# A Thematic Analysis of Letters Written by Individuals with Type 1 Diabetes and Disordered Eating

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Submitted to the University of Hertfordshire in partial fulfilment of the requirements of the requirements of the degree of Doctor in Clinical Psychology.

May 2025

Word count: 30,000

(Excluding: Title Page, Contents Page, Abstract, Acknowledgements, Tables, Figures, References and Appendices).

***"What actual harm could I be doing to myself when I was being told I looked good?"***

**Acknowledgements**

This thesis simply would not have happened if it was not for the brave participants who chose to share their stories and experiences for this project. I will never be able to convey my gratitude. I hope that I have written about your experiences in a way that does them justice. To all those with T1DE who have felt missed or let down by the system; you are not too complex, we see you. Services need to do better for you, and I hope this research plays a small role in getting there.

Thank you to every person, charity and NHS organisation who has shared this research, not only did you help us reach more people, but you also helped keep my stress levels at a reasonable level.

**Dr Jen Heath** and **Dr Julie Evans** the women you are! Thank you for giving me the best supervisory team with your endless knowledge, guidance and belief in me to even do all of this. For providing a space to share the female experience and giving me permission to intertwine it into this work. You are both absolute forces that make clinical psychology and research a much better place. I am forever indebted to you both.

To my mum and dad, **Sue** and **Mick.** Thank you for working so hard throughout my life to give me a new path you did not have access to. For being there during every school play, exam season, essay, graduation, job interview. Cheering me on, picking me up, telling me '*You can'* each time I said, '*I can't'*. For never shrinking my plans down. You are the best parents. I haven't done bad '*considering where I came from*' aye? You can now dine out on the fact your daughter is a doctor (no mum it is not a PhD).

**Callum Spence** you absolute beacon of light and joy. Thank you for reminding me to be patient with this project when I needed it (which was a lot). For making me laugh every single day. For not always understanding what I do but always understanding why I do it. For sitting and listening to me ramble on after asking you '*does this make sense?*'. For sacrificing so much just so I could pursue this little dream of mine. For asking to marry me in the middle of all this (you must *really* mean it because this hasn't always been pretty, has it?).

And to the girls **Mollie**, **Sarah** and **Bethany** who have watched this journey from the very beginning. Thank you for helping me stay connected to the parts of myself that have nothing to do with clinical psychology or this research. For genuinely checking in. For giving me perspective and keeping me grounded. The sleepovers and bottomless brunches revived my

soul more than you will ever know. I am so proud to have such strong and formidable women as my best friends.

## Table of Contents

## Dissemination of this research

**18/06/2024**: Presentation of research aims, protocol and recruitment strategy delivered to First Steps ED charity multi-disciplinary team meeting

**20/05/2025:** Presentation of results of this research delivered to First Steps ED charity multi-disciplinary team meeting

**06/06/2025**: Ades, R., Evans, J., & Heath, J (2025, June). A thematic analysis of letters written by individuals with type 1 diabetes and disordered eating. Presentation at the Diabetes and Disordered Eating Conference 2025. Copenhagen, Denmark. June 2025.

**Published following peer review**: Ades, R., J, Heath., & Evans, J (2025). What does qualitative evidence tell us about how having a diagnosis of Type 1 Diabetes Mellitus impacts an individual's identity? A systematic review. *The Journal of Health Psychology.*

**Under review:** Ades, R., J, Heath., & Evans, J *"What actual harm could I be doing to myself when I was being told I looked good?"* A thematic analysis of letters written by individuals with type 1 diabetes and disordered eating. *Journal of Clinical Psychology*

List of Appendices

## List of Tables

## List of figures

**ABSTRACT**

It is estimated that 40% of individuals with type 1 diabetes mellitus (T1DM) will struggle with disordered eating (T1DE) (Goddard & Oxlad, 2023) and those with T1DE have a 3.2.x higher mortality rate than other eating disorders (ED) (Goebal-Fabbri et al., 2008). There is, however, minimal qualitative research on T1DE (Goddard & Oxlad, 2023; Wisting & Snoek, 2020). Clinical understanding of T1DE is therefore limited, and therapeutic interventions are not adapted to its specific needs, meaning therapy attrition and relapse are higher than in other EDs (Banting & Randle-Phillip, 2018). Research on identity and feelings towards diagnosis are prevalent in the fields of T1DM and EDs (Abdoli et al., 2020; Campbell et al., 1996; Commissariat et al., 2020; Nordbo et al., 2012; Williams & Reid, 2010). A qualitative systematic literature review (Chapter 2) explores current literature that discussed the impact T1DM has on identity. The results emphasise how important identity is in someone's feelings towards and response to their T1DM. Using qualitative methodology, the qualitative empirical study (Chapters 3-5) aimed to explore the role of identity and feelings towards diagnosis in the development and maintenance of T1DE. A convenience sample of 11 female adult participants responded to a research poster or were recruited from an adult NHS ED service. They completed a letter addressed to their ED and another to their T1DM, focusing on their feelings towards both diagnoses and the impact both have had on their identity. Letters were analysed using reflexive thematic analysis (Braun & Clarke, 2019). Six main themes were identified: "*This resentment I had for you*", "*You must do diabetes, or you die*", "*Why did you become my whole identity*", "*Something I needed*", "*Like a slave to a master*" and "*like yin and yang*". Findings are discussed in relation to existing literature, before discussing the strengths, limitations and clinical implications of this research and invitations for future research.

*Keywords*: type 1 diabetes mellitus, T1D, eating disorders, disordered eating, T1DE, diabulimia, identity, qualitative, letter writing

# CHAPTER 1: INTRODUCTION.

## 1.1 Chapter overview.

This chapter introduces the reader to the research area. This is done first through sharing the position of the researcher and the theoretical and epistemological position of this research. A list of definitions of key terms is then provided, and the current research is situated within theory and context. The order in which the current research is discussed is deliberate and in line with the epistemological stance of this research; focusing first on individual factors and realities, then broadening the perspective to consider how underlying societal narratives contribute to the shaping of these realities. The chapter ends with a rationale for the Systematic Literature Review (SLR).

## 1.2 Personal and theoretical positioning

### *1.2.1 Theoretical perspective, ontology and epistemology*

Understanding a researcher's theoretical lens is to understand the research itself; how and why decisions were made, the execution of the research and its methodology. What underpins theory is ontology, defined as an individual's understanding of reality (Guba,1994) and epistemology, which is the 'theory of knowledge' and how we define truth (Crotty, 2003; Duberly et al., 2012).

The researcher adopted Bhaskar's (1975) model of critical realism (CR). Ontologically, therefore, it is assumed that experiences such as identity and emotions exist regardless of whether we are aware of them, and these experiences are shaped by unobservable underlying processes such as biological regulation (Bhaskar, 1978; Maxwell, 2012). Epistemologically, the researcher takes a fallibilist stance meaning experiences in relation to events hold an objective reality for individuals that can be observed and measured, whilst also acknowledging that these experiences are heavily influenced by unobservable causal mechanisms, such as societal stigmas (Bhaskar, 1975). In-line with CR, throughout this research there will be continuous consideration of unobservable mechanisms, such as

societal narratives, that may be influencing participant experiences, with attempts made to observe these in data analysis (Wynn & Williams, 2012).

This research will also be in-line with Bhasker's (1975) argument that causality cannot be directly observed but inferred through the experiences they generate. One way to explore causality, according to Bhasker (2008), is through the process of retroduction. This is where, through data analysis, regularities will be observed within our participant group, which can then be used to infer underlying mechanisms to help explain these regularities.

Finally, CR recognises the researcher as an imperfect observer whose understanding of phenomena is shaped by personal experiences, values, and assumptions (Bhaskar, 1998; Maxwell, 2012). A reflexive approach was therefore embedded throughout this thesis, as outlined in Section 1.2.2, to make these influences transparent and enhance the credibility of the research.

### *1.2.2 Personal positioning and reflexivity*

**Leaving the lids ajar:** Why did I choose this topic? You could say, in Jung's (1951) words, that I am, in some form, a 'wounded healer'. It is, however, one thing stating this and another unpacking it because that requires disturbing the nice, neat boxes I have packed 'my stuff' into. I have no plans to unbox anything here, partly because this is a public document but mainly because this thesis is not about me. Saying this, however, leaving the boxes completely shut would result in the false pretence that nothing about *me* influenced this work. So, as a compromise, I will leave the lids slightly ajar.

As a woman I have learnt that, to the wider public, my body is the most important thing about me. My childhood was filled with the rise of size zero and magazine 'circles of shame'. Every female in my life is on a diet or is talking about going on a diet. By secondary school, I learnt that 'low calorie, low fat, low sugar' meant good and I could be anything I

wanted in this world except for ‘fat’. I have spent too many years of my life trying to shrink myself. It has taken years of wading against the societal tide to try and unlearn all this. Learning that my body is in fact my home and, slowly, I have stopped trying to burn it to the ground.

**Insider researcher.** Having some experience in the research topic makes me an insider researcher (Brannick & Coghlan, 2007; Hellawell, 2006). This position allowed me to understand that what I was asking of my participants was a lot, both practically and emotionally, which subsequently granted me patience and compassion throughout this process. I also believe this was conveyed to the participants, which could have improved the alliance and therefore their willingness to be open and honest in their letters (Bonner & Tolhurst, 2002; Smyth & Holian, 2008). Having insight into the phenomena one is studying, however, also poses challenges. Insider researchers in particular, can have unconscious biases and assumptions that can alter how they interpret the participants’ story meaning the ‘true’ story is no longer heard, reducing the validity of results (DeLyser, 2001; Hewitt-Taylor, 2002).

As an insider researcher, I recognise that I held/hold biases and assumptions within my approach to this research. My position was also not static; I moved from insider to outsider based on the extent to which I identified with the letters collected (Almack, 2008; Bukamal, 2022). A bracketing interview was completed with the principal supervisor to identify my biases in order to try to separate them from what I was studying and to pre-empt how they may influence decision making and data analysis (Fleming, 2018). I continued bracketing through a reflexive journal, extracts of which can be seen in Appendix A, consulting with colleagues external to the project and Experts by Experience (EbE) (Tufford & Newman, 2012).

Reflexive extracts are embedded in tables throughout this thesis to demonstrate bracketing and allow the reader insight into my decision-making processes and thoughts that informed this research.

## 1.3 Defining language and key terms

Table 1 presents key terms and definitions used throughout this research.

**Table 1**

*Definitions of key terms*

| Language and/or Key Term | Definition |
|---|---|
| **Type 1 Diabetes Mellitus (T1DM)** | According to the National Health Service (NHS) (2024) and Diabetes UK (2023) T1DM occurs when an individual's immune system attacks the pancreas so it cannot produce the hormone insulin which controls blood glucose (National Health Service, 2024; Diabetes UK, 2023). This means that blood glucose levels can become too high after eating (hyperglycaemia), or too low (hypoglycaemia) for reasons such as meals being delayed or there is an insufficient carbohydrate intake. In order to manage T1DM, individuals regularly check their blood glucose levels and then, if required, manually administer insulin through injection or pump. |
| **Type 2 Diabetes Mellitus (T2DM)** | T2DM is when someone has high blood sugar levels due to their body not making as much insulin as it used to and the body becoming resistant to insulin (National Health Service, 2025; Diabetes UK, 2023). The main causes of T2DM are obesity (i.e., having an unhealthy weight measurement in relation to gender or |

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| | ethnicity), having excess fat stored in or around the liver or pancreas, and other factors such as high blood pressure and family history of T2DM. |
| **Diabetes Ketoacidosis (DKA)** | A condition seen in diabetes where a severe lack of insulin causes a build-up of ketones in the blood, which can make the blood acidic. It is a dangerous condition and can be life threatening if left untreated. |
| **Eating Disorder (ED)** | EDs are clinically diagnosed psychiatric illnesses defined by The International Classification of Diseases 11th edition (ICD-11) (World Health Organisation, 2019). |
| **Anorexia Nervosa (AN)** | The ICD-11 (World Health Organisation, 2019) define AN as a significantly low body weight in relation to the individual's height, age, development and weight history. This low body weight is not due to a lack of availability of food and is not better explained by a medical condition. Body Mass Index can be used to measure this (below 18 in adults and the 5th percentile in children and adolescents). Rapid weight loss (loss of 20% of weight in six months) can also be used if other criteria are met. Individuals show persistent patterns of behaviours aimed at getting or maintaining an abnormally low body weight typically due to a significant fear of weight gain. These behaviours aim to reduce energy intake (restrictive eating, fasting, low calorie food, slow eating, hiding food, spitting out food), purge calories (self-induced vomiting, laxatives, diuretics, enemas, omission of insulin in T1DE) and increase energy expenditure (excessive exercise, motor hyperactivity, deliberate exposure to cold, and weight loss medication). Low body weight is |

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| | overvalued by the individual and is central to their self-evaluation. Body weight and shape can be inaccurately viewed by the individual. Preoccupation with shape and weight may be significant for an individual and may present itself in body checking, weighing self, monitoring of calories, and/or avoidance of reflections. |
| **Bulimia Nervosa (BN)** | The ICD-11 (World Health Organisation, 2019) define BN as frequent and recurrent episodes of binge eating (once a week or more over a period of at least one month). Binge eating is a distinct period of time where an individual experiences a loss of control over their eating, they eat notably more/differently than usual, and/or feel unable to stop eating. Other characteristics of binge eating can include: eating alone due to embarrassment, eating food that is not part of one's normal diet, eating large amounts of food despite not being hungry, and eating faster than usual. This is alongside repeated inappropriate compensatory behaviours to prevent weight gain that occurs at least once a week for at least a month. The most common behaviour is self-induced vomiting, which typically occurs within an hour of eating. Other behaviours include: fasting, diuretics, laxative use, enemas, and excessive exercise. There is an excessive preoccupation with weight and shape. This can present itself as body checking, weighing self, monitoring of calories, and/or avoidance of reflections. Patterns of binge eating and purging causes distress and/or have significant impact in personal, family, social, educational, occupational, or other areas. |

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| **Binge eating disorder (BED)** | The ICD-11 (World Health Organisation, 2019) define BED as frequent and recurrent episodes of binge eating (once a week or more over a period of three months). Binge eating is a distinct period of time where an individual experiences a loss of control over their eating, they eat notably more/differently than usual, and/or feel unable to stop eating. Other characteristics of binge eating can include eating alone due to embarrassment, eating food that is not part of one's normal diet, eating large amounts of food despite not being hungry, and eating faster than usual. Binge eating is not accompanied by inappropriate compensatory behaviours. The binge eating cannot be better described by another medical or mental health condition. There is marked distress about the pattern of binge eating or significant impairment in important areas of functioning. |
| **Disordered eating (DE)** | Disordered eating has been defined as a wide spectrum of eating-related difficulties, such as dieting, over-exercising, binge eating etc., as an attempt to lose or control weight (Holland et al., 2014). These difficulties occur less frequently or at a lower severity so do not meet the ICD-11 diagnostic criteria for an ED (Pereira & Alvarenga, 2007). |
| **Type 1 diabetes with disordered eating (T1DE)** | T1DE has also been referred to as 'Diabulimia' in literature. According to Diabetes UK, T1DE is an eating disorder that only affects individuals with T1DM. Weight loss is achieved through the deliberate reduction or cessation of taking insulin and/or other behaviours, such as food restriction, binging and compensatory |

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| | behaviours. As of the time this thesis is written, T1DE is not recognised by the ICD-11 as a diagnosable eating disorder. |
| **Identity** | Identity is a framework housing one's self-concept, self-esteem, relationships roles, values and future potential; further influenced by environmental and personal experiences and expectations (Christiansen, 1999; Oyserman & James2011). In addition, identity is shaped through social interaction and what we believe others think about us, resulting in us presenting ourselves in ways that others expect us to, whilst being in line with our own values (Goffman, 1982). |

### *1.3.1 Expanding definitions and a comment on language*

The concepts in this thesis are complex, dynamic, and in some cases hold multiple definitions depending on an individual's perspective. Presenting only brief definitions therefore risks oversimplifying these concepts and confusing the reader about how they are understood within this thesis. This subsection will therefore briefly expand on some of the definitions presented in Table 1.

**Identity.** Identity is a complex and multi-faceted construct that has been theorised in diverse ways across psychology. As outlined in Table 1, this thesis adopts the CR stance that identity is shaped both by the individual, through self-concept, self-esteem, and values (Christiansen, 1999; Oyserman & James, 2011), and by external influences, including social interactions, cultural narratives, and societal structures (Goffman, 1982). External influences can include social expectations, cultural narratives, and experiences of stigma, whereby negative societal attitudes toward certain diagnoses or behaviours shape how individuals are treated and perceived, and may become internalised, affecting identity (Goffman, 1982). Building on this, this research is situated with the Social Identity Theory (Tajfel & Turner,

1979), which argues that identity is constructed through self-categorisation and the categorisation of others into social groups. These group memberships, defined as "in-groups" and "out-groups," influence how people perceive themselves, how they are perceived by others, and the behaviours and social status associated with these identities.

**T1DM.** In expansion of the medical definition of T1DM provided in Table 1, managing T1DM involves complex daily routines, including frequent blood glucose monitoring, either using finger-prick testing or continuous glucose monitoring (CGM) devices, careful planning of meals, and timely insulin administration via injections or insulin pumps. These tasks are not only physically demanding but also carry a substantial emotional and cognitive load, as individuals must constantly balance the risk of hypo- or hyperglycaemia (Browne et al., 2014; Schabert et al., 2013). The visibility of insulin administration, CGM devices, and other self-management behaviours can influence social interactions and contribute to stigma surrounding T1DM (Ashraf et al., 2014; Guo et al., 2023). While this section introduces T1DM, section 1.6. examines in greater depth the psychological and emotional challenges of living with the condition, including experiences of diabetes distress and burnout.

**Eating disorders (ED) and disordered eating (DE).** It is important to expand on Table 1 in stating how this thesis views ED and DE. An ED is when an individual's clinical presentation meets the diagnostic criteria defined by the ICD-11. DE refers to similar patterns of eating seen in ED, such as food restriction, binging and purging behaviours, that still have similar psychological processes to ED, such as preoccupation with shape and weight and the use of food to cope with distress (Fairburn, 2008; Mond et al., 2006) but do not meet full diagnostic criteria. Both ED and DE can cause significant psychological distress, negative self-evaluation, and impaired functioning, and both can shape aspects of identity (Holloway et al., 2017; Jones et al., 2020). This thesis, therefore, adopts a critical perspective in which

both ED and DE are recognised as distressing and impactful on an individual. This research, uses the term ED to include all distress caused by struggles with eating, this is with the exception of T1DE which is explicitly named for clarity. This reflects an acknowledgement that DE can still be clinically significant and highly distressing, even when formal diagnostic criteria are not met. Clarifying this distinction ensures that the thesis accounts for the full spectrum of experiences without minimising the impact of subclinical or non-diagnosed eating behaviours.

**T1DE.** T1DE is a term used to describe disordered eating behaviours that occur specifically in the context of T1DM. The most well-known presentation of T1DE involves deliberate insulin omission or restriction to influence weight, often alongside other behaviours such as food restriction, binge eating, and/or other compensatory behaviours such as self-induced vomiting (Diabetes UK, 2023). As outlined in Table 1, T1DE is not currently recognised in diagnostic systems such as the ICD-11. In the UK however, individuals with T1DE can still be seen in ED services. Research to date has tended to conceptualise T1DE as being most closely aligned with the behaviours and psychological processes of restrictive ED, such as AN and BN, as opposed to patterns seen in BED (Colton et al., 2015; Wisting et al., 2019). This thesis also adopts this conceptualisation, whilst also recognising that while the behavioural features of T1DE overlap with other ED, the presence of T1DM introduces unique risks, challenges, and identity implications. Unlike other ED, T1DE occurs within the context of a lifelong condition that requires constant monitoring of blood glucose, carbohydrate counting, and insulin administration. As such, food and insulin are inseparably tied to survival, and everyday diabetes management tasks requires a knowledge of food and its contents. A particularly distinctive feature of T1DE is the use of insulin omission or underdosing as a method of weight control, which carries acute risks, including DKA and accelerated long-term complications (Treasure et al., 2015). Moreover, because T1DM will

always require active self-management, even in recovery, individuals with T1DE may face unique ongoing challenges around food vigilance and body awareness that can compound distress and shape identity in ways distinct from other ED (Colton et al., 2015; Wisting et al., 2019, 2020).

This thesis explicitly names T1DE when speaking about ED/DE in an individual who also has T1DM. For transparency, however, all research materials seen by participants, separated T1DE into 'T1DM' and an 'ED'. The purpose of this was to encourage participants to explore their feelings towards and impact of the diabetes and ED elements of T1DE to better meet the research aims.

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**A Reflection.**

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*Chapter 1 was mostly written and researched prior to the empirical elements of this thesis being done. Within Chapter 1 I consider T1DM and EDs (without T1DM) separately, and think about how they could intertwine within the context of T1DE. Using existing knowledge of T1DM and ED to try and understand T1DE, however, meant that I separated T1DE in a literal way, into T1DM and an eating disorder. Something that can be seen in the way I wrote participant materials. My intention behind this was to encourage participants to really explore both elements to their T1DE as per the research aims and I do think the findings of this research highlight some value in this seperation. But, I recognise that language is important and I have also consequently reinforced the siloed approach to T1DE that I criticise throughout this thesis.*

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## 1.4 The current context of T1DE

### *1.4.1 The prevalence and risks of T1DE*

Prior to recent years, T1DE has flown relatively under the radar of public and professional awareness. This is despite its prevalence and accompanying risk. Disordered eating and ED are significantly more common in those with T1DM compared to those

without it and an estimated 40% of the T1DM community lives with T1DE (DeJonge et al., 2014; Goddard & Oxlad, 2023). In addition, the risk of mortality in T1DE is 3.2x higher than those with another ED, with an average decreased lifespan of eleven years (Goebal-Fabbri et al., 2008).

Given the prevalence and risks of T1DE, prevention and effective treatment are of high importance (Colton et al., 2015). Despite this importance, the attrition and relapse rates for psychological therapy is significantly higher for those with T1DE compared to those with another ED (Banting & Randle-Phillip 2018; Clery et al., 2017; Colton et al., 2015; Custal et al., 2014). When T1DE clients were asked of their experiences of ED services, Hastings et al. (2016) found that often services were unhelpful as they did not understand or acknowledge the role T1DM played in the client's ED. This could be because ED services are still utilising therapeutic models that were not designed with T1DM in mind, so therefore do not acknowledge or accommodate it (Clery, 2017; Custal et al., 2014), highlighting the current gaps in T1DE research and the care provided to clients.

### *1.4.2 The parliamentary inquiry*

In January 2024, T1DE made its way into national headlines due to its first parliamentary inquiry chaired by Rt. Hon Theresa May MP and Sir George Howarth MP (Howarth & May, 2024). The inquiry gathered and shared testimonies of those with lived experience, healthcare professionals, and clinicians. These voices overwhelmingly highlighted the failures of the current siloed healthcare system that treats T1DE as two separate conditions. The report stated that this siloed approach results in conflicting messages delivered to the individual about approaches to food and in individuals being labelled as 'non-compliant'. In addition, a lack of diagnosis for T1DE, and having no specific T1DE pathway, were also named as system failures.

In 2017, Megan Davidson, who struggled with T1DE, died by suicide. Her parents, Lesley and Neal, spoke publicly about the lack of support given to Megan for T1DE. In her final note she wrote that she no longer had the energy to fight with a system that had no place for her (Breakthrough T1D, January 2024). Following Megan's death, in June 2024, a prevention of future deaths report was published (McCormick, 2024); the main concerns highlighted echoed those of the parliamentary inquiry regarding the lack of integrated healthcare, diagnosis and specific treatment pathway.

The failures in the siloed approach to treating T1DE, alongside the higher relapse and dropout rates from psychological therapy in the T1DE population compared to ED, highlight the need for T1DE to be viewed as its own difficulty and have its unique and nuanced factors accommodated by interventions. Since the death of Megan, NHS England have piloted seven T1DE services, which opened in 2022 and integrate diabetes and ED care. Despite initial positive outcomes (Wild et al., 2023), commissioner funding for these services is due to end in April 2025.

**A Reflection.**

*When I read that Megan wrote in her final note that she could no longer fight a system that had no place for her, I felt a deep sadness. To me the NHS is not a system that should ever be fought against or exclusive. It should be a space that makes everyone feel as though they belong. After working in the NHS for six years I recognise how hard this can be for employees, everything must be proven in order to get funding and often that involves people losing their lives. Reading about Megan reminded me of my experience working in ED services prior to training. Frequently there was no adaptations to care for those with T1DE, meaning service users often did not feel seen by the service, and continuously came back to receive the same care. My clinical experiences, alongside reading further into T1DE influenced my decision to do this thesis on T1DE. They also have formed my hopes for this research to be another brick in building a system where individuals with T1DE feel that they have a place in the NHS where they are seen, understood, taken seriously and cared about. I will make sure that Megan's final note stays with me as long as I practice, to try, as one person, to create spaces where the system does not need to be fought against by clients, but where I advocate for them.*

## 1.5 Predisposing and maintenance factors of T1DE

Previous research has attempted to explore factors that contribute to the development and maintenance of T1DE. The mean age of onset for T1DE is 22.6 (Colton et al., 2015). This is later in life than the mean age of onset for all other ED categories, which are 13-19 (Hudson et al., 2007; Micali et al., 2013; Steinhausen & Jenson, 2015). In terms of development, with the onset of T1DE being approximately 3 years after most cases of T1DM are diagnosed (Ogle et al., 2022), and on average later than the diagnosis of other EDs, this suggests that the pathology and lifestyle of T1DM may increase one's risk of developing T1DE, one that may not have developed without a T1DM diagnosis.

One approach to understanding how T1DM and the factors that surround it could increase the risk of developing T1DE is to first understand how research has conceptualised the factors that contribute to the development and maintenance of ED more generally; T1DM could then be examined to see whether it exacerbates such factors. This was the approach Treasure et al. (2015) (Appendix C) and De Paoli & Rogers, (2018) (Appendix D) adopted, in using Fairburn et al.'s. (2003) transdiagnostic model of ED (Appendix B) and adapting it for their T1DE specific models.

Fairburn et al.'s (2003) transdiagnostic model is one of the most widely used across ED services (Treasure et al., 2015). The underlying theory is that all EDs are cognitive disorders that have a shared core 'pathology' of 'over-evaluation of shape, weight and their control', meaning self-worth is judged by one's body shape and weight, and the ability to control it. This 'pathology' can result in cycles of restriction, binge eating and compensatory behaviours, such as self-induced vomiting, over-exercising, laxative abuse and/or further food restriction, which can also be influenced by life events and mood. The model also acknowledges the role of perfectionism, emotional instability, and low self-esteem as premorbid risk factors for EDs (Fairburn et al., 2003).

In their T1DE models, both Treasure et al., (2015) and De Paoli and Rogers (2018) agree with the transdiagnostic model in that individual traits, such as perfectionism, low self-esteem and emotional instability, all increase one's predisposition to developing T1DE. De Paoli and Rogers (2018) expanded this to consider the specific role of T1DM, arguing how T1DM can exacerbate these traits, e.g. self-esteem can be lowered further due to feeling different because of diabetes.

Both models also argued that the nature of T1DM, in its focus on food and food content, and the environment that surrounds T1DM, significantly contributes to an over-

evaluation of shape, weight and the control one has over both (De Paoli & Rogers., 2018; Treasure et al., 2015). This has been echoed across other research on T1DE; T1DM increases the salience of food content, services place a focus on weight, and some clients make the inaccurate association between insulin injections and weight gain (Fisher & Birch, 2001; Schwartz et al., 2002; Starkey & Wade, 2011). In addition, both models highlight that there can be an expectation in T1DM to be the 'perfect diabetic' and, when this expectation is not met, believing one is 'bad', which can trigger the T1DE cycle. The T1DE cycle of both models refer to cycles of food restriction, binging and compensatory behaviours discussed in Fairburn et al's (2003) model, but with the addition of insulin omission as a compensatory behaviour.

An interesting addition to both models was the role of blood glucose in the T1DE cycle. Treasure et al. (2015) used the food addiction theory (Schulte et al., 2015; Thornley et al., 2008) to explain how fluctuations in blood glucose contribute to the maintenance of T1DE. This theory argues that the dramatic shifts in plasma glucose spikes seen in T1DE, are linked to brain regions associated with reward and cravings and are hypothesised to contribute to food addiction (Lennerz et al., 2013; Merwin et al., 2014; Thornley et al., 2008; Schulte et al.,2014). Treasure et al. (2015), therefore, argued food addiction was a factor in T1DE, further contributing to its maintenance.

De Paoli and Rogers (2018), however, criticised this element of Treasure et al.'s (2015) model, labelling it as problematic as the concept that shifts in plasma glucose, linked to the neuroadaptive changes seen in drug and alcohol addiction, has been found to be inaccurate (Rogers, 2017). Instead, they argue that changes in blood sugar, such as hypoglycaemia, increases the biological urge to eat sugary foods in a disinhibited way, thus contributing to further binge/restrict cycles (Goebal-Fabbri, 2009; Merwin et al., 2014; Strachan et al., 2004).

A drawback of Treasure et al.'s (2015) and De Paoli and Rogers' (2018) approach, however, is that they attempt to fit T1DE into a pre-existing model that was not designed with T1DM in mind. In addition, both studies based their models on existing research, as opposed to asking clients specifically about their experiences and using this information to create a model unique to T1DE. This approach could, therefore, have missed key, diabetes specific, information that provides further insight into the development and maintenance of T1DE.

Harrison et al. (2021) (Appendix E) adopted a different approach in their cognitive behavioural therapy (CBT) model of T1DE. Their model was developed by applying grounded theory to the personal experiences of 23 women with T1DM who either had T1DE, were recovering from T1DE, or were without T1DE.

In the longitudinal element of Harrison et al.'s (2021) model, they argue that predisposing factors such as early life experiences, life transitions, and traits such as perfectionism interact with and contribute to how an individual first experiences their diagnosis of T1DM. In addition, factors such as timing of diagnosis, support, educational resources, and physical experiences prior to diagnosis, such as significant weight loss, also contribute to the beliefs someone develops about T1DM.

Pre-disposing factors and initial experiences of diagnosis influences how an individual then copes with the daily management of diabetes and the physical symptoms they experience because of it. These factors can all result in the development of negative beliefs held by the individual towards their T1DM, eating, weight and shape. In addition, like Treasure et al. (2015) and De Paoli and Rogers (2018), this model also recognises that the nature of diabetes management places a significant focus on food and weight, sensitising individuals to weight, shape, and eating.

These longitudinal factors accumulate and, following specific triggers, result in thoughts, feelings, and behaviours that maintain T1DE (Harrison et al., 2021). For example, someone may become triggered by comparing their body with another, which results in thoughts, such as '*I will be less defective and more acceptable if I am thinner*' (Harrison et al., 2021, p6), and feelings of being out of control and anxious, which lead to behaviours such insulin omission, food restriction etc. as a way to feel in control.

Harrison et al.'s (2021) model supports the two T1DE models in linking T1DM to increasing sensitisation to weight, shape, and food. Harrison et al., (2021), however, also highlights that the role of T1DM in T1DE extends beyond just weight loss. The model describes multiple diabetes-specific factors that develop negative beliefs held towards their diabetes, resulting in daily thoughts, feelings, and behaviours that maintain T1DE. Perhaps, therefore, T1DE is maintained, not just by a want to lose weight, but also a want to avoid, rebel against, and/or express hatred towards the T1DM.

In their qualitative study exploring the reasons for insulin omission in those with T1DE, Coleman and Caswell (2020) echoed the two themes highlighted by Harrison et al. (2021). The dominant reason for omission was the pursuit of weight loss, with many viewing it as more important than the potential medical consequences of insulin misuse. The second reason was the 'hatred' of diabetes; insulin omission allowed some to avoid and/rebel against T1DM and regain control of their body.

The research models of T1DE tell us how the nature of T1DM can result in the increased pursuit of weight loss and control over body weight, and how the various factors of T1DM can result in negative beliefs and hatred towards the illness. What is missing, however, is a more detailed understanding about how the nature of T1DM can result in such

hatred and why T1DE may be viewed differently and is therefore followed, despite such risks to life.

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**A Reflection.**

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*I was shocked that, from my searches, there are only three psychological models on T1DE. In addition, only one of these models was built based on the experiences of those who struggle with T1DE. It was a shock because through doing this thesis I am becoming aware of how devastating T1DE can be for the individual and their systems and found myself thinking 'why aren't more people talking about this?'. In addition, I somewhat struggle with these models and their spotlight on weight and shape, and that this spotlight situates the blame in the person. This struggle could be due to a bias of mine developed from my time working in ED services, that, for 90% of the people I worked with, it was never about the weight or the food, their difficulties went much deeper than that, it was about what weight, food, shape, control represented to that person. This has influenced my approach to the research in my expectations for participants to speak of their experiences beyond shape and weight, and me wanting to consider underlying factors that may be driving a want for control over shape and weight could be linked to such as a form of control and social acceptance.*

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## 1.6 What is it about T1DM that predisposes T1DE?

### *1.6.1 Diabetes burnout*

Maintaining blood glucose levels in T1DM requires a range of daily behaviours, including frequent blood glucose monitoring via finger-prick tests or CGM, calculating carbohydrate intake, administering insulin (via injections or pumps), planning meals and snacks, adjusting insulin for physical activity, and considering how food and beverages impact glucose levels (Ali et al., 2013; Hoover, 1983; Polonsky, 1999; Powers et al., 2017; Rezende Neta et al., 2015). It is well documented that this relentless and demanding nature can result in 'diabetes burnout', a state of physical and emotional exhaustion from diabetes,

frequently causing an individual to struggle with their diabetes management (Hoover, 1983; Polonsky, 1999).

The approach of diabetes care services is a contributing factor to diabetes burnout as it can instil an expectation that clients have to manage their T1DM perfectly or they will face severe physical consequences (Abdoli et al., 2020; Skinner et al., 2020). Similarly to the De Paoli and Rogers (2018) and Treasure et al. (2015) T1DE models, research into diabetes burnout have found that when individuals are deemed by others and/or themselves to have fallen short of perfection in their diabetes management, they hold the belief they are bad diabetics (Hinds, 2023; Stevenson, 2022). The dichotomous narrative of having to perfectly manage T1DM or be a failure, has been linked to diabetes burnout, as one 'gives up' on trying to manage it, and experiences feelings of hatred towards the diabetes (Abdoli et al., 2017).

The nature of T1DM can also reduce the body down to a series of unpredictable numbers, i.e., blood glucose readings, which, for some, ruins the relationship with the body and makes it feel as though it is its a separate entity (Abdoli et al., 2020; Tilden et al., 2005). Diabetes burnout, therefore, can be a way to reject T1DM and attempt to reconnect with the body (Abdoli et al., 2020). A similar phenomena was found in Coleman and Caswell's (2020) study, in that T1DE serves as a way to regain control of the body from T1DM.

Detaching from T1DM, is also a sign of diabetes burnout (Abdoli et al., 2020). Detachment from T1DM is viewing it as something external to the self, serving the purpose of an individual being able to avoid, reject, and experience negative emotions towards it (Abdoli et al., 2020; Balfe, 2009; Skinner et al., 2020). When burnt out, an individual might struggle to accept T1DM as part of themselves, suggesting that another difficulty individuals can face is with the acknowledgement of T1DM as part of their identity.

### *1.6.2 T1DM, illness integration and identity*

Illness integration is defined as the merging of new life experiences around chronic illnesses, with past and present identities (Westra & Rodger, 1991). Within the context of T1DM, integration into identity is conceptualised by an individual reconciling the demands of their T1DM with their existing and wanted identity and social expectations (Oris et al., 2016). Integrating T1DM into the current and future self is an adaptive coping mechanism, whereas those that struggle with integration have the highest level of T1DM avoidance and complications, as well as the lowest treatment adherence and reduced glycaemic control (Commissariat et al., 2020; Felton & Revenson, 1984; Graue et al., 2004; Oris et al., 2016; Schmidt et al., 2018; Seiffge-Krenke., 2001).

Research on T1DM highlights struggles with illness integration for various reasons. Some of these reasons relate to the social narratives that surround 'illness' and T1DM discussed in section 1.8. T1DM has been found to contribute to biographical disruption, meaning it interrupts an individuals' expected life trajectory (Bury, 1982). This is because, for some, T1DM represents illness and abnormality, conflicting with their preferred identity of health and normalcy (Balfe et al., 2013; Carlsund & Sonderberg, 2019; Commissariat et al., 2023; Hains et al., 2007; Oris et al., 2016, 2018). It is also seen to disrupt key identity-shaping experiences like independence, socialising, and career progression (Drew et al., 2010; Mellinger, 2003; Wilson, 2010). Integrating T1DM into identity therefore requires reconciling these disruptions with existing self-concepts, adjusting personal goals and values, and accepting the ongoing presence of a chronic condition (Charmaz, 1987; Oris et al., 2016). Where integration is unsuccessful, individuals may experience minimisation or rejection of T1DM as a threat to their preferred identity, potentially exacerbating emotional distress and complicating self-management (Charmaz, 1987; Commissariat et al., 2020).

In addition, age at diagnosis can shape illness identity and integration by influencing how much the illness disrupts developmental milestones and self-concept. Early-onset T1DM (childhood or adolescence) may coincide with critical periods for identity formation, autonomy, and peer relationships, making integration more challenging (Hains et al., 2007; Oris, Luyckx, Rassart et al., 2016). In contrast, T1DM that onsets in adulthood may interrupt an already established sense of self and routines, potentially provoking biographical disruption and preventing illness integration (Charmaz, 1987; Drew et al., 2010).

Oris, Luyckx, Rassart et al. (2016) identify four illness identity profiles in T1DM: acceptance, where T1DM is integrated into identity alongside other identity elements (Luyckx, Seiffge-Krenke, Schwartz et al., 2008); enrichment, where positive experiences from T1DM enhance identity, such as increased resilience or life appreciation (Tedeschi & Calhoun, 2004); engulfment, where T1DM dominates identity (Morea, Friend & Bennett, 2008); and rejection, where the individual intensely dislikes T1DM and fears being defined by it (Commissariat, Volkening, Weinzimer et al., 2023; Oris, Luyckx, Rassart et al., 2016). Acceptance and enrichment are linked to better treatment adherence, psychological wellbeing, and fewer complications, whereas engulfment and rejection are associated with poorer adherence, wellbeing, and higher complication rates (Commissariat, Volkening, Weinzimer et al., 2023; Morea, Friend & Bennett, 2008; Oris, Luyckx, Rassart et al., 2016).

**A Reflection**

*This section influenced me by making me consider and explore the parts of my identity that I willingly accept and the parts I try to ignore. I asked myself what is it about these parts that align or don't align with my values and who I want to be and what impact might this be having on me?*

### 1.7 The feelings towards an ED

As discussed in section 1.3.1. current research on T1DE often conceptualises it as analogous to restrict/binge ED such as AN and BN, particularly in terms of the behaviours

involved and the potential psychological functions they may serve (Colton et al., 2007; Goebel-Fabbri, 2009). It is important to note that the functions of AN and BN differ from those of BED, which has been found to be less ego-syntonic and has the core function of coping with negative affect or emotional regulation as opposed to over-evaluation of shape, weight and control (Fairburn et al., 2003). Therefore, while direct qualitative evidence on the subjective experience of T1DE is limited, insights from research on AN and BN can help to inform hypotheses about the emotional function of T1DE and role in identity.

The function of an ED such as AN and BN extends beyond just being 'thin' but instead has been found to enhance preferred traits of personality and add to an individual's identity (Bruch, 1974). In particular, AN, has been noted for its ego-syntonic nature where, unlike T1DM, aspects of the illness are highly valued by the individual and are in-line with their identity (Marzola et al., 2015).

Valued aspects of an ED are that it can help an individual achieve a sense of mastery and control, particularly over one's body (Nordbo et al., 2006; Serpell et al., 1999). In addition, having an unstable/disliked sense of identity has been named as a risk factor for an ED (Campbell et al., 1996; Perry et al., 2008; Vartanian, 2009; 2013; 2016). This is because an ED has been perceived as a way for an individual to be rid of their previous, disliked, identity and provide them with a new one that has desired traits, such as being disciplined and high achieving (Espeset et al., 2012; Nordbo et al., 2006). The ego-syntonic nature of some ED can also be understood within the context of patriarchal narratives that surround thinness in women, which is discussed in depth in section 1.8.

Beyond identity, EDs also function as a form of escape for individuals from circumstances caused by both negative physical and emotional experiences and are viewed as a solution to such difficulties (Nordbo et al., 2012; Williams & Reid, 2010). Participants have

also expressed that there is an element of comfort experienced with having an ED; if everything else in their life fails, their ED will be there to 'help' them and be something they can be 'good at' (Nordbo et al., 2012).

Although some aspects of an ED are ego-syntonic, there are still elements that individuals dislike. Research has found common disliked elements of EDs are that they are deceptive, make false promises, isolate them from loved ones, and can consume an individual's life and take control of them (Serpell et al., 1999; Williams & Reid, 2010). These hated elements, however, often do not outweigh the ego-syntonic ones, as individuals often struggle with recovery, highlighting the complexity in the relationship one has with their ED (Berry et al., 2024; Williams & Reid, 2010).

The negative qualities of an ED seem to overlap with those of T1DM in that individuals perceived them as controlling, isolating, and all-consuming. The perceived positive qualities of an ED, however, are in stark contrast to those found in T1DM, where instead of a diagnosis being avoided and rejected, it provides someone with various functions, including an identity that they value.

T1DE may, therefore, offer an alternative identity and sense of purpose, allowing individuals to adopt valued qualities whilst escaping the exhaustion and negative emotions of T1DM. Given the common struggle of feeling like a 'failing diabetic', T1DE could provide a sense of achievement. However, this cycle is complicated by the T1DE'S negative consequences and the permanence of T1DM, leaving individuals feeling trapped between the two.

### *1.7.1 The anorexic voice (AV)*

The AV is a well-established concept in both research and clinical practice (Serpell et al., 1999; Tierney & Fox, 2010). It is experienced as a voice that speaks in second or third

person and comments on the actions of the individual and the consequences of these actions in terms of food, shape, and weight (Pugh & Waller, 2017). Research into the AV has highlighted continuously that there is a relational element to EDs that is important to consider. Earlier research described the AV as intensely negative, sending messages to the individual of how important it is to continue to follow it, meaning it is an important maintenance factor in AN (Pugh & Waller, 2017; Tierney & Fox, 2010; Williams & Reid, 2012).

Burnett-Stuart et al. (2024) interviewed the AV of nine participants using chair work. This study found that the AV viewed the individual as deeply flawed and struggling with many things, such as emotional regulation and identity, all of which the AV had solutions for. Solutions included strict rules and rituals around food and weight loss to enable emotional numbing and to transform the individual's identity into something that is acceptable. In addition, in terms of the relationship between the participant and their AV there was an element of co-dependency, however, in most cases, the AV held the power. This was unwanted by the individual and led to experiences of "*fighting"* and "*rebellion"* (p.10). A primary focus of the AV was to maintain its power and keep itself alive by becoming louder, punishing the individual, and obstructing attempts at recovery.

Although originally conceptualised for AN, some authors have suggested that similar internalised voices may also be relevant in other ED, providing a potential lens for understanding the intrapersonal experience of ED more broadly. For instance, Pugh (2018) proposed a multifactorial model of the 'eating disorder voice' that includes dialogical patterns and early trauma, which could be applicable across different ED subtypes. Additionally, research indicates that individuals with BN may experience voice disorders, suggesting a complex relationship between voice and eating pathology (Rajiah et al., 2012).

Therefore, while the AV was initially conceptualised within the context of AN, its applicability to other ED, could be extended to T1DE to enhance our understanding of its psychological functions and experiences, and its role in identity formation.

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**A Reflection**

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*I think that my inclusion of research on the AV arose from the predominance of research positioning T1DE in an AN-Lense, something that I also observed in clinical ED services whilst working there. This has shaped how I in-turn position T1DE in a similar lens within this introductory chapter and possibly influence how I read and interpret letters in Chapter 4.*

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## 1.8 Wider perspectives

There are stark differences in the perceived identity of T1DM and EDs seen across research, suggesting the powerful influence that wider societal narratives have on how the identities of T1DM and EDs are constructed.

### *1.8.1 The superiority of a 'healthy body'*

Haraway (2013) stated that "*bodies, then, are not born; they are made*"(p.2), meaning that the perceptions of the human body and its health are significantly influenced by the surrounding wider social narratives. Wider narratives have influenced the view on what a healthy body is, positioning it as one without illness that can contribute most productively to the western capitalist society (Foucault, 2008). This positioning of a healthy body, places those without full health as different, curating the stigma associated with chronic illnesses (Crawford, 1994).

Adding to this stigma is the narrative that 'health' is achieved only when an individual is disciplined enough to make the right choices in regard to their health and therefore fight illness (Lupton, 2012). This view results in the narrative that health is earned by the individual, through their own discipline and ability to control themselves and prioritise their

body, which, by default, results in anyone with an illness being viewed as lacking these qualities and somehow causing their illness (Sontag, 1978).

The perception that illness is caused through lack of discipline and control is salient in the context of diabetes. In the sphere of public knowledge, the cause of T2DM is mistakenly attributed only to the overconsumption of fatty and sugary foods and poor lifestyle choices (Ferguson, 2010; Sontag, 1978). Public confusion between T1DM and T2DM means this stigmatising view, resulting from misrepresentation of the aetiology of T2DM, is also placed upon those with T1DM, with many individuals reporting being falsely blamed for causing their T1DM (Dreyer, 2024). This wider stigma and blame is a dominant reason why those with T1DM choose to hide their diagnosis in public spaces as they do not wish to have the identity of being 'to blame', 'uncontrolled', or 'lazy' (Balfe et al., 2013).

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**A Reflection**

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*I think that these narratives around illness serves the purpose of maintaining the capitalist agenda. By placing value in our ability to contribute and the blame of illness in the person, we are spurred to want to contribute more and shame those who cannot contribute as much. This also hides health inequalities, that one is much more likely have a chronic illness if they are from the global majority and of low economic status and instead adds more fuel to the racist and classist systems we live in. Engaging with these wider narrative has shaped the decision I made in this research in multiple way: it has made me more attentive to the way's participant experiences might be influenced by these narratives and sensitised me to the risk of interpreting participant experiences that inadvertently reinforces stigmatising social narratives. Acknowledging this reflexively has been central to generating the themes in the empirical research, particularly by broadening my analytical lens to consider how individual experiences may be shaped by wider social narratives rather than solely by personal or psychological factors.*

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### *1.8.2 'Nothing tastes as good as…': The societal obsession with the female body, the desire for controlled women and the hatred of fatness*

The psychological models previously discussed somewhat imply that the 'over-evaluation of body shape, weight, and their control' is something the individual chooses to value. The assumption, however, that any female authors the ideologies they hold about their body, or their character, is false (Weeden, 1997). Instead, these ideologies are a result of the internalisation of complex systemic narratives about women, which in western society, results in the persistent monitoring and regulation of their body and behaviour to obtain some social power (Turner, 2017; Weeden, 1997).

From the turn of the 20th century, the most dominant narrative championed by white western society is that in order to be beautiful, a woman must be thin (Garner et al., 1980; Owen & Laurel-Seller 2000; Wiseman et al., 1992). With the rise of mass and social media, this sentiment has shifted from being a beauty ideal, to simply a standard every woman must meet in order to gain social acceptance and power (Hosseini & Padhy, 2020). Those who do not meet this standard are viewed as undisciplined and are publicly highlighted and scorned by media tabloids, and on the comments of social media (Chrisler, 2012; Mauss, 2015).

Thinness for women, however, is much more than the shape of the physical body, it also perceived to represent something about her character and identity. Being thin, regardless of how it is achieved, represents to the outside world that one possesses enough self-control to suppress hunger and regularly exercise (Chrisler, 2008; Murnen & Smolak, 2008). Self-control is a trait highly valued by the patriarchal society, continuing to keep women controlled and suppressed (Chrisler, 2008).

