt the importance of staying close to the research question and using my voice to guide the thesis and provide a roadmap to the reader. With the support of my supervisor and growing confidence, writing the thesis became less of an imposing mountain and more an enjoyable climb.

Moving beyond my natural standpoint

The research process taught me to strive for progress not necessarily perfection and reminded me of the importance to look beyond the immediately present and transcend the natural standpoint. In the earlier stages of the research, I held a position towards diabulimia which resonated with the 'common-sense' approach of the healthcare professionals. I did not understand why individuals would restrict their insulin for weight loss given the severe consequences. Attached to this was an air of judgement, an uncomfortable realisation, yet nonetheless one which was present due my naive natural standpoint. I believe this judgemental air is evident in earlier versions of my research question whereby I considered individuals to be "misusing" their insulin, as if they were doing something "wrong."

As my involvement with the research topic and participants developed, so did my understanding of diabulimia. My natural standpoint was highlighted and challenged, as the complexities, polarities, and layers associated with experiencing diabulimia surfaced. David's analogy of a magic pill represented a significant shift in my relationship towards the phenomenon, as it was at this point that I felt able to step into the world of the other and ask myself would I take the magic pill? Initially, I would have simply answered 'no, why would you,' yet now I understand how deep and complicated this question really is. If I was to be asked this question multiple times a day for the rest of my life. I honestly do not know if my answer would always be the same.

I hope that throughout the research, you have come to know Alex, Carley, Jen, David, Catherine, Peggy, and myself as we have shared our experiences and reflections. An ongoing challenge throughout the research was balancing the space assigned to myself, the participants and ensuring that the reader could follow the narrative threads. Upon reflection it may be that I assigned the least amount of space to myself which may leave the reader wanting to know more about my personal relationship with the research or perhaps my situatedness within it. This would be reflective of my positioning with the other outside of a research paradigm, yet to this I would say that my ‘voice,’ is not limited to the reflexive boxes or journal extracts. Rather, every sentence, title, expression, and paragraph are infused with my way of being-in-the-world and how I attempt to resonate and connect with others. Although much is more is needed within the field of diabulimia and T1EDs to help understand and support the individuals, I encourage everyone touched by the topic through personal experience, research, loved ones, or the provision of care to look beyond the surface and attend to intersubjective space between individuals. For as noted by Mackesy (2019) “we can only see our outsides, but nearly everything happens on the inside” (p.28).

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Appendices

Appendix 1: Literature Search Strategy

A comprehensive search was run using the Middlesex University database (Library Search) and the Roehampton University database (accessed through SCONUL membership - Society of College, National and University Libraries), as well as PsycINFO, PsycARTICLES, PubMed, JSTOR, ScienceDirect, SpringerLink, Wiley Online Library, and PEP-Web databases. The following search terms were used: ‘Eating Disorder-Diabetes Mellitus Type 1’ OR ‘Type 1 Diabetes’ OR ‘Type 1 Diabetes Mellitus’ [All fields] AND ‘Eating Disorder’ OR ‘bulimia’ OR ‘anorexia’ OR ‘binge eating’ OR ‘insulin restriction’ OR ‘insulin omission’ OR diabulimia OR ‘disordered eating’ [All fields]. Additional search terms of ‘psychotherapeutic’ OR ‘psychological’ OR ‘psychoeducational’ ‘interventions’ OR ‘treatment’ OR ‘support’ was used in conjunction with original terms when identifying literature related to the treatment and support of individuals with T1DM omitting insulin for weight loss.

The initial online search resulted in approximately 500 papers. Studies that were duplicates, that were not in English, that did not differentiate the diabetes type, focused on type 2 diabetes, or explored other chronic health conditions unrelated to T1DM or eating disorders such as cancer or neurological diseases were excluded. Following the exclusion criteria, roughly 200 papers were retained for the literature review. Initially, no publication date range was used in the search, however as the search progressed the date range was gradually reduced to the previous 20, 10 and then 5 years to ensure the most recent literature was found and included. This further reduced the number of relevant studies to be included into the literature review to approximately 60.

As the literature review advanced additional search strategies were also incorporated. These included the use of Google Scholar, setting up Google Scholar Alerts in line with the named search terms, and searching the reference lists of relevant articles and books akin to a snowballing technique. In this way the papers included the literature review were formed via a continuously back-and-forth process with the literature and search strategies. An online tutorial with a librarian at Middlesex University further helped to develop my literature searching skills.

Appendix 2: Interview Schedule

Interview Schedule

Opening

Create a rapport with the participant. This may involve asking questions (for example) about hobbies, interests, journey to the interview location, general reflections for example on the weather, and inquiring into how they are feeling about the interview. I then ensure the participant is comfortable and whether they need anything such as a bathroom break or a glass of water before we begin.

Following this I would reintroduce myself and reclarify the purpose of interview by introducing the following statement.

“Our conversation today will focus on your experience of using insulin for weight control. I am interested in your experience and how you share it. You are the expert of your own experience so there is no right or wrong. Please answer the questions in as much detail as possible, but you can skip questions at any point should you wish as well as pausing or ending the interview. I may invite you to describe and expand on your experiences more as our conversation progresses. Do you have any questions before we begin?”

Interview Questions

1) Can you tell me what motivated you to take part in the research?
2) What was it like for you when you when you were using insulin for weight control?
   What did the experience bring up for you?

   If needed, additional prompts here include:
   What was this like in terms of how you experienced your; physicality; daily life; your relationships with others; your relationship with yourself; your aims and aspirations.

3) What does diabulimia mean to you?
4) What has it been like for you to talk about your experience with me today?
5) Is there anything that I have not asked you about your experience that you would like me to know?

Prompts/Clarifications

- Can you explain that a little more?
- Can you help me understand what this is like?
- Tell me more
- How do you mean?
- Could you give me an example?
- What happened then?
- What did you think/feel/do?
- I noticed you had a response when you said that, can you say more about what that response was?
- Is there anything else that comes up in response to that?

Additional questions for pilot interview:

- How did you feel during the interview?
- How did you feel about the questions asked?
- Do you feel there was anything that the interview missed out or should have included?
- Do you have any further comments, reflections, or feedback about the interview process?

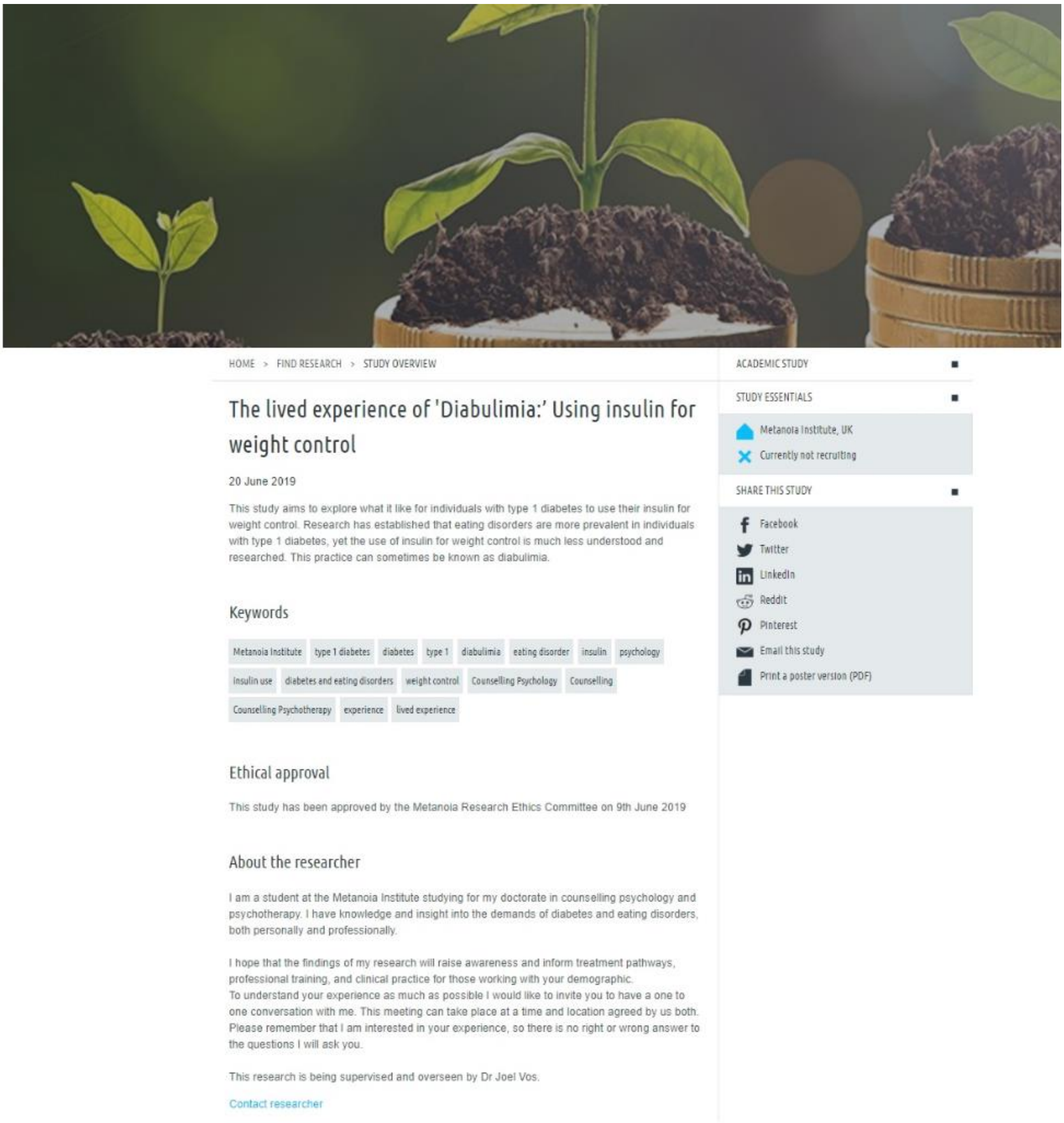
Appendix 3: Demographics Questionnaire

Demographic Questionnaire

Please answer the following question as accurately as possible. If you prefer not to answer, please mark N/A next to the relevant question.

Question	**Your Response**
How old are you?	
What is your gender?	
What is your nationality?	
What is your ethnicity?	
At what age were you diagnosed with Type 1 Diabetes?	
At what age did you first use your insulin for weight control?	
How long did you use your insulin for weight control?	

Appendix 4: Recruitment Advert



HOME > FIND RESEARCH > STUDY OVERVIEW

The lived experience of 'Diabulimia:' Using insulin for weight control

20 June 2019

This study aims to explore what it like for individuals with type 1 diabetes to use their insulin for weight control. Research has established that eating disorders are more prevalent in individuals with type 1 diabetes, yet the use of insulin for weight control is much less understood and researched. This practice can sometimes be known as diabulimia.

Keywords

Metanoia Institute | type 1 diabetes | diabetes | type 1 | diabulimia | eating disorder | insulin | psychology | insulin use | diabetes and eating disorders | weight control | Counselling Psychology | Counselling | Counselling Psychotherapy | experience | lived experience

Ethical approval

This study has been approved by the Metanoia Research Ethics Committee on 9th June 2019

About the researcher

I am a student at the Metanoia Institute studying for my doctorate in counselling psychology and psychotherapy. I have knowledge and insight into the demands of diabetes and eating disorders, both personally and professionally.

I hope that the findings of my research will raise awareness and inform treatment pathways, professional training, and clinical practice for those working with your demographic.
To understand your experience as much as possible I would like to invite you to have a one to one conversation with me. This meeting can take place at a time and location agreed by us both. Please remember that I am interested in your experience, so there is no right or wrong answer to the questions I will ask you.

This research is being supervised and overseen by Dr Joel Vos.

Contact researcher

Appendix 5: Recruitment Stand

THE LIVED EXPERIENCE OF 'DIABULIMIA'

INDIVIDUALS WITH TYPE 1 DIABETES USING INSULIN FOR WEIGHT CONTROL

Sian Morris
Counselling Psychologist Trainee
sian.morris@metanoia.ac.uk

INTRODUCTION

Research has established that eating disorders are more prevalent in individuals with Type 1 diabetes, yet the use of insulin for weight control is much less understood and researched (1,2) . This practice is often known as diabulimia and has severe, often life threatening health consequences (3,4). Treatment interventions currently do not improve both diabetes control and mental health in individuals with Type 1 diabetes and an eating disorder (5,6).

RATIONALE

There is a demographic of individuals with specific needs, yet an unclear understanding of their personal experiences and how best to support them. Overlooking this research avenue risks individuals remaining misunderstood, treatments not being tailored and healthcare professionals, families and friends feeling ill-equipped.

What is the lived experience of individuals with Type 1 diabetes who use insulin for weight control?

AIMS

To investigate the experience of using insulin for weight control in individuals with Type 1 diabetes. Specifically, to identify the different elements of this experience and how it presents itself across the 5 meaning domains of life (7).

METHOD

- 4-6 participants using purposive sampling - recruitment is ongoing.
- Explorative study, qualitative design using semi-structured interviews and an interpretative phenomenological method of analysis (8).
- Credibility of data improved by reflexivity, member checking and peer debriefing (9).

CONTRIBUTIONS

- Provides a platform where experiences are validated and heard.
- Adds to discussions surrounding diagnosis, policies and treatments.
- Informs training for healthcare professionals.
- Helps family and friends understand the experience of their loved one.

SUPERVISED BY DR JOEL VOS

Appendix 6: Recruitment Flyer

Call For Participants

The lived experience of 'Diabulimia:' Using insulin for weight control

60 min(s) to complete

Sincere Gratitude

Interview

London, UK

Metanoia Institute

This study aims to explore what it like for individuals with type 1 diabetes to use their insulin for weight control. Research has established that eating disorders are more prevalent in individuals with type 1 diabetes, yet the use of insulin for weight control is much less understood and researched. This practice can sometimes be known as diabulimia.

Find out more online

Poster printed on 10/06/2020 Study expires on 20/04/2020

More info
by scanning the QR code
or visiting the URL

www.cfp.cc/5NY8F3

Appendix 7: Information Sheet: Frequently Asked Questions

Frequently Asked Questions

The lived experience of 'Diabulimia:' Individuals with Type 1 diabetes using insulin for weight control

Researcher: Sian Morris

Supervisor: Dr Joel Vos

Thank you for expressing your interest in my research. Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Thank you.

What is the purpose of research?

The research aims to explore what it like for individuals with type 1 diabetes to omit and/or restrict their insulin for weight control. Research has established that eating disorders are more prevalent in individuals with type 1 diabetes, yet the omission or use of insulin for weight control is much less understood and researched. This practice can sometimes be known as diabulimia.

By understanding this experience further, I hope that the findings of my research will help inform treatment pathways, diagnostic decisions, professional training and clinical practice for those working with your demographic. Furthermore, I would like my research to act as a platform where the unique issues faced by your demographic are validated and heard, not just by healthcare professionals but also by members of the public who may not know of your difficulties. In this way, my research stands to raise understanding and awareness.

Who can participate?

Take a look at the table below to see if you are able to participate:

You can participate if you	Unfortunately, you are not able to participate if
Are over 18	You do not have a historic/current relationship with support services
Live in the UK	You are not able to independently manage your own insulin
Are fluent in English	You currently live in, or within the past 12 months have been in inpatient/residential treatment settings
Have a diagnosis of type 1 diabetes	
Have experience of omitting and/or restricting insulin for weight control	
Feel well established and stable in your insulin management for at least 12 months	
Have had previous or ongoing contact with a service that offers emotional and psychological support	

Do I have to take part?

No! Even if you meet the criteria in the table, it is up to you to decide whether to take part.

What is involved in taking part?

If you choose to participate, I will ask you to take part in the following parts of the research:

- A brief introductory telephone call. This gives us the opportunity to review the research process together and where I can answer any initial questions you may have. It also allows us to discuss the practicalities of your participation and arranging a meeting
- Review and sign a consent form
- Complete a short demographic questionnaire
- Meet me for an interview which will last approximately one hour and will be audio recorded. You can pause and/or terminate the interview at any stage. You can also skip questions you do not wish to answer.
- After the interview, we will have a short 'debrief' which gives you the opportunity to share your interview experience and ask any questions you may have. At this point, I will also provide details of support services that you can contact should you wish.

What if I change my mind and want to leave the study?

Prior to or during the interview you can withdraw from the study at any point without giving a reason. After the interview, you will have 6 months from the date of our interview to withdraw from the research, or until I have included your data into the analysis section of my research depending on which event occurs first. If your data has already been included in the analysis it cannot be extracted from the research.

Will participation in the study be confidential?

Your anonymity in the research is guaranteed. Your name and contact details will be stored separately from research data. This research will comply with the legal requirements related to the storage and use of personal data as outlined in the Data Protection Act (1998), GDPR and other similar acts. All data will be stored in locked cabinets and/or password protected files.

All identifying information such as names, places, addresses and other individuals referred to in your interview will be altered as a means of securing your anonymity. During our meeting we will discuss the use of pseudonym's together. Please be aware that extracts from the interview may be included in the dissertation to help explain and contextualise findings. Furthermore, the research findings may be published and presented at conferences. A copy of the final dissertation will also be available for the public to read.

Although your confidentiality is critical there are circumstances where your confidentiality would be waived, for example if you disclose intent others, or if I feel you are at imminent risk and no longer safe. In such circumstances, I would share my concerns with you, and we would reach out to your emergency contact/GP. The consent form will ask you to provide details for an emergency contact and/or your GP.

What are the possible risks of taking part in the study?

It is not expected that the interview will cause distress, however you may find it difficult to reflect on your experience and notice that certain emotions are evoked. Please remember that you can skip questions and stop the interview at any time if you find it is more difficult than you anticipated. If you do experience any surprising or strong reactions, we will discuss options for you to explore these responses further. Our meeting is not a therapy session; however, I do have a list of organisations who can offer further support. We will revisit this point in our initial telephone conversation and after our interview during a debriefing.

What are the benefits of taking part in the study?

In taking part you are helping to give voice and raise awareness to a complex difficulty that has remained misunderstood and under-researched for some time. You may find the interview a positive experience as it allows you a space to share your story without judgement or expectation. Research has suggested that the process of saying something out loud in a welcoming space can have beneficial effects on our mood and way we make sense of an event.

Who has reviewed the study?

This research is being undertaken as part of my Doctorate in Counselling Psychology and Psychotherapy at the Metanoia Institute. The Metanoia Research Ethics Committee has reviewed and approved the research.

What if have more questions?

Please contact either the researcher or supervisor on the details below, we are happy to answer any questions you have.

Researcher: Sian Morris, Sian.Morris@Metanoia.ac.uk

Supervisor: Dr Joel Vos, Joel.Vos@Metanoia.ac.uk

Appendix 8: Research Journal Extract: Pilot Study Reflections

The process of interviewing for the first time, felt somewhat similar to the early stages of working therapeutically with individuals. On a conceptual level there was understanding of the desired process, yet this did not always translate fluidly or seamlessly. Interviewing from a phenomenological perspective presented some challenges. In the early stages of the interview I noticed that I was eager to attend to the research question as though as I was seeking something in the participants narratives that would be clear and identifiable. Ultimately, I feel this impacted my ability to 'stay alongside' Jen and her narrative as I was preoccupied and distracted with thoughts such as "is this within the context of my research question?" "are we going off track?" "what shall I ask next?" "where do we go from here?"

Upon reflection I feel this wondering was partially influenced by the anxiety of interviewing, and the realisation that this interview marked the first stage of data collection after such a substantial amount of time talking about the research from a theoretical or practical position. I also wonder whether the interview triggered a historic discomfort around 'not-knowing.' Whilst on one level I was fully accepting of Jen's position of the 'expert,' of her own experience, I noticed another part of me wanting to 'show' Jen that I 'knew' or 'understood.' This was evident in my initial increased presence in the interview at the early stages.

I became aware of this process on a bodily level approximately 10-15 minutes into the interview. I noticed a pain in my stomach, an area where I tend to hold my anxiety. This was a clear signal to reground myself which I did by a simple mindfulness exercise of bringing my awareness back into the room with Jen and my felt sense. Following this moment, I felt more able and comfortable returning to a phenomenological position 'alongside' Jen, characterised by curiosity and openness. I was able to tolerate the sense of 'not-knowing,' and akin to floating in a river felt able to 'go-with' the 'flow' of the interview, following Jen's narrative around the various bends and through the currents of her lived experience. In this way, the pilot interview not only provided an opportunity for me to reflect on my proposed interview schedule, but also facilitated a personal reflection which helped me become aware of what it is like to interview from a phenomenological perspective and the resulting feelings and process which may emerge. I found comfort in an internal reminder to 'be with' as opposed to 'doing to.' I held this in mind for the remainder of Jen's interview and the subsequent five that followed.

Appendix 9: Research Journal Extract: Pre-Interview Reflections

Despite having interviewed several participants previously, it is important I try to set aside the understandings that are emerging from the other transcripts, so I do not lead with the information gained from previous participants. I am about to meet Alex and whilst I have spoken to her previously on the phone to arrange the meeting, I do not know Alex or her experience. Alex is different from the other participants and it is important to allow her the same space and curiosity as the others. I have noticed she has an accent which suggests she did not always live in the city in which we will be meeting. A point which I have not given much space to, yet I am curious as to whether the element of geography will feature in her narrative.

