# Exploring the interplay of psychological states and outcomes, and the mediating effect of resilience in type 1 and 2 diabetes

By

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# Abstract

Type 1 diabetes (T1DM) is a chronic autoimmune disease characterised by the destruction of insulin-producing pancreatic beta cells, which prevents the body from producing sufficient insulin to adequately regulate blood glucose levels. Type 2 diabetes (T2DM) is a result of insufficient insulin secretion and/or insulin resistance, which are strongly correlated with poor diet, sedentary lifestyle habits, and polygenic components (i.e., multiple associated genes). The prevalence of diabetes globally is estimated to be 415 million (90% T2DM) and is expected to rise to 642 million by 2040, placing increased demands on individuals, carers, health systems and society. The relationships between psychological states (e.g., anxiety, fatigue), resilience and diabetes outcomes (e.g., diabetes distress, cognition) are complex, multifaceted, and not well understood. This research focuses on the association between psychological states (anxiety and fatigue) and diabetes outcomes (diabetes distress and cognition), and the potential for resilience to act as a mediator in relation to those relationships. This research is the first to examine all of the aforementioned variables simultaneously, within one model. The overarching aim of this thesis was to develop a novel model to provide recommendations for intervention design, for individuals with T1DM and T2DM. Theoretical understanding and models are important in guiding clinical applications, and are associated with longer lasting intervention changes than those without.

Resilience is a fundamental factor in health psychology and health-based interventions, and so understanding of these underlying relationships in diabetes is necessary to improve health outcomes. Psychological well-being is not only an important outcome, but arguably a pre-requisite for optimal diabetes self-management; Despite this, current UK funding for psychological research in diabetes remains inadequate. Existing findings account for a mediating effect of resilience between variables such as diabetes distress and anxiety, but no studies have examined this mediation effect in these factors simultaneously within one study and therefore, not capturing the complexity of these underlying relationships. This research employed a mixed-methods approach, where correlational and SEM (Structural Equation Modelling; A combination of factor analysis and regression statistical techniques) analyses examined the proposed model, and a combination of deductive and inductive

thematic analyses examined the lived experiences behind the relationships/variables within and outside the model. The findings were evaluated against existing research to compile a list of intervention recommendations.

Study 1: This study explored whether resilience mediated the association between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) within one model, and if any differences existed between diabetes types. Data was collected via an e-survey using the platform Qualtrics. Preliminary correlation analyses followed by SEM revealed a significant mediating effect of resilience between psychological states (anxiety and fatigue) and diabetes outcomes (diabetes distress and cognition), with no difference between T1DM and T2DM groups (*n* =307; T1 = 129, T2 = 178). These findings supported the proposed model to explain the underlying relationships between resilience and psychological factors.

Study 2: This study explored the lived experience of individuals with T1DM and T2DM in the context of the model variables in study 1 (e.g., anxiety, fatigue, resilience, diabetes distress, cognition), and examined factors outside of the model that were relevant to diabetes self-care (e.g., healthcare experiences). Deductive and inductive thematic analyses were performed on responses from questions relating to the lived experiences of diabetes, in the context of variables within the model. Semi-structured interviews were conducted in T1DM (N=12) and T2DM (N=14) participants. Analyses identified five main themes, three of which were deductive: (a) psychological states: MH (Mental Health; a state of well-being enabling individuals to cope with the stresses of life, identify their abilities and function effectively), anxiety, fatigue, cognition; (b) Resilience: anxiety and fatigue, cognition, diabetes distress, coping styles; (c) diabetes management: glucose monitoring and medication, daily functioning. The remaining two themes were inductive: (d) healthcare experiences and attitudes: healthcare provider interactions, healthcare system; and (e) diabetes education and intervention experiences: education, interventions. Findings here provided some support for the model in study 1. Participants highlighted how resilience was an important part of their diabetes management, and generally helped reduce feelings of anxiety, fatigue and diabetes distress. Over half of participants (T1- 58%; T2- 64%) described how resilience aided cognition (i.e., through planning, decision making), but participants were generally more unsure regarding cognition than other factors. Participants also discussed other prevalent factors in their diabetes healthcare experiences that influenced self-management, such as education and lack of support. Intervention uptake rates and satisfaction of these courses (e.g., content, delivery) were generally low. These findings provided insight for intervention-based research and clinical applications.

Study 3: This study investigated the lived experience of the study 1 model variables in a broader sample, and conducted a closer examination of inductive aspects of living with diabetes outside of the model (identified in study 2), such as mental health, education and interventions. Data was collected via an e-survey using the platform Qualtrics (N= 53; T1=20; T2=33). Deductive Thematic Analysis identified three overarching themes: (a) Mental healthcare: accessibility, approaches, quality of care satisfaction; (b) Psychological correlates of diabetes: MH impact (including model variables), cognition, resilience in diabetes self-management; and (c) Education and interventions: education from healthcare providers, intervention experiences and recommendations. Findings provided some support for the model in study 1, and provided more insight into factors identified outside of the model. Both diabetes groups felt there was: a lack of integration of mental healthcare and support within primary healthcare (i.e., healthcare provider and service issues); participants described a range of psychological difficulties in line with the model; and psychological education regarding living with diabetes is lacking in both the public population (diabetes and non-diabetes) and in healthcare providers. Participants made a range of recommendations for interventions: to raise awareness of MH and psychological difficulties; use more layman-friendly language; and improve certain areas of knowledge (e.g., how individualised diabetes can be regarding symptoms, and how unpredictable blood sugars can be, making them hard to control). These findings support the need to increase psychological and MH-based education as part of diabetes care.

Collectively, the thesis findings provide support for the proposed model, and analyses of lived experiences provide insight into the problems diabetes patients are facing. There is a need to develop research-based models, and a need to integrate psychological and MH-based education in primary care and existing interventions; this will help patients feel supported in further understanding their diabetes symptoms, and to improve self-efficacy in managing their diabetes. Taking account of current findings and existing literature, the following recommendations are suggested for intervention design: 1) Implementing theoretical-based interventions; 2) Incorporating mental health and psychological education into primary care and existing interventions; 3) Addressing care approaches and the need for a holistic understanding of diabetes self-management; 4) Better coordination of diabetes and MH care services and signposting; and 5) Integrating patient recommendations and improving intervention uptake.

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# Abbreviations

| | |
|---|---|
| **BMI** | Body Mass Index |
| **CD-RISC** | Connor-Davidson Resilience Scale |
| **CFA** | Confirmatory Factor Analysis |
| **CI** | Confidence Interval |
| **DAFNE** | Dose Adjustment for Normal Eating |
| **DAWN-2** | Diabetes Attitudes, Wishes and Needs Second Study |
| **DESMOND** | Diabetes Education and Self-Management for Ongoing and Newly Diagnosed |
| **DEX** | Dysexecutive Questionnaire |
| **DDS** | Diabetes Distress Scale |
| **DM** | Diabetes Mellitus |
| **DSM** | Diabetes Self-Management |
| **DUK** | Diabetes UK |
| **EB** | Emotional Burden (Diabetes Distress Subscale) |
| **ES** | Effect Sizes |
| **FFS** | Flinder's Fatigue Scale |
| **FoH** | Fear of Hypoglycaemia |
| **GAD** | Generalised Anxiety Disorder |
| **HbA1c** | Haemoglobin A1c |
| **HCP(s)** | Health Care Professional(s) |
| **ID** | Interpersonal Distress (Diabetes Distress Subscale) |
| **MH** | Mental Health |
| **NDPP** | National Diabetes Prevention Program |
| **NHS** | National Health Service |
| **NICE** | National Institute Centre of Excellence |
| **PD** | Physician Related Distress (Diabetes Distress Subscale) |
| **PSWQ** | Penn State Worry Questionnaire |
| **SEM** | Structural Equation Modelling |
| **T1DM** | Type 1 Diabetes Mellitus |
| **T2DM** | Type 2 Diabetes Mellitus |
| **WHO** | World Health Organisation |
| **RCT** | Random Controlled Trials |
| **RRD** | Regimen Related Distress (Diabetes Distress Subscale) |

# Chapter 1. Background of Diabetes Mellitus

## 1.1 Chapter Structure

Chapter 1 provides an overview of Type 1 diabetes mellitus (T1DM; a chronic autoimmune disease characterised by the destruction of insulin-producing pancreatic beta cells, which prevents the body from producing sufficient insulin to adequately regulate blood glucose levels) and Type 2 diabetes mellitus (T2DM; a chronic disease caused by a result of insufficient insulin secretion and/or insulin resistance, which are strongly correlated with poor diet, sedentary lifestyle habits, and polygenic components (i.e., multiple associated genes)), including: prevalence rates, the history and discovery of insulin, the aetiology, risks of development and complications of their respective diabetes type. Furthermore, components of effective diabetes self-management will be discussed (e.g., medication/regimen adherence and emotional management). Next, the NHS Diabetes Prevention Programme 'RightCare Pathway,' will be discussed, which defines the core components of an optimal diabetes service across primary and secondary care for both T1DM and T2DM, in relation to current achieved glycaemic targets in the UK. Finally, the chapter will finish by summarising the main aims and objectives of the thesis, and stating how these will be achieved.

## 1.2 Chapter introduction

Diabetes mellitus describes a spectrum of autoimmune, metabolic and genetic disorders that are characterised by persistent hyperglycaemia (Egan & Dinneen, 2019), an excess of blood glucose (Palta et al., 2014), as a result of partial or total insulin insufficiency, and/or insulin resistance (Egan & Dennis, 2019; Diabetes UK, 2015; Guigliano et al., 2008). There are three main classifications of diabetes: type 1, type 2 (see abstract for definitions), and gestational diabetes, where the hormones during pregnancy can lead to insulin resistance (Egan & Dinneen, 2019). Additionally, there are rarer types of diabetes such as: Maturity Onset Diabetes of the Young (MODY; mutation of a single gene impairing insulin production); Latent Autoimmune Diabetes in Adults (LADA; late onset autoimmune damage of the pancreas); and type 3c (where damage to or removal of the pancreas can result in insufficient insulin production) (Hart et al., 2016; Hoffman et al., 2023; Rajkumar & Levine, 2024).

Diabetes Mellitus is disease spectrum ranging from insulinopenic (i.e., inadequate secretion of insulin, T1DM) to insulin resistant (i.e. T2DM), and the rarer types such as LADA, 3c and MODY present clinical features of both T1DM and T2DM (Rajkumar & Levine, 2024). As such, and due to the rarity of these types, patients are often initially misdiagnosed with T1DM/T2DM.

This PhD focused on T1DM and T2DM, and whilst they share clinically similar symptoms (e.g., hyperglycaemia), the aetiology of the disease types differs significantly (Zaccardi et al, 2016). Both types have a strong genetic component (Zaccardi et al, 2016), and inadequate long-term self-management is associated with greater risk of serious microvascular complications, such as: retinopathy (disease of the retina); neuropathy (disease/damage of the nerves); nephropathy (disease of the kidney); and sexual dysfunction (problems with sexual desire, response, orgasm, and/or pain). Additionally, inadequate long-term self-management is also associated with greater risk of macrovascular complications, such as: atherosclerotic cardiovascular disease (heart and blood vessel disease, typically associated with deposits of fat within arteries); cerebrovascular disease (disorders that affect blood supply to the brain, typically associated with blood clots and strokes); and limb amputations (Faselis et al., 2020; Fowler, 2008). The criteria for diabetes diagnosis are as follows: 1) random plasma glucose concentration ≥11.1 mmol/litre alongside hyperglycaemia, 2) fasting plasma glucose (FPG) ≥7.0 mmol/litre (fasting defined as no caloric intake for 8 hours), 3) plasma glucose ≥11.1 mmol/litre 2 hours after glucose intake, and 4) a glycated haemoglobin (HbA1c; A measure of glycated haemoglobin, where glucose binds to haemoglobin in the bloodstream, to provide average blood sugar levels across 3-6 months) level ≥48 mmol/mol (≥6.5%) (World Health Organisation 2006, 2011).

## 1.3 Prevalence of Diabetes

Global diabetes prevalence rates have reached 415 million, projected to rise to 642 million by 2040, with rates rising more rapidly in low- and middle-income countries (Saeedi et al., 2019; World Health Organisation, 2022). It is a significant public health concern worldwide, placing increased demands on individuals, carers, health systems and society (Forouhi & Wareham, 2019). An estimated 4.9

million people are living with diabetes in the UK, 90% of whom have type 2, 8% have type 1, and 2% have rarer diabetes types (National Diabetes Audit, 2022). An estimated further 850,000 people are currently living with T2DM without a diagnosis (Diabetes UK, 2022). Diabetic limb amputations (leg, foot, toe) reach almost 9600 every year, 185 per week, and diabetes is a major cause of blindness, kidney failure, heart attacks (530 per week) and stroke (Whicher et al., 2020).

The NHS spends £10 billion a year (10% of entire budget) on diabetes, and 80% of this money is used on treating complications. Despite this, roughly a third of people with T2DM, and two thirds of people with T1DM do not achieve target glycated haemoglobin (HbA1c) levels (National Diabetes Audit, 2022). The constant demands of living with diabetes can also take a significant psychological toll, leading to psychological difficulties that impact diabetes self-management such as diabetes-related distress, anxiety and depression (Winkley et al., 2020).

## 1.4 History of Diabetes and the Discovery of Insulin

Descriptions of clinical symptoms concordant with diabetes were first found 3000 years ago in ancient Egyptian papyri and ancient Indian and Chinese medical literature (Karamanou et al., 2016). Recorded history attributes the first complete descriptions and coining of the term ‘diabetes’ to Greek physician Aretaeus of Cappadocia (81-133 AD) (Lakhtakia, 2013); and ‘mellitus’ (Latin for honey-sweet) was later added by English physician Thomas Wallis (1675), as a result of observing the sweetness of urine and blood in diabetic patients (Ahmed, 2002; Karamanou et al., 2016). This sweetness was confirmed by English physician Matthew Dobson (1776), as a result of excess blood glucose.

Milestone diabetes discoveries coincided with the development of experimental medicine, and in 1857, French physiologist Claude Bernard established the role of the liver in glycogenesis (formation of glycogen from sugars, which are then stored in the liver, decreasing blood sugar levels) (Karamanou et al., 2016). This finding promoted further study into glycogenesis, which is stimulated by the hormone insulin. Minkowski and von Mering (1889) then discovered the role of the pancreas in the onset of diabetes, through conducting pancreatectomies on dogs and implanting portions of pancreas in depancreatised dogs. These experiments provided the foundation for Banting et al. (1921), who successfully isolated insulin from dogs' pancreases for the first time. Insulin was yet to be tested in humans, and in 1922 the first insulin injection was administered to Leonard Thompson, a 14-year-old boy who was in critical condition. After the second injection his blood glucose levels had improved significantly and urinary ketones disappeared. This discovery revolutionised the lives of diabetics across the world who were now able to live normal lives, and in 1923 'Iletin' was introduced as the world's first commercially available insulin (Karamou et al., 2016).

## 1.5 Biological Mechanisms involved in Blood Glucose Regulation

Blood glucose regulation is an essential process providing energy, in the form of glucose, to the body and brain (Tirone & Brunicardi, 2001). Typically, this takes the form of a negative feedback loop, where if blood glucose is too high, the pancreas secretes insulin into the blood stimulating the liver, muscles, and cells to store the excess glucose as fat and glycogen. Conversely, if blood glucose is too low, the pancreas will secrete the hormone glucagon to stimulate the breakdown of glycogen stores into glucose, increasing blood glucose levels (Ojha et al., 2019; Suh et al., 2007; Tirone & Brunicardi, 2001). This mechanism working correctly prevents hypoglycaemia (which can lead to altered states of consciousness and death) and hyperglycaemia, whereby prolonged episodes can damage micro and macrovascular systems (Tirone & Brunicardi, 2001) (see section 1.2). However, a number of factors such as genetics, immune response, diet and lifestyle can contribute to blood glucose regulation problems through insulin insufficiency, and/or insulin resistance (Egan & Dennis, 2019; Diabetes UK, 2015; Guigliano et al., 2008). These differ between T1DM and T2DM, discussed in the following sections 1.6 and 1.7.

## 1.6 Type I – Aetiology, Risks, and Complications

Type 1 diabetes is a chronic autoimmune disease, characterised by destruction of insulin-producing pancreatic beta (β) cells; this prevents the body from producing sufficient insulin to adequately regulate blood glucose levels and can result in absolute insulin deficiency (Atkinson et al., 2014; Nibali et al., 2022). However, the reason for this immune response is not well understood. One theory is chronic viral infections of β-cells leads to chronic inflammation and subsequent autoimmunity, and another theory suggests β-cell abnormalities act as a marker for cytotoxic T lymphocytes, resulting in 'β-cell suicide.' (DeMeglio et al, 2018). However, T1DM is also associated with significant genetic components, and environmental interactions (DeMeglio, et al., 2018). For example, one of the largest T1DM pre-diagnosis studies followed 48,026 participants and found a concordance risk of 69% for identical twins which were multiple autoantibody-positive, for T1DM onset, 72% for non-identical twins, compared to 47% in full siblings. This suggests a genetic component involving the autoantibodies and the onset of T1DM (Triolo et al., 2019). Previous studies support this, although reported rates for identical twins are variable (30-70%) (Bogdanos, 2012; Redondo et al., 2008; Triolo et al., 2019). Additionally, a review carried about by Sharif et al. (2018) found evidence for environmental interactions in T1DM diabetes onset. For example, psychological stressors such as anxiety, fatigue, diabetes distress and depression can influence biological mechanisms such as the such as the Hypothalamus-Pituitary Adrenal (HPA) axis to produce a chronic stress response. This can contribute to immunosuppression, inflammation and insulin resistance (Sharma & Singh, 2020). This chronic stress response can contribute to the development of both physical and further psychological disorders (Lu et al., 2021). (See chapter 2 for detailed discussions of psychological stressors except from depression; see also section 1.8 for definitions, descriptions, and types of psychological stress and how they interact with the HPA axis).

Despite advances in care, T1DM continues to be associated with significant financial, medical and psychological burden (Forouhi & Wareham, 2019). Acute complications associated with T1DM are: hypoglycaemia (insufficient blood glucose; where severe episodes can lead to seizures, coma or death), and diabetic ketoacidosis, where ketone levels become excessive due to insulin deficiency and can cause dehydration and comas (Misra & Oliver, 2015). Chronic complications are similar to T2DM, including neuropathy, retinopathy, nephropathy, cardiopathy and sexual dysfunction (Jacobson et al., 2013; Nibali et al., 2022).

## 1.7 Type II – Aetiology, Risks, and Complications

In contrast, the cause of T2DM is significantly associated with poor diet and sedentary lifestyle habits (Kolb & Martin, 2017), with a strong polygenic (i.e., multiple associated genes)/hereditary component (Egan & Dinneen, 2019; Pearson, 2019). Type 2 diabetes is a complex metabolic disorder thought to occur as a result of insufficient insulin secretion and/or insulin resistance (Giugliano et al., 2008), which is associated with β-cell dysfunction/failure and insulin resistance in muscle and liver (Egan & Dineen, 2019; Nibali et al., 2022). Currently there are roughly 400 genetic variants associated with diabetes risk (Pearson, 2019), and research consistently shows combined lifestyle interventions (such as diet and physical activity) can be effective in reducing type 2 diabetes risk by around 50% (Chaterjee et al., 2021; Diabetes UK, 2022). One of the largest meta-analyses undertaken examining combined lifestyle factors in type 2 diabetes (14 studies across USA, Asia and Europe; $n$ = 970,170) found healthy combined lifestyle factors, such as good diet and exercise, were significantly associated with a 75% lower risk of incident T2DM, and 31-56% reduction in total and diabetes-related mortality (Zhang et al., 2020). As with type 1 diabetes, psychological stressors such as anxiety, fatigue, diabetes distress and depression can interact with the HPA axis to produce a chronic stress response, which can contribute to insulin resistance and inflammation (Sharma & Singh, 2020). This chronic stress response can contribute to the development of both physical and further psychological disorders (Lu et al., 2021). (See chapter 2 for detailed discussions of psychological stressors except from depression; see also section 1.8 for definitions, descriptions, and types of psychological stress and how they interact with the HPA axis).

Despite advances in care, T2DM continues to be associated with significant financial, medical and psychological burden (Forouhi & Wareham, 2019). Chronic hyperglycaemia can result in microvascular complications such as neuropathy, nephropathy, retinopathy, and sexual dysfunction which is often overlooked in T2DM (Faselis et al., 2020), and microvascular complications such as atherosclerotic cardiovascular disease, cerebrovascular disease, stroke, and limb amputation (Fowler, 2008). Diabetic retinopathy and nephropathy affect 25% of patients with T2DM, and diabetic neuropathy affects approximately 50% of the diabetic population; sexual dysfunction rates range from

35-90% in diabetic men (Faselis et al., 2020), and estimated at 20-80% of females, although sexual dysfunction in females is relatively neglected in research (Elyasi et al., 2015). These figures are generally consistent, but are not always controlled for or reported in the diabetes literature (see chapter 2).

## 1.8 Factors in Diabetes Self-Management

Diabetes self-management behaviours are essential for achieving optimum glycaemic control and positive health outcomes, however this requires a great deal of motivation and behavioural change (Kalra et al., 2018). Daily management behaviours could involve medication and/or regimen adherence (e.g., physical exercise, diet), blood glucose monitoring (i.e., finger-pricking) (Ahola & Groop, 2012), and emotional control/management, where the impact of unmanaged emotional stress is often overlooked in diabetes research (Kalra et al., 2018). Unmanaged or inadequate emotional stress can significantly negatively impact an individual's psychological wellbeing and glycaemic control, and can contribute to psychological disorders (e.g., depression, anxiety, eating disorders, diabetes distress), social and cognitive difficulties or substance abuse (Kalra et al., 2018; Robinson et al., 2023). These factors have been correlated with reduced diabetes self-management and diabetes outcomes, which can be a precursor to early mortality (e.g., through increased risk of cardiovascular complications; Robinson et al., 2023). Therefore, developing the ability to adapt and overcome emotional/psychological problems is essential for optimal diabetes outcomes. Overall, it is important to take into account factors that facilitate self-management or present barriers in order to improve health outcomes. An examination of several reviews and studies (see Adu et al., 2019; Ahola & Groop, 2012; Atyanti et al., 2021; Kalra et al., 2018; Koetsenruijter et al., 2015; Shi et al., 2020) identifies various significant factors that can act as enablers or provide barriers to optimal diabetes management.