If thinness represents the desired beauty and character of a female, then fatness is the antithesis. One of the countless issues with equating thinness to self-control is that it adopts the assumption that female fatness could be avoided if one simply chose to control

themselves (Chrisler, 2008; Smith, 2012). Therefore, if a female is considered fat, it socially represents deeply flawed characteristics of negligence, irresponsibility, laziness, being over-emotional, and unmotivated (Crandall, 1994; Kleinman et al., 2021; Puhl & Heuer, 2009; Rounsefell et al.,2020; Uzunian & Vitalle, 2015; Zhang & Rios, 2022). These traits are disliked by the patriarchal culture and are considered unattractive; therefore, women who are viewed as being fat have lower social power and value, meaning they face more societal prejudice and discrimination than thinner women and men of any body size (Fikkan & Rothbum, 2012).

According to McKinley and Hyde's (1996) self-objectification theory, not only are these narratives internalised by women, they are used unconsciously to objectify oneself and develop the belief that one's body and identity should meet the expectations of wider society. If these standards are perceived not to be met, women can experience extensive shame and low self-esteem (McKinley & Hyde, 1996).

The internalising of the thin standard, self-objectifying, and experiencing the stigma associated with those who are perceived not to meet the standard are significantly associated with body dissatisfaction and disordered eating (Rounsefell et al.,2020; Uzunian & Vitalle, 2015; Zhang et al., 2022). In relation specifically to those living with T1DE, insulin omission to achieve thinness was viewed as more important than health, due to thinness being the only acceptable body for a female and noticing an increase in social acceptance and power when weight was lost (Ribeiro et al., 2021). Therefore, these results offer an explanation of why some individuals with T1DE view thinness as more valuable than the potential physical risks T1DE causes.

The narrative that T1DM means that one is less socially valuable and to blame for their condition makes it understandable why, amongst the other factors previously discussed,

an individual may struggle with having the diagnosis. If thinness represents beauty and the possession of traits that are the opposite to those associated with T1DM, such as self-control, it is again understandable why an individual with T1DM may develop a T1ED as a way to reject the narratives of T1DM and regain social power and feel in control, through a pursuit of thinness. In addition, pursuing thinness, even when it is at risk to one's health, means one could avoid the narratives associated with fatness, narratives that would further degrade the character and power of those with T1DM.

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**A Reflection**

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*I first noticed myself wanting to write more and more in this section. I think this is because seeing these experiences written down in academic journals, validated my own experiences. Of the countless years spent trying to be 'beautiful' and 'perfect' but never quite getting there because the societal goalposts are always moving. That it wasn't just me, I wasn't doing anything wrong, the system is just rigged. It made me angry. I think it will always make me angry, and this anger fuelled me to want to write more about it, to shout it from the rooftops, that this is the female experience, and it is killing us. Interestingly, however, once this section was finalised, I became nervous about it. What if I become viewed as an 'angry feminist'? What if I get a male examiner and this annoys him? I had the urge to lighten the message a bit, but I didn't. I didn't because that would not only be silencing a strong part of my identity in order to remain unproblematic and 'cool' in the eyes of most men but will also perpetuate the silencing of the female experience that has occurred for centuries, and I did not want to be part of that. Plus, I asked myself what was so bad about being an angry feminist? I couldn't come up with a single answer that didn't relate back to the patriarchy, which gave me more reason to leave this in. Reflecting on this process has been central to my research practice. My positionality and stance, particularly my personal experiences with societal pressures around beauty, perfection, and the thin ideal, shaped how I interpreted and prioritised participants' experiences. I was particularly attentive to how participants' narratives reflected struggles with appearance, societal expectations, and self-worth, often*

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*viewing these experiences through a lens informed by my own encounters with the thin ideal. This also meant I had to remain mindful of the risk of over-emphasising beauty and body-related themes at the expense of other aspects of participants' experiences. Recognising this bias prompted me to deliberately question my interpretations, to consider multiple angles, and to ensure that themes were grounded in participants' accounts rather than solely in my own perspective. My stance ultimately influenced the analytical focus of the study, highlighting how cultural and societal ideals around appearance intersect with identity, while reflexivity helped me balance my own lens with fidelity to participants' diverse voices.*

## 1.9 Rationale for the SLR

The research explored in this chapter has highlighted the significance of identity in the field of T1DM and EDs. Despite acknowledging this significance, a deeper understanding of how T1DM may impact identity for individuals, and their responses to this impact, was absent. By gaining a better understanding of these topics, it is possible to hypothesise why T1DE may develop in some individuals, particularly those who may struggle with accepting T1DM into identity, and the role T1DM plays within T1DE. At the time the following SLR was developed (February 2024) there were no existing reviews on this topic.

# CHAPTER 2: SYSTEMATIC LITERATURE REVIEW

## 2.1. Overview of chapter

This chapter presents the SLR conducted to address gaps in T1DM literature alluded to in Chapter 1. It explores the research question: What does qualitative evidence reveal about how a T1DM diagnosis impacts identity and how individuals respond? The chapter outlines the SLR methodology, presents the thematic synthesis results, and concludes with discussions of its strengths, limitations, clinical implications, and future research recommendations.

## 2.2. Method

### *2.2.1. Question development*

Table 2 describes how the SLR question was developed using the PICo question format, which is used to aid the development of questions for qualitative literature reviews (Stern et al., 2014).

**Table 2**

*PICo format for question development*

| PICo Acronym | Development of question. |
|---|---|
| **P:** Population | Any individuals with a diagnosis of T1DM. |
| **I:** Phenomena of interest | Impact of T1DM diagnosis on identity |
| **Co:** Context | Experiencing an impact on identity as a result of T1DM diagnosis. |

### *2.2.2. Scoping exercise*

Initial scoping exercises were conducted using a range of databases including PROSPERO and The Cochrane Library to identify what existing literature was available on T1DM and identity and assess whether there was a sufficient amount of evidence with which

to conduct a SLR. These scoping exercises revealed an absence of reviews regarding how T1DM may impact identity, providing further rationale for the current SLR.

### *2.2.3. Search strategy*

The PubMed and CINAHL databases were searched. These two databases were chosen because they include both medical and life science journals. It was found that the inclusion of both these types of journals better captured the research required for this SLR. This is opposed to databases such as PsycINFO which only capture social science journals and yielded few results. This could be due to this SLR exploring identity, a topic typically associated with the social sciences, but within the field of T1DM, which has generally been viewed and researched purely as a medical condition. All results found on PsycINFO were captured in the searches of PubMed and CINAHL.

The search terms used were shaped by the SPIDER (Sample, Phenomena of Interest, Design, Evaluation, Research Type) search strategy tool (Cooke et al., 2012). The search terms were amended and broadened to obtain as many relevant studies as possible. Table 3 provides full details of the search terms used.

**Table 3**

*Search terms using SPIDER tool*

| Acronym | Searches |
|---|---|
| **Sample** | **type 1 diabetes OR type 1 diabetes mellitus** |
| | AND |
| **Phenomena of Interest** | identity OR illness identity OR self-concept |
| | AND |
| **Design** | interview* OR focus group OR case study |
| | AND |
| **Evaluation** | view OR experience OR feel OR coping OR psycholog* OR adjustment OR integration OR relationship |
| | AND |
| **Research type** | Qualitative |

**A Reflection**

*In choosing these search terms, my clinical background and experience working with individuals with T1DE informed my decisions. I prioritised terms such as identity*, *illness identity, and self-concept because my clinical experience suggested that chronic conditions like type 1 diabetes often intersect strongly with how people perceive themselves. Including terms like view*, *experience*, *feel*, *coping*, *psychology*, *adjustment*, *integration,* and *relationship reflects my belief, shaped by clinical practice, that understanding the psychological and social dimensions of living with T1D is central to capturing participants' lived experiences. During my initial scoping, I noticed that many studies reported findings related to identity even when they did not explicitly set out to explore it. This observation shaped my approach to the SLR, prompting me to include broader search terms to capture these implicit discussions of identity. My focus on qualitative designs*

*(interview, focus group, case study) aligns with this orientation, privileging rich, subjective accounts over purely quantitative measures. I acknowledge, however, that these choices reflect my own biases: they foreground certain aspects of experience, such as identity and coping, and may have excluded research emphasising other relevant dimensions. Recognising this reflexively allows me to interpret the review's findings with awareness of the perspectives I have highlighted and those that may be underrepresented.*

### *2.2.4. Eligibility criteria*

Table 4 shows the full inclusion and exclusion criteria, with justification, for the reviewed studies using the SPIDER tool.

**Table 4**

*Eligibility criteria used for the selection of included studies with justification*

| | Inclusion | Exclusion | Justification |
|---|---|---|---|
| **Sample** | • Any individual with T1DM.<br>• No age specification.<br>• No gender specification.<br>• No ethnicity specification.<br>• No treatment type specification. | • Individuals with a chronic condition that is not T1DM.<br>• Individuals with T2DM.<br>• Family members, carers or peers of an individual with T1DM. | • No restrictions were placed on age, gender, ethnicity, or the type of treatment being used to manage T1DM. This is because diagnosis of T1DM was the context of reality, as opposed to T1DM and additional, specific contexts such age, gender, etc.<br>• Any studies that only included a sample with a diagnosis of another chronic illness, including T2DM, were excluded. T2DM was excluded due to it differing to T1DM in its management, ability to be placed into remission and its diagnosis generally occurring later in life, which are all factors thought to impact identity differently (Diabetes UK, 2022; Winkley et al., 2020).<br>• Studies that only used family members, carers, or peers of individuals with T1DM were excluded. This is because this review was interested in the accounts and experiences of individuals with T1DM, and how the diagnosis impacts their identity. |
| **Phenomena of Interest** | • Studies that explore how T1DM impacts an individual's identity or sense of self.<br>• Studies that explore how individuals with T1DM may, or may not, integrate their diagnosis into their identity. | • Studies that do not explore, in any form, the impact T1DM has on identity or sense of self. | • The nature of identity, in what it is and how it is formed, is complex and multi-faceted. A diagnosis of a chronic illness, like T1DM, adds to this complexity. Initially the inclusion criteria only focused on research that explored how T1DM impacted identity and how it was (or was not) integrated into identity, so only terms such as |

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| | • Studies that explore how individuals feel towards or experience their T1DM.<br>• Studies that explore the impact of societal stigma of T1DM on identity or sense of self.<br>• Studies that explore participant experiences or views of treatment adherence, diabetes management and/or diabetes related self-care behaviours. | 'identity' and 'self-concept' were used. This approach limited the literature found to studies that mentioned identity explicitly and missed valuable data from participants who still had their identity impacted by their T1DM, but experienced and conveyed this using different language.<br>• It is possible that, by having eligibility criteria that only included research aiming to explicitly explore T1DM and identity, the multiple realities of individuals with T1DM, and how their identity is impacted by it would be misrepresented. By widening the criteria to research exploring and reporting on identity in more subtle ways, such as participants' experiences of and feelings towards T1DM and its treatment, more relevant and rich data was obtained to explore and answer the question of this review.<br>• Studies that explored how T1DM impacts identity or sense of self, how individuals may (or may not) integrate T1DM into their identity, how individuals feel towards or experience their T1DM or how societal stigma impacts' identity were all included.<br>• Studies that also explored diabetes management, treatment adherence or diabetes related self-care behaviours were also included. This is because of the existing literature highlighting struggles with identity/integrating T1DM into identity as a contributing factor(s) to low treatment adherence (Oris et al., 2016). |

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| | | | • Studies that do not explore or report on the impact T1DM has on identity were excluded. |
| **Design** | • Interviews<br>• Focus groups<br>• Case studies | • Questionnaire (including therapeutic outcome measures).<br>• Survey.<br>• Clinical trials. | • The review was interested in qualitative data to better understand patient experiences, views, and feelings which is typically captured in qualitative studies. Studies that used any type of interview, focus groups or case studies were included. This included qualitative elements of mixed method designs.<br>• Quantitative studies were excluded. It has been argued that an issue of quantitative research, in any capacity, is that it takes numerical data, from one point in time and in one context, and makes assumptions of it representing an 'objective' reality for all, which is a stance that aligns with positivism (Park et al., 2020). This therefore does not align with the CR stance of this research. |
| **Evaluation** | • Studies that report how individuals view, experience or feel towards their T1DM in relation to their identity.<br>• Studies that report on how individuals have coped (or not) with having T1DM as part of their identity.<br>• Studies that report on how individuals have or have not adjusted their identities based on their T1DM. | • Studies that do not report any findings relating to identity. | • Eligible studies are any that reported, to any extent, how T1DM impacted identity of individuals with T1DM. This reporting could be in the form of participant experiences, feelings, views, ways of coping, adjustments, relationships with others, themselves or their T1DM, or how they have (or have not) integrated T1DM into their identity.<br>• Any study that did not report any findings related to identity and T1DM were excluded. |

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| | • Studies that report on how individuals have or have not integrated their T1DM into their identity.<br>• Studies that report on how a diagnosis of T1DM impact psychological wellbeing in relation to identity.<br>• Studies that report on how T1DM impact an individual's relationship with the self or others, in the context of identity.<br>• Studies that report on the role of wider social stigma in how T1DM impacts identity.<br>• Studies that report on identity in relation to treatment adherence, diabetes management and/or diabetes self-care. | | |
| **Research.** | • Qualitative.<br>• Mixed method. | • Quantitative. | • The current SLR wants to explore how different individuals feel their T1DM has impacted their identity. This topic encapsulates emotion and experiences, which alongside the concept of identity, are not static phenomena that can be captured in one point in time or generalised as representing the reality of this topic, as a quantitative and/or positivist stance would imply (Parker & Bavel, 2014; Junjie & Yingxin, 2022). Instead, they are dynamic concepts that exist in different realities for each individual, but can still |

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| | be captured by qualitative research and have theories generated to offer an explanation for these experiences which this review will attempt to capture using a CR stance (Parker & Bravel, 2014). |

### *2.2.5. Quality appraisal and appraisal of confidence in the evidence*

To assess the level of confidence of the review findings, the GRADE-CERQual (CERQual) (Lewin et al., 2018) was used. The CERQual aims to assess and describe the level of confidence that can be placed in a review finding. It does this through assessing: (1) Methodological limitations, (2) Coherence, (3) Adequacy and (4) Relevance.

As recommended by Munthe-Kaas et al. (2018), quality appraisal and assessment of methodological limitations of the included studies will be conducted using The Critical Appraisal Skills Programme (CASP) checklist (Critical Appraisal Skills Programme, 2024). The CASP asks ten questions relating to quality of qualitative studies answered as 'yes' (1 point), 'no' (0 points) or 'cannot tell'(0 points). Hanks et al. (2020) argued for a scoring system using the CASP; 0-3: poor quality, 4-6: fair quality, 7-10: good quality. Study quality was assessed and scored and is presented in Table 6. The findings of this assessment contributed to the overall confidence rating given by the CERQual.

Coherence was assessed as the fit between the original data and the themes derived from this review's findings (Colvin et al., 2018). This was done by considering original text segments that subthemes and themes were built upon, alongside any contradictory data or alternative explanations. Adequacy was assessed by reviewing whether the information provided by a study was detailed enough to allow the reviewer to interpret the meaning and context of what was being researched, and the quantity of studies that made up a subtheme (Glenton et al., 2018). Relevance of each study was assessed by reviewing the fit between the context of a primary study and the review question by reviewing the population, setting, and phenomena of interest (Noyes et al., 2018).

Each CERQual domain (methodological limitations, coherence, adequacy and relevance) was given a rating of concern: none, minor, moderate, or serious (Lewin et al., 2018). Once this was complete for each component, the sub-theme was rated with an overall

confidence level of either; high, moderate, low, or very low (Lewin et al., 2018). The approach to this confidence rating is to assume that each finding is of high confidence and should be rated down if there is concern in one or more of the CERQual components (Lewin et al., 2018). The quality appraisal of this SLR, alongside the appraisal of confidence, was conducted by the primary researcher.

Abductive reasoning was used throughout this literature review. This means empirical literature was gathered and read prior to the start of this review, naturally shaping the review questions and assumptions of what the primary researcher expected to find in the results and forming biases in regard to how the data was made sense of. The CERQual was therefore incorporated into the critical appraisal of this review to reduce the impact of assumptions and biases.

#### *2.2.6. Data synthesis*

The data collected in this review was synthesised using thematic synthesis of the results section of each included paper. Thematic synthesis has three stages: coding of the findings of the primary studies, organising codes into descriptive themes, and developing analytic themes (Thomas & Harden, 2008).

Thematic synthesis was chosen as it has been found to be a method that allows systematic reviews to identify key themes and messages from a qualitative body of research, subsequently leading to a greater understanding of an area (Nicholson et al., 2016; Seers, 2012), which is in line with this review's question and aim.

### 2.3. Results

#### *2.3.1. Study Selection*

The full screening process is detailed in Figure 1. The screening process was conducted only by the primary researcher. No additional reviewers or automation tools were used. Database searches identified 140 studies matching the search criteria. After removing

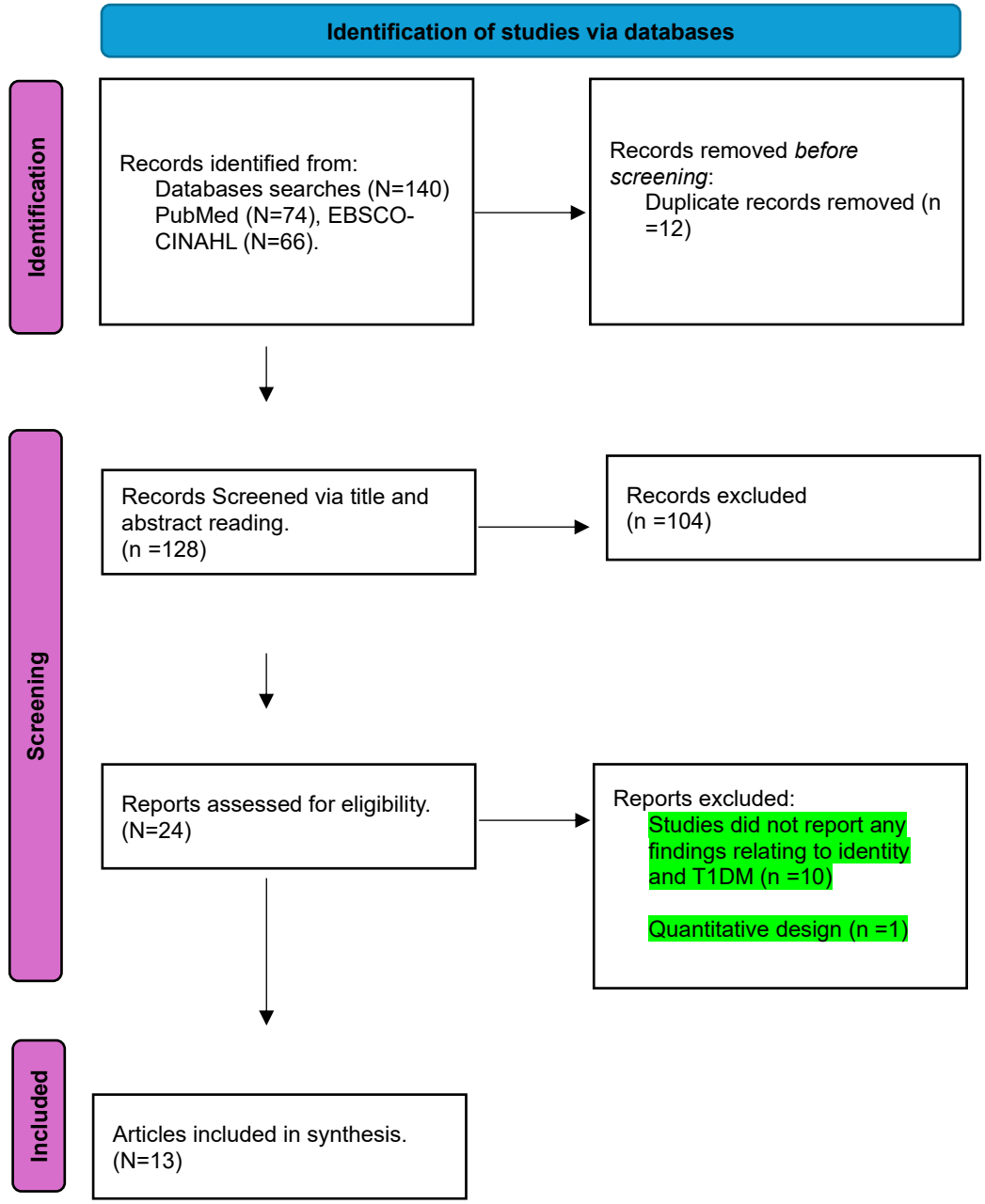
duplicate results using EndNote, and an initial round of manually screening study titles and abstracts against the eligibility criteria, 24 studies were read in full to assess for eligibility.

Of the 24 studies identified, one was excluded as it was a quantitative design and 10 were excluded as they did not report any findings relating to identity and T1DM.

Following this screening process, 13 studies were deemed eligible for inclusion in this review.

**Figure 1**

*PRISMA diagram demonstrating the process and outcome of study selection (Page et al., 2020)*




### *2.3.2. Study characteristics*

Table 5 summarises characteristics of all 13 studies. Data extraction was conducted by the primary research using a pre-piloted extraction form based on the Cochrane's guidance

for extracting qualitative data (Noyes & Lewin, 2011). Extracted information included study characteristics (author, year, country), participant details (age, sex, duration of T1DM), study aims, methods, and findings relevant to illness identity and T1DM. Where specific information was not reported in the study and clarification from authors was not obtained, this was recorded as 'not reported' in Table 5.

In terms of method, 11 studies used interviews, one used a mixture of focus groups and interviews (Sanders et al., 2019), and one was a case study (Tilden et al., 2005). All studies were conducted in outpatient settings with the exception of Kim (2022) who did not specify setting. Four studies were conducted in the United Kingdom, four in the United States of America, two in Italy, one in Iran, one in Canada, and one in Korea.

Eleven studies only used participants with a diagnosis of T1DM. Maietta (2021) included participants with T2DM. Abdoli et al. (2013) included family members of someone with T1DM and individuals without T1DM. Only the results of these two studies that related to the participants with T1DM were analysed for this review.

There were more female participants (N=138) than male (N=114). Sanders et al. (2019) only reported the gender of participants who were interviewed in their study, the gender of 17 participants were therefore not reported.

Eight studies did not report data on the ethnicity of participants. Of the five studies that did report ethnicity, the majority of the participants were White. The exception to this was Commissariat et al. (2016) where 53% of participants were Hispanic and 18% were Black.

This review defines individuals over the age of 18 as adults, those over the age of 13 as adolescents, and those under 13 as children. Six studies recruited adults as their sample (Abdoli et al., 2013; Abdoli et al., 2017; Fioretti & Mugnaini, 2022; Goldman & Maclean.,

1998; Maietta, 2021; Tilden et al., 2005). Five studies used both adolescents and adults (Dovey-Pearce et al., 2007; Chalmers et al., 2022; Commissariat et al., 2016; Kim, 2022; Sanders et al., 2019). One study sampled only adolescents (Williams, 2007). Montali et al. (2022) recruited children, adolescents, and adults into their sample. The participants across all included studies were relatively young, with the reported mean or average age of ten studies being under 30.

A range of sample sizes were recruited across the studies included in the SLR. Hennink and Kaiser (2022) argued that, for qualitative research using interviews a minimum of five interviews are needed for saturation, which all of the studies exceeded. Therefore, it could be argued that these 12 studies using more than 5 interviews were of a sufficient quality. It is important to note, however, that the concept of saturation in qualitative research is complex and has been criticised. It has been argued that a blanket numerical figure stating an adequate sample size is a positivist stance that cannot be applied to qualitative research because of the uniqueness of each study (Islam & Aldaihani, 2022). Adequacy of sample size and data in qualitative research has been argued to be more subjective and based on the researcher's judgement of whether the reality of a topic has been adequately explored with the number of participants acquired (Islam & Aldaihani, 2022). This researcher subjectivity makes commenting on whether the sample sizes of these primary studies were adequate more difficult.

Tilden et al. (2015) used a case study design of a 26-year-old female. The limitations of a case study design have been considered, especially around how the results can be applied to the wider population when they are based on one person's experience (Luck et al., 2006; Meyer, 2001; Tight, 2010). Tilden et al. (2025), however, justified and explained their use of the case study design, and the subsequent decisions made throughout the research, as well as justifying why they chose one particular case over others, meaning their use of a case study

can be considered a credible contribution to the qualitative field (Hallberg, 2013; Morse, 2011). In addition, Thomas (2011) posed that the argument of generalisability in single case studies is redundant as the point of this research is not to be generalised but instead to contribute to the understanding of phenomena.

**Table 5**

*Summary of study characteristics*

| Author(s) | Context and sample: include where the studies were conducted | Phenomena of interest | Study design and method | Findings |
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| **Sanders et al. (2019)** | Context of a structured outpatient education programme designed to facilitate shared learning and self-management among adolescents and young adults with T1DM.<br><br>Conducted in the UK<br><br>Adolescents and adults with type 1 | To explore individual and collective experiences of young adults and adolescents towards managing their diabetes and the key obstacles to self-management as they transition into adulthood. | Qualitative study using focus groups and interviews.<br><br>Seven focus groups conducted at the end of the education group.<br><br>Interviews were conducted after the focus groups. | Participants had the perception that T1DM made them different from others who did not have T1DM. This feeling of difference was an obstacle in accepting T1DM into identity when moving into adulthood as it was perceived that it would stop them being 'normal'.<br><br>Participants felt that their T1DM was not understood by wider circles in their lives and by wider society. They had experienced being blamed for having T1DM which led them to want to isolate and conceal their T1DM in order to socialise with others and be able to do activities they wished to do.<br><br>T1DM caused disruption to participants' sense of self, this contributed to concealing their T1DM in public setting due to wishing to appear 'healthy and normal'. |

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| | diabetes. Aged 16-24 years<br><br>Average age=18 years<br><br>N=32 for focus groups.<br>N=15 for interviews<br><br>Gender of interviews:<br>-N=8 male<br>-N=7 females<br><br>Ethnicity: Not reported (NR)<br><br>Average length of time since T1DM=9 years<br><br>Treatment type: NR | | | |
| **Montali et al. (2022)** | Participants were recruited from an association which support young people with T1DM | To explore the main barriers and facilitators of self-care in individuals with T1DM. | Qualitative study using semi-structured interviews including questions about experiences of T1DM, management of T1DM, the support of the healthcare system, use of technology and relationships with family and friends. | A barrier to self-care was the stigma surrounding T1DM (individuals being lazy, overweight etc.). The stigma led to concealment of T1DM in public settings and wanting to reject from identity. |

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| | who are outpatients.<br><br>The study was conducted in Italy<br><br>Children and adolescents (aged 10-17) and young adults (age 18-30) with a diagnosis of T1DM.<br><br>Age:<br>N=5: over 18 years old,<br>N=17: between 19 and 30 years old.<br><br>Mean age=21.5 years<br><br>N=22<br><br>Gender:<br>-N=7 male<br>-N=15 female | Social support from family and peers, and learning about their T1DM and the skills to manage it in ways that adapted to their life were facilitators for self-care. This is because participants felt equipped and supported in managing their diabetes and this allowed participants to integrate their T1DM into their lives as opposed to feeling that they had to replace their wants with T1DM management. By doing this, their diabetes began to feel normalised, and they no longer felt defined by it, but instead their diabetes became one part of their identity. |

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| | Ethnicity: NR<br><br>Mean Time since diagnosis: 13 years. Range 2-24 years.<br><br>Treatment type: NR | | | |
| **Commissariat et al. (2016)** | Participants were outpatients recruited from a larger mixed-methods study where they were contacted directly from their physician or nurse.<br><br>Study was conducted in the USA<br><br>Participants were aged 13-20. All were | To explore how T1DM affects self-concept, social interaction and self-management in adolescents and young people with T1DM. | Qualitative study using interviews. Interviews were 40 minutes long and were semi-structured. Five broad open-ended questions were designed to prompt a larger discussion about their feelings about diabetes, their treatment regimen, diabetes related effects on peer relationships and how they define their experience of living with diabetes:<br><br>*-Tell me about what it has been like for you to live with diabetes.*<br>*-How do you think you have changed from before you got diabetes until now?*<br>*-How do you think your diabetes has affected the way other people view/think of you?*<br>*-How do you think of yourself compared to your friends or classmates?* | Some participants had incorporated T1DM into their identity and saw management as an active and necessary part of their life. These individuals did not allow negative responses from peers stop them from managing their diabetes. They took direct and active roles and shared their diabetes status openly. These participants saw their diabetes and its management as being integrated into their life rather than seeing it as conflicting with what they would like to do. These people described themselves as being more mature and responsible compared to before their diagnosis and compared to their peers.<br><br>Some participants did not integrate diabetes into their identity and described it as something external to them. These participants struggled to accept aspects of diabetes and struggled to follow |

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| | required to have had T1DM for at least one year<br><br>Mean age 16.5+/-1.89 years<br><br>N=40<br><br>Gender:<br>-N=23 male<br>-N=17 female<br><br>Ethnicity:<br>53% Hispanic<br>18% Black<br><br>Time since diagnosis: NR<br><br>Treatment type: NR | | -*How do you think the way you see yourself as someone living with type 1 diabetes influenced the way you take care of your diabetes?* | management plans. These participants described their dislike and mismanagement of diabetes as a desire to reject it from their identity, whilst acknowledging the health impacts of this. They also tended to hide their diabetes from others as they did not want an identity associated with T1DM.<br><br>Majority of participants had been made to feel different from peers and abnormal. |
| **Maietta, (2021)** | Participants were recruited via social networking, diabetes support groups, online forums and | To examine how illness management can be part of the identity verification process in individuals with diabetes. | Qualitative study using interviews.<br><br>In-depth, semi-structured and open-ended interviews to allow participants with T1DM or T2DM to explore the relationship between diabetes and their identities. | A main theme from this study was participants experiencing their T1DM as preventing their ideal identity from being verified. Hypoglycaemic and hyperglycaemic episodes were commonly discussed as a reason for disrupting identity verification. This is because they often require a quick and deliberate |

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| | advocacy organisations. Used outpatient sample.<br><br>Study was conducted in the USA<br><br>Adults over the age of 18<br><br>Mean age: 45.6 years<br><br>Diagnosis of either T1DM or T2DM.<br><br>N=11 with T1DM<br><br>Gender<br>-N=7 male<br>-N=4 female<br><br>Ethnicity:<br>Black=1<br>Hispanic=2 | Interview guide:<br>-The potential for illness to interfere with identity performances<br>-The experience and impact of diagnosis for the individual<br>-Biographical changes brought on by living with and managing illness<br>-Social aspects of living with illness like support, treatment and expectations from others.<br>-Critical illness-related situations and the social contexts in which they occur<br>-How living with illness affects participants perceptions of their futures. | management response which take people away from their task.<br><br>The language frequently used by participants discussed what they felt their identity 'ought to be' which implied that T1DM can create discrepancy between how their identity comes across and how they feel it should or would like it to be.<br><br>Some individuals felt able to meet the expectations of a social identity, but it was the attitude and language of others who did not think they can meet that identity that prevented them from trying due to receiving negative feedback (e.g. being incapable).<br><br>Those with T1DM spoke about wanting to conceal parts of their condition in spaces where revealing having diabetes violated their social identity, with some participants referring to their T1DM as a 'weakness' or 'vulnerability'.<br><br>Other participants had successfully integrated diabetes management into their identity, this was achieved in various ways. Some reported that acknowledging they had T1DM and that it needed to be managed, taught them that T1DM does not interfere with their identity, but instead they were better able to perform identity |

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| | Indian=1<br>White=7<br><br>Mean time since diagnosis: 28.7 years<br><br>Treatment type: NR | | | congruent activities when theirT1DM is managed. |
| **Abdoli et al. (2013)** | Recruited from Isfahan Endocrinology Research Centre. Outpatient sample.<br><br>Research conducted in Iran<br><br>Adults over the age of 18<br><br>Age range: 16-36 years<br><br>N=26 | Explored diabetes related stigma with people living with T1DM and from those without T1DM who are from Isfahan. | Interviews were used.<br><br>Participants were asked:<br>-*What do people without diabetes think about a person with diabetes?* | Participants had experienced receiving negative social messages about those with T1DM from a young age and had been labelled as 'sick' and 'unable' by their families and wider society. They were viewed as burdens on their families and society. Participants shared that experience of this stigma impacted their identity in terms of how they viewed themselves and their capabilities. |

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| | N=8 with T1DM<br>N=5 with family members of someone with T1D.<br>N=13 people without T1DM<br><br>Gender of T1DM participants:<br>-N=1 male<br>-N=7 female<br><br>Ethnicity: NR<br><br>Range of time since diagnosis: 3-16 years.<br><br>Treatment type: NR | | | |
| **Chalmers et al. (2022)** | They were recruited from a children's | Study aimed to explore adolescent experiences and perspectives on | Use of semi-structured interview.<br><br>Interviews: | The majority of participants articulated how social media presented an opportunity for them to develop their identity and portray themselves as |

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| | hospital as outpatients.<br><br>Study conducted in the USA<br><br>Adolescents (age 13-18) with T1DM<br><br>Mean Age: 14.9 years<br><br>N=35<br><br>Gender<br>-51.4% male<br>-48.6% female<br><br>Ethnicity:<br>-60% White<br>-31.4% Non-white, non-Hispanic<br>-8.6% prefer not to answer<br><br>Time since diagnosis: NR | discussing their T1DM on social media. | -Explored experiences of discussing T1DM on social media with a focus on participant reason for using social media to discuss T1DM<br>-Factors that informed type 1 diabetes social media use<br>-Explored current and past diabetes related social media use and the responses they have received<br>-Explored with those who have not shared their diabetes online their rationale and thoughts about how others would hypothetically react | an individual with T1DM. This allowed them to try and incorporate diabetes into their identity.<br><br>Some shared that disclosing diabetes online shaped their offline social identity and interactions. They shared that misinformation about diabetes has shaped their social identity with peers 'looking at them differently' and making assumptions about their diabetes, mainly that they were to blame for their diabetes.<br><br>Some avoided social media due to this stigma and that they wanted a space where they could focus on other aspects of their identity, to avoid only being defined by their diabetes.<br><br>Others used social media to educate about the stigma and as a tool to allow them to become more comfortable in their identity.<br><br>Since social media is now a space for publicly articulating identity and receiving peer feedback, it highlights how identity development on social media contributes to these social and developmental processes.<br><br>The fact that participants chose to use social media to tell a range of stories about how diabetes fit into their identity whilst others omitted from their online spaces to emphasise |

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| | Treatment type: NR | | | other aspects of their identity, highlights how social media identity formation is significant. |
| **Tilden et al. (2005)** | Case study of an outpatient receiving psychological intervention for poor treatment adherence for their T1DM.<br><br>Study conducted in the UK<br><br>Age: 26<br><br>Gender: Female<br><br>Ethnicity: White<br><br>Time since diagnosis: 16 years | The aim of this study was to extract major themes that emerged during a period of cognitive analytic therapy with an adult with T1DM who had ongoing, poor adherence to diabetes management. | Qualitative case-study. Transcripts from nine sessions of cognitive analytic therapy were analysed. | The authors of this study curated the theme of this participant rejecting their T1DM from their identity. Their participant reported feeling their father only gave her attention because of her diabetes.<br><br>This participant viewed the constant attention on her diabetes as an intrusion by others and a rejection of herself as a whole. There was a common theme across this study of the participant wanting her whole self to be recognised and valued, not just her diabetes.<br><br>In addition, the participant reported not wanting to accept the social identity of being diabetic as this would threaten her personal identity and potential. |

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| | Treatment type: NR | | | |
| **Dovey-Pearce et al. (2007)** | Participants were part of a wider study being conducted. This study was the first stage. Participants were recruited from a specialised outpatient diabetes service via their GPs.<br><br>Study conducted in the UK<br><br>Age range: 16-25<br>Mean age: 19.9 years<br><br>N=19 | The study used reflective accounts of adolescents and young adults with T1DM with the aim of gaining a conceptual understanding of the impact of diabetes upon adolescent and young adult development. | Qualitative study using semi-structured interviews to explore participant account of developmental impact of diabetes and their experience of using diabetes services which was reported in this study. | A shift in personal identity occurred for participants at the point of being diagnosed with T1DM, they had to learn about T1DM and now had to engage in new behaviours to maintain self-care.<br><br>Participants described ongoing social experiences that made them feel different from others and to their peers which seemed to reinforce the initial impact the diagnosis had upon their sense of self.<br><br>Participants described the impact of T1DM on their personal identity. There was a common experience of being labelled by others as being different, abnormal, and unwell. Participants also found that social situations they have been in have reinforced this feeling of being different. These experiences led some participants to feel as though they now had to redefine themselves in relation to others and their future because of their diabetes. |

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| | -N=8 male<br>-N=11 female<br><br>Ethnicity: NR<br><br>Time since diagnosis: NR<br><br>Treatment type: NR | | | |
| **Abdoli et al. (2017)** | Participants were recruited via public advertisement in healthcare and university facilities and social media. Outpatient sample was used.<br><br>Study conducted in the USA<br><br>Age range: 18-30 years old | The purpose was to explore and describe the perceptions and experiences of young adults with T1DM living in the USA state of Tennessee. | Qualitative study using interviews which began with open-ended questions about participants' lives with diabetes and questions continued based on their responses. | Participants described a type of rebellion against diabetes management when being faced with the possibility of living away from parents. Their focus was more on having fun then managing their diabetes as they found their diabetes was difficult to accept and found it unfair that they had to accept and manage it.<br><br>Participants spoke of being aware that they needed to integrate their diabetes into their identity as opposed to viewing it as an external responsibility but struggled with actioning this.<br><br>Participants spoke of the wider social stigma that surrounds T1DM which made it hard for them to share their diagnosis with others and accept it as part of themselves. Participants shared that others viewed their T1DM as being 'self-inflicted' 'contagious' or that they were a 'drunk or drug abuser'. |

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| | N=9<br><br>Gender<br><br>-N=3 male<br>-N=6 female<br><br>Ethnicity: NR<br><br>Time since diagnosis: NR<br><br>Treatment type: NR | | | Some mentioned that their T1DM makes them viewed to be different from others, and others view them as disabled rather than as a whole person.<br><br>Some participants spoke of how they view T1DM as part of who they are and that they have integrated it into their identity. One way they did this was focus on the positive aspects of having T1DM and began to view it as something that changed their identity and life for the better.<br><br>Participants, did however, mention the difficulties of living with T1DM such as the burden, defining who they were as a person, and fear of complications. |
| **Fioretti & Mugnaini, (2022)** | All participants were members of an Italian diabetes association for young adults with diabetes. Outpatient sample. | The purpose of the study was to investigate how emerging adults with T1DM manage this developmental phase, considering that the condition can cause them difficulties, or it may create a tool | Qualitative design via semi-structured interviews.<br><br>The first part of the interview was to collect social and personal data of gender, age, age at the time of diagnosis, clinical condition, marital status, profession and residence.<br><br>The second part of the interview consisted of three main questions:<br>-*What is the participants' story of their* | The construction of identity in this study seemed to be formed by two different needs: the desire to be recognised as a person and not a sick person and diabetes as an accelerator of a process of identity development and personal growth.<br><br>Very few participants expressed a desire of having an identity of a 'diabetic person', but instead wanted to be recognised by others as a person not defined by their condition. This was linked to some participants not wanting to make |

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| | Study was conducted in Italy<br><br>N=30 adults aged between 18 and 34 with T1DM<br><br>Gender<br>-N=11 male<br>-N=19 female<br><br>Ethnicity: NR<br><br>Time since diagnosis: NR<br><br>Treatment type: NR | for resilience and growth. | *illness?*<br>*-What does living with T1DM mean to them?*<br>*-Has T1DM taught you about anything or contributed to your personal growth?* | their condition visible due to the way this may impact how others see them.<br><br>Some did express how diabetes is an empowering tool for them for personal growth and identity development. Themes of how T1DM has facilitated this included: individuals seeing themselves as resilient, taking on greater responsibility and maturity, becoming more empathetic and wanting to help others and being more motivated to look after themselves.<br><br>Some participants reported having no concerns about their future and were able to plan their lives regardless of their T1DM and for some it was a motivation to undertake specific university or work careers. However, others feared that the management of their diabetes would interfere with them doing what they wanted to do due to the demanding nature of keeping up with its management or it interfering with their capabilities. |
| **Kim, (2022)** | Participants were recruited from a hospital. Not reported if outpatient or | The purpose of this study was to use grounded theory to understand what meaning participants with T1DM give to their | Qualitative study via interviews that used open-ended and semi-structured questions<br><br>-Interviews began with general questions such as '*when and how did you get diagnosed with T1D?*' and included | Many participants felt that themselves and their lives were heavily constrained by their T1DM.<br><br>Some participants described feeling that being diagnosed with T1DM was them being banished and isolated from their original selves who had health. |

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| | inpatient sample.<br><br>Study was conducted in Korea<br><br>Participants were aged 13-19 and must have had T1DM for more than 1 year<br><br>Age:<br>-16.7% were aged 13-15 years old<br>-50% were aged 15-17 years old<br>-33.3% were aged 17-20 years old<br><br>N=12 | experience of the illness and the social context that influences these experiences. | specific questions such as '*tell me about what you experienced or felt while living with T1D'* | Participants described that a diabetic identity made them different from peers and limited their lives and functioning.<br><br>Participants shared being surrounded by stigma which was sometimes hidden in the form of sympathy and caring. All expressed being blamed by others for their T1DM.<br><br>A theme emerged of participants wanting to run away from their diabetes. Part of this was avoiding and denying external systems that surround the self. For example, throwing away food that parents gave them to help regulate their blood sugar. Running away also included withdrawing from diabetic needs in fear of a negative reaction from others.<br><br>A way participants moved towards acceptance of diabetes is communicating with external systems about their diabetes, through things like seeking solutions, development of diabetes management skills and accepting help. A key solution for individuals was no longer allowing diabetes to overcome their identity and be perceived by themselves and others as a fault.<br><br>A key process to accepting diabetes into the self, included participants redefining their perspective |

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| | Gender<br>-58.3% female<br>-41.7% male<br><br>Ethnicity: NR<br><br>Time since diagnosis:<br>-NR<br><br>Treatment type: All used insulin injections. | | | of what diabetes is which replaced previously installed knowledge of what they were told about diabetes. In addition, the process of accepting diabetes is acknowledging that they cannot avoid it, and this perception was not defeatist or passive, but actually an approval of the self. |
| **Williams, (1999)** | Recruited directly from diabetes nurses working in four hospitals across south-west London, advertisement in a magazine, via their GP or through snowballing technique. | The paper explored how gender and adolescent age interact to influence how young people live with diabetes. | Qualitative study using flexible semi-structured interviews which were made up of a series of prompts relating to topics such as treatment, stigma and gender. | Gender had an impact on the extent to which participants had incorporated their T1DM into their identity. All females had incorporated it, whereas 9/10 males managed their diabetes by making it a small part of their lives. They did this through hiding their diabetes due to concerns that it would violate their masculine image.<br><br>Males were more likely to outsource the responsibility of diabetes management to their parents, whereas females had taken on the responsibility of their own care.<br><br>Some male participants avoided their diabetes and its management as much as possible. |

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| | Outpatient sample.<br><br>Study conducted in the UK<br><br>Aged between 15-18 years<br><br>N=20<br><br>Gender<br>-N=10 male<br>-N=10 female<br><br>Ethnicity:<br>75% white<br>25% ethnic minority<br><br>Time since diagnosis: At least one year<br><br>Treatment type: NR | | | Some males did share adhering to their treatment to fight against their diabetes, so it does not impact their lives, rather than from a place of acceptance. |
| **Goldman and Maclean, (1998 )** | Qualitative study using retrospective data in the form of | To explore the impact of type 1 diabetes on someone's identity. This exploration | Re-analysis of a previous qualitative study. Original study used semi-structured interviews where participants were encouraged to discuss issues with personal experiences of diabetes. | The authors analysed a theme which detailed the confrontation between participant identity and their diagnosis of T1DM. |

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| | interviews from a previous study with individuals with T1DM. Participants were originally recruited via adverts in a newspaper and radio and outpatient diabetes education programmes.<br><br>Study conducted in Canada<br><br>Age Range: 20-76 years<br><br>N=30<br><br>Gender:<br>-N=13 male<br>-N=17 female | was an extension of a previous study where narratives around type 1 diabetes were collected during interviews. The authors of the current study re-analysed this data using narrative analysis. | Interviews were re-analysed in this paper using narrative analysis.<br>Stories were constructed around central identity issues. | All participants, at the time of being diagnosed, understood the significance of diabetes and the demands of it, and it made them consider their past identities and re-consider future expectations of themselves. All experienced a disruption and challenge to their identity when diagnosed as their diagnosis meant alterations in their perception of their identity and a drastic change in their daily behaviours. These challenges to identity were experienced in different ways and different aspects of the self were threatened depending on the individual's personal and social history.<br><br>The authors shared stories of different participants on how they felt their identity had been threatened by their diagnosis of T1DM, for example, one participant previously saw themselves as strong and healthy and their diagnosis had dismantled that.<br><br>Diabetes also seemed to threaten participants' views of their future self and threatened their social identity.<br><br>The authors also discussed the role of acceptance/rejection of T1DM in identity in participants managing or not managing their diabetes.<br><br>The demanding nature of diabetes led some participants to redefine their identity to |

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| | Ethnicity: NR<br><br>Time since diagnosis range: 1-37 years<br><br>Treatment type: NR | incorporate their chronic illness. The recognition of diabetes as a serious and real condition that imposes limitations and requires adjustments led to an active process of change for some participants in regard to their relationship with diabetes and this facilitated acceptance. These participants had good management of their diabetes.<br><br>Other participants struggled to find a way to accept and incorporate their diabetes into their identity and therefore had ongoing struggles with managing their diabetes.<br><br>Some participants personalised their diabetes and saw it as part of themselves, whereas others saw it as an external and separate thing which generally created more resentment towards diabetes. |

### *2.3.3. Quality appraisal and appraisal of confidence in results*

Table 6 shows the breakdown of the CASP tool (Critical Appraisal Skills Programme, 2024) for each included study. An example of how the CASP tool was used to score one paper of this SLR can be seen in Appendix F. A full qualitative summary of the findings relating to the CASP can be found in Appendix G.