I have arrived at the interview room ahead of time and notice I am preoccupied with the space. It looks more office like than I had hoped and feel conscious of trying to create a more relaxed space as opposed to one which feels clinical or transactional. I have moved the chairs, so we are at an angle towards each other as opposed to sitting behind desks. It was as though the desks presented a barrier or an image of power and status depending on which side you were sat. Now happy with the 'feel' of the environment I will wait for Alex's arrival. My phone remains near until she arrives and taking a couple of deep breaths helps me to become grounded and attuned with my felt sense. I am aware that I am about to be welcomed into a personal narrative of someone. They will share an incredibly personal experience in as much depth as they feel willing and able to do so. This is a privilege and a responsibility; I am aware I have never offered up any of my personal experiences in a way similar to my participants. As I wait for Alex I reflect on the emerging sense of bravery and admiration I have towards the participants.

Appendix 10: Consent Form

Participant Consent Form

The lived experience of 'Diabulimia:' Individuals with Type 1 diabetes using insulin for weight control

Researcher: Sian Morris

Supervisor: Dr Joel Vos

Thank you for agreeing to participate in my research. Your time and contributions are valued. Prior to consenting to participate, please review and consider the points listed below. Please ask me if you require any further clarification or have any questions.

<u>By consenting to participate in this research, I confirm that:</u>

1. I have read received, read and understood the 'frequently asked questions sheet.' The researcher has explained the aims of the research, along with what is involved in taking part
2. My participation is voluntary, and I will co-operate with the researcher to the best of my ability
3. I understand that the interview will be audio-recorded
4. I understand that all personal data will be stored securely, and in accordance to the Data Protection Act (1998, section 5) will not be kept longer than is necessary for the research
5. I understand that my anonymity will be preserved but quotations from my interview may be used in the dissertation write-up
6. I understand that the findings of the research may be published in academic journals and presented at conferences
7. I understand that whilst confidentiality is prioritised, there may be circumstances where confidentiality is wavered, for example, if I disclosure intent to harm myself and/or others
8. I allow the researcher to get in touch with my emergency contact/GP if she is significantly concerned for the wellbeing/safety of myself or another
9. I understand that I can pause or terminate the interview at any point without reason and there will be no negative consequences from doing so
10. I understand that after the interview I have 6 months from this date to withdraw from the research, or until my data has been included into the analysis section of the research depending on which event occurs first. If my data has already been included in the analysis it cannot be extracted from the research.
11. By signing below, I have read and agree to the conditions listed above and consent to participating in this study

Participant Name: _____________ **Participant Signature:** _____________ **Date:** ____

Researcher Name: _____________ **Researcher Signature:** _____________ **Date:** ____

Emergency Contact Details:

Name: Email address:

Contact number/s: Address:

Appendix 11: Distress Protocol

Participant Distress Protocol

The following protocol has been developed in the event of participants becoming distressed during their participation. As a trainee Counselling Psychologist and Psychotherapist, I have experience in responding to and managing situations where distress occurs. Whilst extreme distress is not expected to occur, the protocol outlines numerous indications of distress along with actions to be taken.

Mild distress

What to look out for:

1) Behaviours suggesting that the interview is becoming stressful/distressing, for example, shaking, fidgeting, restlessness
2) Emotion appears present in voice, participant may become choked, struggle to speak or their voice trembles when doing so
3) Tearfulness, this may be accompanied by colouring of cheeks and/or break in eye contact

Response:

1) Check in with the participant, would they like to continue
2) Ask if they would like to pause the interview and take a moment to collect themselves
3) Remind the participant that there is no pressure to continue, they can withdraw/stop the interview at any point without offering an explanation. Clarify they would not be disadvantaged in any way for choosing to terminate the interview

Severe distress

What to look out for:

1) Uncontrolled crying and difficultly in articulating themselves
2) The ‘buckling’ of physical self in response to emotional intensity, for example leaning forward to hug knees if seated, resemblance of foetal position. Rocking or other such physical displays to provide comfort/self-soothing
3) Signs of high anxiety or panic attacks, for example, reported shortness of breath, tightness in chest, struggling to catch one’s breath, hyperventilation

Response:

1) Terminate interview and begin debriefing immediately
2) Try and assist participant to regulate their breathing either through ‘shadow’ breathing or by relaxation techniques
3) Display compassion and understanding of their current difficulties. Explain that reflecting on the topic can resurface multiple emotions and responses, re-assure them that this is not an unusual reaction to reduce any self-consciousness, worry, concern or embarrassment that may be arising as a result
4) Should any issues arise which present themselves as significant and unresolved to the participant, clarify the boundaries of the interview context in that it is not designed for therapeutic interaction but suggest they discuss this matter further with other mental health professionals

5) Provide participants with the details of additional support services as detailed on the participant debrief form
6) Ensure the participant is safe to leave the interview setting before doing so. For example, if the participant is driving ensure they are collected and calm enough or explore an alternative way of getting home, Taxi, someone to pick them up.

Extreme distress:

What to look out for:

1) Extreme agitation, verbal or physical aggression
2) Sudden exiting of the interview space
3) Loss of rational and coherence, speech may become muddled and not make any sense
4) Escalation of physical displays of distress, for instance breathing may still be very disrupted, tightness of chest worsening
5) Indication of suicide

Response:

1) Prioritise safety of participant and researcher
2) If the researcher has concerns for the safety of the participant or other individuals inform the participant of such concerns and explain how as a result, the researcher has a duty to inform other services/professionals, for example their GP/emergency contact. At this point, it could also be suggested that the participant present themselves to the nearest A&E department and ask for the psychiatric liaison team
3) If the participant becomes violent and unwilling to seek assistance, emergency services could be called. This response would only be acted upon in an emergency.

Appendix 12: Debriefing Sheet

Debrief Sheet

Thank you participating in my research, your contribution is appreciated.

If you have any questions regarding any stage of the research, please do not hesitate to contact either myself or my supervisor:

Researcher: Sian Morris, Sian.Morris@metanoia.ac.uk
Supervisor: Dr Joel Vos, Joel.Vos@metanoia.ac.uk

Debriefing is an opportunity for you to discuss any feelings, thoughts or ideas that have surfaced as a result of the interview. If you should find that you are left with strong feelings and emotions after the debriefing period, I would advise you to seek support from a trusted friend, family member, your GP or the support service you have a current/historical relationship with. You will also be able to speak to contacts at the support services listed below should you feel you need counselling or further support. If you feel you are at immediate risk, please go to your nearest Accident and Emergency Department.

Diabetics with Eating Disorders (DWED)
Website: http://dwed.org.uk/online-support
Information: DWED has a closed Facebook Group; access can be requested by following the above link

Diabetes UK
Helpline: 0345 123 2399
Website: https://www.diabetes.org.uk/Guide-to-diabetes/Life-with-diabetes/Diabulimia

BEAT Eating Disorders
Helpline: 0808 801 0677 (open daily 3.00pm – 10.00pm)
Website: https://www.beateatingdisorders.org.uk/

Samaritans
Tel: 08457 90 90 90
Website: http://www.samaritans.org

MIND
Tel: 0300 123 3393
Website: www.mind.org

The British Psychological Society: Directory of chartered psychologists
Tel: 0116 254 9568
Website: http://www.bps.org.uk/bpslegacy/dcp

The British Association for Counselling and Psychotherapy: Find a therapist
Tel: 01455 883300
Website: http://www.itsgoodtotalk.org.uk/therapists

The United Kingdom Council for Psychotherapy: **Find a therapist**
Tel: 0207 014 9955
Website: https://www.psychotherapy.org.uk/find-a-therapist/

Your GP will also be able to direct you to free psychological support in your area.

Thank you, Sian

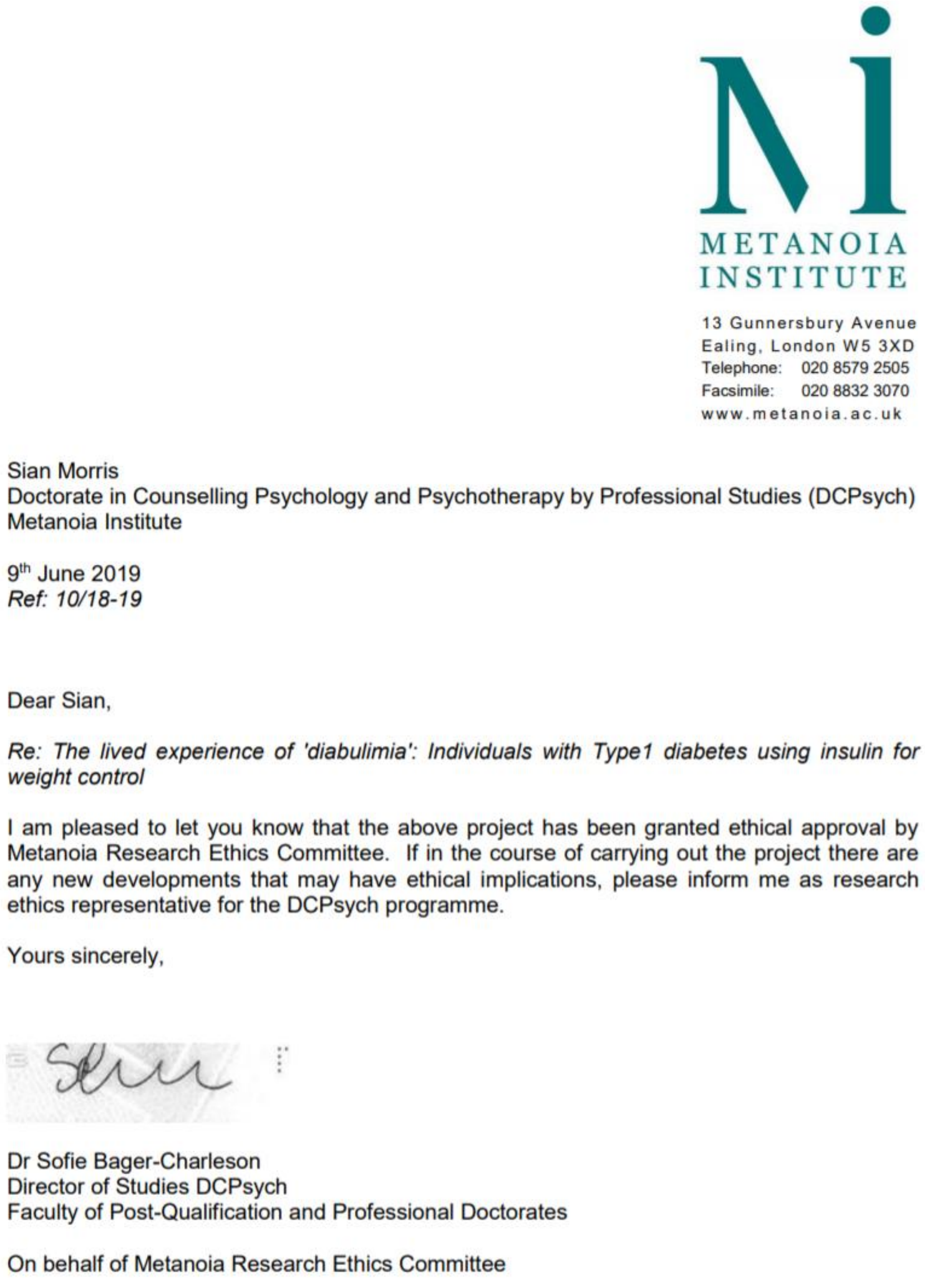
Appendix 13: Research Journal Extract: Post-Interview Reflections

Up to this point the health implications mentioned by the participants because of their insulin restriction have all been internal or at least 'invisible,' such that you cannot always outwardly 'see' organ difficulties or strokes. To see the physical body being impacted in the way evident by this participant was impactful and perhaps on some level felt more 'significant?' An interesting point of reflection as this in turn applies the currency of 'looking unwell' on the physical surface level. Perhaps this is the natural standpoint of society, how does someone look? Is this our primary 'data point' from which we make assumptions and decisions? Indeed, if someone 'looks okay,' does our line of enquiry become limited?

Interestingly although the physical appearance of this participant initially captured some of my attention and curiosity, as the interview progressed, I noticed that this was no longer a focal point. Indeed, I was 'moving beyond' the surface presentation of this participant and was connecting to the layer's underneath, as the participant shared their experience and meanings. It felt important to allow time for this participant to become comfortable in the interview space, I noticed we spent a little more time talking on 'daily points' before very slowly starting to enter the space of lived experience. It was important to build this relational connection, and as we did the participant started to share their reflections in the moment.

A particularly powerful moment was when the participant sat back in their chair and placed their hands behind their head before commenting that they were thinking and reflecting on a particular moment for the first time. It struck me that whilst the interviews were useful for me from a 'data collection' perspective, they also provided the participants with a space to reflect and make sense of things. I felt moved by the emotion that entered the room, it felt heavy with thought. At this point, I came to see the difference between a transactional style interview and the phenomenological process of co-construction.

Appendix 14: Ethical Approval Letter



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Sian Morris
Doctorate in Counselling Psychology and Psychotherapy by Professional Studies (DCPsych)
Metanoia Institute

9th June 2019
Ref: 10/18-19

Dear Sian,

Re: The lived experience of 'diabulimia': Individuals with Type1 diabetes using insulin for weight control

I am pleased to let you know that the above project has been granted ethical approval by Metanoia Research Ethics Committee. If in the course of carrying out the project there are any new developments that may have ethical implications, please inform me as research ethics representative for the DCPsych programme.

Yours sincerely,

Dr Sofie Bager-Charleson
Director of Studies DCPsych
Faculty of Post-Qualification and Professional Doctorates

On behalf of Metanoia Research Ethics Committee

Appendix 15: Health and Safety Risk Assessment

INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT

This proforma must be completed as part of the research ethics submission for all field/location work. It is to be completed by the person carrying out the field/location work (which in most cases is the candidate) in conjunction with the research supervisor.

FIELD/LOCATION WORK DETAILS

Name of person carrying out field/location work: Sian Morris

Name of research supervisor: Dr Joel Vos

Telephone numbers and name of next of kin who may be contacted in the event of an accident

FIELD/LOCATION WORK NEXT OF KIN

Name: REDACTED

Phone: REDACTED

Physical or psychological limitations to carrying out the proposed/location work:

I am physically and psychologically fit and well. To ensure this remains the case throughout the research I will attend to my own self-care by using my supervisor, therapist, friends and family as means of support. I will ensure that I strike an appropriate work-life balance and continue to participate in the physical activities that I enjoy such as running, Pilates, swimming and cycling.

Any health problems (full details) which may be relevant to proposed field/location work activity in case of emergencies:

N/A

Locality (Country and Region)

All interviews will be carried out in the UK therefore Visa, permits and international health insurance and vaccinations are not required

Travel arrangements

Personal car or public transport (train, underground). Travel arrangements will be shared with my research supervisor and next of kin. Additional details provided in the hazard tables below.

NB: Comprehensive travel and health insurance must always be obtained for independent overseas field/location work.

Dates of travel and field/location work

Once ethical approval is granted, recruitment can commence, and interviews arranged. I aim to start interviewing participants in July/August 2019 and will ensure my next of kin and research supervisor are aware of my travel arrangements, location of interviews and timings.

Hazard Identification and Risk Assessment

List the localities to be visited or specify routes to be followed (Col. 1). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 2).

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

1. LOCALITY/ROUTE	2. POTENTIAL HAZARDS
Travelling to and from interviews	Travelling to and from interviews – traffic, pollution, accidents, travelling alone, overnight accommodation may be necessary
Conducting interviews	Lone working, it may be difficult to summon immediate help and the participants remains relatively unknown to me. The participant is a member of the public and I need to remain vigilant not to cause offense/intrusion and be aware of pollical/ethnic/cultural/socio-economic differences and the roles they may play

3. PRECAUTIONS/CONTROL MEASURES	4. RISK ASSESSMENT (Low, moderate, high)	5. SAFETY/EQUIPMENT
Take the most direct travel route possible and do not take unnecessary travel risks (e.g. speeding, running for trains doors as they close). Thus, reducing risk of traffic, pollution and accidents	Low	Use of Sat Nav and travel apps to assist with route identification. Ensure car insurance and breakdown cover is not expired
Share planned route, location and expected return times to significant others (fiancé, next of kin, supervisor)	Moderate	Communicate via phone, ensure battery is charged, take a spare battery and charger. Turn on 'find my friends' location device
Establish emergency procedures for example, if I have not contacted my significant others by the expected time, they will have the means to track my location and contact the institution where the interview took place, e.g. university or library	Low	Physical and verbal violence is not expected. Nonetheless, having a personal alarm on my persons in interviews will help raise the alarm in an emergency.
Arrange interviews in a public place with the required privacy such as study rooms in universities or libraries. Home visits will not be permitted, the location will be neutral	Moderate	Identify and arrange appropriate locations for interviews ahead of time

Make use of psychotherapy/counselling skills to defuse and contain any emerging conflict	Low	
Wear clothing unlikely to cause offence or unwanted attention. Present as both professional and approachable.	Low	
Seek information on any social/cultural/political features of the interview area	Low	Conduct personal research to ensure my understanding on these features is adequate. Seek further guidance from research supervisor if necessary
If an oversight stay is required, hotels will be booked in advance and known ‘chains’ used. Ensure only significant others are aware of accommodation details.	Low	
Ensure professional indemnity insurance is current	Low	

DECLARATION: The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork/location work period and additional precautions taken or fieldwork/location work discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker/ location worker (Candidate/Staff)

Sian Morris

Date: 6 June 2019

Dr Joel Vos 6 June 2019

Appendix 16: Research Journal Extract: Research Question Reflections

Formulating a research question (2017)

Early editions of my research question:

- How do individuals identifying as having diabulimia experience being diagnosed with (insert alternative eating disorder diagnosis)?
- What is the experience of people who identify as having diabulimia if they receive a different diagnosis?
- What is the lived experience of individuals with type one diabetes misusing insulin for weight control?

Reflections

What is behind my conceptualisation of a research question which includes the element of diagnosis? Where does it come from? What is it made of?

My draw to include the notion of diagnosis in a research question may be influenced by an awareness of the current absence of diabulimia in diagnostic manuals or guidelines. Within the sparse literature and studies available there is a growing notion that by not officially being recognised as a distinct eating disorder identity, the availability and appropriateness of support available to the demographic is impacted. Yet my proposed questions in relation to diagnosis, would not sit in line with a phenomenological methodology as they seem to mask an implicit agenda and bias, namely, to support a movement towards the recognition of diabulimia as a distinct eating disorder, and the assumption that this would be 'good' thing for the demographic. Yet I cannot begin a research journey with a 'hoped-for' outcome whilst also claiming to be 'open and curious.' Doing so would feel fraudulent and compromise the integrity of myself as a researcher, practitioner and person and any emerging findings as a result.

Today I became aware of my use of the word 'misuse' through presenting my research proposal to a research panel. The tone of the word feels judgemental, as though these individuals have done 'something wrong.' Is this how I feel towards this demographic? Is there a part of me that is judging their relationship with their insulin? Are they doing something 'wrong' or does this reflect my naivety? Considering myself as a judgemental person is an uncomfortable self-image, yet it is something we all are and do in varying degrees. How might the use of this word influence the way individuals feel about participating in this research and sharing their experience? If it were me, I suppose I would feel the interviewer had already passed a judgement without hearing my story. They had not stopped to listen. I am advocating a research project which will help to give voice to a currently unheard and unpresented demographic, and so this must be the case. I feel any initial responses I may have towards the use of insulin as a means of weight control comes from a position of ‘outsider naivety.’ I genuinely do not know what this is like for these individuals, what it means to them and how they experience it. To find out it is important to allow an open research space. One which is not predefined by judgments and assumptions. A truly phenomenological and open research question needs to be sought.

Appendix 17: Research Journal Extract: Transcription Reflections

Whilst transcribing Catherine's transcript I became aware that I was engaging in a very critical self-narrative. Thoughts such as "I should have asked XYZ" or "why didn't I do this" or "I should have known better," started to build and circulate. This provoked another layer of reflection. Historically, I have not experienced myself as being overly self-critical and because of this I started to wonder how much of this emerging process was 'mine,' and how much may reflect the self-loathing and low self-esteem that is permeating Catherine's narrative (and that of several other participants). Whilst immersion into the transcript is an important part, so too is self-care and knowing when it may be necessary to take a step back from the often challenging and confronting transcripts of the participants.

Taking this reflection to my research supervisor and indeed personal therapy helped me to make sense of what may be going on and appreciate the emotional toll that can come from spending prolonged periods of time with difficult narratives. I reflected to my supervisor and therapist, that when I work therapeutically with a client there is a sense of working through something together often over a prolonged period of time. In contrast the interview experience resulted in very rich and in-depth experiences being shared in a short period of time, that I then engage with personally and alone from a static transcript. At these points I found it useful to take breaks away from the transcripts and re-engage with self-care activities like speaking to friends or cycling.