1) Social support: This is defined as an individual's perception of assistance being available should they need it (Ahola & Groop, 2012), and can vary in terms of content: a) emotional support, b) instrumental support (i.e., assistance to meet tangible needs), c) informational support, and d) appraisal support (i.e., validation) (Jolly, Kong & Kim, 2020). Research shows that effective social

support from individual support networks (e.g., friends, family, workplace colleagues/supervisors, healthcare providers), and community networks (e.g., Diabetes UK support groups) is positively correlated with increased glycaemic control in T1DM and T2DM (Chan et al., 2020; Karimy et al., 2018). Additionally, individuals who are more isolated from social support have been found to experience decreased motivation to make dietary changes for their diabetes (Sriram et al., 2019).

2) Knowledge and health literacy: Adu et al. (2019) found educational qualifications and diabetes education were predictors of self-management skills. Health literacy has also been found to significantly predict efficacy of self-management behaviours (Ahola & Groop, 2012; Zahedi et al., 2020), and so has clinical implications on health outcomes. However, whilst knowledge is important, it is unlikely to be sufficient in improving glycaemic control alone; for example, Hurst et al. (2020) found self-efficacy to be the strongest predictor of glycaemic control in T2DM compared to diabetes knowledge, suggesting whilst diabetes-based knowledge is important, self-efficacy (see below) is important in applying the knowledge in self-care behaviours (e.g., medicine, regiment adherence). This suggests the importance of taking a holistic approach when considering barriers of diabetes self-management.

3) Self-efficacy: This is defined as one’s belief in their competency to successfully complete a task (Ahola & Groop, 2012). Higher self-efficacy is associated with improved glycaemic control and more adaptive coping methods (problem-focused) (King et al., 2010; Sharoni & Wu, 2012). Interestingly, Adu et al. (2019) found higher rates of self-efficacy in T1DM patients than T2DM. This could be explained by diabetes duration, and on average T2DM patients are diagnosed later in life, requiring behavioural changes at later life stages. Self-efficacy is also a well-established component of resilience, which has implications for intervention (see chapter 4). A brief definition of resilience is the capacity to adapt and maintain psychological and physical wellbeing in the face of adversity (Terte et al., 2014), through several attributes such as determination, personal strength, emotional regulation and supportive relationships (Brown et al., 2022; Dubois et al., 2020). See chapter 3 for more detailed discussion.

4) Locus of control: These are the views people hold regarding how much personal control they have over their lives (Ahola & Groop, 2012). Research suggests attributing control internally (rather than externally) correlates with improved glycaemic control in both T1DM and T2DM (Besen et al., 2016; Mansour-Ghanaei et al., 2013; Sloan, Pardon & Platt, 2009). This is because internal control is associated with increased autonomy and therefore patients will be more likely to take control of their diabetes; rather than attributing health outcomes to chance or environment (Besen et al., 2016). This is also an established component of resilience, which has implications for intervention (Connor & Davidson, 2003).

5) Psychological stress: Stress is defined as homeostasis being challenged by three types of stress: 1) sustress (inadequate stress), 2) eustress (good stress) and distress (bad stress). Both sustress and distress might impair physiological and psychological functioning, whereas eustress may help benefit health (Lu et al., 2021). The intensity of stressors beyond a threshold and chronic stress can commonly activate the Hypothalamic-Pituitary-Adrenal (HPA) axis, which produces cortisol; a stress hormone that increases gluconeogenesis in the liver and glucose levels in the blood, but supresses insulin secretion. This can contribute to insulin resistance and inflammation (Sharma & Singh, 2020). This chronic stress response can contribute to the development of both physical and psychological disorders (Lu et al., 2021). Psychological stress can be defined as the perception of stress, strain or pressure an individual experiences from different sources, e.g., life events, occupation or finance (Kuo et al., 2019). Specifically, psychological stress can be categorised into four types: 1) emotional stress, such as anxiety, depression, grief, anger; 2) cognitive stress, e.g., information overload, disruptions, mental fatigue; 3) perceptual stress, e.g., competition, addiction; and 4) psychosocial stress, e.g., feelings of social defeat, social confrontations, life trauma and racial disparity (Kuo et al., 2019; Lu et al., 2021).

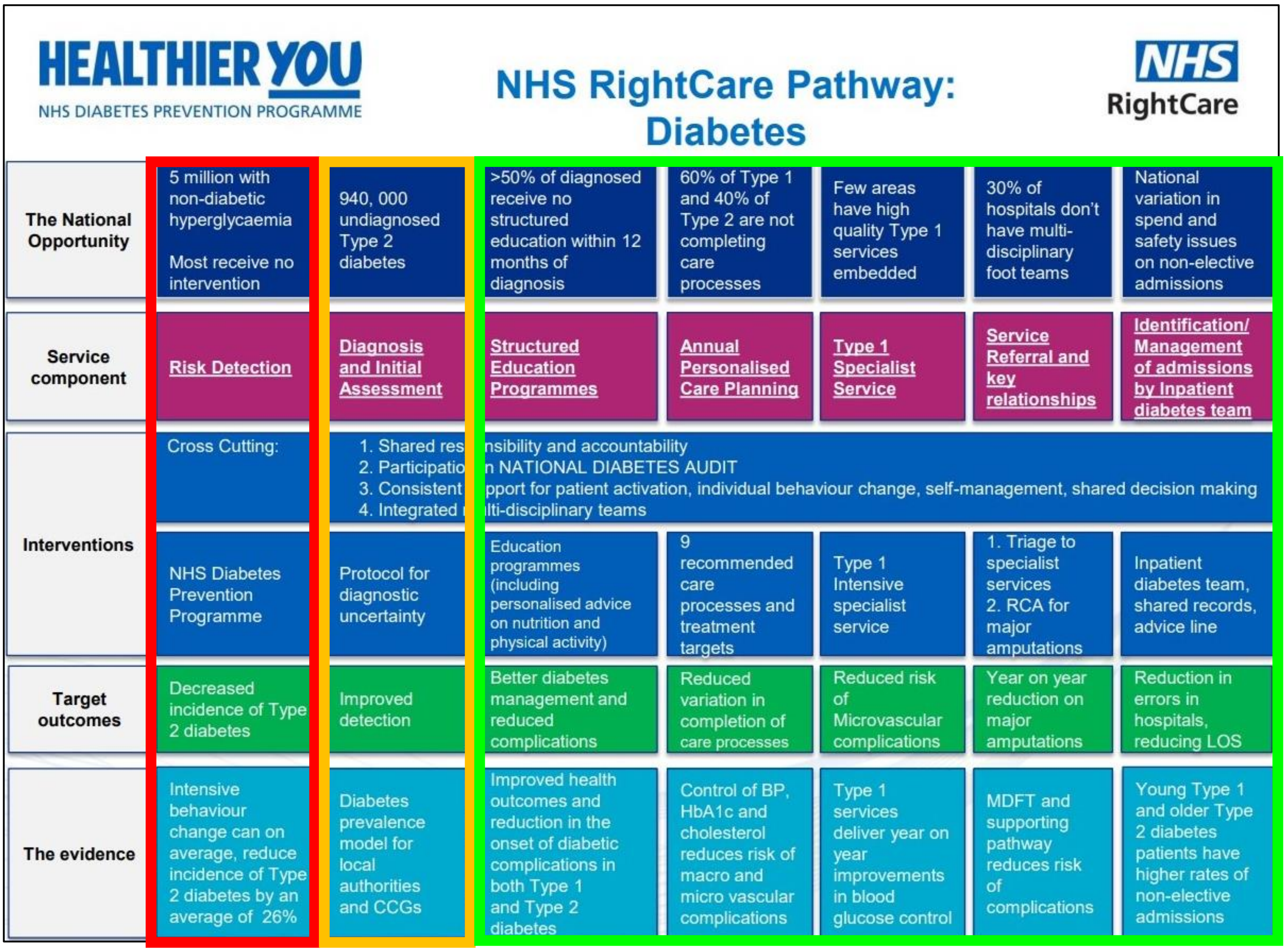
There is a clear association between increased psychological stress (via anxiety, depression, diabetes distress, etc.), and poorer glycaemic levels and adverse health outcomes in those with T1DM and T2DM (Kalra, Jena & Yeravdekar, 2018; See also chapter 2 for a review). This also includes the fear of hypoglycaemia (FoH), which is reported more in T1DM, but also experienced by those with T2DM

(Ahola & Groop, 2012). This is the fear of blood glucose levels dropping too low, and due to the fear of adverse complications (e.g., coma), the patient may exhibit tendencies to maintain hyperglycaemia. Furthermore, studies have shown increased emotional control, specifically regulating negative emotions is associated with increased glycaemic control and lower diabetes distress in T1DM and T2DM (Coccaro, Lazaurus, Joeseph et al., 2021). Generally, there is a lot of overlap between diabetes self-management factors, and the underlying relationships are numerous and complex, warranting further study in both T1DM and T2DM diabetes populations.

## 1.9 NHS Diabetes Prevention Programme: Diabetes RightCare Pathway

The NHS Diabetes RightCare Pathway (NHS, 2018) is a guide detailing the core components of an optimal diabetes service, and provides examples of good practice between primary, secondary, and integrated care, designed to encourage evaluation and improvements of existing care systems. It was developed as a collaboration between UK clinical directors for diabetes and obesity, the NHS, diabetes UK and other stakeholders.

**Figure 1. NHS Diabetes RightCare Pathway**



HEALTHIER YOU
NHS DIABETES PREVENTION PROGRAMME

NHS RightCare Pathway: Diabetes

NHS RightCare

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| **The National Opportunity** | 5 million with non-diabetic hyperglycaemia<br>Most receive no intervention | 940, 000 undiagnosed Type 2 diabetes | >50% of diagnosed receive no structured education within 12 months of diagnosis | 60% of Type 1 and 40% of Type 2 are not completing care processes | Few areas have high quality Type 1 services embedded | 30% of hospitals don't have multi-disciplinary foot teams | National variation in spend and safety issues on non-elective admissions |
| **Service component** | Risk Detection | Diagnosis and Initial Assessment | Structured Education Programmes | Annual Personalised Care Planning | Type 1 Specialist Service | Service Referral and key relationships | Identification/ Management of admissions by Inpatient diabetes team |
| **Interventions** | Cross Cutting: | 1. Shared res nsibility and accountability<br>2. Participatio n NATIONAL DIABETES AUDIT<br>3. Consistent pport for patient activation, individual behaviour change, self-management, shared decision making<br>4. Integrated lti-disciplinary teams | | | | | |
| | NHS Diabetes Prevention Programme | Protocol for diagnostic uncertainty | Education programmes (including personalised advice on nutrition and physical activity) | 9 recommended care processes and treatment targets | Type 1 Intensive specialist service | 1. Triage to specialist services<br>2. RCA for major amputations | Inpatient diabetes team, shared records, advice line |
| **Target outcomes** | Decreased incidence of Type 2 diabetes | Improved detection | Better diabetes management and reduced complications | Reduced variation in completion of care processes | Reduced risk of Microvascular complications | Year on year reduction on major amputations | Reduction in errors in hospitals, reducing LOS |
| **The evidence** | Intensive behaviour change can on average, reduce incidence of Type 2 diabetes by an average of 26% | Diabetes prevalence model for local authorities and CCGs | Improved health outcomes and reduction in the onset of diabetic complications in both Type 1 and Type 2 diabetes | Control of BP, HbA1c and cholesterol reduces risk of macro and micro vascular complications | Type 1 services deliver year on year improvements in blood glucose control | MDFT and supporting pathway reduces risk of complications | Young Type 1 and older Type 2 diabetes patients have higher rates of non-elective admissions |

**Fig. 1**

Diabetes RightCare Pathway (NHS, 2018). This diagram defines the core components of an optimal diabetes service across primary and secondary care; designed to provide commissioners with an optimal guide to encourage evaluation and improvements of existing care systems. The added red, yellow and green boxes indicate components of: 1) risk detection; 2) diagnosis and initial assessment; and 3) care and management of the disease, respectively.

The main aim objectives behind the RightCare Pathway are to reduce variation in care delivery, and base care and interventions on evidence to gain maximum benefit (both clinically and financially). The RightCare Pathway can be categorised into three areas regarding diabetes services: 1) risk detection; 2) diagnosis and initial assessment; and 3) care and management of the disease. These will be considered in the context of this PhD:

1) The model developed as part of study 1 informs the ‘risk detection’ stage of the RightCare Pathway. Risk detection involves identifying individuals that have higher risk of developing diabetes, and those who may have non-diabetic hyperglycaemia (i.e., prediabetes), so that appropriate action can be taken to counter the onset of diabetes. By better understanding the psychological mechanisms and factors which may contribute to the onset of diabetes, education of these factors and preventative healthcare can be improved. 2) This PhD does not inform the diagnosis and initial assessment stage. 3) The findings from studies 2 and 3 inform both the ‘risk detection’ and ‘care and management’ stage. Specifically, the studies evaluate participant experiences in context of the model factors, with the aim of further understanding psychological factors and interactions of these (risk detection). Additionally, by examining service and healthcare issues, patient care experiences, and intervention experiences (care and management), this PhD provides a list of tangible recommendations for improving interventions (e.g., psychoeducational care) and healthcare services.

Notable summary points from the RightCare Pathway are stated below, with clear indications of how this PhD informs them:

- *‘The onset of Type 2 diabetes can be prevented and/or delayed by finding and intervening early with individuals at high risk’* ***(Risk detection; informed by study 1 model, e.g., understanding mediating effects of resilience between anxiety/fatigue and diabetes distress/ cognition).***
- *All people newly diagnosed with diabetes are offered an initial assessment and personalised care planning appointment with a member of their care team (MDT), preferably within *4-6 weeks* ***(Diagnosis and initial assessment; not informed by this PhD).***
- *‘All people with diabetes should be assigned a multidisciplinary team. Teams should be assigned to people with both Type 1 and Type 2’* **(Care and Management; informed by studies 2 and 3, e.g., participant experiences were not reflective of this).**
- *‘Structured Care planning should occur immediately after diagnosis to determine the needs and priorities of the patient. This needs to address the individual patient’s needs and co-*

*morbidities.'* ***(Care and Management; informed by studies 2 and 3, e.g., participant experiences were not reflective of this).***

- *'All people with diabetes should have access to ongoing care, education and support planning to agree goals and priorities to access: — a comprehensive education programme (Type 1 and Type 2) — a carbohydrate counting educational programme (Type 1 and Type 2) — an insulin pump service (Type 1) — continuous glucose monitoring for those who would benefit-as per NICE guidance (Type 1) — psychological support (Type 1 and Type 2) — access to appropriate technology to help individuals manage their diabetes (Type 1 and Type 2) — referrals directly into specialist care services or community based services where clinically indicated'* ***(Care and Management; informed by studies 2 and 3, e.g., participant experiences were not reflective of this, especially in regards to psychological support).***
- *'As a minimum an annual care planning review should happen for everyone with diabetes, more frequent reviews and monitoring will be required on the basis of individual needs, priorities, and test results.'* ***(Care and Management; informed by studies 2 and 3, e.g., this was not always reflected in participants' experiences, and a common theme was needing individualised care).***

Additionally, the RightCare Pathway estimates that 5 million people in the UK are living with pre-diabetes, and yet currently most receive no intervention. Reaching these people to reduce diabetes risk is another key element of NHS England's mandate from government (2018/19).

## 1.10 Evaluation of the Pathway and Relevant Literature

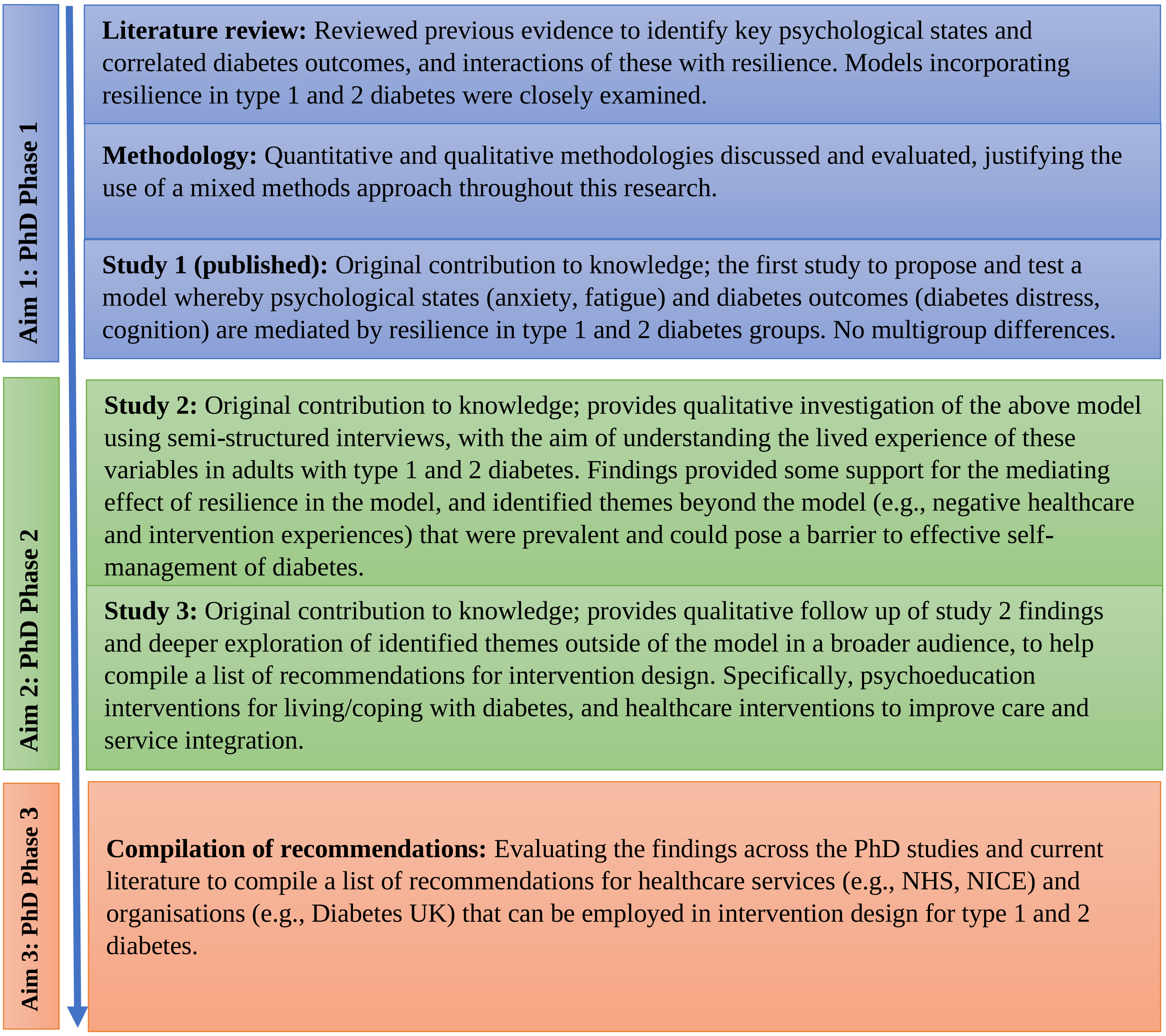
Currently, there are still a significant number of individuals not meeting their glycaemic targets (roughly 30% of type 2 patients, and 60% of type 1 patients; NHS). The UK Diabetes Position Statements report (2020) presents some concerning statistics; roughly 40% of people with diabetes report diminished psychological wellbeing (wellbeing is defined as "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity," WHO, 2014), and fewer than 15% of diabetes patients feel they receive the emotional and psychological treatment that they need from the NHS. Also, 30% of general practitioners agreed current mental health resources are inadequate, and pathways within the NHS (links between different levels of care) for referring patients to the specialist mental healthcare ‘just do not exist’ (Primary Care Diabetes Society, 2018). Many patients voice the concern that their mental wellbeing is either not discussed or taken seriously enough (Whicher, O’Neill & Holt, 2020). This demonstrates the importance of working towards improving MH support for those with diabetes (MH; Mental Health, a state of well-being enabling individuals to cope with the stresses of life, identify their abilities and function effectively, WHO, 2022).

The RightCare Pathway is consistent with the literature on areas for diabetes care improvement, such as mental healthcare support, and all patients needing access to multi-disciplinary teams (Benton et al., 2023). Additionally, the literature supports need for evidence-based interventions, where several systematic reviews reveal a gap in the literature for theory and evidence-based diabetes interventions (Chew, et al., 2017; Winkley et al., 2020; Zhao et al., 2017). Therefore, this programme of research will take into account the above research limitations and the RightCare Pathway to test and develop a new model based on a review of existing literatures, which may inform relationships between resilience and psychological correlates of diabetes. This could have implications for intervention, if supported with further cross-sectional and longitudinal research.

## 1.11 Thesis Aims and Objectives

The overarching aim of this PhD is to provide recommendations for researchers who develop interventions for individuals with type 1 and type 2 diabetes. This will be achieved across three aims: 1) Reviewing existing literature to examine relationships between psychological states and diabetes outcomes, with resilience as a potential mediator, to develop and test a more comprehensive model to explain these relationships. 2) To qualitatively explore the lived experience of individuals with T1DM and T2DM in the context of the model, and to identify and explore themes identified outside of the model. 3) Compiling the findings across the PhD and evaluating against current literature to compile a list of recommendations for further research that can be used to inform intervention guidance (e.g., psychoeducation, healthcare service integration). See Figure 2 for a flow chart that maps each thesis aim to the respective tasks/studies carried out.

**Figure 2. Flow Chart of PhD Aims and Respective PhD Stages**



**Literature review:** Reviewed previous evidence to identify key psychological states and correlated diabetes outcomes, and interactions of these with resilience. Models incorporating resilience in type 1 and 2 diabetes were closely examined.

**Methodology:** Quantitative and qualitative methodologies discussed and evaluated, justifying the use of a mixed methods approach throughout this research.

**Study 1 (published):** Original contribution to knowledge; the first study to propose and test a model whereby psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) are mediated by resilience in type 1 and 2 diabetes groups. No multigroup differences.

**Study 2:** Original contribution to knowledge; provides qualitative investigation of the above model using semi-structured interviews, with the aim of understanding the lived experience of these variables in adults with type 1 and 2 diabetes. Findings provided some support for the mediating effect of resilience in the model, and identified themes beyond the model (e.g., negative healthcare and intervention experiences) that were prevalent and could pose a barrier to effective self-management of diabetes.

**Study 3:** Original contribution to knowledge; provides qualitative follow up of study 2 findings and deeper exploration of identified themes outside of the model in a broader audience, to help compile a list of recommendations for intervention design. Specifically, psychoeducation interventions for living/coping with diabetes, and healthcare interventions to improve care and service integration.

**Compilation of recommendations:** Evaluating the findings across the PhD studies and current literature to compile a list of recommendations for healthcare services (e.g., NHS, NICE) and organisations (e.g., Diabetes UK) that can be employed in intervention design for type 1 and 2 diabetes.