**Table 6**

*Critical appraisal of the included studies using the CASP tool*

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **Disruptive illness contexts and liminality in the accounts of young people with type 1 diabetes**<br><br>**Sanders et al. (2019)** | Yes. | Yes. | Yes. | Yes. | Yes. | Yes. | Cannot tell. | Yes. | Yes. | Yes.<br>The research highlighted the social pressures of living with T1DM and how individuals have felt they have had to struggle against stigma that surrounds T1DM. The authors linked these pressures to some concealing their diagnosis and refusing to manage it in public so not to adopt the social identity of T1DM. These findings had implications for clinical services, for healthcare professionals in needing to be aware of the social pressures around T1DM that contribute to an individual's desire to maintain a 'normal self' in public resulting in poorer management of their diabetes. The findings suggested for healthcare professionals to offer advice on how young people can navigate the stigma of T1DM and how to manage their condition in social situations. | 9/10<br>Good |

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **Barriers and facilitators of type 1 diabetes self-care in adolescents and young adults**<br><br>**Montali et al. (2022)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Yes. | Yes. | Yes. | Yes.<br>The findings of this study further our understanding of the barriers and facilitators to self-care for individuals with T1DM. A common barrier was social stigma of T1DM which led to concealment of the condition and rejecting it from their identity. The authors highlighted an implication of this finding was the need to de-stigmatise T1DM in public spaces such as school and work. They also found social support and learning skills facilitated self-care and helped participants to integrate T1DM into their identity, highlighting the importance of empowering individuals with T1DM with knowledge and skill development. | 9/10<br>Good |
| **Developing a personal and social identity with type 1 diabetes during adolescence: A hypothesis** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Cannot tell. | Yes. | Yes. | Yes.<br>Previous literature has highlighted the influence of peer groups on diabetes self-care behaviours. The findings of this study added to this literature by offering a different perspective by finding that how adolescents with T1DM identify themselves, has a greater | 8/10<br>Good |

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| **generative study**<br><br>**Commissariat et al. (2016)** | | | | | | | | | | influence on how they feel about their T1DM, their mental health and how well they manage their T1DM, than how their peers perceive them. A clinical implication of this research was that healthcare professionals should work with the individuals and their families to help them to incorporate T1DM into identity to benefit the individual's mental health and T1DM management. | |
| **Integrating illness management into identity verification process**<br><br>**Maietta, (2021)** | No. | Yes. | Yes. | Yes. | Yes. | No. | Cannot tell. | Yes. | Yes. | Yes<br>The study explored how T1DM and its management impacts an individual's identity. The findings highlighted that the challenges of T1DM can lead to challenges in individuals accepting it into their identity. Participants highlighted that the social performance involved in managing T1DM posed a significant challenge in them accepting it into their identity. This is because the social image of T1DM and the social consequences of publicly managing it disrupts the social image participants wanted to display. These finding highlighted that services should not just pay attention to the health consequences of not managing T1DM, but also consider the social consequences and the subsequent impact on identity for individuals. | 7/10<br>Good |

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **Exploring diabetes type 1-related stigma**<br><br>**Abdoli et al. (2013)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Yes. | Cannot tell. | Yes. | Yes.<br>The findings of this paper highlighted that there is significant social stigma surrounding those with T1DM in Isfahan. The stigma shaped the way individuals with T1DM identified themselves and were identified by others. | 8/10<br>Good |
| **Identity and adherence in a diabetes patient: transformations in psychotherapy**<br><br>**Tilden et al, (2005)** | Yes. | Yes. | Yes. | Cannot tell. | Yes. | No. | Cannot tell. | Yes. | Yes. | Yes.<br>The results of the interpretative phenomenological analysis were that the underlying experience of challenges with management was the individual rejecting the diabetic identity. This was facilitated by the individual feeling engulfed by the diabetic identity and losing themselves and thus feeling that others only cared about their diabetes and not them. The implications of this research for healthcare professionals is that the identity of individuals, and how T1DM may impact it, should be a part of the management of the condition. | 7/10<br>Good |

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **The influence of diabetes upon adolescent and young adult development: A qualitative study**<br><br>**Dovey-Pearce et al. (2007)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Cannot tell. | Yes. | Yes. | Yes.<br>Participants of this study shared the impact T1DM has had on their personal identity. They felt they had been labelled and treated as different and unwell and this led to them feeling that they needed to redefine themselves. One of the key challenges participants faced was adjusting self-concepts and their future in light of their T1DM. This research highlighted clinical implications specifically for psychologists working within NHS healthcare teams and the need to utilise their knowledge of biopsychosocial models, formulations and intervention to support patients with their T1DM and how it has impacted their concept of self. | 8/10<br>Good |
| **The complexities of "struggling to live life": The experiences of young adults with T1DM living** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Yes. | Yes. | Yes. | The findings of this study highlighted the social stigma around T1DM, and that participants felt it was due to society confusing T1DM with T2DM. For some this stigma made it hard to accept having T1DM. This research added to existing literature on T1DM and identity, in that it shared that participants who found value in | |

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| **in Appalachia Abdoli et al. (2017)** | | | | | | | | | | their diabetes were better at accepting it into their identity. The findings also highlighted the need for greater community education on what T1DM is, what causes it and how it is managed. | |
| **"It got likes, but I don't think people understood": A qualitative study of adolescent experiences discussing type 1 diabetes on social media**<br><br>**Chalmers et al. (2022)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | No. | Yes. | Yes. | Yes.<br>This study explored social media use in adolescents with T1DM and found that social media offers adolescents an avenue for identity development and identity validation from close peers and wider communities who also struggle with T1DM, meaning that social media can be used as a resource in individuals understanding and accepting T1DM into their identity. Saying this, the results also found that some participants chose to hide their diagnosis on social media as they did not wish to be subjected to the stigma that surrounds it, highlighting that wider education on T1DM to reduce the stigma is needed. | 8/10<br>Good |

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **The significance of identity in the adjustment to diabetes among insulin users**<br><br>**Goldman & Maclean, (1998)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Cannot Tell. | Yes. | Yes. | Yes.<br>This study contributed to existing literature on T1DM and identity by highlighting that it is the time of diagnosis that is a particularly difficult as participants interpret what this diagnosis means practically in terms of making behavioural adaptations and what it means for their identity. The stories of the participants found that the extent that T1DM impacts identity varies for each person, for some it will have little impact and integrating it into identity is fairly easy, whereas for others it can take years. The authors argued the challenge of a diabetes diagnosis is learning to integrate it into the existing identity. These authors contributed to literature by highlighting that integrating T1DM into identity is not a static task that is completed once and not again, but instead an ongoing and fluctuating process, that can be improved and disrupted at any time in a person's life. The findings of this study can be applied to clinical spaces as it highlights the importance of listening to each individual story and exploring how their identity has been impacted by their diagnosis. | 8/10<br>Good |

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **Living with type 1 diabetes mellitus in emerging adulthood: A qualitative study**<br><br>**Fioretti & Mugnaini, (2022)** | Yes. | Yes. | Yes. | Yes. | Yes. | Yes. | Cannot tell. | Yes. | Yes. | Yes.<br>The current study added to existing literature by focusing on the specific developmental period of emerging adulthood and the impact a diagnosis of T1DM has for individuals during this period. The authors found the positive impact T1DM can have on an individual's identity development, particularly in terms of how having T1DM, for some participants, taught them they are resilient and enabled them to grow as a person. Participants also expressed a desire to not be defined by their T1DM and be viewed as a 'sick' person, which was linked to social narratives around T1DM, which drove them to want to 'reclaim their identity' from T1DM and led some to hide their identity in social settings. | 9/10<br>Good |

| Paper title, author(s) and date | Was there a clear statement of the aims of the research? | Is a qualitative methodology appropriate? | Was the research design appropriate to address the aims of the research? | Was the recruitment strategy appropriate to the aims of the research? | Was the data collected in a way that addressed the research issue? | Has the relationship between researcher and participants been adequately considered? | Have ethical issues been taken into consideration? | Was the data analysis sufficiently rigorous? | Is there a clear statement of findings? | How valuable is the research? | Scoring |
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| **Illness experiences of adolescents with type 1 diabetes**<br><br>**Kim, (2022)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Yes. | Yes. | Yes. | Yes.<br>The study used grounded theory to understand how participants understand their T1DM and its management, and how this understanding is influenced by wider society. The author generated five processes within this theory of; feeling 'tied' and constrained by diabetes, 'overwhelmed' which included feeling banished from the self and surrounded by stigma, 'running away', 'struggling' and finally 'conciliating'. This theory could be applied to training of healthcare staff to deeper the understanding of the experience of those with T1DM. | 9/10<br>Good |
| **Gender, adolescents and the management of diabetes**<br><br>**Williams, (1999)** | Yes. | Yes. | Yes. | Yes. | Yes. | No. | Yes. | Yes. | Yes. | Yes<br>The results of this paper added to the current literature by exploring how a diagnosis of T1DM interacts specifically with gender. It found that T1DM had a gendered meaning and so its experience and impact on identity, and its assimilation into identity, differed for males and females. | 9/10<br>Good |

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| | | | The authors also highlighted how the social narratives surrounding gender and identity impacted the ways in which participants managed their diabetes. For example, males were more likely to manage their blood sugars at home in private due to the social view that illness management contradicts the masculine image. Females are more likely to conceal when they are not adhering to their treatment and experience greater blame and shame. These results imply for clinical health workers to consider gender when helping those with T1DM and adapt practice accordingly. |

The breakdown of the CERQual tool can be seen in Table 7, which also provides an overall confidence rating for each sub-theme. All of the sub-themes, with the exception of two, were rated as having a high level of confidence. High confidence was due to the majority of the primary studies that made up these sub-themes being appraised as having no concerns.

Externalising diabetes from identity and being defined by a diabetic identity were rated as having moderate confidence levels. These ratings were given due to the majority of the CERQual criteria having minor or moderate concerns. For both sub-themes, these concerns came from the authors of the primary studies not reporting or describing data that explicitly shared experiences of participants externalising their T1DM or feeling defined by it, meaning there were varying concerns about the adequacy and coherence of the primary studies in relation to these two subthemes. The reason why the confidence level was deemed moderate, not low, was firstly due to some of the primary studies, not having any concerns in the CERQual criteria. Secondly, the data that was reported by all primary studies for these sub-themes was given in such detail that it allowed for interpretation to develop them.

**Table 7**

*Appraisal of confidence of themes generated from this analysis, using the CERQual.*

| 1.1.**Stigma** | | | | | |
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| **Primary study** | **Methodological Limitations (assessed using the CASP tool)** | **Coherence** | **Adequacy** | **Relevance** | **Overall confidence rating in subtheme** |
| **Sanders et al. (2019)** | **None.** | **None.** There is a good fit between the original data of this study and this subtheme. The study provides analysis and original quotes relating to stigma faced by participants relating to T1DM. | **None**. The authors provide explicit detail regarding the type of stigma participants have faced, the contexts in which they face this stigma and the consequences of this stigma including feeling blamed and concealing their diabetes in public spaces. | **Minor.** Population-high relevance, 16–24-year-olds all with diagnosis of T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the United Kingdom in an outpatient setting.<br><br>Phenomena of interest-low relevance as the study was exploring the acceptability of a specific T1DM education programme. | **High confidence** rating as there was no concerns regarding the majority of features for these primary studies. There were two features which did have concerns, but these were minor. |
| **Abdoli et al. (2017)** | **None.** | **None**. | **None**. | **None**. | |

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| | | Original data from this study discusses the experience of and impact of social stigma on how participants experienced T1DM and their identity. | The authors provided clear and detailed data analysis with quotes from original data about the social stigma participants have faced and the impact it has had upon how they viewed their diabetes and subsequently themselves. | Population-high relevance, adults aged 18-30 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as was to use grounded theory to explain the meaning adolescents give to their experience of having T1DM. |
| **Kim, (2022)** | **None.** | **None.**<br>There is a good fit between the data found from this study. The study provided clear results, | **None.**<br>The study provided detailed results regarding the stigma participants faced | **None**.<br>Population-high relevance, adults aged 13-19 with a diagnosis of T1DM. Males and female genders included. |

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| | | alongside quotes relating to the social stigma participants faced regarding their T1DM. | regarding their T1DM and how this shaped their experience of having T1DM which allowed interpretation for how T1DM impacted identity. | Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |
| **Chalmers et al. (2022)** | **Minor.** | **None.**<br>Through data analysis the authors of this study discuss the stigma participants have faced as a result of having T1DM and how this can influence the way others identify them. | **None.**<br>The authors provide detail about what stigma surrounds T1DM and how this has impacted the way they view diabetes and themselves. | **Minor.**<br>Population-high relevance, adults aged 13-18 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-not |

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| | | | | directly relevant, the study aimed to explore the experiences of individuals who have shared their T1DM on social media. |
| **Goldman & Maclean, (1998)** | **None.** | **None.**<br>The data from this study reports how the identity of participants shifted once diagnosed with T1DM which was linked to the social stigma surrounding T1DM. | **None.**<br>The authors provide details about the role of wider social stigma attributing meaning to the diagnosis of T1DM. They described how this meaning subsequently influenced their participants perceptions of having diabetes and what this | **None.**<br>Population-high relevance, recruited male and female individuals with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of |

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| | | | meant for their identity. | individuals living with T1DM. | |
| | | | 1.2.**Attitudes of others** | | |
| **Sanders et al. (2019)** | **None.** | **None**. There is a good fit between this subtheme and the data from this study. The author provides original quotes, analysis and interpretation relating to the views and attitudes others hold towards those with T1DM. | **None**. Authors provide detailed information in their results section explicitly expressing that their participants had been made to feel different by others as a result of how others perceive individuals with T1DM. The author details the emotions participants feel as a result of this and how they cope. | **Minor.** Population-high relevance, 16–24-year-olds all with diagnosis of T1DM. Male and female genders were included.<br><br>Setting-high relevance, conducted in the United Kingdom in an outpatient setting.<br><br>Phenomena of interest-low relevance as the study was exploring the acceptability of a specific T1DM education programme. | High confidence as all of the sections, apart from one, had no concerns. The one section with concerns was minor. |

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| **Dovey-Pearce et al. (2007)** | **None.** | **None.** There is a good fit between this subtheme and the data from this study as the authors use their data analysis, alongside quotes from their participants to report on the impact of social interactions and attitudes of others towards T1DM on how participants viewed themselves and their diabetes. | **None.** The authors provide detail about both ill and well intentioned attitudes and gestures of others towards participants with T1DM and how this began to shape how participants their diabetes and their identity. | **None.** Population-high relevance, 16–25-year-olds all with diagnosis of T1DM. Male and female genders were included.<br><br>Setting-high relevance, conducted in the United Kingdom in an outpatient setting.<br><br>Phenomena of interest-high relevance as the study aimed to understand how T1DM impacts the development of young adults. |
| **Abdoli et al. (2017)** | **None.** | **None.** A good fit between this subtheme and the data from | **None**. The authors explained how participants | **None.** Population-high relevance, adults aged 18-30 with a diagnosis of |

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| | | this study. This is because the author discussed the negative attitudes of others and how this relates to societal stigma and identity format | had experienced negative attitudes and views from others in relation to their diabetes and how this has impacted their identity. | T1DM. Males and female genders included.<br><br>Setting-high relevance, outpatient service.<br><br>Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |
| **Kim, (2022)** | **None.** | **None.**<br>The data from this study linked societal stigma to how participants had been treated by others and the attitudes wider society held towards them as someone with T1DM. | **None.**<br>The authors detailed the attitudes participants have faced from others and how this shaped the way they experienced their T1DM and subsequently how they | **None**.<br>Population-high relevance, adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service. |

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| | | | viewed themselves. | Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |
| **Commissariat et al. (2016)** | **None.** | **None.**<br>The results of this study reported how the negative attitudes others held towards T1DM, shaped the experiences of their participants in terms of how they viewed their diabetes and manage it, and how they viewed themselves. | **None.**<br>The results of this study detailed how the attitudes of others (both negative and well-intentioned) impact the way participants viewed themselves in relation to their T1DM. | **None**.<br>Population-high relevance, adults aged 13-20 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as was to explore the development of adolescent personal and social identity in relation |

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| **Maietta, (2021)** | **Minor.** | **None.** The data from this study report the impact negative attitudes of others has on how participants of this study perceived themselves for having T1DM, and how their social identity was formed. | **None.** The authors detailed how wider attitudes towards illness in general and T1DM influenced identity formation in participants. Specifically, how they viewed themselves and their social identity, and these perceptions led to behaviour changes in social settings to conceal T1DM. | **None**. Population-high relevance, adults aged 28-71 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as was to explore how T1DM may challenge identity. |
| **Abdoli et al. (2013)** | **Minor.** | **None.** The data of | **None.** | **Minor.** |

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| | | this study clearly depicts the negative attitudes others hold towards T1DM and how these attitudes have an impact on the identity of the participants with T1DM. | The author details throughout the results section the negative attitudes held by others towards T1DM and how those with T1DM have experienced these negative attitudes. The authors detail using quotes how these attitudes have shaped the identity of those with T1DM, allowing us to further develop this theme. | Population-moderate relevance, the population included individuals with T1DM, but also included their family members and individuals without T1DM. Male and female participants included.<br><br>Setting-high relevance, recruited from an outpatient T1DM service.<br><br>Phenomena of interest-high relevance as it explore the diabetes-related stigma individuals with T1DM faced. |
| **Montali et al. (2022)** | **None.** | **None**. | **None**. | **None.** |

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| | | There is a good fit between the data of this study and this subtheme. In regard to social barriers to diabetes self-care the authors report how the stigma surrounding T1DM led to others viewing and treating some participants negatively. The authors also reported how these attitudes shaped the identity of their participants. | The authors detailed how wider stigma can shaped wider attitudes toward those with T1DM and how these attitudes subsequently impacted how participants experienced their T1DM and the impact it had on their identity. | Population-high relevance, the participants were adolescents and young adults with T1DM. Males and female genders included.<br><br>Setting-high relevance, recruited from an outpatient T1DM service.<br><br>Phenomena of interest-high relevance as it wished to explore the main facilitators and barriers of diabetes self-care. | |
| 1.3.**Internalised identity** | | | | | |
| **Sanders et al. (2019)** | **None.** | **Minor.** The data from this study does not explicitly link to this | **None.** The authors provided extensive detail | **Minor.** Population-high relevance, 16–24-year-olds all with diagnosis of | High confidence rating as there was no concerns regarding the majority of features for these primary studies. There were two features which did have concerns, but these were minor. |

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| | | subtheme. However, through interpretation, the findings of stigma, negative attitudes of others and being made to feel different as a result of this, does fit within this subtheme. | regarding how stigma of T1DM and how they were treated by others made them believe they were different. This detail allowed this review to interpret these findings to link to how stigma and attitudes of others can lead to internalised views of self. | T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the United Kingdom in an outpatient setting.<br><br>Phenomena of interest-low relevance as the study was exploring the acceptability of a specific T1DM education programme. |
| **Kim, (2022)** | **None.** | **None.**<br>The data from this study discusses how societal stigma and negative attitudes from others led to some participants internalising | **None.**<br>Authors of this study detailed how the overwhelming nature of being diagnosed with T1DM, | **None**.<br>Population-high relevance, adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, |

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| | | this stigma and these attitudes, impacting identity. | alongside the stigma and attitudes that surround this led to some participants internalising negative attitudes and viewing themselves as flawed. | conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |
| **Goldman & Maclean, (1998)** | **None**. | **None**.<br>The data from this study speaks to the process of how the stigma that surrounds T1DM and the negative attitudes of others shaped theparticipants' perceptions of themselves. | **None**.<br>The authors provide detail about how participants perceive their identity as a result of having T1DM. The authors then detail how these perceptions are linked to T1DM being a social phenomenon, | **None.**<br>Population-high relevance, recruited male and female individuals with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the |

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| | | | meaning it is assigned value and traits by wider society that individuals then internalise. | paper was interested in exploring and understanding the experiences of individuals living with T1DM. |
| **Dovey-Pearce et al. (2007)** | **None.** | **None.**<br>There is a good fit between this subtheme and the data from this study as the authors use their data analysis, alongside quotes from their participants to report on the impact of social interactions and attitudes of others towards T1DM on how participants viewed | **None.**<br>The authors provide detail about both ill and well intentioned attitudes and gestures of others towards participants with T1DM and how this began to shape how participants view their diabetes and their identity of being 'different' and 'abnormal'. | **None.**<br>Population-high relevance, 16–25-year-olds all with diagnosis of T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the United Kingdom in an outpatient setting.<br><br>Phenomena of interest-high relevance as the study aimed to understand how T1DM impacts the development of young adults. |

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| | | themselves and their diabetes. | | | |
| **Commissariat et al. (2016)** | **None.** | **None.** The results of this study reported how the negative attitudes others held towards T1DM led to some participants to internalise these views and shape how they view themselves. | **None.** The results of this study detailed how the attitudes of others (both negative and well-intentioned) impact the way participants viewed themselves in relation to their T1DM. | **None**. Population-high relevance, adults aged 13-20 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as was to explore the development of adolescent personal and social identity in relation to being diagnosed with T1DM . | |
| | | | **2.1. Disruption to identity** | | |
| **Goldman & Maclean, (1998)** | **None.** | **None.** Extensive data from this study speaks to how | **None.** The authors detailed the various ways | **None.** Population-high relevance, recruited male and | High confidence as all sections, apart from one, had no concerns. The one section with concerns was minor. |

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| | | many participants experienced a disruption to their identity because of T1DM. | that T1DM disrupt identity and why the disruption occurred for some. The authors then explained the various consequences of this identity disruption in terms of feelings and behaviours of their participants. | female individuals with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of individuals living with T1DM. |
| **Maietta, (2021)** | **Minor.**. | **None**. There is a good fit between this subtheme and the results of this study. The data analysis and quotes from participants | **None.** The authors provide sufficient detail regarding how participants felt their T1DM disrupted | **None**. Population-high relevance, adults aged 28-71 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, |

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| | | throughout the results section report on how having T1DM regularly disrupt the identity participants wish to portray, with a particular focus on social identity. | their ideal identity, how this disruption occurred and how the disruption linked to stigma and attitudes of others towards T1DM. This detail also included how participants experienced this identity disruption and how they managed it. | conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as explored how T1DM may challenge identity. |
| **Williams, (1999)** | **None.** | **Minor**. The results of this study reported that it was mainly male participants who found that the social identity of T1DM disrupted their | **Minor.** Detail is provided regarding how gender of participants interacts with how T1DM is experienced and whether it is viewed as disrupting | **None**. Population-high relevance, participants aged 15-18 years with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, |

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| | | wanted identity. Whereas data from female participants contradicts this in that T1DM was not violating to their identity. | towards identity. | conducted within an outpatient service in the UK.<br><br>Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM |
| **Tilden et al. (2005)** | **Minor.** | **None.** There is a strong fit between this subtheme and this primary study. The data analysis, supported by quotes, extensively report how having T1DM disrupted identity. | **None.** The authors reported in extensive detail how their participant felt their T1DM impacted their identity, how others treated them to contribute to this disruption and how this identity disruption linked to | **None**. Population-very minor concerns with relevance. Participant did have T1DM which impacted their identity but it was one adult female participant.<br><br>Setting-high relevance, conducted within an outpatient service in the UKm during therapy exploring |

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| | | | diabetes management. | identity and T1DM.<br><br>Phenomena of interest-high relevance as was to explore the themes from a course of CAT therapy to try and understand struggles with treatment adherence in T1DM. |
| **Kim, (2022)** | **None.** | **None**.<br>The data analysis from this study discussed how having T1DM can go against the identity participants wanted for themselves, this led to participants denying having T1DM. | **None**.<br>The authors detailed that the negative depiction of T1DM resulting in some participants running away from and denying their T1DM. This data analysis was done in sufficient detail to allow | **None**.<br>Population-high relevance, adolescents and adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service. |

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| | | | the authors of this review to interpret that this denial allowed participants to reject T1DM from their identity, as they did not wish to adopt the negative associations of T1DM into their identity. | Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |
| **Dovey-Pearce et al. (2007)** | **None.** | **None.**<br>The findings of this study report the disruptive nature of T1DM on identity, particularly at the point of diagnosis. The data from this study therefore fit well into this subtheme. | **None**.<br>The authors provide sufficient detail about how T1DM can disrupt identity, especially at the point of diagnosis. The authors detail this disruption generally centred | **None.**<br>Population-high relevance, 16–25-year-olds all with diagnosis of T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the UK in an outpatient setting.<br><br>Phenomena of |

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| | | | around participants feeling 'different' to others and who they thought they were as a result of T1DM. | interest-high relevance as the study aimed to understand how T1DM impacts the development of young adults. |
| **Sanders et al. (2019)** | **None.** | **None.** Good fit of original data from this study and this subtheme. Author used the experiences of participants, the themes they derived from their data and quotes to discuss how T1DM can disrupt personal and social identity. | **None.** Authors provided a detailed analysis regarding how T1DM disrupted the identity of some participants and how this disruption led to experiences of their identity feeling threatened. This experience was linked to behaviours | **Minor.** Population-high relevance, 16–24-year-olds all with diagnosis of T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the UK in an outpatient setting.<br><br>Phenomena of interest-low relevance as the study was exploring the acceptability of a specific T1DM |

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| | | | such as treatment adherence. | education programme. |
| **Commissariat et al. (2016)** | **None.** | **Minor.** The data of this study mainly reports the overall disruptive nature of having T1DM on participants' lives. The authors then interprets the disruptive nature of T1DM as meaning that the development of identity of participants also becomes disrupted. | **None.** Explicit data is provided regarding the disruptive nature of T1DM on the participants' lives, alongside a detailed interpretation from the authors of this study regarding how this overall disruption can also disrupt identity development. This allowed the authors of this review to use the data to contribute to this subtheme. | **None**. Population-high relevance, adults aged 13-20 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM .<br><br>Phenomena of interest-high relevance as was to explore the development of adolescent personal and social identity in relation to being diagnosed with T1DM . |

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| **2.2 Defined by a diabetic identity** | | | | | |
| **Chalmers et al. (2022)** | **Minor.** | **Very minor.**<br>The data does not explicitly state participants feel defined by their diabetes. The data from this study does report that participants have a desire to define their identity and take ownership of it by highlighting aspects of themselves go beyond their diabetes. | **Moderate.**<br>The authors discuss participants wanting to define their own story and portray an identity beyond their diabetes, but this is described in very little detail in terms of experiences of being identified via their diabetes and the impact this has had on them. | **Minor**.<br>Population-high relevance, adults aged 13-18 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-not directly relevant, the study aimed to explore the experiences of individuals who have shared their T1DM on social media. | Moderate.<br>There were concerns with most sections assessing the confidence of this subtheme. These concerns were mainly only minor. |
| **Tilden et al. (2005)** | **Minor.** | **None.**<br>The data in this study shares their participants' experience of | **None.**<br>The authors detail how others had treated them and spoke to | **None**.<br>Population-very minor concerns with relevance. Participant did have T1DM which | |

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| | | feeling they were identified and defined by having T1DM and how being defined by their T1DM contributed to them wanting to reject it from their identity. | them to make them feel defined by their T1DM and how this definition contributed to the struggles accepting T1DM into their identity. | impacted their identity, but it was one adult female participant.<br><br>Setting-high relevance, conducted within an outpatient service in the UK during therapy exploring identity and T1DM.<br><br>Phenomena of interest-high relevance as was to explore the themes from a course of CAT therapy to try and understand struggles with treatment adherence in T1DM. |
| **Abdoli et al. (2017)** | **None.** | **Minor**. The results of this study do not explicitly state the experience of | **Minor**. The results of this study do not describe the experience of | **None**. Population-high relevance, adults aged 18-30 with a diagnosis of T1DM. Males and |

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| | | their participants as them feeling defined by their diabetes. This study was included in this subtheme because the authors of this review interpreting participants referral to self as 'diabetic' and being viewed by others as a 'diabetic' as them being defined by their T1DM. | their participants as them feeling defined by their diabetes. This study was included in this subtheme because the authors of this review interpreting participants referral to self as 'diabetic' and being viewed by others as a 'diabetic' as them being defined by their T1DM. | female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |
| **Fioretti & Mugnaini, (2022)** | **None.** | **Minor**. There are minor concerns about the fit between this subtheme and the findings of this | **Minor**. This study was included in this subtheme because the authors of this review | **None**. Population-high relevance, adults aged 18-34 with a diagnosis of T1DM. Males and female genders included. |

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| | | study. This is because the results of this study do not explicitly state the experience of their participants as them feeling defined by their diabetes. This study was included in this subtheme because the authors of this review interpreting participants referral to self as 'diabetic' and being viewed by others as a 'diabetic' as them being defined by their T1DM. | interpreting participants referral to self as 'diabetic' and being viewed by others as a 'diabetic' as them being defined by their T1DM. This study does not explicitly detail the experience of their participants as them feeling defined by their diabetes. | Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as was to explore the experiences of being a young adult with T1DM. |
| **Kim, (2022)** | **None.** | **None.**<br>There is a good fit between the | **None.**<br>The authors detailed the process from | **None**.<br>Population-high relevance, adolescents and |

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| | | data of this study and this subtheme as the authors share their data analysis and discussion of how being diagnosed with T1DM can result in identity being overtaken by the diabetes. | being diagnosed with T1DM, facing stigma and negative attitudes from others to internalising negative assumptions about having T1DM and adopting it into their identity. | adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |
| **Goldman & Maclean, (1998)** | **None.** | **Minor.**<br>The data and original quotes of this study report the shift in how participants identified themselves to viewing themselves as just a | **None.**<br>The authors provide a lot of detail regarding the disruption to participant identity because of having T1DM and the subsequent | **None.**<br>Population-high relevance, recruited male and female individuals with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian |

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| | | ‘diabetic’. The data of this study did not explicitly speak to the concept that individuals feel defined by their diabetes. | shift in how participants viewed their identity as a result of this. The details provided about the shift in identity was sufficient to allow the authors of this review to interpret that T1DM had led participants to only view themselves as a diabetic. | outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of individuals living with T1DM. |
| **Dovey-Pearce et al. (2007)** | **None.** | **Minor.**<br>The data and original quotes of this study report how participants identified themselves and felt others identified them as a ‘diabetic’. The data of | **Minor.**<br>The authors provide some detail regarding a shift to identifying themselves as ‘just a diabetic’, but this detail does not | **None.**<br>Population-high relevance, 16–25-year-olds all with diagnosis of T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the |

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| | | this study did not explicitly speak to the concept that individuals feel defined by their diabetes. | extend to how this shift occurs or the impact it has on the individual. The authors of this review, however, were still able to interpret these findings to contribute sufficiently to this subtheme. | UK in an outpatient setting.<br><br>Phenomena of interest-high relevance as the study aimed to understand how T1DM impacts the development of young adults. | |
| **3.1: T1DM violating identity** | | | | | |
| **Maietta, (2021)** | **Minor.** | **None**. There is a good fit between this subtheme and the results of this study. The data analysis and quotes from participants throughout the results section report on how T1DM | **None**. The authors provide extensive details and examples of the contexts in which participants felt T1DM violated their identity alongside how this violation | **None**. Population-high relevance, adults aged 28-71 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM. | High confidence rating as there were no concerns regarding the majority of features for these primary studies. There were four features which did have concerns, but these were minor |

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| | | violated the identity participants wished to portray. | linked to stigma and attitudes of others towards T1DM. This detail also included how participants experienced and managed T1DM when they felt it violated their ideal identity. | Phenomena of interest-high relevance as was to explore how T1DM may challenge identity. |
| **Tilden et al. (2005)** | **Minor.** | **None**. The data analysis and quotes from the study report the identity violation caused by T1DM and its impact on the participant. There is, therefore, a good fit between this primacy study | **None**. The authors provided extensive detail regarding why their participant felt their T1DM violated their identity, how this violation occurred and the impact of it in regard to their daily | **None**. Population-very minor concerns with relevance. Participant did have T1DM which impacted their identity, but it was one adult female participant.<br><br>Setting-high relevance, conducted within an outpatient service in the UK |

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| | | and this subtheme. | living and management of T1DM. | during therapy exploring identity and T1DM.<br><br>Phenomena of interest-high relevance as was to explore the themes from a course of CAT therapy to try and understand struggles with treatment adherence in T1DM. |
| **Williams, (1999)** | **None.** | **Minor**. The results of this study reported that it was mainly male participants who found that the social identity of T1DM disrupted their wanted identity. Whereas data from female | **Minor.** Detail is provided regarding how gender of participants interacts with how T1DM is experienced and whether it is viewed as disrupting towards identity. | **None**. Population-high relevance, participants aged 15-18 years with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service in the UK. |

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| | | participants contradicts this in that T1DM was not violating to their identity. | | Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM |
| **Goldman & Maclean, (1998)** | **None.** | **None.** There is a good fit between the data of this study and this subtheme. This is because the data analysis of this study, alongside the use of quotes, depict that some participants feel T1DM had violated and threatened their identity. | **None.** The authors provided detail on how participants felt that their identity had been violated by their T1DM. They described the feelings of threat towards T1DM in relation to identity and the personal and social qualities of the individuals that experienced identity | **None.** Population-high relevance, recruited male and female individuals with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of |

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| | | | violation because of T1DM. | individuals living with T1DM. |
| **Montali et al. (2022)** | **None**. | **Minor.** The data from this study does not directly report participants experiencing T1DM as violating to their identity. The data does, however, report the stigmatised perceptions participants have of T1DM and not wishing to have this as part of their identity. | **Minor.** The study provides detail about the impact of societal stigma participants have faced and how it has shaped how participants perceive T1DM and led to challenges with management of T1DM. This detail allowed the authors of this review to interpret that the stigma associated with T1DM may violate | **None.** Population-high relevance, the participants were adolescents and young adults with T1DM. Males and female genders included.<br><br>Setting-high relevance, recruited from an outpatient T1DM service.<br><br>Phenomena of interest-high relevance as it explored the main facilitators and barriers of diabetes self-care. |

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| | | | the identity of participants. | |
| **Kim, (2022)** | **None.** | **None.** The data analysis from this study discussed how having T1DM can go against the identity participants wanted for themselves, this led to participants denying having T1DM. | **None.** The authors detailed that the negative depiction of T1DM resulting in some participants running away from and denying their T1DM. This data analysis was sufficient in detail to allow the authors of this review to interpret that this denial allowed participants to reject T1DM from their identity, as they did not wish to adopt the negative associations | **None**. Population-high relevance, adolescents and adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |

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| | | | of T1DM into their identity. | | |
| | | | **3.2. Externalising T1DM from identity** | | |
| **Commissariat et al. (2016)** | **None** | **Moderate.** The data from the study does not report explicitly that participants externalise their T1DM to reject it. Original quotes do express participants referring to their diabetes as a separate entity to themselves, so the process of externalising was interpreted by the authors of this review. | **Minor.** Original quotes showed participants speaking about their diabetes as a separate entity e.g., "it" and "the diabetes". The authors of this study interpreted this to mean a form of externalising but the authors of this primary study did not detail this. | **None**. Population-high relevance, adolescents and adults aged 13-20 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as explored the development of adolescent personal and social identity in relation to being diagnosed with T1DM . | **Moderate.** There were concerns with most sections assessing the confidence of this subtheme. These concerns were however only minor. |

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| **Goldman & Maclean, (1998)** | **None** | **Minor.**<br>This study does not state that some participants externalise their T1DM as a method to reject it. The results do however use quotes from participants who felt their identity has been violated by T1DM spoke to their diabetes as 'it', implying they view it as a separate entity to the self. | **None.**<br>The authors provide detail on how participants who have rejected T1DM from their identity speak about their diabetes compared to those who have accepted it. Those who have accepted their diabetes spoke about it as part of themselves compared to those who had rejected it who referred to diabetes as 'it' and a separate entity. This detail allowed the authors of this review to interpret that | **None.**<br>Population-high relevance recruited male and female individuals of both genders with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of individuals living with T1DM. |

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| | | | a way participants reject their T1DM is through externalising. | |
| **Abdoli et al. (2017)** | **None.** | **Minor.** The data of this research highlight how some participants viewed their T1DM as an extra, external responsibility for them to take on and manage. This could, however, not be a sign of rejecting T1DM from their identity as some participants shared that viewing their T1DM as an external responsibility | **Minor.** The authors described throughout their results, quotes and analysis of participants viewing and treating their T1DM as an external responsibility to them. This detail led to the interpretation that for some, T1DM was viewed as an external entity as a way for individuals to manage their diabetes whilst not | **None.** Population-high relevance, adults aged 18-30 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |

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| | | helped them to better accept it into identity. | accepting it into their identity. | |
| **Kim, (2022)** | **None**. | **Minor.** The original quotes and data from this study imply that participants have externalised their T1DM as they speak about it as if it is a separate entity, but the authors and analysis of this study did not explicitly state this. | **None.** The authors provide detailed descriptions of some participants running away from, denying and concealing their T1DM, alongside quotes of participants describing their diabetes as a separate entity. This detail allowed the authors of this review to interpret these findings to mean a way to cope with rejecting T1DM is to externalise it. | **None**. Population-high relevance, adolescents and adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |

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| **Williams, (1999)** | **None.** | **None**. The quotes used and the data analysis reported how some participants who were rejecting T1DM spoke about it as a separate being. There was therefore a good fit between this subtheme and the data from this study. | **None**. Detail is given about how participants who were struggling to accept T1DM, were instead 'fighting against it' to push it away from their identity. This detail was enough to allow further interpretation of and enrichment of this subtheme. | **None**. Population-high relevance, participants aged 15-18 years with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service in the UK.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM | |
| **3.3. Challenges with management** | | | | | |
| **Goldman & Maclean, (1998)** | **None**. | **None.** There is a strong fit between the original data of this study and this subtheme. | **None.** Extensive detail is provided about the link between participants in | **None.** Population-high relevance, recruited male and female individuals with T1DM aged | High confidence as there were no concerns with any section of confidence, with the exception of one where there were only minor concerns. |

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| | | The authors use their data analysis and quotes to depict how individuals who have rejected T1DM from their identity struggle more with their diabetes management. | the study who have rejected T1DM from their identity and having worse diabetes management. The detail provided about this link allowed for the interpretation that challenges with management is a way for individuals to physically reject and deny their T1DM. | 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of individuals living with T1DM. |
| **Tilden et al. (2005)** | **Minor.** | **None**. The data analysis and quotes from the study reported how the rejection of T1DM from | **None**. The authors provided extensive detail regarding why their participant | **None**. Population-very minor concerns with relevance. Participant did have T1DM which impacted their identity, but it was |

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| | | identity linked to their participant struggling to manage their T1DM. | struggled to adhere to their T1DM treatment and how this was linked to rejecting their T1DM from their identity. | one adult female participant.<br><br>Setting-high relevance, conducted within an outpatient service in the UK during therapy exploring identity and T1DM.<br><br>Phenomena of interest-high relevance as was to explore the themes from a course of CAT therapy to try and understand struggles with treatment adherence in T1DM. |
| **Williams, (1999)** | **None**. | **None.** There is a strong fit between the original data of this study and this subtheme as the results | **None.** Detail is provided alongside quotes from participants who share their | **None**. Population-high relevance, participants aged 15-18 years with a diagnosis of T1DM. Males and |

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| | | extensively report the link between rejection of T1DM and poor diabetes management. | experience of struggling to accept their diabetes and how this is linked to having challenges with management of their diabetes. The results share why management is difficult when diabetes is not accepted and the impact it has on identity. | female genders included.<br><br>Setting-high relevance, conducted within an outpatient service in the UK.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM |
| **Sanders et al. (2019)** | **None.** | **None.**<br>Original data from this study fits well with this subtheme. This is because the authors regularly discuss how challenges | **None.**<br>This is because the authors regularly discuss various themes regarding the negative | **Minor.**<br><br>Population-high relevance, 16–24-year-olds all with diagnosis of T1DM. Male and female participants were included. |

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| | with management of T1DM occurs and how it links to identity. | stigma surrounding T1DM and how T1DM can negatively impact identity. The authors regularly link these topics with challenges with management of T1DM throughout their analysis and using quotes from the experiences of participants. This allowed the authors of this review to interpret these findings further to link how stigma and identity | Setting-high relevance, conducted in the UK in an outpatient setting.<br><br>Phenomena of interest-low relevance as the study was exploring the acceptability of a specific T1DM education programme. |

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| | | | disruption can result in challenges with management. | |
| **Abdoli et al. (2017)** | **None.** | **None.** The data from this study depicts participants' experience of struggling to manage their T1DM alongside analysis and discussion as to the various reasons why various participants had poor diabetes management. | **None.** The authors of this study provided detail throughout their result section regarding how, when a participant had a difficult relationship with their T1DM, this led to not prioritising its management. This allowed for development of this subtheme, and the overall theme of rejection. | **None.** Population-high relevance, adults aged 18-30 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as was to explore the experiences and perceptions of individuals with T1DM. |

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| **Commissariat et al. (2016 )** | **None.** | **None.**<br>Data from this study provided data analysis and quotes regarding the link between struggling to accept diabetes as part of the identity and struggling to adhere to the treatment regime of T1DM. | **None.**<br>The authors provide detail throughout their data analysis regarding how the burden of T1DM and what it represented for their identity led to participants to face challenges with the management of T1DM. | **None**.<br>Population-high relevance, adolescents and adults aged 13-20 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as explored the development of adolescent personal and social identity in relation to being diagnosed with T1DM . | |
| **4.1. Acceptance of T1DM into identity** | | | | | |
| **Goldman & Maclean, (1998)** | **None.** | **None**.<br>The data in this study shares the experiences of | **None**.<br>Substantial detail is provided regarding the | **None.**<br>Population-high relevance, recruited male and female individuals | High confidence as there were no concerns with any section of confidence, with the exception of one where there were only minor concerns. |

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| | participants who had come to accept their T1DM into their identity. Original quotes from these participants were used to convey the experiences of this acceptance. | process of reaching acceptance in terms of T1DM and identity and the impact this has had on how participants view themselves, the level of satisfaction they have with their lives and their diabetes management. This detail enabled the authors of this review to further develop this subtheme to suggest how acceptance of T1DM into identity may be achieved. | with T1DM aged 26-76.<br><br>Setting-high relevance, conducted in a Canadian outpatient clinic for T1DM.<br><br>Phenomena of interest-high relevance, the paper was interested in exploring and understanding the experiences of individuals living with T1DM. |

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| **Maietta, (2021)** | **Minor.** | **None**.<br>The data from this study shared how participants processed and verified their new identity with T1DM to accept it into their identity. It is therefore a good fit within this subtheme. | **None**.<br>The authors detailed how some of their participants went through a process of verifying their identity with T1DM which aided them to address any challenges they had with their diabetes and accept it into their identity. The authors detailed some of the ways that participants achieved this. | **None**.<br>Population-high relevance, adults aged 28-71 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as explored how T1DM may challenge identity. |
| **Abdoli et al. (2017)** | **None.** | **None.**<br>There is a good fit between this study and subtheme. The authors | **None.**<br>Authors provide rich data about the process of how participants come to | **None**.<br>Population-high relevance, adults aged 18-30 with a diagnosis of T1DM. Males and female genders included. |

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| | | provide data analysis, quotes and discussion of themes relating to acceptance of T1DM into identity. | accept T1DM into identity and the consequences of this acceptance in terms of how participants view themselves, how they interact with others and their diabetes related behaviours. | Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |
| **Fioretti & Mugnaini, (2022)** | **None**. | **None.**<br>The results of this study report the process of feelings towards and achievement of acceptance of T1DM into identity for some of their participants. There is therefore a good fit | **None.**<br>The authors detailed the process that some participants had towards accepting their T1DM. This included the struggles some participants had towards acceptance and the | **None**.<br>Population-high relevance, adults aged 18-34 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.. |

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| | | between this subtheme and this study. | process towards acceptance of T1DM into identity. | Phenomena of interest-high relevance as explored the experiences of being a young adult with T1DM. |
| **Kim, (2022)** | **None.** | **None.**<br>There is a good fit between this theme and the data collected in this study. This is because the study reported their results and analysis of the process of how individuals accepted T1DM into their identity. | **None.**<br>The authors described the process of accepting T1DM into identity. They detailed how participants achieved acceptance and the impact this had on participant experience of T1DM, their identity and their behaviours. | **None**.<br>Population-high relevance, adolescents and adults aged 13-19 with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |

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| **Williams, (1999)** | **None**. | **Minor**. Little evidence is provided regarding how and why participants accept T1DM into their identity. The authors do report about mainly female participants accepting T1DM into identity and attribute this to greater flexibility and adaptability. | **Minor**. Limited detail is provided regarding how and why participants move to accepting their T1DM into identity. The authors do however, explain how adaptability and flexibility is a factor in acceptance. | **None**. Population-high relevance, participants aged 15-18 years with a diagnosis of T1DM. Males and female genders included.<br><br>Setting-high relevance, conducted within an outpatient service in the UK.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM |
| **Commissariat et al. (2016)** | **None**. | **None.** The data of this study fits well with this subtheme. This is because the study reported how some | **None.** The authors described the processes participants went through that led to the acceptance of | **None**. Population-high relevance, adolescents and adults aged 13-20 with a diagnosis of T1DM. Male and |

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| | | participants had incorporated and accepted T1DM into their identity. | T1DM into their identity and lives. This detail allowed the authors of this review to further enrich this subtheme. | female participants included.<br><br>Setting-high relevance, conducted within an outpatient service for T1DM.<br><br>Phenomena of interest-high relevance as explored the development of adolescent personal and social identity in relation to being diagnosed with T1DM . |
| **Montali et al. (2022)** | **None**. | **None**. The data from this study and this subtheme fit well. The results from the data analysis reported what was needed for participants to accept T1DM into their | **None**. The authors provided details on how some of their participants worked to accept their T1DM and integrate it into their identity. This | **None.** Population-high relevance, the participants were adolescents and young adults with T1DM. Male and female participants included.<br><br>Setting-high relevance, recruited from an |

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| | | identity and the positive impact this acceptance had on participants and their diabetes management. | detail allowed for the authors of this current review to better understand how T1DM becomes accepted by participants and integrated into their identity. | outpatient T1DM service.<br><br>Phenomena of interest-high relevance as it wished to explore the main facilitators and barriers of diabetes self-care. |
| **Sanders et al. (2019)** | **None**. | **None.**<br>There is a good fit between this subtheme and the data found from this study. The data reported about learning to manage the complexity of having T1DM and how this facilitated the acceptance of diabetes into identity. | **None.**<br>The authors detailed the process of how some of their participants reached acceptance of T1DM into their identity and the impact this had on the way they viewed themselves, their diabetes | **Minor.**<br><br>Population-high relevance, 16–24-year-olds all with diagnosis of T1DM. Male and female participants were included.<br><br>Setting-high relevance, conducted in the UK in an outpatient setting.<br><br>Phenomena of interest-low |

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| | | | management and their emotions. | relevance as the study was exploring the acceptability of a specific T1DM education programme. | |
| **4.2. Positive aspects of T1DM** | | | | | |
| **Abdoli et al. (2017)** | **None**. | **None.** There is a good fit between this study and subtheme. The authors provide data analysis, quotes and discussion of themes relating to how participants have learnt positive traits about themselves, through having T1DM, and | **None.** Authors provide rich data about the process of how T1DM has taught them positive aspects of their character and identity. This was provided in enough detail to interpret the link between noticing the positive impact of | **None.** Population-high relevance, adults aged 18-30 with a diagnosis of T1DM. Male and female participants included.<br><br>Setting-high relevance, conducted within an outpatient service.<br><br>Phenomena of interest-high relevance as explored the experiences and perceptions of | High confidence as there were no concerns with any section of the confidence appraisal. |

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| | | have adopted this into their identity. | T1DM on identity and accepting it as part of the self. | individuals with T1DM. |
| **Kim, (2022)** | **None**. | **None.** Results from this study stated that a process within diabetes acceptance is acknowledging the positive aspects of having T1DM and what that means about their identity. | **None.** The authors described how identifying the positives of T1DM was a key process in them accepting T1DM into their identity. They detailed how participants achieved acceptance and the impact this had on participant experience of T1DM, their identity and | **None**. Population-high relevance, adolescents and adults aged 13-19 with a diagnosis of T1DM. Male and female participants included. Setting-high relevance, conducted within an outpatient service. Phenomena of interest-high relevance as explored the experiences and perceptions of individuals with T1DM. |

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| | | | their behaviours. | |
| **Commissariat et al. (2016)** | **None**. | **None.** There is a good fit between the data of this study and this subtheme. This is because the results of the study shared that those who had accepted T1DM and incorporated it into their identity, also found positive elements of having T1DM. | **None.** The authors detailed how acceptance of T1DM into identity was linked with finding positives of having T1DM and adopting these traits into identity. | **None**. Population-high relevance, adolescents and adults aged 13-20 with a diagnosis of T1DM. Male and female participants included. Setting-high relevance, conducted within an outpatient service for T1DM. Phenomena of interest-high relevance as explored the development of adolescent personal and social identity in relation to being diagnosed with T1DM . |
| **Fioretti & Mugnaini, (2022)** | **None**. | **None**. There is a strong fit between this subtheme and | **None**. The authors detail the process of some | **None**. Population-high relevance, adults aged 18-34 with a diagnosis of |

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| | the results of this study. The authors report how some of their participants found the positives in their diagnosis and what these positives were. | participants towards finding the positives in their diagnosis and what these positives were. They also detailed the various consequences of seeing the positives in their diagnosis in terms of emotions and behaviour. | T1DM. Male and female participants included. Setting-high relevance, conducted within an outpatient service for T1DM. Phenomena of interest-high relevance as explored the experiences of being a young adult with T1DM. |

### *2.3.4. Critical synthesis*

Across the 13 included studies, several consistent strengths were identified. Most studies clearly stated their aims, used appropriate qualitative designs, and employed robust data collection methods, primarily interviews, with sample sizes generally sufficient to support thematic saturation. Samples were heterogeneous in terms of age, clinical setting, and participant experience, enhancing the credibility and transferability of findings. Purposive and theoretical sampling methods were appropriately applied, supporting the recruitment of participants across diverse experiences of T1DM. Additionally, all studies reported clear findings, and most addressed ethical considerations such as informed consent and confidentiality.