Appendix 18: Example of Annotated Transcript (Peggy)

	Transcription **P: Peggy (Participant)** **S: Sian (Interviewer)**	**Exploratory Comments** **Blue – Descriptive** **Red – Linguistic** **Green – Conceptual**	**Emerging Themes** **Purple**
P14	Talking to someone I don't just really enabled me to speak freely about my experience and now I think honestly, maybe not with my parents because I feel like they contributed to the experience obviously not all but I feel that some of what I experienced came from their views on weight and exercise and that sort of thing, but I speak openly with my friends and I'm very active you know I tell all my appointments and I look forward to them and I prepare for them, and I think about what I need to talk about and questions that I have about how I need to look after myself	Feels able to speak freely with friends and with medical professionals. Pro-actively sharing and engaging in self-care. Yet hesitations around parental discourse due to the internalisation of their views on weight and exercise. Influence of external systems and environment on physical ideals and norms and relationship with self.	Talking freely outside family unit Systemic influences on body image
S15	What is it like to discuss it and share your experiences?		
P15	Getting it out really helps you know bottling it up internalising all those thoughts and feelings really makes it worse, especially when you're not taking your insulin because it makes you a really irrational personal, you get this kind of mind fog where you can't think straight, you can't rationally and you're angry all the time and you're anxious all the time, and I think I'm predisposed to being anxious and a bit miserable you know, a bit depressive anyway so you know it's really kind of exasperated by poor insulin control, you're not able to manage your own thoughts or know what you need to do for yourself or how to care for yourself, it's quite a helpless situation.......yeah it's.....it's been a good journey for me I think taking my insulin and realising I feel like it makes me a good person, or it's made me into a much better	Value of giving voice to her thoughts and feelings. Reality of insulin omission Mind fog, irrational, angry, anxious – a helpless situation. Perspective of self as being predisposed to being miserable, anxious, and depressed. Predisposed as an essence of 'it's not my fault, I can't help it? Medicalised language? Insulin makes her a good person. No longer a tool that 'makes her fat' Shift from 'bad to good.' Previous attempts at change/recovery disrupted intermittently by weight gain. Attempted to self-motivate by reflecting on the 'great six months' whilst taking insulin. Realising her opportunities for development and potential.	Consequences of insulin omission Perspective of self Non-linear process of change and recovery Motivations to change/recover Recovery as a process not a static destination Experiencing a different quality of life as a protective factor for relapse

	person than I was when I was omitted my insulin you know especially in the last, my care has been really good for about 11 or 12 months now kind of when I started the programme you know I would do 6 months, I would put on a stone and be like fuck this I need to stop, so I would stop taking it again and then I would go for another 6 months of not taking it and think okay Peggy you need to start taking it because look at that great six months you had but now I, now that I've been taking it for a year you know I reflect on myself in much more positive way, you know I realise the person that I can be now and things I can achieve now I look after my health and now I'm much more level headed so I think I you know obviously the conversations I have with my doctors and stuff they're very honest and we talk about the fact that I know might relapse again and we put in a plan of what to do in that kind of scenario but you know I feel much more confident now, it's unlikely that I will do that again because I have realised how great life can be now that I look after myself and I beat myself up about the fact that it took me eight or nine years to realise this but you know I also in a way I don't regret the experience because I feel it has taught me a lot and life is this very big learning curve and you experience these shitty things along the way that teach you things	Attending to health is now the avenue for success as opposed to thinness. Shift. Relationship with doctors as positive, honest. Recovery/change as ongoing, potential for relapse protected against by realisation of how 'great life can be.' Refers to herself in the third person. Essences of self-critical narrative remain, but counteracted by reflective, self-aware position.	
S16	mmm		
P16	and I think now I'm glad that I had the experience and I'm able to talk about the experience because you know I can sit here and talk to you and I can attend the conference and some input in that. I've talked to them a lot about it, I've done interviews and things with then, so	Desire to help others Finding light and positives out of what was a difficult and dark experience. Taking control and ownership of her experiences and channelling into a healthier altruistic avenue.	

	you know if me doing this can help just one person then it makes the whole experience really worthwhile, shit but kind of worth it	Role of the other, motivation to speak out and desire to help.	
S17	Shit but kind of worth it		
P17	Yeah Yeah, the lessens that it has taught me about the importance of health and the importance of looking after myself I don’t know if I would have got to this point otherwise	‘Needed’ the experience of insulin omission to become open to self-care.	
S18	Mmm can you tell me a little bit more about those lessons?		
P18	I think quite a bit of it has been the side effects, the medical side effects of not taking my insulin they have really kind of forced me to be better, the problems that I have with my eyes you know even though they're not severe I know they could be and they are probably likely to get worse and you know now I have the motivation to look after myself because of learning this is what happens to you if you don't take it, you know being skinny yeah you might think it's great, but you know your eyes are also fantastic and they're super helpful and so are your feet and you know your heart and your kidneys and all the things. You know you have a dead organ or a really poorly functioning organ in your body so you don't want to add to the list, I think you know the journey of learning to value myself and respect myself has been kind of intertwined with I don’t know, realising what could happen and that it's super important to look after and protect myself as much as possible because I remember when I got diagnosed, the first thing the doctor said to me was you’re got diabetes and by the way you've likely to die 15 to 20 years younger than everyone else in your age group, you know a massive stroke or a heart attack or	Side effects as ‘lessons’ to self-care. Deteriorating eyesight Reprioritising physical functioning away from being skinny. Recovery/change journey involved learning to value and respect herself. Journey involves seeing herself as worthy of recovery. Diagnosis experience: Nihilism and Hedonism – what is the point. Her life is not worth living. Shattering the illusion of immortality and replacing it with inevitable-soon-to-be-death and vulnerability during adolescence, where independence and risk taking are often aimed-for/experienced. Provoked a sense of rebellion and disengagement from diabetes care? Access to the future cut-off.	Consequences of insulin omission as a motivator to change Relationship with self Impact of diagnosis experience – nihilism and hedonism

	something and you know I think at the age I was diagnosed, you know puberty, an awful time for anyone it's so difficult and at the time I was like oh fuck it if I'm going to die what is the point of looking after myself, if I'm going to have this, if this is going to happen to me one day then what's the point		
S19	mmmm		
P19	and I think that kind of mentality and then the kind of pain on my body image that kind of grew at that time as well kind of intertwined and became really difficult and I think they are the two factors that stopped me taking my insulin because for a while I use to make myself sick quite a lot and I was like this isn't really doing anything like I can't stop eating because I love food so much. I'm really fucking greedy so and then I found out oh if I stop taking my insulin I'm going to lose weight and it's like it's magic because you can eat what you like and you lose weight and it's fantastic and you get fed by other people and I think that was what was a really big driver for me to continue you know, people would say you look great you know you've lost weight and I'd feel just so great after being told that but it disgusts me now that I out so much value on my appearance and my body weight but it was just such a huge driving force you know other people's response to the way that I looked and I think that's what lead to the thought pattern of well if I'm skinny then everything will be fine because everyone will respect me and everyone will find me attractive and people will think oh she's really strong and she's exercising and she eats well but that's kind of the imagine I wanted to portray, you know I didn't eat well I ate terribly and I didn't	Combination of Nihilistic/hedonistic approach to life combined with difficulties with body-image contributed to insulin omission/restriction. Previous experience of disordered eating through vomiting. Conceptualization of insulin omission as magic as food restriction not needed. Role-of-the-other and external systems/environments as motivational factors. Self-worth and value externalised onto people's perception of her. Experienced praise – inclusion? Difference in internal reality vs what she wanted to portray externally to the world. "Different realities of the body"	'Magic' of insulin omission External validation from the Other as a motivation to continue. Seeking external validation/affirmation from the Other Fantasy of being skinny External vs Internal split reality of insulin omission

	exercise because I had no energy whatsoever. I found it hard to get out of bed in the morning and I would be exhausted from just walking to the tube and getting the tube to uni or to work I just felt exhausted all the time		
S20	mmm		
P20	but I could hide behind this persona		
S21	The image that you were portraying		
P21	Yeah and I think that's the image that society we are taught, this is what you are meant to look like, this is what being great looks like and obviously over the last couple of years I have really tried to alter the way I think about my body but I don't ever judge, I don't project the same thoughts onto other people's bodies. You know I don't see someone who might be a size 14, I don't think horrible things about them, I never have the same feelings towards myself you know I really respect other people's lives and the way that their bodies function and their live choices and whether they want to do to the gym or they don't or whether they want to eat pizza you know you do you that's totally fine so long as you're happy with yourself but I can't turn that understanding and acceptance inwards, I can't view myself in that same way so I think the acceptance of my body will be a really long journey and I think I have kind of come to terms with the fact that maybe I will never really like it, maybe I will always look at myself in the mirror and think oh I would really like to be thinner or I would like to change this bit or that bit, because I thought for a long time that I was just going to wake up one day and everything will be fine and I will love myself and I will be able to do, you know I think rationally or	Influence of societal/cultural conceptualisation of 'beauty.' Ongoing journey of accepting body with the acknowledgement that it may never be so. The body as an uncomfortable and critical territory, yet ongoing commitment to developing that relationship and appreciation. Essence that she is talking to herself about her body. Emergency of compassion "it is trying it's hardest." Motherhood as an avenue for further bodily appreciation. The creator and barer of life. Wondering about the future – access.	The body as an uncomfortable and critical territory Historic longing for instant change Relationship with body-ongoing

	realistically my opinion of myself will never really be that forgiving but I hope I have experiences in my life that make me value the strength of my body more you know I had brain surgery last January and that made me feel you know love your body respect your body because look what it's doing for you, you know not all of it works and some of it is shit but it's trying it's hardest. You know if I have a child, I hope that I will be able to grow a different level of understanding and respect for my body so I don't know I don't feel it now but here's hoping that I will carry on with this learning curve and I learn new things about myself and new ways to look after myself and do the right thing		
S22	It's quite a journey		
P22	Yeah and I think being a diabetic is also quite a journey, and now I I never post but I read up a lot on the forums online and I feel much more involved and not excited by diabetes but I feel an acceptance of having diabetes and I I'm trying to be like way more proactive about being in a community and talking to people and looking things up and I'm going to go on the DAFNYE course at some point which is a nice feeling because I've never been in the right place with my mental health or my self-care for that experience because it's quite daunting you know being in a room full of people with a similar condition I always thought there was this one up Manship with diabetics you know oh my blood sugar are better than your and I'm more stable but I've realised that it's not like that everyone has crazy highs that they don't know how to explain, you know no one is between four and eight all the time, it just doesn't work like that, but the more I have opened myself	Concerns around body-image remain yet acceptance of diabetes has emerged. Participation in DAFNYE represents development in mental health and self-care. In that she both wants to learn to look after herself – she deserves the care, and that is able to face up to her diabetes reality and not deny its existence? One up Manship: Assumed competitiveness. The Other would be a place of competition, comparison, and judgement. Disproved. Talks to herself "you know what Peggy" The development of her own compassionate integrated voice, shifting away from perfectionism. Naming of self-pride in the midst of self-critical narrative, indicates self-reflection, process and development in how she views herself.	Acceptance and integration of diabetes Distancing from perfectionism

	up to learning about diabetes and being in touch with other people I think you know what Peggy you don't have to be so hard on yourself about this, you know other people, no one is perfect everyone will have good days and bad days so I think that has helped me with my self-care and care for my diabetes and I have been able to drop the strive for perfection in one part of my life which is nice it feels different, yeah I'm pleased and I'm proud that I have been able to do that, you know give myself a bit of a break because I'm really really good at beating myself up and thinking horrible things about myself and being negative so it's a small achievement for me you know I've been able to be lenient and accepting of what diabetes is and how it plays itself out		
S23	Mmmm can you tell a little bit more about your journey and what it was like for you?		
P23	So, one day I just stopped taking my insulin and it was about three three and half years after that I didn't take it once which is mad because I should have gone to hospital in the first six weeks, but I didn't	Instant decision to stop takin insulin	
S24	Okay		
P24	and I never you know never really had Ketoacidosis, well I probably did but I would never collapse or got to the point where I felt my body was really falling apart and I needed or someone else felt that I needed to go to hospital so that really kind of drove me on	"really kind of drove me on." Bodily response to lack of insulin as a motivator. Continued to push, to find her physical limits.	Death as the only marker – testing the limits of her bodily and her mortality
S25	mmm		
P25	In a way I was like, okay I'm doing this and I'm not I'm not falling apart just yet so I can keep going, I don't have to talk my insulin this is fine, I'm not dying this is fine	By not dying or falling apart, she was able to maintain an illusion/fantasy that she doesn't need to take her insulin – therefore perhaps she is not like 'other diabetes,' or potentially that she can pretend she does	Death as the only marker – testing the limits of her bodily and her mortality Denial of diabetes reality

		not have diabetes. Denying its presence.	Hedonism: I'm not dead yet
S26	mmm		
P26	which is a real motivator, I know of other people I've spoken to who have had the same experience, they've been through the same experience of having diabulimia and they were in and out of hospital and always you know in that situation but I never really had it which confuses me slightly but it was a really big motivator you know I'm doing this but how am I getting away with it because no one knows and I'm not ill so I can carry on forever but obviously I didn't because I'm here and I did something about it	Not reaching physical limits as an ongoing motivator for insulin omission. Sense of invincibility in the face of impending mortality? Doctors said she was going to die sooner, but she is not taking insulin and not getting ill. Cheating death and deceiving others (doctors, parents?)	Sense of invincibility in the face of impending mortality Escaping harm/punishment/death – cheating death. (then punishes herself because she feels she should have died, survivors guilt?)
S27	That sense there I could keep going, what was it like to be in that place		
P27	Awful, I felt tired all the time and I'd you know I'd be going to the loo like twice an hour you know all the classic symptoms awful horrible breath, weeing all the time no energy, super tired, super weak you know that clouded mind I ended up dropping out of uni because my epilepsy, it's why I had the brain sugary, but my epilepsy got really bad so I took six months off and when I went back I thought this is isn't what I want to do, but I think that was also driven by not doing very well at uni not feeling like I was doing very well, I mean I would go to lectures and I would drift off and not listen, not understand and I found it so hard to do my essays and the exams so I think just, just every, *(pause 3 seconds)* actually omitted my insulin omitted every part of my life, you know relationships with other people, I was so angry all the time, I would fly off the handle into a rage. I made friendships really	It was 'awful' being invincible? Her body's reality to her invincibility. Reality of insulin omission: exhaustion, horrible breath, weak, need to urinate. Dropped out of uni. Epilepsy Omitting my insulin omitted every part of my life. Global impact of insulin omission Pushing all those away, who may interfere with the number 1 priority of being thin. Distance from the Other. Literal distancing from the other and imagined distancing from the other in that she was the only one with the difficulty. Impending isolation from all angles.	Global impact of insulin omission across all areas of her life.

	difficult and I really regret that you know because I have some really kind, loyal and understanding friends because they're all still here but I look back and I understand the way I jeopardized my friendships and the way I was with my parents and my family, I was a really horrible difficult person but somehow I was able to ignore all of those things and that side of my life and think well it doesn't matter because you are skinny and that's all that matters who cares if your friends don't like you as you are, you're skinny which is it's such a bonkers irrational way to think but it was truly what I believed for a really long time		
S28	mm that was what was going on for you		
P28	Yeah and I think slowly, I think I knew all along that it wasn't the right thing to do, you know that thought of everything's going to be fine if I lose this weight, that was able to drown out the rational side of my brain or the rational voice that I had that was telling me this was the worst thing I could possibly be doing for myself, my health, my life it was the worst thing and I think over time it just got louder louder and louder and I thought I can't ignore this anymore because I think I finally got to the point where I realised this wasn't solving any of problems and it wasn't making my life any better and I realised I needed to stop fighting this monster that is diabetes you know, I just need to talk to the monster and then we can walk side by side I know it's a stupid analogy but the way I kind of like to visualise things like that and I see it as this stupid horrible bear that you think is going to kill you but then you calm down and the bear calms down and you're side by side and it's	Internal battle Rational voice gained strength and got louder until it could not be ignored. Realisation that insulin omission was not the 'magic' gateway to 'success' as previously anticipated. Facing up to the reality as opposed to chasing the fantasy. Metaphor of diabetes as a bear. Captures the journey from fearing that the bear will kill you, to walking alongside it (integration, acceptance, no longer denial) side by side. The bear is something big, powerful and scary that could kill you at any time – metaphor for perceiving diabetes as a death sentence/imminent death? Represents a threat to her existence, to the order of her world? Shifted from being a threat to her existence to being part of her existence.	Internal battle Breaking the fantasy of being skinny Metaphor of diabetes as a bear (from a threat to her existence to a part of her existence – integration and recovery/change)

	totally fine and you get on with one another that's my kind of diabetes analogy, that's how I think of it, so after a long while I thought well try it Peggy because if it doesn't work you can go back, and if things don't sort themselves out well then you've tried go back to omitting your insulin by try it first because you never know the difference it could make	"Well try it Peggy" Sense of negotiating with herself to try a new tactic with the reassurance that if it doesn't work, she can go back to insulin omission	
S29	The diabetes being a bear type image, you said at one point, you thought the bear might kill you		
P29	Yeah and I think when you are first told about diabetes or maybe the way other way people think about diabetes and the things people know you're going to lose your eyes or your feet or have a heart attack or I mean obviously rightfully so you are warned about these things by your doctor and you do need to be aware of you know what might happen but it kind of makes it into this terrifying thing that it doesn't necessarily need to be	Influence of diabetes diagnosis and the external world's perception of diabetes. Messages of fear and terror which are not necessary. Internalisation of these external messages from society and HCP on diabetes and being thin. Now on a journey to redefine what they mean for her and how to manage them.	Experience of diagnosis and external systems perception of diagnosis
S30	mmmmm		
P30	yeah it is it's quite scary thinking about the things that might happen but there is one thing I can do to preventative thing that I can do to do what I can to stop them and it's looking after my insulin, but yeah that was my introduction into having diabetes you know with what the doctor said about the stroke or heart attack and yeah it is scary	Fear of consequences remain but understanding that attending to insulin is the best form of protection. Experience of diabetes diagnosis.	Experience of diabetes diagnosis

S31	Yeah it sounds scary		
P31	But with experience if you look after it and keep on top of it then it's fine and you get into your routine and you learn more about it and it's not easy but it is kind of easy most days I don't think about it, much more now I feel like I'm on autopilot I know when to check my sugars I know when to take insulin you know some days some days, I think everyone says this, <u>I would really like a week off you know a little holiday just like one week that I didn't have to think about it or think about what I ate or drank all the time all day</u> you know even though I do it is manageable. it really isn't as bad as I built it up to be, <u>I feel comfortable with it, which is something that I never thought I would say or feel so it's nice to say it out loud</u>	Integration of diabetes routine into daily life, less preoccupied with it – but would still like a break from diabetes management/reality. 'Endlessness' of diabetes management. Never stops. Function as an organ is a 24/7 job that most people do not have.	Endlessness of diabetes reality Shift in self-perception through recovery
S32	Yeah, what is it like to say it out loud?		
P32	It's a nice feeling, I don't want to sound big headed when I say it, but I feel really proud of myself	Proud of herself for getting to a place of comfort, acceptance, and tolerance around diabetes management. Signifies her journey of change and recovery. Pride related to recovery	
S33	mmm		
P33	Yeah, I do feel proud of myself, proud of getting through it and getting on with it and feel like I'm quite a resilient person and I feel quite good about that. I am able to acknowledge the inner strength that I have and not be embarrassed to say it out loud now which is nice	Signifies her journey of change and recovery. Self-perception.	
S34	What was that embarrassment?		
P34	I think I used to feel embarrassed about having the condition and it not being something that anyone understood and then feeling that if I had this then I'm a failure because I have this thing and then now everyone else tells me they're really proud of me and I've	Used to feel embarrassed about having the condition (diabetes, diabulimia, both?) External validation from others through pride and achievement not weight-loss. But also internal validation now which is a newer	

	achieved so much and I don't want to sound up my own arse or that I'm trying to show off by talking about it, and I'm not but I am quietly proud about being able to make it through this journey and being on the other side	piece that she has worked on and continues to work on.	
S35	mmmm if we look at that journey, a little be earlier you said that I actually effected every single area of your life and I'm just wondering you could tell me a little bit more about that		
P35	I think with the uni thing and having a job, I could not function I could not concentrate you know, so on one hand I didn't feel like I was doing my job well I couldn't do my job you know I'm quite, now at work I'm super proactive and I'm super dedicated to what I do but I didn't feel like I was able to show that at uni and in my first job so then that would play into my own opinion about myself and I would beat myself up and be like well you're really shit you can't even work this job, you can't even get a degree look how terrible you are, you're fat and you're terrible so I think that and I think my relationships with other people, you know I said a bit about my friends and I was really rude and horrible to my parents and I think with men having that really low self-esteem and opinion about myself lead me to make very poor choices with men and what I would do with men you know, yeah it just I think it's the effect that it had on my mental health was the biggest thing. You know I knew on one hand that it was really screwing up my body and I was really punishing my body and you know making it ill and doing all the wrong things for my body but I think the effect it had on my mental health was like 85% of it for me, it just lead me to making poor decisions and I think it	Cycle: Physical/social consequences of insulin omission reinforced a negative self-narrative which pushed her to seek external validation (through men) to combat this negative self-narrative. Historic self narrative Impact of insulin omission was noticed on physical and mental wellbeing. Mostly mental wellbeing. Punishing my body – for what, why? Insulin omission as a punishment – as a form of self-harm? Seeking approval and affirmation from the external other. This was underlying her desire to be thin, to engage in casual relationships – a desire to be approved and accepted. Seeking external affirmation and validation from men in casual sexual relationships. All external nothing internal at this point.	Seeking approval and affirmation from the Other as a result of low self

	was a lack of self-esteem and just the weight I would place on other people's approval was such a big driver you know if a man found me attractive and wanted to have sex with me I would think wow this is amazing you know this what I want from life, this is fine, you know affirmation from other people this is what life is about		
S36	mmm		
P36	and now in my life I don't look for that because if a man doesn't find me attractive then sod him who cares I don't I'm not here to please everyone and my body is not here to please everyone as well you know but you know it did continue for a long time you know having those feelings and acting on those feelings that in a way I knew deep down I didn't really want to do but I did it anyway because I thought it would give me this affirmation and this rush and you know I can't muster this self-confidence for myself so let me try and find it from as many other people as possible	No longer seeks approval/acceptance from The Other – she is no longer objectifying herself to meet the needs of the other. She is moving towards self-approval and acceptance. Rational for trying to gain affirmation from the other, but an acknowledgement of a different 'internal feeling' – beginning of her autonomy/self-voice towards change/recovery?	
S37	mmm yeah		
P37	but I don't feel ashamed about having that experience it's what happened and it taught me a lot of things because now you know I have a respect for myself and I value my body and I understand the importance of treating yourself like that as well of self-care yeah so it's why I don't regret this whole experience you know it really has taught me a lot of things that I'm not sure I would have learnt otherwise or may have leant them in a different way but you know a lot has come out of this journey that I am on and still on I guess	No regret or shame – owning her experiences. Not disowning them or disassociating from them – integrated and processed. Her self-development journey is ongoing. In a sphere wider than insulin omission, that was a piece of her journey around her 'self' but it does not end with that experience.	
S38	Yeah, and there's something there around valuing yourself and that's something you are progressing with at the moment but reflecting back		