# Chapter 2. Psychological Correlates of Diabetes

## 2.1 Structure of Chapter

This chapter presents a summary of the literature review process, and a scoping review of the literature that has examined psychological states (anxiety, fatigue, diabetes distress and cognition) found to influence diabetes management in T1DM and T2DM groups. Inter-correlations between these factors are discussed before a summary of research strengths and limitations is presented. This is to determine the suitability of these factors for a potential SEM (Structural Equation Model: A combination of factor analysis and regression statistical techniques, used to examine a model of structural relationships between one or more measured variables and latent constructs; Boateng, 2018).

## 2.2 Chapter Introduction

Research reviews have shown a clear association between diabetes and mental health problems (Knowles et al., 2020; Robinson et al., 2018), and there is a paucity of systematic evaluations between psychological factors and diabetes outcomes (Knowles et al., 2020). Living with the constant demands of diabetes can take a significant psychological toll, and as a result many individuals experience distress, depressed mood, anxiety, and fatigue (Ducat et al., 2015; Wylie et al., 2019). The presence of these psychological issues can exacerbate and accelerate adverse diabetes complications, and are significantly associated with reduced self-care activities, poorer glycaemic control and thus, quality of life (Berry et al., 2015; Robinson et al., 2018; Smith et al., 2018). Diabetes research has largely focused on the role of depression (Jones et al., 2016; Roy & Lloyd, 2012), and Major Depressive Disorder (MDD) is one of the most common and investigated psychiatric disorders (Pashaki et al., 2019), therefore it is not the focus of the present programme of research. Other psychosocial factors such as diabetes distress, anxiety and fatigue are relatively understudied in the diabetes literature (Naiker et al., 2017; Robinson et al., 2018; Wylie et al., 2019), and there is research to suggest that anxiety is just as, if not more, pervasive than depression in the context of diabetes (Chaturvedi et al., 2019).

Specifically, the decision to focus on anxiety, fatigue, diabetes distress and cognition was based on several factors, underpinned by the literature review (see section 2.3 onwards). First, the decision to include or exclude psychological constructs was driven by conceptual/mediational models (e.g., fatigue and diabetes distress; Park et al., 2015), theories (e.g., resiliency theory; Zimmerman, 2013) and findings in the literature (e.g., systematic reviews identifying associations/increased risk factors in type 1 and type 2 diabetes; Denick et al., 2016; Mersha et al., 2022; Romadlon et al., 2022; van Duinkerken & Ryan, 2020). Secondly, construct inclusion/exclusion was then driven by pragmatic factors and the need to construct a parsimonious model (which is especially important in structural equation modelling; Boateng et al., 2018). For example, factors such as sleep disturbances and appraisal were initially considered, but ultimately excluded as they are key factors of fatigue and resilience, respectively, hence there is conceptual overlap (e.g., Griggs & Morris, 2018; Petri-Romao et al., 2024). Additionally, coping strategies were considered in addition to resilience, and conceptual overlaps and differences of these factors are considered in Chapter 3. Studies have shown that resilience and coping are both clearly related but distinct constructs with respect to their impact on behavioural changes and health outcomes (Van der Hallen et al., 2020; Wu et al., 2020). As such, both factors could have been included within this study, but only resilience was chosen to ensure a parsimonious model. This decision was based on definitions of both terms and what they measure (i.e., resilience refers to persevering and adapting to stressors/adversity, whereas coping pertains to behavioural and cognitive strategies used to manage stressful events/situations; Wu et al., 2020. See Chapter 3 for more detail). As the researcher wanted to focus on the capacity to adapt to stressors (i.e., chronic illness and associated challenges), resilience was identified as a likely strong mechanism of change and the potential mediator variable within the proposed model. Coping may be an alternative mediator variable, hence this is addressed in the Discussion (Chapter 10) within the context of future research.

Factors such as trauma can be seen as more predispositional variables, which was not within the scope of this study. Considering the gaps in the diabetes literature, it seemed more appropriate to target more broad, unexplored issues (e.g., interactions between anxiety, fatigue, cognition and distress) that may affect individuals with diabetes on a daily basis. Future research could investigate other variables such as coping and appraisal as it would provide further insight into management of psychological stress. The mechanistic links between these factors are numerous and complex (Lancet Editorial, 2015), therefore understanding the structural relationships of these less known disorders will have potential applications for intervention research, with the aim of improving treatments and quality of life for those with diabetes. Therefore, the first step in the PhD was to conduct a review of existing research, examining psychological research into type 1 and 2 diabetes groups.

## 2.3 Literature Review Process

The literature review followed a more scoped/general approach over a systematic approach. A systematic review is used to identify, appraise and synthesise evidence about a precise question, where all studies examined must follow clear pre-determined criteria to ensure limited clinical heterogeneity (i.e., differences in participant characteristics, types, outcome measures and characteristics; Chess & Gagnier, 2016; Powell & Koelemay, 2021). In contrast, scoping reviews are more exploratory, and typically examine broader research questions than systematic reviews. Scoping reviews aim to map the literature on a broader research area or across topics to identify key concepts/definitions, gaps in the research, and to examine the types and sources of evidence available (Pham et al., 2014).

A systematic review was not used for several reasons: 1) The initial research questions (see below) were broad and required pulling together many findings across several topics within diabetes research, and required looking at the intercorrelations of each variable (e.g., anxiety, fatigue, diabetes distress and cognition). Therefore, the questions being addressed were more broad and less suitable for a systematic review, where typically single and specific questions are asked (Munn et al., 2018; Powell & Koelemay, 2021). Examples of questions addressed as part of the thesis review were: are the aforementioned variables significantly correlated to each other, is this the case across both T1DM and T2DM groups, and what methods have been used to investigate these variables in diabetes groups. 2) Secondly, the research area was lacking in certain areas (e.g., cognition in T1DM and T2DM groups) and therefore it would be unsuitable to exclude studies based on their methodology/power, as the aim was to understand the relationships between the aforementioned variables. Additionally, some studies would examine certain variables in the context of another as a confounding variable, rather than a primary outcome (e.g., anxiety and fatigue, respectively). 3) Systematic reviews tend to examine adequately powered (large) RCTs (Powell & Koelemay, 2021), whereas this was not always the case for this research area. 4) Lastly, being a relatively inexperienced researcher at the start of the PhD will have affected early methodological decisions made. Powell & Koelemay (2021) suggest a scoping review could be useful at the start of a thesis, and is often more useful and less time consuming than a systematic review.

However, it is important to acknowledge the limitations of not using a systematic review; scoping/ general reviews do not aim to produce a critically appraised and synthesised to a specific question, but rather an overview of the available literature (Munn et al., 2018). As such, scoping reviews can lack quality assessment (of the studies and methodologies), and limitations in rigour and duration (Grant & Booth, 2009; Powell & Koelemay, 2021). Although this thesis has provided tables of critical research findings (see Appendix 16) identifying methodological strengths and limitations, and made effort to evaluate the studies discussed throughout chapter 2, this is admittedly not as rigorous as a systematic review. For future improvement, the scoping/general review could be used as a precursor to a systematic review.

The literature search was originally conducted in 2017 to examine empirical studies that have measured either ‘anxiety,’ ‘fatigue,’ ‘diabetes distress,’ ‘cognition,’ and ‘resilience’ in type 1 and/or 2 diabetes. The search was rerun and updated every 3-4 months onwards (with the exception of course interruptions across the PhD). Searches were completed using the following databases/search engines: PubMed Central, Scopus, Elsevier, Research Gate, Google Scholar, MEDLINE, PSYCHINFO, Springer Link, and Cochrane Library. The search procedure used the following terms, for both “**Type 1 diabetes**” and “**Type 2 diabetes**”:

1) **Associations between psychological states and outcome variables:**

   (“Anxiety” OR “Fatigue” OR “Diabetes Distress” OR “Cognition” OR “Executive Function”)

AND (“Anxiety” OR “Fatigue” OR “Diabetes Distress” OR “Cognition” OR “Executive Function”) AND (“Correlation” OR “Association” OR “Structural Equation Model”)

2) **Associations between predictor/outcome variables and resilience:**
   “Resilience” AND (“Anxiety” OR “Fatigue” OR “Diabetes Distress” OR “Cognition” OR “Executive Function”) AND (“Structural Equation Modelling” OR “Mediation/ing” OR “Correlation” OR “Association).

## 2.4 Anxiety

Anxiety disorders are a group of affective disorders characterised by feelings of excessive fear and worry, that significantly impact the occupational and social functioning of an individual (American Psychological Association, 2013). Anxiety disorders are among the most prevalent affective disorders (Smith et al., 2018) affecting approximately 30% of adults (Bandelow & Michaelis, 2015), and individuals with diabetes have 17-20% higher lifetime prevalence of developing anxiety compared to age matched controls (Tareen & Tareen, 2017). Additionally, there are anxieties that are unique to diabetes, such as fear of complications and fear of hypoglycaemia; worries concerning potential long-term complications is generally rated as the most distressing part of both T1DM and T2DM (de Groot et al., 2016; Snoek et al., 2000). Research has found significant associations between anxiety disorders and reduced quality of life (Smith, et al. 2018), and increased diabetes complications (Collins et al., 2009; de Groot et al., 2016). Although anxiety disorders often co-occur with depression, anxiety is far less understood as a comorbidity of diabetes (Naicker et al., 2017). The prevalence of generalised anxiety disorder (GAD; excessive worry and tension about everyday events and problems for at least 6 months, where the individual experiences distress and/or has marked difficulty in daily tasks, APA, 2013) is approximately three times higher in individuals with diabetes than reported in the general population (Huang et al., 2014), and having T1DM or T2DM increases the risk of clinically significant anxiety by up to 48% (Amiri & Behnezhad, 2019). This is supported by Mersha et al. (2022), who found diabetes (pooled T1DM and T2DM) was associated with 41% higher risk of anxiety disorders (meta-analysis, *n*=2,128,029; see T1DM section below). Research suggests anxiety is significantly correlated with poorer diabetes self-management and less effective coping strategies, such as avoidance (Sultan et al., 2019). In some cases, fear of hypoglycaemic episodes (which can occur in both T1DM and T2DM), may elicit self-care behaviours to purposely raise blood glucose levels above recommended levels to prevent future hypoglycaemic episodes (e.g., missing insulin doses or excessive eating) (Shepard et al., 2014; Zeitoun et al., 2023).

### *2.4.1 Type 1*

Several cross-sectional and longitudinal studies, systematic reviews and meta-analyses support an association between anxiety and T1DM (Buchberger et al., 2016; Smith, Beland, Clyde et al., 2013; Shaban, Fosbury, Cavan et al., 2009). A recent systematic review and meta-analysis undertaken by Mersha et al. (2022) assessed 68 studies (cross sectional, longitudinal, case study) across every continent (*n*=2,128,029) to examine the bidirectional relationship (and risk) between diabetes and anxiety. The prevalence of anxiety disorders was 28% (95% CI (confidence interval; an interval estimate of an unknown population parameter): 26%, 31%), and the prevalence of diabetes among individuals with anxiety disorders were 12% (95% CI: 9%, 16%). Individuals with anxiety disorders were found to have a 19% higher risk of diabetes (ES (effect size; The quantitative measure of the magnitude of differences between variables, i.e., the strength of the relationship)= 1.19, 95% CI: 1.13, 1.26), and diabetic patients were found to have 41% higher risk of developing anxiety disorders (ES = 1.41, 95% CI: 1.19, 1.62). This study illustrates a bidirectional nature of anxiety and diabetes (i.e., anxiety is associated with diabetes onset and vice versa) and included studies from across the world. However, it is not without limitations; the variability in screening scales used and type of anxiety reported could have affected the clinical homogeneity of the review, and the study pooled T1DM and T2DM populations together. Despite this, previous studies that examined T1DM independently have found concordant results, although significant effect sizes tend to be small, especially relative to T2DM research (see section 2.3.2). Smaller effect sizes suggest a smaller difference between groups (i.e., less strength of effect/relationship, in this case anxiety and type 1 diabetes), although it is important to note small effect sizes can still be meaningful, particularly when applied to large populations (Carey et al., 2023). Effect sizes for between groups are as follows: 1) t-tests – small, 0.2; medium, 0.5; large, 0.8; 2) Odds Ratios (OR) – small, 1.5; medium, 2; large, 3; and

3) Relative Risk (RR) – small, 2; medium, 3; large, 4. Effect sizes for associations such as pearson's *r* correlation are as follows: small ± 0.2, medium/moderate ± 0.5, large ± 0.8 (Cohen, 1988; Sullivan & Fein, 2012).

Shaban et al. (2009) found anxiety predicted HbA1c levels (*n*=259), after controlling for demographic and medical covariates ($r = 0.14$; $p < 0.001$), and this was mediated through diabetes distress symptoms. A recent cross-sectional study (Zeitoun et al., 2023) further supported this; they examined anxiety, depression and fear of hypoglycaemia (n=325) and found high prevalence of anxiety (76.3%). Anxiety was independently correlated with HbA1c levels (OR: 1.45, 95% CI: 1.14-1.8, p = .003). However, female gender only significantly associated with depression, not anxiety ($p = 0.026$ and $p = 0.887$, respectively). This is interesting as the sample was only 45% female, whereas typically, diabetes research examining anxiety, depression and distress tends to be in female majority populations. A strength of this study was that blood samples were used to determine HbA1c levels, rather than self-report.

High prevalence rates of anxiety have been found particularly in younger adults, reporting higher emotional and behavioural problems such as anxiety (Buchberger, Huppertz, Krabbe et al., 2016). However, studies examining anxiety in T1DM tend to focus on child/adolescent populations (Amiri & Behnezhad, 2019; Smith et al., 2013), and therefore raises the need to study anxiety in older adult populations (Mersha et al., 2022). One method of assessing efficacy of diabetes management is through glycaemic control, and fewer than 25% of younger adults in the UK achieve the recommended long-term target for glycaemic control (HbA1c < 7.5, without frequent hypoglycaemia) (Martinez et al., 2016). Findings suggest anxiety scores can predict glycaemic control (Hillard et al., 2011; Shaban et al., 2009). This is also supported by Sultan et al. (2007); they examined the effects of anxiety and coping on glycaemic control (*n=115*) and found anxiety and coping directly predicted glycaemic and health outcomes across 5 years, with higher anxiety significantly associating with poorer coping styles (e.g. avoidance, distraction). This demonstrates the importance of understanding the effects of anxiety in order to improve health outcomes. Additionally, research suggests factors such as female gender are significantly associated with poorer physical (e.g., lower glycaemic control) and psychosocial functioning, more maladaptive coping strategies and higher incidences of anxiety than male controls (Catellano-Geurrero et al., 2018; Daneman et al., 2002; Enzin et al., 2002; Mersha et al., 2022; Undén et al., 2008). Also, longitudinal studies demonstrate higher risk of developing anxiety disorders in T1DM cohorts (*n*=1302) compared against sex and age control participants (*n*=6422), reporting 14.3% and 6.2%, respectively (Cooper et al., 2017). Diabetes durations over 26 years have increased risk of developing anxiety disorders by 2.5 times (Cooper er al., 2017). Alvarado et al. (2019) also found anxiety to be a significant predictor of diabetes self-care in T1DM, where higher anxiety reduced self-care efficacy (r = -0.19; p < 0.001).

### *2.4.2 Type 2*

Research findings also report a higher prevalence of clinical anxiety disorders and elevated anxiety symptoms in adults with T2DM, relative to the general population (Chaturvedi et al., 2019; Chaudhary, et al., 2017; Bulut & Bulut, 2016; Smith et al., 2013; Fisher et al., 2008). In a 15-nation study of anxiety disorders and type 2 diabetes (*n*=3170), Santosh et al. (2019) administered the MINI (Mini-international Neuropsychiatric Interview, widely validated and reliable scale used in a range of populations) and found a high prevalence of anxiety (18%), with the most common anxiety orders reported as GAD (8.5%) and panic disorder (5.1%). These were significantly associated with poorer glycaemic control, as a function of HbA1c levels, in comparison to diabetes patients without anxiety disorders (GAD: t=3.08, *p*=0.002; PD: t=1.98, *p*=0.04). A strength of this was the application of the same methodology across all countries, making comparisons more appropriate. Female gender, diabetes duration, diabetes complications and poorer glycaemic control were all significantly associated with anxiety disorders in T2DM. This suggests further understanding and addressing anxiety could have positive implications for improving diabetes health outcomes.

Similar findings were found in the meta-analysis conducted by Mersha et al. (2022) who found a 12% higher risk for developing anxiety in those with T2DM than T1DM, although research findings for anxiety risk are mixed (e.g., Bulut & Bulut, 2016; Chaudhary et al., 2017; Roy & Lloyd, 2012). One explanation for higher anxiety rates in T2DM is that diabetes-associated complications such as neuropathy, retinopathy and renal injury are more common in T2DM, which may cause further anxiety in these individuals (Teliti et al., 2018). In support, Perez-Pinar et al. (2016) conducted a cohort study in the UK (*n*=524,952; aged ≥30 years) and participants with anxiety disorders were found to have an increased risk of incident T2DM diagnosis (Hazard Ratio: 1.31; 1.25–1.37; p<.001), after controlling for age, gender, ethnicity and medications. These findings support the bi-directional association with diabetes. Longitudinal studies also support these findings (Naiker et al., 2017; *n*=64,177), where anxiety was associated with increased mortality in those with T2DM, independently of depression.

Additionally, anxiety in T2DM has been associated with female gender, low socioeconomic status, and younger age (Chaturvedi, et al., 2019; Remes et al., 2016; Santosh et al., 2019). In studies that used diagnostic interviews to assess anxiety in T2DM patients, anxiety was significantly associated with hyperglycaemia and poor glycaemic control (Anderson, Grigsby, Freedland & de Groot, 2002). A recent study (Itturalde et al., 2019; n=143,573) found that anxiety is highly comorbid in those with T2DM, and independently associated with high-cost resource healthcare use (e.g., emergency visits, higher cost) compared to T2DM patients without anxiety symptoms (see also Pouwer & Nefs, 2019). Lastly, anxiety has been significantly positively associated with perceived severity of diabetes, and negatively with self-efficacy (p<.001 for both; Indelicato et al., 2017).

## 2.5 Fatigue

Fatigue is another prevalent complaint among individuals with diabetes (Fritschi & Quinn, 2010; Jensen et al., 2017). It is important to note that within diabetes literature, the definitions of fatigue are often inconsistent or not defined, complicated by the subjective perception of fatigue (Griggs & Morris, 2018; Hidayat et al., 2020; Jensen et al., 2017). Terms such as fatigue, sleepiness, tiredness, lacking energy, and exhaustion are sometimes used interchangeably, which makes defining causes, indicators and effects more challenging (Fritschi & Quinn, 2010; Philips, 2015). Fatigue is largely defined as subjective symptom, e.g., "*an overwhelming sense of tiredness, lack of energy and a feeling of exhaustion, associated with impaired physical and/or cognitive functioning"* (Shen et al., 2006). Fatigue has also been defined as an objective performance decrement, e.g., "*a diminished capacity for work and decrements in attention, perception, decision making, and skill performance*"

(Cercarelli & Ryan et al., 1996). Fatigue is also acknowledged as a multifaceted variable, encompassing physiological, psychological, and environmental components; for example, an overwhelming and sustained feeling of exhaustion, that decreases one's ability to initiate and/or sustain attentional (mental fatigue) and physical activities (physical fatigue), including working effectively and functioning at a typical level in family or social roles (Dantzer et al. 2014; Lavidor et al. 2002).

However, physical and mental fatigue are interrelated but distinct variables; for example, they have different underlying causes, but mental fatigue has been found to significantly impair physical performance (balance, strength; Pires et al., 2018). Physical fatigue is a form of tiredness resulting from repeated muscle movements (Mizuno et al., 2011; Kunasegaran et al., 2023), whereas mental fatigue is defined as a psychobiological state of tiredness, resulting from prolonged periods of performing demanding, cognitive-load-inducing tasks, reducing efficiency in cognitive performance (Craik, 2014; Kunasegaran et al., 2023). This thesis will operationalise fatigue as mental fatigue using the above definition. Mental fatigue can arise from high mental load and capacity overload (Kunasegaran et al., 2023). Mental load is the amount of information involved in processing a task (Forster & Lavie, 2016), and high mental load can occur from tasks requiring executive functioning skills (i.e., sustained attention, shifting attention, working memory, inhibition; see section 2.7). As these skills are vital in planning, decision-making, working memory and organisation, this is an important factor to consider in regard to diabetes management. Processing capacity is defined as the amount of information one can process at a given time (Hancock et al., 2021), and once capacity is reached, processing new information becomes difficult (i.e., mental overload). Experiencing periods of mental overload can lead to mental fatigue and reduced executive functioning; and this is supported by neuroimaging studies (e.g., Electroencephalography; see Tran et al., 2020 and Qi et al., 2019).

Fatigue is correlated with a range of environmental factors, one of the most notable predictors being demanding occupations, including working long hours and job strain (Jalilian et al., 2019; Weber et al., 2020). This can in turn lead to increased physical disorders, anxiety disorders and chronic tiredness (e.g., Nagashima et al., 2007; Petrut et al., 2020). This increased fatigue can be explained through individuals being exposed to many/lengthy tasks requiring executive functions, increasing mental load (Diamond et al., 2013). Additionally, another correlate of general fatigue (i.e., physical and mental) is childcare responsibility (Giallo et al., 2012; Loutzenhiser et al., 2015). Caregiving requires planning, adapting to complex demands and emotional regulation, all of which require executive functioning. Especially so if the child is has type 1 diabetes as this requires additional care planning and health concerns (e.g., Saßmann et al., 2022). Another factor of mental and physical fatigue is lower income, through having to work more due to low financial resources (Bick et al., 2018), or from the mental load of managing the challenges associated with poverty (e.g., threat of losing job with little resources) (Rocha et al., 2007; Smartt et al., 2016). Other factors such as increased stress levels and poorer health status (e.g., Park et al., 2012), and increased anxiety (see section 2.9) are associated with increased mental and physical fatigue.

Fatigue is a bi-directional comorbid factor of diabetes (Beehan-Quirk et al., 2020), and is associated with diabetes distress, cognition, and anxiety (Robinson et al., 2018; Park et al., 2015; Goendorp et al., 2014). Fatigue can increase the burden of diabetes self-care behaviours, and engagement with these (Griggs & Morris, 2018). For example, fatigue may result in reduced ability to test blood glucose, prepare optimal foods, and engage in regular physical exercise, which have been found to negatively affect health and quality of life (Fritschi & Quinn, 2010; Nefs et al., 2015; Darwish et al., 2018). Glycaemic control is fundamental to diabetes management and optimal health outcomes, and so fatigue is an important factor to consider when examining factors in diabetes self-management. The following studies refer to general fatigue as opposed to diabetes-related fatigue due to measures used (e.g., Multidimensional Fatigue Inventory, which measures general fatigue, and specific components including mental and physical fatigue; see Chapter 5 for more information).