Despite these strengths, several gaps and limitations in the existing literature are evident. While some studies reported ethnicity, many did not, and the majority of reported participants were White, indicating that cultural and social influences on identity in T1DM remain underexplored. Developmental considerations were also limited, with few studies focusing specifically on children or examining transitions across adolescence to adulthood. Only two studies explicitly reflected on researcher positionality and potential biases, raising concerns about how researcher perspectives may have influenced data collection and analysis. Ethical reporting was inconsistent, particularly regarding participant debriefing, management of risk, and sharing findings with participants. Furthermore, the majority of studies were conducted in outpatient or clinical settings, potentially missing experiences of individuals in broader social, educational, or occupational contexts. These gaps highlight that current research provides an incomplete picture of how identity is shaped by T1DM across social, cultural, and developmental dimensions, and suggest directions for future research to address these underexplored areas.

### 2.4. Findings from thematic synthesis

Table 8 presents the themes and subthemes from the thematic synthesis of the primary studies and which primary studies contributed to each subtheme.

**Table 8**

*Summary of main themes and sub themes, with supporting papers*

| Theme and subtheme(s) | Primary papers that support the theme |
|---|---|
| | **(1) Social identity** |
| **1.1. Stigma** | Abdoli et al. (2017)<br>Chalmers et al. (2022)<br>Goldman and Maclean, (1998)<br>Kim, (2022)<br>Sanders et al. (2019) |
| **1.2. Attitudes of others** | Abdoli et al. (2013)<br>Abdoli et al. (2017)<br>Commissariat et al. (2016)<br>Dovey-Pearce et al. (2007)<br>Kim, (2022)<br>Maietta, (2021)<br>Montali et al. (2022)<br>Sanders et al. (2019) |
| **1.3. Internalised narratives** | Dovey-Pearce, (2007)<br>Commissariat et al.(2016)<br>Goldman and Maclean, (1998)<br>Kim, (2022)<br>Sanders et al. (2019) |
| | **(2) Loss of self** |
| **2.1. Disruption to identity** | Commissariat et al. (2016)<br>Dovey-Pearce et al. (2007)<br>Goldman and Maclean, (1998)<br>Kim, (2022)<br>Maietta, (2021)<br>Sanders et al. (2019)<br>Tilden et al. (2005)<br>Williams, (1999) |
| **2.2. Defined by diabetic identity** | Abdoli et al. (2017)<br>Chalmers et al. (2022)<br>Dovey-Pearce et al. (2007)<br>Fioretti & Mugnaini, (2022)<br>Goldman and Maclean, (1998)<br>Kim, (2022)<br>Tilden et al. (2005) |
| | **(3) Rejection** |

| | |
|---|---|
| **3.1.T1DM violating identity** | Goldman and Maclean, (1998)<br>Kim, (2022)<br>Maietta, (2021)<br>Montali et al. (2022)<br>Tilden et al. (2005)<br>Williams, (1999) |
| **3.2. Externalising T1DM from identity** | Abdoli et al. (2017)<br>Commissariat et al. (2016)<br>Goldman and Maclean, (1998)<br>Kim, (2022)<br>Williams, (1999) |
| **3.3 Challenges with management** | Abdoli et al. (2017)<br>Commissariat et al. (2016)<br>Goldman and Maclean, (1998)<br>Sanders et al. (2019)<br>Tilden et al. (2005)<br>Williams, (1999) |
| **(4) Integration** | |
| **4.1. Acceptance of T1DM: integrate into self, inevitability** | Abdoli et al. (2017)<br>Commissariat et al. (2016)<br>Fioretti and Mugnaini, (2022)<br>Goldman and Maclean, (1998)<br>Kim, (2022)<br>Maietta, (2021)<br>Montali et al. (2022)<br>Sanders et al. (2019)<br>Williams, (1999) |
| **4.2. Positive aspects of T1DM** | Abdoli et al. (2017)<br>Commissariat et al. (2016)<br>Fioretti and Mugnaini, (2022)<br>Kim, (2022) |

### *2.4.1. Theme one: Social identity*

This theme represents how T1DM impacts the social identity of participants. It highlights how the wider stigmatised narratives surrounding T1DM influence the attitudes held by others towards T1DM and those with it, which is subsequently internalised and shapes the identity of those living with T1DM.

**Stigma (5 studies of 13).** The reviewed studies found substantial stigma surrounding the diagnosis of T1DM that participants had been directly and indirectly exposed to. The dominant stigma around T1DM is that it is caused by being overweight, resulting in judgemental and blaming comments and reactions from others (Abdoli et al., 2017; Chalmers

et al., 2022; Goldman & Maclean, 1998; Kim, 2022; Sanders et al., 2019). For example, a participant from Chalmers et al. (2021) shared others being shocked they had T1DM, saying "*how do you have diabetes, you are not fat"* (p.3.). Another participant shared that others attributed their T1DM to them being "*overweight or that you did something bad to yourself or your parents didn't take care of you"* (Abdoli et al., 2017, p.6). Some participants shared that they thought this stigma was due to public confusion between T1DM and T2DM (Abdoli et al., 2017). These findings imply that a common experience for those with T1DM is that they were blamed for their diabetes and this blame was associated with the food they consumed and the size of their bodies. The consequence of this stigma resulted in participants not being met with sympathy but instead being blamed and shamed for their T1DM (Abdoli et al., 2017; Goldman & Maclean, 1998; Kim, 2022). Such stigmatising narratives could do more than misrepresent the cause of T1DM, they could place responsibility and fault onto the individual, which can destabilise their sense of identity as responsible, competent, and health-conscious people.

**Attitudes and behaviours of others towards T1DM (9 studies of 13).** There is consensus across the studies that, as a result of the stigma surrounding T1DM, participants with T1DM are treated differently by others *because* of their diabetes (Abdoli 2013; Abdoli 2017; Commissariat et al., 2016; Dovey-Pearce et al., 2007; Fioretti & Mugnaini, 2022; Kim, 2022; Maietta, 2021; Montali et al., 2022; Sanders et al., 2019). For some, different treatment came from well-intentioned gestures, such as having posters about diabetes emergencies in classrooms (Dovey-Pearce et al., 2007). In other cases, being treated differently was in the form of being alienated from social groups, bullied, and discriminated against (Abdoli et al, 2013; Abdoli et al., 2017; Commissariat et al., 2016; Kim, 2022; Montali et al., 2022). For example, a participant in Montali et al.'s (2022) study shared, "*The human resources office called me and said, "We found out that you have diabetes, and we do not want sick people*

*because you risk fainting, feeling bad'*" (p.4), denying them a job after discovering they had diabetes.

Regardless of the severity, all actions were viewed by participants as singling them out from their group and drawing greater attention to their diabetes which was generally a negative experience for participants (Abdoli et al., 2013; Abdoli et al., 2017; Commissariat et al., 2016; Dovey-Pearce et al., 2007; Kim, 2022; Montali et al., 2022; Sanders et al., 2019). Differential treatment and being singled out as a result of T1DM could challenge a person's sense of belonging to the wider group and shape identity in the sense that they feel they do not belong to it, they are made to feel that they sit on the outside. For example, one participant described needing different food to their peers, making them feel "*a reject because I was different to everyone else because I couldn't do the same thing that they were doing"* (Dovey-Pearce et al., 2007, p.7), highlighting the impact stigma which surrounds T1DM, and how others treat those with T1DM as a result, has on an individuals identity in that they are made to feel rejected from the wider group, that they are different.

Participants described that others viewed them as being "*people who are always sick, miserable and able to do nothing*" and "*a patient who can do nothing"*, (Abdoli et al., 2013, p.3) because of T1DM; to others *"...you have a disability. You're not like the rest of us so you can't work like the rest of us"* (Abdoli et al., 2017, p.6). These views could be viewed as labels placed onto individuals with T1DM. Not only do these labels further place those with T1DM on the outside of social groups (e.g. of those that are 'healthy'), but could also be internalised and become part of how an individual identifies themselves.

Nine of the 13 reviewed studies found that, as a result of the attitudes and behaviours shown by others towards participants with T1DM, participants concealed their diagnosis in public settings. Participants did this as they did not wish to be socially grouped as having a

diabetic identity because they anticipated T1DM being viewed as a "*weakness" (*Maietta, 2021, p.7*)* and them being seen as a "*liability" (*Maietta, 2021, p.7*)* particularly in work environments; instead, they wanted to appear healthy and therefore concealed their diabetes (Abdoli et al., 2017; Chalmers et al., 2022; Commissariat et al., 2016; Fioretti & Muganini, 2022; Kim, 2022; Maietta, 2021; Montali et al., 2022; Sanders et al., 2019; Williams, 1999). These findings also highlight the impact these attitudes have on individuals, in that the negative experience of them is enough to influence behaviours regarding the management of the condition and shows the interplay between social perception, identity and diabetes self-management.

**Internalised narratives (5 studies of 13).** Some participants expressed internalising these stigmatising narratives which subsequently impacted their identity. Participants across four studies implied feeling different, flawed, unwell and abnormal because of T1DM (Commissariat et al, 2016; Dovey-Pearce et al., 2007; Kim, 2022; Sanders, 2019). For example, a participant shared that T1DM "*was my one flaw. I should be a straight person without blemishes"* (Kim, 2022, p.3).

Participants expressed a drastic shift in how they viewed their identity after being diagnosed with T1DM, as depicted in a quote from one participant in Goldman and Maclean's (1998) study, "*I am now a diabetic. And having always personally felt that I am a very strong person, suddenly you become a weakling"* (p. 4). The sudden shift of viewing oneself as "*strong"* to *"weakling"*, could indicate that the social stigma and attitudes of others towards T1DM, which shape social identity, could also be internalised, shaping the way participants view themselves.

**A Reflection**

*In interpreting the theme of stigma surrounding type 1 diabetes and its impact on identity, my clinical background and critical realist (CR) stance shaped my perspective. From a CR position, I recognise that social structures, including stigma, exist independently of individuals' perceptions but are experienced and interpreted subjectively. This orientation, alongside my wider reading on the capitalist stance of illness, made me particularly sensitive to how participants described feeling judged, blamed, or socially marginalised, and how these experiences influenced their sense of self. At the same time, I acknowledge that this focus could have led me to emphasise experiences of stigma over other dimensions of identity that participants discussed. Reflexively recognising this has been important in ensuring that, to the best of my ability, my analysis remains grounded in participants' accounts, rather than predominantly reflecting my own assumptions about how social stigma operates in T1D. This awareness guided me to balance highlighting the influence of stigma with preserving the broader diversity of participants' identity experiences.*

### *2.4.2. Theme two: Loss of self*

This theme articulates the sense of loss participants felt towards their non-diabetic identity once diagnosed with T1DM and it being replaced by a 'diabetic identity'.

**Disruption to identity (8 studies of 13).** Participants expressed that, prior to their diagnosis of T1DM, they had established an idea of what their identity was and/or what they wanted it to be. Generally, there was a discrepancy between these ideas and the identity that was attached to their diagnosis of T1DM (as discussed in theme one), meaning that participants experienced their T1DM as being disruptive to their established identity (Commissariat et al., 2016; Dovey-Pearce et al., 2007; Goldman & Maclean, 1998; Maietta, 2021; Kim, 2022; Sanders et al., 2019; Tilden et al., 2005; Williams, 1999).

Several factors contributed to this disruption. Some participants had preconceived ideas about T1DM and what it means about a person, so when they received the diagnosis, it

disrupted their established idea of self. This is depicted in Goldman and Maclean's (1998) study, where a participant shared that being diagnosed with T1DM disrupted the idea that they were "*the strong one in the family"* as "*suddenly I'm this diabetic…it changed my way of thinking…I am not who I thought I was"* (p.4). Being diagnosed with T1DM also results in significant lifestyle changes, due to constant monitoring and regulation of blood glucose, which can disrupt other behaviours that help an individual fulfil another identity, such as completing a work task (Maietta, 2021). This is demonstrated in Maietta's (2021) study where a participant expressed wanting to portray a student identity during a presentation but experienced hypoglycaemia and said, "*professionally they looked unprepared"* (p.7).

**Defined by a diabetic identity (7 studies of 13).** Participants felt that a consequence of having T1DM is their identity becoming defined by it (Abdoli et al., 2017; Chalmers et al., 2022; Dovey-Pearce et al., 2007; Fioretti & Mugnanini, 2022; Goldman & Maclean, 1998; Kim, 2022; Montali et al., 2022; Tilden et al., 2005). Participants expressed this in different ways. Some participants identified themselves through their diabetes, for example participants stated, "*I'm this diabetic"* and *"I am now a diabetic"* (Goldman & Maclean, 1998, p.4). Others shared being identified by their T1DM, it "*identifies me a lot among my friends: I am the diabetic one…for now my identity is dictated by my condition"* (Fioretti & Mugnaini, 2022, p.9). Similarly, a participant from Dovey-Pearce et al. (2019) described leaving the hospital after being diagnosed with T1DM as "*going into the hospital a normal person and [coming] out with this label on me"* (p.6). For some, their healthcare team had a significant role in this experience. Participants felt, during appointments, professionals only cared for the medical elements of their T1DM, such as their glucose reading and treatment adherence, and they were never asked how they were doing beyond condition-specific questions (Chalmers et al., 2022; Tilden et al., 2005).

A result of only being defined by their T1DM appears to be the loss of recognising all other traits, qualities, goals, values etc. that also construct identity. Participants spoke of others not caring about them and their identity beyond their diagnosis, and that, to others, their diabetes came above everything else (Fioretti & Mugnaini., 2022; Tilden et al., 2005). These participants subsequently expressed a sense of loss in only being identified by their diabetes and not a whole person. This was echoed by Goldman & Maclean, (1998) who shared one participant's experience of previously identifying themselves as a "*woman, a girl, mother*", but that now being lost to "*thinking of myself as a disease*" and as a "*diabetic"* (p.4).

### *2.4.3. Theme three: Rejecting T1DM from identity*

Some participants in the reviewed studies described a desire to reject T1DM from their identity completely. Many articulated that the identity they associated with T1DM violated their established identity, resulting in them facilitating their rejection via externalising T1DM from themselves and not adhering to their diabetes management.

**Violating identity (6 studies of 13).** For many participants, the identity attached to T1DM did not just disrupt their identity (theme two), but violated it (Goldman & Maclean, 1998; Kim, 2022; Maietta, 2021; Montali et al., 2022; Tilden et al., 2005; Williams., 1999). Participants expressed not wanting to accept the identity of 'diabetic' because it violated their preferred identity and potential. For example, some believed that accepting T1DM would 'banish' them from themselves (Kim, 2022), T1DM would "*pull me down with it. I'll feel tired and weak*" (Williams, 1999, p.5). Others believed their diabetes violated their identity in specific situations, such as at work. For example, a participant in Maietta's (2021) study writes of giving a work presentation and experiencing hypoglycaemia "*I was totally ready…I was confident…and I got low…and then all of a sudden you're standing in front of a bunch of professionals wearing a suit and you look like a kid in your dad's suit…and then you look*

*unprepared. Because you are unprepared in that moment. You're not able to put together your words and ideas that adequately represents how you ought to be able to do it."*(p7).

The violation T1DM has on participants' identity, seems to also extend to the future self. Goldman and Maclean (1998) and Fioretti and Muganini (2022) both found that, for some, being diagnosed with T1DM seemed to destroy the future identity they wanted for themselves.

The perceived violation of T1DM on identity could be a barrier to participants accepting T1DM into identity. Participants believed that acceptance of T1DM would mean no longer being able to adhere to/be/achieve the identity they had prior to T1DM or the identity that they wanted. A way to manage this, therefore, is continuous active rejection of T1DM from identity (Kim, 2022; Maietta, 2021; Tilden et al., 2005; Williams, 1999). This appears to be a very dichotomous view of identity and T1DM; one must either succumb to the perceived identity of someone with T1DM, losing their wanted identity, or completely reject T1DM.

**Externalising T1DM (5 studies of 13).** For some participants, rejection of T1DM was facilitated in a more literal sense by talking about and treating their T1DM as something that was completely external to themselves, as opposed to something that needed to be integrated into their identity and life (Abdoli et al., 2017; Commissariat et al., 2016; Goldman & Maclean, 1998; Kim, 2022; Williams., 1999). Participants would depersonalise their diabetes, speaking about 'it' as a separate part of their life, as opposed to something within themselves, for example "*I don't really check as often, I don't inject as often. Mainly because I don't even really want it"* and *"I almost sabotage myself...because I want to get back at it or rebel"* (Commissariat et al., 2016, p.9).

Permanently externalising T1DM could be viewed as a coping technique that participants use to protect their sense of self from the identity that accompanies T1DM. It

could also mean that T1DM is experienced as a foreign entity that poses threat to the self that participants must continually work against. This idea is reflected in a theme found by Kim, (2022), where some attempt to run away from their diagnosis through pretending to not have it.

**Challenges with management (6 studies of 13).** Participants who were rejecting T1DM from their identity generally faced challenges with the management of their diabetes, which was defined as poor glycaemic control, increased episodes of hypo/hyper glycaemia, and increased diabetes complications (Abdoli et al., 2017; Commissariat et al., 2016; Goldman and Maclean, 1998; Tilden et al., 2005; Sanders et al, 2019; Williams, 1999). Performing any behaviours associated with having T1DM, particularly checking blood glucose and injecting insulin, were viewed as accepting T1DM into identity (Goldman & Maclean, 1998; Tilden et al., 2005; Williams, 1999). Therefore, neglecting diabetes management and the need to perform diabetes self-care, particularly in public settings, is a method participants used to deny, rebel against, and continually reject T1DM from their identity.

Not adhering to diabetes management also seemed to be an act of rebellion against factors beyond the diabetes. For some, this rebellion was against the strict management routines and limitations imposed by healthcare professionals, alongside being viewed only as someone with T1DM, limiting their identity to just this. For example, a participant who was not adhering to their management stated when talking about their professionals "*it's all diabetes…they don't give a sod about me…it's not me as a person. I'm just a number on that diabetic bar…I really want to feel like some sort of person"* (Tilden et al., 2005, p.6). There was also an echo of frustration for participants when healthcare professionals incorrectly perceived their non-adherence to be the result of poor choices and lack of knowledge of the dangerous side effects. Healthcare professions reprimanded them and provided medical

information they already knew, as opposed to exploring deeper causes of their non-adherence (Sanders et al., 2019; Tilden et al., 2005).

For others, the rebellion appeared to be against the life that they viewed to be associated with the diabetic identity, one associated with a lack of socialising, limitations and being different from others. Instead, participants wanted to pursue a life of fun and socialising (Abdoli et al., 2017; Commissariat et al., 2016; Sanders et al., 2019).

#### *2.4.4. Theme four: Acceptance into identity*

**Integrating diabetes into identity (9 studies of 13).** Some participants were able to integrate their diabetes into their identity, making it part of their everyday life. Participants argued that, to achieve this, they first had to recognise they had T1DM; a serious, complex and, at times, difficult condition to live with (Abdoli et al., 2017; Goldman & Maclean, 1998; Sanders et al., 2019). All participants, whether they rejected or accepted T1DM into identity, recognised T1DM as a complex disorder that does not go away (Kim, 2022). The key difference it seems, between those who reject and those who accept T1DM, is that those who had been able to accept it viewed the permanent nature of T1DM as a reason to embrace it into identity, whereas those continuing to reject it viewed acceptance as defeatist (Kim, 2022). For example, a participant shared "*Most people do not want to accept it. Some people give up. But I just do it…how can I not do it?"* (Kim, 2022, p.6), whilst another stated "*It's something I know I'm going to live with for the rest of my life, I know there's nothing I can do except learn to take care of it and be healthier about it"* (Commissariat et al., 2016, p.8).

An important factor in integrating T1DM into identity was the acquisition and application of personal knowledge of T1DM, how to manage it, and what it is like to live with, as opposed to simply accepting the views that others, such as healthcare professionals and guardians, had imposed upon them (Commissariat et al., 2016; Kim, 2022; Sanders et al., 2019). Montali et al. (2022) found that by developing personal knowledge and experience,

participants were able to normalise their T1DM, which helped them to integrate it into their identity (Goldman and Maclean, 1998). When participants had acquired this knowledge and T1DM had begun to be normalised, they were more accepting of their diagnosis as part of their identity, for example a participant referred to T1DM as being "*part of me now"* (Montali et al., 2022, p.6), and had become better at managing it (Abdoli et al., 2017; Commissariat et al., 2016; Goldman & Maclean, 1998; Williams, 1999).

Acceptance and management of T1DM enabled participants to be better able to follow their identity-based values and goals, as their health was improved (Abdoli et al., 2017; Fioretti & Mugnaini, 2022; Goldman & Maclean, 1998; Maietta., 2021; Montali et al., 2022). Through these experiences, participants learnt that accepting and integrating their T1DM into their identity did not result in their whole identity becoming about their diabetes; diabetes became more of a background element to their life and they were able to do everything their 'healthy' peers could (Commissariat et al., 2016; Fioretti &Mugnaini, 2022; Goldman & Maclean., 1998; Maietta., 2021; Montali et al., 2022; Sanders et al., 2019; Williams, 1999).These findings are in stark contrast to those found in the rejection theme; participants seemed to adopt a more dichotomous view on diabetes management, believing they had to choose between managing their diabetes or continuing doing all that they valued and enjoyed.

**Positive aspects of T1DM (4 studies of 13).** Participants identified as having accepted and integrated T1DM into their identity shared that T1DM had also added to their identity (Abdoli et al., 2017; Commissariat et al., 2016; Fioretti & Mugnaini., 2022; Kim, 2022). For example, one participant wrote "*My diabetes has helped me in my personal growth because it made me stronger…because you have to prove to yourself that you can make it…but yes I wouldn't be the way that I if I hadn't had diabetes."* (Fioretti & Mugnaini, 2021, p.10). Another wrote "*So my confidence has been built up from my just being confident*

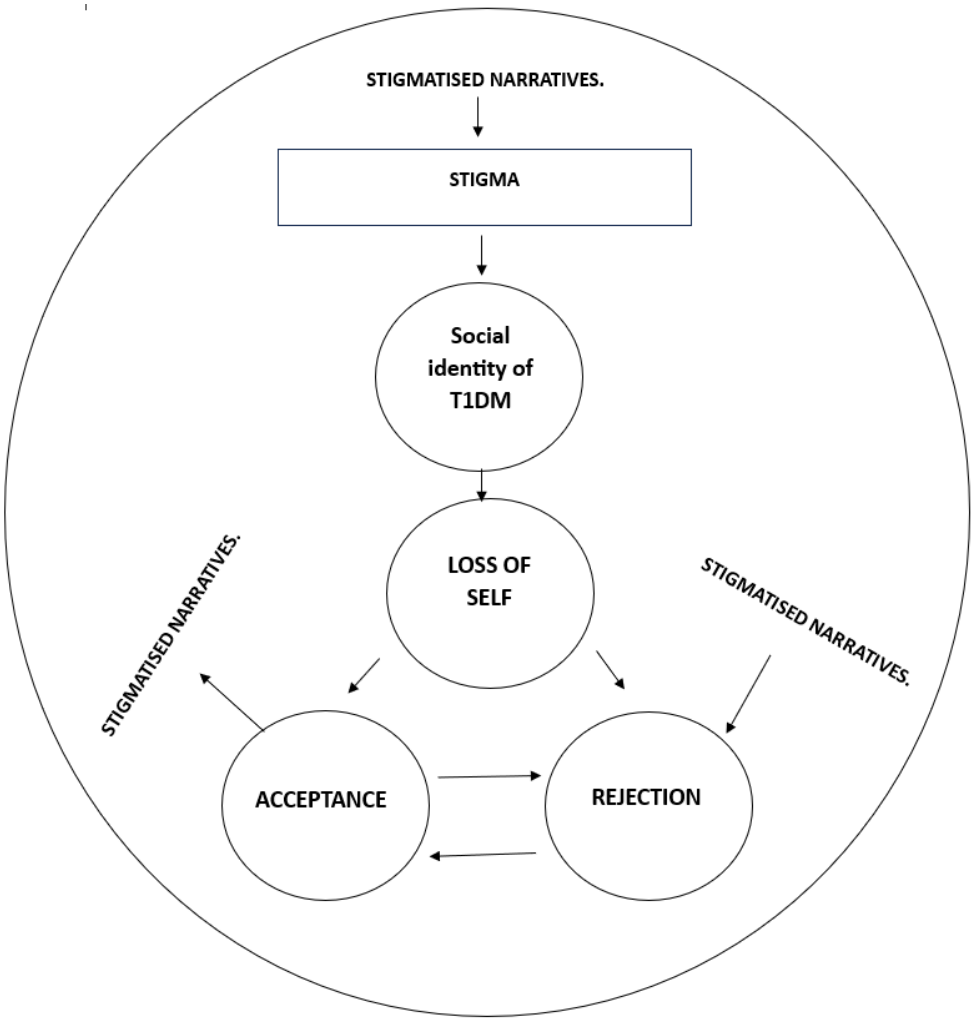
*with dealing with diabetes day to day*" (Sanders et al., 2019, p.11). Having T1DM also made participants aware of the importance of their health and helped them live a healthier lifestyle. In addition, participants shared that having T1DM made them feel more inclined to help others (Abdoli et al., 2017; Fioretti & Mugnaini., 2022), with one participant attributing their T1DM in helping them to *"understand what I want to do in the future…I want a healthcare university career"* (Fioretti & Muganini, 2022, p.8)

## 2.5. Discussion.

### *2.5.1. The interaction between themes and relation to existing literature.*

**Figure 2**

*An image to convey how the main themes of this literature review could interact*



The findings of this SLR imply an interaction between themes which relate to existing literature discussed in Chapter 1. Figure 2 attempts to demonstrate this interaction.

Dreyer (2024) highlighted the stigmatised, blaming narratives surrounding T1DM. The findings of theme one support this, showing how these narratives shape external perceptions and, in turn, influence self-identity as individuals internalise them (Abdoli et al., 2013, 2017; Commissariat et al., 2016; Dovey-Pearce et al., 2007; Fioretti & Mugnaini, 2022; Kim, 2022; Maietta, 2021; Montali et al., 2022).

Such narratives disrupt personal identity (Commissariat et al., 2016; Dovey-Pearce et al., 2007; Goldman & Maclean, 1998; Maietta, 2021; Kim, 2022; Sanders et al., 2019; Tilden et al., 2005; Williams, 1999), aligning with Charmaz (1987) and Oris et al. (2016), who argue that integrating illness into identity is challenging when the associated identity is socially or personally unacceptable.

Additionally, the perception that others focus solely on their diabetes may cause individuals to feel their identity has been replaced by a T1DM, leading to a loss of self (Abdoli et al., 2017; Chalmers et al., 2022; Fioretti & Mugnaini, 2022; Goldman & Maclean, 1998; Kim, 2022; Montali et al., 2022; Tilden et al., 2005). This loss of self appears to result in either rejecting or accepting the identity of T1DM.

Rejection of T1DM appears to happen when stigma clashes with one's existing identity, leading individuals to push T1DM away to avoid embodying negative narratives (Goldman & Maclean, 1998; Kim, 2022; Maietta, 2021; Montali et al., 2022; Tilden et al., 2005; Williams, 1999). Rejection led to externalising diabetes and avoiding its management (Abdoli et al., 2017; Commissariat et al., 2016; Goldman & Maclean, 1998; Kim, 2022; Tilden et al., 2005;

Williams., 1999), supporting previous literature (Abdoli, 2020; Balfe, 2009; Skinner et al., 2020).

Acceptance occurs when individuals acknowledge T1DM as a lifelong challenge (Abdoli et al., 2017; Goldman & Maclean, 1998; Sanders et al., 2019). Gaining personal experience and knowledge of T1DM plays a key role in this process (Commissariat et al., 2016; Kim, 2022; Sanders et al., 2019). As they adapt to managing diabetes while maintaining their usual lifestyle, they begin to reject the social narrative of being "sick and unable," realising effective management enables them to fulfil their desired identity.

### *2.5.2. Medical versus psychological diagnoses in shaping identity*

An important point of discussion to consider in interpreting the findings of this review is why a condition such as T1DM might be treated as more 'core' to identity than psychological diagnoses, for example, being labelled an 'anxious child'. Chronic medical illnesses, like T1DM, are often visible, embodied, and require ongoing management, meaning that they intrude into daily life in ways that shape both self-perception and social identity (Charmaz, 1995; Williams, 2000). By contrast, psychological conditions may be less visible, more situational, and more easily questioned by others, which can affect whether they are perceived as legitimate or central to identity (Pilgrim & Rogers, 2005).

The cultural hierarchy of diagnoses means that medical conditions such as T1DM are often understood as 'real' as they are biologically grounded, whereas psychological diagnoses are sometimes seen as more socially constructed, subjective and therefore less valid (Hacking, 1999; Pilgrim & Rogers, 2005). This distinction may explain why participants in the reviewed studies often described T1DM as a defining aspect of who they are, while conditions such as anxiety might be more readily positioned as secondary or transient aspects of identity.

Moreover, stigma also plays a role: visible medical conditions can result in social reactions that directly impact one's sense of self (Goffman, 1963; Scambler, 2009), whereas psychological conditions may lead to more hidden or internalised forms of stigma that do not always receive the same recognition. These differences suggest that future research on illness identity should continue to interrogate how the perceived legitimacy, visibility, and social consequences of different diagnoses shape their centrality to identity across contexts.

### *2.5.3. Clinical implications*

In considering what qualitative evidence tells us about how having a diagnosis of T1DM impacts individuals' identity, this review has highlighted important implications for clinical practice. It appears that diabetes services focus mainly on the medical elements of T1DM, such as informing patients what diabetes is and how to manage it, and attend only to the medical readings of patients during appointments. These experiences can lead to individuals feeling as though their diabetes is the only part of themselves that is cared about (Chalmers et al., 2022; Tilden et al., 2005). In addition, diabetes services seem to instill strict expectations of how patients should manage their diabetes, reprimanding them for not adhering to these, due to the assumption that non-adherence is through patient choice and a lack of understanding of the medical consequences of not managing diabetes. This leads some to feel misunderstood by services and restricted by their diabetes in terms of what they can do and eat, leading to a desire to want to rebel against medical professionals and the condition itself (Dovey-Pearce et al., 2007; Chalmers et al., 2022).

The general medical approach to T1DM takes a reductionist view that T1DM only impacts the body of the individual. The findings of this SLR indicate that T1DM impacts most aspect of an individual's life, in terms of their mental health, how they view themselves, how they behave, and how others view and treat them. Therefore, services need to take the time in appointments to speak with their patients about how they are doing beyond their

diabetes. Services also need to appreciate that there are multiple and complex reasons as to why an individual may struggle to adhere to their diabetes management and explore these with service-users.

Clinical psychologists in the UK play an important role in diabetes services and form part of the multi-disciplinary care offered to patients (NICE, 2022). The findings from this SLR imply that it would be valuable if clinical psychologists working with individuals with T1DM explored identity in their assessment and incorporated it into their formulation and intervention if relevant for the individual.

The use of third-wave psychological therapies, such as Acceptance and Commitment Therapy (ACT) and Compassion Focused Therapy (CFT), may be useful interventions in helping those with T1DM who are struggling with identity. ACT could be used with individuals who believe having T1DM means they are unable to follow their values and goals in life. Psychologists/therapists could work with them to incorporate activities into daily life that adhere to these values (Bennett & Oliver, 2019), expanding identity beyond 'just' T1DM. Techniques from CFT, such as building a compassionate self (Gilbert, 2009), may also be useful for individuals who may be experiencing significant amounts of shame/self-criticism as a result of T1DM and internalised stigma.

It is also important to note that the findings of this SLR highlight that the impact of T1DM on identity extends beyond the individual, with wider societal factors, such as stigma and the attitudes of others, playing a significant role in the construction of the diabetic identity, and how individuals subsequently respond to it. Therefore, it is important that services acknowledge and begin to address these wider factors. Ways that such factors could be addressed by clinical psychologists includes using techniques from systemic therapeutic interventions. An example is using techniques from narrative therapy, such as the tree of life

(Ncube, 2006), which explores the individual's stories, life, interests, and strengths to help extend identity beyond just their diabetes (Casdagli et al., 2017; Mishali et al., 2010). In addition, services could also implement wider-scale change by co-producing educational materials, such as workshops, posters, and teaching materials, with service-users to distribute across local communities.

### *2.5.4. Strengths, limitations, and recommendations for future research*

A strength of this SLR was that the primary studies used a variety of participants from various countries, a fairly even representation of male and female participants, with a wide age range of 10-76. Despite this heterogeneity, the results of the primary studies showed consistency in terms of how T1DM impacts identity, how participants respond to this impact, and some of the influencing factors, indicating a robustness in the importance of considering identity in T1DM.

In addition, another strength of this review was the careful appraisal of the literature included in the thematic synthesis. The CERQual tool showed all sub-themes, except for two with a moderate confidence level, were rated as having a high level of confidence. This was due to most of the primary studies comprising these themes having no concerns. This detailed appraisal indicates that the themes drawn from the data analysis accurately represented the data collected, increasing the strength of the conclusions drawn from this review.

This review used two databases for its literature search. Whilst it may be considered that only searching two databases for relevant literature is a limitation, with Ewald et al. (2022) finding that searching two or less databases has been found to miss more relevant articles than searching three or more, there is confidence that all relevant literature was found due to the scoping exercises informing the search strategy described earlier. There were, however, no date limits were set on the literature search resulting in 4 of the 13 collected studies being over ten years old. This means that the experiences collected in the research

may not represent social narratives and service experiences that are held today, which may reduce the validity of these findings.

A limitation of this review is that screening and data extraction were conducted by a single reviewer, without independent verification. This increases the risk of bias and contrasts with Cochrane recommendations, which advise at least two reviewers to reduce errors and improve reliability (Higgins et al., 2022; Noyes & Lewin, 2011).This limitation related to the exclusion of Browne et al. (2014). Due to the complex and multi-faceted nature of identity, the study did not initially appear directly relevant to the review question and was therefore excluded. Retrospectively, it contains data pertinent to the impact of T1DM on identity. This highlights how relying on a single reviewer may increase the risk of overlooking relevant studies, which could have been mitigated with a secondary reviewer.

Another limitation of this review is the potential for an incomplete search strategy. Although systematic methods were used, only 140 studies were initially captured, which is a relatively small number for a topic of this scope and may reflect the difficulty in capturing all relevant literature. Identity is a dynamic and multi-faceted construct, and qualitative research may use diverse language to describe similar phenomena. This increases the risk of bias and reduces the replicability of the screening and extraction process, which goes against recommendations from Cochrane (Higgins et al., 2022; Noyes & Lewin, 2011).

The topic of this SLR was limited to specifically examining *how* T1DM impacts identity. This meant that it did not report on the consequences of this impact on individuals with T1DM. For example, individuals who reject their T1DM from identity have been found to have higher levels of mental health difficulties, such as depression and anxiety, both of which subsequently further impact participants' relationship with their T1DM (Oris et al., 2016; Rassart et al., 2021).

Further investigation into the consequences of impacted identity may provide a deeper understanding of the significance of identity in the field of T1DM. It is apparent that the evidence base is missing research that aims to understand how identity in T1DM may be linked to the experiences of comorbid mental health difficulties.

### 2.6. Rationale for current study

Chapter 1 highlighted that current interventions are unsuccessful in helping those with T1ED, and clients have expressed that current services do not understand the role that diabetes has within their ED. It also portrayed a wealth of evidence indicating the importance of an individual's feelings towards T1DM and ED as diagnoses, and how EDs are perceived to impact identity. The findings of this SLR also highlight that T1DM has a significant impact on identity, resulting in a mixed feelings towards T1DM.

Exploring how individuals with T1DE feel towards their T1DM and ED, how they feel their identity has been impacted by both, and if there are differences between the two could offer further insight into how T1DE is being maintained. This provides the rationale for the study that follows.

### 2.7. Aim and research questions

Informed by literature presented in the introduction (Chapter 1) and the findings of the SLR (Chapter 2), Chapter 3 will describe a study that aimed to explore the following research questions:

1. How do clients with T1DE feel towards their T1DM and what impact does the diagnosis of T1DM have on their identity?
2. How do clients with T1DE feel towards their T1DE and what impact does T1DE have on their identity?
3. What are the roles of identity and feelings towards diagnoses in maintaining T1DE?

According to Fryer (2023), in order for qualitative research to align with a CR stance, at least one research question needs to relate to casual mechanisms, this has been attempted in question three.

# CHAPTER 3: METHOD

## 3.1. Chapter overview

The purpose of this research is to understand how participants with T1DE relate to their T1DM and ED, how they perceive both to have impacted their identity, and to explore the role of identity and relationship with diagnoses in maintaining T1DE. This chapter describes how this purpose was achieved through the researcher's methodology. The chapter opens with an explanation of the research design, why it was chosen, and how it links to the researcher's epistemological position. It then moves through the research process covering consultation, data collection, procedure, participant demographics, and ethical consideration. The chapter closes with a discussion on quality appraisal.

## 3.2. Design

### *3.2.1 A qualitative stance*

The aim of qualitative methods is to explore the individuality and subjectiveness of human experiences through leaning on the concept of intersubjectivity, which argues that each individual will construct and attach their own meanings of an experience based on previous experiences and social context (Austin & Sutton, 2014; Creswell, 2014; Todd et al., 2004).

The study's aims are to explore how individuals with T1DE relate to their T1DM and ED, and how they feel both have impacted their identity. A qualitative approach, therefore, is suitable to achieve these aims as it captures participants' unique and subjective lived experiences that quantitative methods would not (Hennink et al., 2020; Padgett, 2016; Willig

& Rogers., 2017). In addition, the shortage of knowledge about T1DE, has been attributed to the lack of qualitative research exploring the experiential perspectives of clients (Goddard & Oxlad, 2023; Wisting & Snoek, 2020). Using a qualitative approach in this research would, therefore, also begin to fill gaps in the current research literature about T1DE.

In addition, a qualitative design is better suited to the CR stance of this research. The use of a quantitative approach would have entailed capturing numerical data used to represent an objective reality, which is in line with a positivist stance (Park et al., 2020). A CR stance wishes instead to encapsulate emotions, experiences, and identity, which are dynamic concepts that exist within the unique realities of each individual but can still be captured and analysed using qualitative methodologies (Junjie & Yingxin, 2022; Parker & Bavel, 2014).

### *3.2.2 Reflexive thematic analysis*

Reflexive thematic analysis (RTA) is a theoretically flexible, interpretative approach to qualitative data that identifies and analyses patterns to create broad descriptions and understandings of individual experiences using a six-step model (Braun & Clarke, 2012, 2022).

The reflexive element of RTA is to highlight that the researcher holds pre-existing and ongoing ideas and biases toward their data, which will play an active role in the knowledge produced from their analyses (Braun & Clarke, 2019). When using RTA, the researcher is therefore expected to be thoughtful and reflexive when engaging with their data to consider how their assumptions and biases are influencing their interpretation (Braun & Clarke, 2019).

As this research aimed to explore repeated and consistent patterns of meaning across participants, RTA was chosen as the most suitable method of analysis (Braun & Clarke, 2006). In addition, RTA is theoretically flexible, meaning that it could be adapted to fit this research (Braun & Clarke, 2020; Fryer, 2022). This does not mean RTA is atheoretical.

Instead, Braun and Clarke (2020) argue that it is the job of the researcher to reflect on the theory informing their use of RTA, in relation to their: epistemological framing, orientation to the data, whether latent or semantic coding was used, and their qualitative framework. How this research used and adapted theory to inform the use of RTA is described in the following paragraphs.

In regard to epistemology, initially Braun and Clarke (2006) argued that RTA was suitable to be used within any stance. More recently, both authors have moved away from this thinking, and instead argued that RTA is best used within constructivist and CR stances and to avoid positivist approaches (Braun & Clarke, 2019; 2020). This view is in line with the epistemological stance of this research and thus contributed to why it was chosen.

In terms of orientation to data, this research will take an inductive stance, which is also favoured by RTA (Braun & Clarke, 2012). An inductive approach is more in line with the aims of this research because it allows the data analysis to be driven by the participants' experiences, as opposed to reducing it to fit within pre-created themes, limiting the richness of the data analysis (Braun & Clarke, 2012).

This research used both semantic and latent coding and did not prioritise one over the other so not to miss valuable meaning from the data collected. This research acknowledged that the participants would construct meaning within their data that could be collected via semantic coding, but the researcher would also ascribe meaning to the data, that could be captured by latent coding (Braun & Clark, 2012; 2013; Bryne, 2022).

In addition, this research adopted an experiential qualitative framework. This framework focuses on participant experiences and perspectives and looks for meaning given to the data by participants (Braun & Clarke, 2012; Bryne, 2022. This is opposed to a critical approach, which attempts to analyse data to comment on the social construction of the

research topic (Terry et al., 2017). An experiential approach was, therefore, directly in line with this research's aims. Adoption of an experiential orientation for data analysis also suits a CR stance, as it acknowledges the data produced are the thoughts, feelings, and experiences that exist as objective truths within the unique reality of each participant but can be influenced by wider narratives and analysed to produce tangible understanding (Bryne, 2022).

### *3.2.3. Considerations of alternative methods*

Various qualitative approaches were considered when exploring what method would best answer the research questions of this research and facilitate its aims. A brief outline of alternative methods and rationale for their rejection, along with the rationale for choosing RTA, is presented in Table 9.

**Table 9**

*Consideration of other methods and rationale for RTA*

| Alternative qualitative method | Description of alternative method | Reason for rejection and choice of RTA |
|---|---|---|
| Narrative analysis | Focuses on the socially constructed stories participants narrate in their data due to the underlying theoretical assumption that stories are a crucial way humans understand their experiences (Earthy & Cronin, 2008; Smith, 2016; Frosh & Emerson, 2005). There is a focus | This method was considered for this research, but the focus on how participants' stories are told to make sense of their lived experience, did not best fit the aims for this study (Burck, 2005). This is because the aims and questions of this study were not around the stories of the |

| | | |
|---|---|---|
| | on how the story has been told and organised to make sense of a lived experience (Reissman, 2007). | participant, but instead what their experiences were to find consistent themes.<br><br>RTA instead looks for broader themes across participants' data that represent their experiences and can be interpreted to try to understand the deeper meanings behind these experiences, which was better suited for the aims of this research (Smith, 2016). |
| Grounded theory | The aim of grounded theory is to construct a theory/theories which develop explanatory frameworks for *how* social phenomena can occur (Tarozzi, 2020; Turner et al., 2021). | The aim of this research was to explore *what* the experiences were of participants with T1DE and interpret the meaning behind them, as opposed to *how* these phenomena occur.<br>RTA was therefore deemed more suitable for this purpose. |
| Discourse analysis | Discourse analysis aims to understand how and why participants use language to | The aim of this thesis was not to understand why participants used the language they did in their |

| | | |
|---|---|---|
| | describe an experience(s), and how this language shapes and is shaped by social contexts (Biggerstaff & Thompson, 2008; Cheek, 2004; Hjelm, 2021; Smith & Thompson, 2015). | letters. Instead, this research wanted to identify the patterns across the data collected and interpret the meanings behind them, which is better suited to RTA. |
| Interpretive Phenomenological Analysis (IPA) | IPA explores human experiences of a phenomenon of interest by directly asking those who are experiencing it (Reicher, 2000). Through this exploration IPA seeks to makes sense of how individuals make sense of their unique experience (Smith, 2015; Smith & Nizza, 2022). | RTA looks for broader themes and meanings of experience which, unlike IPA, can be generalised to broader populations which is in-line with one of the hopes of this research of being applied to broader clinical T1DE settings (Tuffour, 2017).<br><br>In addition, IPA generally only collects data using interviews which this research was not using for data collection, whereas RTA can be applied to any qualitative data collection (Murray & Wilde, 2020). |

### *3.2.4 Limitations of RTA*

A dominant critique of all forms of thematic analysis is that theme generation is highly subjective (Terry et al., 2017). RTA was adopted by Braun and Clarke (2023) to acknowledge this subjectivity throughout the research process. Despite reflexivity being an inherent part of RTA, there is often a lack/inappropriate use of reflexivity in research. In their critical review, Braun and Clarke (2023) argued that RTA is significantly limited when researchers do not detail how they were reflexive and fail to acknowledge the power they hold, which has an unavoidable influence on the research process (Braun & Clarke, 2022). Failure to properly use reflexivity in RTA creates the false assumption that the themes produced were formed objectively and thus weakens the analysis. In addition, the flexibility of RTA can lead to an inconsistent and incoherent approach to theme generation, resulting in lower quality themes that lack reliability and validity (Holloway & Todres, 2003).

## 3.3. Consultation with experts by experience (EBE)

Working alongside individuals who have lived experiences of the study's phenomena of interest is invaluable and improves the quality of the research process and outcomes (Trivedi & Wykes, 2002). Following contacting the BEAT ED charity asking for potential EBEs to consult on this research, two individuals contacted me via email and agreed to consult. Both individuals were male. One was white British, one was black British with African heritage. Both described themselves as being recovered from T1DE consented to consult in the research process and shared their excitement about the prospect of the research, both viewing it as a widely neglected topic.

Working alongside these consultants was highly valuable and significantly shaped this research. Both highlighted the importance of recruiting from non-clinical settings, as well as clinical ED settings, because often individuals with T1DE are missed by clinical services for reasons such as T1DE not being a formal diagnosis. In addition, it was originally planned for

this research to ask participants to only write letters to their T1DE. One consultant expressed their concern that this approach would be a continuation of the narratives they had experienced in services, that their T1DM was not included in the consideration of their T1DE. Therefore, data collection plans were changed to also include a letter to T1DM. The consultants also helped to refine the letter writing instructions given to participants to ensure the language was acceptable and captured the purpose of the letters.

## 3.4 Data collection

Data collection took place between April 2024 and December 2024. Advertisements inviting participation were disseminated via social media, charities, and an NHS service, as described in Figure 3 and section 3.6.

### *3.4.1 Online survey*

A survey, hosted on Qualtrics, was used to screen participants based on the inclusion and exclusion criteria (Table 11). Subsequently, from eligible participants, the survey collected: demographic information, email address, a self-assigned ID number, and whether they would like to be entered into a prize-draw and receive the final write up of the research. Email addresses were collected to be able to send participants letter writing instructions, information for further support, reminder emails, prize-draw vouchers, and the final write up. The demographic questions asked about participants' gender identity, current age, their age at diagnosis of T1DM and T1DE. Justification for the collection of this demographic information can be seen in Table 10.

**Table 10**

*Demographic data collected with justification*

| Demographic collected | Justification |
|---|---|
| Gender identity | Previous research found gender differences in disordered eating behaviours, relationship with diagnosis and body dissatisfaction in individuals with T1DE (de Lima et al., 2017). By collecting information on gender, it is possible this research may observe differences in themes between gender identities which can then support or challenge previous research. It may also lead to the opportunity of further study of the data we collect, specifically analysing if there are gender differences present in the letters or if particular gender identities are missing, to consider why this could be to advise future research. |
| Age of ED diagnosis/age when first began struggling with ED (T1DE) | According to existing research, a diagnosis of T1DM generally occurs prior to struggling with an ED, leading to T1DM being named as a risk factor for T1DE (Ogle et al., 2022; Hudson et al., 2007; Micali et al., 2013; Steinhausen & Jenson, 2015). Collecting information regarding age of diagnoses will contribute to the existing evidence base and to the understanding of clinical risk factors for T1DE and possibly result in opportunities for future research to explore the relationship between ages of diagnoses and T1DE, for example to explore prevention. |

### *3.4.2 Letter writing*

Data on how participants' felt towards their diagnoses, and how they felt their diagnoses had impacted their identity, were collected via the writing of two letters. One letter was addressed to their T1DM and the other to their T1DE. Participants were given the choice to hand write, electronically write or speak their letters. A set of letter writing instructions (Appendix H) were created and emailed to eligible participants. These instructions informed participants that the purpose of the letters was to explore their feelings towards their T1DM and ED and how they feel both have impacted their identity. Participants were instructed to write as if speaking directly to their T1DM and ED and assured there was no right way to write their letters but instead to share what felt right for them. The instructions also included broad guidance and prompts on possible topics participants could write about. Examples of the prompts include '*How has your diabetes/eating disorder influenced the way you view yourself?'* and '*what are your feelings towards your diabetes/eating disorder? Why do you think these are your feelings?'.* The letter-writing instructions were deliberately broad, allowing participants to focus on the aspects of their experience they considered most important, rather than directing them toward predefined topics. The instructions also detailed how to send their letters to the research team.