P38	I just thought I was the worst person ever, I thought I didn’t deserve anything in my life you know I wasn’t funny enough or interesting enough or cleaver enough, you know I wasn’t any of these things you know so I don't deserve a boyfriend or a good job and I don’t deserve other people being kind to me because I'm a shit person and because I'm a shit person I need to beat myself up for being a terrible person, yeah I thought I was rubbish like trash, awful and it didn't matter that I was abusing my body this way by omitting insulin because you know I didn’t deserve to be happy or health, you know I shouldn't have had that	Historic relationship with self in the midst of omitting insulin. Worthless, undeserving of The Other Consequences to self are irrelevant and self-abuse did not matter. Nihilism towards her own life – it doesn’t matter.	
S39	You shouldn’t have had that		
P39	Yeah I shouldn't have been happy you know, it's so silly your body has these problems you deserve to have these problems you deserve to have diabetes and epilepsy, you have brought this on yourself even though I haven’t you know some of us just have faulty bodies, some bits just don’t work but I felt for a really long time that I deserved all this, and I deserved to struggle and have all of these shitty experiences	Blaming herself for having diabetes and epilepsy she deserves them. She deserves to suffer with these conditions because she is a terrible person therefore insulin omission is a further self-punishment/harm.	Self blame
S40	And then you mentioned there that the way you would punish yourself would be to omit the insulin		
P40	Yeah it just felt easy and right, and it was really, because you know injecting and checking your sugars is really boring and a bit painful something, so you know it's a really easy thing to stop	Accessibility and ease of accessing the world of ‘insulin omission.’ It punishes her whilst giving her a break from the diabetes reality at the same time.	
S41	Yeah		
P41	It's just really simple		
S42	mmmm		
P42	you know I was really terrible in many other ways, I would go out and get stupidly drunk and take drugs and all that, you know and everyone does it at uni but I think I went through a stage where I had	Ongoing naming of needing to punish self – extended to alcohol and drunks as well as insulin omission	

	to go above everyone else, I had to be worse, I don't know it's kind of hard to explain but I just I really needed to punish myself	I had to be worse, I really needed to punish myself Sense of hedonism, I'm going to die anyway so I may as well. No access to the future. Why do people punish themselves? Punishment is usually reserved when people do something 'wrong' – what had she felt she had done 'wrong' to deserve it?	
S43	What is that sense of punishment, what does it mean to punish yourself		
P43	I think at the time as I said, I felt that the punishment was what I deserved like one of these monks that self-flagellate themselves I had to create that pain for myself so I could, I don't really know why but I think on one hand I deserved these feelings and I think on the other hand I I think there were two driving forces, well many many things that lead me to stop taking my insulin but I think there were three but two of the main one's were that I feel like I have to punish myself and then somehow being able to control the shitty things in my life by or you know I could control one thing even if I couldn't control all the others	Control and punishment Religious language – comparing her self-punishment to religious practice of self-flagellation showing remorse for a sin? – a bodily-sin? Punishing her body – trying to rid something? Guilt? Refers to three main reasons for omitting insulin but only discloses two: punishment and control. What might the third be?	Self-punishment
S44	mmmm		
P44	I don't know, a lot of things played into what it kind of turned into yeah, once of those elements was a sense of control. Yeah as I said, it's a really difficult time from being diagnosed you know me kind of being at the end of secondary school, ending college and going to uni it's a really, especially when you're going to uni it's a huge upheaval and it's so different and you have to meet all these new people	Sense of control from insulin omission Maintain control during unsettling developmental life transitions e.g. uni.	
S45	mmmm		
P45	and I'm not a really great social butterfly anyway, I don't know it's	Social situations may have been difficult if she is seeking approval	

	just a really difficult time where you you are kind of forced to grow up and learn all of these about yourself and you are exposed to how difficult the world is and the difficult things in life	and acceptance at all costs. Pressure, panic that she might not fit in? Did diabetes make her grow up in that it exposed her vulnerabilities and mortality as a human – exposed to this at a young age, in addition to life transitions and age developments. Overwhelming exposure on the reality of life. Retreated and gained a sense of safety and security through insulin omission	
S46	mmmm		
P46	and I think that's kind of, why I clutched onto omitting my insulin so so much because that was the one thing that I could, that was all down to me I could control it no one else can influence the way I behave or what is happening to me you know it's all me	Earlier conceptual wondering appears to be inline with Peggy's experience. No one else (..) it's all me suggests that she may have previously not been able to influence what is happening to her by another (the other).	Control
S47	mmmmm		
P47	and I felt like I was doing the right thing for myself, you know this good for you don't take your insulin, what's happening to you because you're not taking it is good for you	Self-punishing narrative, encouraging the decline of her emotional and physical self. It's good for you. Voice of the eating disorder/insulin omission – who's voice is it?	
S48	It's good for you		
P48	Yeah and now I love the sense of control I have but it's a positive sense of control over my own health which at the time it was the complete opposite and it still felt right, but like it gave me power and drive and motivation and just to carry on doing it because look how good it makes you feel	Changing essence of control – from punishment to nourishment and self-care.	
S49	A different sense of control, a positive one that makes you feel good.		
P49	Yeah, that was the thing you know the other eating disorders out there feel like take quite a lot of effort, and you know I said was too greedy to stop eating completely	Sense of comparison/idealisation towards anorexia. Perhaps she wasn't even 'good enough' for this ED – failed again?	Comparison/idealisation towards anorexia Diabulimia as magic

	obviously I wish I had the drive and the will power to have anorexia but I don't I love food you know I take such pleasure out of eating so I found the greatest, you know it is magic, diabulimia omitting your insulin you get to get what you like and you eat more and more because your body is crying out for energy and nutrients and whatever, so you eat more and more and more and people used to marvel about how much I ate, you know I would have dinner and then I would go out and get two chocolate bars and a packet of crisps and coke, then I would come back and have pudding and everyone was like wow your metabolism is like so fast and you're so skinny and you're so active and I don't know it's, I'm kind of smiling about it now thinking about it, just how great it was but yeah it was just yeah it was just so easy once I started it was so easy, you know the weight dropped off, everyone said I looked great I could eat anything I liked yeah it was great	It is magic Found an ideal situation where she could eat what she wanted, loose weight and get the validation from others externally. Smiling about it now, thinking about just how great it was: Sense of loss, grieving, missing it. Omitting insulin, held meaning – it meant something to her. She developed a relationship to and with it. Although it caused physical and emotional anguish – it still holds the ability to make her smile. Is their a longing in the smile, a sadness for a time gone by?	Affirmation/Validation from the other Loss of a past time/self
S50	It was great, making you smile		
P50	Yeah, I think I'm smiling because it's it not funny ha ha it's just thinking about, I don't know just think about I don't know just how weird the situation was <u>and how well hidden the eating disorder was. No one spotted it, everyone thought I was just super active and had a fast metabolism or I was eating healthily, or I was really active, you know it's such a good cover story.</u> You know I used to stick my pen in me and just not do anything with it and because people don't know that much about diabetes they don't know if you're injecting or not they don't know, so I kind of just covered up yeah I'm injecting yeah it's fine yeah it was just a really easy thing	Smiling at well hidden the eating disorder was. Smiling in a sense that she succeeded in keeping it hidden and deceived/tricked everyone? Used people's ignorance and unknowing of diabetes to her advantage. Proactively kept it hidden. Sense that whilst she was actively hiding it, the lack of understanding meant it went unnoticed. Which may have been 'good' as it meant she could continue in this way – but also adding to her sense of isolation, feeling trapped alone and not able to ask for help.	Invisible to the 'unknowing eye' The unknowing Other facilitates invisibility of diabulimia (which may in turn increase sense of isolation and loneliness)

	to cover. I think it's because the general public don't really know that much about diabetes, I mean why should they they don’t have it but you know when you slap an eating disorder on top of that that is related to insulin omission it becomes super complicated people understand and know of anorexia and bulimia and those you know but you know but when you combine an eating disorder with a medical condition it becomes far more complicated. People don't know of it or they don't understand it so it's really easy for it not to be noticed.	It being unnoticed therefore has a complex reality.	

Appendix 19: Example of Emerging Themes Table (Alex)

Theme No.	Emergent Theme	Key Phrase	Text Reference
1.	Diabulimia as complicated love (deadly love affair)	It was great, I loved it and probably not a lot of people say that I was anorexic and bulimic before I was diagnosed and I had never managed to get to the weight that I did when I was diabulimic (…) so I loved it until I didn't until it started killing me. It hadn't have been for that I probably would have kept going like being honest I got retinopathy and that was like oh god and then I lost a couple of friends and that was really what made me go urgh but for a long time my diabulimia was my happy place, you know waking up in the morning being four pounds lighter nothing like it	**A3**
2.	Historic disordered eating	I was anorexic and bulimic before I was diagnosed	**A3**
3.	Function of diabulimia	It was my coping mechanism	**A4**
4.	Aversion to weight gain	I was diagnosed I was 14, I wasn't I had lost 3 stone when I was diagnosed so of course as soon as I started injecting that weight went on and I was like well I'm not doing it then	**A4**
5.	Treatment tension (ED vs T1DM) Function of food	ironically the recovery from an eating disorder is like oh you don't have to think about your food anymore you have to make sure that you're not obsessing and you're not doing this and I had worked really hard to do that and when I was diagnosed it was like someone had gone you know that work you've done, well heres your eating disorder back	**A5**
6.	Diabulimia as a complicated love	It made me really happy because I was mentally ill and yeah	**A5**
7.	Lack of choice/control Inevitability of diabulimia	I never had a chance to not be diabulimia I don't think	**A5**
8.	Recovery attempt Aversion to weight gain Immediacacy of diabulimia	I was over the moon that I had lost this weight that I had put on during my bulimia phase in my recovery from bulimia and me being me I thought well this is great because I've been trying to eat healthily and I had been exercising but I had been doing it in a healthy way that's not eating disorder so when I started losing weight I thought this is great and everything that everyone has told me is true it is just diet and exercise in moderation rah rah rah rah and of course the weight fell off then I was diagnosed and erm as soon as I started taking my insulin the weight just went on and I was like wait what happens if I	**A7**

		don't do that and it came back off and that was it I was diabulimic within a week of being diagnosed	
9.	Obsessional thinness ideal Impact on body	I had a stroke that didn't stop me like you know because that was the most important thing in my life was being thin, it was the only thing that mattered, it was obsessional	**A8**
10.	Impact on body	I would be shattered because I would not have slept through the night because I would be up peeing through the night (..)I only ever checked to make sure that I was in Ketoacidosis I used to know that I had pushed it too far when I got problems with my lungs	**A9**
11.	Proximity to death/dying Survivors guilt	I mean I went 3 weeks without insulin once. I think to be honest though I was probably larder because I had that really prolonged period of like the honeymoon period and also I had like times when I should have been dead there's no way I would have survived that had I not had still some functioning left	**A10**
12.	Performance of illness	Everyone everywhere just thought I was having a diabetes attack do you know what I mean and I played up to that you know like I would lie and say I had this condition called brittle diabetes which means that sometimes it's just too much for me and of course my boss his brother had type 1 diabetes and he had never worked a day in his life so I was like a saint to this boss do you know what I mean it was like oh you're so brave you're so brave you know and so I managed to get away with it for a really long time	**A11**
13.	Perpetuating role of external environment/systems	the smaller I got the happier my manager was because the better our photographs looked and every time I would think maybe I shouldn't be doing this it would be like oh you've got a photoshoot next week. I think kept me really sick for a really long time was because I was in this environment where people were taking pictures of me like all the time	**A11**
14.	Impact on body	so being in DKA is like being on speed, it's like you're tired but wired do you know what I mean because it's like your body is burning itself so you can't sleep because your body is like a nervous ball of energy so even though you physically feel like oh my god maybe I can't, like walking up the stairs would become a chore for example you're like	**A14**
15.	Secrecy of diabulimia Performance	being in DKA meant that I could have a job, I was in a band this went on for a long time and I never lost a job, I was very very high functioning very high functioning. Day to day you wouldn't know and people would say to me oh my god you must	**A15**

		do so much exercise, you know and I would be like yeah sitting there eating a Mars Bar.	
16.	Obsessive weight loss – thinness ideal	but it was never about the food that's the thing, sitting there eating sugar I never like it, I was anorexic you know what I mean so the thought of doing that keeping it in your system and not throwing it up but food was now I lost weight right so the tables had completely turned so food is now the friend you just eat eat eat and you lose weight you know it was so odd but I think that's why for me my eating disorders have always been obsessive weight loss disorders because it's not so much about the food it's about the weight	**A15**
17.	Obsessive weight loss – thinness ideal	its not necessarily about the food it's about weight loss	**A17**
18.	Lack of choice/control Inevitability of diabulimia	if you've had an eating disorder before and then you get diagnosed with type 1 you don't have a chance in hell you know	**A17**
19.	Function of diabulimia Descriptive imagery of weight loss	that was my coping mechanism actually the fact that I was in DKA and wasn't really thinking about anything other than losing weight losing weight losing weight (..)yes that's fat that I'm peeing out, I don't really know how to like yeah I loved my eating disorder it made everything really simple	**A19**
20.	Obsessive weight loss – thinness ideal	I cried happy tears was when I got into a pair of size 6 trousers. I don't think even on the day that I get married that I will be as happy as I was in that changing room, like I was on the floor sobbing with happiness	**A19**
21.	Critical voice Denying her thinness ideal	I would be like you're not that small you cannot be that size look at the state of you. I'm still in about 20 grands worth of debt from clothes shopping when I was diabulimic because I was convinced, it was the only way to sort of rest my mind from this panic that you're not that size, look at you how can you be that size you're disgusting you know what I mean	**A23**
22.	Critical voice Denying her thinness ideal	it's a size 6 you tried all the size 6's on in the shop and then I would be like people are looking at you they know, they know that you're not really this thin, they know that you're really fat	**A24**
23.	Loss of relational contact Silencing of authentic voice/self	I had a very very fractured relationship with my parents at that point, I didn't speak to them for about 18 months erm at one point because I went on a protest, an anti-war protest and that was enough for them to not speak to me for 18 months but I was fine with that so they don't live here so you know I would be in hospital and they wouldn't even know, mum sent someone round to my house once, a policeman to see if I was still	**A27**

		alive because I wasn’t talking to her, but she decided then that she was going to talk to, because she couldn't get in touch me she decided to send a policeman round but it was her who hadn't spoken to me in the eighteen months before then, do you know what I mean so it was fractured	
24.	Hedonism Proximity to death/dying	my friends we were all just a big mad party crew anyway you know what I mean, everyone was fucked, our house had a Myspace so that whenever we ran out of booze or drugs we would just have a party and get people round	**A27**
25.	Reinvention of self as someone ‘not known’	I wanted to look androgynous that was always my thing, I loved that ambiguity of what are you, who are you, do you know what I mean whereas before I had been this chubby girl with big boobs and that never really felt like me the real me felt like that tiny androgynous stick thin keyboard player, that was all I had ever wanted in my life and diabulimia gave me it	**A31**
26.	Diabulimia as a complicated love Obsessive weight loss – thinness ideal (ongoing)	I miss it, despite everything I've done since I actually think if you said to me right now we'll take away all of your achievements but you'll be a size 6 for life I would take that, in fact if they said we'll kill everyone that you've ever loved but you’ll be a size 6 for life I would struggle with that, I would struggle with that if I’m being really brutally honest about it	**A32**
27.	Early relational experiences – bullying Loss of choice/control	I was really badly bullied when I was younger for being overweight and it's a bit of a cliché I suppose but that's why I stopped eating in the first place or one of the reasons why I stopped in the first place and then I would stop eating and my mum and dad would find out and they would force feed me and that put me into the bulimia cycle and you know it was just, they didn’t handle it very well but yeah the thing that kicked it all off really was that I was bullied for being overweight and you know the irony is now that I look back at the pictures and I was a little bit chubby at 5 like the bullying started really early like really really early, and yeah I just too early I think, too early for it to every really leave	**A36**
28.	Obsessive weight loss Obsession transferred from weight loss to education - distraction attempt	nothing is more important than being thin and everything I have done in my life since I got better has been to counteract that voice I don’t think I will ever be able to counteract I'll definitely never not believe it, I’ll never ever think that my life wouldn't be better if I was a size 6 because I know that, I've got a PhD do you think I cried with tears of joy when I got my PhD, no.	**A39**

29.	Thinness ideal Reinvention of self as someone ‘not known’	when I was diabulimic it was just like yes I've done it, now I get to stay here and now I can be beautiful and thin and nobody knows if I’m a boy or a girl	**A40**
30.	Treatment experience (Attended to diabetes but desire for care/connection/compassion left unattended to?)	I went to hospital and they were like, because I could still talk and stuff like that they were like oh you've had a TIA everything will be fine bla bla bla but of course they hooked me up to insulin so I unhooked myself and discharged myself, I didn’t even stay it was like I’m not putting that shit in my body and they let me walk out because what else could they do once I had discharged myself no sectioning no nothing so off I went so the first thing that I did of course was weight myself	**A32**
31.	Loss of/influence of relational contact on illness escalation	I would rather die, I would rather die, I would rather OD, I would rather have a stoke at that point anyway, things were really bleak at that point I had broken up with someone who I absolutely adored and loved him, when that fell apart I sort of, that's when things got really bad	**A49**
32.	Function of diabulimia – coping mechanism (and protective) Value of thinness ideal	there was nothing more valuable than being thin not even life at that point, that's what I'm saying about it being a coping mechanism like everything else was falling apart the only thing keeping me together was the fact that I was thin do you know what I mean, the only reason that I didn't end up killing myself or becoming a drug addict or an alcoholic was because I could hold onto the fact was that I had the one thing that was more important than anything else which is that I was thin	**A50**
33.	Seeking safety in thinness dd Loosing weight as a means of gaining care and connection from the other (as opposed to being bullied) Transformation/eradication of the self (Thinness as a means to erase/distance herself from past self)	I felt safe being thin, like in a way that like it felt safe like nobody could, like you can't call me fat cow anymore like you can't, when I was about 12, 13 was when I made the concerted effort to stop eating erm and dropped a lot of weight and of course everyone was really nice to me being really thin felt superior and also made me feel like nothing can touch me like that person that you bullied she doesn't exist anymore like she has literally disappeared (….) I suppose but it felt safe and superior and it make me feel like that person who really bad things had happened to she was literally gone I had pissed her down the toilet	**A50** **A51**
34.	Recovery/change journey Relational connection Treatment/health service experience	I’ve had to find another way of getting my self-worth erm and I think that I have done that through achieving academically (..) Peer support really was the thing that helped me and seeing people actually die that I cared about erm made me really angry at this general health service that was letting these people that I loved die	**A55**

35.	Transformation of self	I suppose doing what I do now is again a different person	**A57**
36.	Relational connection/role of the other in recovery/change	I really started valuing the life's of other people going through what I was going through and that really made me feel like, I really feel like I got better for myself I feel like I got better for them and being better for them is what has kept me well because I don't think I could have ever got better for myself	**A57**
37.	Recovery as ongoing Distraction Relational connection/role of the other in recovery/change/relapse prevention	I still struggle to take care of my diabetes a lot you know like I keep myself completely distracted and I mean completely distracted I want to help people but I run run run run so that nothing catches up with me do you know what I mean, like once I had finished my PhD I pretty much had a a full on breakdown because all of this stuff that I had been like we'll deal with this after we'll deal with this after you know it just came spewing to the fore you know and my blood sugar control went to shit and if it hadn't have been for my partner I think I would have probably relapsed happily I might add	**A58**
38.	Recovery as ongoing	I still do think like I just can't do this today and I'm really anxious and I've got all this stuff going on and you know what would made me feel better, being half a stone lighter by this time tomorrow	**A59**
39.	Distraction from thinness ideal Relational connection/role of the other in recovery/change/relapse prevention	I have to consistently talk myself out of that and remind me that it's not just me because if there's no me then there's no charity, and if there's no charity then all those people they don't get any support and what about my family because I now do get on with them and more importantly what about Jason it's not fair for him, we're supposed to be partners he's not my carer I got through a checklist you can hear it almost in my head of all the reasons not to relapse and not one of them is because you deserve not to relapse because you know you are doing important work rah rah rah it's all like if you relapse then this will happen to this person, this will happen to that person I just I don't care because in my mind really all I want to do is be thin and everything else is distraction	**A60**
40.	Proximity to death/dying Survivors guilt	Yeah there are so many people that aren't here I made it and I really shouldn't have erm yeah I've lost so many friends to this illness that that's another thing that goes through my head now when I think I just can't do this, well you know I'm sure Sean would have loved the opportunity to do it for another day, sorry that was my best friend who died, or Eve or Charlotte or Elise or	**A62**