### *2.5.1 Type 1*

Systematic reviews (Griggs & Morris, 2018; Jensen et al., 2017) have found fatigue rates varying between 23-42% of adults with T1DM (*n*=10 studies), and fatigue was determined as one of the most troublesome symptoms with regards to self-management in T1DM (*n*=13 studies). Romadlon et al.

(2022) conducted one of the only meta-analyses examining fatigue prevalence rates and associated factors in T1DM (19 studies; *n*=7,131) and T2DM (32 studies; *n*=34,994) separately; this is a strength of the research as diabetes research often pools both types together. Overall prevalence rates for T1DM were 44% (95%, CI: .32 .56), with highest prevalence rates reported in France, the UK and Canada (73.9%, 72% and 62%, respectively). Data showed significant associations between fatigue and: anxiety, self-efficacy, diabetes duration and number of complications (Romadlon et al., 2022). It is important to note the variety of measurement tools and definitions of fatigue in patients with T1DM may limit internal validity of the findings; for example, only four and five studies of T1 and T2DM, respectively, employed validated questionnaires to measure fatigue, whereas other studies used a single item. However, this study used a large sample size across varying countries, increasing generalisability of findings.

Additionally, Goedendorp et al. (2014) found significantly higher chronic fatigue in 214 T1DM outpatients (40%; 95% CI: 34–47%) compared to matched controls (7%; 95% CI: 3–10%). This is supported by Segerstedt et al. (2015), in a comparison between 268 T1DM patients and 1,557 control patients. Longitudinal studies (e.g., Menting et al., 2017) reported patients (*n*=194, across 43 months) with persistent fatigue had significantly more diabetes complications, and fatigue and sleeping difficulties were significantly associated with poorer glycaemic control (higher HbA1c level). Fatigue is also correlated with poor sleep quality and reduced sleep duration (Griggs & Morris, 2018), with 31-35% of adults with T1DM reporting subjective sleep impairment (Bernard et al., 2016; Nefs et al., 2015; van Dijk, Donga & van Dijk, 2011). Research suggests hypoglycaemia and fear of hypoglycaemia were common causes for sleep disruption, and are major barriers in achieving glycaemic stability and good quality of life (Bernard et al., 2016; Goedendorp, et al., 2014).

Fatigue in T1DM literature has been consistently related to four main themes: diabetes-related physiological factors, psychological symptoms, situational factors and sociodemographic factors (Griggs & Morris, 2018). This includes: diabetes distress and anxiety (Nefs, et al., 2015; Hill et al., 2013; Romadlon et al. 2022); female gender (Segerstedt et al., 2015), younger age (Goedendorp et al., 2014), and poorer academic performance (Hill, Gingras & Gucciardi, 2013). A limitation of the literature is studies examining fatigue are typically limited to smaller sample sizes and cross-sectional designs (Griggs & Morris, 2018; Romadlon et al., 2022).

### *2.5.2 Type 2*

In comparison to T1DM, T2DM fatigue prevalence rates vary more but with higher rates reported (Lasselin et al., 2012), with estimates ranging from 24.6% (Sudore et al., 2012) to 61.% (Drivsholm et al., 2005). This could be explained by the varying measures used to assess fatigue (Ba et al, 2020). Empirical data from a meta-analysis (Ba et al., 2020) found similar fatigue levels based on the Diabetes Symptom Checklist (DSC) and DSC-R: 1.77 (95% CI = 1.70–1.84, $p < 0.001$) and 1.73 (95% CI = 1.57–1.90, $p < 0.001$), respectively. These levels are higher than those recorded in healthy adults (0.54, Adriaanse et al., 2005), suggesting individuals with T2DM experience fatigue at a much higher level than a healthy population. Although a wide range of instruments can be used to measure diabetes-related fatigue, there is a lack of standardisation in existing research; therefore, a strength of this review (Ba et al., 2020) is controlling the instrument used, allowing for more effective comparison across studies. These findings are supported by a recent meta-analysis (Romadlon et al., 2022; see previous section for methodology), where overall prevalence rates were 50% in T2DM (95%, CI: 0.44–0.56) (see also Hidayat et al., 2020 for a systematic review).

Research also suggests fatigue in T2DM is significantly correlated with comorbidities, such as mood states (e.g., anxiety, diabetes distress; Park et al., 2015), and higher levels of fatigue have been reported in females compared to males (Kirk et al., 2015). Fatigue was also found to be related to (r = -0.39, $p < 0.001$), and a predictor of, diabetes self-care behaviours (r = -0.29, $p = 0.039$), after controlling for age, diabetes duration and sleep (Zhu et al., 2018; supported by Castonguay & Miquelon, 2018, Kirk et al., 2015). Research also supports an association between fatigue and HbA1c levels (e.g., $r = .14$, $p < 0.05$; Van der Does et al., 1995), however findings are mixed. For example, Park et al. (2015) found a significant indirect association of fatigue and HbA1c levels, mediated by diabetes distress and depression, but only in poorly controlled T2DM patients (HbA1c > 7%). longitudinal cohort study (Chao et al., 2018) examined fatigue in T2DM across 3.14 years ($n$=560,795), and found fatigue was independently associated with higher mortality in patients, after controlling for comorbidities and lifestyle factors: HR 1.3 (95% CI: 1.27-1.34). However, there is still a paucity of longitudinal studies in the T2DM fatigue literature (Chao et al., 2018; Romadlon et al., 2022). It is important to acknowledge physiological and psychological factors associated with fatigue may differ between T1DM and T2DM patients, although it is a prevalent and distressing problem for both that can impact on diabetes self-care (Griggs & Morris, 2018). It is thought that the association between fatigue and psychological health is bidirectional (Visser & Smets, 1998; Griggs & Morris, 2018).

## 2.6 Diabetes Distress

Diabetes Distress (DD) is defined as a significant and negative emotional state to coping with the demands of managing diabetes (American Diabetes Association, 2019; Berry at al., 2015). This psychological distress is specific to diabetes and encompasses a broad range of emotions, such as worry, frustration, discouragement and experiencing emotional 'burnout' (Aljuaid et al. 2018; Perrin, et al., 2017), and comprises four distinct domains: 1) EB; Emotional Burden (defined as feeling overwhelmed by the demands of living with diabetes); 2) PRD; Physician-Related Distress (distress relating to diabetes healthcare providers, e.g., feeling the healthcare provider does not take the patients' diabetes concerns seriously enough); 3) RRD; Regimen-Related Distress (distress relating to regimen difficulties, such as adhering to meal/exercise/medicine plans); and 4) ID; interpersonal distress (distress from interpersonal relationships, e.g., feeling friends and family do not appreciate the difficulties of living with diabetes) (Polonsky et al., 2005). DD is a prevalent emotional state in both T1DM and T2DM (Fisher et al., 2010), and is directly and significantly associated with poorer glycaemic control and increased mortality (Asuzu et al., 2017; Dieter & Laurer, 2017). Research suggests DD indirectly reduces glycaemic control (Fisher et al., 2008) through reduced self-efficacy and self-management behaviours, such as poorer medication adherence and blood glucose monitoring (Rariden, 2019; Lin et al., 2017; Indelicato et al., 2017; Perrin et al., 2017; Berry et al., 2015). DD also has a direct association with glycaemic control; DD can also increase cortisol production, which has been shown to supress insulin production (Chen et al., 2019), which can subsequently raise HbA1c levels (Wibowo et al., 2022). Other research (e.g., Lee et al., 2018) has identified factors that correlate with DD, such as depression (positively) and resilience (negatively), which can affect diabetes outcomes such as glycaemic control and quality of life. Poor glycaemic control carries greater subsequent risk of health complications, poorer quality of life and mortality (Lloyd et al., 2018). Therefore, it is important to consider the implications of DD in research, treatments and interventions to ensure effective diabetes outcomes in patients.

It is important to acknowledge there is an overlap of major depressive disorder (MDD) and DD symptoms, especially as both are significantly associated with and prevalent in both types of diabetes (Berry et al., 2015; Dieter & Laurer, 2017). For example: depressed mood; feeling emotionally overwhelmed/burnt-out/irritated; decreased efficiency/ability of routine (e.g., self-care) tasks; interpersonal/social related distress; fatigue; and low energy (DSM-5, American Psychiatric Association, 2013; Polonksy et al., 2005; Robinson et al., 2023). As a result of these overlapping symptoms, MDD may be over-diagnosed (and DD under-diagnosed) in people with diabetes (Berry et al., 2015; Esbitt et al., 2013). This could also explain inconsistences within diabetes literature, since research generally uses symptom-based factors to diagnose MDD, which does not account for the context of diabetes. Despite the overlap of depressive symptoms, DD is conceptually distinct from and does not meet the qualifications for MDD (Krieder, 2017). DD is a significant emotional reaction to diagnosis, threat of complications, unsupportive social/healthcare structures surrounding diabetes and is conceptually rooted in the demands of diabetes management (Berry et al., 2015; Krieder, 2017). This is another justification for the PhD focus on DD and not depression, in addition to being relatively understudied and less known than MDD in diabetes (Roy & Lloyd, 2012). Additionally, some research (also discussed below) showed significant direct associations between DD and glycaemic control, but not MDD (see Asuzu et al., 2017; Fisher et al., 2010), suggesting differences in behavioural outcomes. DD is measured using the Diabetes Distress Scale (DDS), or the Problem Areas in Diabetes (PAID) scale, both of which are widely validated in T1DM and T2DM populations (see Robinson et al., 2023 for a review; see also chapter 5).

### 2.6.1 Type 1

Cross sectional data and meta-analyses suggest a significant association between ‘clinically relevant’ or elevated diabetes distress and T1DM (Dennick et al., 2016; Hagger et al., 2016; Sturt et al., 2015). For example, Dennick at el., (2016) conducted a systematic review of DD research in T1DM (58 studies across 14 countries, $n$=17,667) and found an average proportion of elevated DD at 0.22 (95% CI: 0.19-0.26, $p<.001$), with significant heterogeneity; this suggests the findings reflect real differences between studies as opposed to sampling errors (see also Hagger et al., 2016). Generally, existing studies report prevalence of elevated DD in T1DM between 17% and 31% (Hermans et al., 2006, 2009; Joensen et al., 2013; Kibbey et al., 2013; Nicolucci et al., 2013; Schmitt et al., 2014; Shiels et al., 2012; Speight et al., 2017). These prevalence rates are supported by recent research, (Jabeen et al., 2022), where the DDS was administered to 117 T1DM patients: 34.2% participants reported diabetes distress, of which 31.6% was moderate and 2.6% was severe, and DD correlated significantly with HbA1c levels ($r$=.570, n= 117, p = <.001).

Associations between DD and HbA1c/self-care has been supported in cross sectional studies. Law et al. (2013) assessed 203 T1DM adolescents and found significant positive moderate correlations between DD and HbA1c ($r = .30$), and negative beliefs about the consequences of diabetes ($r = .33$), but negatively associated with self-efficacy ($r = -.39$). These factors also explained 24% of the variance in DD scores (HbA1c: $\beta = .23$. $p < .001$; beliefs about diabetes consequences: $\beta = .19$, $p < .01$; and adolescent self-efficacy: $\beta = -.30$, $p < .001$). These findings were also confirmed in a systematic review by Hagger et al. (2016), who found small to moderate positive correlations between HbA1c and DD in 8 of 12 studies examined ($r = 0.13 - 0.30$, $p < 0.05$). A limitation of this research is DD was examined in adolescents only, which is likely to fluctuate over time in response to normative developmental processes and diabetes-specific stressors surrounding these. However, these findings have also been found in adults; Strandberg et al. (2014) conducted regression analyses in T1DM patients (n=319) and found diabetes-specific emotional distress was significantly related to glycaemic control in both DDS and PAID scales, respectively (0.038, P<.001; 0.021, p<0.007). More specifically, Regimen-Related Distress (RRD) was independently related to HbA1c in T1DM (0.056, P<.001). Qualitative research supports the association between DD and glycaemic control: an interview study found individuals with elevated DD were unable to convert strongly desired self-care intentions into actions, which can lead to poorer health outcomes (Sturt et al., 2015a).

These associations have been supported in longitudinal studies, where emotional burden and regimen distress components significantly associated with HbA1c levels ($r$=0.40, p < .001; 0.47, p < .001, respectively) (Strandberg et al., 2015). A more recent study (Deniz-Garcia et al., 2022) also confirmed a significant independent association between diabetes distress and HbA1c. Additionally, intervention-related changes in DD are associated with significant changes in HbA1c, suggesting an effect of DD on diabetes self-management behaviours (Robertson et al., 2017; Schmidt et al., 2018; Sturt et al., 2015). For example, Scmidt et al. (2018) conducted a systematic analysis of DD intervention studies ($n$= 9 RCTs) and found a pooled moderate effect size of diabetes-distress of 0.48 (Cohen's d), Z=3.91, $p$< .001, and a significant effect of diabetes-specific distress interventions on HbA1c levels. These findings are also supported in the T2DM literature (Zagarins et al., 2012).

The most commonly reported emotional stressors in T1DM relate to fear of hypoglycaemia and complications, worry about future and complications, and blood sugar reactions (Martyn-Nemeth, et al., 2014; Niccoluci et al., 2016; Reddy et al., 2013). Other risk factors for DD in T1DM positively correlated with longer diabetes duration (Sturt et al., 2015; Joensen et al., 2013), female gender (Jabeen et al., 2022; Luo et al., 2021), and episodes of hypoglycaemia (Lermon-Garber et al., 2003). The majority of T1DM research is in young adults, and in Scandinavian countries, namely Norway and Denmark, and so relatively little is known from UK studies in middle-aged to older-aged adults (Sturt et al., 2015).

### *2.6.2 Type 2*

Literature within T2DM research reports concordant findings to that of T1DM; but with slightly higher prevalence sizes, and contextual differences between sources of diabetes distress (e.g., fear of hypoglycaemia/frustration with unexplainable BG changes) is reported more in T1DM, whereas more regimen-related distress is reported in T2DM (Fischer et al., 2015; Perrin et al., 2017; Schmidt et al., 2018; Wardian et al., 2018). In comparison to T1DM, the most common stressors reported in type II diabetes relates more to goal setting, regimen adherence and food restrictions (Niccoluci et al., 2016; Reddy et al., 2013). Cross sectional data and meta-analyses suggest a significant association between 'clinically relevant' or elevated diabetes distress and T2DM. For example, the first meta-analysis (Perrin et al., 2017) to examine diabetes distress in people with T2DM (55 studies across 17 countries, *n*=36,998), revealed a prevalence rate of 36% (fixed-pooled ES 0.356, 95% CI: 0.351, 0.361) for significant diabetes-specific distress, with significantly higher prevalence rates within female-majority groups and individuals with depressive symptoms. Diabetes distress has also been significantly correlated with glycaemic control and poorer self-management (Aljuaid et al., 2018; Lee et al., 2018; Martinez et al., 2018). Generally, studies report prevalence of elevated DD in T1DM or pooled T1DM and T2DM between 18-40% (Snoek et al., 2015; van Duinkerken et al., 2020): 21% in UK primary care (Sturt et al., 2015); 4% and 19% of primary and secondary care patients Netherlands, respectively (Stoop et al., 2014); 28% in Australia (Speight et al., 2017); 44% in South Africa (Ramkisson et al., 2016); 42% in China (Zhou et al., 2017). These levels are comparatively higher and wider ranging than those of T1DM.

A recent systematic review (Wibowo et al., 2022) examined 17 studies (*n*=11,976) and found DD had a significant low to moderate positive correlation with HbA1c, and in line with T1DM findings, emotional burden and regimen-related DD domains were significantly higher than physician-related and interpersonal distress (supported by German et al., 2023; Sturt et al., 2015; Wardian et al., 2018). Also, cross-sectional studies typically demonstrate strong to moderate correlations between DD and poor diabetes management; for example, Wardian et al. (2018) compared domains of the DDS (Diabetes Distress Scale) between T1DM (*n*=149), T2DM (*n*=103) and T2DM-i (insulin treated; *n*=333) as part of a diabetes clinical visit. After controlling for covariates (age, sex, diabetes duration, BMI (A measure of body fat, calculated by dividing an individual's weight (KG) by their height in metres squared) and HbA1c), the average proportion of elevated DD was 0.22 (95% CIs 0.19 to 0.26, $p<.001$), and each DD domain was associated with significantly higher HbA1c levels (EB: $\beta = 0.171$; RRD: $\beta = 0.184$; PRD: $\beta = 0.056$; ID: $\beta = 0.084$). Interestingly, the T2DM samples were significantly higher for the emotional burden and regimen related distress domains than the T1DM sample, and significantly explained 11.9% and 15.6% of total DD variance across samples. This has implications for education and interventions between T1DM and T2DM. A strength of this study was the inclusion of T2DM-insulin treated patients, as majority of studies do not distinguish between T2DM treatments.

Longitudinal studies also support an association between DD and diabetes self-management, as a function of HbA1c. Fisher at al. (2010) investigated the effects of DD, MDD and depressive symptoms on glycaemic control in both cross-sectional and longitudinal analyses. (n=506). MDD, DD, depressive symptoms, self-management behaviours and HbA1c were assessed at baseline time, and 9 and 12 months later. Findings revealed DD, MDD and depressive symptoms were moderately correlated, but only DD was significantly associated with HbA1c levels cross-sectionally and over time. In another longitudinal study, Asuzu et al. (2017) examined the pathways by which DD, depression and fatalism can affect diabetes outcomes, as a function of glycaemic control. Structural equation modelling was used to analyse data (n=615), and the final model showed higher DD scores were directly and significantly correlated to decreased self-care behaviours and increased HbA1c levels (indicative of poorer glycaemic control; ES: 0.69, moderate; $p<0.001$) (See also, Strandberg et al., 2015). SEM produces direct and indirect effect sizes, which informs whether a construct has a substantive impact on another one, directly or indirectly (depending on the model). Values of 0.2, 0.5 and 0.8 can be interpreted as small, medium or large effects, respectively (Verdam et al., 2017), with larger effects suggesting a stronger effect of a predictor variable on the outcome variable.

Studies also identified demographic variables such as female gender, younger age, and comorbid psychological disorders such as anxiety and depression, being significantly associated with higher levels of DD in T2DM (Fisher et al., 2009; Karlsen et al., 2012; Kuniss et al., 2017; Perrin et al., 2017; Wibowo et al., 2022). The association with female gender could be explained by social conventions regarding gender, where men are less likely to seek help or admit distress (Doyal, 2000). The vast majority of studies have significantly higher rates of females than males in their samples, although one study that was the opposite (79% male), were consistent with literature findings; for example, higher HbA1c (ES: 0.15; 95%; CI: 0.06, 0.23) were significantly associated with higher regimen-related distress (German et al., 2023). Diabetes distress is also positively correlated associated with a longer duration of diabetes diagnosis, reduced treatment adherence and diabetes complications (Mathiesen et al., 2019; Wardian et al., 2018).

## 2.7 Executive Function (Cognition)

Executive cognitive functions are defined as higher order, self-regulatory cognitive processes, such as working memory, attention and inhibitory processes; these functions allow the coordination of thought and action to achieve a specific goal, which are essential for effective diabetes management (Carlson et al., 2016; Miller & Wallis, 2009). Individuals living with diabetes (T1DM or T2DM) are at risk for significant decline in cognitive function, in addition to vascular dementia and Alzheimer's (Dao et al., 2023). The risk of cognitive decline and dementia increases in the general population with ageing, however the nature of diabetes means microvascular changes/complications are more likely to develop, which can in turn adversely impact brain function and structure (van Duinkerken & Ryan, 2020). Due to this, it is important to consider the cognitive effects of diabetes and how that may impact self-management and health outcomes.

Cognitive and neuroimaging research shows an association between accelerated cognitive decline, structural brain abnormalities (e.g., neuronal damage via hyperglycaemia), changes in brain activity or atrophy lesions, in both T1DM (Shalimova et al., 2019; Goendorp et al., 2014) and T2DM (Bissels & Despa, 2019; Brownless, 2005; Geiiselares et al., 2015; Van Bussel et al., 2017). Associations have also been found between T1DM and T2DM diabetes and an increased risk of neurodegenerative dementias, especially Alzheimer's disease (Arnold et al., 2018; Biessels et al., 2008; Dao et al., 2023; Gonzalez-Reyes, et al., 2016; Lacy et al., 2018).

### *2.7.1 Type 1*

A fundamental part of diabetes-associated cognitive dysfunction appears to be slowed information processing, and executive functions. Cognitive decrements have been found in individuals with T1DM across the lifespan, at clinically relevant levels (van Duinkerken & Ryan, 2020; see also van

Duinkirken et al., 2020). Compared to nondiabetic controls, T1DM is associated with reduced psychomotor control (Ryan et al., 2003), cognitive flexibility (Smolina et al., 2015), visual processing speed, constant attention and hand-eye coordination (Moheet et al., 2015). Neuroimaging studies have also found cognitive impairments including psychomotor speed and learning, in T1DM (Shalimova et al., 2019; Dahlquist & Kallen, 2007). For example, results from several meta-analyses (Biessels et al., 2008; Gaudieri et al., 2008; Tonoli et al., 2014) totalling over 15 cross sectional studies show in those diagnosed within the first 4-6 years of life, small to medium effect sizes (Cohen's d) in almost all cognitive domains when compared to healthy peers: learning and memory (d= -.50); executive functioning including attention (d= -.40); psychomotor speed (d= -.37) and verbal intelligence (d= -.35). Those diagnosed after the age of 6 years show much smaller differences (d < 0.2) on a smaller range of domains; verbal intelligence and psychomotor speed are consistently affected, executive functioning is sometimes affected and learning and memory are typically intact. Conversely, T1DM adults exhibit larger effect sizes, particularly within the domains of: verbal intelligence (d= -.80); psychomotor speed (d = -.60); attention (d = -.35); and executive functioning (d= -.50). Learning and memory were typically unaffected (Brands et al., 2005). Interestingly, higher rates of micro- and macrovascular complications contributed to these larger effect sizes, but episodes of hypoglycaemia did not. This was also supported by Mauras et al. (2015).

Currently, only a few studies have systematically examined cognition longitudinally in T1DM adults over the age of 50 (van Duinkerken & Ryan, 2020). This could be explained by the fact life expectancy for this population was historically lower than that of T2DM or the general population; as such, researchers may have ignored this age group. However, significant improvements in diabetes care have increased longevity for T1DM considerably. One of the first longitudinal studies in adults > 50 (Brands et al., 2006) examined 40 patients and 40 control participants across 4 years. Results showed T1DM scored slightly worse across cognitive function domains, but only processing speed was statistically lower than matched controls (d= -.34). After a 4 year follow up (with 36/40 patients and 29/40 of controls attending), no evidence of accelerated cognitive decline was found in T1DM, unless the patient had experienced a cardiovascular event, which was associated with a steeper decline in cognition and processing speed. This is supported by more recent research by Ryan et al., 2016a; Weinstock et al., 2016; van Duinkerken et al., 2011). Chaytor et al. (2019) also found clinically significant cognitive impairment in 48% of older adults (n=201; ≥ 60 years), and after controlling for age, gender, education and diabetes duration, increased odds of clinically significant cognitive impairment (OR: 1.01-2.61) was associated with: hypoglycaemia unawareness, microvascular complications, and higher HbA1c. These studies demonstrate associations within the cognitive effects of diabetes, however more longitudinal research is needed to determine if the aforementioned variables predict cognitive decline.