Participants were given four weeks from completion of the survey on Qualtrics to send their letters. A prompt email was sent to participants at two and four weeks if their letters had not been received.

Collecting data in the form of a letter was chosen for various reasons. Compared to interviews, letter-writing allows a greater degree of confidentiality (Stamper, 2020), as well as allowing participants to use their own language and focus on issues they feel are most important to them, as opposed to being guided by the researcher (Flemming, 2020). Letter writing directly to diagnoses also facilitates externalising, a technique used in narrative therapy where a 'problem' is positioned outside of the person (Chimpen-Lopez & Arriazu-Munoz, 2021). Externalising has been found to help the individual disengage from their problem, allowing them to explore their relationship with it and the impact it has had on them (Lock et al, 2004; White, 2004), which is line with the aims of this research.

In addition, the use of writing two letters to an externalised AN as a 'friend' and as a 'foe' is a current therapeutic technique used in The Maudsley Model of Anorexia Nervosa Treatment for Adults (Schmidt, Startup & Treasure, 2018). The technique has been found to be an effective tool for clients to explore the complex relationship they have with their illness and acknowledge the function of AN; clients have expressed finding it easier to write about their difficulties rather than speak about them (Serpell, 1999; Williams & Reid, 2010).

Writing letters to T1DM was found to be liberating and reduce feelings of resentment and isolation commonly experienced by this patient group (Piana et al., 2010). Given the current use of letter writing in this field to produce meaningful data, and potential benefits this method has been shown to have for this population within clinical settings (Williams, 2024), the use of letter writing in this study was deemed suitable.

**A Reflection**

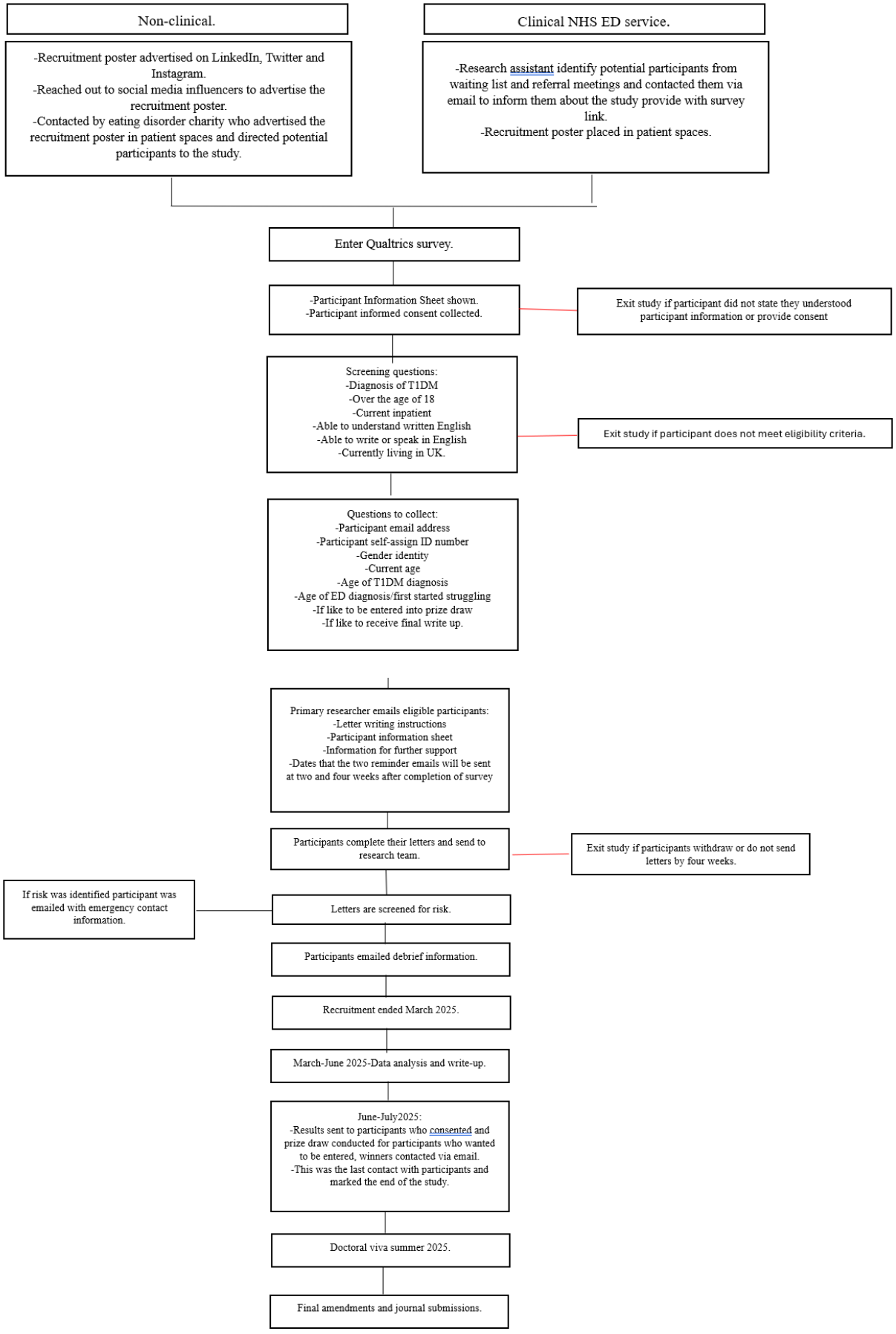
*I had a dilemma for a while over what way I wanted to collect my data between either letter writing or interviews. I viewed interviews as a more 'traditional' way to collect data in qualitative research that papers may prefer when it came to publishing. I was also very worried about recruitment, my thinking was that T1DE was niche anyway, so I anticipated getting people through the door would be difficult, then asking them to write two letters, in their own time, might be too much. Whereas interviews felt safer, people had an appointed time with a researcher so there was some 'accountability'. But, I thought that if the data we could collect with letters, where participants had their own space and time to write to and explore these two diagnoses that have been so prominent in their lives, would be so powerful. I went back and explored one of my 'whys' behind this research, and it wasn't about the (potentially) quickest and easiest way to collect data, it was about wanting to present something that is meaningful and serve the client group that this is all for-this led to my decision to choose letter writing as the data collection method.*

### 3.5 Procedure

Figure 3 portrays the full procedure of this study.

**Figure 3**

*Procedure of empirical research*


Non-clinical.
-Recruitment poster advertised on LinkedIn, Twitter and Instagram.
-Reached out to social media influencers to advertise the recruitment poster.
-Contacted by eating disorder charity who advertised the recruitment poster in patient spaces and directed potential participants to the study.
Clinical NHS ED service.
-Research assistant identify potential participants from waiting list and referral meetings and contacted them via email to inform them about the study provide with survey link.
-Recruitment poster placed in patient spaces.
Enter Qualtrics survey.
-Participant Information Sheet shown.
-Participant informed consent collected.
Exit study if participant did not state they understood participant information or provide consent
Screening questions:
-Diagnosis of T1DM
-Over the age of 18
-Current inpatient
-Able to understand written English
-Able to write or speak in English
-Currently living in UK.
Exit study if participant does not meet eligibility criteria.
Questions to collect:
-Participant email address
-Participant self-assign ID number
-Gender identity
-Current age
-Age of T1DM diagnosis
-Age of ED diagnosis/first started struggling
-If like to be entered into prize draw
-If like to receive final write up.
Primary researcher emails eligible participants:
-Letter writing instructions
-Participant information sheet
-Information for further support
-Dates that the two reminder emails will be sent at two and four weeks after completion of survey
Participants complete their letters and send to research team.
Exit study if participants withdraw or do not send letters by four weeks.
If risk was identified participant was emailed with emergency contact information.
Letters are screened for risk.
Participants emailed debrief information.
Recruitment ended March 2025.
March-June 2025-Data analysis and write-up.
June-July2025:
-Results sent to participants who consented and prize draw conducted for participants who wanted to be entered, winners contacted via email.
-This was the last contact with participants and marked the end of the study.
Doctoral viva summer 2025.
Final amendments and journal submissions.

## 3.6 Participants

### *3.6.1 Sampling and Recruitment*

As guided by an EBE consultant, participants were recruited from clinical and non-clinical settings. Given the nature of data collection relying on participant motivation to complete the letters in their own time, participant recruitment was anticipated to be one of the biggest challenges for this research. Convenience sampling was therefore used as it has been found to ease recruitment when it is anticipated to be difficult (Stratton, 2021). In addition, various avenues of recruitment strategies were used.

### *3.6.2 Recruitment from non-clinical settings*

A recruitment poster (Appendix I) was created and distributed on the social media platforms LinkedIn, X, and Instagram. These platforms were chosen for their wide reach and their provision of allowing potential participants to contact the primary researcher to ask questions (Bender et al., 2017). Research accounts were created for Instagram and X for the purpose of research advertisement and recruitment, and both were closed when recruitment ended. A UK ED charity reached out after seeing the poster on LinkedIn to enquire about the nature of the research. After presenting the research aims and questions to the team, the charity agreed to place the poster in their patient spaces and make potential participants aware of the research.

The charities Diabetes UK and Breakthrough T1D (formerly JDRF), whom have a significant reach in the UK for those with T1DM, shared the study on their websites and social media platforms. Social media influencers who had T1DM were also contacted by the primary researcher because of their wide-reaching audience and the fact that influencers speaking about mental health has been found to encourage the public to also speak about and engage with their mental health (Horgan & Sweeney, 2010). Some influencers shared the recruitment poster on Instagram ‘stories’ and expressed their views on the importance of this research for the T1DM community.

### *3.6.3 Recruitment from clinical settings*

The clinical setting used to recruit participants was an NHS adult eating disorder service that will remain anonymous to protect participant confidentiality. This service was chosen due to it serving a large and diverse population. The study was introduced to the service manager, lead psychologist, research assistant, and the service's research meeting was attended by the primary researcher to discuss a recruitment strategy.

The research assistant used the service's waiting list and referral meetings to identify potential participants. Once identified, the research assistant contacted potential participants via email providing them with the study information and a link to the survey. The recruitment poster was also placed in patient waiting rooms. A psychological lead from another NHS ED service also saw the recruitment poster on LinkedIn and made contact to enquire whether the poster could be displayed in their patient waiting room. This was arranged and facilitated following consultation with the NHS ethics committee.

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**A Reflection**

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*The decision to recruit participants from both NHS and non-NHS settings was shaped by reflexive consideration of the research context and input from EBEs. EBEs highlighted that because T1DE is not an official diagnosis, many individuals do not access NHS services, and those who do may face strict eligibility criteria due to overburdened services, excluding many from meeting service remit. Recognising this, I understood that limiting recruitment to NHS settings would risk excluding a substantial portion of the population whose experiences are central to the research question. By including non-NHS settings, I was able to access a more diverse range of experiences, capturing perspectives that might otherwise remain invisible in research prioritising formal clinical pathways. In addition, the choice for the clinical recruitment pathway to be based in an ED service also stems from me as the primary researcher. I know the ED service and their research processes well, meaning direct contact with them was quicker and smoother compared to reaching out to a new service, which in the context of a DClinPsych thesis where time is very limited, was preferable.*

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### *3.6.4 Participant criteria*

The full list of inclusion and exclusion criteria can be seen in Table 11.

**Table 11**

*Participant inclusion and exclusion criteria*

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| Diagnosis of type 1 diabetes mellitus | Diagnosis of type 2 diabetes mellitus |
| A current or historical diagnosis of an eating disorder or self-identify as having disordered eating | Currently an inpatient in a general or ED hospital |
| Over the age of 18 | Under the age of 18 |
| Able to understand written English | Unable to understand written English |
| Able to write or speak in English | Unable to write or speak in English |
| Currently living in the United Kingdom | Currently living outside of the United Kingdom |

All participants needed to be over the age of 18 at the time they completed the Qualtrics survey. Anyone under the age of 18 was excluded to ensure that this research did not recruit minors, meaning participants were all adults and able to give informed consent for their own participation.

Participants who were an inpatient in a general or ED hospital were also excluded from the study. This is because, when an individual is hospitalised, they are more vulnerable due to the risk posed to their physical and mental health (Bracken-Roche et al., 2016). In addition, some individuals hospitalised for a physical or mental health condition may lack

capacity to consent for their participation (Moran-Sanchez et al., 2016). Therefore, asking hospitalised participants to complete two letters that have the potential to cause distress, with the possibility they were unable to provide informed consent, would have been unethical.

Participants who were not in the UK were excluded because information for further support provided to participants were UK based and thus would only be relevant and accessible to those within the UK. Participants who could not understand, speak and/or write in English were excluded. This was because this research had a limited budget; transcription services could not be used, and participant letters could not be translated to English. Participant materials were also all written in English and an understanding of English was required to make an informed decision about participation and to provide consent.

### *3.6.5 Participants demographics*

To participate in the study, participants had to complete the Qualtrics survey and meet the inclusion criteria. In total, there were 52 responses to the survey. Twenty-three participants did not meet the inclusion criteria (3=outside of the UK, 20=did not have T1DM). Of the 29 participants that did meet criteria, one participant did not want to provide their email address and 17 did not send their letters within the four-week timeframe. The final sample size was 11 participants: two recruited from a clinical setting, nine recruited from a non-clinical setting. Demographic information, as well as age of diagnosis for T1DM and ED, are presented in Table 12.

**A Reflection**

*Control is a word that makes a significant appearance throughout this project and the recruitment stage highlighted that it has a significant role in my life. Heavy workloads do not, generally, stress me out, in fact weirdly I enjoy them. What does stress me out, as this stage of this thesis taught me, was having a heavy workload and not being able to 'do' anything to progress. At one stage everything I could be 'doing' for this thesis had been done, and I had to sit and wait for participants and letters to come in. This was not a good time. I found myself caught in the cycle of thinking 'what if I get no one?' 'I should have been safer and done interviews', checking my Qualtrics responses and emails for outstanding letters multiple times a day, endlessly scrolling social media for influencers to reach out to as an attempt to trick myself into thinking I was doing something 'productive'. When really, as I should have known, it simply fuelled my stress and anxiety and the cycle repeated. During this time, I found myself projecting the high standards I set for myself onto participants; 'why enter a study and not do the main bit?', 'why are they making me wait?'. I aired this cycle and frustration to my partner who said the most helpful thing he could have done; 'this is your entire world right now, whereas it is one tiny part of theirs, life happens, and people get busy but trust that you will get there'. I reflected back to an early page in my reflexive journal where I wrote that my choice of letter writing could be risky as it places all the burden and responsibility on the participant to carve out time in their own lives to complete a heavy task. Many times, during recruitment, especially when participants did not send their letters, I wanted to change everything and do interviews. This choice would have been the wrong one. Not only because I know now it did all work out, but because that decision would have been driven by me wanting to place some control back in my hands. Hindsight is known to be wonderful, but reflecting on this time, knowing the outcome, has taught me the importance of resting and letting go of your research for a while and trusting your participants, because that would have been a much more 'productive' use of my time then scrolling reddit threads on 'what to do if you get no participants'. I also neglected my journal in these times because I was too caught up in the cycle. I think if I'd have paused and I could have explored sooner where this anxiety was coming from and what I was trying to achieve through my actions.*

**Table 12**

*Participant demographics*

| Pseudonym | Age | Gender | Age of T1DM diagnosis | Age of ED diagnosis OR age when first began to struggle with ED |
|---|---|---|---|---|
| Charlotte | 19 | Female | 4 | 17 |
| Emma | 52 | Female | 5 | 30 |
| Abigail | 57 | Female | 12 | 23 |
| Susan | 32 | Female | 16 | 28 |
| Alice | 28 | Female | 5 | 22 |
| Grace | 43 | Female | 11 | 42 |
| Amelia | 25 | Female | 12 | 17 |
| Jane | 28 | Female | 8 | 23 |
| Eve | 35 | Female | 34 | 14 |
| Taylor | 37 | Female | 27 | 13 |
| Luna | 59 | Female | 9 | 57 |

**A Reflection**

*There is an ongoing pattern in ED research that those who identify as male are underrepresented. This research continues this pattern because all the participants that entered the study (including all those that were excluded or withdrew) identified as female. I have continued to reflect and think about why no males participated in this research. It could be because the non-clinical route of recruitment involved me circulating the research poster on my social media platform which are predominately networks of women. The clinical route was through a service whose client group are also predominately female, but I think it runs deeper than that. As documented throughout this research, I strongly align with the female element of my identity and feel passionately about the continued discourses around and pressures upon the female body. I think this created a blind spot in me which meant that when I saw all the participants I was getting were female, I did not stop and adjust my recruitment strategy to try and recruit more men. In brutal honesty, I did not see it as a problem. My positionality may have also influenced how I coded the letters, attuning me more readily to experiences and themes that resonated with my understanding of female experiences of T1DE, linking participants semantic experiences back to patriarchal discourses of thinness and beauty.*

*Will this experience change the way I recruit in the future to try and capture the male experience? Yes. But I don't think there being men that exist in the UK who struggle with T1DE, which we did not capture in this study, undermines the experiences and stories of the women that we did represent. Instead, it further highlights the need to challenge patriarchal discourses around masculinity and what mental health difficulties men are, and are not, 'allowed' to struggle with, which was not the job of this research.*

### 3.7 Ethical considerations

Ethical approval was obtained from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (HSETECDA)

(protocol number: acLMS/PGR/UH/05560(1)) (Appendix J) for recruitment from non-clinical populations. Approval was also needed from the NHS Health Research Authority (HRA) in order to recruit from the selected NHS Trust. The application was then reviewed by the Research Ethics Committee (REC) and discussed with the research team at the REC meeting. The REC then sent their amendments, which were responded to (Appendix K). NHS HRA approval was granted on 06/06/2024; IRAS Project ID: 340832, REC reference: 24/LO/0400 (Appendix L).

Following HRA approval, the Trust's Research and Development (R&D) Department was contacted for confirmation of the Trust's capacity and capability (C&C) for the trust to have the status of a research site through authorising the organisation information document (OID) (Appendix L). Full sponsorship was then requested and granted from the University of Hertfordshire HSETECDA (Appendix L).

### *3.7.1 Informed consent*

Upon accessing the initial Qualtrics survey, prospective participants saw the participant information sheet (PIS) (Appendix M). The PIS outlined the purpose of the study, their right to withdraw and how to do so, inclusion and exclusion criteria, what the study involved, potential risks and benefits, the risk management protocol, confidentiality statement, and information about the prize draw. Following this information, participants were asked for their informed consent to participate (Appendix N). If they did not wish to provide their consent, their involvement in the study ended.

### *3.7.2 Right to withdraw*

Participants were made aware, via the PIS, that their participation in the study was voluntary and they had the right to withdraw up to two weeks after they had sent their letters. They were also informed about the process to do this. If participants had completed the survey but had not sent their letters after four weeks, it was assumed they had withdrawn.

### *3.7.3 Confidentiality*

No identifiable information was collected from participants until they passed the screening questions and provided informed consent. The only identifiable information collected from consenting participants was their email address. Eligible participants self-assigned a six-digit ID number that was used to store participant data and link letters to survey answers anonymously. Participants were asked not to include any identifiable information in their letters and, if any was included, it was redacted by the primary researcher prior to saving. Each set of letters were assigned a pseudonym by the primary researcher for the write up of the findings. All participants were also informed in the PIS that the findings would be written up and disseminated, which would include anonymised quotes from the letters.

### *3.7.4 Data protection*

Demographic data was collected on Qualtrics, which is a secure, password-protected online platform. Once a participant had completed the survey, their information was transferred to a password protected Excel spreadsheet saved onto the University of Hertfordshire (UoH) secure OneDrive, and the information on Qualtrics was deleted. The excel spreadsheet was deleted once the study was completed. Only the primary researcher had access to these platforms.

Electronically written and spoken letters were sent to and stored on the UoH outlook of the primary researcher, which was secured by a two-factor authentication system. Written letters were posted to the DClinPsy administrators office at UoH. These letters were then scanned by the primary researcher and stored in a password protected folder on the UoH OneDrive until transcription. All original copies of the letters were permanently deleted or destroyed in confidential waste.

All letters were transcribed onto a password protected Microsoft word document by the primary researcher. All letters were stored in a password protected folder on the UoH OneDrive that only the primary researcher had access to.

Participants who opted to be entered into the prize draw signed pay agreements that were emailed to them and stored on a password protected folder on the UoH OneDrive until study completion. They were then permanently deleted.

The full anonymised versions of participants letters will be stored by the principal supervisor for five years for potential re-analysis and as a teaching tool for trainee and qualified health professionals. After five years, these letters will be permanently deleted.

### *3.7.5 Risk of distress and management of risk*

The letter writing task had potential to cause distress for some participants, due to it possibly surfacing difficult emotions. Participants were informed in the PIS that letter writing may be an emotional process. To mitigate distress, they were encouraged to speak to someone they trusted and their diabetes/ED team about participating, and, if they chose to participate, reach out to these individuals if they found any element of the study difficult.

Prior to writing their letters, participants were also provided with information of where to seek further support if needed, and this information was sent again in the debrief sheet (Appendix O). Participants were informed of, and consented to, the agreement that it was their responsibility to keep themselves safe during and after the study, and to seek support should they feel that they need to. In the letter writing instructions, participants were encouraged to take their time and informed that they could stop writing and withdraw from the study at any time if they felt it was too distressing. It was also recommended that participants plan self-care activities for once they had finished their letters.

There was also the potential of participants disclosing risk to self in their letters. A risk protocol was put in place and conveyed in the PIS. All letters were screened for risk by the primary researcher. If the letter did elicit risk concerns, a risk email was to be sent to participants conveying these concerns and information for risk management and emergency services that they were encouraged to contact (Appendix P). No risk emails needed to be sent in this study.

The content of letters was emotive to read and analyse and, as a result, the primary researcher needed to be aware of and protect their emotional wellbeing. A reflexive journal was used to keep note of the emotional reactions experienced by the primary researcher when reading the letters and explored the possible reasons why some letters elicited stronger reactions than others, such as whether it hit close to personal context and experiences. By continuously taking note and reflecting on emotions, the primary researcher was able to become aware of the potential biases they held during the RTA analysis (i.e., paying more attention to extracts that caused a greater emotional response). In addition to journalling and using supervision to share any emotional impact, the primary researcher tried to maintain their overall mental wellbeing during this time.

### *3.7.6 Thanking participants*

Participants were given the opportunity to be entered into a prize draw as a thank you for their participation. The first name drawn was gifted a £40 Love2Shop voucher and the second name was gifted a £20 Love2Shop voucher. Names were drawn in June 2025 and the winning participants were informed via email. Participants were entered into this prize draw even if they had withdrawn from the study.

### *3.7.7 Redacted information*

Any references participants made to specific calories, rules or rituals they followed as a result of their ED, or how their ED perceived insulin, were redacted. This was to reduce any

distress experienced by readers of any output resulting from this work, and to reduce the risk of comparison or planting new thoughts or beliefs for any reader struggling with T1DE.

### 3.8 Data analysis

Data analysis of anonymised letters followed the six-steps of RTA (Table 13) outlined by Braun and Clarke (2012; 2013; 2014; 2020). A breakdown of how these steps were followed is detailed in Table 13. These phases were not followed linearly but, instead, moved forwards and backwards when necessary (Braun & Clarke, 2020).

**Table 13**

*The six steps of RTA (Braun & Clarke, 2012; 2013; 2014; 2020)*

| RTA Phase | How it was carried out by researcher |
|---|---|
| **Phase 1: Data familiarisation** | The primary researcher read each letter transcript multiple times to become familiar with and immersed in the letter's content. Letters were read electronically, and initial annotations were made to record initial thoughts, trends, patterns and links. Familiarisation doodles (Braun & Clarke, 2013) were then developed from these annotations. |
| **Phase 2: Generating initial codes** | Each letter was coded by the primary researcher manually by annotating a PDF version of the letter. Each letter was read verbatim with the aim of the primary researcher to code all words and phrases that related to the research question. The T1DM letters were read and initially coded first, then the T1DE letters. An example of initial coding can be seen in Appendix Q. Two random letters and initial codes were shared with the secondary supervisor to reflect on whether these met expectations, highlight any biases and introduce any additional initial codes they found. Three letters were also shared and coded in an advanced RTA |

| | |
|---|---|
| | workshop to uncover any further biases and generate any missed codes. Once second coding was completed 74 codes were developed from the T1DM letters and 60 codes from the T1DE letters. |
| **Phase 3: Generating initial themes** | All codes for T1DM were written onto sticky notes. As each note was written, the quote linked to it was reviewed to assure it fit the research questions. Any codes or quotes that did not were removed. The remaining sticky notes were then grouped via shared meanings and/or patterns across the data. Gradually thematic maps were built which led to the generation of three themes and five subthemes. This same process was repeated for the T1DE letters, resulting in the generation of three themes and six subthemes. All themes and subthemes received consultation from the research team. Examples of the initial process of generating themes can be seen in Appendix Q. The final thematic map for T1DM and letters can be seen in Appendix Q. |
| **Phase 4: Reviewing potential themes** | With time, distinct themes were created from the data. Each theme and its subthemes were reviewed and discussed at length by the primary researcher and secondary supervisor in regard to how they related to a research question(s), their coherence and how they were able to represent meaning. |
| **Phase 5: Refining, defining and naming themes** | The principle and secondary supervisor consulted to refine, define and name all themes and subthemes. Each theme and subtheme was organised and named according to the quotations they represented, and all quotations were reviewed to ensure they were represented by the theme/subtheme and had a coherent narrative. The final themes and subthemes were then presented to the research team. |

| | |
|---|---|
| **Phase 6: Write up** | Themes were written up with care and attention to ensure that the participant voice was maintained and honoured. This was done by including direct quotes which were highlighted and embedded throughout the write up of the results. |

**A Reflection**

*When going through the process of data analysis there were letters that went against my biases and expectations. I had the initial temptation to play down these experiences, as they did not fit my agenda. Not engaging fully with this data would have been an unethical use of power as the researcher. In addition, it would have falsely implied that the participants' experiences all fit into neat binary boxes (e.g. like/dislike) and thus neglect the fact that the experiences of these participants, and those we see in services, are complex and diverse. To overcome this, I used my diary to re-connect with my 'why' for doing this research, which was to amplify a hugely neglected client group a voice, and I would not be doing this if I silenced parts that did not fit my biases.*

## 3.9. Qualitative appraisal, validity of this research, and self-reflexivity

### *3.9.1 Quality Appraisal*

A dominant critique of qualitative research is that it lacks the scientific rigour and therefore reliability of quantitative research (Noble & Smith, 2015). These critiques often stem from the fact that qualitative methods are dynamic, they often will be used differently by each individual and, therefore, produce different results (Morse, 2020). This difference, however, is often due to qualitative researchers not sufficiently justifying the chosen method and their lack of regard for the influence of researcher bias in data analysis, and transparency in the data analysis process (Morse, 2020; Rolfe, 2006; Sandelowski, 1993). This research

has attempted to address the common critiques of qualitative methods in this Chapter and via a qualitative appraisal that can be seen in Table 14.

### *3.9.2 Validity and reliability*

Brink's (1993) criteria for valid and reliable qualitative research addresses four areas that can threaten the research. Table 14 presents these four criteria and uses them to assess the qualitative method of this research.

**Table 14**

*Assessment of validity and reliability of empirical study*

| Brink (1993) criteria | Assessment of validity and reliability |
|---|---|
| **The researcher** | • Brink (1993) argued that the main way data is gathered in qualitative research is through the researcher themselves. Brink (1993) therefore argued that the first way to minimise researcher bias is for the researcher to be aware of their biases and how it can influence their research.<br>• Researcher bias was considered from the conception of this study. As a result, bracketing in the form of a continuous reflexive journal, interview and discussions with others external to the project were completed throughout in order to remain conscious of biases, uncover new biases as the study progressed, consider how the research was being influenced by the biases and attempt to overcome them. |

| | |
|---|---|
| | • Brink (1993) argues each researcher should declare their underlying biases and assumptions, which have been embedded throughout this research.<br>• Brink (1993) also suggests a dominant way researcher bias effects the validity and reliability of the research is through the presence of the researcher with the participants. This was eliminated in this study via the letter writing data collection method. The participants were never in the presence of the researchers and wrote their letters on their own with minimal guidance or input from the research team. |
| **The subjects participating in the project** | • Brink (1993) argued that participants may not be completely truthful when providing their data. This could be due to lack of clarity in the purpose of the research, not wanting to disclose certain information and/or feeling pressured to give the researcher what they want. This was somewhat mitigated through the use of letter writing. Letter writing which, as previously mentioned in subsection 3.4.2., has a greater degree of confidentiality, allowing participants to write what they wish, without the influence of a researcher present (Flemming, 2020; Stamper, 2020), increasing the likeliness that the data collected in this study was honest.<br>• To increase the validity of the responses of this study the participant information sheet was given to participants prior to the study starting to ensure they were clear on the nature of the research. |

| | |
|---|---|
| | • The bracketing interview highlighted a researcher bias towards T1DE letters being more 'positive' and T1DM being more 'negative'. It was noticed this bias influenced the original wording of the letter writing instructions participants received as guidance for their letters. In addition, an expert by experience also noticed that the original instructions were more prescriptive. Both were addressed by making the language used more neutral and having the instructions more open in their guidance. |
| **The situational context** | • Brink (1993) argued that the social context in which the study takes place can influence the reliability and validity of the study as participants may behave differently under different circumstances (e.g., one to one with the researcher, in a group etc).<br>• Participants wrote their letters away from researchers reducing the threat to reliability and validity.<br>• Where participants wrote their letters was their choice but it is possible that letters were written in the presence of others, and/or participants may have had concerns their letters would be found and read by another person. This may have influenced what they had written on their letters. In an attempt to reduce this threat, the letter writing instructions encouraged participants to write their letters in a space that felt safe and where they felt comfortable to be as open as they wanted to be. |

| | |
|---|---|
| **The methods of data collection and analysis** | • Lack of clarity in explaining the method used in a qualitative study can reduce the ability for another researcher to replicate it and therefore reduce the reliability and validity of the study (Brent, 2003).<br>• Throughout Chapter 3, attempts were made to clearly explain the methodology and analytic process of this study.<br>• Brent (1993) argues the importance of triangulation in qualitative methods to increase their validity. This study had limited resources and was time constrained, which meant this was not possible at this time, but invites future research to consider this. |

# CHAPTER 4: RESULTS

## 4.1. Chapter overview

Chapter 4 presents the findings of the RTA (Braun & Clarke, 2006; 2013; 2019) of the 11 pairs of letters written for this research. As in Bhasker's (1975) model of CR, the experience of events will hold a unique reality for each individual, influenced by unobservable mechanisms. In saying this, it is important to acknowledge that the themes generated from participant letters may have looked different should another researcher have carried out the RTA. This is because how the primary researcher experienced their reality of these letters is likely influenced by factors, such as their experiences, beliefs, values, and expectations.

## 4.2. Presentation of results

Table 15 presents the themes and subthemes generated from participant letters. The three themes and five subthemes from the T1DM letters will be presented first, followed by the three themes and six subthemes from the T1DE letters. This structure mirrors the two-letter format and enhances readability but may falsely suggest a linear progression from T1DM to T1DE. In reality, T1DE experiences were more complex, many participants experienced a back-and-forth dynamic between their T1DM and T1DE, whilst others were diagnosed with T1DM after their T1DE which slightly changed the experiences conveyed yet still showed that the T1DE continued to have a purpose within the context of T1DM.

### *4.2.1. A comment on the letters*

All 11 letters were written in explicit detail, averaging a length of two sides of A4 for both ED and T1DM letters. Although assessing emotional expression is subjective and will therefore vary for each researcher, the authors of this research deem the both T1DM and T1DE letters to have a high amount of emotional expression. All participants addressed their letters to T1DE.

All participants received prompts in the letter writing instructions that they had the choice to use, as explained in in 3.4.2 and shown in Appendix H. It was not apparent from the letters that any prompts explicitly informed any themes, but the reader should be aware that some content of the letters, that inform the themes could be linked to the prompts provided.

**Table 15**

*Thematic table*

| **Letters to T1DM** | |
|---|---|
| **Theme** | **Subthemes** |
| **Theme one: "*This resentment I had for you*"** | 1. *"A job you never asked for"*<br>2. *"Diabetes controls your life"* |
| **Theme two: "*You must do diabetes, or you die*"** | - |
| **Theme three: "*Why did you become my whole identity?*"** | 1. *"The diabetic one"*<br>2. *"The odd one out"*<br>3. *"You have also given me some great strengths"* |
| **Letters to T1DE** | |
| **Theme four: "*Something I needed*"** | 1. *"Throw caution to the wind"*<br>2. *"There you are"*<br>3. *"You help me belong"* |
| **Theme five: "*Like a slave to a master*"** | 1. "*Wrapped around their little finger"*<br>2. *"Google said 'go to hospital' you didn't care"* |

| | |
|---|---|
| | 3. *"Your voice is loud, but I am louder"* |
| **Theme six: "*Like yin and yang"*** | - |

### *4.2.1. Theme one: "This resentment I had for you"*

This theme captures the mixture of participant emotions and experiences that resulted in an overwhelming feeling of resentment that plagued their relationship with T1DM. Resentment is defined as, '*a feeling of anger because you have been forced to accept something you do not like'* (Cambridge Dictionary, 2024a).

Through its two sub-themes, this theme aims to convey to the reader the feelings of unfairness and anger participants experienced in having T1DM and having no choice but to take on its burden, and the lack of control over their bodies and lives.

#### ***Sub-theme: "A job you never asked for"***

Across the letters, participants conveyed that T1DM was very much unwanted in their lives. Abigail writes that their T1DM "*crashed uninvited into my life when I was 12 years old"*. Participants shared that when diagnosed with T1DM, their autonomy was taken away; they did not choose to have T1DM, they did not wish to live with it, but had no choice but to carry its burden.

*"...but instead of you being able to have the freedom to choose a job of choice, you have NO choice when diagnosed with diabetes, it is a job you never asked for and wish every day that you didn't have." (*Jane)

*"I became a nurse of myself, dietician, an accountant, and an event manager, all at the age of 11." (*Grace)

In the first quote above, Jane uses the metaphor of T1DM being a full-time job one did not want to communicate the lack of choice. Using this metaphor, Jane conveys the

unfairness of T1DM; not only did they have no choice in being diagnosed, but then had to take on the labour and responsibility. In addition, the quote could also be conveying an experience of violation. It would be a violation to anyone's rights to force them to work a job, let alone one that requires you to work 24/7, as theme two will discuss. In the second quote, by listing the job roles they had to take on as a child, Grace further highlights the complexity of skills T1DM requires. The roles Grace lists are also ones that adults choose to do after years of training. Grace, however, never chose these jobs and had to learn them "*all at the age of 11".* This unfair nature of the lack of choice and level of responsibility at a young age was echoed by Luna who wrote, *"Diabetes has medicalised every part of my life from the age of 9. I was never prepared for any of this, but I had to grow up really quickly".*

***Sub-theme: "Diabetes controls your life"***

*"...being told I couldn't eat sugar because I had you in the background like a dark cloud raining over me every time something with sugar entered my mouth it made me desperate, wild and angry"(*Alice)

All participants referenced the all-encompassing, controlling nature of T1DM. One common way T1DM controlled participants was through food, in particular sugar. In the first quote below, Alice writes of their diabetes constantly being there in the background preventing them from eating sugary foods. Describing this control as making them feel "*desperate, wild and angry"* could convey the extent of deprivation caused by T1DM. One tends to want something more desperately the more they have been strictly deprived of it. Feeling "*wild"* conveys the image of an animal that has been locked up and wants to be free and could also link to wanting to 'go wild' and rebel against diabetes. 'Anger', therefore, is an understandable response to this control.

*"That word, **control**, is prominent in the world of diabetes because you do feel like Diabetes controls all your life … It controls your mood, what you can eat, your energy levels, your mental health…everything. I do try to believe that I am the one in control, but it is hard when you get days when you planned to get loads done and then you are attacked with low blood sugar continuously and lose all that energy you had at the beginning of the day"* (Jane)

The controlling relationship with T1DM extends beyond just food. Jane highlights that diabetes controls everything from their external life, as well as the internal functioning of their body. Their depiction of having times where they believe they have the control in the relationship, only to have established plans ruined through diabetes '*attacking'*, carries an image of violence, and likens to the idiom of getting the rug pulled from under you.

This level of control implied an underlying sense that T1DM held the power within the relationship. Susans writes that as they "*try to regain control [from T1DM], you [T1DM] still has the upper hand. I will never be free of you"* whilst to their T1DM Luna writes "*you never let me do the things that I wanted"* and "*you made me projectile vomit and nearly lose my foot"* implying a sense of resentment and frustration towards T1DM for the control placed on them and enforcing distressing experiences. These feelings seemed to increase when, despite attempts to regain some control, diabetes always took it back. For example, Emma wrote *"I try very hard to do all the right things to keep myself well yet you find a way to remind me I am never truly in control".*

Some participants faced significant loss because of the power and control held by diabetes. Losses included having a childhood, a sense of freedom, enjoyment, and connection with the body, and diabetes also took away from significant life events such as pregnancy. Luna shared they had to sell all of their "*high heels",* their "*favourite footwear",* due to the damage T1DM caused to their feet and ankles. This seemingly small loss has a striking

impact; an individual cannot even keep the small things they love, that make them who they are, from diabetes.

Due to these losses, there were strong implications of anger and hatred towards T1DM, as conveyed in the below quote by Charlotte. Similarly to Luna, Charlotte talks about the seemingly small things T1DM took from them by writing *"you invaded my life before I even knew how to spell your name. Before I really knew what birthday cake tasted like"* and "*you robbed me of the carefree nature of being a child*". Charlotte use of language such as "*invaded*" and "*robbed*", which conveys violent and traumatic imagery that the takeover of diabetes was not a peaceful one.

*"I truly was certain I was going to live life as my full wild adventurous self had intended to, I was more determined to not let you T1D stop me…In fact I was so certain you was not going to stop me, that I pushed you to the side, you was no longer in my way, I was feeling the freedom of what life had to offer me."* (Grace)

As shared by Grace in the quote below, for some, anger and resentment, and the perception that diabetes had taken away from life, resulted in attempts to push diabetes away in order to get a life that was wanted. This implied that, for some, it was only when diabetes was not fully present that they could experience full freedom. Grace, however, uses past tense in this extract, that they "***were"*** so certain diabetes would not stop them. This implies that perhaps now they are not so sure, that maybe no matter how hard they have tried to push aside their T1DM, it will always have some level of control.

*"…this resentment I had for you began to morph into resentment for everyone else around me…Resentment towards strangers who seemed to take for granted having lives without you in it. Having freedom when I was feeling suffocated by you."* (Charlotte)

In the above quote Charlotte highlights the unfair discrepancy between a life with and without T1DM, mainly in the freedom that comes with not having T1DM and that this is taken for granted. Others taking their freedom for granted seemed to have left Charlotte feeling somewhat separated and uncared for by the world. That they were left to feel "*suffocated*" by their diabetes, a word which implies that T1DM can feel so big and overwhelming at times that it leaves no room to breathe. For Charlotte, this resulted in the resentment felt for T1DM extending to others, conveying how one's relationship with T1DM can influence relationships with others.

#### *4.2.2. Theme two: "You must do diabetes or you die"*

This theme conveys to the reader the relentless nature of T1DM and how this influenced participants relationship with their diabetes and their feelings towards it

*"...you [T1DM] are in one word-RELENTLESS"* (Emma)

*"Everyday I have to think about what my blood glucose is, which way is it heading, what I'm going to eat, how many carbs are in it, what am I going to be doing in the next few hours, do I need more or less insulin because of that. Do I need to take extra equipment with me today, I have to carry hypo treatment and spare pump supplies everywhere, I have to plan events around you. I can't just eat on a whim or binge without you there making me do maths and plan ahead every few hours. I don't do certain activities because I know you'll bite me in the bum and then I have to do extra extra things."* (Taylor)

Participants shared the unseen relentlessness of T1DM. This included diabetes always being on their mind, being able to read their thoughts, constant mental checklists, and worries regarding how T1DM may affect them or react to certain food, drinks, or activities. Taylor writes of this relentless nature in the quote below. Reading aloud the long mental checklist they go through each day leaves the reader needing to catch their breath, embodying the

never-ending nature of T1DM. In addition, as the quote goes on, Taylor stops naming all they have to consider, instead they say "*then I have to do extra extra things*"; this could be interpreted that Taylor lost their breath, that the list was too long for them to carry on writing it.

*"I pushed you aside…it wasn't until I was a teenager that you truly hit me, that you was still with me, and you wasn't going to go away…No matter how many times I would hide from the diabetes nurses when they came to my house. No matter how many times I said my bloods were ok, when they were not, no matter how many times I faked it, I had no control over you T1D. I couldn't escape you."* (Grace)

The relentlessness of T1DM left many participants sharing their desperation for a break. Emma wrote, "*what I would give for a day off, wow!! I would even take two hours as a treat".* Jane wrote of understanding why some do not follow their T1DM "*because it is so heart breaking realising that we will constantly have to be on the ball with our blood sugars, we will never get a break",* a realisation that getting a break will not happen, that they are "*stuck with you[diabetes] until the day I die*" (Luna). T1DM, therefore, is not only relentless in the constant demands it places on an individual each day but also in the sense that it will never go away. This is conveyed in the above quote by Grace, who despite listing their various attempts to avoid diabetes and push it away, could never outrun it.

"*you must do diabetes or you die*" (Susan)

"*As a young girl I was threatened with complications and told if I didn't follow the rules I would go blind, I would lose my legs and end up on dialysis. What a horrifying introduction to you, I still remember those words clearly 45 years later, such overwhelming fear.*"

(Abigail)

Most participants expressed that the relentless rules of T1DM were followed out of fear. This fear was related to the various life altering and threatening complications that can occur as a result of not adhering to T1DM management practices that were stressed by health professionals at the time of diagnosis, and at subsequent appointments, as conveyed in quotes above from Susan and Abigail. There is an implied threatening aspect to the relationship with diabetes; participants have to keep up with the exhaustiveness and relentlessness of T1DM or else face the awful consequences, creating the image of someone being trapped, echoing the trapped animal imagery conveyed in the quote by Alice in theme one.

There was an underlying implication that, for some participants, since T1DM was not going anywhere, they surrendered to having it as part of their life. This surrender was not always a happy one, with some participants writing "*so I drag you along with me"* (Charlotte), implying that T1DM was a burdensome relationship that participants had to put up with. A powerful image is conjured from this quote; someone dragging along a ball and chain. Even when T1DM is accepted in some way, it does not create freedom, the diabetes does not magically become lighter or easier to carry.

### *4.2.3. Theme three: "Why did you become my whole identity?"*

This theme aims to explore how T1DM impacted participants' identity. The three sub-themes will share how participants felt their identity was taken over by T1DM, the influence of others on identity, and acknowledgement of the positive aspects of having T1DM.

#### ***Sub-theme: "The diabetic one"***

Across letters many participants wrote to their diabetes stating that it had taken over and/or changed their identity, leaving them to question who they were. T1DM was written as *"infiltrating me of every thought and how I view myself"* (Alice). One definition of infiltrated is to '*secretly become part of a group to get information or influence their thinking or*

*behaviour*' (Cambridge Dictionary, 2024b). This choice of the word suggests that Alice may feel their diabetes secretly took over them, and influences who they are. Similarly, Grace writes their T1DM had "*taken nearly every part of me*". Both accounts imply that diabetes taking over identity was against the will of the person and left them unable to develop their own identity. Having T1DM take over identity could be linked to themes one and two in that as it constantly requires so much responsibility, it could feel as though managing T1DM is all the individual does.

*"Why did my teachers refer to me as 'the diabetic one'?...Why did you become my whole identity before I had the chance to figure out who I wanted to be…?*" (Charlotte)

*"All anyone knew me as was the girl who is sick or has you T1D. I had no identity, I wanted you to be a little part of me, not all of me."* (Grace)

Participants also wrote that being labelled by others influenced feeling that T1DM had taken over their identity. Above, Charlotte and Grace shared this, in writing that others referred to them as "*the diabetic one"* and "*the girl who is sick".* Both then referred to T1DM becoming their "*whole identity"* meaning they had "*no identity*". Perhaps the labels of '*diabetic'* and '*sick'* are experienced as being limiting, as it is all others see them as, and therefore all they feel able to be.

"*I began to view myself as boring. That the only noteworthy thing about me was you and everything else fell short. It didn't matter if I got good grades because my A1C was still higher than the doctors would like. It didn't matter that I liked going to the gym with my friends because low blood sugar attacks caused by you seemed to hold everyone back.*"

(Charlotte)

In addition, there was a pattern across the letters of T1DM being the only thing others seemed to care about regarding the participants. For example, Grace shared that their diabetes

team "*just lectured them on diabetes, they never asked about [them] or how [they] felt".* Similarly, Luna wrote that they were "*nothing but numbers to healthcare professionals".* In the quote above, Charlotte shares a similar experience. They wrote of themselves as "*boring*" and T1DM was the only "*noteworthy"* thing about them as that was all others focused on; no matter what they achieved it would always come second to their diabetes.

A possible meaning behind these experiences is that some individuals are made to feel as though the parts of their identity that are not T1DM-related are less important, discouraging their development and thus further reinforcing diabetes to become their whole identity. This could link to the development of T1DE. The all-encompassing nature of T1DE, as explored in later themes, could be viewed as something to overshadow T1DM and move attention away from the diabetes for a while, to have something else that is "*noteworthy"* about them.

***Sub-theme: "The odd one out"***

Universally, participants wrote about how they were made to feel different because of their T1DM. Feeling different mostly references not feeling able to do the things peers were doing, such as drinking alcohol, wearing certain clothes, and going on school trips. Charlotte and Jane made specific references to school lunches being a salient time where they felt different, where they were made to leave for lunch early and eat lunch away from peers.

*"I know that you made me feel ostracised from my friends constantly at school because I was so obviously the 'odd one out.' For example, at lunch time, I used to inject my insulin in the school toilets in the cubicle, away from everyone else's beady eyes and whispers."* (Jane)

*"The surgeon said 'That's what we do to diabetics.'"* (Luna)

In the first above quote, Jane writes of being "*the odd one out"* making them feel excluded from their friendship group. Within this quote, Jane also writes of wanting to inject

her insulin in a toilet cubicle, "*away from everyone else's beady eyes and whispers".* This could convey the experience of being othered; being pushed out of groups and forced to hide their diabetes. Similarly, in the second quote, Luna writes of an experience where they were othered. Luna is writing about a surgeon wanting her consent for a foot amputation that they did not want. The surgeon saying, "*that is what we **do to** diabetics"* reads as though those with diabetes are another species, one that does not have the medical right to autonomy of their own bodies and should be punished. It also links to the fear discussed in theme two. The experience of being 'othered' resulted in some participants believing that they did not belong anywhere, as written below in the quote by Alice.

*"Being diagnosed with diabetes at the mere age of 5 already made me feel like I had entered the world on a bad note. It felt like I didn't belong in this world and I was a mistake."* (Alice)

Many participants, therefore, hid their T1DM in public, even if this led to negative health consequences. This could be because this treatment by others made some feel as though their diabetes was something to be ashamed of, that obviously othered them from wider groups. For example, Amelia shared that they hid their insulin pump as they believed it would make her look "*defective"*. This gave the sense that some participants could not bring their whole selves to social situations, which could be why several participants referred to having T1DM as isolating.

***Sub-theme: "You have also given me some strengths"***

*"You've taught me to love my body. I'm in awe of how strong it is, of all that it can do and continues to do, even with living with you. You've helped me to be proud of it. Proud of me. You've helped show me how important taking care of me is."* (Eve)

Every letter to T1DM wrote about what the participant has also gained from it. Eve, whose T1DM came after struggling with an ED, shared that diabetes reconnected them with and helped them to be proud of their body.