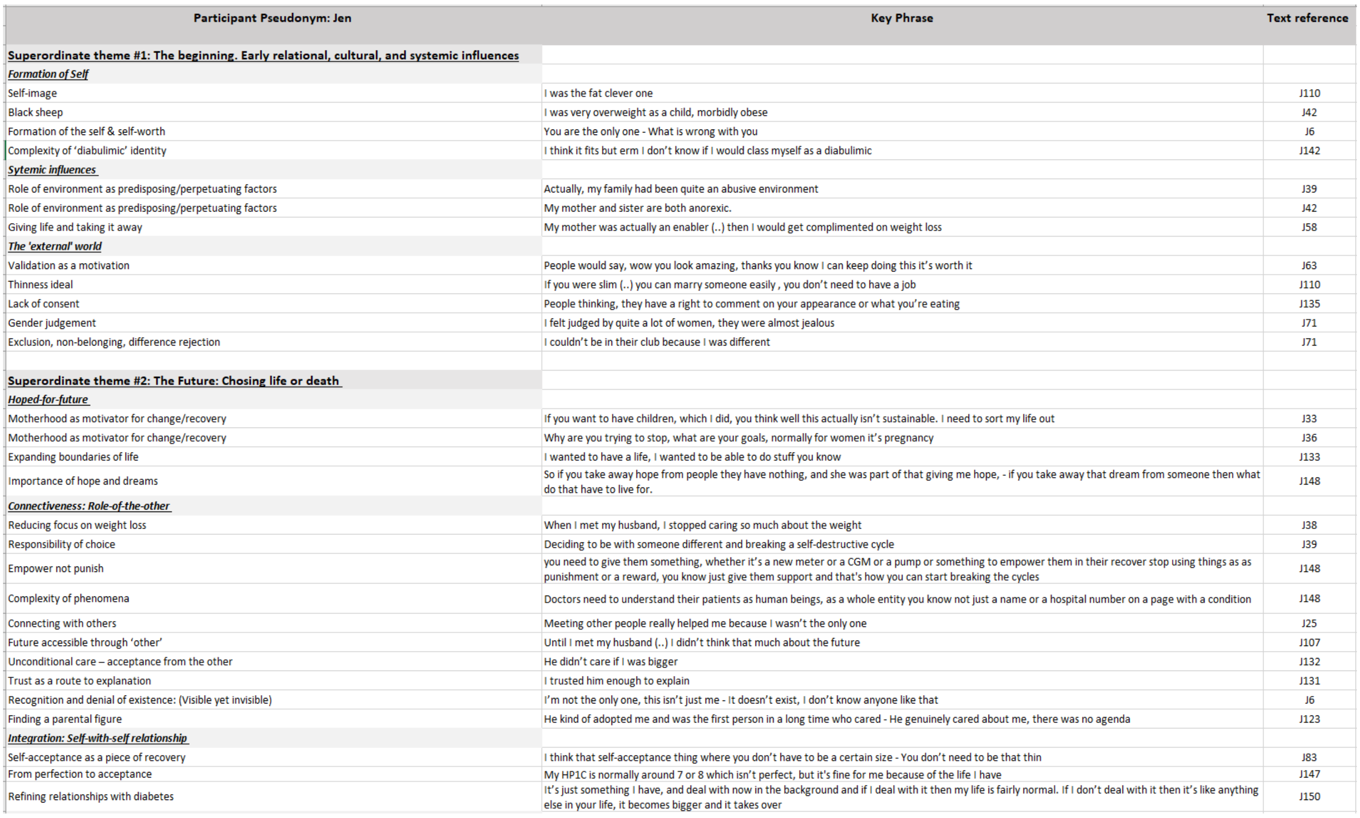
		Katie and that's kind of like you know pick yourself up bitch and let's get going because it's not right for you to have thoughts when actually they're not even here so yeah I think a lot of my coping comes from guilt (…) Survivors guilt, it is absolutely survivors guilt yeah	
41.	Proximity to death/dying	I just don't want that to happen to anyone else especially because it's so unnecessary	**A64**
42.	Journey of change/recovery	I used to starve or throw up or be thin now I work that's what I do to cope	**A64**
43.	Historic difficulties with food and ingestion	when I was younger I used to regurgitate my food and spit it out, I was three like my mum used to say you always used to smell of sick and I like I I've always had these feeding issues for as long as I can remember, I can't remember a time where I could just eat do you know what I mean like literally even when I was younger I was regurgitating my food	**A65**
44.	Relational connection/role of the other in recovery/change/relapse prevention	I always thought it was going to be music that would pull me out of it but actually that just made things so much worse erm and in the end it was the support group that was more important than my killing myself being able to be there for someone else and that's where it all started in terms of me getting better it was like okay well let's we'll call each other tonight and see how we are getting (…) other diabulimics saved me	**A65**
45.	Relational connection/role of the other in recovery/change/relapse prevention Validation through shared experiences Imagery – insulin as fat	It was more of a community, I remember I would think of course other people do this but I must be the only person stupid enough to have a stroke and not stop do you know what I mean and then you meet girls and they have gone blind and not stopped, they've lost limbs any they've not stopped do you know what I mean and suddenly you realise like oh I'm mentally ill. I'm actually mental like there is something wrong with me here, like I had always known that there was something wrong but that's when I realised, this is a syndrome, this is a syndrome we all think that our insulin is lard everyone in the group is talking about how they imagine that it's fat or oil or grease, everyone is talking about how carb counting makes them feel and I was like this is a fucking syndrome	**A68**
46.	Treatment experience Death/Dying Gaining control through academia and training	It's not anorexia, it's not bulimia it's something else and it's all of us going through all this terrible treatment (…) I was going through this everyone in the group was talking about how oh I had a DSM told me to take my injections and get on with it today, like we had this collective experience of complete incompetence and then	**A69**

		we start dying and that was when I was like right I'm not doing this anymore I am going to get better. I'll say I had a very bad psychologist, so she like to this day to this day erm but yeah that was really the turning point	
47.	Transformation of self (developed understanding that it may be linked to wanting to disappear in response to feelings of inadequacy)	I felt very inadequate and it was very much again that kind of that I just wanted to disappear and be someone else	**A69**
48.	Journey of change/recovery - Anger as a motivator - Collective suffering of the other - Redirecting obsessive tendencies	being really determined putting some of that obsession into something a little more healthy maybe but yeah for me in terms of getting better it was the collective seeing everyone suffering in the same way so needlessly and it was so stupid you know like someone would come up and be like you will never guess what the psychologist said to me, I had a girl who was overseas, they took her insulin off her in case she would overdose on it I had to phone her mum and be like do you understand why this is not a good idea, like and to be honest peoples stupidity made me really angry so yeah fury got me into eating disorders and also back out of eating disorders	**A69**
49.	Treatment recommendation	people who have had eating disorders should be immediate red flags for a type 1 diabetes diagnosis I mean you could have seen this, I mean Stevie Wonder could have seen this coming you know like you know what I mean and the amount of money that I have cost the NHS	**A75**
50.	Transformation of self	It's fine to talk about it because it's a different person. Maybe I'm quite good at compartmentalising or moving on from that but that's just another erm part of my life that is done do you know what I mean like I was a musician that's finished I did a degree in English that's done, I was bullied at school that's over and now I am what I am now and I think I think I'm quite disconnected from it almost	**A75**
51.	Diabulimia term	It's just lazy it's really lazy oh look there's the first bit of diabetes and let's just put bulimic at the end of it, like why not diorexia it seems to be complete arbitrary and erm yeah I think it's lazy and I think it's compartmental of two very different illnesses and I think that actually the term diabulimia has been really problematic I mean I've had people come to me and be like oh but I don't throw up do you know what I mean, like I'm a type 1 diabetic but I don't throw up, am	**A79**

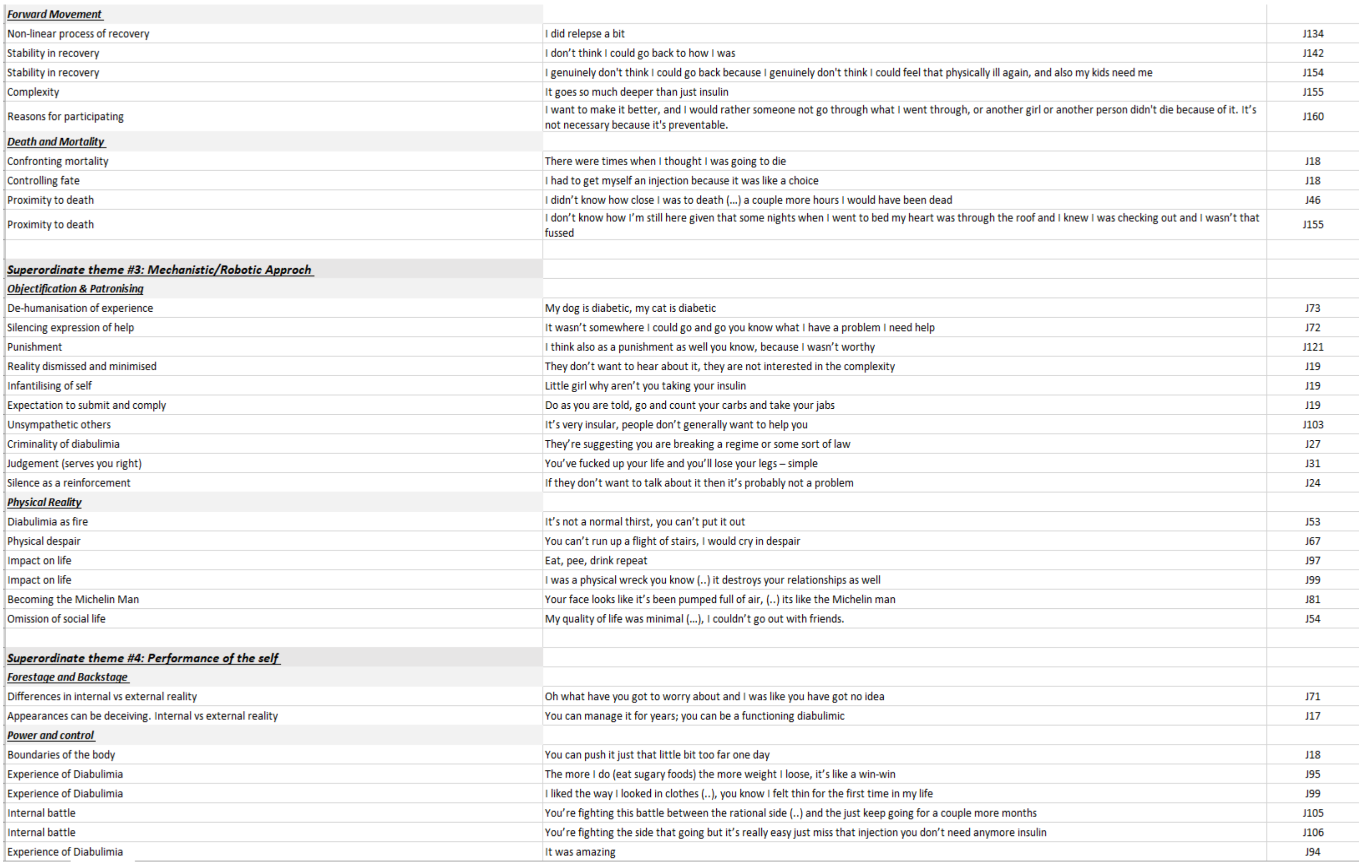
		I like well do you not take your insulin and they're like oh no of course not so I'm like well you're actually, that is diabulimia, oh I didn't know	
52.	Treatment recommendation	the treatment that I needed at that point when I was restricting my food instead of restricting my insulin is completely different	**A79**
53.	Diabulimia term Call for recognition/validation	it needs to have a different name something that takes us out of standard eating disorders completely (…)I don't like it and I think we need a proper diagnostic. The thing is they're going to have to do it at some point because otherwise you're just wasting NHS money like sending someone to the priory for six months for anorexia when they are not taking their insulin, that's nice way to lose a lot of money, so I don’t like the name but I will use it until the point where there is something better and more descriptive that the patients uptake themselves, yeah	**A79**
54.	Treatment recommendation Medically not belonging	People need to think about as well is erm capacity like when I discharged myself after having my stroke erm I asked them, well can you section me and they said no because insulin is not a psychiatric medication so like there were several times when I was like I’m either discharging myself or you're discharging me but I am going to be back here in three weeks’ time unless there is somewhere else for me to go, but I was consistently told that there was nowhere to go	**A81**
55.	Medical/psychological unattendance/distance from the other as a reinforcer.	my shitty psychologist used to say to me oh are you going to take your insulin and I would say no, and it's like wait a minute I’m trained now that if someone says to me I'm going to go and take my own life then that's a crisis, she let me walk out that door every week and that almost reinforced my belief that it's not that bad do you know what I mean, oh it can't be that bad even though I was having strokes and my kidneys were fucked and my eyes were fucked but you know can't be as bad as like killing myself because they let me out	**A81**
56.	Treatment experience/recommendation	why am I sitting in a therapy room with someone when I'm in DKA or when I'm hypoglycaemic like you wouldn't do that with anorexia you have to feed people first and then they wonder why is this therapy not working well because I'm not even there	**A81**
57.	Treatment/recovery experience	it was an absolutely horrible, harrowing, this is I’m not talking about having diabulimia I'm talking about recovering from diabulimia was worse, was so much worse than the diabulimia itself	**A81**
58.	Diabulimia as a complicated love – a gift from God.	I loved my diabulimia like I felt when I first got type 1 diabetes and I realised I could do this, I	**A81**

	Treatment/recovery experience Desire to 'disappear' – transformation of self Role of the other – connecting to others in recovery/change	thought it was a gift from God trying it get over it was the most horrible, worst thing I've ever had to do in my life, I've never met so many people that didn't know what they were doing, didn't know what they were looking at, even though they were competent in every other area this was just like this huge blind spot and it seemed so obvious to me and all I wanted was support with it and it wasn't there which made me feel again like I wanted to disappear like it completely validated everything I thought about myself which was that I was mental which is why other diabulimics saved me because I was like it's not just me,	
59.	Recovery experience as a protective factor	once you are better you feel so shitty when you start, you can't really go back to it once you have go to prolonged recovery do you know what I mean because you feel like death like diabulimia isn't just something where you wake up one morning and be like oh well I'm not going to take my insulin today it tends to be a gradual blood sugar gets higher and higher so you don't notice it, it's like the boiling frog right but when you are in like normal, sorry typical diabetic and you try to relapse and I know this, it feels shit it really feels like shit so there's a lot to be said about do the recovery and do it once because it is horrible its awful yeah	**A83**
60.	Recovery as punishment	it's shit and you put on a lot of weight and your complications come on quicker, it's the only illness I know of where you get punished for getting better	**A84**
61.	Recovery as punishment Punishment for being alive, for moving away from her 'authentic self.'	I felt like I was being punished (..) for trying to escape who I really am which is this twig androgynous twig that's who you really are and you're going to get punished because that is how you were supposed to die like that, that's how you were supposed to die rather than some fat old person	**A86**

Appendix 20: Example of Initial Superordinate Themes Table (Jen)



Participant Pseudonym: Jen	**Key Phrase**	**Text reference**
Superordinate theme #1: The beginning. Early relational, cultural, and systemic influences		
Formation of Self		
Self-image	I was the fat clever one	J110
Black sheep	I was very overweight as a child, morbidly obese	J42
Formation of the self & self-worth	You are the only one - What is wrong with you	J6
Complexity of 'diabulimic' identity	I think it fits but erm I don't know if I would class myself as a diabulimic	J142
Sytemic influences		
Role of environment as predisposing/perpetuating factors	Actually, my family had been quite an abusive environment	J39
Role of environment as predisposing/perpetuating factors	My mother and sister are both anorexic.	J42
Giving life and taking it away	My mother was actually an enabler (..) then I would get complimented on weight loss	J58
The 'external' world		
Validation as a motivation	People would say, wow you look amazing, thanks you know I can keep doing this it's worth it	J63
Thinness ideal	If you were slim (..) you can marry someone easily , you don't need to have a job	J110
Lack of consent	People thinking, they have a right to comment on your appearance or what you're eating	J135
Gender judgement	I felt judged by quite a lot of women, they were almost jealous	J71
Exclusion, non-belonging, difference rejection	I couldn't be in their club because I was different	J71
Superordinate theme #2: The Future: Chosing life or death		
Hoped-for-future		
Motherhood as motivator for change/recovery	If you want to have children, which I did, you think well this actually isn't sustainable. I need to sort my life out	J33
Motherhood as motivator for change/recovery	Why are you trying to stop, what are your goals, normally for women it's pregnancy	J36
Expanding boundaries of life	I wanted to have a life, I wanted to be able to do stuff you know	J133
Importance of hope and dreams	So if you take away hope from people they have nothing, and she was part of that giving me hope, - if you take away that dream from someone then what do that have to live for.	J148
Connectiveness: Role-of-the-other		
Reducing focus on weight loss	When I met my husband, I stopped caring so much about the weight	J38
Responsibility of choice	Deciding to be with someone different and breaking a self-destructive cycle	J39
Empower not punish	you need to give them something, whether it's a new meter or a CGM or a pump or something to empower them in their recover stop using things as as punishment or a reward, you know just give them support and that's how you can start breaking the cycles	J148
Complexity of phenomena	Doctors need to understand their patients as human beings, as a whole entity you know not just a name or a hospital number on a page with a condition	J148
Connecting with others	Meeting other people really helped me because I wasn't the only one	J25
Future accessible through 'other'	Until I met my husband (..) I didn't think that much about the future	J107
Unconditional care – acceptance from the other	He didn't care if I was bigger	J132
Trust as a route to explanation	I trusted him enough to explain	J131
Recognition and denial of existence: (Visible yet invisible)	I'm not the only one, this isn't just me - It doesn't exist, I don't know anyone like that	J6
Finding a parental figure	He kind of adopted me and was the first person in a long time who cared - He genuinely cared about me, there was no agenda	J123
Integration: Self-with-self relationship		
Self-acceptance as a piece of recovery	I think that self-acceptance thing where you don't have to be a certain size - You don't need to be that thin	J83
From perfection to acceptance	My HP1C is normally around 7 or 8 which isn't perfect, but it's fine for me because of the life I have	J147
Refining relationships with diabetes	It's just something I have, and deal with now in the background and if I deal with it then my life is fairly normal. If I don't deal with it then it's like anything else in your life, it becomes bigger and it takes over	J150



Forward Movement		
Non-linear process of recovery	I did relepse a bit	J134
Stability in recovery	I don't think I could go back to how I was	J142
Stability in recovery	I genuinely don't think I could go back because I genuinely don't think I could feel that physically ill again, and also my kids need me	J154
Complexity	It goes so much deeper than just insulin	J155
Reasons for participating	I want to make it better, and I would rather someone not go through what I went through, or another girl or another person didn't die because of it. It's not necessary because it's preventable.	J160
Death and Mortality		
Confronting mortality	There were times when I thought I was going to die	J18
Controlling fate	I had to get myself an injection because it was like a choice	J18
Proximity to death	I didn't know how close I was to death (...) a couple more hours I would have been dead	J46
Proximity to death	I don't know how I'm still here given that some nights when I went to bed my heart was through the roof and I knew I was checking out and I wasn't that fussed	J155
Superordinate theme #3: Mechanistic/Robotic Approch		
Objectification & Patronising		
De-humanisation of experience	My dog is diabetic, my cat is diabetic	J73
Silencing expression of help	It wasn't somewhere I could go and go you know what I have a problem I need help	J72
Punishment	I think also as a punishment as well you know, because I wasn't worthy	J121
Reality dismissed and minimised	They don't want to hear about it, they are not interested in the complexity	J19
Infantilising of self	Little girl why aren't you taking your insulin	J19
Expectation to submit and comply	Do as you are told, go and count your carbs and take your jabs	J19
Unsympathetic others	It's very insular, people don't generally want to help you	J103
Criminality of diabulimia	They're suggesting you are breaking a regime or some sort of law	J27
Judgement (serves you right)	You've fucked up your life and you'll lose your legs – simple	J31
Silence as a reinforcement	If they don't want to talk about it then it's probably not a problem	J24
Physical Reality		
Diabulimia as fire	It's not a normal thirst, you can't put it out	J53
Physical despair	You can't run up a flight of stairs, I would cry in despair	J67
Impact on life	Eat, pee, drink repeat	J97
Impact on life	I was a physical wreck you know (..) it destroys your relationships as well	J99
Becoming the Michelin Man	Your face looks like it's been pumped full of air, (..) its like the Michelin man	J81
Omission of social life	My quality of life was minimal (...), I couldn't go out with friends.	J54
Superordinate theme #4: Performance of the self		
Forestage and Backstage		
Differences in internal vs external reality	Oh what have you got to worry about and I was like you have got no idea	J71
Appearances can be deceiving. Internal vs external reality	You can manage it for years; you can be a functioning diabulimic	J17
Power and control		
Boundaries of the body	You can push it just that little bit too far one day	J18
Experience of Diabulimia	The more I do (eat sugary foods) the more weight I loose, it's like a win-win	J95
Experience of Diabulimia	I liked the way I looked in clothes (..), you know I felt thin for the first time in my life	J99
Internal battle	You're fighting this battle between the rational side (..) and the just keep going for a couple more months	J105
Internal battle	You're fighting the side that going but it's really easy just miss that injection you don't need anymore insulin	J106
Experience of Diabulimia	It was amazing	J94