There are only a few studies that examine the association of diabetes and dementia in T1DM (van Duinkerken et al., 2020). Smolina et al. (2015) found the relative risk for (n=10,786; England) T1DM patients was 1.65 (95% CI: 1.61 – 1.68), suggesting an increased risk of any type of dementia in T1DM populations. However, this elevated risk appears to be driven by the risk of vascular-associated dementia (OR: 2.21; 95% CI: 2.13–2.28), and the risk of Alzheimer's was less elevated (OR:1.10; 95% CI: 1.05–1.15). Lastly, the severity of cognitive deficits is affected by factors such as diabetes onset age and diabetes duration, with younger age onset and longer durations being correlated with increased cognitive deficits (Brands et al, 2005; Shalimova et al., 2019). Although there is an association between cognitive impairments and glycaemic variability in T1DM, there is a lack of research in middle-older aged adults. As such, treatment guidelines for this age group are based on T2DM diabetes research (Bispham et al., 2020); this provides further justification for assessing cognition within T1DM middle-older aged adults in the thesis studies.

### *2.7.2 Type 2*

Similar findings have been found in T2DM populations; diabetes has been significantly associated with cognitive deficits typically involving learning, memory and information processing speed (Cheng et al., 2012) and executive functioning (Huang et al., 2016; Bottiroli et al. 2014; Nazaribadie et al., 2014; Primozic et al., 2012; Manschot et al., 2007). Research suggests cognitive functions deteriorate with age, with T2DM producing faster cognitive decline compared to age and education matched controls (Messier, 2005; van Duinkerken & Ryan, 2020), and deficits in executive function are positively correlated with longer diabetes durations (Gao et al., 2015; Vincent & Hall, 2015).

In contrast to T1DM, there is a much larger literature base, that strongly suggests clinically significant levels of cognitive impairment (Reijmet er al., 2010). A relatively recent review (Palta et al., 2014; n=3351) across 24 studies identified moderate effect sizes for cognitive impairments across almost all domains (d= -.30), except for attention (d= -.20), and largest effect sizes/impairments were found in psychomotor speed (d= -.60) and planning (d= -.40). Also, a large literature base supports an association between dementia and T2DM, but as with T1DM, longitudinal studies on this topic are more scarce. A recent longitudinal study (Xie et al., 2022) assessed 732 T2DM patients and found significantly lower performance in cognitive tasks across a 5 and 8 year follow up; particularly on verbal short-term and long-term memory tasks. Memory-related domains were found to be sensitive to T2DM. These findings are concordant with previous research (see van Duinkerken & Ryan, 2022), and could be explained as the hippocampus (involved in memory cognitive processes) contains a high level of insulin receptors, and abnormal (reduced) activity in this area is significantly associated with cognitive decline and Alzheimer’s disease (Soto et al., 2019).

Other findings suggest reduced connectivity of the Default Mode Network (i.e., network of active brain regions at rest) found in those with diabetes was associated with impaired memory, executive functioning, verbal fluency and lower global cognition (Zhou et al., 2015; Zhou et al., 2010). Additionally, MRI studies consistently demonstrate altered neuronal activity/connectivity in patients with T2DM with cognitive deficits (van Bussel et al., 2017). Hyperglycaemia as a result of T2DM has been found to negatively affect brain structures such as the hippocampus and regions in the frontal lobes, which are necessary for memory, learning and executive functioning (Bottiroli et al., 2014). Brain imaging studies have found significant reductions in hippocampal volumes in people within the first 10 years of diagnosis, compared to controls (Bottiroli et al., 2014; Shalimova et al., 2019). It is important to note studying this population can present difficulty as people with T2DM tend to be diagnosed later in life, and comorbid disorders are frequently reported in this population (Feinkohl et al., 2015), making it harder to ascertain the source of any cognitive decline.

## 2.8 Associations between Psychological States (Anxiety, Fatigue) and Diabetes Outcomes (Diabetes Distress, Cognition)

The following sections will discuss research examining interactions between the aforementioned variables, where this thesis operationalises anxiety and fatigue as psychological states, and diabetes distress and cognition as diabetes outcomes. It is important to note within the literature these interactions are sparsely examined or do not exist (to the best of the author's knowledge; supported by van Duinkerken et al., 2020). These variables are typically treated as secondary outcome measures in diabetes research, or a confounder variable of the other; for example, the emotional effects of diabetes (e.g., anxiety) are often treated as a confounder rather than a factor of interest (van Duinkerken et al., 2020). Additionally, studies tend to group T1DM and T2DM together as a single group. Therefore, ascertaining the interactions between these variables can be difficult. Interactions between 'fatigue and DD,' and 'cognition and anxiety' are particularly sparse, so I have tried to examine these interactions in non-diabetic populations in the absence of diabetes data.

## 2.9 Associations between Anxiety and Fatigue in Diabetes

Fatigue and anxiety/worry are common co-morbid problems reported in individuals living with diabetes (Singh & Kluding, 2013; Frtischi & Quinn, 2010), and research suggests the relationship between these two variables is bi-directional. Fatigue can cause problems with mobility, self-care activities, work/social roles, and therefore presents an increased risk for psychological disorders, such as anxiety and depression (Newland & Betterncourt, 2020). Conversely, anxiety itself can lead to mental exhaustion, contributing to fatigue, which is listed as a symptom of generalised anxiety disorder in the DSM-5 (American Psychological Association, 2013). Key findings will be discussed in relation to diabetes type.

### *2.9.1 Type 1*

Several systematic reviews and meta-analyses discuss evidence for significant associations between anxiety and fatigue in T1DM (Griggs & Morris, 2018; Kalra et al., 2018; Romadlon et al., 2022). Cross-sectional studies also support this, for example, Jensen et al. (2018) examined fatigue and fatigue predictors (one of them anxiety) in 322 T1DM patients; multivariate regression analysis found an OR of 2.76 (95% CCI: 1.42-5.35, *p* = .003), suggesting a significant association between fatigue and anxiety. A high level of anxiety was also associated with a high total fatigue score and increased prevalence of chronic fatigue, suggesting a bi-directional association between anxiety and fatigue. Also, Nefs et al. (2015) conducted a cross-sectional study in T1DM patients (*n*=267) and found participants who reported poor sleep quality and fatigue (PSQI > 5; 31%) were significantly more likely to experience elevated anxiety symptoms (d = 1.01, p < .001). Interestingly, these rates were stronger than the T2DM group. Additionally, Alkbekairy et al. (2018) found a correlation in diabetes patients between increased anxiety risk and lower physical activity, and longer stays during hospitalisation. This could be explained through fatigue, which is indirectly associated with a lack of physical activity (Matura, Malone, Jaime-Lara & Riegel, 2018; Fritschi & Quinn, 2010). Additionally, Rechenberg et al. (2020) found improved sleep characteristics (e.g., rest-activity rhythm) were significantly correlated with lower trait anxiety symptoms (*r* = –.47, *p* < .05), and a more robust sleep rhythm was significantly associated with better diabetes self-management (*r* = .40, *p* < .05). This research area is lacking in longitudinal studies, and studies tend to research anxiety in the context of fatigue as a confounding variable, rather than primary outcome.

### *2.9.2 Type 2*

Similar findings exist for T2DM as seen in T1DM populations (see Romadlon et al., 2022 for a recent review). Nefs et al. (2015; see T1DM section above) also examined fatigue and anxiety in 361 T2DM patients, found participants who reported poor sleep quality and fatigue (PSQI > 5; 42%) were significantly more likely to experience elevated anxiety symptoms (d = .69, p< .001). Interestingly, adults with T2DM had higher average fatigue (PSQI) global scores than those with T1DM (Cohen's *d* = 0.21), and were somewhat more likely to report poor sleep disturbances, short sleep duration, and suboptimal sleep efficiency (Cohen's *d* = 0.17, 0.21 and 0.26, respectively). Additionally, these findings have been supported in a recent aromatherapy treatment study (Abdollati & Mobadery, 2020), where primary outcomes assessed the effect on fatigue and anxiety symptoms in 60 T2DM patients. Anxiety and fatigue scores decreased significantly after the treatment, and no differences were found in the control group. This suggests that there is an interaction between anxiety and fatigue in diabetes. However, the treatment was over the course of three days, and so it would be beneficial to examine this over a longer period. As with T1DM, interactions between fatigue and anxiety are understudied in T2DM patients, and would benefit from more longitudinal studies (Abdollati & Mobadery, 2020).

## 2.10 Associations between Anxiety and Diabetes Distress

Diabetes-specific Distress (DD) and anxiety are both prevalent conditions in those with diabetes (Strandberg et al., 2015; Berry et al., 2015; Fisher et al. 2008). However, anxiety disorders have not been explored as systematically or extensively in the context of diabetes, especially relative to disorders such as DD despite established co-morbidities (Amiri & Behnezhad, 2019; Wylie et al., 2019; Naiker et al., 2017). Diabetes Distress and anxiety are distinct variables; anxiety is assessed in the absence of life-context, whereas DD is an emotional response to the specific challenges of living with diabetes (Hagger at al., 2016; Fisher et al., 2014). Research has found significant associations between anxiety and DD and higher prevalence of both in T1DM and T2DM populations (e.g., Fishcer et al., 2008; Garcia-Lara et al., 2022), and both variables have been significantly associated with glycaemic control and quality of life in diabetes patients (see sections 2.3; 2.5).

### *2.10.1 Type 1*

There is relatively little understanding of the emotional mechanisms that contribute to the development and chronicity of DD (Fisher et al., 2017). Recent research has attempted to address this, although there is comparatively less research examining anxiety and DD in T1DM than T2DM. Often studies will assess the effect of anxiety and DD on HbA1c, but not between these variables themselves (e.g., Stranberg et al., 2014). However, cross-sectional findings from Shaban et al. (2009) found anxiety was significantly correlated with DD, ($r$=.69; $p$ <.001) (n=259), and also found a mediating effect of DD between anxiety and HbA1c levels. A strength of this study was using a larger cohort of people with T1DM within the literature, although effect sizes compared to T2DM literature were smaller; this suggested the need for consideration of other behavioural and psychological variables that may affect HbA1c and diabetes self-care (e.g., fatigue, resilience). More recent cross-sectional research (Nguyen et al., 2020) supports these findings; higher diabetes distress was significantly related to symptoms of anxiety (*b* = 0.07, *p* = 0.001) in 171 adolescents.

Longitudinal research also supports these findings, for example, Vesco et al. (2021) investigated the indirect effects of anxiety on glycated haemoglobin via DD and negative thinking in adolescents (n=264) across 8-, 12-, 16- and 28-months post baseline (retention across follow up was 96%). A large, significant positive correlation was found between anxiety and diabetes distress ($r = 0.58$, $p < .05$), and longitudinal mediation analysis revealed anxiety significantly predicted diabetes distress and negative thinking (0.009, 95% CI: .003 – 0.019, $p<0.05$). HbA1c was also significantly predicted by diabetes distress but not negative thinking; this could suggest diabetes distress mediates the effect of anxiety on glycated haemoglobin, which demonstrates a directional association between anxiety and diabetes distress. For anxiety, females reported significantly higher anxiety scores and diabetes distress scores, whereas age and diabetes duration did not have any significant effects on measured outcomes. Itturalde et al. (2019) also found significantly higher levels of anxiety in in those with higher reported DD than lower (n=264).

### *2.10.2 Type 2*

A recent cross-sectional study (Trief et al., 2022) examined factors associated with diabetes distress in younger adults with T2DM (n=438), and found significantly higher anxiety symptoms in the high diabetes distress group compared to low (28% vs. 6%, $P < 0.001$), and for each subscale of the DDS. Significantly higher HbA1c levels, female gender and being treated with insulin were all significantly related to higher levels of diabetes distress and anxiety. Additionally, Kintzoglanakis et al. (2022) cross-sectionally examined DD levels against depression and anxiety levels in *n*=182 adults with a T2DM diagnosis of at least 6 months (primary Care). Participant anxiety (measured through the GAD-7) was significantly positively associated with each subscale of the DDS (EB ($r = .519$, $p < .001$), PD ($r = .270$, $p < .001$), RD ($r = .348$, $p < .001$), and ID ($r = .428$, $p < .001$), in males and females. A notable strength of this study was psychological status assessments of the participants were characterised by increased frequency of clinically significant symptoms for DD (DDS), anxiety (GAD-7) and depression (PHQ-9).

Additionally, McInerny et al. (2022) conducted a network analysis (n=1,796) to explore interactions between items assessing DD, depression and anxiety. All items of the GAD-7 were significantly correlated with the items of the DDS (all correlations were small-medium apart from 2 large ones). Regimen-related and physician-related problems were among the most central (highly connected) and influential (most positive connections) in the diabetes distress network. The anxiety symptoms of ‘worrying too much,’ ‘uncontrollable worry,’ and ‘trouble relaxing’ were identified as bridging factors linking anxiety to diabetes distress items. Similarly, when examining the interplay between diabetes distress and anxiety, anxiety symptoms were the most influential. These findings are important because with a network approach, the bridging connections between items is a function of ‘spreading activation’ from one mental health difficulty to another, and is suggested to be central in explaining comorbidities. Therefore, this could be significant in understanding the interplay between mental health problems in individuals with diabetes.

These findings have also been supported by Lipscombe et al. (2015) where longitudinal trajectories of DD distress were examined over 4 years; one of the first DD studies to examine time periods greater than 18 months, within a framework that can account for longitudinal changes. Trajectories are important in identifying high risk characteristics, which in this case can be used to help individuals at risk for high DD. Anxiety symptoms were significantly associated with trajectories of DD, where higher levels of DD were significantly associated with greater anxiety symptoms. Lastly, consistent with the T1DM literature, DD is significantly associated with HbA1c levels, but anxiety is not (e.g., Indelicato et al., 2017). Due to the associations found between DD and anxiety, this relationship might be better explained through a mediator such as resilience.

Diabetes distress is generally more prevalent than anxiety disorders in T2DM patients (see Garcia-Lara et al., 2022 for a meta-analysis), and although the relationship seems bi-directional (Ahmed et al., 2022), both T1DM and T2DM studies show DD significantly predicting HbA1c, and can mediate anxiety and HbA1c. Therefore, DD seems more appropriate as outcome variable in the model for study 1.

## 2.11 Associations between Anxiety and Cognition

Affective states and disorders (e.g., anxiety, depression) have been found to significantly impact cognition in typical populations, increasingly with age (Schweizer et al., 2019; Potvin et al., 2010). It is argued that executive functions such as inhibitory control (i.e., the ability to refrain from responding to or attending to distractions, objects, thoughts and activities) are associated with anxiety, which has been found in non-diabetes populations (e.g., DeGutis et al., 2015; Schmeichel & Tang, 2015). Those who have lower inhibition are more likely to attend to anxious thoughts and have difficulty attentionally shifting from those thoughts, and better inhibition is associated with less anxiety through more effective coping strategies and flexible adaptation to stressors (e.g., Martel et al., 2007). Anxiety is also associated with inflammation (Murdock et al., 2016) and increased inflammation is known to be a predictor of diabetes onset and diabetes progression over time (Stehouwer et al., 2002). Therefore, there are cognitive and physiological explanations linking anxiety and cognition in diabetes populations (Murdock et al., 2016). Additionally, Eysenck & Derakshan (2011) argue compromised EFs and cognition are negatively associated with increased excessive and uncontrollable worry (the core symptom of generalised anxiety disorder, GAD). Zainal & Newman (2018) confirmed this using a nationally representative sample (n=2605), and found global cognition predicted GAD severity and diagnosis, and poor inhibition, attentional shifting, working memory, inductive reasoning and global cognition predicted heightened GAD, across 9 years.

### *2.11.1 Type 1*

In youth and adulthood, T1DM is independently related to both, mild cognitive decrements (particularly EFs such as attention, processing speed and working memory) and affective disorders, such as anxiety and depression (van Duinkerken, Snoek & de Wit, 2020). Despite this, there are no (to my knowledge) any studies that have examined these together within T1DM. There is research into negative attribution (i.e., cognition), but research typically looks at depression as secondary or cofounder variables rather than anxiety (e.g., McLaughlin et al., 2010). Additionally, Wearden et al.

(2010) found significant associations between increased anxiety and negative attribution, but in partners of T1DM patients rather than the patients themselves. This research area is lacking in T1DM specific populations.

### *2.11.2 Type 2*

As with T1DM this research area is lacking, although a few relevant studies were found. Raffield et al. (2016) examined whether anxiety and depression contributed to lowered cognitive performance through cognitive and psychological testing, supported with MRI (Magnetic Resonance Imaging) scans (n=655). Analyses controlled for age, sex, education, and medication, and those with comorbid anxiety scored significantly lower on all cognitive testing measures ($p \leq 0.005$), increased white matter lesion volume ($p=0.015$), and decreased grey matter cerebral blood flow and volume ($p=0.002$). White matter is essential for impulse conduction and therefore transmission of information across neural networks (Fields, 2010), and grey matter is responsible for functional processing and learning in the brain (Mercadante & Tadi et al., 2023). These results demonstrate strong support for an association between anxiety and cognition (EF) in T2DM. Strengths of this study were combining cognitive testing and brain imaging, and cognitive functions were assessed via several validated EF tests (e.g., Mini-Mental State Examination, Stroop Task, Digit Symbol Substitution, Fluency tasks and Rey Auditory Verbal Learning Task), and a large sample size which is not typical in brain imaging studies.

Further support can be seen in biological mechanism studies; Fluoxetine, an antidepressant that exerts anxiolytic effects, was used successfully used to mitigate anxiety and prevent cognitive dysfunction in diabetic mice (Yuan, Zhang, Li & Song, 2019). However, it is important to acknowledge this is an animal model and not necessarily valid in humans. Additionally, Degmecic et al. (2014) found significantly higher incidences of anxiety and cognitive dysfunction in $n=108$ T2DM participants, compared to a control group. A strength of this study was the use of psychiatrists in administering cognitive and psychological tests.

## 2.12 Associations between Fatigue and Diabetes Distress

The bidirectional relationship between fatigue and diabetes distress can be explained through the inability to adequately self-manage diabetes. This could lead to increased fatiguability, which can contribute to increased diabetes distress, emotional burnout and further fatigue (Kalra & Sashay, 2018).

### *2.12.1 Type 1*

It is important to note FoH (fear of hypoglycaemia) is a bigger concern in T1DM generally, and this can result in behavioural responses to avoid this, such as worrying, feeling stressed, and not sleeping as much (Zhu et al., 2020), all of which can contribute to fatigue (see respective sections in chapter 2). This is supported by physiological explanations, where insufficient sleep can cause inflammation, which is associated with diabetes risk and worsening symptoms such as diabetes distress (Grandner et al., 2017). Sleep intervention studies provide support for a positive association between fatigue and diabetes distress. For example, Bisio et al. (2021) found significant treatment-related improvements in sleep quality, with significant reductions in DD, anxiety and HbA1c levels, in n=13 children with T1DM. This is supported in larger studies using T1DM. For example, Hayek & Dawish, (2020) administered a sleep intervention (n=95) and found significant improvements in sleep quality, DD, and glycaemic control after 3 months. Additionally, Nefs et al. (2015) found poor sleep quality was significantly associated with increased fatigue, anxiety symptoms, and elevated DD in both T1DM (n=267) and T2DM (n=361) adults. Sleep duration intervention studies have also found significant reductions in fatigue and diabetes distress in T1DM and T2DM adults, compared to a control group (Martyn-Nementh et al., 2020).

Lastly, Park et al. (2015) conducted a path analysis and found an indirect link between fatigue and diabetes distress in both T1DM and T2DM groups, mediated through diabetes symptoms. This could be explained by an indirect mediational effect of resilience; fatigue in diabetes can be minimised by effective management of diabetes distress achieved through resilience intervention (Kalra & Sashay, 2018).

### *2.12.2 Type 2*

Ba et al. (2021) conducted a meta-analysis of ten studies (n=1082), and found fatigue was significantly associated with diabetes distress in T2DM, and fatigue was negatively related to self-care behaviours. Additionally, Park et al. (2015) conducted a cross-sectional SEM (n=155 adults), and found that fatigue was significantly related to DD (r = 0.359, $p = 0.001$) in both controlled and uncontrolled HbA1c groups. Furthermore, in patients with poorly controlled HbA1c (> 7%), fatigue was significantly indirectly related to HbA1c through diabetes distress, diabetes symptoms and depression. This supports the findings of Fritschi et al. (2012), who reported a moderate relationship between DD and fatigue (r = 0.445, $p < 0.01$), although in further regression analyses of fatigue predictors, DD was no longer significant in the final model with depressive symptoms, BMI and diabetes symptoms. Park et al. (2015) argue this may because depressive symptoms seen in diabetes is rather diabetes emotional distress (Zagarins et al., 2012), and their findings suggest DD is a dynamic construct that co-varies with other stressful factors such as fatigue. Additionally, Nefs et al. (2015) found poor sleep quality was significantly associated with increased fatigue, anxiety symptoms, and elevated DD in both T1DM (n=267) and T2DM (n=361) adults. Lastly, Zhou et al. (2017) found overall diabetes-related distress and emotional burden subscale scores were significantly associated with fatigue (through poorer sleep time) and lower diabetes self-efficacy, suggesting an indirect link between DD and fatigue symptoms.

## 2.13 Associations between Fatigue and Cognition

An association between increased fatigue and impaired cognition (in particular, executive functions) has been well established in general literature (see Abd-Elfattah et al., 2015), and replicated in T1DM and T2DM populations (e.g., Goedendorp et al., 2014; Hill et al., 2013; Fritschi & Quinn, 2010; Sommerfield et al., 2004). Fatigue in diabetes is significantly correlated with poorer glycaemic control, which is associated to poorer mental and physical functioning (Lee et al., 2017). Decreased sleep duration and fatigue have been strongly associated with reduced cognition, and increased health sequelae (Lock, Bonetti & Campbell, 2018). Cognitive decline in older adults has also been associated with mental fatigue (Zhang et al., 2023).