> *"Type 1 you have also given me some great strengths. I know I am super resilient, very organized, and I guess better at numbers than I ever thought I would be.*" (Emma)

Like in the quote above by Emma, participants also wrote about how having T1DM taught them about their identity; they would not know about their strength and resilience if it wasn't for T1DM. In some cases, having T1DM highlighted personal values, which helped to shape career paths.

> *"…I have travelled all over the world, sky dived, sailed, cycled, spent a week in the desert…."* (Luna)

In their letter, Luna wrote an extensive list of activities T1DM has not stopped them from doing. The list reads as one of defiance, claiming some joy and ownership of life, and following values despite the difficulties T1DM has posed.

Some participants wrote of accepting T1DM into their identity. These participants wrote of this acceptance involving the ability to acknowledge that there are aspects to T1DM that are negative, whilst also valuing other aspects. This highlights the complexities of human relationships and experiences of chronic illnesses, often they are not dichotomous or stagnant, but instead are complex and dynamic.

#### *4.2.4. Theme Four: "Something I needed"*

This theme conveys that, for many participants, T1DE provided them with some thing(s) needed at the time it developed. This is done using three sub-themes described below.

***Sub-theme: "Throw caution to the wind"***

This sub-theme explores the initial experience of an T1DE allowing participants to regain control over their lives, bodies, and food, which in turn offered temporary freedom and escape from the situations they were in.

*"You gave me a sense of control which I must have needed, it's like you knew that. I felt like finally I could choose what I was doing and when. If I didn't want to eat, you would help remind me that I didn't need to eat [redacted]. You were my rock and I needed that."* (Taylor)

In the quote above, Taylor writes of their T1DE giving them *"a sense of control"* that they "*needed"*. This control was "*finally"* being able to choose what they did. For example, not eating if they did not want to, things other participants referenced not being able to do because of T1DM, implying T1DE provides something that is taken away by diabetes. In addition, Taylor's reference to their T1DE as "*their rock*" implies that T1DE could provide reliability and stability in life, which is the opposite to the unpredictable nature of T1DM.

*"When you are with me, I feel I let all rules and sense just disappear. I literally allow myself to throw caution to the wind and eat as much of anything that I want or can actually find…I can eat away all kinds of stuff and no one is around to judge, to stop me, to monitor what and how much I am eating. It feels like a rush of excitement and adrenaline when I know I can eat and not be interrupted or seen."* (Emma)

Regaining control also meant regaining power, allowing participants to change or drop rules that they had been following. In the quote above, Emma writes that when their T1DE is "*with"* them, all rules around food "*disappear"* and they "*allow"* themselves to "*throw caution to the wind"*. This use of this phrase implies that, for Taylor, T1DE allowed them to be free to act impulsively and recklessly. This could be something they usually are unable to do, which could be why, when they act this way, they get a "*rush of excitement and*

*adrenaline",* conveying an image of a teenager rebelling against a strict parent. The ability to "*throw caution to the wind"* is in a direct contrast to the previously discussed rigid and relentless nature of T1DM.

***Sub-theme: "There you are"***

This sub-theme explores how, for some, T1DE offered something that they needed.

*"I didn't need to think, I just was."* (Susan)

In the quote above, Susan writes that when with their T1DE, they are not having to think, being able to simply exist. T1DE could therefore serve as an off switch from any turbulence going on in an individual's life. One way it could do this is by reducing one's world down to just food and weight, meaning there is nothing else to think about. Providing an off-switch parallels participants in theme two desperately wanting a break from T1DM.

*"A way of managing emotions that I did not know how to control… I didn't want to feel anymore and you allowed me to be numb.'"* (Susan)

*"If I get emotional there you are."* (Emma)

As expressed in the first quote above, a common experience across the letters was that the T1DE provided participants with a way to regulate their emotions. Susan writes that, for them, their T1DE did this by allowing them to be "*numb*". In the second quote by Emma, they write that their T1DE is there when they become emotional. It is ambiguous whether "*there you are"* is said in comfort or anguish. Either way, there is a consistency in the nature of the T1DE being "*there"* in times of emotional distress.

*"I'm so grateful that you were there to help me feel safe in all the times I needed…I will see you and acknowledge you for what you're trying to do, to protect me."* (Eve)

The consistency of the T1DE written about by Emma, and Taylor referring to their T1DE as "*their rock"* in the previous sub-theme, links to various references across the letters to the T1DE providing safety. Above, Eve expresses gratitude to their T1DE for helping them "*feel safe"* and acknowledged their T1DE was trying to "*protect*" them. Jane similarly spoke of their T1DE helping them feel safe by "*eating the same thing every single day".* Safety could be provided by putting all focus on what is controllable and predictable, protecting them from the chaos of the outside world.

*"...something I've loved and hated. Wanted rid of but then glad I knew you would show up again, glad when you did show up."* (Eve)

*"You could say I kept my enemy close, so close that I never disclosed, even after being asked by a specialist if I'd taken drugs, was this the cause for my irate BG's, DKA or even when told that they didn't want me to be the next person they lose, I still hid you."*(Grace)

There was an underlying sense from some of the letters that the T1DE provided a level of comfort. Above, Eve writes of the complexity of one's relationship with an T1DE, in that they hated it whilst also being "*glad"* that their T1DE would and did show up. Grace speaks of viewing their T1DE as an "*enemy"* but still "*hiding"* it from others. This could be due to experiences of shame and/or being let down by services making disclosure of an T1DE difficult; it could also convey a wanting to protect their T1DE in order to keep it.

***Sub-theme: "You helped me belong"***

This sub-theme conveys how T1DE can offer a seemingly positive social experience and identity for individuals.

In their letters, participants implied that, before their T1DE, they had a negative perception of their identity and struggled to feel as though they belonged in social settings.

*"…after years of never feeling good enough, like I didn't fit in, that there was something wrong with me and like I didn't matter…you help me belong and that people accept me when you're with me."* (Susan)

In the above quote written by Susan, there is the sense that their T1DE solved all the negative things they felt about themselves, resulting in them "*belonging"* and being accepted by others. Not fitting in, feeling as though something is "*wrong with them",* and that they "*didn't matter"* mirrors the findings in subthemes "*odd one out"* and "*the diabetic one"*, highlighting a potential function of T1DE is to counteract the negative identity and social experiences caused by T1DM.

"*Weight started falling off me, people started to praise me, tell me I looked good."* (Abigail)

*"My social life blossomed and I felt more confident than ever…I was finally getting the body and life that I had always wanted."* (Charlotte)

The increasing sense of belonging and preferred identity attributed to the T1DE was also likened to the social approval that came with weight loss. In the above quote, Abigail references receiving praise from others when they lost weight. Similarly, Charlotte drew a parallel between their social life and confidence growing as they got closer to the body "*they always wanted"*. Both imply that an T1DE makes one more socially "*acceptable*" and reinforces it:

### *4.2.5. Theme Five: "Like a slave to a master"*

*"I feel like a slave to a master and you have control of every decision, moment and role I do and carry out."* (Alice)

Through three sub-themes, this theme captures the omnipotent nature of the participants' T1DE and the strength of participants in resisting it. The theme name was inspired by Alice who used the simile "*like a slave to a master"* to describe their relationship

with their T1DE. The use of this phrase not only reveals the level of power an ED can have over a person, but also how the T1DE obtains this power, through exerting dominance, dehumanising the person, and using threat; the T1DE leaves the person with no sense of worth, freedom, or connection with others.

***Sub-theme: "Wrapped around their little finger"***

This sub-theme describes participants' experiences of the power and control of their T1DE.

*"You made me believe I had power, I was in control then once I was hooked, you switched it up and you had the power. I was powerless to your control and you took over my life."* (Taylor)

Participants wrote that their T1DE initially allowed them to feel in control, but this slowly shifted to being controlled. In the above quote, Taylor writes of this shift. Their description of their T1DE initially reads as if it was almost alluring to them, drawing them in under the false pretence of giving them the control they needed. But, once they felt they could not live without it, the T1DE snatched control back, rendering them "*powerless*".

*"Realistically, the eating disorder has you wrapped around their little finger because they are controlling when you think you are worthy of food or not. You no longer have the freedom to eat when you are hungry or eat something with more carbs in because you don't want to have to give extra insulin."* (Jane)

*"Birthdays, social events, holidays, work duties, pet owner duties, health duties all come into practice after I have pleased you…from the moment I wake up the first thing on my mind is how I plan on organising my day so you are happy…I feel I must please you.*" (Alice)

Similarly, above Jane writes that they were "*wrapped about their [T1DE's] little finger",* a phrase used to describe when one thing has complete control over another, getting them to do whatever they want. The experience of being controlled was expanded by Alice who writes that, because they "*must please"* their T1DE, they organised their life around keeping the T1DE "*happy*" meaning their other values came second. Saying they "*must please"* echoes Alice's previous simile of "*like a slave to a master"*, they had no choice but to adapt their life and neglect their values and needs.

> *"…Anna's [eating disorder] voice gets so loud I cannot concentrate on anything but this voice in my head telling me [rule removed]…Anna makes me think that unless [rule removed], losing weight or [rule removed] then I am failing at life, and I am not worth much unless I keep up with the eating disorder."* (Jane)

Participants predominantly wrote that their T1DE enforced its control through food and weight loss, resulting in the following multitude of rules and rituals. Jane's quote describes the experience of having to follow rules set by T1DE; how loud it is and how hard it is to ignore. The T1DE "*making"* Alice think also conveys the sheer power of the T1DE; the T1DE even has control of an individual's internal world and influences their thoughts, beliefs, and values. Jane also writes of the consequence of not meeting the rules and expectations of the T1DE, it means they are "*failing at life"*.

The consequence of being punished and downtrodden by the T1DE, if one fails to meet its expectations, was a common experience across letters. Often participants depicted an image of their T1DE screaming abuse at them, making them believe that they were fundamentally a failure, worthless, out of control, disgusting, unlovable, pathetic, and undeserving of eating and being happy. Participants described their T1DE as making them believe that they can only be happy, liked, and good enough if they follow it. Like in the

previous quote by Jane, one is "*not worth much unless"* they *"keep up with"* the T1DE. These experiences give insight into how the T1DE keeps control through fear; a person would be nothing without it (T1DE).

***Sub-theme: "Google said 'go to hospital', you didn't care"***

This sub-theme captures the extent of the control the T1DE had over participants in that it was followed despite significant risks to health and life.

*"Ketone levels were reading at 7.0. Google said 'Go to hospital.' You didn't care….I'm losing weight. DKA became normal. Blood sugar readings above 20 were normal. The thirst became normal. Even the ear infection that lasted eight months became my new normal. You told me that these things were necessary for me to be beautiful…I spent most of my days sleeping or laying in bed too exhausted to move. You told me exercise didn't matter; I was losing weight anyway."* (Charlotte)

Above, Charlotte describes this control. Even when their body was shutting down, and the resources found via google were informing them to go to hospital, the T1DE persisted. Charlotte writes this happened because their T1DE didn't care because they were still achieving the most important thing to it, weight loss. Charlotte also writes of a common experience found across letters, that the T1DE kept control by making an individual warp their sense of health to suit what it needed to continue. Convincing them that a poor state of health is normal and "*necessary"* for them to be "*beautiful"* and that "*beauty"* was more important that health.

*"…hoping deep down I wont need anymore hypo treatment. Not because I want to keep the hypo at bay but because I do not want the extra [redacted] calories per jelly baby to add to my intake which is gonna add to my weight gain."*(Alice)

Similarly, Alice shares wanting to avoid hypoglycaemia, not because of their health, but because they wanted to avoid eating foods that their T1DE views as a calorie number that would add to weight gain. In its view, weight gain is worse than any impact of a *"hypo"*. Alice's sharing of this experience conveys how an T1DE and T1DM can clash and implies that, often, those with T1DE have a battle in their head; do I treat the T1DM and face the wrath of the T1DE, or do I keep the T1DE happy at the risk my health?

*"The comments I got about weight loss were a powerful driver, I mean what actual harm could I be doing to myself when I was being told I looked good? the positive comments I was receiving were bizarre."* (Abigail)

Participants also wrote how the control of their T1DE was reinforced and validated by external praise. For example, above Abigail writes how the complements they received for their weight loss was a "*powerful driver"* to continue with their T1DE. They also speak of the widely shared and confusing experience of living with something detrimental to health but being praised for it. Abigail speaks to how this praise made them question the severity of their struggles, and reflects on the "*bizarre"* nature of others praising them for weight loss, when their mental and physical health was so poor.

***Sub-theme: "Your voice is loud, but I am louder"***

Following from the previous two sub-themes conveying the controlling and powerful nature of T1DE, this theme describes the incredible resilience and strength of each participant in their moments of resistance against it.

*"You also reminded me that I am strong. That your voice is loud, but I am louder. I deserve a life with joy and excitement. I am a good person."* (Charlotte)

*"I'm more than numbers, more than restriction…more than surviving the days with you."* (Eve)

Most participants wrote of what fighting against and recovering from their T1DE taught them about themselves. For example, Abigail wrote that "*having to deal with you [T1DE] has made me strong and determined*". Other participants wrote that, in their movements towards recovery, they began to uncover the lies of their T1DE that were discussed in the previous sub-themes. Charlotte, for example, wrote that they do "*deserve a life with joy and excitement*" and that they are "*a good person"*. Eve writes of a similar realisation, that their identity and worth expands far beyond the constraints placed upon them by their T1DE.

By writing these words directly to their T1DE, both quotes read as though they are arguing with and standing up against their T1DE -which in and of itself is a movement of resistance and reclaiming of identity.

### *4.2.6. Theme Six: "Like yin and yang"*

Theme six explores the interactions explicitly named by participants' between their T1DM and T1DE, inferring parallels between them.

*"I know deep in my heart that I struggled with food from the moment I was diagnosed with type one diabetes at the age of 8. The need to constantly think about what you are eating, how it will impact your blood sugars, how much insulin to give for everything you eat and monitoring your blood sugars constantly was honestly such a debilitating realisation*." (Jane)

In some letters to T1DM, references were made about how diabetes contributed to the development of T1DE. Jane writes that "*from the moment* [they] *were diagnosed with type one diabetes at the age of 8*" they struggled with food due to diabetes making the content of food and its impact on the body more salient. Similar experiences were written across letters. "*Type one turned every mouthful [of food] into a number; a calculation making me focus on*

*carbs, insulin and weight gain*" (Luna). Consequently, an association developed between "*carbs, insulin, and weight gain so I began to omit insulin"* (Grace).

*"When you first came into my life I was fully in my eating disorder, I had worked out how to have control in my life and then you took that away. Suddenly I had to track not only calories but carbohydrates too and I had to look at what I was eating in depth. I had to have sugary things because of you. You ruined everything"* (Taylor)

Taylor writes of a similar experience. Like Jane, Taylor writes of T1DM causing them to increase their knowledge of food content. Taylor's perspective is also novel in that they were diagnosed with T1DM after struggling with an ED, and highlights T1DM adds to list of requirements of food knowledge that perhaps even the ED had not thought of, in needing to *"track not only calories but carbohydrates too and I had to look at what I was eating in depth",* further increasing food preoccupation.

Throughout this Chapter, calories and sugar is named as a central focus of T1DM. Above Taylor writes of the tension this causes with their ED, of having to eat sugar because of T1DM and how this has "*ruined everything*". With the findings from 4.2.5 which depicts the food rules and fear the T1DE places on an individual, one could assume Taylor means the need to eat sugar ruins the attempts to keep their T1DE happy, thus increasing their distress. This again highlights the bind individuals with T1DE are placed in of needing to eat certain food to maintain T1DM, but these foods being restricted and fear by the T1DE, and the experience they are either being controlled by their T1DM or their T1DE.

*"Like an old flame that is constantly in the background judging my every move, that is why you and your friend the eating disorder have so much in common. Like ying and yang you fit perfectly and make my life feel like it is being built around both your desires."* (Alice)

Alice directly commented on the interaction between their T1DM and T1DE. Above, Alice first writes of their T1DE being a "*friend*" of their T1DM, stating this friendship is because they "*have so much in common*". It is implied in this quote the commonalities between T1DM and T1DE is the scrutiny both place on an individual, "*judging my every move*" and building someone's life around what they both want, once again showing the control both T1DE and T1DM want to place over the individual. Alice depicts this further by writing of their T1DM and T1DE as being like "*yin and yang"*. Yin and Yang are two opposite forces, which complement each other, and make up all aspects of life. Describing T1DE in this way is powerful; despite being different in many ways, T1DM and T1DE are interconnected, resulting in the complete eclipse of the person they have taken over.

## A Reflection

*Placing a reflection at the end of this results section was a conscious choice—I did not want my voice to disrupt the voices of the participants. However, I also wanted to acknowledge how these letters and themes affected me, because this impact shaped the way I interpreted and presented the data. These themes elicited in me many emotions. Many times, when participants wrote of their distress and stuck-ness, I just wanted to give them a hug. I wanted to shout with them that no, nothing about what they have gone through has been fair. I wanted to tell them that I am so damn proud of them for every hurdle they have overcome. I felt anger at services for leaving this level of pain for someone else to deal with. I was also faced with my own privilege of not once having to consider or worry about my blood sugars, and I recognise how much easier that has made my life—a realisation that has informed my sensitivity in interpreting participant experiences.This emotional engagement shaped what I focused on in the results: I paid particular attention to aspects of the letters that elicited strong emotional responses in me, such as participants' distress, resilience, and the impact of services. Reflexively, I recognise that this focus may have meant I prioritised certain elements over others—other researchers might have noticed different subtleties, or emphasised aspects I did not. This does not invalidate the findings, but highlights that my positionality and emotional engagement actively shaped the interpretation and presentation of the data.*

*I am glad I used bracketing and continued reflection to make my biases less blind to me; without this, I might have missed elements of the letters that contribute to their richness and highlight the complexity of the human experience such as the strengths T1D provided some participant. Through a CR lens, I see that these interpretations were shaped both by participants' accounts and by the broader social structures influencing their experiences. My awareness of the ways capitalist stigma shapes perceptions of T1D, alongside societal pressures around the thinness ideal for women, sensitised me to the social and identity-related forces that might be operating in participants' experiences. This reflexive engagement ensured that the results were not just a product of my assumptions or emotional reactions, but an effort to faithfully represent participants' perspectives while remaining critically aware of how my positionality, theoretical stance, and understanding of broader social narratives influenced which aspects of the letters I attended to and prioritised in interpretation.*

# CHAPTER 5: DISCUSSION

## 5.1. Chapter overview

This chapter provides a summary of the findings of this study. Each theme will be discussed in detail, including how it relates to existing theory and research. The strengths, limitations, and clinical implications of this study will then be presented, followed by invitations for future research and a critical appraisal of this research.

## 5.2. Research questions

The aim of the current study was to explore the following research questions:

1. How do clients with T1DE feel towards their T1DM and what impact does T1DM have on their identity?
2. How do clients with T1DE feel towards their T1DE and what impact does the T1DE have on their identity?
3. What is the role of identity and feelings towards diagnoses in maintaining T1DE?

## 5.3. Summary of findings

The research questions were explored by analysing participant letters using RTA (Braun & Clarke, 2006, 2013, 2019). The letters written were expressive and emotive in their content and, in many aspects, mirrored existing research on T1DE, such as struggling with the nature of T1DM being a significant contributing factor to the development of T1DE. Findings from this research were also novel, such as how complex and dynamic one's relationship with their T1DM and T1DE is, and the significance of emotions and identity in the development and maintenance of T1DE. It is also important to note that the epistemological stance of this research is CR; the findings should not be viewed as one objective truth, but instead an insight into how the participants, within their own contexts, experienced T1DE.

Letters to T1DM conveyed difficult emotions towards the condition, of resentment, anger, exhaustion, fear and sadness. These emotions were a result of the control T1DM places on participants and the relentlessness of its management. Participants also wrote of T1DM disrupting their identity and completely taking it over e.g. becoming identified as the diabetic, making them feel that they were different from their peers.

Participants initially expressed feelings of gratitude and relief towards T1DE due to it providing them with various things they felt they needed e.g. to regain control from T1DM, a break from T1DM, safety. T1DE also appeared to provide participants with an identity where they were accepted into social groups and received praise. But, as T1DE progressed, participants also expressed being controlled by it and fearing the consequences of not following each rule and ritual it made them follow.

When emotions toward T1DM and T1DE were compared, a dynamic interplay emerged that highlights their possible role in the maintenance of T1DE. T1DM generated difficult emotions, while T1DE appeared to offer temporary relief: for example, the resentment caused by T1DM's burden was countered by T1DE providing a sense of control. Similarly, where T1DM produced an all-encompassing and stigmatising identity, T1DE could replace this with one where participants felt accepted. Yet, this counterbalancing dynamic eventually shifted as T1DE itself became more controlling and fear-inducing, leaving participants caught between the competing demands of T1DM and T1DE.5.4. Discussion of findings

### *5.4.1. "This resentment I had for you"*

Participants felt a strong resentment towards their T1DM. This resentment was linked to the unfair nature of T1DM (i.e., how it invades one's life without cause or warning) and the significant level of restriction and control it then places on the individual and their life.

Participants related the restriction and control of T1DM to the experiences of significant loss(es) they had faced throughout their lives.

Current models of T1DE (De Paoli & Rogers, 2018; Harrison et al., 2021; Treasure et al., 2015), as discussed in Chapter 1, focus on the relentless nature of T1DM and its increased salience of food, as specific features that increase the risk of developing T1DE. This theme, however, highlights that the unfair and controlling nature of T1DM are also features of the condition that participants struggled with. T1DM violently took away autonomy, burdened and controlled participants from a young age. The lack of choice and control over one's body and life are linked to theme four; the T1DE gave back choice to participants. Therefore, these findings highlight that the unfair and controlling nature of T1DM could be considered as a contributing factor to T1DE, adding to the existing literature.

The subtheme "*diabetes controls your life*" shows the resentment felt towards T1DM as result of the control it places upon the participants, providing support for existing models that name the T1DE as a way to regain a sense of control of one's life through one's body and food (De Paoli & Rogers, 2018; Harrison et al., 2021; Treasure et al., 2015). These findings, however, expand upon existing literature regarding how the need for control is understood in T1DE. Participants wrote of T1DM not just controlling their life (i.e., their plans, what they eat, etc.) but also their body (i.e., blood glucose, energy, mood), making one's body and mind unpredictable and out of the control of the individual. The findings highlight that, in T1DE, one's relationship with and want for control is complex; the want/need for control expands far beyond a want to control one's life, but perhaps a want to also have control and predictability in the internal functioning of one's body and brain.

Extending on this complexity, participants wrote of the many losses they faced as a result of the control T1DM had over them. These losses were written using violent language

and implied feelings of anger and hatred, which contributed to the resentment towards T1DM, resulting in some trying to push it away. These findings support Coleman and Caswell's (2020) study which found hatred of diabetes to be the second most prominent reason why individuals with T1DE omitted insulin. These losses lead to further consideration of the possible functions of the behaviours seen in T1DE. Currently, T1DE models focus on these behaviours functioning as a way for an individual to feel in control (Harrison et al., 2024; Treasure et al., 2015). However, these findings, and those of Coleman & Caswell (2020), suggest that the function of these behaviours could expand beyond this; T1DE functions as way to express the difficult emotions felt towards T1DM and perhaps is viewed as a means to get back the things it has taken from them.

The role of one's difficult emotion(s) towards T1DM, and how they contribute to T1DE, has not yet been explicitly considered by existing T1DE models. Harrison et al.'s (2021) model does, however, consider the role of negative beliefs towards T1DM in contributing to the daily maintenance of T1DE. However, these negative beliefs were argued to be formed only from vulnerability factors, first encounters, and physical experiences of T1DM. Findings from this study, highlight that one's emotional experience of T1DM is also significant in how they view and act towards their T1DM. This research found that most of the participants' experiences of T1DM (e.g., when first diagnosed, physical side-effects, having their life taken over and controlled, having things 'robbed' from them) are all underpinned by the emotional experience of resentment. Therefore. these findings contribute to the existing understanding of T1DE, highlighting the importance of resentment towards T1DM in one's experience of it and, therefore, the possible role of resentment in contributing to the negative beliefs held towards diabetes and, thus, the development of T1DE.

### *5.4.2. "You must do diabetes, or you die"*

This theme shared the feelings of exhaustion experienced by participants as a result of the relentlessness of T1DM. This exhaustion was linked to participants desperately wanting a break from their diabetes, and feelings of sadness towards the reality that this would not be possible. The feeling of fear was extensively written about and that this fear commonly stemmed from information provided by healthcare professionals (i.e., participants feared that, unless they constantly kept up with the management of T1DM, they would face severe physical complications).

The findings of this theme support the literature on diabetes burnout, presented in Chapter 1, by echoing that it is the relentlessness of diabetes management, reinforced by healthcare professionals, that contributes to the exhaustion linked with diabetes burnout (Ali et al., 2013; Hoover, 1983; Polonsky, 1999; Powers et al., 2017; Rezende Neta et al., 2015). Findings from this theme also bolster this existing literature in highlighting that exhaustion from T1DM is not just a result of its daily management, but also the mental toll of knowing that this management will have to be sustained over the individual's lifetime.

Participants also conveyed a feeling of sadness in the knowledge that T1DM will not leave them, an emotion that has not yet been fully considered in current T1DM research. Perhaps this sadness is a way to express and adapt to grief; grief of what has already been lost and grief of a life without T1DM. The presence of sadness could be important in conceptualising how T1DE is developed and maintained. Sadness has been found to be a key emotion in the development and maintenance of BN, BED and AN, as the behaviours seen in these diagnoses have been conceptualised to regulate this sadness (Reichenberger et al., 2021). This could be similar in T1DE, but it is also possible T1DE could be viewed by the individual as a way to reject this sadness by living a life that was once grieved, one without T1DM.

It could be useful to apply the Health Belief Model (HBM) (Rosenstock, 1966) to these findings to further understand why individuals with T1DM continue to adhere to treatment despite the exhaustion it causes them. The HBM (Rosenstock, 1966) argues an individual adheres to health behaviour(s) under four different conditions (Table 16). Perceived susceptibility and threat particularly map onto the experiences of participants; being told by professionals of the severe complications of T1DM, such as blindness, loss of legs, and death (high severity) that *will* happen if they do not follow 'the rules' of management (high susceptibility).

The HBM (Rosenstock, 1966) has, however, been criticised for being reductionist in its considerations of factors that impact health behaviours; the HBM ignores strong influences on human behaviour such societal narratives (Oriji, Vassileva & Mandryk, 2012). In addition, the predictive power of the HBM, particularly 'perceived severity', has been shown to poorly predict health-related behaviour (Munroe, 2007). This not only challenges the validity of the HBM (Rosenstock, 1966) but also highlights its failure to explain why some individuals with T1DM stop adhering to management and develop T1DE, despite the susceptibility and severity of complications of diabetes remaining the same and even increasing with T1DE.

Oriji, Vassileva and Mandryx, (2012) extended the HBM (EHMB) to include four additional factors (Table 16). The addition of these four elements have been found to improve the predictive capacity of the EHBM by 78% (Oriji, Vassileva & Mandryk, 2012) compared to the HBM (Rosenstock, 1966). As the present discussion progresses, links between the results of this research and the EHBM will be made. This discussion will consider how participants shifted from adhering to T1DM towards T1DE in the hopes it will contribute to the understanding of T1DE development and maintenance.

**Table 16**

*Outline of the HBM and EHBM*

| **The factors of the Health Belief Model (HBM)** | **The Extended Health Belief Model (EHBM) (in addition to the factors of the HBM)** |
|---|---|
| ***Perceived susceptibility*** is when an individual believes they are highly likely to experience a health condition/outcome. | ***Consideration of future consequences*** is when an individual cannot see the immediate benefits of their health behaviour, so must trust they will experience them in the future (Adams, 2012). |
| ***Perceived severity*** is when an individual believes that the complications of not performing a health behaviour will be severe. | ***Self-identity*** argues that in order for someone to adhere to or stop a behaviour, they must adopt it into their identity i.e. someone is less likely to stop smoking if they still identify as a smoker (Szalavitz, 2012). |
| ***Perceived Benefits*** is an individual evaluation of the positive outcomes that will happen as a result of their health behaviour. | ***Concern for appearance*** is based on the research which has found behaviour is more influenced and motivated by concern about appearance, attractiveness and popularity than health consequences, due to the importance society places on appearance (Hayes & Ross, 1987; Kai-Yan, 2002). |

| | |
|---|---|
| ***Perceived barrier*** is an individual's opinion regarding the difficulty or cost of adopting a health behaviour. | ***Perceived importance*** references the value an individual attaches to the outcome of a behaviour (Oriji, Vassileva & Mandryx, 2012). |

### *5.4.3.“Why did you become my whole identity?”*

Participants wrote of the ways that T1DM had impacted their identity. Through the actions of others, participants were made to feel that their identity had been taken over by T1DM and, because of this, they sat on the outside of social groups.

In the subtheme “*the diabetic one”,* participants wrote of their identity being labelled as “*sick”* or “*diabetic”*, which was also found in theme two of the SLR (Abdoli et al., 2017; Chalmers et al., 2022; Fioretti & Mugnanini, 2022; Goldman & Maclean, 1998; Kim, 2022; Montali et al., 2022; Tilden et al., 2005). The social identity theory (Tajifel & Turner,1979) can be applied to understand the significance of this labelling. Being identified by one's T1DM could place individuals into the social category of ‘diabetic’*,* which is outside of the majority ‘in-group’ in places such as school and work, as the majority do not have T1DM. This could explain why many feel on the outside of social groups. In addition, it could be argued that labelling someone's identity as “*diabetic*” or “*sick*” could limit the individual's view of their abilities and prospects due to the wider social narratives depicting those with illness as being less than or weak (Foucault, 2008), as discussed in Chapter 1.

Not wanting to have the identity of “*diabetic”* and “*sick”* and not wanting to be on the outside of social groups, could also explain why some with T1DM struggle with illness integration (Charmaz, 1987; Oris et al., 2016). The theory of illness integration (Charmaz, 1987), however, also implies that an individual must have an *established* identity for the illness to then be integrated into. Participants of this study wrote of their diabetes taking over

their identity *before* it was fully established, and/or "*infiltrating"* their identity and robbing it completely. Perhaps, therefore, individuals feel that they have no identity in the first place for T1DM to be integrated into.

The experience of T1DM taking over identity was also attributed to T1DM being the main focus and concern of other people. Participants of the current and previous research shared that healthcare professionals particularly drive this experience by focusing on biomedical markers and glycaemic control over emotional and psychological wellbeing (Abdoli et al., 2020; Chalmers et al., 2022; Tilden et al., 2005). These findings highlight how this focus of the medical system may inadvertently reinforce the dominance of T1DM within identity, which may in turn limit an individual's opportunity to explore and construct other elements of their identity beyond their diabetes.

Not all participants wrote of not accepting the identity of diabetes. Participants who appeared to be more accepting of T1DM in relation to their identity wrote of acknowledging that diabetes has both difficult and valuable elements. This acknowledgement highlights that, often, relationships with and feelings towards chronic illness are complex. They are not dichotomous in the sense that when an individual accepts their diabetes it means they like everything about it. Nor are they stagnant, in that acceptance in that once it happens, is present and strong every day. Instead, they are dynamic and evolving, as seen in the letters written. For some, acceptance was written as embracing and being grateful to their T1DM, whereas for others, T1DM was reluctantly accepted.

Despite its hardships, every participant wrote of what T1DM taught them about identity. Traits such as strength and resilience were frequently written about, as well as reconnection with the body and teaching the value of health. Similar traits were found in theme four of the SLR (Abdoli et al., 2017; Commissariat et al., 2016; Fioretti & Mugnaini., 2022; Kim, 2022).

Individuals with T1DM viewing themselves as strong and resilient reads as a powerful reclaiming of identity, a reclaiming from the negative narratives that surround diabetes and illness, as well as being labelled and treated differently by others as a result of the condition. A reclaiming that is, currently, mainly driven by the individual alone, unsupported by professionals and social narratives.

### *5.4.4.“Something I needed”*

Participants wrote of the various ways their T1DE provided them with the things that they needed, and the feelings of relief, comfort, and gratitude felt because of this.

In the subtheme “*throw caution to the wind”,* participants implied a feeling of gratitude towards their T1DE for giving them freedom from the control of T1DM. For some, this freedom was rejecting food rules instilled by T1DM and choosing to eat (or not) when they wanted. The idea that T1DE initially provides some individuals with the opportunity to reduce control around food if they wanted to, is interesting. This is because, often, a key function of an ED (without T1DM) is providing an initial feeling of control through providing *more* control around food (Froreich et al., 2016). This suggests that the function of T1DE in relation to control could initially differ from other EDs.

As discussed in theme one, participants felt their internal and external worlds were controlled by T1DM, resulting in many losses. Rather than the feeling of control just being provided by strict rules and control around food, perhaps in T1DE, it is provided by taking control away from T1DM and initially giving it back to the individual through giving them choice. This choice is not only regarding whether to eat, eat sugar, binge, restrict etc., there is also the choice to do whatever the individual wants, when they want to. T1DE serving as a way to take control back from T1DM mirrors the findings of Coleman and Caswell (2020), that for many, T1DE is used as way to regain control of one’s body and life from T1DM.

In theme two, participants shared wanting a break from the exhaustive relentlessness of T1DM. Participants wrote of their ED providing this, for example, Susan shared that with their ED they "*didn't need to think"*, they could just exist. This experience implied that many participants felt an initial sense of relief because of the break the T1DE provided, giving them physical and mental space to breathe. Similarly, Harrison et al.'s (2021) CBT model names T1DE providing a break from T1DM as a maintenance factor. This highlights that T1DE's provision of a break from diabetes, and the relief this gives to an individual, are significant contributing factors towards its development and maintenance.

The T1DE also provided some participants with a feeling of safety and comfort. The provision of safety and comfort T1DE provides is similar to other EDs. For example, Serpell et al. (1999) found one of the most valued traits of AN was it being a guardian that kept them safe. Given the unpredictability of one's life and body caused by T1DM, and the prominent feeling of fear towards T1DM because of its potential complications, it is understandable why the safety T1DE seemingly offers is so appealing. It is also understandable, therefore, why participants also wrote of wanting to protect it, implying that just the idea of having the ED as an option if one ever needs it again, also provides a sense of safety.

A significant parallel can be made between participants writing of the identity of T1DM forcing them to be on the outside of social groups, and their T1DE helping them to feel that they belong and are accepted. It is important to first consider reasons as to why this shift from outsider to insider in social groups, happens.

As mentioned in Chapter 1, an ED can be used by an individual to rid them of the parts of their identity that they dislike (Espeset et al., 2012; Nordbo et al., 2006;). Findings from this research suggest that T1DE has a similar function. Participants wrote of their ED getting rid of unwanted elements of their identity that were forced upon them by T1DM. For example,

Susan wrote that because of their ED, they no longer felt like "*something was wrong with them and like they didn't matter"*. Similarly in other T1DE research, a function of T1DE is to distance oneself from the unwanted diabetic image (Embick, 2023; Harrison et al., 2021).

To explore why T1DE is able to counterbalance the unwanted elements of a diabetic identity, it is important to consider the wider narratives, discussed in Chapter 1, around female thinness, fatness and control, as well as the narratives around health and illness. Narratives around health depict those with illness as innately flawed and 'less than' (Lupton, 2012; Sontag, 1978). Narratives around thinness and control, however, mean that women are granted more social acceptance and power the thinner they become (Hosseini & Padhy, 2020). These narratives are reflected in participant experiences, when many were praised by others the more they followed their T1DE and, therefore, the more confident they became. This is a direct contrast to feeling the odd one out and othered because of T1DM.

Applying the self-identity component of the EHBM (Oriji, Vassileva & Mandryk, 2012), one could argue, therefore, that the movement away from the health behaviours of T1DM, towards T1DE, is due to the individual no longer wanting this identity of "*diabetic*" and the negative narratives that it holds. This concept links to Tajifel and Turner's (1979) social identity theory; through an individual no longer performing behaviours related to diabetes, T1DE could provide a mechanism to move from the social identity of "*diabetic*" to the majority in-group.

However, it is important to comment that, in other EDs, models such as CBT-E (Fairburn, 2008) can be used to challenge negative beliefs one holds towards themselves and to build a valued life outside of the ED, thus challenging its purpose and the need for it. With T1DE, the life individuals have without it will always involve T1DM and its stigmatised identity, control, relentlessness, and making someone different and be treated differently. This could

imply that the care of T1DE is more complex and requires multi-disciplinary input to help soften the load of management and provide psychological support. It also implies that the required care extends beyond a therapeutic room or hospital ward and into wider society-a society that currently views T1DM, and those who live with it, in such a negative light.

### *5.4.5. "Like a slave to a master"*

Similarly to the research discussed in Chapter 1 on the anorexic voice (AV) (Pugh & Waller, 2016; Tierney & Fox, 2010; Williams & Reid, 2012), participants of this research described T1DE as a powerful figure that eventually gained complete control over them. This control related to following many rules and rituals installed by the T1DE in order to "*please"* it. The way the T1DE held this control was through using threat and instilling fear, convincing the individual that T1DE was the only way they could be happy and accepted, without it they were a failure and worthless.

These findings are similar to those of Burnett-Stuart et al. (2024) who explored the role of the AV from the perspective of AN. They found that AN held the power in the relationship with the individual, but there were also elements of co-dependency. The participants believed they needed AN to solve their flaws, whilst AN needed the individual to keep itself alive. The findings of this study echo this; a power imbalance between the individual and their T1DE and a co-dependency between the two. This highlights that those with T1DE are held in a similar bind to that seen in other EDs.

The results of this study, however, could also imply an additional complexity in the bind one is held in with T1DE. Previous research on the AV speaks of the 'voice' threatening the individual with hypothetical scenarios of rejection and undesired personality traits they would possess if they did not follow it (Burnett-Stuart et al., 2024; Pugh & Waller, 2016; Tierney & Fox, 2010; Williams & Reid, 2012). This finding was also supported by the findings of the current study. However, what is different in T1DE is that these scenarios of rejection and

perceived undesired traits are not always hypothetical. As discussed in previous themes and in Chapter 2, individuals with T1DM spend many years sitting on the outside of social groups being viewed as a flawed 'diabetic', meaning these threats could instead be based in some reality. Without T1DE, the individual goes back to T1DM and all that is associated with it (Embick, 2023). This could mean that the threats that T1DE makes to the individual, and the fear this results in, may be harder to challenge. Recovering from T1DE could be perceived as going back to the unwanted reality of diabetes. Therapeutic intervention, therefore, may need to adapt to accommodate this.

The subtheme "*google said 'go to hospital', you didn't care"* shared the persistence of T1DE despite significant threat to life. This persistence occurred through the ongoing threats and punishments by T1DE, but also T1DE warping the participants' sense of 'normality' when it comes to their health. Charlotte, for example, wrote of DKA and infections all becoming the "*new normal"*.

Participants of this research also linked the control T1DE had over them to them fearing weight gain. This research supports other T1DE research which also found a link between a fear of gaining weight and individuals continuing to follow T1DE; participants stating they would rather be "*unwell"* or "*die"* than be "*fat*" (Coleman & Caswell, 2020. p.4; Harrison et al., 2021 p.6.) as thinness was more important than health (Ribeiro et al., 2021). This can lead to the question, why is feeling unwell and/or death considered preferable to being fat in T1DE? The narratives surrounding fatness, shared in Chapter 1, can help to answer this question.

There is the reality that women in particular are granted more social power and acceptance when they are perceived to be thin (Hosseini & Padhy, 2020) and face grave social consequences if they are considered 'fat' (Fikkan & Rothbum, 2012). Participants of

this study wrote of these narratives being reinforced because of the praise they received for their weight loss despite their poor state of health. In addition, this praise may have also reinforced T1DE, including the warping of normality when it comes to the individual's health and minimising the perceived severity of complications. The praise of others may have also reinforced T1DE in its telling to participants that all they were experiencing was necessary to be beautiful, and beauty was the most important thing. The want to lose weight and be beautiful, therefore, appeared to be a key driving factor of behaviour. These findings support the 'concern for appearance' addition in the EHBM (Hayes & Ross, 1987; Kai-Yan, 2002); social acceptance is a bigger influence on behaviour than concern for health, implying the motivation behind behaviour shifts in T1DE.

In addition, it is reasonable to assume that the severe complications faced by participants because of T1DE would have led to others in their lives, such as carers, friends, and professionals, showing them concern and worry. It is important to question whether this concern has a function. In theme three, participants shared their dislike for T1DM being all that others focused on. Perhaps, therefore, T1DE has a function of being something else for an individual to be noted for, and for others to focus on.

The findings of the subtheme "*your voice is loud, but I am louder"* shares the strength and resilience of the participants in their moments of resistance against T1DE. A key implication of these findings is that recovery may be supported when individuals begin to challenge the internalised messages of T1DE, reframing themselves as more than what the condition dictates them to be. This reflects wider recovery literature which highlights the importance of resisting illness-imposed identities and reclaiming alternative, more valued aspects of self (de Vos et al., 2017; Reid & Burr, 2001). For example, one participant's statement that they are "*more than numbers, more than restriction*" illustrates a rejection not only of T1DE's rigid focus on food and body control, but also of the medicalisation of

identity often experienced in T1DM, where individuals report being reduced to glucose readings or other clinical outcomes (Abdoli et al., 2020; Charmaz, 1995). This suggests that recovery from T1DE may involve not only resisting the rules of the ED, but also challenging broader cultural and medical narratives that risk defining individuals primarily by their illness.

### *5.4.6. "Like yin and yang"*

This theme explored specific references made by participants regarding how T1DM and T1DE interact. This exploration used the simile offered by Alice who said their T1DM and T1DE were "*like yin and yang"* as they are "*friends*" who "*fit perfectly*" together, conveying the image that, despite being opposite, T1DM and T1DE complement each other. A prominent way they do this is through food. Participants wrote of their T1DM increasing their salience of food and weight, acting as a key contributor to the development of T1DE, and supporting all three models of T1DE discussed in Chapter 1 (De Paoli & Rogers, 2018; Harrison et al., 2021; Treasure et al., 2015). In addition, these findings align with previous qualitative research highlighting how both T1DM and ED behaviours exert control over daily life, particularly around food and routines, reinforcing each other's impact on the individual (Wisting & Snoek, 2020; Colton et al., 2015).

Taylor's account highlights the unique tension in T1DE when an ED pre-dates T1DM. Unlike participants who developed an T1DE after T1DM, Taylor experienced the introduction of diabetes management as an additional layer of control over food on top of their ED, requiring them to track not only calories but also carbohydrates and to consume foods (e.g., sugar) that conflicted with their ED rules. This is consistent with previous findings that T1DM increases nutritional knowledge and food monitoring to a degree not typically seen in other EDs (Colton et al., 2015; Wisting & Snoek, 2020). This result could indicate that for those with an existing ED, the demands of T1DM may intensify

preoccupation with food, weight, and control already caused by an ED, compounding distress and undermining recovery efforts. The bind Taylor describes, feeling forced to choose between appeasing the ED or following T1DM requirements, has also been observed in qualitative studies, where people report T1DM and ED "competing" for dominance in identity and behavior (Goddard & Oxlad, 2023). These findings suggest that the sequencing of diagnoses may be a key developmental factor shaping how identity disruption and food-related distress unfold in T1DE, with important implications for tailoring interventions to account for different pathways into the condition.

An observed, shared characteristic of T1DM and T1DE is the power and control they held over participants. This control resulted in occasions of a power struggle between the two. Alice depicted this power struggle when they wrote of hoping not to need any more treatment for hypoglycaemia because they "*do not want the extra [redacted] calories per jelly baby to add to [their] intake*". Not only does this convey power of T1DM and T1DE, but also how little autonomy individuals have when struggling with T1DE; the option is either to listen to T1DM or T1DE, there is no room to consider what they themselves would like. Individuals could also experience feelings of frustration and being overwhelmed when these two diagnoses struggle for power. These findings highlight the need for MDTs, particularly psychological therapists, to explore these feelings and support in the exploration of who an individual is outside of T1DE and T1DM.

Findings of this research as a whole also support Goddard & Oxlad (2023) and Wisting & Snoek (2020), advocating for the importance of qualitative research in furthering the understanding of T1DE. As outlined in the 3.2.1, the shortage of knowledge about T1DE has been attributed to the lack of qualitative research exploring clients' experiential perspectives. By adopting a qualitative, letter-writing approach, this study helps to address this gap, offering insights into the unique emotional and identity-related dimensions of T1DE that are

inaccessible through quantitative measures alone. Importantly, the use of qualitative methodology means these findings also contribute to research starting to clarifying the unique ways of T1DE, helping to distinguish it from other ED such as AN and BN. This distinction is essential both for theory development and for ensuring that treatment approaches are tailored to the specific dynamics of T1DE rather than assuming it can be understood or treated in the same way as other EDs.

The length of this theme is shorter than the others. This does not, however, necessarily indicate a weakness in this theme. In their work on thematic analysis and RTA, Braun and Clarke (2006) argue that the meaningfulness of a theme cannot be captured by quantifiable measures, such as its length of the amount of participant who contribute to it. Instead, what makes a theme meaningful is its ability to capture something important in relation to the research (Braun & Clarke, 2006). Theme six captures the meaningful experience of a few participants who explicitly reflect on the interaction between their T1DM and T1DE, highlighting ways interactions and the emotions felt as a result, could contribute to the maintenance of T1DE.

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**A Reflection**

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*I put off writing the discussion for a long time, something I had not done for any other section. Each time I went to write, I found a million other things to do, something that is really out of my character. There was such a sense of responsibility following the results. I now had my interpretation of people's experiences and what was needed, so I needed this section to be powerful and articulate for readers to take it seriously, to remember it, to want to make change. What if my points are not powerful enough? What if I let my participants down? What if it just is not good enough? Eventually I just took it theme by theme. I had time to be slow, to be curious in what theories best fit and where these findings deviate and what this could mean. I gave myself permission to write whatever I thought could*

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*be interesting. To write 'badly' to start with, knowing there was time to go back and edit. Initially I did get caught up in 'no but this point isn't good, it needs to be polished', but with time, sitting with the discomfort of not everything being 'polished' immediately, I began to enjoy it. I think it is exciting, the idea this research could have an impact, could lead to more research and change.*

## 5.5. Strengths and limitations

### *5.5.1. Strengths*

The limited understanding of T1DE is largely due to a lack of qualitative studies on the topic (Goddard & Oxlad, 2023; Wisting & Snoek, 2020). This study used qualitative methodology to explore with participants their emotions towards T1DE and the impact it has on their identity, therefore aiding to address the current gap and contributing to the current understanding of T1DE. Participants wrote of the multifaceted relational dynamics and emotional experiences between themselves and their T1DM and T1DE, which integrated to develop and maintain T1DE. The difficulties faced as a result of T1DM, the T1DE offered a solution for, but these solutions came at a significant cost and can keep the individual trapped in the cycle of T1DE.

The use of letter writing added various strengths to this research. The sample size of letters obtained in this research was firstly adequate (Williams, 2024), increasing its credibility. The flexibility of how participants could send and produce their letters increased the accessibility of this research. In addition, externalising T1DM and T1DE, so participants wrote directly *to* them, meant that participants were able to harbour their raw emotional experiences and express them (Lock et al., 2004; White, 2004). This is opposed to using other qualitative methods, such as interviews, where participants would have been speaking *about* their T1DE and T1DM *to* a researcher, meaning the emotion conveyed may have been

diluted. It also meant that participants had autonomy over what they wrote as opposed to following the agenda of a researcher (Flemming, 2020). This means that the themes derived from the collected data are based on what participants believed to be important to them, increasing their relevancy in the application to clinical care.

The use of reflexivity and bracketing from the earliest stages of this research are both strengths. This is because the influence of personal biases was considered and pre-empted throughout the process, to reduce the extent of their impact on the decisions made in this research and data analysis, increasing the trustworthiness of this research (Fleming, 2018).