Appendix 21: Example of Master Table of Themes with Quotes

Superordinate theme 2: A deadly love	
Subordinate theme: The magic of diabulimia	
Participant	**Quote and transcript location**
Jen	It was amazing, it was a win win (J94)
Dave	Imagine I said to you right here's a magic pill, continue eating what you want. In fact, the more you eat the better it's going to work continue eating what you want, the more you eat the better it will work erm and the weight will just drop off you and all you've got to do is take this magic pill. There is some small print though, but no one reads them do they. You might go blind, you mind damage your kidney's, you might bla bla bla all the complications that you know what do you want to do live for now or live for the long term. If you gave that option to a number of people without diabetes, I actually think more than 40% would say 'yeah I'll take it' It's the magic pill with the horrible small print (D142)
Catherine	I was really elated by it (weight loss) because like although the eating disorder was not primarily about weight that was the outcome I was wanting. I needed to keep doing it and this was the magic tool that I needed (C43)
Peggy	If I stop taking my insulin I'm going to lose weight and it's like it's magic because you can eat what you like and you lose weight and it's fantastic and you get fed by other people and I think that was what was a really big driver for me to continue you know, people would say you look great you know you've lost weight and I'd feel just so great after being told that (P19) I found the greatest, you know it is magic, diabulimia omitting your insulin you get to get what you like and you eat more and more because your body is crying out for energy and nutrients and whatever, so you eat more and more and more and people used to marvel about how much I ate, everyone was like wow your metabolism is like so fast and you're so skinny and you're so active and I don't know it's, I'm kind of smiling about it now thinking about it, just how great it was but yeah it was just yeah it was just so easy once I started it was so easy, you know the weight dropped off, everyone said I looked great I could eat anything I liked yeah it was great (P49)
Alex	It was great, I loved it and probably not a lot of people say that, so I loved it until I didn't until it started killing me. It hadn't have been for that I probably would have kept going like being honest I got retinopathy and that was like oh god and then I lost a couple of friends and that was really what made me go urgh but for a long time my diabulimia was my happy place, you know waking up in the morning being four pounds lighter nothing like it (A3) I loved my diabulimia like I felt when I first got type 1 diabetes and I realised I could do this, I thought it was a gift from God (A81) I miss it, despite everything I've done since I actually think if you said to me right now we'll take away all of your achievements but you'll be a size 6 for life I would take that, in fact if they said we'll kill everyone that you've ever loved but you'll be a size 6 for life I would struggle with that, I would struggle with that if I'm being really brutally honest about it (A32)
Carley	I hate it, its stereotypical I didn't ask for this, I don't want it, I don't want to take the insulin, it makes me different I can't take a break there's no pause on it. (Carley: CAR39)

Subordinate theme: The polarity of magic	
Jen	My quality of life was minimal, I would come home from work, sometimes I would fall asleep after work and I'd wake up, peeing through the night but not until the next morning. Yeah, I couldn't go out with my friends, if I went out drinking, I would be seriously ill for a couple of days afterwards (J48) I was struggling to hold down my job. I was going to the loo twice three times every hour (J54) You can't run up a flight of stairs, you feel faint your chest gets tight you're out of breath, you know I would cry in despair sometimes if I had got downstairs and I had left something upstairs. I would be in tears because I would have to go back up again. I was getting up every twenty minutes to half an hour through the night to pee, and drink and pee some more. I likened it, I had never had kids, but it must have been like having a new-born baby, cos you're literally constantly up. (Jen: J67)
Dave	I was being half the person, half the teacher, half the family man, half of everything I could and have should have been (D30) I had so little energy that I had to prioritise my energy for what went on in the classroom, talking to, teaching the kids you know. I loved the teaching but that wore me out to a point where I didn't have energy for it. (David: D36)
Catherine	I was getting more and more unwell so by by the end of that year I changed to a different course partly because I just couldn't cope physically with the demands of it (C24) I made a couple of friends at university but not many and most of that was because I didn't have the energy to kind of invest in friendships and when you're spending such a large part of your day so exhausted and feeling so unwell erm yeah it's hard, like I didn't go out in the evenings or anything. (Catherine: C33)
Peggy	I felt awful. I felt tired all the time and I'd you know I'd be going to the loo like twice an hour you know all the classic symptoms awful horrible breath, weeing all the time no energy, super tired, super weak you know that clouded mind I ended up dropping out of uni (…) (Pause 3 seconds) actually, omitting insulin omitted every part of my life. (Peggy: P27) You know relationships with other people, I was so angry all the time, I would fly off the handle into a rage. I made friendships really difficult and I really regret that you know because I have some really kind, loyal and understanding friends because they're all still here but I look back and I understand the way I jeopardized my friendships and the way I was with my parents and my family. I was a really horrible difficult person but somehow I was able to ignore all of those things and that side of my life and think well it doesn't matter because you are skinny and that's all that matters which is it's such a bonkers irrational way to think but it was truly what I believed for a really long time. (Peggy: P27) I found the greatest, you know it is magic, diabulimia omitting your insulin you get to eat what you like and you eat more and more because your body is crying out for energy and nutrients and whatever, so you eat more and more (…) everyone was like wow your metabolism is like so fast and you're so skinny and you're so active and I don't know it's (breaks out into a large smile), I'm kind of smiling about it now thinking about it, just how great it was but yeah it was just yeah it was just so easy once I started it was so easy, you know the weight dropped off, I could eat anything I liked yeah it was great. (Peggy: P49)

Alex	I would get up in the morning and I would be shattered because I would not have slept through the night because I would be up peeing through the night (..) and I couldn't breathe properly, so it's caused Kussmaul breathing and it's actually a thing and you get fluid in your lungs as a by-product of Ketoacidosis. (Alex: A10) I didn't really start feeling the physical complications for a while but I mean I had a stroke that didn't stop me like you know because that was the most important thing in my life was being thin (A8) I would get up in the morning and ash I would be shattered because I would not have slept through the night because I would be up peeing through the night (A9) I miss it, despite everything I've done since I actually think if you said to me right now we'll take away all of your achievements but you'll be a size 6 for life I would take that. In fact if they said we'll kill everyone that you've ever loved but you'll be a size 6 for life I would struggle with that, I would struggle with that if I'm being really brutally honest about it. (Alex: A32)
Subordinate theme: Walking the 'tightrope' between life and death	
Jen	I know from my own experiences that there were times when I thought I was going to die, this was it and that was when I had to give myself an injection because it was like a choice, I was lucky I had that choice. (Jen: J18)
Catherine	I would go 3 or 4 days not taking insulin and I would get to the point where I felt that I was about to collapse and at that point I would take a massive dose of insulin and then kind of hope for the best, I mean I think I'm really lucky that I didn't end up killing myself doing that. (Catherine: C25)
Alex	There are so many people that aren't here, I made it and I really shouldn't have, erm yeah I've lost so many friends. When I think I just can't do this, I think well you know I'm sure Sean would have loved the opportunity to it for another day or Eve or Charlotte or Elise or Katie and that's kind of like you know pick yourself up bitch and let's get going because it's not right for you to have thoughts when actually they're not even here so yeah I think a lot of my coping comes from guilt (…) survivors guilt, it is absolutely survivors guilt yeah. (Alex: A62) I felt like I was being punished (..) for trying to escape who I really am which is this twig androgynous twig that's who you really are and you're going to get punished because that is how you were supposed to die like that, that's how you were supposed to die rather than some fat old person. (Alex: A86)
Carley	I always make the joke that I'm not going to live until I'm fifty cos of damage that I've done so (…) and you know you make that joke of oh yeah I'm probably not going to live until I'm fifty and you know you joke about it but a lot of the time the things people actually joke about are things that are effecting them. (Carley: CAR26) I don't know how long I am going to exist for because all of this shit diabetes stuff, I think the future is going to be really bleak and I don't know what's going to happen. There is that genuine belief that I will not actually life to a high age because of all the stuff I have done (Carley: C68/77)

Appendix 22: Initial Research Proposal (May 2018)

METANOIA INSTITUTE/MIDDLESEX UNIVERSITY

DOCTORATE IN COUNSELLING PSYCHOLOGY AND PSYCHOTHERAPY BY PROFESSIONAL STUDIES (DCPSYCH)

Cover Sheet for Written Assignments

This cover sheet is designed for assignments submitted in DCPsych Years 1, 2, 3 and 4

Name of candidate: Sian Morris

Year of course: Year 3

Primary Course Tutor: Dr Werner Prall

Title of assignment: Exploring the lived experience of individuals who identify as having diabulimia yet receive a different diagnosis.

Word count: 6,600

Date assignment due: Friday 18th May 2018

Date assignment submitted: Friday 18th May 2018

Exploring the lived experience of individuals who identify as having diabulimia yet receive a different diagnosis

1. Introduction

"Every day I have to make the choice between life and death. I know it sounds dramatic but it is true. Every injection brings with it guilt, a conscious decision to care for myself. But I ask you this, why would you save someone you despised?" (Stavoru, 2009, p.35)

This quote is from a young woman describing what it is like to live with diabulimia. Each time I read her words I notice a knot in my stomach and a tightening of my chest. The situation the young woman describes feels complex, complicated and sad. I ask myself the posed question but instead of clarity I am faced with feelings of confusion and wonderings; what do you do in that situation, where can you go for help, who can help?

I turned to the literature to seek answers but instead emerged with more curiosity and questions. The literature explains that the deliberate restriction or omission of insulin for the purposes of weight loss is a phenomenon unique to eating disorders (EDs) in Type 1 Diabetes Mellitus (T1DM) (Goebel-Fabbri, 2017). This phenomenon is known as diabulimia (Allan, 2014; Murray and Anderson, 2015). Diabulimia is not recognised as a mental health disorder yet the term is used by the diabetes community to describe what they see as a unique illness identity that they feel should be distinguished from other eating disorder subtypes (Allan, 2015).

The severe and fatal consequences of diabulimia have resulted in the phenomenon being described as 'a flirtatious relationship with toxicity and fatality' (Zabka, 2011 p.221) and 'the world's most dangerous eating disorder' (British Broadcasting Cooperation, 2017). Yet despite an acknowledgement of the severity of diabulimia, the question of how best to treat this clinical population remains unanswered. Research has demonstrated that the diabulimia cohort do not respond to standard eating disorder (ED) interventions and is now starting to explore the role that self-categorising as having diabulimia may have on recovery (Allan and Nash, 2014; Hastings et al., 2016: Colton, Olmsted, Wong and Rodin, 2015).

The current situation is that you have individuals identifying as having diabulimia, research indicating the importance of valuing this identity for recovery and the impossibility of receiving an official diagnosis of diabulimia. At the centre of this triad are the individuals themselves and their lived experiences. To date, there is no research that has explored what it is like for individuals who do identify as having diabulimia to receive a different diagnosis. This knowledge could inform discussions around treatment and recovery, contribute to professional training and update the way we work clinically with this client group. It is the aim of my research to address this gap in our understanding.

2. Literature review

The forthcoming chapter will identify the theories and studies which have influenced the choice of research topic and selected methodology. In writing the chapter a decision was made to place a greater emphasis on the diabetic literature as opposed to EDs. The rational is that individuals are first responding to T1DM, and do not feel that their self-identification is currently captured in the ED categories that exist. Thus, an emphasis on the ED literature may be likened to the current position of the diabulimia cohort in which they feel they are placed into categories where their unique subjective experiences are overlooked.

2.1. Psychological Perspectives of Diabetes

T1DM is a chronic disease typically occurring during childhood and adolescence where the immune system attacks the pancreatic cells that produce insulin (Fisher et al., 2015). An exploration of how diabetes has been conceptualised reveals a vast body of literature with numerous ways to make sense of the phenomena.

Building on Freud’s (1924) idea that psychic energy can discharge itself into bodily symptoms, Dunbar (1954) proposed that when energy does not dissipate in this process it drains through the autonomic nervous system and causes organ disorders. In this model the personality profile of diabetic individuals is characterised by overpowering chronic, unconscious anxiety. This fear prevents the individual from discharging emotional tensions and diabetes occurs when the personality is no longer able to cope with its problems (Dunbar, 1954). Similar propositions are made by Lowe (1948), Daniels (1936), Newburgh and Camp (1926) and Weiss and English (1950), who observed profound anxiety and states of tension in the diabetic individual which they were unaware of. As well as suppressed emotions, it has been proposed that diabetes occurs in response to unmet demands for love and affection (Alexander, 1948; Jung and Hinkle, 1925). In such circumstances the body develops an intense desire for food or increases sugar excretion thus leading to diabetes (Elhardt, Lardy and Hose, 1956).

Diabetes has been further conceptualised as reinforcing the fear of a second annihilating anxiety where the first results from birth trauma (Freud, 1924). This position has been used to explain poor medical adherence in T1DM. Studies have reported that individuals fear hypoglycaemia because of the loss of self-cohesion experienced (Alberton, Nardi and Zucchini, 2012; Vamos, 2006). Subsequently individuals keep their blood sugar levels high to avoid this state. Medical nonadherence can therefore be viewed as a protective function against the psychic death felt by an individual when they find themselves overwhelmed with anxiety and helplessness (Alberton et al., 2012; Freud, 1924).

Another way of understanding diabetes is to consider the illness to represent situated freedom and the givens of existence (Morris, 2008). Consequently, an individual’s options are limited to their own existential situation and the restrictions that are particular to them, such as their ‘throwness’ into a diabetic body (Heidegger, 1978; Morris, 2008). Stephenson and Murphy (1986) explain that society does not choose to confront its mortality yet when individuals become chronically ill they are thrown into a position of baring witness to a truth that society does want to acknowledge. Adapting to a life with T1DM requires grieving the loss of the former self and acknowledging the pain associated with the loss (Alberton et al., 2012; Vamos, 2006). Therefore it can be reasoned that those living with T1DM or any chronic illness are closer to a more authentic existence than the rest of society.

2.2. Psychological Perspectives of ED

Early psychodynamic descriptions of anorexia nervosa (AN) stress the importance of attending to both the condition of the individual and the preoccupation of those who surround him/her (Laseegue, 1873). From a psychoanalytic perspective AN was seen as a variation of neurosis and has an established relationship with hysteria (see Silverstein and Perlick, 1995). Both hysteria and AN were considered to be ‘adaptive processes’ in the face of environment factors; sexual repression for hysteria while AN was seen as a response to new environmental demands that promoted the desirability of thinness (Orbach, 1979; Treasure, Schmidt and van Furth, 2003). The observation that extreme thinness merges with what is considered to be ‘normal’ or ‘culturally acceptable’, formed the basis of the continuum hypothesis (Button and Whitehouse, 1991; Clarke and Palmer, 1983; Treasure et al., 2003). This hypothesis placed dieting at one end of the spectrum and the various extreme forms of disordered eating namely AN and bulimia nervosa (BN) at the other.

In existential thinking disordered eating is seen as expressing problems with being-in-the-world (Heidegger, 1978). From this perspective EDs can be understood in many ways across the four dimensions of existence. For example, the body expressing the otherwise inexpressible (Umwelt), quelling a desperate sense of isolation and uncertainty (Mitwelt), punishment to absolve personal guilt for failure (Eigenwelt) and/or a means of avoiding responsibility for one’s own choice and actions (Uberwelt) (van Deurzen, 2012; Merleau-Ponty, 1962). Furthermore symptoms of eating problems are considered to resemble those of addiction (Treasure et al., 2015). To Heidegger (1978) addiction is a response to one’s thrownness in the world and is situated between the individual and the world. Thus, individuals with disordered eating can be seen to be cutting themselves off from authentic relatedness.

More recently, changes in family life, meal structure and social media have all been linked to cultural explanations of EDs. Several studies point to a possible link between changes in traditional diet and the impact on weight consciousness brought on by a culture of ‘fast-food’ (Nasser; 1997; Robertson, 1992), while multiple authors have written about the ‘shared global environment’ made possible from the use of social media and the internet (Morley and Robins, 1997). For Treasure et al. (2003), these are psychic and social challenges and from her perspective their impact on the body needs to be the next level of research to assist with ED treatment and understanding.

2.3. T1DM and Diabetes Distress

A large proportion of research exploring the psychological morbidity in individuals with T1DM has focused on serious psychopathology, meaning mental health conditions diagnosable by the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) (American Psychiatric Association [APA], 2013). These studies show that individuals with T1DM are at an increased risk for depression, anxiety and EDs (Anderson et al., 2001; Anderson, 2010; Balfe et al., 2013; Esbitt, Tanenbaum and Gonzalez, 2013; Gonzalez, Fisher and Polonsky, 2011; Hislop et al., 2008). However researchers have recently begun to argue that a much larger number of individuals with T1DM experience sub-clinical diabetes-related distress than experience above-threshold psychological disorders (Balfe et al., 2013).

The emotional and behavioural challenges generated by T1DM have been labelled Diabetes Distress (DD) (Fisher et al., 2012). Unlike clinical depression and anxiety, DD has been directly linked to poor glycaemic control and problematic self-care behaviours (Delahanty et al., 2007; Hessler et al., 2014). One particular study by Fisher et al., (2015) explored the sources of DD in adults with T1DM. This research, involving structured interviews with 25 adults, found seven common sources of DD unique to individuals with T1DM with powerlessness (a broad sense of feeling discouraged by diabetes) and eating distress (concerns that one’s eating is out of control) having the highest mean levels. These findings add to a growing literature suggesting the need for targeted, patient-directed attention to DD in clinical care, whilst also providing a much richer understanding of what it is like to live with diabetes than seen in studies taking a symptom based approach (Fisher, Gonzalez and Polonksy, 2014).

2.4. EDs in T1DM

This review is particularly interested in studies that have explored the relationship between T1DM and EDs. Such studies report that diabetes is the only physical illness that is associated with increased risk of developing an ED, and that an ED is the main psychiatric problem for individuals with T1DM (Goodwin, Hoven and Spitzer, 2003; Weaver, 2012). Women with T1DM are up to 2.5 times the risk of developing an ED than women without diabetes (Jones et al., 2000). Research exploring why these rates are so high have identified a number of risk factors associated with the development of EDs in T1DM – dietary rules, weight gain and the effect of developing a medical condition (Goebel-Fabbri et al., 2008; Rodin et al., 2002; Colton et al 2015; Olmsted et al., 2008; Weaver, 2012). A consequence of having dietary rules linked with timing, quantity and type of food leaves an individual vulnerable to ED behaviour (Goebel-Fabbri et al., 2014). Such rules can interact with and encourage perfectionism which can lead to an unhelpful focus on food and body weight (Bryden et al., 1999; Rydall et al., 1997; Treasure et al., 2015; Verrotti et al., 1999). Furthermore, these rules are often imposed by family members and healthcare professionals, thus resulting in the individual feeling out of control (Starkey and Wade, 2010).

Building on the theme of feeling out of control and powerless, Weaver (2012) proposes that as an individual with T1DM reaches adolescence and young adulthood they may attempt to regulate their body weight and shape as a means of gaining independence and develop a sense of control. This proposal is supported by research which reports highest rates of diabulimia in adolescence and young adulthood, as well as literature which named these developmental periods as being times of increased instability (Arnett, 2007; Lucken & Gress, 2010).

2.5. Diabulimia

It is estimated that as many as 30% of people with T1DM have intentionally restricted their insulin in order to control their weight, making diabulimia a significantly pervasive health issue which affects the lives of a considerable portion of individuals with T1DM (Brookes, 2016; Davidson, 2014; Goebel-Fabbri et al., 2009). Insulin restriction can lead to rapid and dramatic weight loss but it has serious consequences such as kidney disease, retinopathy, ketoacidosis, heart attacks and strokes (Bryden et al., 1999; Goebel-Fabbri, 2017; Goebel-Fabbri et al., 2009). The consequences of diabulimia are well established, with studies reporting a threefold increase of death from diabetic related complications in individuals who restrict insulin to control their weight, compared to non-insulin restricting controls (Goebel-Fabbri, et al., 2008). Moreover, compared to those who take their required insulin dosages, the life expectancy of individuals affected by diabulimia can be reduced by as much as thirteen years (Shih, 2011).

There is no question that the studies reporting on the prevalence and consequences of diabulimia assist in raising awareness and understanding of the phenomenon. Yet, nearly all of the research has involved Caucasian female adults and adolescents. This may be due to a number of factors; stigma surrounding men with EDs (Collier, 2013; Weltzin et al., 2005), male responses to stress which are typically externalised through antisocial behaviour (Broidy, 2001; De Coster, 2005), or perhaps this is only this demographic which experiences diabulimia. Whatever the reasons may be, the limited demographic of research participants to date restricts the generalisability of findings to other populations. So whilst we know little about diabulimia in the cases of young, Caucasian women, we know even less if anything, about how this health phenomenon affects other demographics, if indeed it does.