### *2.13.1 Type 1*

Goendorp et al. (2014) conducted a cross-sectional study (n=214) and found chronically fatigued individuals displayed significantly more cognitive behavioural impairments, relative to matched controls in T1DM (Goedendorp, Tack & Steggink, 2014). Longitudinal findings by Menting et al. (2016) also found the strongest predictors of fatigue were cognitive-behavioural factors after a 3.5 year follow up. Additionally, Hill et al. (2013) found significant associations between poorer academic scores and problems in concentration and focus, in university students. Cognitive Behavioural Therapy (CBT) interventions also provide support for an association between fatigue and cognitive processes. For example, Menting et al. (2017) employed a blended CBT intervention (incorporating web-based and face-to face elements; *n*=120) to target cognitions and behaviours associated with diabetes self-care. Those in the CBT group (*n*=60) had significantly lower fatigue severity scores and functional impairment after 5 months (see also Menting et al., 2015). Studies on fatigue within T1DM populations often report small samples and cross-sectional designs with few randomized controlled trials addressing fatigue and diabetes-related symptoms (see also Menting et al., 2015). More research is needed to understand the interplay between cognition and fatigue (see Griggs & Morris, 2018; Romadlon et al., 2022).

### *2.13.2 Type 2*

Several studies have reported fatigue as a correlate of cognitive impairment in people with diabetes (see Alkethiri et al., 2021 for a review). For example, Sommerfield et al. (2004) found that acute hypoglycaemic episodes were significantly associated with loss of cognitive function and heightened fatigue. Lasselin et al. (2013) found significantly higher scores of fatigue and cognitive differences (longer reaction times and impaired spatial planning) in T2DM patients, compared to T1DM and control groups. Also, Alfahadi et al. (2020) found significantly high fatigue scores and reduced neurocognitive functions (motor performance, attentional flexibility and working memory) in T2DM patients compared to healthy controls. The affected cognitions map onto executive functions (see section 2.6), which are well-established correlates of T2DM. Additionally, CBT interventions have been used to support the association between fatigue and cognition. For example, Alshehri et al. (2020) administered a CBT intervention in T2DM adults and healthy controls (*n*=13 in both groups) and found a significant reduction in fatigue levels, self-care behaviours and HbA1c, suggesting improved glycaemic control.  However, as with T1DM research, studies typically report small sample sizes, and more research is needed to understand the interplay between cognition and fatigue (see Griggs & Morris, 2018; Romadlon et al., 2022).

## 2.14 Associations between Cognition and Diabetes Distress

Executive functions (inhibition, attention, working memory, and cognitive flexibility) play a fundamental role in emotion regulation (Diamond, 2013) and therefore DD, which is a negative emotional response to coping with the demands of diabetes. Emotional regulation is defined as the ability to monitor and evaluate appropriate emotional responses to situations (Eadeh, 2021), and research suggests patients with higher levels of DD are more likely to: critically judge their emotions, react to them impulsively, ruminate, negatively appraise situations, and be less mindful of their emotional experiences related to diabetes (Fisher et al., 2018; Lansing & Berg, 2014). Considering that DD is directly and significantly associated with poorer glycaemic control and increased mortality (Asuzu et al., 2017; Dieter & Laurer, 2017), it is important to understand the interactions between cognition and DD.

### *2.14.1 Type 1*

Van Duinkerken et al. (2020) conducted a meta-analysis of cognitive and psychological factors across different age ranges (childhood, young-to-middle adulthood, late adulthood), and found prevalent cognitive decrements and diabetes distress across the lifespan. Cognitive decrements typically presented as reduced processing speed, attention, and executive functions. Additionally, Fisher et al. (2018) tested a structural equation model (*n*=347); a good level of fit was achieved, and significant pathways were found between both, emotional regulation and cognitive processes, and diabetes distress. DD was also significantly linked to glycaemic control. CBT interventions have also been used to reduce levels of DD, HbA1c levels and psychological wellbeing (see Abbas et al., 2023; Snoek et al., 2001).

### *2.14.2 Type 2*

Findings also demonstrate a bidirectional relationship between diabetes distress and cognitive skills, where improvements in emotional regulation and cognitive skills drive significant reductions in diabetes distress (Fisher et al., 2019). For example, Coccaro et al. (2021) examined *n*=298 adults with diabetes and found emotional regulation experience directly related to DD, and emotional regulation skill was negatively related to DD (medium pooled effect size). This suggests addressing negative/poor emotional regulation may ease DD, and this has been supported in CBT intervention studies in both T1DM and T2DM (e.g., Hermanns et al., 2015; van Son et al. 2014).

## 2.15 Chapter summary and areas for further research

To summarise, anxiety, fatigue, diabetes distress and cognition are all significant psychological factors that can negatively influence self-management in both T1DM and T2DM. There is a paucity of systematic evaluations between psychological factors and diabetes outcomes (Knowles et al., 2020), and currently no qualitative or quantitative studies have explored the relationships between the variables in this chapter comprehensively and within one study. Relative to T2DM research, there are fewer available T1DM studies (see meta-analyses throughout chapter 2), and population samples tend to be mostly female in both diabetes types. A lot of research also tends to pool T1DM and T2DM findings together when examining associations with risk factors (e.g., DD; Perrin et al., 2017); this is problematic because the way in which these factors manifest may be contextually different (e.g., contributing factors to DD levels, such as fear of hypoglycaemia is more prominent in T1DM compared to feelings of guilt and shame in T2DM). Additionally, studies with a psychosocial focus are small in comparison to those with a biological focus. Jones et al. (2016) analysed annual reports and funded-research databases from representative funding organisations (American Diabetes Association, the Canadian Diabetes Association, Diabetes Australia, Diabetes UK, the Dutch Diabetes Research foundation and the European Foundation for Diabetes) over 5 years, and found a mean ratio of 17:1 between funded biomedical and psychosocial studies, respectively. An explanation for this could be that the application of biomedical reductionism to understand and treat disease is viewed more favourably in comparison to psychosocial research; however, a more comprehensive approach should be taken when treating people for diabetes (Jones et al., 2016). Future studies should focus on understanding the underlying relationships of psychosocial factors further, which is one of the overarching aims of this PhD (see chapter 5 for methodology).

To conclude, an examination of relevant literatures points to the need for an examination of associations between the aforementioned psychological factors within one study, for T1DM and T2DM separately, with the aim of developing a more comprehensive model. Next, these factors will be examined in relation to resilience, which has been identified as a potential mechanism of change/mediator variable for the aforementioned psychological variables in this chapter.

# Chapter 3: Resilience in the Context of Diabetes

## 3.1 Structure of the Chapter

Chapter 3 first discusses the concepts of resilience and coping, and explains how resilience (as a mechanism of change) fits into the proposed model with factors discussed in Chapter 2. Then, the role of resilience in diabetes self-management. Next, the chapter reviews the potential mediating role of resilience in the following relationships, where anxiety and fatigue are operationalised as psychological states, and diabetes and cognition are operationalised as diabetes outcomes: 1) Anxiety and Resilience; 2) Fatigue and Resilience; 3) Diabetes Distress and Resilience; and 4) Cognition and Resilience.

## 3.2 Chapter Introduction

Previous studies have identified resilience as a mechanism of change through improving processes such as cognitive flexibility/appraisal, emotional regulation, and active coping (see section 3.2.1). Resilience and coping are two distinct but interrelated concepts, which inform how individuals manage problems/difficulties and recover from adversity/change (Van der Hallen, 2020); Both concepts are associated with health outcomes. The problem within the literature is these terms are used interchangeably, where in fact they inform different concepts. Coping is a broad concept, defined as the thoughts and behaviours utilised to manage stressful internal and external situations (Aglorani & Gupta, 2023), and many distinctions have been made to categorise coping responses. The two most commonly employed coping distinctions are: 1) problem-focused coping (i.e., changing the situation, removing the stressor or managing the problem) vs emotion-focused coping (i.e., removing or reducing negative emotions related to a problem); and 2) engagement coping (i.e., active attempts to manage the associated stressors/emotions) versus disengagement coping (i.e., distancing oneself from the stressor or any related feelings) (see Carver 2010; Skinner, 2003; Van der Hallen, 2020).

Problem-focused coping might include planning, direct action, or seeking instruction to address a problem, and is typically associated with longer lasting reductions in strain levels and increased psychological functioning (Ewert et al., 2021; Connor-Smith & Flachsbart, 2007; Theodoratou et al., 2023). However, this is not always the case, and sometimes emotion-focused coping can be more effective where a threat cannot be controlled, such as terminal disease or death of a loved one (Carver & Connor-Smith, 2010; Ewert et al., 2021). Emotion coping can be further differentiated into emotional approach coping (e.g., cognitive reframing, self-soothing, acceptance) or emotional avoidance coping (e.g., denial, distraction, wishful thinking) (e.g., Schnider et al., 2007). Problem-focused coping and emotional approach coping are typically referred to as adaptive behaviours, whereas emotional avoidance coping is nearly always maladaptive, as it does not affect the impact of a threat long-term (Ewert et al., 2021; Van der Hallen et al., 2020). Lastly, safety behaviours are conceptually distinct from coping behaviours, but share several overlaps, making them hard to distinguish between (Hoffman & Chu, 2019). Safety behaviours are covert/overt behaviours used to prevent or minimise feared outcomes (Salkovskis et al., 1996), usually motivated by inaccurate/exaggerated perception of a threat (e.g., repetitive information seeking to avoid uncertainty regarding decision making). However, this could be seen as an adaptive coping mechanism in other contexts (e.g., selecting a surgeon for a procedure) (Baker et al., 2021). Safety behaviours can facilitate/perpetuate rigidity, threat perception and avoidance of feared situations, whereas coping behaviours facilitate flexible approach of feared situations; therefore, it is important to understand the function and motivation of the behaviour (Hoffman & Chu, 2019).

Whilst coping refers to the thoughts and behaviours utilised in managing stressful situations, resilience is defined as the capacity of a dynamic system to withstand or recover from significant challenges/adversity (Van der Hallen et al., 2020).  Over the past two decades, there has been much discussion and disagreement regarding definitions of resilience, due to ambiguities in terminology, instability of concepts, and inconsistencies within experiences of resilience (Ollis et al., 2022). The concept has changed from trait-orientated (i.e., an intrinsic process that remains relatively stable over time), to a dynamic process (i.e., variable state across time, influenced by internal and external factors) (Chmitorz et al., 2018). An example of trait-oriented approach of resilience would be a ‘hardy’ personality type, but there is only weak empirical evidence supporting resilience as an intrinsic and stable attribute (Kalisch et al., 2017). Generally, literature now supports resilience as dynamic process that accounts for both internal (e.g., epigenetics, personality traits, beliefs, self-efficacy) and external factors (e.g., social support, financial and environmental resources including stability/access to these). For example, increased resilience is associated with more resource-rich and stable environments (Hobfoll et al., 2015; Chmitorz et al., 2018). Resilience as a dynamic process, can be conceptualised as mental health in relation to stressor load (Chmitorz et al., 2018), and as such can be trained and utilised as part of intervention studies.

Resilience is an increasingly important factor in diabetes self-management, however the operationalisation of this construct is varied in the diabetes literature (Torabizadeh et al., 2020). Definitions of resilience have changed over the years, but the generally agreed definition is the capacity to adapt and maintain psychological and physical ‘wellbeing’ in the face of adversity (Rutter, 2012; Terte et al., 2014), through several attributes such as determination, personal strength, positive adaptation to stress, emotional regulation and supportive relationships (Brown et al., 2022; Dubois et al., 2020). As such, this PhD will operationalise resilience as a dynamic protective factor, which acts as a mediator variable in the proposed model (see Fig 3).

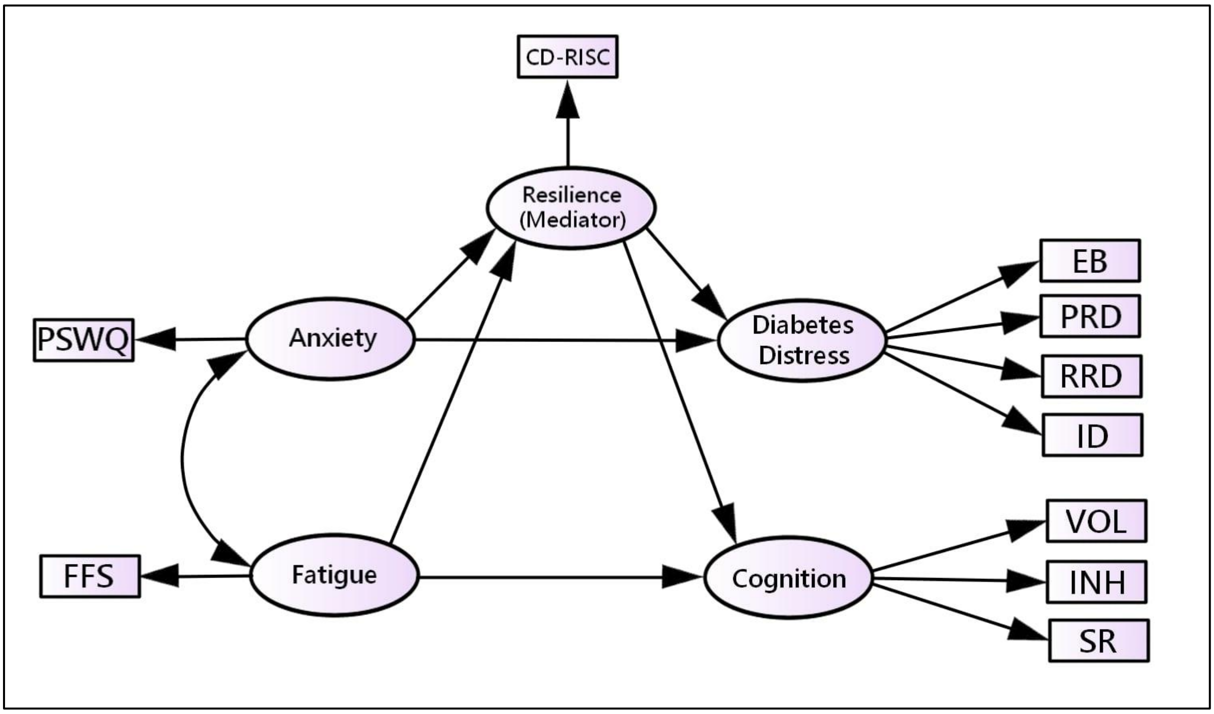
The progression of symptomology in chronic diseases such as diabetes can be related to resilience, where low resilience has been correlated with maladaptive coping strategies (i.e., emotional avoidance coping such as denial), higher distress, poor glycaemic control and reduced quality of life, in both T1DM (Yi-Frazier et al., 2010 & 2015) and T2DM (Pesantes et al., 2015; Wilson et al., 2017). Observational studies show increased psychological resilience improves glycaemic control through promoting self-management behaviours in T1DM and T2DM diabetes (Luo et al., 2019; McGavock et al., 2018). This can be explained through individuals with higher resilience being able to perceive and utilise more available resources to cope with a difficult environment, and present a stronger adaptability to stressors (Zhang et al., 2022). This is supported empirically, where higher resilience is significantly associated with increased cognitive function (e.g., Jung et al., 2021). After controlling for confounding variables, Jiang et al., (2024) found psychological resilience predicted changes in cognitive function across 5 years, suggesting higher resilience levels may protect against cognitive impairment.

Adversity and protection are two major components of resilience (Hilliard et al., 2012), where adversity is defined as exposure to risk factors that are statistically associated with suboptimal health outcomes (e.g., managing and meeting the demands of a chronic illness such as diabetes), which can be compounded by socio-economic and/or environmental factors (Hilliard et al., 2012). Protective factors (e.g., adaptive problem-solving), can help act as a buffer against negative effects associated with diabetes (e.g., anxiety, fatigue), and in turn improve self-management and glycaemic control (e.g., Yi-Frazier, 2015). Risks and protective processes can occur at an individual, interpersonal and social/culture level, suggesting resilience is a complex and multifactorial process (Burt & Paysnick, 2012; Hilliard et al., 2012; Vanderbilt-Adriance & Shaw, 2008). Resilience is achieved through a dynamic process of engagement and surmounting of risk factors (Rutter, 2012), and diabetes-specific resilience is defined as the attainment of one or more positive diabetes outcomes, e.g., glycaemic targets, engagement with self-management behaviours, good quality of life; which is why it is important to understand the relationships between the factors and diabetes outcomes with resilience (Hilliard, Harris & Weissberg-Benchell, 2012). Resilience has also been correlated with greater health behaviour adherence and reduced mortality in T1DM and T2DM (Massey et al., 2019), and as such, resilience is a key factor in many health intervention studies (Massey et al., 2019). Next, resilience is discussed in the context of the proposed model and variables discussed throughout Chapter 2, followed by a review of existing literatures in diabetes.

### *3.2.1 Resilience as a Mechanism of Change – Model Context*

Previous studies have identified resilience as a mechanism of change through improving processes such as cognitive flexibility/appraisal, emotional regulation, and active coping (Liu et al., 2018). Cognitive appraisal of stressors (i.e., perceived stress severity) can influence the impact of stressors on cognitive functioning, and higher perceived stress severity is associated with higher cortisol production which can lead to stress disorders (e.g., anxiety and depression. Jiang et al., 2017; Woody et al., 2018). Emotional regulation is also important; aversive emotions in response to stressors (e.g., fear, anxiety) can impair cognitive functioning (e.g., attentional bias, cognitive flexibility, memory and learning impairments), and further aggravate the intensity of a stressor (Gray et al., 2017; Palamarchuk & Vaillancourt, 2021). High levels of fear or anger (i.e., difficulties with emotion regulation) can affect decision-making through impulsivity/inhibition difficulties (e.g., Gupta et al., 2011). Lastly, executive functioning plays a vital role in decision-making and organisation and is important in the execution of coping behaviours (see chapter 2). These resilience-based processes (cognitive flexibility, emotional regulation, coping behaviours) are also supported in neuroimaging studies/animal models. For example, Rooij et al., (2022) found greater functional activation of the hippocampus (i.e., a key brain region involved in emotional regulation and memory) following stressful traumatic experiences. The limbic system and prefrontal cortex are two key brain regions that function to regulate emotional processing (Palamarchuk & Vaillancourt, 2021), and this can impact the interpretation of a stressor. Taking the above information into account with consideration from the literature review, the proposed model will be explained (see Figure 3 below).

**Figure 3:** *Proposed Structural Model: Psychological States (Anxiety, Fatigue), and Diabetes Outcomes (Diabetes Distress, Cognition), with Resilience as Mediator (See section 6.2 for more details)*



***Key**: PSWQ (Penn State Worry Questionnaire); FFS (Flinder's Fatigue Scale); CD-RISC (Connor-Davidson Resilience Scale), DDS (Diabetes Distress Scale, using four subscales: Emotional Burden, Physician Related Distress, Regimen Related Distress, Interpersonal Distress); DEX (Dysexecutive Questionnaire, using three subscales: Volition, Inhibition and Social Regulation).*

### Anxiety – Resilience – DD

Research examining anxiety and DD tends to be correlational, which cannot inform whether one variable causes the other to occur. However, there are some studies which suggest the direction from anxiety to DD. For example, anxiety was indirectly related to HbA1c through DD as a mediator (Shaban et al., 2009). These findings were also confirmed longitudinally, where anxiety significantly predicted DD levels and negative thinking (Vesco et al., 2021. See also Lipscombe et al., 2015). Lastly, McInerny et al., (2022) found that anxiety had the most influence on DD using network analysis. As DD is significantly associated with HbA1c levels, but anxiety is not (e.g., Indelicato et al., 2017). This relationship might be better explained through a mediator such as resilience, and as such anxiety was placed on the left of the model as a predictor variable. In the interest of being thorough, and recognising DD as a distinct psychological stressor, study 1 analyses an alternative model where DD is also placed on the left (this model fitted poorly).

### Anxiety – Resilience – Cognition

Correlational studies have established significant associations between anxiety and cognition (e.g., Schweizer et al., 2019; van Duinkerken, Snoek & de Wit, 2020), but research in diabetes specific populations is limited. In general populations, brain imaging and cognitive testing studies found significant associations between anxiety and executive dysfunction, in particular problems associated with attentional inhibition/getting distracted and working memory (e.g., Degmecic et al., 2014; Raffield et al., 2016). Due to the bi-directional nature of anxiety and cognition (Suddell et al., 2023), cognition could be argued as a predictor variable or outcome variable in the model. However, there is some research to suggest direction, for example, fluoxetine (an anxiolytic) was successfully used to mitigate anxiety and prevent cognitive dysfunction in diabetic mice (Yuan et al., 2019). Additionally, resilience has been shown to mediate psychological stressors (e.g., anxiety, stress) and cognition (i.e., cognitive appraisal/emotion regulation; Palamarchuk & Vaillancourt, 2021). Therefore, cognition was operationalised as an outcome variable within the model.

### Fatigue – Resilience – DD

Several studies have found significant positive associations between fatigue and DD levels (e.g., Ba et al., 2021; Fritschi et al., 2012), and research describes bi-directional interactions through the inability to adequately to self-manage diabetes. This could lead to increased fatiguability, which can contribute to increased diabetes distress, emotional burnout and further fatigue (Kalra & Sashay, 2018). Fatigue was chosen as a predictor variable, and DD as an outcome variable in the model due to several research papers. For example, Park et al., (2015) conducted a SEM study and found DD indirectly mediated the relationship between fatigue and HbA1c levels (also supported by Zhou et al., 2017). Additionally, sleep intervention studies, where studies with the aim of reducing fatigue and improving sleep quality found significant treatment-related improvements in DD levels after 3 months (e.g., Hayek & Dawish, 2020; Martyn-Nementh et al., 2020; Nefs et al., 2015). Resilience could explain the link between fatigue and DD, through cognitive appraisal and behavioural coping.

**Fatigue – Resilience – Cognition**

Associations between increased fatigue and impaired cognition (in particular, executive functions) have been well established in general literature (see Abd-Elfattah et al., 2015), and replicated in T1DM and T2DM populations (e.g., Goedendorp et al., 2014; Hill et al., 2013; Fritschi & Quinn, 2010; Sommerfield et al., 2004). Although cognition could be a predictor or outcome variable in this relationship, it has been operationalised as an outcome variable for several reasons. Firstly, fatigue in diabetes is significantly correlated with poorer glycaemic control, which is associated with poorer mental and physical functioning (Lee et al., 2017). A possible mediator for this relationship could be resilience, through cognitive appraisal, which could ease cognitive loads of perceived stressors. Cognitive decline in older adults has also been associated with mental fatigue (Zhang et al., 2023). Additionally, fatigue is a psychological stressor, and chronic fatigue (which is often associated with T1DM and T2DM) can lead to HPA axis activation and lead to cortisol production (Sharma & Singh, 2020). This can contribute to insulin resistance, which is thought to be the cause of diabetes-related cognitive impairment (and increased risk of Alzheimer's Disease), as there are insulin receptor dense areas in the brain (e.g., hippocampus) needed for executive functioning and emotional regulation (Cater & Holter 2022; Liu et al., 2022). More evidence examining the relationship between fatigue and cognitive impairment in patients with chronic illnesses is needed (Menzies et al., 2021).