### *5.5.2. Limitations*

Despite elements of letter writing being a strength of this research, other elements of this data collection method could be considered limitations. Letter writing, particularly writing two letters, placed a significant burden on participants. It relied on them having enough time, space, motivation, and emotional capacity to complete both letters. It is therefore likely that the data collection method of this research asked too much of participants and contributed to 58.6% of eligible participants not completing their letters. A suggestion to make the research more accessible in future is to reduce the number of letters to one (i.e., one addressed to T1DE as a whole).

In addition, another limitation of using letter writing is that although letters allowed participants to focus on what they deemed to be important, it also meant that aspects of the letters, relevant to the research, were left unexplored or unexpanded, meaning they were not explored in depth in this research. In contrast, qualitative methods like unstructured or semi-structured interviews and focus groups, where the researcher is present during questioning, enable follow-up questions for deeper exploration (Brinkmann, 2014). A potential solution could have been interactive letter writing, where the researcher responds with questions for participants to address (Burtt, 2021).

Having only female participants impacts the transferability of these results. Similar rates of insulin omission and body dissatisfaction have been found in males and females with T1DM, but the perception of an ideal body shape differs between genders (Araia et al., 2017). Engagement with disordered eating behaviours in males are attributed to the want to obtain a 'masculine' body shape of a slim body with large muscles, as opposed to thinness for females (Mond et al., 2014). These gender differences in disordered eating behaviours reflect broader patriarchal narratives about body ideals that impact men like the thin ideal impacts women; in order for men to be considered masculine they must have muscle (Leit, 2001), which shapes how men perceive their bodies and engage with eating behaviours. The results of this study, therefore, may not represent the experience of males with T1DE, and therefore cannot be applied to this population.

A proportion of participants self-identified as having an ED rather than having a formal clinical diagnosis. While this allowed inclusion of individuals who may not have accessed services, it introduces some uncertainty regarding diagnostic specificity, as experiences of self-identified EDs may differ from those with clinically verified diagnoses (Fairburn & Harrison, 2003). Recruitment from both clinical and non-clinical settings further contributed to sample diversity, capturing a broader range of experiences but potentially introducing variability in severity and treatment exposure. These decisions were made to balance accessibility, representativeness, and feasibility, yet they should be considered when interpreting the findings, as they may have shaped the themes and perspectives captured in the study.

This study did not control for the timing of T1DM and T1DE diagnoses. This meant the participant group was mixed in regard to what they were diagnosed with first. The majority of participants were diagnosed with T1DM before their T1DE, but a small portion struggled with an ED before T1DM. This factor was not controlled for because no prior

research was found by the primary researcher regarding this factor's influence of one's experiences of T1DE. The content of the letters did appear to somewhat differ depending on the timing of diagnosis, the extent of these differences were not examined in depth as this was not the purpose of this research. This being said, this distinction highlights how timing of diagnosis may alter the way identity is disrupted in relation to the developmental phase an individual is in (Helgeson et al., 2008). For example, being diagnosed with T1DM during early adolescence, a key stage in identity formation, may foster a sense of difference or otherness at a critical developmental period. Whereas receiving an ED diagnosis first may shape identity through a different set of mechanisms, such as body image or control, that are later compounded by T1DM. Due to the majority of this participant group being diagnosed first with T1DM, it is likely that the results represent their experiences to a greater extent, and findings may have differed if more participants had experienced an ED prior to T1DM.

A further limitation is that demographic information such as ethnicity and cultural background was not collected, in line with NHS ethical guidance that discourages requesting sensitive information unless it is central to the research aims; however, this constrains consideration of how identity may be shaped by these factors.

### 5.6. Clinical implications

This research highlights the complex and intertwined nature of T1DM and T1DE, particularly in how identity and emotions toward each diagnosis interact in ways that may sustain the difficulties. While these findings are based on a small qualitative sample, they contribute experiential evidence that aligns with concerns raised by the 2024 Parliamentary Inquiry (Howarth & May, 2024) and the Prevention of Future Death Report (McCormick, 2024) about the limitations of a siloed healthcare approach. Rather than suggesting this study alone demonstrates the need for integrated pathways, the findings add depth to these wider

calls by illustrating how service users themselves experience T1DE as inseparable from their diabetes care.

These findings demonstrate how impactful the approach of healthcare professionals is on how individuals feel towards their T1DM. Participants highlighted that healthcare professionals contributed to the fear in them, made them feel like a set of numbers, and that they did not matter outside of their T1DM, all of which seemed to contribute to the development of T1DE. Healthcare professionals, therefore, need to adopt a curious and compassionate stance with service-users; asking how they are, exploring reasons why they may be struggling with management, and finding a balanced, person-centred, way of informing service-users of the complications of T1DM without causing fear.

Participants shared an array of complex emotions towards their T1DM and T1DE. These findings emphasise for the need of psychological professionals in the care of T1DE. Compassion focused therapy (CFT) could be used to explore the various emotions experienced towards T1DM and T1DE. These emotions can then be met with understanding and compassion to reduce the shame and self-criticism that may be experienced as a result of T1DE (Gilbert, 2013).

Acceptance and Commitment Therapy (ACT) could also be effective in helping service-users to practice acceptance, particularly towards their T1DM. In ACT, acceptance is viewed as leaning into the pain of life that is unfair, such as having T1DM, in order to reduce resistance and avoidance of it (Bennett & Oliver, 2019). ACT also teaches diffusion from the negative judgement we can often have towards this pain (i.e., I am defective for having T1DM) to reduce the distress felt by the individual (Bennett & Oliver, 2019). In addition, ACT can be used to explore the values of the individual and start to plan for committed action towards these values to build a life worth living (Bennett & Oliver, 2019). This work

can help an individual to explore and encourage the development of their identity outside of T1DM and T1DE; moving away from diabetes being their whole identity and challenging the belief that their ideal identity can only be achieved through T1DE. It is not just the responsibility of the individual, however, to recover from T1DE.

The result of both the empirical study highlight the significant role of societal narratives of T1DM and thinness on T1DE. Funding into public education on T1DM, particularly around its causes, management, and lack of impact on capability, is vital in beginning to reduce the stigmatised view of the condition. Efforts also need to be made on a national level to dismantle the inaccurate and sexist narratives that thinness equals health, beauty, and self-control, and fatness is the antithesis. This could involve challenging the beliefs that 'fatness' is caused only by the individual, by providing education on its biological, societal and systemic causes, and that health is represented by more than one body type.

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**A Reflection**

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*When writing the clinical implications section I actually felt a lot of anger. To me, most of the things written here, such as being curious, T1DE needing to be a specialist service, really does seem like common sense. Saying this, I recognise my bias here. T1DE is a topic that I have given most of my attention to for about two years, so of course these things seem 'obvious' to me, but to other professionals, particularly those who worked under a more medicalised model, these implications will likely (hopefully) be useful.*

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### 5.7. Invitations for future research

It is vital for future T1DE research to adopt a qualitative stance. This is so the field continues to amplify the voices of this neglected population by exploring and understanding their experiences of T1DE. This knowledge will help to continue to build a clinical picture of T1DE, specific to its unique qualities and needs.

As previously mentioned, this study did not control for timings of diagnosis, nor did it explore whether this factor created a difference in the experience of T1DE. Although not examined in depth in this research, developmental stage and timing of diagnosis may be key to understanding how identity and emotions towards each condition contribute to the onset and maintenance of T1DE. Future research should examine how these pathways differ, for example comparing the impact of T1DM diagnosed in childhood versus adulthood, or ED emerging before versus after T1DM, to better understand the developmental contexts in which T1DE takes hold.

A question this research has left is, if T1DM is so disliked and unwanted, what is one's incentive to recover from T1DE when it involves returning back to T1DM? It would be beneficial for future research to explore with those with T1DE their idea of recovery; what are their barriers to recovery? What do they think recovery means for them? Is there a fear about returning to life with T1DM? Understanding these barriers provides the ability to then discuss how services provide support to overcome them.

This empirical study highlights the need for a T1DE specific intervention. The safe management of people with Type 1 diabetes and eating disorders study (STEADY) (Zaremba et al., 2022), a T1DE-specific CBT intervention for those with mild-moderate symptoms, showed promise in a recent feasibility study by reducing anxiety, depression, ED cognitions and behaviours (Stadler et al., 2025). These findings reinforce the need for specialised T1DE interventions and continued trials on such interventions are vital.

### 5.8. Critical appraisal

The ten criteria of the CASP (Critical Appraisal Skills Programme, 2024) tool were applied to this study to critically appraise its quality (Table 17). The tool was used and scored in the same way as described in Chapter 2 (subsection 2.1.6.). The CASP was completed by

the principle and secondary supervisor and reviewed by an external researcher to reduce risk of bias.

**Table 17**

*Quality appraisal of empirical study*

| CASP criteria including description | Quality appraisal | Rating |
|---|---|---|
| **Section A: Are the results valid?** | | |
| **Was there a clear statement of the aims of the research?**<br><br>***Consider: 1) what was the goal of the research? 2) why it was thought important? 3) its relevance*** | ✓ The research aims are outlined in Chapter 2 (Section 2.7). | 1 |
| **Is a qualitative methodology appropriate?**<br><br>***Consider: 1) If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants, 2) Is qualitative research the right methodology for addressing the research goal?*** | ✓ The aim of this research was to *explore* participant *feelings,* and the impact T1DM/ED has had on their identity.<br>✓ The researcher justifies the use of a qualitative method in Chapter 3 (Subsection 3.2.1). | 1 |
| **Is it worth continuing?** | | |

| | | |
|---|---|---|
| **Was the research design appropriate to address the aims of the research?**<br><br>***Consider: 1) If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)*** | ✓ The decision-making process for choosing the research design is discussed in Chapter 3 (section 3.2). | 1 |
| **Was the recruitment strategy appropriate to the aims of the research?**<br><br>***Consider: 1) If the researcher has explained how the participants were selected, 2) If they explained why the participants, they selected were the most appropriate to provide access to the type of knowledge sought by the study, 3) If there are any discussions around recruitment (e.g., why some people chose not to take part)*** | ✓ A detailed outline of the recruitment strategy was given in Chapter 3 (subsection 3.6.1).<br>✓ The two pathways for recruitment (as developed via consultation with EBE) were explained with justifications provided in subsections 3.6.2. and 3.6.3.<br>✓ An inclusion and exclusion criteria with justification was provided in chapter 3 (subsection 3.6.4). | 1 |

| | | |
|---|---|---|
| | ✗ Researchers were unaware of why some participants chose not to take part. | |
| **Was the data collected in a way that addressed the research issue?**<br><br>***Consider: 1) If the setting for the data collection was justified, 2) If it is clear how data were collected (e.g., focus group, semi-structured interview etc.), 3) If the researcher has justified the methods chosen, 4) If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews are conducted, or did they use a topic guide), 5) If methods were modified during the study. If so, has the researcher explained how and why, 6) If the form of data is clear (e.g., tape recordings, video material, notes etc.), 7) If the researcher has*** | ✓ The data collection method was explained and justified in detail in Chapter 3 (subsection 3.4.2).<br>✓ The guidance participants were given to follow regarding letter writing were provided in Appendix H.<br>✓ Participants were given the option of hand-writing letters, typing letters or voice noting them.<br>✓ The form of data collection was clear; written, typed or spoken letters.<br><br>✗ The researcher did not discuss data saturation | 1 |

| | | | |
|---|---|---|---|
| ***discussed saturation of data*** | | | |
| **Has the relationship between researcher and participants been adequately considered?**<br><br>***Consider: 1) If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location, 2) How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*** | ✓<br><br>✓ | The relationship between the researcher and participants was discussed throughout this research using reflective tables, extracts from a reflexive journal and bracketing interview (Appendix A). These share how the primary researcher responded to events during the study and how this influenced decision making.<br>In Chapter 1 (section 1.2) the author discussed their personal positioning as an insider researcher to this topic. | 1 |
| **Section B: What are the results?** | | | |
| **Have ethical issues been taken into consideration?**<br><br>***Consider: 1) If there are sufficient details of how the research was explained to participants for the*** | ✓<br><br>✓ | The researcher explained what ethical approval was needed and when both were granted (Appendix J and Appendix L).<br>The researcher provided how ethical considerations were | 1 |

| | | | |
|---|---|---|---|
| ***reader to assess whether ethical standards were maintained, 2) If the researcher has discussed issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study), 3) If approval has been sought from the ethics committee*** | | conveyed to participants prior to them taking part; participant information sheet (Appendix M) and informed consent (Appendix N).<br>✓ A debrief sheet was provided to participants after the study and this is included in Appendix O. | |
| **Was the data analysis sufficiently rigorous?**<br><br>***Consider: 1) If there is an in-depth description of the analysis process, 2) If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data, 3) Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process, 4) If sufficient data are presented to*** | ✓<br>✓<br>✓<br>✓ | A description of how the six-step process of RTA was followed was provided in table 13.<br>The process of RTA, including examples of coding, the coding process and thematic maps are provided in Appendix Q .<br>Sufficient data is provided in quotations to support each theme.<br>The researcher continually shared and reflected on their biases and how these may have | 1 |

| | | |
|---|---|---|
| ***support the findings, 5) To what extent contradictory data are taken into account, 6) Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*** | influenced their interpretation of the data collected.<br>× Contradictory was somewhat covered in reference to how some participants accepted/valued their T1DM compared to those who did not.<br>× It is not clear how the presented data was selected from the original sample. | |
| **Is there a clear statement of findings?**<br><br>***Consider: 1) If the findings are explicit, 2) If there is adequate discussion of the evidence both for and against the researcher's arguments, 3) If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst), 4) If the findings are discussed in relation to the original research question*** | ✓ Findings are explicitly given, under clear headings and subheadings.<br>✓ Each theme is discussed in relation to existing literature; supporting and not existing literature.<br>✓ Table 14 shows an assessment of the credibility of the findings of this research through assessing their reliability and validity. | 1 |

| | | |
|---|---|---|
| | ✓ Findings are discussed in relation to the research questions. | |
| **Section C: Will the results help locally?** | | |
| **How valuable is the research?**<br><br>***Consider: 1) If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research based literature If they identify new areas where research is necessary If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used )*** | ✓ The researcher discussed how the findings of this research contribute to the existing knowledge and understanding of T1DE.<br>✓ The researcher discusses how these findings can influence further research, clinical practice and makes suggestions for changes in the current policies and service provisions for T1DE. | 1 |
| | | **Total Rating:** 10/10 |

### 5.9. Conclusion

The aim of this research was to explore how individuals with T1DE feel towards their T1DM and ED, how they perceive both to have impacted their identity, and to understand what the roles of identity and emotion towards diagnoses are in maintaining T1DE. Through the letters written by participants, various themes relating to emotions and identity were identified. Participants shared: resentment towards T1DM, exhaustion at its relentlessness, T1DM taking over their identity, relief and gratitude as a result of their ED, being controlled by their ED and, finally, how T1DM and T1DE interact with each other. Findings are discussed in relation to building upon, supporting, and contradicting existing literature to continue to build an evidence base that is adapted to this neglected population.

If nothing else, I hope this research has shared the stories of its participants. I hope these stories inspire researchers and clinicians to continue to explore how we can adapt services to suit the needs of this population, as opposed to trying to make this population fit into systems not designed with them in mind.

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## Appendices

### Appendix A: Bracketing examples.

Ai: Reflective journal extracts

**SLR**

| Date | Title and extract |
|---|---|
| 15/06/2023 | ***Creating a title***<br>We had a lecture today about creating a good title for the SLR and it confronted me with the fact where I am in position to start thinking about this, but I have been avoiding it because I hate thinking of titles. I feel like there is a lot of pressure attached to it, because once you have settled on it as an idea than that is it and it shapes a piece of what that will take up so much time and effort. What if I get halfway through and realise it isn't meaningful? What if I hate it and get stuck with it?<br><br>Ironically, I also feel less overwhelmed having many words to write. Having the words in writing paragraphs, to explain my point and thoughts is comforting. The few words we have in title just makes it feel overwhelming and exposing, I am not good at cutting words down. Hence the avoidance. But I also know I just need to write out a title, no matter how bad it is, and that is a starting point, and I can go from there… |
| 23/06/2023 | ***The search process***<br>Trying to find the exact phrasing for words in my search is really tricky. I am missing a lot of research where identity is explored but does not come up in my current searches. I think it is because identity is spoken about but is not the specific focus of the research so it isn't the thing that is explicitly evaluated. I need to keep looking at key words and words mentioned in these texts which requires a lot of concentration on something mundane and tedious and it is tempting to ignore this and hope for the best with my current approach, but I won't. I want to do this research as well as I can. |
| 07/07/2023 | I am feeling a lot better about my search now. I have added in a lot more terms for evaluation and are now getting relevant papers that I think will be really useful and meaningful for this research. Which means the tediousness of finding more search term was worth it. |

| | |
|---|---|
| 14/07/2023 | ***Data extraction***<br>I am halfway through my data extraction table, and it is killing me. I am finding it so lengthy and boring, which makes it hard to concentrate which then means I miss things and have to go back and add it in which then makes this whole thing longer. I am also finding myself rushing because I want to get it over with, which also adds to making mistakes. I think the rushing is also coming from my constant internal drive to be moving forward, making progress and deep fear that I will run out of time. Which is stupid, because I think I am pretty ahead of schedule. I think there is a risk that this want to get on with things and finish will lower the quality of the work I do, which creates its own problems so I am trying to keep an eye on that so when I notice myself wanting to rush I have been practicing just taking a deep breathe, walking away from a bit, and coming back to the work a bit later, which is actually helpful.<br><br>I am learning a lot from this work and it is making me think deeply about all the intricacies of my studies, which is great for thinking critically about them and I am looking forward to that element of this research where I consider get to think critically and share these thoughts, but this part of getting there is awful. |
| 01/09/2023 | ***Quality appraisal***<br>I think that this is part of the SLR so far that has taught me the most Previously, I have mainly worked with quantitative research, so being able to critically appraise qualitative research is a newer thing for me and so has tested me and helped me to develop my critical appraisal skills which is great. I have questioned many times why I have made life harder for myself doing the GRADECer Qual rather than just the CASP, and I have been tempted many times to pretend I was never aware of this tool to make my life easier. But I knew that I would never not do it. At the start of this thesis, I wanted it to test me and be the best it can be and I believe that involves doing a really in depth critical appraisal, so despite the extra time it is taking me and many headaches it has caused I am still pushing through to uphold that promise to myself. |
| 07/10/2023 | **Data analysis**<br>I am currently working through the coding stage of thematic synthesis and something that has really struck me that I felt was important to reflect on. Stigma of T1DM is so prevalent in the studies I have gathered. Participants have shared so much about being blamed for their condition, being discriminated against for it, being isolated for it etc. I had no idea about this stigma and never considered that this would be something those with T1DM-or any chronic illness-faced. It speaks my own naivety and the privilege I hold in having a 'healthy' body and blind spots that come with this. It has also highlighted to me that this work will teach me so much as long as I stay open to learning from it and not get swept up with just the 'doing' of work. It also shows that this work will go far beyond the words that I write and the knowledge that I gain, it will also influence the way I act in the world. I have started following advocacy pages for diabetes and other long-term conditions to learn more about the stigma this group(s) of people face. |

**Empirical study**

| Date | Title and extract |
|---|---|
| | ***Data collection*** |
| 18/03/2024 | **Letter writing or interviews** |

| | |
|---|---|
| | I have a dilemma. I am currently trying to make a decision on whether to choose letter writing as my data collection method where I ask people to write to their diagnoses or we do interviews where we get people to talk about it. My gut is saying the letters. I think externalising is so powerful and taps into experiences that I just do not think we would get in an interview talking about something. I also think the experience of writing these letters will be powerful for the participants. Just having space and time to explore something that is or has been such a prominent part of their lives is powerful. Saying this, my logical side knows that letters is a bit different, they are not used a lot in research and they place such a burden on participants. Interviews, however, are well known, participants have an appointment they go to and have the researcher there. So, it would be easier recruitment wise I think. But this research for me isn't about, what is the easiest and quickest way I can get through this. It is about what is the way that I can produce something that is meaningful and will serve the people that it is for. And writing that point makes me think it is the letter writing, that is the route best attached to my values and intention behind this research. |
| ***Ethics*** | |
| 05/05/2024 | **Ethics form**<br>I am working my way through the NHS ethics form and it is everything everyone said it would be; long, boring and tedious. I am proud of what I have done though, I have put so much detail into my answers to avoid further work done the line as best as I can, but it has also caused me to slow down, consider why I am doing everything I am doing, defending it, and I feel these are all useful skills for viva. I was nervous about being the one who made all of the decisions about research but this process, where I have had to defend and justify all of my choices, has actually given me confidence. I just find the form so confusing and I find it frustrating how ambiguous some of the questions are so I feel like I am guessing a lot. Each time I think I have nearly finished I also realise I have about ten more pages to go so I am very burnout by forms. We were told today that it is good practice to pre-register our SLRs and I had every intent to but then I saw the form that it requires, and I just cannot face it alongside IRAS, so I think I will leave it. |
| 16/05/2024 | **Ethical panel**<br>I attended the HRA panel today and it was fine. I am writing because I noticed myself getting defensive at one panel member who pointed out some flaws in our risk protocol. Their concerns were valid and very helpful but I felt my chest getting a bit tighter and being really short in my answers and dismissive of the point, which is unlike me I normally am open to feedback and constructive criticism. I think I felt so defensive because this form has taken me so long. I have poured everything into it and put in so much detail and got it to a place that I was happy with and then to have someone point out a flaw I just thought, 'I do not want to do more work on this, I just want it to be over' and so my defensiveness was my desperation to not have to do more on this. Which obviously not how ethics work, my fatigue and sickness of this form does not come above the safety of participants and I think I next time I do this process I need to hold this in mind. That this person on the panel was not against me or trying to prolong my pain, but instead was doing just as I wrote, holding participant safety above everything. |
| 06/06/2024 | **Ethical approval**<br>I GOT FULL ETHICAL APPROVAL!!!!<br>I could cry, this is suchhh a milestone and I feel like I can finally go forward with this. I am so proud of myself for this one and I am very glad I did not let other people put me off doing NHS ethics. |

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| | |
| ***Recruitment*** | |
| 24/06/2024 | **Social media**<br>I have been getting a lot of positive responses on social media regarding this project. I have had multiple messages on LinkedIn and Instagram about how many people have been impacted by it, how unseen people have felt by services and by research and how happy people are that this research is happening. It made the ethics form worth it. It has made everything so far worth it. I am glad I chose this. So glad I didn't pick an 'easier' route to this research. |
| 07/07/2024 | **Anxiety about recruitment**<br>I am finding recruitment really really difficult. All I can think about is recruitment and I have been checking my survey so much, even before I go to sleep, which then makes me sit up and worry 'what if I don't get anyone' 'no one is going to participate'. I just think I have chosen too niche of a group and asked too much of people. I am convinced I will not get anyone. Whenever I tell people about what I am doing the general response is 'well good luck' and that makes everything worse. It is hard doing something 'different' in research and I can see why people do not try and do things a bit differently. Right now, I wish I would have stuck to the well-trodden path of interviews. I think if I had done that I would be getting more people and feeling better. I toy with the idea of doing an ethics change most days but I am resisting because I really do think the data we get from letters will be so much richer and more powerful than interviews and I hope one day I look back on this entry and feel glad I stuck with it. This is the first point where I have had no control over this research. I am great at getting my head down, getting on with things, planning, organising my time, knowing exactly what I can do and when I can do it. But I can't do that with this. I do not know how many people will do this and when they will do this. I have such an urge to just get on with things but there is nothing to get on with. Everything I could do; my ethics, my intro, my SLR, my method are all done. So now I have to sit here, with this uncertainty and wait. I am trying to observe these worries and thoughts and urges to act-like contacting people directly, forums etc. which is definitely against my ethics- and not get too involved with them. WHICH IS SO HARD and so humbling and it has remined me of what we ask our service-users to do. I know that I will get through this time, and I will look back and be like 'see Bec, it was all fine' but getting is really hard right now. |
| ***Data analysis*** | |
| 10/08/2024 | **Response to reading letters**<br>I have just read through a new letter. I underestimated the impact these letters would have on me reading them. They are just so powerful and full of emotion. They really convey what having T1DE is like, and I am finding them so valuable. I find myself experiencing so many emotions when I read them. I have cried more than once. Crying because I feel angry, sad, devastated in many cases. Crying out of pride when they talk about their recovery. I get the urge to want to change everything in this system that is so clearly broken for this client group. A system that has left so many to figure it out on their own. A system that has told these participants they are too complicated. And it is hard because I do not know where to put this anger sometimes. I try and use it to carry the drive to make this research the best that it can be to try and |

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| | make a change, no matter how small. But I have also been learning to share this stuff in supervision because I typically just hold onto it all and I know I cannot do that now, it will just lead me to burn myself out which is no good for anyone. |
| 05/09/2024 | ***Coding***<br>I initially found coding really fun and exciting. I liked looking at every word and thinking about what it means and represents. Now…I feel tired by it. I think I am getting a bit blind to the data if that is even a term. Like, I am not looking for anything new, in the last letter I did I noticed myself just looking for codes I have done before. Which is bad isn't it, what every paper on RTA warns you about. I have been coding a lot, back to back as well, so it makes sense why I feel so fatigued. I have marked the letters I think I have been bias on and created blank copies. I think I will go back to them in about a week, which seems like a long time but I feel like if I try again tomorrow, or even a few days the same thing will just happen again. |
| 25/10/2024 | ***Themes***<br>I haven't used NVIVO for any of my analysis. I never really considered it as an option because I like the practicality of touching things, being able to move this around and write what I need to. I have am now grateful for my choice in theming. I using post-it notes and I just love the ability to physically pick things up and move them, see where they look in different groups. What is interesting though, and what I was not anticipating, is that I noticing when I grouping for themes, an immense sense of pressure. It is in my stomach. I just think of the amount of effort the participants went to for these letters. How much they shared with me. And I just want to get it right for them. I want to get it perfect for them. I want whatever themes I choose to represent every single one of them. So, I am questioning every single thing and each decision is taking so long. Each time I think I am reaching an end, I then questioning everything and doubting it and moving everything again.<br><br>I just had supervision and spoke about everything I wrote about. It was so helpful. It helped me to recognise that the job of this research is not to share the exact story of each participant. But to use the data we have to answer the questions we have set out to answer. And that is okay. I feel a lot better about it now, and more confident in the themes I am coming towards. |

## Appendix B

Fairburn et al. (2003) transdiagnostic model of eating disorders

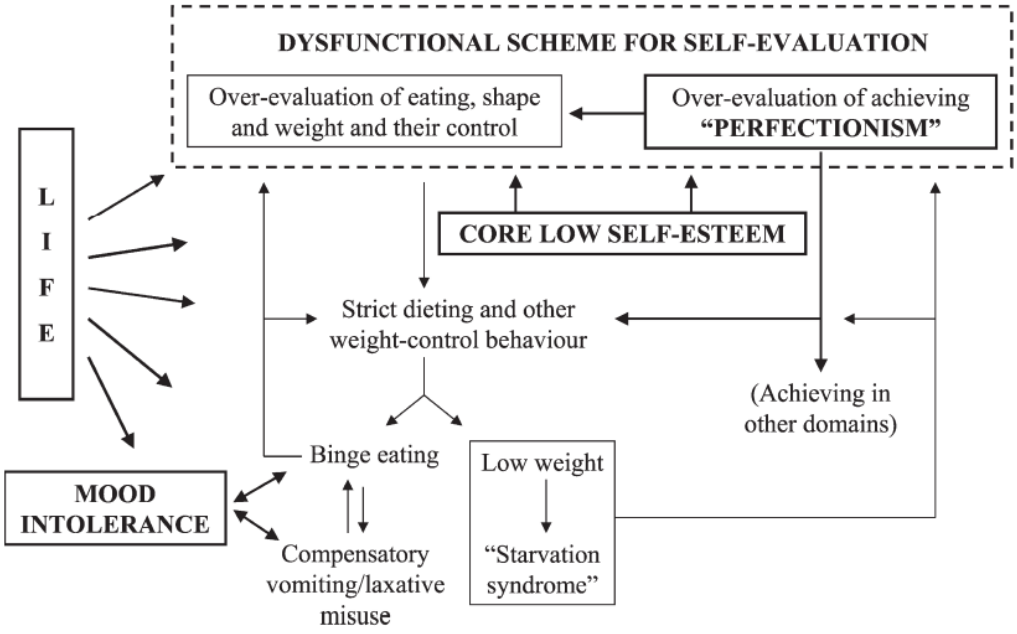


Fig. 4. A schematic representation of the 'transdiagnostic' theory of the maintenance of eating disorders. 'Life' is shorthand for interpersonal life.

## Appendix C

Treasure et al. (2015) maintenance model for disordered eating in type 1 diabetes.

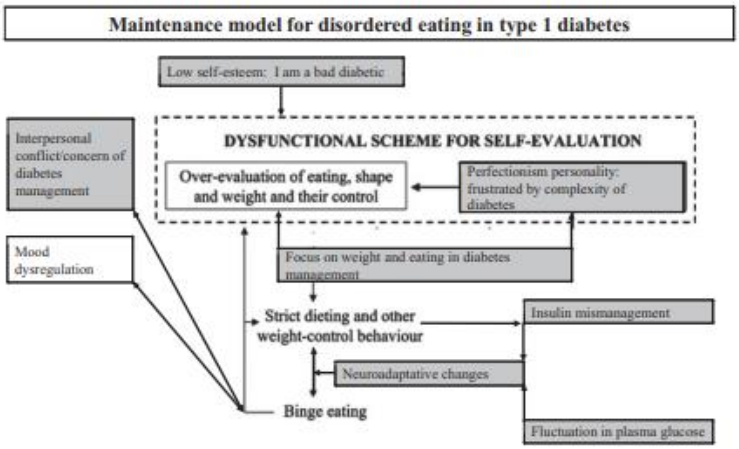


FIGURE 1 Maintenance model for disordered eating in Type 1 diabetes. Diabetes-specific mechanism are indicated in grey. Source: Figure adapted by authors from transdiagnostic maintenance model for eating disorders [11] and the dual-pathway model [12].

## Appendix D

De Paoli and Rogers' (2018) transdiagnostic model applied to T1DE

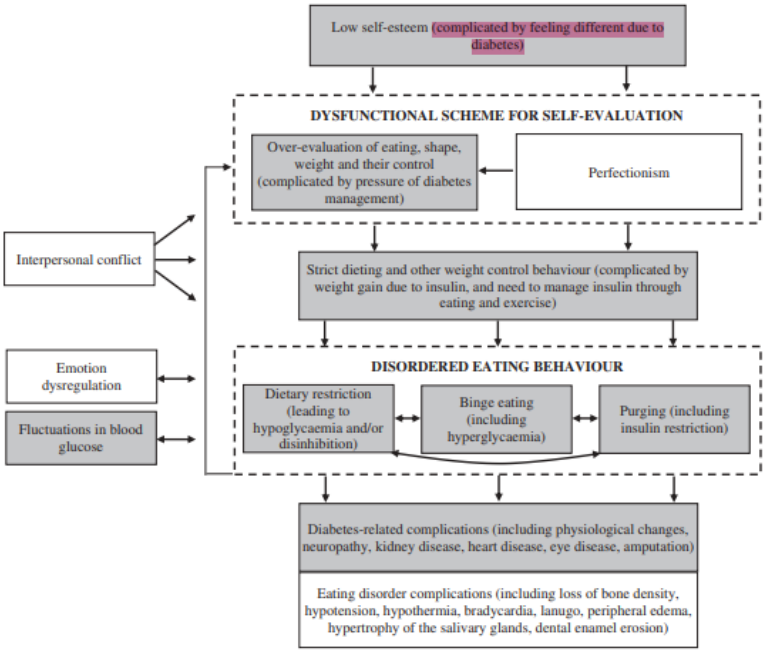


**Figure 2.** The transdiagnostic model of disordered eating in T1D. Diabetes-specific mechanisms are indicated in grey. Figure adapted from Fairburn et al. (2003) transdiagnostic maintenance model of disordered eating and Treasure et al.'s (2015) maintenance model for disordered eating in T1D.

## Appendix E

Harrison et al. (2021) CBT maintenance model of T1DE

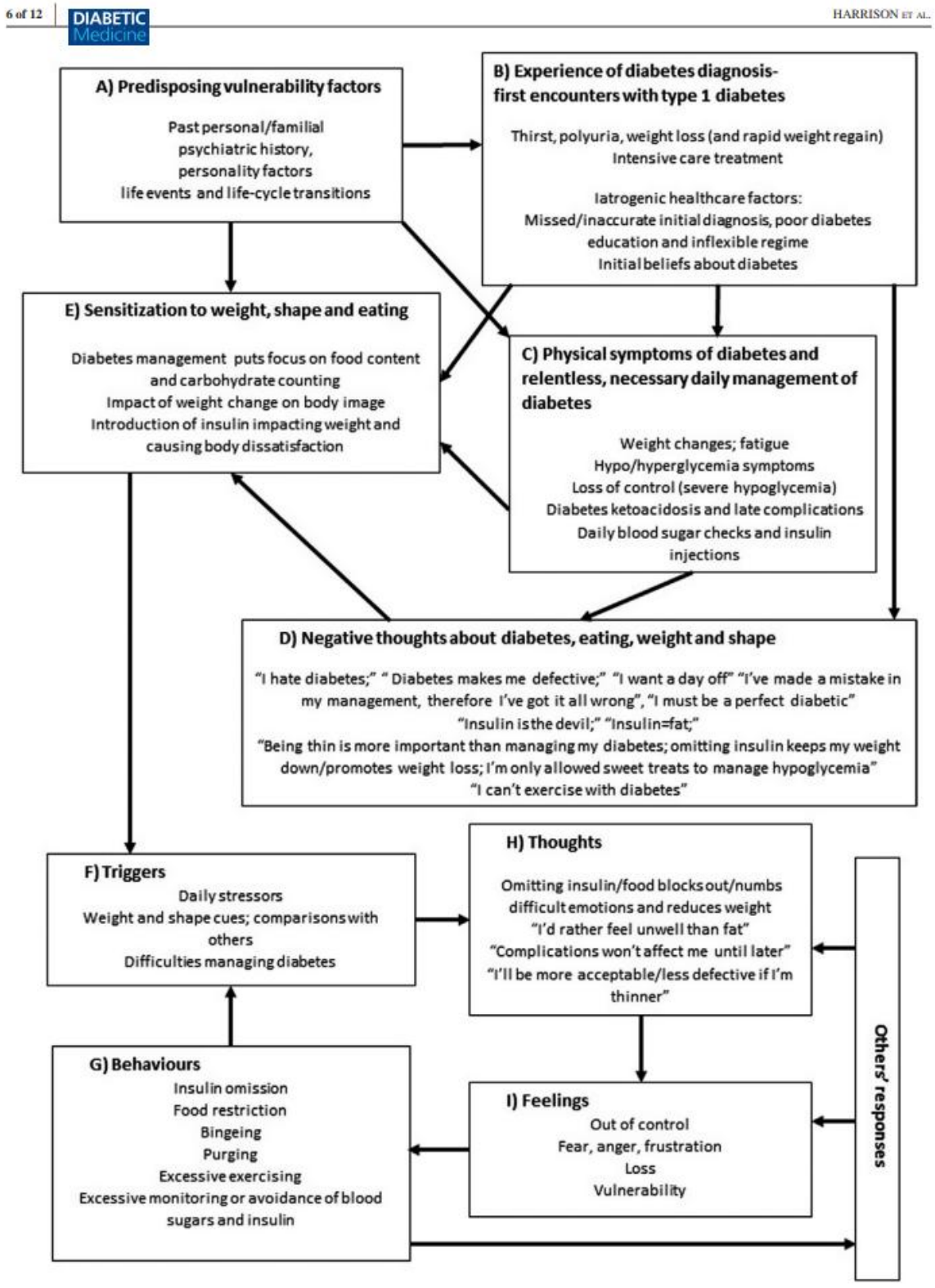


FIGURE 2 A development/maintenance model of disordered eating in type 1 diabetes

**Appendix F**

Sample of CASP for a SLR paper

Commissariat et al. (2016)

| CASP Criteria including description. | Quality Appraisal | Rating |
|---|---|---|
| **Section A: Are the results valid?** | | |
| Was there a clear statement of the aims of the research?<br><br>***Consider**: 1) what was the goal of the research? 2) why it was thought important?, 3) its relevance* | **Yes**.<br>**Goal**: to explore adolescent personal and social identity development in relation to T1DM. **Important**: current management of T1DM in adolescence is poor, this research explores if identity is a significant contributing to this.<br>**Relevance**: the impact of T1DM on adolescent identity is thought to be significant, given the context of adolescence in terms of self-image, socialising and therefore could contribute to difficulty in management. | 1 |
| Is a qualitative methodology appropriate?<br><br>***Consider**: 1) If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants, 2) Is qualitative research the right methodology for addressing the research goal?* | Yes. This study was part of wider project but focused only on the qualitative data. Thematic analysis was used which was appropriate given the aim was to use interview data to explore key themes on how living with T1DM impacts identity. | 1 |
| **Is it worth continuing?** | | |
| Was the research design appropriate to address the aims of the research?<br><br>***Consider**: 1) If the researcher has justified the research design (e.g. have they discussed how they* | **Yes.** The design was appropriate given the aims of this research. The authors justified the design in relation to their goals. | 1 |

| | | |
|---|---|---|
| *decided which method to use)* | | |
| Was the recruitment strategy appropriate to the aims of the research?<br><br>***Consider**: 1) If the researcher has explained how the participants were selected, 2) If they explained why the participants, they selected were the most appropriate to provide access to the type of knowledge sought by the study, 3) If there are any discussions around recruitment (e.g., why some people chose not to take part)* | **Yes.** The authors gave detail in how the participants were selected to participate in this research. The participants were appropriate due to having T1DM and were referred by healthcare professionals due to their struggles with T1DM management (therefore making them relevant in the exploration of whether identity impacts diabetes management). There was discussion around exclusion criteria and therefore why some were not chosen to participant. | 1 |
| Was the data collected in a way that addressed the research issue?<br><br>***Consider**: 1) If the setting for the data collection was justified, 2) If it is clear how data were collected (e.g., focus group, semi-structured interview etc.), 3) If the researcher has justified the methods chosen, 4) If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews are conducted, or did they use a topic guide), 5) If methods were modified during the* | **Yes.** The interviews were conducted in a research institute, the authors did not explain why this was the case. The authors were clear on their choice of interview, included the five open questions used in every interview. The authors discussed and justified their choice of questions. All interviews were tape recorded. No modifications were made. No discussion of saturation. | 1 |

| | | |
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| *study. If so, has the researcher explained how and why, 6) If the form of data is clear (e.g., tape recordings, video material, notes etc.), 7) If the researcher has discussed saturation of data* | | |
| Has the relationship between researcher and participants been adequately considered?<br><br>***Consider**: 1) If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location, 2) How the researcher responded to events during the study and whether they considered the implications of any changes in the research design* | **No**. There is no evidence that the researcher considered or reflected on their role in this research and how they influenced it through personal biases etc. The authors did not discuss how they responded to events in the research. | 0 |
| **Section B: What are the results?** | | |
| Have ethical issues been taken into consideration?<br><br>***Consider**: 1) If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained, 2) If the researcher has discussed* | **Cannot tell**. There is not sufficient detail about how the research was explained to participants. No information about any issues that may have occurred in the research. | 0 |

| | | |
|---|---|---|
| *issues raised by the study (e.g., issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study), 3) If approval has been sought from the ethics committee* | | |
| Was the data analysis sufficiently rigorous?<br><br>***Consider**: 1) If there is an in-depth description of the analysis process, 2) If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data, 3) Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process, 4) If sufficient data are presented to support the findings, 5) To what extent contradictory data are taken into account, 6) Whether the researcher critically examined their own role, potential bias and influence during analysis and* | **Yes.** The authors detail their analysis process, including the guidelines they followed for thematic analysis, the amount of coders used, the types of coding, method of coding etc. and how these codes turned into themes. Meaning that is clear how authors got the results from their analysis. Authors explain how they manages disagreements in analysis and contradictory data. No discussion of researcher considering their role in analysis. | 1 |

| | | |
|---|---|---|
| *selection of data for presentation* | | |
| Is there a clear statement of findings?<br><br>***Consider:*** *1) If the findings are explicit, 2) If there is adequate discussion of the evidence both for and against the researcher's arguments, 3) If the researcher has discussed the credibility of their findings (e.g., triangulation, respondent validation, more than one analyst), 4) If the findings are discussed in relation to the original research question* | **Yes.** There is a clear statement of findings, with extensive discussion for these findings. There is limited discussion of evidence that goes against these findings. Credibility is discussed. Findings are discussed in relation to the goals of the research. | 1 |
| **Section C: Will the results help locally?** | | |
| How valuable is the research?<br><br>***Consider****: 1) If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research based literature If they identify new areas where research is necessary If the researchers have discussed whether or how the findings can be transferred to* | Yes.<br>Previous literature has highlighted the influence of peer groups on diabetes self-care behaviours. The findings of this study added to this literature by offering a different perspective by reporting that how adolescents with T1DM identify themselves, has a greater influence on how they feel about their T1DM, their mental health and how well they manage their T1DM, than how their peers perceive them. A clinical implication of this research was that healthcare professionals should work with the individuals and their families to help them to incorporate T1DM into identity to benefit the individual's mental health and T1DM management. | 1 |

| | | |
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| *other populations or considered*<br>*other ways the research may be*<br>*used )* | | |
| | | **Score**: 8/10 |

**Appendix G**

*A qualitative summary of CASP data.*

A consistent strength is that of the 13 studies, 12 clearly stated their aim(s) (item 1). The exception was Maietta, (2021). In addition, items 9 and 10 were scored as 'yes' across all 13 studies. These findings make sense given it is unlikely for a paper to be published without clear aims, findings and valuable outcomes. The design of all the studies were also appropriate.

Data collection was also consistent. Interviews were chosen by all studies except for Sanders et al. (2019) who used interviews and focus groups and Tilden et al. (2005) who used a case study design.

Most of the studies used purposive sampling to recruit participants. Maietta (2021) used a snowballing technique as well as purposive, Montali et al. (2022) only used the snowballing method, and Kim (2022) used theoretical sampling due to using grounded theory. These recruitment methods were all appropriate within the aims of the studies and facilitated the recruitment of male and female individuals with T1DM, from a range of ages and in both clinical and non-clinical settings.

Only two of the 13 primary studies considered and commented on their relationship with the participant group they were working with and the data they were collecting and analysing. Sanders et al. (2019) reflected on how each researcher came from either a psychological or sociological professional background, which led to them having different approaches to their interviews and relationships with the research, subsequently leading to different interpretations of the interview data they collected. This prompted the researchers to reflect on their lenses and interpretations and attempt to reduce their bias by finding objective examples from the data to support their codes and themes. Fioretti & Mugnaini, (2022) used Braun and Clarke's (2006) model of thematic analysis for their data analysis. As part of this

model, researchers are asked to reflect on their position within the research and their potential biases towards interpreting the data they collect. Fioretti and Mugnaini (2022) commented on how they adhered to this in their research, by having regular research team reflective group spaces and having each research keep a self-reflexive account on their resonance and reactions to the data they collected.

Most of the studies addressed ethical considerations to some extent. The majority did this by stating they had approval from the relevant ethics board, and by sharing how they obtained informed consent from participants and ensured their confidentiality. It was, however, difficult to assess whether most studies met and maintained ethical standards according to the criteria of the CASP tool in relation to participant information, debrief, managing risk of harm and sharing the results of the research with participants should they wish to know. Chalmers et al., (2022) was the only study to make no comment in regard to how they took ethics into consideration.

## Appendix H

*Letter writing instructions*

**Letter Writing Instructions.**

IRAS Number: 340832

University of Hertfordshire Ethics Number: cLMS/PGR/UH/05560

We will now ask you to write two letters. One letter will be addressed to your type 1 diabetes, the other will be addressed to your eating disorder. The purpose of these letters is to explore your relationship with your diabetes and eating disorder and how both may have impacted you and your identity.

You can choose to handwrite, electronically write, **or** speak your letters. Instructions on how to send us whatever version you choose is on the next page. **Please do not include any identifiable information in your letter such as your address.**

We would recommend writing your letters directly to your diabetes and eating disorder, for example *'Dear diabetes'* or a name you may have for either one. We would also recommend writing your letter as if you are talking directly to your diabetes/eating disorder through using the second person (e.g. ***you*** make me feel this…).

Please, however, note that there is no 'right' way to write these letters. Write what feels right for you. There is also no expectation for your feelings and relationship towards your diabetes/eating disorder to be only 'good' or 'bad'. A lot of the time our relationship with our difficulties can be complex. There can be parts of it that are more positive and parts that are more negative.

Please note that we will be doing an in-depth analysis on the letters you write, so please include everything you would like us to know about your experiences.

Below we have written some prompts to consider before or during your writing. You may not relate to these prompts and you do not have to use them if you do not want to.

- *What are your feelings towards your diabetes/eating disorder? Why do you think these are your feelings?*
  *-For example: 'You have made me feel_____ because _____'*
- *How has your diabetes/eating disorder influenced the way you view yourself?*
- *How does your diabetes/eating disorder affect you most days?*
- *How has your diabetes/eating disorder impacted your life? E.g., your social life, relationships, hobbies*

- *What do you think your diabetes/eating disorder has added to your life/allowed you to do?*
- *What do you think your diabetes/eating disorder has taken away from your life/stopped you from doing?*

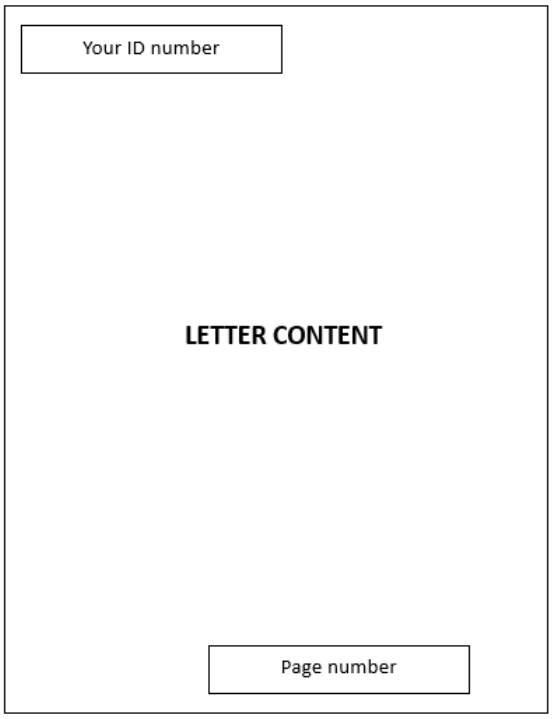
It is important to remember that you do not need to complete these letters in one go. Please take your time with them and give yourself breaks if you need them. During these breaks and after finishing your letters please take the time you need to look after yourself. Looking after ourselves looks different for us all, for some it may be spending time with loved ones or a pet, for others it may be spending time alone reading, being outside or having a bath. Have in mind a few things that you can do to look after yourself before starting to write your letters.