2.5.1. Medical Status

Although diabulimia is not named as a distinct mental health condition the DSM-V mentions insulin omission under the criteria for AN and BN (APA, 2013):

“*Individuals with diabetes mellitus and bulimia nervosa may omit or reduce insulin doses in order to reduce the metabolism of food consumed during eating binges.”*

“Individuals with anorexia nervosa may misuse medications, such as by manipulating dosages, in order to achieve weight loss or avoid weight gain. Individual’s with diabetes mellitus may omit or reduce insulin does in order to minimise carbohydrate metabolism.”

The discussion around the ‘status’ of diabulimia raises questions around who does, can and should be able to name mental health conditions and related health phenomena. The position by Fleischman (2001) is that diagnostic names and labels should only result from specialist consensus. Yet this makes me wonder whether Fleischman’s position restricts the individual in their discursive construction when attempting to explain and make sense of their subjective experiences, whilst also keeping medical professionals in a position of omnipotence.

The consequences of being ‘discursively disempowered’ are highlighted in Allan’s (2015) paper in which she notes how individuals approaching healthcare professionals with the self-diagnosis of diabulimia have been told that it ‘doesn’t exist’ and was ‘made up on the internet.’ The result is that the relationship between those who identify as having diabulimia and healthcare professionals has been considered unhelpful, dismissive and hostile (Hastings et al., 2016; Stevenson, McNamara and Muldoon, 2014; Tierney et al., 2009), with individuals disengaging from support services as they do not feel accepted or taken seriously (Leonidas & dos Santos, 2014; Linville et al., 2012).

2.5.2. Treatment

Individuals who are identified as omitting insulin are typically referred to their local ED service (Allan, 2014). The issue here is that the ED professionals are not experts in diabetes or the psychological implications of diabulimia. Meaning professionals often see the problem as one related to food alone rather than one of food, insulin and the additional stresses of the diabetes routine (Allan, 2014). ED treatment models that do not address the diabetes-related factors fail objectively (Ismail, Maissi and Thomas, 2010; Rodin, Craven and Littlefield., 1991; Smith, Latchford, Hall and Dickson, 2008). In this environment lower partial and full recovery rates are reported and individuals drop out of treatment at an earlier stage (Colton et al., 2015; Peveler and Fairburn, 1992).

When looking at research on the effectiveness of interventions for individuals with T1DM and EDs it becomes clear that there is need for a joint or tailored ‘diabetes-associated ED intervention’ (Clery et al., 2017). A report by Clery et al., (2017) found that current interventions (CBT, inpatient or outpatient therapy) do not produce significant improvements in glycaemic control, with outpatient therapy reporting fewer differences in ED symptoms compared with inpatient therapy (Dickens et al., 2014; Takii et al., 2003). Whilst the review supports momentum for a multidisciplinary treatment model that attends to the specific needs of each illness, its findings should not be viewed unquestionably. A significant limitation to the review was the small number of studies included (6), of which the reliability and presence of bias in each study varied. For example, two studies did not have comparison groups (Custal et al., 2014; Dickens et al., 2014) and not all of the studies named the type of eating disorder they were working with. In addition to a lack of treatment guidelines for the co-occurrence of T1DM and insulin omission (Pinhas-Hamiel and Levy-Shagra, 2013; Volpe et al., 2015), research has also captured the views of healthcare professionals and psychologists working with this cohort. During all interviews, professionals reiterated their lack of expertise in managing insulin omission and T1DM, a topic that is not covered in their training, meetings or conferences (Macdonald, 2017; Tierney et al., 2009).

What strikes me at this point in the literature is the way individuals appear to be compartmentalised into having T1DM or an ED and the perceived dismissal of the diabulimia identity. There seems to be little room to consider or treat an individual as a ‘whole-being’ acknowledging them in their entirety and complexity. If we briefly turn to the therapeutic schools, although they differ in styles and philosophy all seem to unite in acknowledging that we are contextual beings. Currently, research seems to be prioritising prevalence rates and certain ‘categories’ of an individual’s being such as, the diabetes, insulin omission or relationship with food. The consequence is that we have a dearth of research that helps us understand the subjective experiences of diabulimia from the perspective of those who have first-hand lived experience of it.

2.5.3. Identity

In addition to advocating a multidisciplinary approach to treatment, recent research has suggested that an important barrier to recovery could be related to how the diabulimia cohort self-categorises as an illness group. A study by Allan (2015) saw 98 participants with T1DM and EDs complete a questionnaire exploring the terminology used to describe their ED. 95% of participants reported omitting insulin for weight loss and all but four of the participants said they had diabulimia. Although this was only a small study, it highlights a disconnect between what an individual feels they have and what they are actually being diagnosed with.

It has been proposed that the absence of recognising diabulimia as a distinct identity can hinder recovery due to a lack of tailored mental health services and professional training (Tierney et al., 2009), misunderstanding on the part of family and friends (Pinhas-Hamiel et al., 2015), and the inability to establish relationships with other individuals taking part in group ED interventions (Colten et al., 2015). If individual progress can occur in the context of moving from an illness identity to a recovery identity within a group, then someone identifying as having diabulimia may not be able to share the group’s recovery identity due to their perceptions of the unique nature of their difficulties (Hastings et al., 2016). Literature on social identity and recovery stresses the importance of identity congruent support services, as connecting with similar others can promote recovery and act as valuable support network (Cruwys et al., 2015).

2.6. Research Rationale

The literature gives us reason to believe that are tensions related to identity and perception when looking at the current landscape in which diabulimia sits. There is arguably a validity in people's experiences of this phenomena that is not being heard or recognised to its full potential. Failure to explore and understand the diabulimia identity further could increase feelings of powerlessness and being dismissed which are already permeating through the diabulimia cohort. Moreover, without this knowledge professionals are likely to continue to feel deskilled and inadequate when working with these clients. What's more, it is probable that individuals will keep being referred to treatments which are not tailored to their needs. If we do not attempt to broaden our knowledge of diabulimia we cannot expect individuals to recover or treatments to improve, which in this case could lead to fatal consequences. The importance of recognising the diabulimia identity therefore warrants further exploration. This proposal will address this position by exploring what it is like for individuals who identity as having diabulimia to receive a different diagnosis.

3. Research question and aims

To investigate the named phenomenon the following research question will be asked:

- What is the experience of individuals who identify as having diabulimia yet receive a different diagnosis?

I am interested in exploring what diabulimia means to these individuals and what it is like to receive a diagnosis at odds with one's self-identification. By attending to the subjective lived experience of this phenomenon, I hope that what emerges will give important insight into working with and treating this client group.

As will be evident from my linguistic treatment of it so far and in the chapters to come, I have elected to use the term diabulimia throughout the proposal without semi-colons. This could be interpreted as a sign that I perceive this phenomenon to be a 'truth.' Mindful of the debate that surrounds the term, I aim to approach this issue with an open mind and noting my own views on the matter. It is not the aim of this research to judge or argue for or against the validity of diabulimia as a distinguished mental health disorder; rather it is to understand how individuals are making sense of a particular experience.

5. Methodology

5.1. Philosophical positioning

5.1.1. Ontology

Throughout the proposal it is explicit that the research is concerned with the importance of meaning making and context rather than that which pertains to ‘truth’ and objectivity. In this way the research embraces the idea of multiple realities. As researcher I acknowledge that I hold a different reality to that of the participants and those who may come into contact with the research. By asking a question orientated around lived experience the research is positioned to be able to report on multiple realities by highlighting how participants view their subjective experiences of the named phenomenon (Moustakas, 1994).

5.1.2. Epistemology

This research will take a social constructivist perspective. Social constructivism takes the view that there is no objective social reality that can be known with certainty and precision (McLeod, 2014). In this worldview, individuals seek understanding of the world in which they live and work, thus subjective meanings of experiences are developed (McLeod, 1996). These meanings are informed by social interactions, historical and cultural norms (McLeod, 2014). This epistemological position is echoed in the proposals stance of not searching for ‘truths’ or certainty around diabulimia. The research will remain open to the complexity of individual views and will attempt to make sense of the meanings others have around the named social phenomenon. In this way the social constructivist position of subjective meanings of experiences aligns with the ontological position of multiple realities.

The social constructivist position espouses a hermeneutical approach, which maintains that meaning is hidden and can be brought to the surface through deep reflection (Ponterotto, 2005; Sciarra, 1999). Thus, the centrality of the interaction between the investigator and area of investigation is a defining feature of social constructivism (Ponterotto, 2005). If interaction and reflection are seen as avenues through which deeper meaning can be uncovered, then social constructivism resonates with my personal values and integrative framework for practice. In both social constructivism and integrative psychotherapy, there is a notion of co-creation within all relationships and a philosophical position that there can be no one truth (Gilbert and Orlans, 2011). Taking this position requires me to hold ambiguities both in practice and research and involves a commitment to collaboration with the other (Gilbert and Orlans, 2011).

A social constructivist approach is therefore well suited to this research area as it aims to understand the lived experience and meaning of the named phenomenon from the point of view of those who live it day to day (Schwandt, 2002). Furthermore, this worldview resonates with my personal axiological assumption that we cannot ‘leave ourselves out,’ as the way we interpret meanings others have about the world is shaped by our own cultural, personal and historical experiences (Ponterotto, 2005).

5.2 Methodology: Interpretative phenomological analysis (IPA)

IPA has been chosen as the most suitable methodological approach for the intended study for a number of reasons. Firstly, IPA endorses the social constructivist positioning of the research by claiming that sociocultural and historical processes are central to how we experience and understand our lives (Willig and Stainton-Rogers, 2013).

IPA is concerned with the detailed examination of lived experiences and how individuals make sense of that experience (Smith, 2015). These two commitments point to IPA’s theoretical underpinnings in phenomenology and hermeneutics. Alike to social constructivism, phenomenology is concerned with attending to the way things appear to individuals through experience (Pietkiewicz and Smith, 2012). While the hermeneutic element welcomes an active role of the researcher and tasks them to engage in a double hermeneutic, where the researcher makes sense of the participants sense making (Finley, 2011).

Joining IPA in the realm of phenomological methodologies is descriptive phenomenology (DP). DP assumes there are features of lived experiences that will be shared by all individuals who have the same experience (Langdridge, 2007). These ‘universal essences’ are of primary interest to DP. However this is in opposition to the social constructivist stance taken by this proposal, which argues against being able to find universal ‘truths.’ Furthermore, DP requires the researcher to ‘bracket’ all past knowledge and preconceptions about the phenomena, however one questions to what degree this is even possible or desirable (Willig, 2008).

IPA seems to have a natural affinity with the various forms of narrative analysis. They are interpretative, focus on first person accounts and are interested in meaning and understanding (Griffin and May, 2012). However as voiced by Griffin and May (2012), many social scientists using narrative enquiry are particularly interested in the social aspects of the narrative. That is, the social origins of the narratives that the individual tells and the social impacts the narrative have. Through interviewing participants, my research aims to analyse what they say in order to try and learn about how they are making sense of the named experience. If a narrative or discourse analysis was applied over IPA, the research would be at risk of orientating itself towards how individuals are constructing accounts of their experiences as opposed to making sense of their experiences (Smith, 2011). Whilst this may produce useful findings, it risks leaving the current research question unanswered.

Holding the research question in mind IPA would enable me as researcher to try and understand the participant’s world and to describe ‘what it is like’ to experience the named phenomenon. IPA will answer how the phenomenon is understood by the participant, what it means for them and stands to produce a renewed insight into the diabulimia phenomenon. The flexibility of the approach, layers of analysis and consistency with the epistemological position of the research makes IPA a suitable methodology for the proposed research.

5.3. Data collection

IPA prioritises full appreciation to each participant's experience, meaning that samples are usually small to allow for a detailed case-by-case analysis (Pietkiewiez and Smith, 2012). Subsequently, 6-8 participants will be recruited for the study, including one pilot interview (Smith, Flowers and Larkin, 2009). Data will be collected through semi-structured interviews that will last approximately one hour and will be audio-recorded (Smith, Flowers & Larkin, 2009). An interview schedule will guide the course of the interview, however if a participant opens up a related and unforeseen area of inquiry this will be pursued (Appendix 1). Interviews will be face-to-face and participants will be asked to complete a demographic questionnaire (Appendix 7). This information will assist with contextualising the findings and the subsequent analysis, interpretation and discussion.

5.4. Inclusion and exclusion criteria

The research will be open to all individuals who meet the following the criteria:

- Identify as having diabulimia as defined by Allan and Nash (2014) as being the practice of omitting or restricting insulin for weight-loss purposes in individuals with T1DM
- Diagnosis of T1DM
- Current or previous mental health diagnosis as defined by the DSM-V
- Fluent in English
- Over 18
- Living in the UK

Individuals who are currently in inpatient and/or residential treatment settings will be excluded from the study. This is also the case for individuals who have been in these treatment settings within the past 12months. This is due to ethical considerations around informed consent and protecting participants from harm.

5.5. Sampling and recruitment

Participants will be recruited using a purposeful sampling method to ensure that all participants have experienced the named phenomenon of interest (Landridge and Hagger-Johnson, 2009). To recruit participants, a study page will be created on callforparticipants.com which will act as an online advert for the research (Appendix 3). Requests will be made to the relevant online platforms to post the online advert, specifically; Diabetes UK, Diabetics with ED (DWED), Diabulimia Helpline, BEAT and Diabetes Times. In addition to online recruitment, I will make use of personal connections with the founder of the charity DWED. It has been agreed that DWED will assist with recruitment by advertising the research on their private forums and webpage. Raising awareness of my research at this summer's conference 'Diabetes and Eating Disorders – A complex combination' may also open additional recruitment avenues.

5.6 Data credibility

Creswell and Miller (2000) propose that the choice of validity procedures is governed by two perspectives: the lens the researcher chooses to validate their studies and researchers' paradigm assumptions. In the context of this research this involves using a lens which is established using the views of the researcher and participants within the paradigm of social constructivism.

To establish validity there will be a search for disconfirming or negative evidence against the preliminary themes and categories identified in the data (Creswell and Miller, 2000). This will provide support for data credibility and the paradigm by highlighting the complex and multiple nature of reality (Yardley, 2000). Additionally, the setting, participants and themes of the study will be described in rich detail. The vivid detail stands to support the integrity of the account whilst assisting readers to make decisions about the applicability of the findings to other settings or contexts (Creswell and Miller, 2000). I will also keep an account of my personal assumptions, beliefs and biases which may shape my inquiry in the form of a research journal and a section addressing the ‘role of the researcher.’ This will allow readers to understand my position and in turn increase the trustworthiness of the research. Finally, through discussions with fellow trainees and research supervisors I will engage in peer debriefing, thus I will remain open to challenges relating to research decisions and personal assumptions (Creswell and Miller, 2000).

6. Ethical considerations

In the planning and design of the research proposal the British Psychological Society (BPS) ‘code of ethics and conduct’ (2009) and ‘code of human research ethics’ (2010) were consulted. Information has also been sought from the Health and Care Professions Council’s (HCPC) ‘standards of proficiency for practitioner psychologists’ (2015) and Metanoia Research Ethics Guidelines (2015)

In accordance with the code of ethics and conduct (BPS, 2009), informed consent will be obtained from all participants. This means providing participants with information related to; the aims of the study, participation requirements, right to withdraw, data use, risk and any limitations associated with confidentiality (Appendix 4 and 5).

6.1. Protecting participants from harm

It is not anticipated that participation in the research will pose a risk to participants. However, given the topic of exploration, participants may find it distressing to reflect on their experience. As such, I will be continuously alert towards how the interview is affecting the participant. A distress protocol for responding to participant distress based upon Cockling’s (2008) template has been drafted (Appendix 2). Following the interview participants will be offered the opportunity to ask questions and a debriefing sheet will be discussed together (Appendix 6). It is my intention that all participants leave the interview in an emotional position matching or better than that which they arrived in.

The notion of total confidentially within qualitative research has been described as an ‘illusion’ which is ‘not absolute in law’ (BPS, 2010; Smith, Flowers and Larkin, 2009). Within the research all identifying information will be removed so as to protect participant anonymity and pseudonyms will be used. Tapes and transcripts will not be labelled in ways which could compromise anonymity, and all data will be stored in locked cabinets and/or password protected files. Participants will also be given the opportunity to review their transcript before analysis. Transcription of interviews will not be outsourced.

The information participants provide will be treated as confidential unless in exceptional circumstances whereby duties such as the duty to protect individuals from harm will be prioritised (BPS, 2010). As part of the consent procedure participants will be made aware of the circumstances in which confidentiality may be waivered, for example suicidal intent. Together with my research team, I intend to discuss what constitutes such exceptional circumstances and the appropriate action to take.

6.2. Protecting researcher from harm

The first time I will meet the participants in person is likely to be on the day of the interview. This could also be in an unfamiliar location. To minimise risk to myself I intend to arrange interviews in public spaces where there is the necessary privacy required but also others nearby, for example, arranging a study room in a local library. I will also notify a colleague of the timings and location of the meetings and arrange to make contact with them after the interview.

Brinkmann and Kvale (2008) propose that the human interaction in qualitative research affects both researchers and participants as the knowledge produced alters our understanding of the condition under exploration. As such, it will be important for me to attend to my own well-being throughout the research process. I intend to seek support from my therapist, research supervisor, friends and family. The former two cases will involve deeper discussions of the research and my relationship to it. I also intend to form a ‘peer support group’ with other Metanoia trainees using IPA and arrange to meet regularly. In addition, it will be important to allow time for friends and family so as to maintain sufficient balance between the research and ‘leisure’ activities. As ethical issues cannot be addressed and ‘solved’ during the planning stages, I intend to be ethically attuned throughout the research process (Brinkmann and Kvale, 2008).

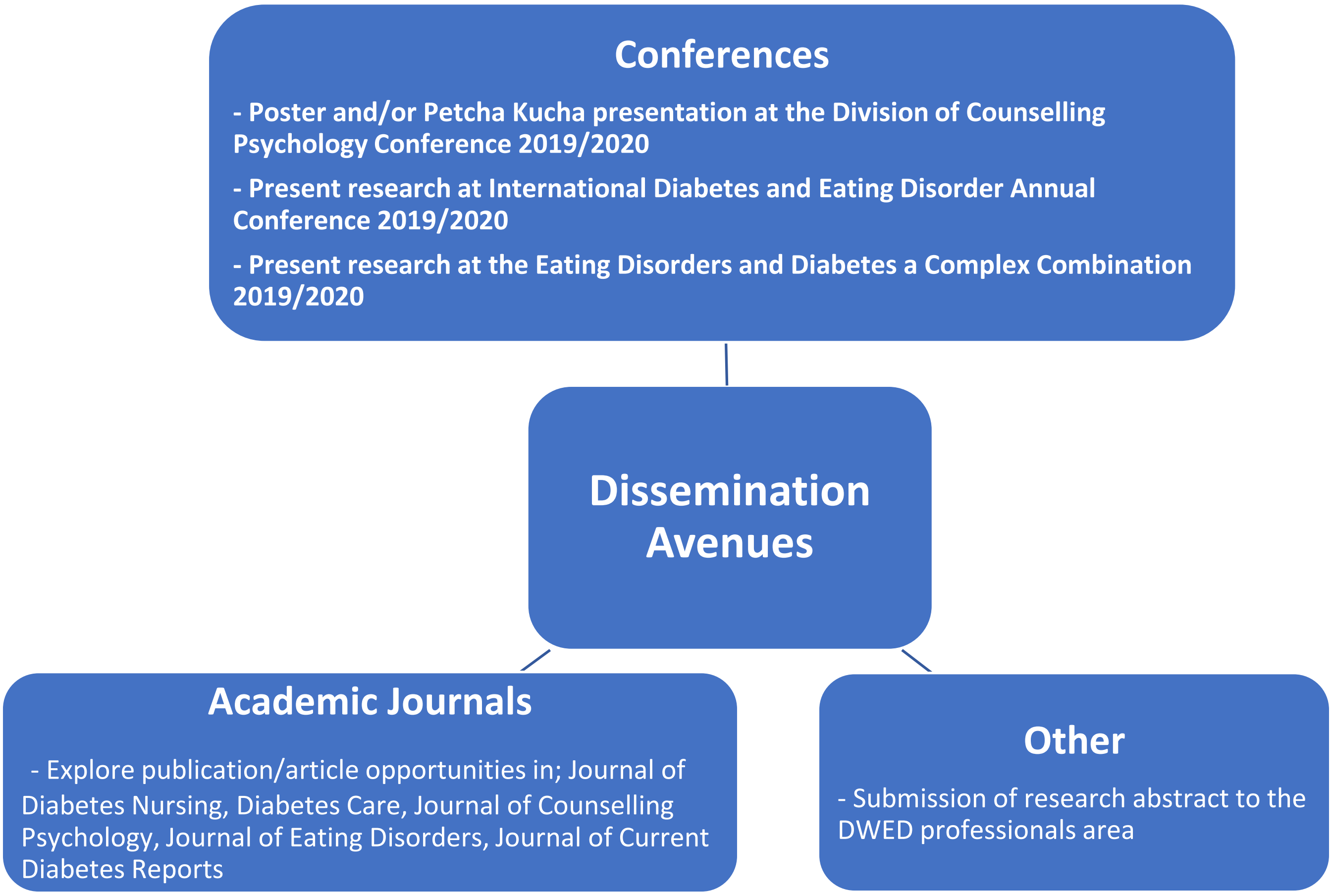
7. Potential contributions

By exploring the named phenomenon my research will provide a platform where the unique issues faced by the diabulimia cohort are validated and heard. In doing so the individuals with first-hand knowledge and experience of diabulimia can be included in the broader discussions, debates and decisions surrounding the topic and proposed treatment models. In short, my research will assist this cohort to be ‘seen,’ and generate more awareness and understanding. This knowledge could then lead to greater levels of empathy and support from friends, family and healthcare professionals.