## 3.3 Resilience and Diabetes Self-Management

### *3.3.1 Type 1*

In a study undertaken by Yi-Frazer et al. (2015), individuals with lower resilience were found to use significantly more maladaptive coping strategies (e.g., avoidance), and were at greatest risk of poor health outcomes. Conversely, individuals who displayed higher levels of resilience reported significantly lower levels of anxiety, and healthier levels of psychological adaptation and function (Ruiz-Aranda et al., 2020). This provides further support for a buffering effect of resilience, against diabetes risk factors in T1DM. Skegdell et al., (2021) also found adults utilised protective factors associated with resilience in three main ways to manage their diabetes: 1) Social strategies: seeking tangible interpersonal support from family and emotional support from friends and healthcare providers; 2) Cognitive strategies: appraisal and believing one can live a normal life with T1DM; and 3) Behavioural strategies: proactive planning, flexibility in routine, balancing diabetes/non-diabetes activities, and utilising technologies to support diabetes management. These protective factors may explain pathways through which resilience may mediate/facilitate good diabetes self-management and engaging with associated challenges. Research has also found significant correlations between low resilience and poor glycaemic control and quality of life (Yi-Frazier et al., 2013); these findings are supported by resilience-promoting interventions which have found increased resilience significantly associated with decreased HbA1c, reduced stress, increased self-efficacy and quality of life after 6 months (Wu et al., 2023). Within the literature there appears to be relatively less research in T1DM compared to T2DM, possibly explained by the relative abundance of those with T2DM (90% as opposed to 8% of the UK diabetes population).

### *3.3.2 Type 2*

Resilience research in T2DM is concordant with that of T1DM. Significant correlations have been found between increased resilience and lower HbA1c (improved glycaemic control) (Pesantes, Porras, Dabrh, Avila-Ramirez et al., 2015). Furthermore, a longitudinal study (Yi-Frazer et al., 2008) revealed individuals with T2DM and low resilience favoured maladaptive coping strategies, such as avoidance of managing diabetes (e.g., not performing blood glucose testing as often as required) and exhibited fewer self-care behaviours (e.g., seeking help, exercising regularly, maintaining a healthy diet). Supporting this, increased resilience is correlated with a reduction in maladaptive strategies and improvements in diabetes self-management (Wilson et al., 2017), making it a useful factor in intervention studies. Resilience-based intervention studies found higher resilience correlated with significantly lower levels of diabetes distress and anxiety (Ryan et al., 2020), demonstrating a protective buffer against poorer mental health outcomes. Resilience training programs have been found to improve self-efficacy in T2DM, a core component in resilience, which is correlated with improved self-management behaviours (Torabizadeh, et al., 2019). Research also suggests a mediating role of resilience between mental health (depression) and adherence to diabetes care (Rahimi, Jalali, Nouri & Rahimi, 2020).

## 3.4 Resilience and Psychological Correlates

Research in the diabetes literature suggest associations between resilience and the psychological states discussed in Chapter 2. A review of existing literature was undertaken, where anxiety and fatigue are operationalised as psychological states, and diabetes distress and cognition are operationalised as diabetes outcomes. It is important to note this research often groups examines both T1DM and T2DM together, so rather than using separated sections, I have taken time to address group differences where they occur. Additionally, research can be limited with factors such as cognition and fatigue, as typically diabetes resilience studies focus on self-efficacy, HbA1c and DD as outcomes measures.

## 3.5 Resilience and Psychological States (Anxiety, Fatigue)

### *3.5.1 Anxiety and Resilience*

Findings show higher levels of mood states such as anxiety, are significantly correlated with lower resilience levels in both T1DM and T2DM patients (Ruiz-Aranda et al., 2020; Santos et al., 2013). This supports earlier research findings; low resilience groups display significantly more anxious maladaptive coping styles than high resilience groups (Yi-Frazier, Smith, Peter, Vitaliano, 2010). Research examining T1DM and T2DM patients after a lower limb amputation (as a result of diabetic complication) found anxiety and negative emotional states significantly correlated with lower resilience; findings also suggest anxiety hinders coping with trauma, whereas increased resilience has a protective effect (Makai, Ratvai, Veszely, Pethes et al., 2019). Mediating effects of resilience have been found between anxiety and quality of life; individuals with higher resilience reported healthier levels of psychological adaptation to the diabetes (Ruiz-Aranda, Mateo-Rodriguez, Olmedo, Garcia et al., 2020). This suggests resilience may act as a buffer against the negative effects of psychiatric disorders, such as anxiety, which are highly prevalent in diabetes.

### *3.5.2 Fatigue and Resilience*

Fatigue can impair physical and mental functioning (Kalra & Sashay, 2018), which can negatively impact psychological resilience. Several components of resilience involve adaptive coping, problem appraisal/solving skills, emotional intelligence and regulation (Terte, Stephens & Huddleston, 2014), all of which require effective mental functioning. Research suggests increased psychological resilience is significantly correlated to lower fatigue and sleep dysfunction in T1DM and T2DM (Wojujutari, Alabi & Emmanuel, 2019), and higher psychological resilience has also been correlated with significantly improved sleep quality T2DM diabetes (Wang et al., 2021). Resilience-based interventions have also been found to significantly reduce fatigue in T2DM (Alshehri, et al., 2022) and in T1DM (Menting et al., 2017).

## 3.6 Resilience and Diabetes Outcomes (Diabetes Distress, Cognition)

### *3.6.1 Diabetes Distress and Resilience*

Research findings have established a negative correlation between greater resilience and decreased diabetes distress, in both T1DM and T2DM (Wang, Hsu & Kao et al., 2017; Wang et al., 2016; Yi Frazer et al., 2015; Yi, Vitaliano, Smith et al., 2010). Since lower levels of diabetes distress are significantly associated with increased and more effective self-care behaviours (Yi-Frazer et al., 2013; Yi, Vitaliano, Smith et al., 2010), it could be argued that resilience could provide an indirect buffer against the negative effects of diabetes-distress. This is supported by resilience intervention studies, where results found significant reductions in diabetes distress in T1DM and T2DM (Scott et al., 2020; Hood et al., 2018). Some research also supports a moderating effect of resilience on diabetes distress (Luo et al., 2020), and data suggests diabetes distress is significantly associated with regulating negative emotions in both T1DM and T2DM (Coccaro et al., 2021). Emotional control plays a key role in resilience, supporting an association between diabetes distress and resilience.

### *3.6.2 Cognition and Resilience*

Parsons et al. (2016) argues a key element in promoting resilience is the development of affective-cognitive systems, to help identify and modify maladaptive thinking and behaviours. Cognitive dysfunction is a well-established correlate of T1DM and T2DM (Castillo et al., 2018), and increased resilience behaviours are associated with better vascular health and better cognitive function (Vemuri et al., 2019). Therefore, individuals who manage their diabetes more effectively should be less prone to diabetes-related cognitive deficits. This is supported by Frazao et al. (2018), where a significant positive correlation was observed between resilience and cognitive functional capacity in older adults with T1DM and T2DM (functional capacity is the ability to perform daily activities within normal standards). Maladaptive coping behaviours are indicative of poor resilience (Yi-Frazier, Smith, Peter, Vitaliano, 2010), and these have been significantly correlated with reduced executive functioning (inhibition) (Murdock et al., 2016). Core resilience factors such as self-efficacy, locus of control, and optimism have been found to improve cognition in T1DM and T2DM diabetes through improving cognitive appraisal of the difficulties of living with diabetes (Wu et al., 2023; meta-analysis, *n*=2048 across 17 studies). Jalayer et al. (2022) also found compassion-focused interventions significantly improved emotional schemas and resilience in diabetes patients, demonstrating the effectiveness of emotional regulation on resilience.

## 3.7 General research limitations

A recent review (de Wit et al., 2020) of the past 25 years' research on social issues in diabetes identifies several gaps in resilience; A number of observational studies have been carried out into resilience and diabetes, however they rarely addressed the nature of the adversity e.g., diagnosis, living with the condition, comorbidities, socioeconomic factors. Additionally, only a component of resilience tends to be operationalised (e.g., self-efficacy), often statistically identified from non-validated questionnaire data, rather than using a comprehensive resilience scale, such as the Connor-Davidson Resilience Scale (2003) (e.g., Hadj-abo et al., 2020; Yifrazier et al., 2010). The diabetes research area is lacking in longitudinal resilience studies (de Wit et al., 2020) and qualitative resilience research in both T1DM (Nishio & Chujo, 2017; Skegnell et al., 2020) and T2DM (Pesantes et a., 2015; Wilson et al., 2017). Another limitation of the resilience research area is that studies tend to measure psychological wellbeing through generalised scales, rather than specific measures for anxiety or fatigue (see Hosseini et al., 2021).

## 3.8 Implications for Intervention

Evidence for a mediation effect exists when a variable (resilience in this case) is associated with both the potential predictor and outcome (Hayes, 2022). The review of research in chapters 2-3 suggest a need for a comprehensive examination of psychological factors of diabetes and resilience, and this is the focus of the present research. If a mediational effect of resilience is confirmed, this would provide an informed basis for further confirmatory studies and intervention design in T1DM and T2DM diabetes. It is important to note, in order for findings to be utilised in intervention studies, the findings from this thesis would need to be supported from further multiple studies with larger sample sizes and differing populations, and longitudinal findings also.

The mediating effect of resilience (in the context of anxiety/fatigue) could be utilised in early education interventions (e.g., conversion maps) to improve knowledge and management of diabetes outcomes, which can prevent serious diabetes complications (e.g., limb loss). Resilience training would provide a protective measure against negative psychological states/disorders (e.g., diabetes distress, fatigue), and help improve health outcomes; this would be widely applicable to other areas of life and managing other chronic diseases.

# Chapter 4. Diabetes Interventions

## 4.1 Chapter Structure

Chapter 4 describes current diabetes interventions, first discussing educational interventions offered by the NHS, such as DESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed) and DAFNE (Dose Adjusting for Normal Eating). Lastly, psychological and resilience-based interventions will be discussed.

## 4.2 Overview

In healthcare, an intervention is defined as any activity undertaken with the aim of improving health via preventing disease, reducing the severity or duration of an existing disease or restoring lost function (Smith, Morrow & Ross, 2015). Specifically, interventions can be classified as preventative (reducing incidence of the disease) and therapeutic (treating or mitigating effects, to reduce fatality or morbidity associated with disease). These activities can range from (but are not limited to) health education, behavioural change strategies, health planning, and self-management methods (Smith, Morrow & Ross, 2015). Interventions are especially important considering individuals with diabetes spend an average of three hours with a healthcare professional per year, therefore must manage their diabetes the rest of the year themselves (Wicher, O'Neill & Holt, 2020). Therefore, their education and health literacy is crucial for adequate diabetes management (Balogun-Katung et al., 2021).

Diabetes education is a core component of diabetes treatment, where the goals of this are to provide knowledge and skills (e.g., awareness of cardiovascular complications and how to avoid them), increasing motivation to engage with therapeutic recommendations, improving psychological resilience and health outcomes/quality of life (Stotz et al., 2023; Wicher, O'Neill & Holt, 2020). Diabetes education interventions are associated with positive health outcomes, such as improved HbA1c levels, healthcare engagement and fewer complications (see section 4.3). However, a National Diabetes Audit Report (2019) found that while 49% of those with T1DM were offered structured education, only 7.6% attended. Corresponding data for T2DM were 90% and 10.4%, respectively. Uptake rates of structured diabetes education is poor, and the NHS spends approximately £10 billion a year on diabetes, 80% of which is spent treating complications. This suggests more should be done to target improving structured education as a preventative measure against complications and poorer health outcomes.

## 4.3 NHS-Supported Interventions (DAFNE, DESMOND).

DAFNE is the leading structured skills-based education course for adults with T1DM, enabling patients to self-manage their diabetes (DAFNE, 2013). The original pilot study (Amiel et al., 2002) administered DAFNE in a RCT (Randomised Controlled Trial; study design where participants are randomly assigned to an experimental or control group) (N=169 with poor or moderate T1DM control), and found significant improvements in treatment satisfaction, psychological wellbeing and quality of life after 6 months compared to those without DAFNE attendance. These findings were replicated in other longitudinal studies, where significant reductions in anxiety, depression, distress and HbA1c were found after a year (Hopkins et al., 2012). Additionally, other studies found that DAFNE reduced severe hypoglycaemic events requiring emergency treatment by 82% (Elliot et al., 2014), and sustained quality of life improvements 4 years after attending DAFNE. Conversely, DESMOND is the leading structured education course for adults with T2DM, providing patients with the skills and education to manage their diabetes. The original study (Skinner et al., 2002) administered DESMOND in 236 individuals with T2DM, and significantly found reduced and lower HbA1c levels after 3 months. Illness beliefs also significantly improved, and participants felt more able to control their diabetes. Longitudinal research has also found significantly reduced diabetes-distress, and improved self-efficacy after 8 weeks (Hadjiconstantinou et al., 2021), and significant reductions in HbA1c levels after 12 months (Chatterjee et al., 2018).

However, despite these education courses being positively received and clinically effective (e.g., reducing HbA1c levels), course uptake in the UK is low (Whicher et al., 2020; see section 7.5), and a common criticism of these courses and structured education as a whole is the lack of emotional/psychological information (Diabetes UK, 2019; Primary Care Diabetes Society, 2018). For example:

> *"I feel that there should be a more structured support system in place for newly diagnosed diabetics. The DAFNE course is fantastic, but it does not deal with the emotional aspects of living with diabetes day-to-day. I think that there is a lot that can be done."* Person with T1DM (Diabetes UK, 2019).

As psychological wellbeing and physical health have a bi-directional relationship, it is essential to educate individuals, especially recently diagnosed, on how to manage the psychological side to living with diabetes. Although psychological problems may not affect everyone, or to the same extent, it works to prevent complications in the long term, as psychological difficulties can significantly impair diabetes self-care, health outcomes, and quality of life (see chapter 2).

## 4.4 Psychological and Resilience Based Interventions

A range of psychological interventions exist for diabetes patients, such as but not limited to: cognitive behavioural therapy (CBT), mindfulness interventions, problem solving therapy, and structured education (see Mei et al., 2023; Oyedeji, 2022). CBT is one of the most evidence-based psychological interventions used to treat several psychiatric disorders such as anxiety and depression (Gautam et al., 2020). The cognitive aspect focuses on the relationship between thoughts and emotions, and the behavioural aspect focuses on overruling learned associations. Through this, individuals can identify and challenge negative thoughts and beliefs, and develop more effective coping strategies to better manage stress and diabetes-related challenges (Fuller et al., 2020; Hessler et al., 2017). CBT is a commonly used therapeutic approach within diabetes interventions to enhance resilience-based skills and health outcomes such as HbA1c or DD (Pinto et al., 2024; Wu et al., 2023). Considering the variables discussed in chapter 2 (anxiety, fatigue, DD and cognition), CBT has been effective in significantly reducing health anxiety and DD, improving treatment adherence and quality of life (see Abbas et al., 2023).

For example, several meta-analyses studies examined CBT interventions in T1DM and T2DM and found significant reductions in HbA1c levels (i.e, improved diabetes management and health outcomes), DD, and anxiety from 3 to 8 months post-intervention (e.g., Jenkinson et al., 2022: n=4,123, 22 RCTs; Uchendu & Blake, 2017; Dong et al., 2023). These findings are also supported by Yang et al., (2020), who also found CBT interventions emphasising completing homework tasks, stress management and interpersonal strategies delivered by group work had the strongest reductions in HbA1c levels. Additionally, behavioural strategies had a better effect on glycaemic control, and cognitive strategies had a better effect on psychological symptoms (e.g., depression). In addition to CBT, mindfulness interventions are also utilised to foster greater attention to and awareness in one's present moment experience, and to encourage adopting an attitude of openness and acceptance to one's experience in a non-reactive orientation (Creswell, 2016; Gregg et al., 2019). As with CBT, this can aid cognitive appraisal and emotional regulation, and has successfully improved glycaemic control and reduced diabetes distress levels in T1DM and T2DM in 1 to 6 months post-intervention (e.g., Ngan et al., 2021; Ni et al., 2020). Other meta-analyses also report significant reductions in anxiety and stress in individuals with diabetes (e.g., Hamasaki, 2023). Collectively these findings suggest CBT and mindfulness are effective behavioural change techniques in relation to diabetes self-management.

Additionally, fatigue is largely overlooked in clinical diabetes settings, and few effective interventions target diabetes-related fatigue in T1DM and T2DM (see Romadlon et al., 2022, for a review). To my knowledge, the most recent review on DD-based intervention effects in T1DM and T2DM is by Scmidt et al. (2018); they found a stable medium effect size of psychological intervention treatment on DD, and a significant reduction in HbA1c levels. However, this improvement in glycaemic control was only significant if the psychological intervention was specific to diabetes (as opposed to general mindful-ness based interventions). This demonstrates a need for psychological-based interventions to be diabetes-tailored, for optimal therapeutic effects.

Based on available meta-analyses, DD and resilience appears to be the most targeted variable in psychological-based interventions, due to effectiveness in improving clinical outcomes (e.g., HbA1c and diabetes self-management). For example, a recent meta-analysis (Jin et al., 2023) found a bi-directional, positive relationship (medium effect size) between resilience and self-care across several chronic diseases (e.g., diabetes, chronic kidney disease, colon cancer, osteoarthritis). There is substantial research to suggest that regardless of age and disease status, resilience can be improved and maintained at any stage of life through learning and training (Babić et al., 2020; Jin et al., 2023;

Linz et al., 2020). Resilience intervention studies have found significant reductions in DD and HbA1c levels, and significant improvements in self-efficacy, quality of life and empowerment in T1DM and T2DM patients (e.g., Mei et al., 2023; Kusnanto et al., 2022; Luo et al., 2019; Torabizadeh et al., 2019; Wang et al., 2017; Hood et al., 2018). A recent meta-analysis across both T1DM and T2DM (*n*=2048; Wu et al., 2023) found resilience interventions significantly improved quality of life, DD levels, and reduced HbA1c up to 6 months after. Hood et al. (2018) found a resilience intervention significantly reduced DD, and at 16 months post intervention. Resilience interventions in T1DM and T2DM are abundant and suggest a variety of therapeutic effects (see also chapter 3). Despite this, there is a lack of consensus about any single framework to guide the development of resilience interventions in the context of diabetes (Pesantes et al., 2015; Speight et al., 2020; Davies et al., 2022).

## 4.5 Intervention Design

Complex interventions can be defined as interventions comprising of multiple interacting components, e.g., range of behaviours, number of components, methods of organising and delivering interventions (e.g., expertise or skills required), the number of groups, settings or levels targeted (Skivington et al., 2021). There are several existing frameworks, such as intervention mapping and the PRECEDE-PROCEED model (see Wight et al., 2016). The UK Medical Research Council (MRC) provides widely used comprehensive guidelines for the developing and evaluating health interventions, which will be described below (see Skivington et al., 2021; Wight et al., 2016). The aim of these guidelines are to facilitate interventions that are scientifically valid and practically applicable to improving health outcomes.

The framework outlines complex interventions through four phases; it is important to note a research programme may begin in any phase, as the process is iterative rather than linear. Phase 1 of this process is development; this stage involves reviewing the existing literature to define the problem, suggested causes, and clarifying which causal/contextual factors are malleable and have scope for change. This also includes identifying mechanisms of change and how these factors may develop a new or adapt an existing intervention. This PhD informs phase 1, as the aims are to further understand the relationships between psychological factors associated with diabetes, and how these may be mediated by resilience. However, further cross-sectional and longitudinal support will be required to support the findings of this PhD, before any considerations within intervention design can be made. Potential models for change, such as the COM-B model could be considered in designing interventions to implement the changes (Whittal et al., 2020). The COM-B model states there are 3 components to behaviour: Capability (i.e., physically able to do so); Opportunity (i.e., the social/physical opportunity for the behaviour); and Motivation (i.e., the need or want to carry out the behaviour). Therefore, interventions must target one or more of these components to deliver and maintain behavioural change (Whittal et al., 2020).

Phase 2 is feasibility, where researchers determine whether the intervention components can be implemented effectively. This stage may include piloting the study design to inform recruitment, retention, and identifying potential barriers and facilitators that may influence delivery/effectiveness of the intervention. Phase 3 is evaluation, where researchers test the efficacy of the intervention, typically through RCTs. This develops understanding of the intervention impact, and relationships between outcomes and intervention components. Lastly, phase 4 consists of implementation, where larger scale implementation of the intervention is delivered. This stage can also include disseminating findings to stakeholders, policymakers or practitioners, and integration of the intervention into real-world settings, requiring further adaptation. In the context of this framework, it is important that researchers monitor and evaluate the intervention over time to ensure it remains effective and applicable in changing contexts, especially in the face of new evidence. Throughout the process, researchers will also need to consider issues such as cost effectiveness, wider changes occurring as a result of the intervention, and how might the intervention effects be mediated by different settings and contexts (Skivington et al., 2021; Wight et al., 2016)

## 4.6 Summary of Overall Aim and Thesis Objectives

Before discussing the methodology of the thesis, the aims of this programme of research will be re-summarised. Overall, the thesis aims to provide recommendations for those who develop interventions for T1DM and T2DM groups. More specifically, to examine the relationships between psychological states and diabetes outcomes, with resilience as a potential mediator, in order to develop a more comprehensive model for type 1 and 2 diabetes. Also, to qualitatively explore the lived experience of individuals with diabetes, with a focus on elements from the model, and to gain insight into their healthcare education and experiences. See Figure 2 (section 1.11) for a flow chart that maps each thesis aim to the respective tasks/studies carried out across the PhD.

# Chapter 5. Methodology

## 5.1 Chapter Structure

Chapter 5 discusses and justifies the methodology chosen throughout this PhD (see respective study chapters for more specific information). First, the four types of mixed-methods approaches are outlined and reasons for adopting a sequential explanatory design are discussed. Then the chapter is presented in two sections, quantitative methods (study 1; questionnaires, correlations, SEM) and qualitative methods (studies 2 and 3; interviewing, thematic analysis), describing the associated methodology and respective justifications. Lastly, ethical approval and informed consent are described.