**How to send your letters.**

***Handwritten letters:***

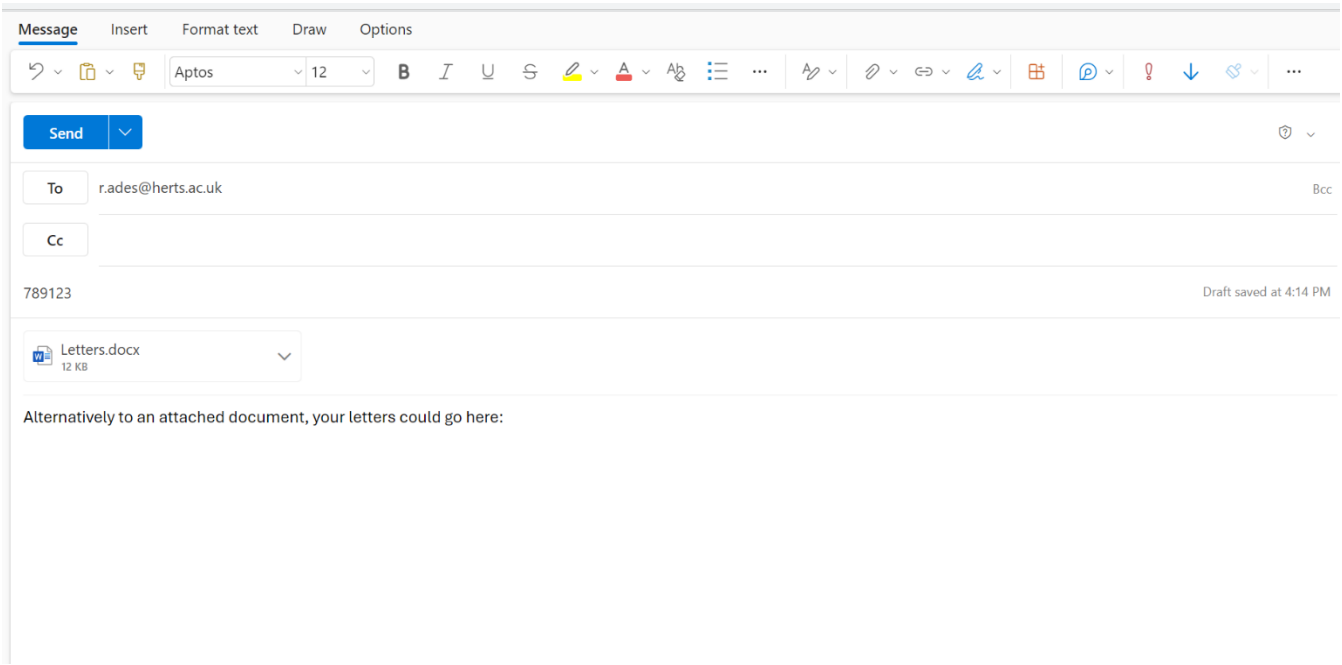
- Please write your self-assigned six-digit identity number on the **top left-hand corner** of every page of your letters.
- Please number your pages according to the order they go in on the **bottom left-hand corner** of each page. This is so we know what order your pages go in.
- Post your letters to the following address:

  Rebecca Ades and Dr Jen Heath
  Room B104, Main Building, College Lane Campus
  University of Hertfordshire
  Hatfield
  AL10 9AB
- Example:



***Electronic letters:***

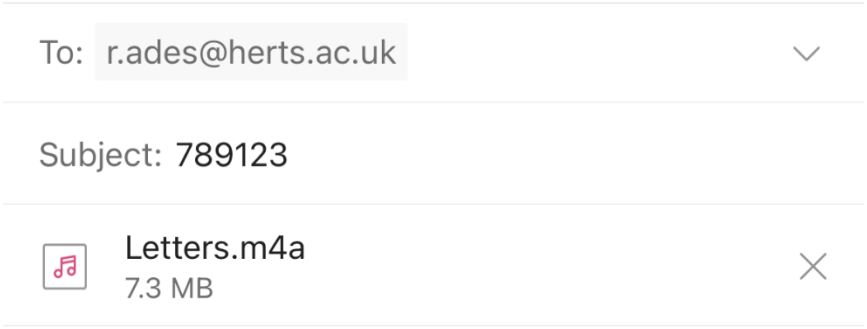
- You can write your letters on whatever online software (such as Microsoft Word) that you prefer to use, or you can write your letters directly into the body of an email.
- Please remember to take regular screen breaks if you choose to write your letters in this way to prevent screen-fatigue, headaches, eye strain etc.
- Once you have finished your letters, please attach them to an email if they are not already in the body of your email.
- Please make the subject of your email your self-assigned six-digit identity number
- Please then email your letters to Rebecca on the email address: **r.ades@herts.ac.uk**
- Example:




Spoken letters.

- You can speak your letters and record them into a voice recorder app, some examples of these are:
  *-Apple Products: built-in Voice Memo app*
  *-Android Products: built-in Voice Recorder app*
  *-Google recorder app (for phones and laptops).*

- Save the file(s) of your voice recordings onto your device.
- Attach the file(s) of your voice recordings to an email
- Make the subject of the email your six-digit identity number
- Send the email to Rebecca on: r.ades@herts.ac.uk
- Example:



**Appendix I**

*Recruitment poster*

## Appendix J

Ethical approval obtained from the University of Hertfordshire Health, Science, Engineering and Technology Ethics committee with delegated authority.

University of Hertfordshire UH

**HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA**

## ETHICS APPROVAL NOTIFICATION

| | |
|---|---|
| **TO** | Rebecca Ades |
| **CC** | Dr Jennifer Heath |
| **FROM** | Dr Rebecca Knight, Health, Science, Engineering and Technology ECDA Vice-Chair |
| **DATE** | 15/02/2024 |

---

| | |
|---|---|
| Protocol number: | **cLMS/PGR/UH/05560** |
| Title of study: | All the things I would say: A thematic analysis of letters written to type 1 diabetes and an eating disorder by individuals with type 1 diabetes and an eating disorder (T1DE). |

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

**Members of the University of Hertfordshire's Doctorate in Clinical Psychology advanced research methods thematic analysis workshop may be shown anonymised data to support the data analysis of this research and help to develop themes.**

**Dr Julie Evans, secondary supervisor, Julie.evans46@nhs.net, Lead Clinical Psychologist, Barnet and Enfield NHS Foundation Trust**

### Conditions of approval specific to your study:

Ethics approval has been granted subject to the following conditions being seen and approved by the supervisor as addressed prior to recruitment and data collection:

As stated in the application, this approval only covers data collection of non-clinical populations and the applicant will require further NHS REC approval for the data collection of clinical populations.

### General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

**Permissions**: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

**External communications**: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

**Invasive procedures**: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

**Submission**: Students must include this Approval Notification with their submission.

**Validity:**

This approval is valid:

From: 15/02/2024

To: 30/04/2025

**Please note:**

**Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.**
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

**Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.**
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

**Failure to report adverse circumstance/s may be considered misconduct.**
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

**Appendix K**

*List of amendments sent by HRA with responses*

| | **Ethical Review - Conditions of Provisional Opinion** | **Response from the applicant** |
|---|---|---|
| 1. | The Committee requested that the document listing the support agencies and services that participants would be signposted to be submitted for review. | This information has now been provided. Information for further support will be provided to all participants prior to writing their letters and as part of the debrief information sent once letters have been received or participants choose to withdraw from the study. |
| 2. | The Committee noted that there is a duty of care to the participants due to the sensitive nature of the letters and the possibility of bringing up difficult emotions without support. The Committee requested that the way in which participants will be supported and signposted to other services be reconsidered, and in particular what will be done if a participant discloses concerning information in their letter. | Information of services and resources that participants can access for support will be provided to them, via email, both before and after their letter writing. In the PIS we have also recommended in the "What are the potential risks of taking part?" that participants inform their NHS service of their participation and the potential distress so the service are aware and can provide additional support if needed. This has been highlighted in the PIS.<br><br>If the content of a participant's letter discloses concerning information regarding their safety the primary |

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| | | researcher will directly email the participant using the address they have provided on the survey to highlight these concerns, provide information for crisis services both in the body of the email and as a separate PDF attachment. A template of this email and the PDF attachment has been included for review. As we are not collecting participant names or GP information, we are unable to inform any services of these concerns. |
| 3. | The Committee requested the following changes to the PIS:<br>a) Please add details about all procedures in place for handling concerning disclosures from participants or supporting participants with difficult emotions brought to the surface.<br><br>b) Please add the information in the survey regarding how to receive results and entering the prize draw, so that participants have all the information before signing consent. | a) Information of where to seek further support will be provided to all participants before and after writing their letters. This information is included in the 'What are the potential risks' section where we have also encouraged participants to share their participation in this research with their NHS service. This is so the service is aware that there may be distress as a result of participation and can provide support if required. A section has been added to the PIS regarding what happens if we become concerned about their wellbeing. In this section we detail that the primary research will email the participant |

| | | |
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| | c) Please make it clear that participants with poor literacy are able to complete audio recordings instead of writing letters.<br><br>d) Please make it clear that the content of the letters may be used for teaching purposes and explain how this will be done<br><br>e) Please soften the wording regarding participant's responsibility for their own safety.<br><br>f) Please explain exactly what is meant by the 'content' of the letters which will be kept and how they will be anonymised.<br><br>The Committee noted that the PIS is overly long and has some repetition in parts and requested that the entire document be reviewed and amended as | directly to highlight these concerns, and provide information for crisis services which we encourage them to reach out to. This section has been highlighted for the review.<br><br>b) In the 'email communication' portion of "what does this study involve?", "what is the prize draw?" and "how can I know the results of the study?" of the PIS, information has been added to inform participants that they will receive results and prize draw via email. These sections have been highlighted for the review. This sheet is shown to participants prior to the consent form.<br><br>c) A specific paragraph highlighting this has been added to the PIS and has been highlighted for review.<br><br>d) This has been added in a final paragraph of the "What happens to the data collected within this study?" section of the PIS and been highlighted for |

| | | |
|---|---|---|
| | necessary to make it easier to process. E.g. adding flowcharts etc instead of long paragraphs about study visits etc. | review.<br><br>E) this wording has now been softened whilst still highlighting to participants their responsibility in knowing the potential risks of participating. This has been highlighted for review.<br><br>f) The stored content will be the letters without identifiable information. Handwritten letters will be typed with any identifiable information being removed and stored as a password protected word document under the ID number of the participant. The original copy of the letter will be shredded in confidential waste once it has been transcribed. Audio and digitally written letters will also be transcribed, have any identifiable information removed and stored as a password protected word document under the ID of the participant. The emails containing the original audio and digital |

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| | | letters will be deleted once they are transcribed. This has been mentioned in the "How will my taking part in this study be kept confidential?" and "What will happen to my data collected in this study?" sections of the PIS.<br><br>The research team have attempted to reduce the length of PIS as much as possible and removed any repeated information. Unfortunately, due to the PIS being presented to participants on Qualtrics, we are unable to convey some of the information using diagrams. |
| 4. | The Committee requested that separate tick boxes be added to each separate point on the consent form. | This has now been added and shown on the participant informed consent sheet. |
| 5. | The Committee noted that the timescale in the protocol refers to finalising literary review in July 2024 but that recruitment would only begin in October 2024 and requested confirmation that this was an error | The timescale in this proposal was written prior to starting the ethics application process. We wanted to account for any delays in the process to ensure there was still adequate time for recruitment, this is why NHS recruitment was estimated to begin in October 2024. The literature review mentioned, to be finalised in July 2024, refers to the systematic literature review that is required as part of the |

| | | |
|---|---|---|
| | | doctoral qualification in clinical psychology and is conducted alongside recruitment and data collection for this empirical study. The systematic literature review is still estimated to be completed by July 2024, but we hope for recruitment to being sooner, e.g., July 2024 once ethical approval is granted. |
| 6. | The Committee queried whether the software used to collect participants self-assigned IDs would block duplicates of the same ID? | Qualtrics has been programmed to not accept any ID numbers that have been used by other participants. |
| The Committee delegated authority to confirm its final opinion on the application to the Chair together with Dr Jacqueline Tavabie | | |

| **HRA and HCRW assessment - Further Information Required** | **Response from the applicant** |
|---|---|
| Please add to the top of the PIS that the research is being conducted as part of a student study | This has been added to the top of the PIS and highlighted for the review. |
| Please add a definition of the end of study to the protocol | This has been added to the protocol and highlighted for the review. |

| | |
|---|---|
| To ensure compliance with the GDPR transparency requirement (https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/templates/transparency-wording-for-all-sponsors/), please add the following sentences:<br>In this research study we will use information from [you] [your medical records] [your GP] [**OTHER**]. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.<br><br>•□□□□□□□□□We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.<br>**Where can you find out more about how your information is used?**<br>You can find out more about how we use your information<br><br>•□□□□□□□□□at www.hra.nhs.uk/information-about-patients/<br><br>•□□□□□□□□□our leaflet available from [**X**]<br><br>•□□□□□□□□□by asking one of the research team<br><br>•□□□□□□□□□by sending an email to [**email**], or<br><br>•□□□□□□□□□by ringing us on [**phone number**].<br>**NOTE: At least one of these sources must be able to point people directly to the sponsor's Data Protection Officer.** | This information has been added to the PIS form and highlighted for the review. |

## Appendix L

*Li) Full HRA approval*

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Dr Jennifer Heath
Health Research Building
Hatfield
Hertfordshire
AL10 9PN

Email: approvals@hra.nhs.uk

06 June 2024

Dear Dr Heath,

**HRA and Health and Care Research Wales (HCRW) Approval Letter**

| | |
|---|---|
| **Study title:** | **All the things I would say: A thematic analysis of letters written to type 1 diabetes and an eating disorder by individuals with type 1 diabetes and an eating disorder (T1DE).** |
| **IRAS project ID:** | **340832** |
| **Protocol number:** | **TBC** |
| **REC reference:** | **24/LO/0400** |
| **Sponsor** | **University of Hertfordshire** |

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

**How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

---

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

**How should I work with participating non-NHS organisations?**
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

**What are my notification responsibilities during the study?**

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

**Who should I contact for further information?**
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **340832**. Please quote this on all correspondence.

Yours sincerely,
Chris King

Approvals Specialist

Email: approvals@hra.nhs.uk

*Copy to:* *Ms Leire Vallejo, Sponsor's Representative*

*Lii) R&D confirmation of capability and capacity and OID*

**From:** NOCLOR, Contact (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST) <contact.noclor@nhs.net>
**Sent:** Thursday, July 11, 2024 4:37 PM
**To:** EVANS, Julie (BARNET, ENFIELD AND HARINGEY MENTAL HEALTH NHS TRUST) <julie.evans46@nhs.net>; 'j.heath@herts.ac.uk' <j.heath@herts.ac.uk>
**Cc:** 'Rebecca Ades [Student-LMS]' <r.ades@herts.ac.uk>; NOCLOR, Contact (CENTRAL AND NORTH WEST LONDON NHS FOUNDATION TRUST) <contact.noclor@nhs.net>
**Subject:** Confirmation of Capacity & Capability: IRAS 340832 - BEH

Dear Dr Heath and Dr Evans,

| | |
|---|---|
| **Study Title:** | T1DE |
| **IRAS Ref:** | 340832 |
| **HRA Approval:** | 06/06/24 |
| **Protocol Version:** | V1 19.04.24 (Research Proposal), v2 29.05.24 (Protocol Flowchart) |
| **Amendments:** | N/A |
| **Attachments:** | FE OID |

We are pleased to confirm capacity and capability at **Barnet Enfield and Haringey Mental Health Trust** for the above referenced study. Please find attached the fully authorised OID.

The study end date for this site is 10th October 2025. We will close the study record one month after this date if we have not received communication from yourself or the sponsor regarding study extension beyond this date.

Please notify R&D of any amendments, research-related incidents and study end by emailing contact.noclor@nhs.net.

Kind regards,
Jonathan

**Jonathan**
**Oommen** (he/they)
Research Facilitator

Home | News | Contact | Location | Twitter | Training

*Liii) Sponsorship in full*

University of Hertfordshire UH

**University of Hertfordshire**
Higher Education Corporation
Hatfield, Hertfordshire
AL10 9AB

Telephone +44 (0) 1707 284000
Fax +44 (0) 1707 284115
Website www.herts.ac.uk

Professor Wendy Wills
PhD, MSc, BSc, SFHEA, Reg Nutr (Public Health)
Professor of Food and Public Health
Pro Vice-Chancellor (Research and Enterprise)
Director, NIHR Applied Research Collaboration (ARC) East of England

Dr Jennifer Heath (Rebecca Ades – student)
Department of Psychology, Sports and Geography
School of Life and Medical Sciences

15 April 2024

Dear Jennifer,

**Re:** **UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN PRINCIPLE for the following:**
**RESEARCH STUDY TITLE:** All the things I would say: A thematic analysis of letters written to type 1 diabetes and an eating disorder, written by individuals with type 1 diabetes and an eating disorder (T1DE).
**NAME OF CHIEF INVESTIGATOR (Supervisor):** Dr Jennifer Heath
**NAME OF INVESTIGATOR (Student):** Rebecca Ades

This letter is to confirm your research study detailed above has been reviewed and accepted, and I agree to give University of Hertfordshire sponsorship in principle.

Before you commence your research you must be in full compliance with all Health Research Authority governance requirements. You must also secure full University of Hertfordshire sponsorship, for which you will need to have supplied the following documentation:

- Final version of the submitted IRAS form (pdf)
- Approval from the relevant Health Research Authority (HRA) Research Ethics Committee (REC) as well as confirmation of favourable opinion of any amendments arising during approval
- Evidence of relevant NHS Permissions (eg Research Passport) and Confirmations of capacity and capability as they are received
- Confirmation of University protocol number
- The final versions of the protocol, patient information leaflet and informed consent form
- For externally funded research, confirmation of adequate funding in the form of the award letter
- Any other regulatory permissions required, eg from the National Information Governance Board (NIGB), under the Human Tissue Act or the Ionising Radiation (Medical Exposure) Regulations
- If applicable, copies of any contracts/agreements with external organisations (eg funders, collaborators, co-sponsors) involved in your research study.

As a condition of receiving full sponsorship, it is the responsibility of the Chief Investigator to inform the Sponsor of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements. It is also the responsibility of the Chief Investigator to inform the funder, the HRA NHS Research Ethics Committee (REC) and any other

**Appendix M**

*Participant information sheet*

University of Hertfordshire UH Ethics Committee

**UNIVERSITY OF HERTFORDSHIRE**

**ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS**
**('ETHICS COMMITTEE')**

**FORM EC6: PARTICIPANT INFORMATION SHEET**

IRAS Number: 340832

University of Hertfordshire Ethics Number: cLMS/PGR/UH/05560

1 **Title of study**

All the things I would say: A thematic analysis of letters written to type 1 diabetes and an eating disorder by individuals with type 1 diabetes and an eating disorder (T1DE).

2 **Introduction**

My name is Rebecca, and I am a Trainee Clinical Psychologist at the University of Hertfordshire. I would like to invite you to participate in a research project to explore the experiences of those who have type 1 diabetes and live with or have previously lived with an eating disorder. This is an important topic that, to date, has received little attention.

You are being invited to take part. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information. Please do take your time to decide whether or not you wish to take part.

The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

## 3 What is the purpose of this study?

We know from previous research that standard therapy models for eating disorders are often not well suited to treating those who are also diagnosed with Type 1 Diabetes. It has also been found that services do not understand the role diabetes plays in eating disorder development and maintenance. An area that appears to be relevant for those with type 1 diabetes and an eating disorder (T1ED) is how individuals relate to their type 1 diabetes and eating disorder and the impact these difficulties can have on their identity.

This study seeks individuals who have type 1 diabetes and either a diagnosed or self-identified eating disorder. This project aims to contribute to gaps in current research by exploring with these individuals how they relate to their diabetes and their eating disorder and how they feel both may have impacted their identity. It is hoped that this research could inform treatment by examining how a person's relationship with T1DE could maintain an eating disorder.

## 4 Do I have to take part?

It is up to you whether or not you decide to take part in this study. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

Agreeing to join the study does not mean that you must complete it. You are free to withdraw without giving a reason. If you would like to withdraw from the study, you will have two weeks from the completion of your letters. To withdraw please email r.ades@herts.ac.uk with your six-digit identity number.

## 5 Are there any age or other restrictions that may prevent me from participating?

You will be able to take part in this study if you:

- Are diagnosed with type 1 diabetes
- Currently experiencing, or have previous experience of, a diagnosed or self-identified eating disorder
- Are over the age of 18
- Currently live in the UK
- Are able to understand written English
- Are able to speak or write in English

It important to note that if you meet the following criteria, you will, unfortunately, not be able to take part in the study:

- You are currently an inpatient in an eating disorder unit.
- You are currently an inpatient in a general hospital ward.
- You have type 2 diabetes.
- You are under the age of 18.
- You cannot understand written English.
- You cannot write or speak English.
- You are living outside of the UK.

To take part we will need you to provide your informed consent. This will be asked for after this information sheet.

## 6 How long will my part in the study take?

The length of time this study will take depends on how long you choose to spend on writing your letters. From completing the survey, which is estimated to take 10-15 minutes, you will have up to four weeks to complete your letters. We will also email you a prompt at 2 weeks and 4 weeks after completing your survey if we have not received your letters. You may choose to write your letters as soon as you receive the instructions, or you may wish to take the full four weeks. The time it takes to complete the letters themselves will also depend on how long you would like to spend on them – you could write them in one sitting or completed them in segments over a few days or weeks.

## 7 What will happen to me if I take part?

This study will involve the following:

*-Survey questions:*

You will be asked to complete a series of questions that help us determine if our study is appropriate for you. These questions will ask you to confirm; you are over the age of 18, you have type 1 diabetes (as opposed to type 2), that you are not a current inpatient, you are currently living in the UK, you are able to understand written English and are able to speak or write in English.

If the study is suitable for you, you will be asked to give yourself a six-digit identity number. This identity number will allow us to link your answers to the survey questions and your letters and means we will be able to store your data under this number. It is important that you make note of this number as we will ask you to use it when writing your letters. You will also need it should you wish to withdraw your data. Please do not make your ID number your date of birth, as this is a piece of information that can identify you. We will also ask you to provide an email address for the primary researcher to contact you

on.

You will then be asked to complete a survey that includes questions about: your gender identity, current age, the age when you were diagnosed with type 1 diabetes and the age you were diagnosed with/began to experience an eating disorder. This information can help us to see if what we find in this study matches what previous findings have found regarding how gender and age may impact how an individual experiences type 1 diabetes and an eating disorder. You will also be asked if you would like to be entered into a prize draw for your participation and if you would like to receive the results of this study.

*-Writing letters:*

After you have completed the survey, if the study is appropriate for you, you will be asked to write two letters. One will be addressed to your type 1 diabetes, the other will be addressed to your eating disorder. You will be provided with an instruction sheet to help guide you when writing these letters. The reason we are asking you to write letters in this way is because previous research has found, for both eating disorders and type 1 diabetes, that writing letters to the difficulties as if they are something separate from the person has various benefits. For example, writing letters to an eating disorder has been found to help individuals explore what their relationship is like with it and the impact the eating disorder has had on them (Serpell et al., 1999). In addition, writing letters to type 1 diabetes has been found to have a positive impact on an individual as it allows them the freedom to explore and express their feelings towards the diagnosis (Piana et al, 2010). You will be able to complete your letters in three ways; handwritten, electronically written or verbally spoken. **You will be given four weeks from finishing the survey to send the research team your letters.**

*-Email communication:*

If this study is suitable for you, we will ask you to provide us with an email address that you are happy for us to contact you on. We will only contact you about this research. The first email all participants will receive will contain this information sheet, a set of instructions for writing your letters, information about where to seek further support should you need it, and the final date you need to send us your letters. The second email will be sent to all participants once their letters have been received by the research team or the deadline to send their letters has passed. It will contain a debrief information sheet. If you have completed the survey but we don’t receive your letter a week before the final date, we will send you a reminder email. You may receive further emails should you win the prize draw if you have opted to enter it and with the final, annoymised write up of this study if you stated you wanted to receive the results.

8 **What are the possible disadvantages of taking part?**

There is the potential for the letter writing process to be emotive and may, in some cases, cause some distress. Please note that there is no requirement for you to complete your letters in one go. It is completely okay and encouraged for you to take your time with your letters and give yourself breaks if they are emotive and/or distressing for you.

It is important for you to note that by reading this information sheet and providing your informed consent it means that you have made an informed decision to participate in this research, which includes knowing the potential risks. It is, therefore, your responsibility to be able to keep yourself safe both during and after the research process.

9 **What are the possible benefits of taking part?**

The information that we gather in this research will help us to contribute to the current gaps in research and possibly have clinical implications on how we can adapt current eating disorder therapies to help those who also have type 1 diabetes. In addition, writing to your diabetes and eating disorder may be beneficial as it could help you to explore and possibly make sense of the relationship you have with both conditions, and how you feel they may impact your identity. You may choose to share what you have written or learnt with your healthcare provider(s).

10 **How will my taking part in this study be kept confidential?**

The data you provide during this study will be kept confidential and anonymous in accordance with the 1998 UK Data Protection Act. Any data gathered as part of this study will only be published in an anonymised form, so responses cannot be traced back to individual participants.

We will ask you to assign yourself a random six-digit identity number. This identity number will allow us to store your letters under this number as opposed to any identifiable information.

Your email address and the other information that you provide us in the survey will be stored on a password protected Microsoft Excel Spreadsheet. This spreadsheet will be saved on the secure, GDPR compliant, University of Hertfordshire One Drive. Only the primary researcher and principal supervisor will have the password to access the spreadsheet.

If you wish to handwrite your letter, we will ask you to write your six-digit identity number at the top left-hand corner of each page so we can match your letter and question answers without needing identifiable information. The letters will be scanned onto the secure, GDPR complaint, University of Hertfordshire One Drive into a password protected folder that only the primary researcher and principal supervisor will have access to, until the primary researcher is able to transcribe them. Only the primary researcher and principal supervisor will have the password to this folder.

Electronically written and spoken letters will be emailed to the primary researcher with the subject of the email being your six-digit identity number. They will be stored on a two-factor authentication email that only the primary researcher will have access to, until the primary researcher is able to transcribe them.

All letters will be written out by the primary researcher onto a password-protected Microsoft Word document and any identifiable information will be removed. The letters will be saved under the name of your six-digit identity number and onto a secure shared drive at the University of Hertfordshire where only the research team will have access to it.

The final study report will be written in a way that is confidential using pseudonyms. The results of the research will be written up in a report as part of Rebecca's Doctorate in Clinical Psychology. This may contain anonymised quotes from the letters. The research will be written up for submission to peer-reviewed academic journals and conferences, so that other health professionals can learn from the research.

11 **What will happen to the data collected within this study?**

Only the primary researcher will have access to the data collected on the secure survey platform Qualtrics. The data collected on Qualtrics will be transferred to a password protected Microsoft excel spreadsheet. Once the data has been transferred, the data collected on Qualtrics will be deleted.

The following information will be stored on a password protected Microsoft Excel spreadsheet which will be saved on a secure shared drive at the University of Hertfordshire:

- Age
- Email address
- Gender identity
- Age of diabetes diagnosis
- Age of eating disorder diagnosis/age when first began to struggle with an eating disorder
- Date you submitted your survey answers
- Final date for you to send your letters to the research team
- Whether you would like to know the results of this study
- Whether you would like to be entered into a prize draw for participating

This spreadsheet will be deleted once the study is completed.

Letters that are handwritten will be scanned and stored securely in a password-protected folder on the secure University of Hertfordshire one-drive. The primary researcher will type each handwritten letter, removing any identifiable information, and save it under the six-digit number you provide on a password protected Microsoft word-document on the secure University of Hertfordshire's shared drive that only the primary researcher and principal

supervisor will have access to. Once your letters have been scanned the original copy of the letter will be shredded in confidential waste. Once your letters have been transcribed the scanned copy of the letter will be permanently deleted.

Electronic and spoken letters that are emailed in will be stored on an email account that has a two-factor authentication process in order to access it, that only the primary researcher will have access to. The primary researcher will type each letter, removing any identifiable information, and save it under the six-digit number you provide on a password protected Microsoft word-document on the secure University of Hertfordshire's shared drive that only the primary researcher and principal supervisor will have access to. The email and original letters you sent will then be permanently deleted.

Should you wish to be entered into a prize draw for your participation you will need to sign a pay agreement document. These forms will be stored on the secure University of Hertfordshire's one-drive in a password protected folder until the completion of the study. They will then be deleted once the study is completed and the degree is awarded.

The information given in the letters that you provide will be anonymised and kept by the Lead Supervisor for up to five years for potential re-analysis. This means that another researcher would have access to the annonymised data and analyse it in a different way to the current research to find more out about this area. The annonymised data may also be used as a tool to guide teaching. After these five years, this information will be deleted.

12. **What is the prize draw?**

The prize draw will be for any participant of the study that has been asked to write the letters, including participants who may wish to withdraw from the study. The first-place prize will be a £40 'love2shop' voucher. The second-place prize will be a £20 'love2shop' voucher.

If you say 'yes' to the survey question 'Would you like to be entered into a prize draw for your participation?', the primary researcher will make note of this on a password-protected excel spreadsheet and you will be allocated a random number. All of the numbers of participants who wished to be entered into a prize draw will be put into a random number generator and two numbers will be selected. If your number is selected, you will be emailed a pay agreement form to complete and send back to the primary researcher. Once this is completed you will be emailed the voucher.

**13. How can I know the results of this study?**

You will be asked on the survey whether you would like to know the results of this study. If you answer 'yes' to this question, the final, annonymised write up of this study will be emailed to you.

**14. Will the data be required for use in further studies?**

The annonymised data that is collected in this study will be kept for five years by the principal supervisor. This is so future researchers can re-analyse the annonymised data in a different way to the current study, to find out more information. Once the five years has past, the annonymised data will be permanently deleted. No identifiable data will be stored or used beyond the completion of this study.

**15. Who has reviewed this study?**

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is cLMS/PGR/UJ/05560

**16. Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with either or both of the following:

| **Name.** | **Role and information.** |
|---|---|
| Rebecca Ades | Lead researcher for this project.<br>Trainee Clinical Psychologist<br>University of Hertfordshire<br>Email: r.ades@herts.ac.uk. |
| Dr Jennifer Heath | Clinical Psychologist and Principal Lecturer within the Doctorate of Clinical Psychology at the University of Hertfordshire.<br>Principal Supervisor of this research project. |

**Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:**

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

**Thank you very much for reading this information and giving consideration to taking part in this study.**

**Appendix N**

*Informed consent: Form presented on the Qualtrics platform*

Participant Informed Consent Form (This will be displayed on Qualtrics).

IRAS Number: 340832

University of Hertfordshire Ethics Number: cLMS/PGR/UH/05560

Thank you for considering taking part in this research. This next question will ask you to provide your informed consent to participate. Before providing your informed consent, please ensure you have read the previous participant information sheet closely.

By providing your consent in means that you are agreeing with the following:

| | Tick the box if you understand and agree to each statement. | Please tick this box if you do not agree to the statement. |
|---|---|---|
| • I confirm that I have read and understood the Participant Information Sheet for this study. I have had the opportunity to consider the information and ask questions if I have needed to, by emailing the research team via the information provided in the participant information sheet, which have been answered satisfactorily. | ☐ | ☐ |
| • I understand that my participation is voluntary and that I can withdraw my information up to 14 days after submitting my letters. I do not need to provide a reasons as to why I would like to withdraw, but I do need to provide the lead researcher with the six-digit identity number I will give myself following this consent form. | ☐ | ☐ |
| • I confirm that I have been told how my data will be handled, stored confidentially, who will have access to it and what it will be used for. | ☐ | ☐ |

| | | |
|---|---|---|
| • I confirm that I have been told how long my data will be stored for and how it will be deleted. | | |
| • I understand that my letters will be typed up and anonymised by the lead researcher and stored confidentially on a password-protected word document saved on to the secure University of Hertfordshire One Drive. | | |
| • I understand the potential risks of participating in this study and that it is my responsibility to keep myself safe during and after the study. | ☐ | ☐ |
| • I understand that when a report is written about this study, which could potentially be published in a peer-reviewed journal, that quotes/sentences from my letters may be used, but all identifying information will be removed or change. | ☐ | ☐ |
| • I understand that the information that I provide for this research project could be used in various anonymised outputs such as conference presentations. | ☐ | ☐ |
| • I understand that my anonymised letter will be stored until the completion of this project and up to 5 years for potential similar projects of research. | ☐ | ☐ |
| • I understand my anonymised letters will be kept to guide teaching and training for healthcare professionals. | ☐ | ☐ |

I agree to the above and provide my consent to take part in this study. ☐

I do not provide my consent to take part in this study. ☐

## Appendix O

*Debrief*

**Debrief sheet**.

**Contact Information**

Primary Researcher: Rebecca Ades
Email: r.ades@herts.ac.uk

Principal Supervisor: Dr Jen Heath
Email: j.heath@herts.ac.uk

Thank you for taking the time to participate in our study. It is greatly appreciated.

The aims of this research were:

1. To explore how individuals diagnosed with or self-identify with having T1ED relate to their type 1 diabetes and how it has impacted their identity.
2. To explore how individuals diagnosed with or self-identify with having T1ED relate to their eating disorder and how it has impacted their identity.
3. To compare the emerging themes from these explorations to ascertain if there are key differences in how clients relate to their type 1 diabetes and eating disorder and the impact both diagnoses have on identity.
4. To infer whether identity and relationship with type 1 diabetes is a possible maintenance factor in T1ED.

*T1ED=Type 1 diabetes with an eating disorder.*

We also want to answer the following questions with this study:

1. How do clients with T1DE relate to their T1DM and what impact does the diagnosis have on their identity?
2. How do clients with T1DE relate to their ED and what impact does the diagnosis have on their identity?
3. What is the role of identity and relationship with diagnoses in maintaining T1DE?

We appreciate that writing these letters may have caused some distress for you. The professional code of conduct and ethical approval of this study means that Rebecca Ades cannot personally support individuals beyond the remit of this study. We have,

therefore, included below a list of resources that we hope you will find helpful should you feel that you need further support. Please note this sheet should not be considered equivalent to a consultation with a professional, please seek support if you feel that you need it.

- **Your GP**
- **Your diabetes service**
- **Your eating disorder service if you are under one**
- **Diabetes UK**: https://www.diabetes.org.uk/
- **BEAT Eating Disorders Charity:**
  -Website: https://www.beateatingdisorders.org.uk/

  -Online Support groups: https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/

  -Helpline information: https://www.beateatingdisorders.org.uk/get-information-and-support/get-help-for-myself/i-need-support-now/helplines/.

- **If you are in need of urgent help:**
  -Call 999 or The Samaritans on 116 123

Please remember that you have a right to withdraw your data from this study up to 14 days after you have submitted it. If you would like to do this, please email Rebecca Ades on r.ades@herts.ac.uk with you six-digit identity number and your data will be removed from the study.

Every participant will be able to have access to the final results and write up of this study once it has been completed. Should you wish to have access to this, please email Rebecca Ades on r.ades@herts.ac.uk.

## Appendix P

*Risk email sent to participants who flagged risk*

IRAS Number: 340832

Date: 24/05/2024

Version: 2

**Email template to send to participants that disclose concerning information in their letters.**

Dear participant (ID number),

Thank you for sending us your letters and participating in this research, we deeply appreciate it.

We are reaching out to you after reading your letters, as we have concerns about your safety. We would encourage you to seek support from one or more of the following services in order to receive care and keep yourself safe.

**If you are in a mental health crisis and need immediate help.**

- Call 999 or ask someone to call 999 for you
- Attend A&E or ask someone to take you to A&E

**If you need some support right now but do not want to go to A&E.**

- Call Samaritans 116 123
- If it is in working hours contact your GP and make an emergency appointment
- SHOUT crisis text line:
  -crisistextline.uk
  -Text 'SHOUT' to 85258
- Call 111 and request mental health support.
- Contact your local NHS crisis service.

**Further general support for when you are not in a mental health crisis.**

- MIND mental health charity:
  -For information on mental health conditions, resources for support and a directory for local MIND services in the UK.
  -mind.org.uk
- BEAT eating disorder charity:
  -Information on different eating disorders.
  -Online support groups.
  -Text and phone support.
  -https://www.beateatingdisorders.org.uk
- Inform your diabetes team or eating disorder service about how you are feeling.

We have put this information in a PDF file and attached it to this email for your ease and access.

If you have any further questions for us about your participation in this research please do not hesitate to email us on r.ades@herts.ac.uk.

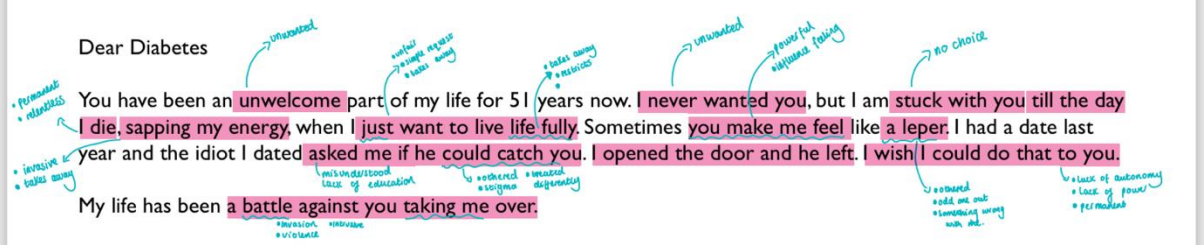
With best wishes,

The research team.

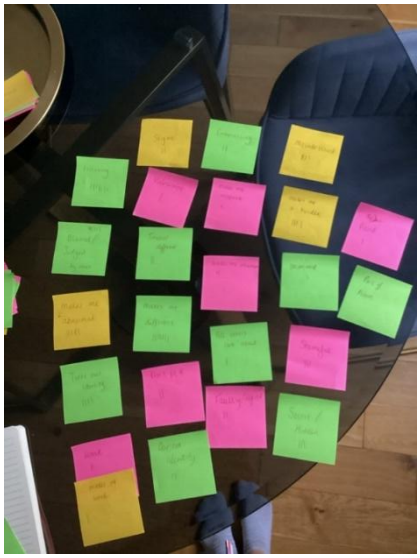
## Appendix Q

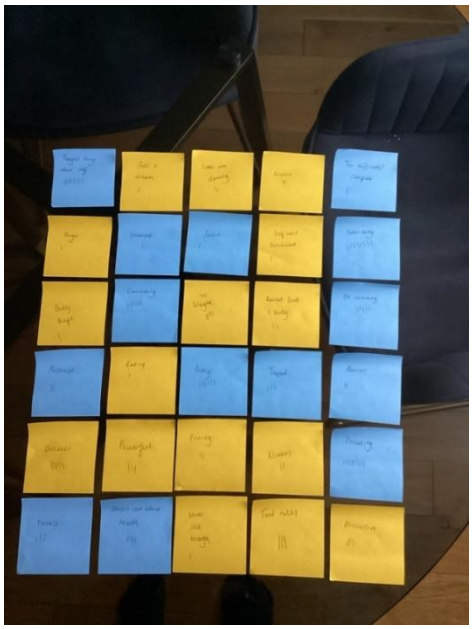
## Process of RTA

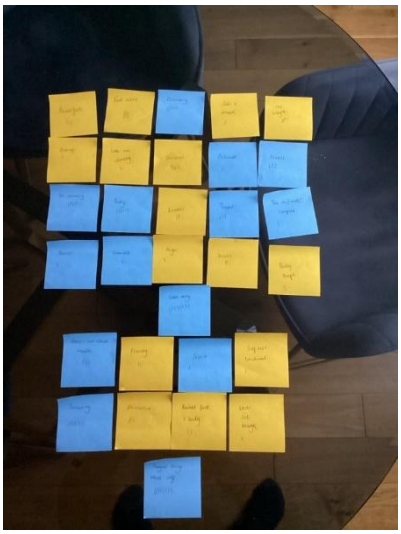
*Qi) Example of initial coding*



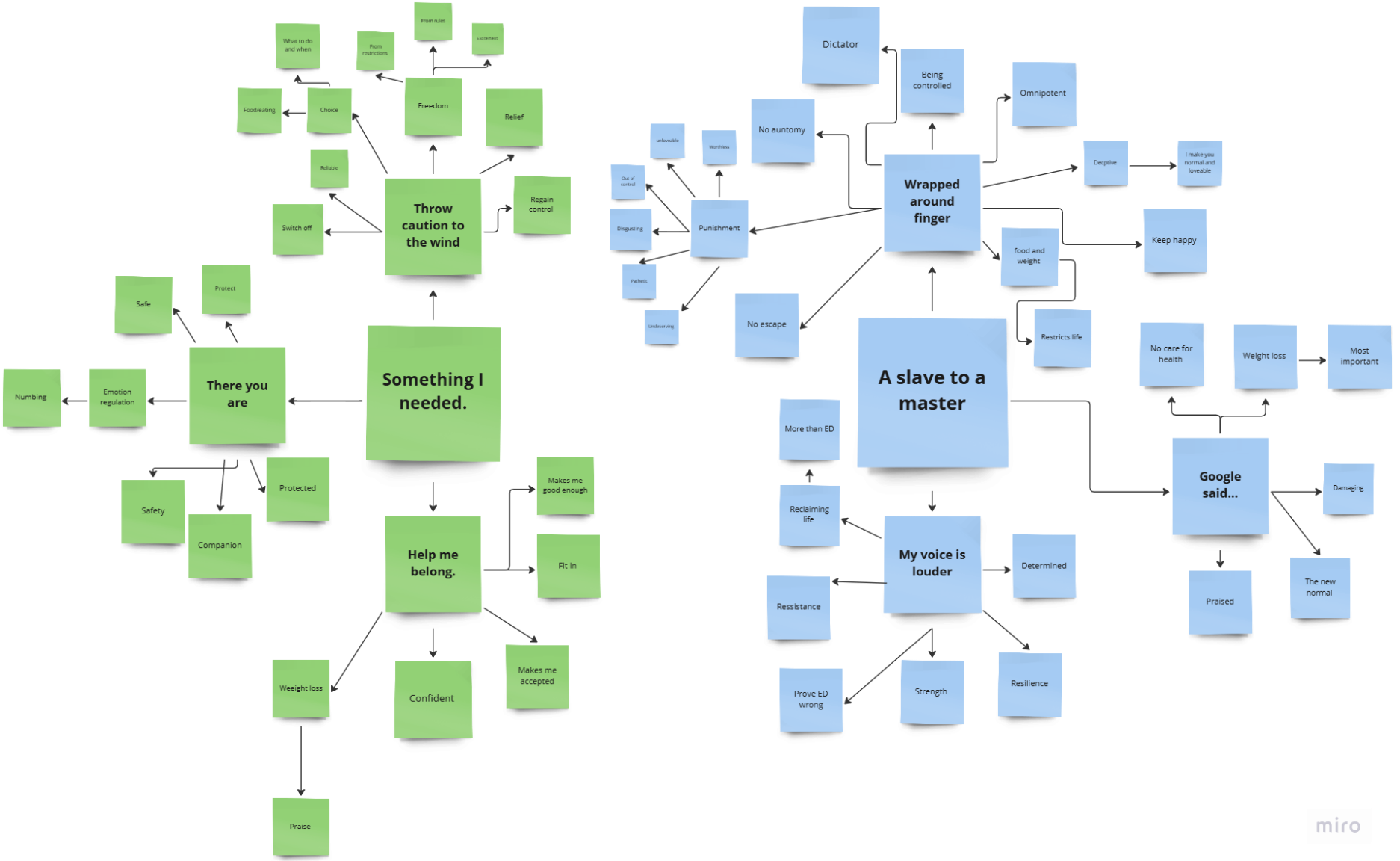

*Qii) Generating themes for T1DM identity theme (top) and slave to master theme (bottom)*

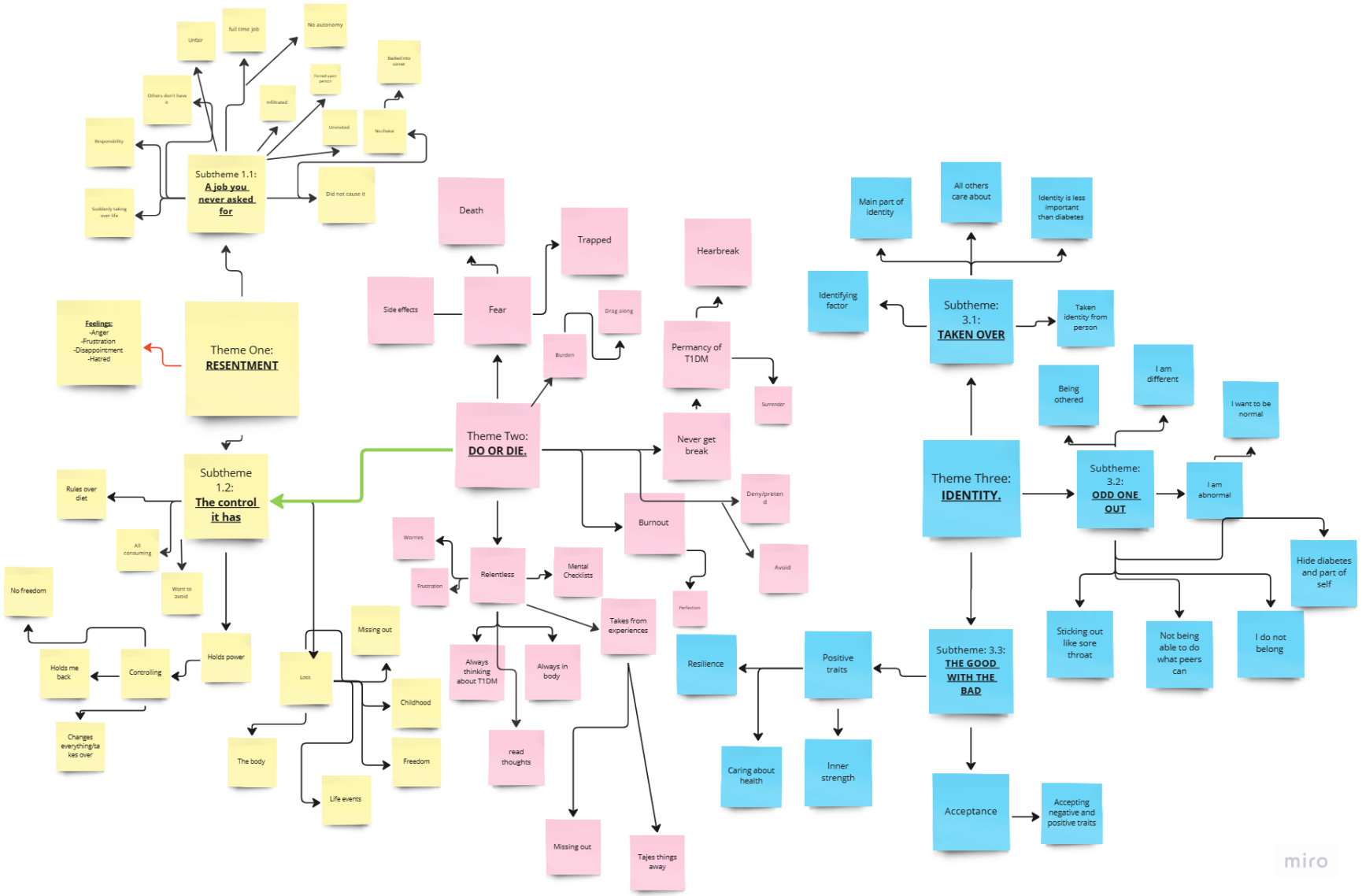






*Qiii)Thematic maps*




Theme One: RESENTMENT
Feelings: -Anger -Frustration -Disappointment -Hatred
Subtheme 1.1: A job you never asked for
Unfair
full time job
No autonomy
Others don't have it
Infiltrated
Forced upon person
Backed into corner
Unwanted
No choice
Responsibility
Suddenly taking over life
Did not cause it
Subtheme 1.2: The control it has
Rules over diet
All consuming
Want to avoid
No freedom
Holds me back
Controlling
Holds power
Changes everything/takes over
Theme Two: DO OR DIE.
Death
Trapped
Side effects
Fear
Drag along
Burden
Hearbreak
Permancy of T1DM
Surrender
Never get break
Burnout
Deny/pretend
Avoid
Worries
Frustration
Relentless
Mental Checklists
Perfection
Takes from experiences
Always thinking about T1DM
Always in body
read thoughts
Missing out
Tajes things away
Loss
Missing out
Childhood
The body
Freedom
Life events
Theme Three: IDENTITY.
Main part of identity
All others care about
Identity is less important than diabetes
Identifying factor
Subtheme: 3.1: TAKEN OVER
Taken identity from person
Being othered
I am different
I want to be normal
Subtheme: 3.2: ODD ONE OUT
I am abnormal
Hide diabetes and part of self
Sticking out like sore throat
Not being able to do what peers can
I do not belong
Subtheme: 3.3: THE GOOD WITH THE BAD
Positive traits
Resilience
Caring about health
Inner strength
Acceptance
Accepting negative and positive traits
miro