The research also has the potential to elicit very specific knowledge and understandings from participants, which could then be incorporated into training programmes, treatment models and inform the ways in which this cohort is worked with clinically. The angle of the research is not to conclude on the ‘appropriateness’ of the term diabulimia, but rather show to practitioners, psychotherapists, GP’s, Diabetes Specialists and other healthcare professionals that this is how some individuals may present and experience the named phenomenon. In time this may influence relationships between healthcare professionals and the diabulimia cohort to one which is built on respect, collaboration and empathy even in the absence of agreement. A stronger working alliance with professionals as well as support and understanding from friends and family stands to increase likelihood of positive outcomes in therapeutic interventions (Glass and Arnkoff, 2000; Gilbert and Orlans, 2011).

Insulin omission and T1DM have recently been added to the national institute for health and care excellence (NICE) ED guidelines, however there are calls for the next version of the DSM to differentiate between diabulimia and reflect the need for specialised treatment protocols (Allan, 2017; Allan and Nash, 2014). My research therefore has the potential to contribute to forthcoming discussions around the existing diagnostic criteria, inform future policies, guidelines and funding allocations.

8. Dissemination Avenues



Conferences

- Poster and/or Petcha Kucha presentation at the Division of Counselling Psychology Conference 2019/2020

- Present research at International Diabetes and Eating Disorder Annual Conference 2019/2020

- Present research at the Eating Disorders and Diabetes a Complex Combination 2019/2020

Dissemination Avenues

Academic Journals

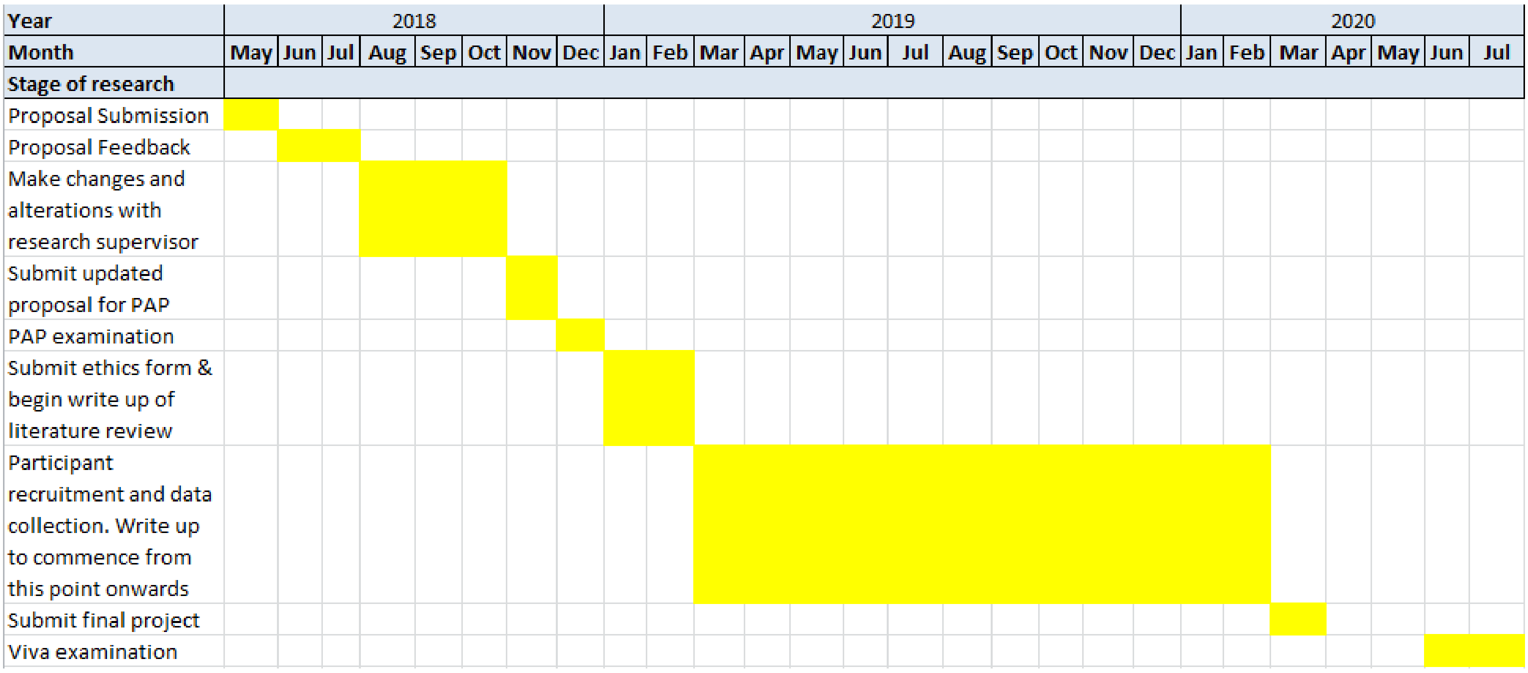
- Explore publication/article opportunities in; Journal of Diabetes Nursing, Diabetes Care, Journal of Counselling Psychology, Journal of Eating Disorders, Journal of Current Diabetes Reports

Other

- Submission of research abstract to the DWED professionals area

9. Timeline

The following image represents a tentative timeline for the research process.



Year	2018								2019												2020						
Month	**May**	**Jun**	**Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**	**Aug**	**Sep**	**Oct**	**Nov**	**Dec**	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**	**Jul**
Stage of research																											
Proposal Submission	■																										
Proposal Feedback		■	■																								
Make changes and alterations with research supervisor				■	■	■																					
Submit updated proposal for PAP							■																				
PAP examination								■																			
Submit ethics form & begin write up of literature review									■	■																	
Participant recruitment and data collection. Write up to commence from this point onwards											■	■	■	■	■	■	■	■	■	■	■	■					
Submit final project																							■				
Viva examination																										■	■

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Draft - Interview Schedule

Opening

Interviewer introduces herself and purpose of interview – to explore the experience of identifying as having diabulimia yet receiving a different diagnosis.

"In today's interview we will be exploring your experience of identifying as having diabulimia yet receiving a different diagnosis. I am interested in your experience and how you tell it. You are the expert of your own experience so there is no 'right or wrong.' Please answer the questions in as much detail as possible, but you can skip questions at any point should you wish. The interview will last for approximately one hour and you are able to pause and/or terminate the interview at any point. Do you have any questions before we begin?"

Specific points to address

- Recording and confidentiality (only for transcribing purposes)
- Transcription – only small, anonymous quotes will be used

Body of interview

- Could you tell me what motivated you to take part in the research?
  This question intends to unpack the participant's relationship to the research in greater detail whist also easing them into the interviewing process.
- Can you tell me about your diabulimia and what it means to you?
  Prompts: What it is like for your sense of self, identity, values?
- How did you experience the diagnosis you received?
  Prompts: Psychologically, physically, socially and emotionally

Closing interview

- Is there anything I have not asked you about your experience that you feel is important for me to know?
- Thank you and debriefing

Proposed additional questions to be asked in the pilot interview

- Do you feel there was anything that could have been done better?
- Do you feel there was anything that the interview missed out?
- Do you have any further comments?
- What was it like for you to take part in the interview?

Draft - Protocol for responding to participant distress

The following protocol has been developed in the event of participants becoming distressed during their participation. As a trainee Counselling Psychologist and Psychotherapist, I have experience in responding to and managing situations where distress occurs. Whilst extreme distress is not expected to occur, the protocol outlines numerous indications of distress along with actions to be taken.

Mild distress

What to look out for:

4) Behaviours suggesting that the interview is becoming stressful/distressing, for example, shaking, fidgeting, restlessness
5) Emotion appears present in voice, participant may become choked, struggle to speak or their voice trembles when doing so
6) Tearfulness, this may be accompanied by colouring of cheeks and/or break in eye contact

Response:

4) Check in with the participant, would they like to continue
5) Ask if they would like to pause the interview and take a moment to collect themselves
6) Remind the participant that there is no pressure to continue, they can withdraw/stop the interview at any point without offering an explanation. Clarify they would not be disadvantaged in any way for choosing to terminate the interview

Severe distress

What to look out for:

4) Uncontrolled crying, wailing, difficultly in articulating themselves
5) The ‘buckling’ of physical self in response to emotional intensity, for example leaning forward to hug knees if seated, resemblance of foetal position. Rocking or other such physical displays to provide comfort/self-soothing
6) Signs of high anxiety or panic attacks, for example, reported shortness of breath, tightness in chest, struggling to catch one’s breath, hyperventilation

Response:

7) Terminate interview and begin debrief immediately
8) Try and assist participant to regulate their breathing either through ‘shadow’ breathing or by relaxation techniques
9) Display compassion and understanding of their current difficulties. Explain that reflecting back on decision making processes can resurface multiple emotions and responses, re-assure them that this is not an unusual reaction to reduce any self-consciousness, worry, concern or embarrassment that may be arising as a result
10) Should any issues arise which present themselves as significant and unresolved to the participant, clarify the boundaries of the interview context in that it is not designed for therapeutic interaction but suggest they discuss this matter further with other mental health professionals
11) Provide participants with the details of additional support services as detailed on the participant debrief form

12) Ensure the participant is safe to leave the interview setting before doing so. For example, if the participant is driving ensure they are collected and calm enough or explore an alternative way of getting home, Taxi, someone to pick them up.

Extreme distress:

What to look out for:

6) Extreme agitation, verbal or physical aggression
7) Sudden exiting of the interview space
8) Loss of rational and coherence, speech may become muddled and not make any sense
9) Escalation of physical displays of distress, for instance breathing may still be very disrupted, tightness of chest worsening
10) Indication of suicide

Response:

4) Prioritise safety of participant and researcher
5) If the researcher has concerns for the safety of the participant or other individuals inform the participant of such concerns and explain how as a result, the researcher has a duty to inform other services/professionals. At this point, it could also be suggested that the participant present themselves to the nearest A&E department and ask for the psychiatric liaison team
6) If the participant becomes violent and unwilling to seek assistance, emergency services could be called. This response would only be acted upon in an emergency situation

Draft – Call for Participants

PARTICIPANTS FOR DOCTORAL RESEARCH NEEDED

Exploring the lived experience of identifying as having diabulimia yet receiving a different diagnosis

Sian Morris

Dear reader,

I am conducting a study as part of my doctorate in counselling psychology and psychotherapy at the Metanoia Institute. The investigation aims to explore what it is like for individuals who identify as having diabulimia to receive a different diagnosis. I hope that the findings of my research will help inform treatment pathways, diagnostic decisions, professional training and clinical practice for those working with this client group.

To understand this experience as much as possible all participants will be invited to an interview. This interview will take place and a time and location agreed by us both. Please note that I am interested in your experience, so there is no wrong or right answer to the questions I will ask you.

The research has been reviewed and approved by the Metanoia Research Ethics Committee, and is being supervised by XXXXXXX.

If you are interested in participating please contact me (Sian Morris) at Sian.Morris@metanoia.ac.uk, and I will send you a detailed information sheet.

Your interest is much appreciated.

Best wishes,

Sian

Draft - Participant Information Sheet

Exploring the lived experience of identifying as having diabulimia and receiving a different diagnosis

Researcher: Sian Morris

Supervisor: XXXXX

Thank you for expressing your interest in my research. Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Thank you.

Purpose of research

The research aims to explore what it like for individuals who identify as having diabulimia to receive a different diagnosis. To date, there has been little research around what it is like to have diabulimia and nothing which explores the experience of receiving a different diagnosis. I hope that the findings of my research will help inform treatment pathways, diagnostic decisions, professional training and clinical practice for those working with this client group.

I hope that my research will provide a platform where the unique issues faced by your demographic are validated, heard and included in the broader discussions, debates and decisions surrounding diabulimia.

Who can participate?

It is important that all participants in the study are individuals who identify as having diabulimia but have received a different diagnosis. In order for me to study this experience, it must be one that participants have had.

To take part in this study you will need to:

- Identify as having diabulimia as defined by Allan and Nash (2014) as being the practice of omitting or restricting insulin for weight-loss purposes in individuals with Type 1 Diabetes.
- Have a diagnosis of Type 1 diabetes
- Have a current or previous mental health diagnosis as defined by the Diagnostic and Statistical Manual of Mental Disorders 5th edition.
- Be over 18
- Be fluent in English
- Live in the UK

Individuals who are currently in inpatient and/or residential treatment settings are not able to participate in the study. This is also the case for individuals who have been in these treatment settings within the past 12months. This is due to ethical considerations around informed consent and protecting participants from harm.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part and fit the inclusion criteria listed in the previous point you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without any adverse consequences or giving a reason.

What is involved in taking part?

We will arrange a time, date and location for a face-to-face interview. The interview will be semi-structured meaning that I will have some key questions in mind but these are flexible as my priority is to understand your experience. There is no right or wrong answer.

To assist with the analysis and transcription of the interview they will be audio recorded. Please be aware that extracts from the interview may be included in the dissertation to help explain and contextualise findings. All identifying information excluded and you will be given the opportunity to review the transcript after the interview and before analysis takes place.

Will participation in the study be confidential?

All information that is collected about you during the course of the research will be kept anonymous. Any signed documents and transcripts will be kept securely and all identifying information will be removed. The research findings may be published and a copy of the final dissertation will be available to other researchers in the Metanoia Institute Library.

Your confidentiality is critical and protocols are set up to ensure it is maintained. However there are circumstances where your right to confidentiality would be waived, for example if you disclose intent to harm yourself and/or others. I am happy to discuss this point further with you if you have any concerns or would like further clarification.

If you decide to participate you will be given a signed a copy of the information sheet and a signed consent form to keep.

What are the possible risks of taking part in the study?

It is not expected that the interview will call distress; however you may find it difficult to reflect on your experience. You are able to skip questions and stop the interview at any time if you find it is more difficult than you anticipated. There will be time after the interview to discuss how you found the interview. At this point you will be given the details of additional support services and a debriefing sheet.

Who has reviewed the study?

This research is being undertaken as part of my doctorate in counselling psychology and psychotherapy at the Metanoia Institute. The Metanoia Research Ethics Committee has reviewed and approved the research.

Contacts for further information

If you have any questions please contact either the researcher or supervisor on the details below:

Researcher: Name: Sian Morris Email: Sian.Morris@Metanoia.ac.uk

Supervisor: Name: XXXX Email: XXXX

Draft – Participant Consent Form

Exploring the lived experience of identifying as having diabulimia yet receiving a different diagnosis

Researcher: Sian Morris

Supervisor: XXXXXXX

Thank you for agreeing to participate in my research. Your time and contributions are valued. Prior to consenting to participate, please review and consider the points listed below. Please ask me if you require any further clarification or have any questions.

By consenting to participate in this research, I confirm that:

12. I have read received, read and understood the 'participation information sheet.' The researcher has explained the aims of the research, along with what is involved in taking part
13. My participation is voluntary and I will co-operate with the researcher to the best of my ability
14. I understand that the interview will be audio-recorded
15. I understand that all personal data will be stored securely, and in accordance to the Data Protection Act (1998, section 5) will not be kept longer than is necessary for the research
16. I understand that my anonymity will be preserved but quotations from my interview may be used in the dissertation write-up
17. I understand that the findings of the research may be published in academic journals and presented at conferences
18. I understand that whilst confidentiality is prioritised, there may be circumstances where confidentiality is wavered, for example, if I disclosure intent to harm myself and/or others
19. I understand that I am free to withdraw from the study at any point during the interview without reason and there will no negative consequences from doing so
20. By signing below I have read and agree to the conditions listed above and consent to participating in this study

Participant Name: **Participant Signature:** **Date:**

Researcher Name: **Researcher Signature:** **Date:**

Thank you for agreeing to participate!

Draft – Debrief Sheet

Thank you participating in my research, you contribution is greatly appreciated.

If you have any questions regarding any stage of the research please do not hesitate to contact either myself or my supervisor:

Researcher: Sian Morris at Sian.Morris@metanoia.ac.uk
Supervisor: XXXX

Debriefing is an opportunity for you to discuss any feelings, thoughts or ideas that have been brought on by the interview. If you should find that you are left with strong feelings and emotions after the debriefing period, I would advise you to seek support from a trusted friend, family member or your GP. You will also be able to speak to contacts at the support services listed below should you feel you need counselling or further support.

Diabetics with Eating Disorders (DWED)
Website: http://dwed.org.uk/online-support
Information: DWED has a closed Facebook Group; access can be requested by following the above link

Diabetes UK
Helpline: 0345 123 2399
Website: https://www.diabetes.org.uk/Guide-to-diabetes/Life-with-diabetes/Diabulimia

BEAT Eating Disorders
Helpline: 0808 801 0677 (open daily 3.00pm – 10.00pm)
Website: https://www.beateatingdisorders.org.uk/

Samaritans
Tel: 08457 90 90 90
Website: http://www.samaritans.org

MIND
Tel: 0300 123 3393
Website: www.mind.org

The British Psychological Society: Directory of chartered psychologists
Tel: 0116 254 9568
Website: http://www.bps.org.uk/bpslegacy/dcp

The British Association for Counselling and Psychotherapy: Find a therapist
Tel: 01455 883300
Website: http://www.itsgoodtotalk.org.uk/therapists

The United Kingdom Council for Psychotherapy: **Find a therapist**
Tel: 0207 014 9955
Website: https://www.psychotherapy.org.uk/find-a-therapist/

Your GP will also be able to direct you to free psychological support in your area.

If you would like to see a copy of the research following write up, you can request to do so by contacting me via the contact details above. Estimated completion date is September 2020.

Thank you again, Sian

<u>**Draft – Demographic Questionnaire**</u>

For each question participants will have the option to ‘prefer not to say.’

1) How old are you?
2) What gender are you?
3) What nationality are you?
4) At what age were you diagnosed with Type 1 Diabetes?
5) How long have you identified as having diabulimia?
6) Do you currently have a metal health diagnosis? (Yes/No)
   If yes, what is the diagnosis and when did you receive it?
7) Have you received a mental health diagnosis in the past? (Yes/No)
   Please list the diagnosis which you received and when

Appendix 23: Research Journal Extract: A Poem of Reflection

An air of curiosity walked through the door
Why are you researching this, what is it for?
Why do you care, what good will it do?
I sensed she was asking - can I talk to you?

With eyes firmly stuck to the ground
and her body shifted away
A breath was drawn, a moment taken,
and she shared her journey to today.

She spoke of feeling alone and trapped in a world that no one could reach
Where self-worth was banished, acceptance vanished
and self-blame was all that she preached.

She called this world magic as membership was easy to gain,
you eat what you want whenever you want,
but the small print is nothing but pain.

The mind fog that descends is impenetrable,
the physical cost a toll,
your friends and family won't know who you are
but none of that will matter at all.

You will keep this world a secret, tell no one that it is there
the fight you have is personal, it is you or the diabetes bear.
It wants to take away from you, your limbs, your life, your sight.
This is the message that came from the Doctor and they're the expert….right?

You cannot fail in your diabetes care, perfection you must obtain,
but skip a dose here, lower one there
the ultimate enemy is weight gain.

Power and control are central to it all
in a life that you have no grasp,
but with every appointment or physical change
comes a reminder that this life cannot last.

The relationship with this world is complicated,
as though you never truly leave.
It is the stamp from the bar in the water-proof ink
and a part of yourself to grieve.
Because amongst the darkness it brought you,
there are some memories that make you smile.
A part of you that misses it and will continue to do so for a while.
As you took me on your journey there were somethings I started to hear,

the emergence of self-compassion and a distancing from fear.
The diabetes bear you so passionately fought, wanted to live side by side.
And perhaps the most significant of all was the naming of your pride.

You are proud of your strength to have survived a world that many have not done.
You are passionate to make sure that those suffering know they're not the only one.
You have entrusted me with your story, your experiences and your pain.
A responsibility I will not take for granted; your sharing has not been in vain.
To close this piece a thank you for bringing your honest self,
it was an honour and pleasure to meet you amongst the city bookshelves.

Appendix 24: Extract Format Details

Direct quotes from participants, including grammatical errors, are used throughout the Analysis chapter. Following each quote, the participants pseudonym and transcript location are included in parentheses (Peggy: P15). Transcript location is depicted via two steps: participant name, initial and response number. Omitted material is indicated by; (…). Where clarification is needed, additional explanations are marked by italicised text in parentheses: *(being thin).* Non-verbal language is also marked in parentheses (sighs), while pauses are indicated by: (…)

In selecting material across each theme, I aimed to capture the lived experiences of all participants, whilst ensuring that the voice of each participant was present throughout the analysis. In some themes, it felt important to include a wider range of accounts to capture the texture, polarity, similarities and differences present in the experience, whereas for other themes I chose to select quotations from a smaller number of participants, whose narratives may have contained rich, metaphoric descriptions or the phenomenon or provoke insights (Young, 2019).