## 5.2 Mixed Methods Designs and Justification for use in Health-Based Research and this Thesis

In the last decade, mixed methods have become a more widely used paradigm for investigating phenomena especially in social sciences and health. (Rapport & Braithwaite, 2018; Shan, 2022). Mixed methods designs are defined as the combination of qualitative and quantitative research approaches regarding questions, methods, data collection, analysis, and inferencing within a project or study (Guest & Fleming, 2015; Schoonenboom & Johnson, 2017). The aim of combining approaches is to provide a deeper understanding of phenomena than a single method approach, by providing a fuller and more holistic picture (Guest & Fleming, 2015; Wasti et al., 2022). Due to the complex and multifactorial nature of diseases such as diabetes, no single research method is superior; an integration of quantitative and qualitative approaches is considered the most effective for gaining a more comprehensive understanding of the research issue (Creswell & Plano Clark, 2017; Kaur, 2016; Holloway & Wheeler, 2010). Both quantitative and qualitative mixed methods research contribute to clinical practice, that can be used to inform health care policies and interventions (Rapport and Braithwaite, 2018).

Creswell and Plano Clark (2011) suggested several advantages of integrating research approaches, which will be discussed in the context of this thesis. First, the strengths of one approach may offset limitations of another, for example, use of questionnaires in study 1 will allow observation of larger scale population traits and associations (i.e., breadth), although these measures have a limited number of structured questions and may not capture sufficient depth. Therefore, using qualitative methods in studies 2 and 3 could produce additional insight and support into factors already identified (via deductive analysis), and potentially capture other unanticipated topic facets that may be relevant to the research (via inductive analysis). Second, the ability to answer questions that a single method approach cannot, for example, quantitative methods are unable to effectively answer research questions regarding lived experience. Third, one data source may be insufficient to answer the research question. For example, the development of a model in study 1 is useful, but the overall aim is to apply the model to existing health-based interventions; therefore, an understanding of the lived experience underpinning this would be more sufficient. Fourth, to explain initial or exploratory findings, which is addressed by studies 2 and 3.

The nature of human health and disease is complex and multifactorial, and for diseases such as diabetes, the underlying psychological mechanisms are still not understood (Knowles et al., 2020; Wylie et al., 2019). Therefore, an integration of methods will best allow the benefits from each approach whilst minimising their disadvantages, allowing for a deeper and more valid understanding (Smajic, 2022). Furthermore, Hennick et al. (2015) conducted a systematic review of methodologies across 30 years of diabetes research (1980-2011). Out of 554 eligible articles, only 122 (22%) utilised mixed method approaches, where 10% of those were evaluative, and 9% were exploratory. This suggests there is a paucity of mixed methods research in this field, which needs to be addressed because evidence suggests using mixed methods can contribute to more effective and sustainable intervention development (Guest & Fleming, 2015; Wasti et al., 2022).

Creswell and Plano Clark (2017) argue that four main types of mixed methods design exist, triangulation, embedded, explanatory and exploratory: (a) Triangulation is a one-phase design used to directly compare and contrast quantitative and qualitative findings, or to validate quantitative results with qualitative data; (b) Embedded designs include both quantitative and qualitative data collection, but one data type plays a supplemental role within the overall design; (c) Explanatory designs include a two-phase process starting with collection and analysis of quantitative data, followed by a subsequent collection and analysis of qualitative data; (d) Exploratory designs are similar to explanatory, but begin with qualitative data testing and are followed by quantitative (Creswell & Plano Clark, 2017). In table 1, the general strengths and challenges for each design are considered.

Table 1. Evaluation summary of mixed-method designs

| Design | Strengths | Challenges |
|---|---|---|
| *Triangulation* | *Intuitive design; efficient due to concurrent data collection; both data types can be collected and analysed separately, making it effective for team research.* | *Effort and expertise required due to concurrent data collection and equal weight for both data types; difficulties may arise from non-concordant qual and quant results.* |
| *Embedded* | *Can be used when time is limited, since one data type is less weighted; logistically more manageable for graduate students; more appealing to funding agencies because primary design focus is traditionally quant.* | *Clearly specified purpose of collecting qual/quant as part of a larger qual/quant study needed; difficulty integrating results when the two methods are answering different research questions; sparse literature on embedding quant data within traditionally qual designs.* |
| *Explanatory* | *Straightforward implementation due to two-phase structure (suited to single researchers); final report can be written in two clear phases; design lends well to multiphase investigations; appeals to quant researchers, as it often begins with strong quant orientation.* | *Requires sufficient time for implementing two phases (and one phase may take longer than the other depending on research emphasis); researcher must decide whether to use same or different sample for both phases; second phase dependent on first phase findings and changes will need to be considered accordingly.* |
| *Exploratory* | *Straightforward implementation due to two-phase structure (suited to single researchers); final report can be written in two clear phases; inclusion of quant component can make qual aspect more acceptable to quant-based audiences; easily applied design to multiphase and single research studies.* | *Requires considerable implementation and planning time; researcher must decide whether to use same or different sample for both phases; second phase dependent on first phase findings and changes will need to be considered accordingly.* |

*Edited from Creswell & Plano Clark (2017)*

Choosing an appropriate design requires careful consideration of which approach is most suitable for answering the research question, the timing of data collection (i.e., concurrent/sequential) and whether the process is inductive or deductive where applicable (Schoonenboom & Johnson, 2017). This thesis adopts a sequential explanatory design; a two-phase process starting with collection and analysis of quantitative data, and the findings inform qualitative data collection and analysis. The first phase involves quantitative methods, as the first thesis objective was to develop and test a model based on a review of existing literatures. The quantitative method chosen was SEM, which is a group of multivariate statistical analysis methods that are used to examine a model of structural relationships between one or more measured variables and latent constructs (Abrahim et al., 2019). Using SEM is appropriate as it allows for simultaneous investigation of relationships between constructs, which will help to understand the interplay between the psychological and outcome variables (anxiety, fatigue, diabetes distress, cognition), and the potential for mediation by resilience. Additionally, this will provide a basis for further qualitative study into the model (i.e., second phase), which could provide insight into unaccounted factors, and help explain initial findings.

Another type of methodological design is Proof-of-Concept (POC); POC studies are designed to provide preliminary evidence of efficacy and feasibility regarding a concept or product, where typical examples could be drug testing/development or animal models (Boutrand, 2020; Karlsson et al., 2013). Whilst it could be argued study 1 is a POC by testing the feasibility of the model in adults with diabetes, sequential explanatory design is a more appropriate term for the design because: 1) it is a common term used in mixed methods research, which this PhD is, and 2) it provides more information than POC; i.e., it informs the order of processes and what type of research each phase consists of (e.g., quantitative phase followed by qualitative).

Table 2. Summary of PhD studies and their respective methodologies

| Study | Methodology |
|---|---|
| Study 1:<br>**PhD Phase 1** | **Quantitative Study (Correlations, SEM):** *Exploring the interplay of psychological states and diabetes outcomes, and the mediating effect of resilience: A structural equation model in adults with T1DM and T2DM* |
| Study 2:<br>**PhD Phase 2** | **Qualitative Study (Semi-Structured Interviews, Deductive & Inductive Thematic Analysis):** *A qualitative examination of the model developed in study 1: psychological states, resilience, diabetes outcomes and interventions in T1DM and T2DM* |
| Study 3:<br>**PhD Phase 2** | **Qualitative Study (Questionnaire Design, Deductive Thematic Analysis):** *A qualitative examination of resilience, diabetes education and intervention experiences in T1DM and T2DM patients* |

## 5.3 Study 1: Quantitative Design and Methods

### *5.3.1 Sample size*

Three key methods have been proposed to determine SEM sample size requirements: (a) the Satorra and Saris method (1985), (b) the MacCallum, Browne and Sugawara method (1996) and (c) the Monte Carlo simulation method (Muthén & Muthén, 2002). However, determining sample size in SEM can be challenging, and often ‘rule of thumb’ estimates are used to calculate these requirements (Wolf, Harrington, Clark & Miller, 2013). These rules can be problematic, and possibly lead to under- or overestimated sample size requirements. Some examples are: (a) a minimum sample size of 100 or 200 (Boomsma, 1982); (b) five or ten observations per estimated parameter (Bentler & Chou, 1987; see also Bollen, 1985) and (c) ten cases per variable (Nunnally, 1967).

Although there is no definitive consensus regarding SEM sample size, larger samples are more effective and less prone to technical problems in the analysis (Kline, 2016). However, some research has demonstrated SEM can perform well with smaller samples. For example, Wolf, Harrington, Clark & Miller (2013) conducted sample size requirements using the Monte Carlo analyses and found sufficient sample size requirements across CFAs (confirmatory factor analyses; A statistical technique to verify the factor structure of a set of observed variables) ranging from 30 (one factor CFA with four indicators loading at .80) to 460 (two-factor CFA and three indicators loading at .50). They also found the number of indicators in a model had an inverse effect on sample size requirements, and increasing the complexity of a model (e.g., member of factors) would necessitate an increased sample size. Sideris et al. (2014) also found a sample size of 50-70 was sufficient for a model of functional brain connectivity involving four latent variables. Iacobucci (2010) argues that if the measurements used have good reliabilities, each factor has three or four indicators and the structural path is not overly complicated, then samples of 50-100 can be sufficient. Planned sample size for the SEM was aimed for over *n* >200 (which was achieved).

### *5.3.2 Self-Report Measures used in Study 1*

The following measures were used in study 1; for all measures no recommended cut off points were observed to preserve the continuous nature of the constructs, rather than forcing a dichotomy which is not naturally occurring. Also, to prevent any floor and ceiling effects occurring. All scales are widely validated for use and reliable measures for their respective construct (see below).

Table 3. Summary of Questionnaires used in Study 1

| Questionnaire | Measure | No. of items | Scales/Subscales | Reported Cronbach's alpha |
|---|---|---|---|---|
| **Demographic Questionnaire** | Demographics (Diabetes type, age, gender, nationality, HbA1c, medication(s), treatment(s) for MH problems related to Diabetes). | 9 | N/A | N/A |
| **Diabetes Distress Scale** (DDS; Polonksy et al., 2005) | Diabetes Distress | 17 | Emotional Burden (EB),<br>Physician Related Distress (PRD),<br>Regimen Related Distress (RRD),<br>Interpersonal Distress (ID) | Total= .93,<br>EB= .88,<br>PRD= .88,<br>RRD= .90,<br>ID= .88. |
| **Penn State Worry Questionnaire** (PSWQ; Meyer et al., 1990). | Anxiety/Worry | 16 | Single factor | Total= .94 |
| **Flinder's Fatigue Scale** (FFS; Gradisar et al., 2007) | Fatigue | 7 | Single factor | Total= .88 |
| **Dysexecutive Questionnaire** (DEX; Wilson et al., 1996) | Executive dysfunction | 20 | Three-factor (Volition, Inhibition and Social Regulation). | Total= .90 (across 4 different raters) |
| **Connor-Davidson Resilience Scale** (CD-RISC: Connor & Davidson, 2003) | Resilience | 25 | Single factor | Total= .89 |

**Key:** *Diabetes Distress Scale (DDS); Emotional Burden (EB); Physician-Related Distress (PRD); Regimen-Related Distress (RRD); Interpersonal Distress (ID); Penn State Worry Questionnaire (PSWQ); Flinder's Fatigue Scale (FFS); Dysexecutive Questionnaire (DEX); Volition (VOL); Inhibition (INH); Social Regulation (SR); Connor-Davidson Resilience Scale (CD-RISC). For definitions, please see glossary (section 13).*

## *Participant Demographic Questionnaire*

The demographic questionnaire used in study 1 recorded the following: Diabetes type, age, gender, nationality, HbA1c, medications, and any treatment for mental health problems related to their diabetes (e.g., depression, anxiety, etc).

## *Penn State Worry Questionnaire (PSWQ)*

The PSWQ (Meyer et al., 1990) is a 16-item single factor scale, that measures the worry component of generalised anxiety disorder (GAD). Items use a 5-point Likert scale (1=very typical, 5=not typical at all), and scores range between 16 and 80, with a higher score indicating higher anxiety. Reported internal consistency (Cronbach's alpha) for this measure is .94 (.97 and .98 for study 1 diabetes groups, respectively).

The PSWQ was chosen for several reasons. Firstly, the PSWQ has been one of the most frequently used measures of generalised worry over the past 30 years, and is considered the 'gold standard' for measuring general anxiety/unspecific worry (Puccinelli et al., 2023). Additionally, the PSWQ displays psychometrically robust properties; it has been widely validated for use and reported internal consistency for this measure is .94 (Hanrahan et al., 2013; Ruiz et al., 2018). Considerations were also made for the GAD-7 scale, which is a broader tool designed to assess general anxiety disorders, including panic disorder, social anxiety and post-traumatic stress disorder (Spitzer et al., 2006). However, despite both being used as effective clinical and non-clinical measures (see Dear et al., 2011), the PSWQ provides a more nuanced understanding of the worry component of generalised anxiety disorder. As such, the GAD-7 was excluded and the PSWQ was chosen for this research.

### *Flinder's Fatigue Scale (FFS)*

The FFS (Gradisar et al., 2007) is a 7-item single factor scale measuring daytime fatigue (e.g., frequency, severity), often associated with insomnia. Six items use a 5-point Likert scale (1= not at all, 5=extremely), and item 5 uses a multiple item checklist. Scores range between 0-31, with higher scores indicating greater fatigue. Reported internal consistency for this measure is .91 (.92 and .90 for study 1 diabetes groups, respectively).

The FFS was chosen for several reasons. Firstly, the FFS was designed to be applicable across a range of chronic illnesses that frequently present fatigue as a symptom (e.g., chronic fatigue syndrome, chronic kidney disease, heart disease, fibromyalgia, autoimmune diseases; Gradisar et al., 2007). Fatigue and the aforementioned symptoms are all established comorbidities of diabetes (see Martinez-Ortega et al., 2022; Nowakowska et al., 2019), and so the FFS would be appropriate to diabetes populations. More specifically, the FFS measures a number of symptoms associated with daytime fatigue, such as: poor attention and concentration, memory impairment, mood disturbance, lack of motivation/energy, social/vocational dysfunction and daytime sleepiness; all of which are relevant to the operationalised definition of mental fatigue, stated in section 2.5. Secondly, the FSS was developed to address limitations of the Multifactorial Fatigue Inventory (MFI) and Fatigue Severity Scale (FSS), with regards to a lack of brevity and clinical sensitivity, respectively. The FFS has been validated and shown to have good convergent and divergent validity, and internal consistency (e.g., Cameron et al., 2017; Wen et al., 2020). It was chosen over the MFI due to brevity and strong psychometric properties (e.g., Cronbach's alpha values between 0.86-0.91, figures comparable to those found in MFI and FSS).

### *Diabetes Distress Scale (DDS)*

The DDS (Polonsky et al., 2005) measures diabetes-specific stress using a 17-item, 4-factor measure consisting of emotional, physician, regimen and interpersonal distress subscales (overall and subscale scores were used in correlational analyses, but only subscale totals were used in the SEM). Items use a 6-point Likert scale (1= not a problem, 6= very serious problem), and scores range between 17-102, where higher scores indicate greater distress. Items relating to their respective factor are averaged, where a mean score of 3 or higher indicates moderate distress, worthy of clinical attention. Reported internal consistencies for this measure were: .93 (total), .88 (Emotional Burden); .88 (Physician Related Distress); .90 (Regimen Related Distress), and .88 (Interpersonal Distress) (Total .94 and .95 for study 1 diabetes groups, respectively).

The DDS was chosen for several reasons. Currently, there are two widely and statistically accepted measures of DD (Berry et al., 2015): the Diabetes Distress Scale (DDS) and the Problem Areas in Diabetes (PAID) scale (see Polonsky et al., 2005; Welch et al., 2003). PAID and DDS scores are significantly associated with glycaemic control and self-care behaviours (McGuire et al., 2010; Asuzu et al., 2017), and both measures display good psychometric properties (e.g., high internal consistency, content validity). As such, they are used widely in research and clinical screening (Graue et al., 2012). Research also supports the cross-cultural applications of the PAID and DDS scales (e.g., Chew et al., 2015; Graue et al., 2012; Matsumoto et al., 2018). However, the PAID scale has two main limitations;

no questions address perceptions about health practitioners and received care (which are arguably important factors in DD), and no subscales are used to distinguish between elements of diabetes distress (e.g., interpersonal distress, physician-related distress or regimen-related distress; Berry et al., 2015; Polonksy, Fisher & Earles, 2005). The DDS was developed in response to these criticisms and as such was chosen for use in this programme of research.

### *Dysexecutive Questionnaire (DEX)*

The DEX (Wilson et al., 1996) measures cognition, specifically executive functioning, across a 20-item, three-factor measure consisting of volition, inhibition and social regulation subscales. Items use a 5-point Likert scale (1=never, 5= very often) and scores range between 0-80, with higher scores indicating greater problems with EF. Reported internal consistency for this measure was .90 (.88 for both study 1 diabetes groups).

**Factors**: There is discussion surrounding the issue of whether the DEX is a single or multiple factor model. Initially the DEX was released as a single factor model (Wilson et al., 1996), however some studies have found support for three factors (cognition, behaviour and emotion; see Wilson et al., 1998), four and five factors (inhibition, executive memory, intentionality, positive affect and negative affect; see Amevia, Phillips & Sala, 2003; Mooney et al., 2006). These mixed findings could be a result of sample characteristics such as participants' age range or whether they are a clinical population, as the DEX is typically used in small clinical populations with limited age ranges (Gerstorf et al., 2008). Shaw et al. (2015) conducted the first CFA (*n*=997; community 663, psychiatric e.g., anxiety 214; neurologically impaired 120) to validate factor structure in the DEX, where previous factor analyses were exploratory, and therefore less stringent than CFA. Results confirmed a three-factor structure as the most parsimonious (Inhibition, Volition, and Social Regulation), which was superior to several other three-, four- or five-factor models tested. The model also demonstrated good psychometric properties (e.g., internal consistency for community, psychiatric and neurological sample was .90, .91, and .91, respectively). As such, the three-factor model of DEX (Shaw et al., 2015) was used in the current research, which was supported by study 1 CFA findings.

The DEX scale was chosen for several reasons. Firstly, the DEX was developed to provide ecological validity for the Behavioral Assessment of the Dysexecutive Syndrome (BADS; Wilson et al., 1996), meaning the DEX is designed to assess difficulties experienced in everyday life, rather than more artificial tests. As the DEX targets a range of executive functions in daily settings/examples (e.g., planning, organisation, problem solving, attention, social regulation). This provides good face validity in terms of assessing executive functioning. Secondly, the DEX displays psychometrically robust properties across validation studies; for example, internal consistency values of ≥ .90 across 4 different types of raters (Bennett, Ong & Ponsford, 2005. See also Emmanouel et al., 2014; Shaw et al., 2015; Wakely et al., 2022). Considerations were also made for the BRIEF-Adult scale (Roth et al., 2005), which is 75-item scale, designed to measure executive functioning across 9 subscales. Given that both scales are psychometrically robust, the BRIEF-A was excluded for the DEX due to brevity (so as not to heavily burden participants).

### *Connor-Davidson Resilience Scale (CD-RISC)*

The CD-RISC (Connor & Davidson, 2003) measures resilience across a 25-item single factor scale, where resilience is defined as the capacity to adapt and maintain psychological and physical wellbeing in the face of stress, adversity or trauma (Terte et al., 2014). Items use a 5-point Likert scale (1=not true at all, 5=true nearly all the time) and scores range between 0-100, where higher scores indicate greater resilience. Reported internal consistency for this measure was .89 (.95 for both study 1 diabetes groups).

The CD-RISC was chosen for several reasons. Firstly, reviews (e.g., Salisu & Hashim, 2017; Windle et al., 2011) identified the best psychometrically rated scales used in resilience research: 1) CD-RISC; 2) Brief Resilience Scale (BRS); and 3) Resilience Scale for Adults (RSA). The CD-RISC is one of the most widely used instruments to assess psychological resilience due to its strong psychometric properties (Gonzalez et al., 2015; Velickovic et al., 2020). Secondly, CD-RISC has been used and validated in a wide range of fields (e.g., Gonzalez et al., 2015; Velickovic et al., 2020) but particularly in medical-based fields, so would seem appropriate for examining resilience in populations with chronic illnesses (i.e. diabetes).

The BRS and RSA were compared with the CD-RISC and eventually excluded due to their limitations. For example, a major criticism of the BRS is that it conceptually only centres around one's belief in recovering/bouncing back from stressors, and does not consider external factors such as social support which play an important role in resilience (Ye et al., 2022; see also Chapter 3). In contrast, the CD-RISC considers a multifactorial approach including accessibility to social and environmental resources (i.e., close and secure relationships, and knowing where to access help). Additionally, although the RSA and CD-RISC both assess a multifactorial perspective of resilience (i.e., both internal and external factors), the RSA does not include a timescale in the instructions, and statements are based on assessing protective factors which may foster resilience as opposed to directly assessing the ability to cope (Hjemdal et al., 2015; Ollis et al., 2022). As such, Ollis et al., (2022) recommends using the CD-RISC if researchers are more interested in overall ability to withstand stress despite challenges, whereas the RSA is more suited to examining protective factors that may foster resilience. The CD-RISC was therefore chosen as most appropriate scale for this PhD.

Lastly, it is important to note that the CD-RISC 25-item version was used in this study, although a shorter 10-item scale exists. Comparison studies report both scales with good internal consistency (e.g., Kuiper et al., 2019; Miller et al., 2021), although Kuiper et al., (2019) demonstrated improved convergent validity in the CD-RISC 10. Although both scales are valid and psychometrically robust, the shorter version should have been used instead; this will be taken into account in future research and is discussed further in the discussion (Chapter 9).

### *5.3.3 Analytical Strategy: Correlational and SEM Design*

Correlations were used to confirm associations between psychological states. Pearson's correlations measure the strength of the linear relationship between two variables; it has a value range between -1 to 1, where -1 suggests a total negative correlation, 0 suggests no correlation, and +1 suggests a total positive correlation (Bonett & Wright, 2000). Correlations were conducted on all variables in study 1;

this was to examine the relationship between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition), the potential for a mediating effect of resilience between psychological states and outcomes, and to assess multicollinearity between variables (to determine suitability for CFA and SEM).

Structural Equation Modelling is a combination of factor analysis and regression or path analysis (Boateng, 2018; Hancock, Stapleton & Mueller, 2018), which allows for complex and multidimensional analysis of empirical data, as well as relations between abstract concepts or theoretical constructs (Tarka, 2018). There are several advantages of using this technique for analysis; SEM allows researchers to investigate complex relationships in an integrative process, it is able to measure unobserved (latent) variables using observed variables (accounting for error measurement, rather than treating it separately) and SEM analysis simultaneously produces model fit indices alongside individual parameter estimates (Boateng, 2018; Schumacker & Lomax, 2010). For the above reasons, SEM was chosen as the most appropriate method for analysis. However, it is important to acknowledge limitations as the SEM conducted was not longitudinal, and so cannot inform structural relationships across time.

## 5.4 Studies 2 and 3: Qualitative Design and Methods

### *5.4.1 Sample size*

Reviews indicate qualitative research demonstrates a lower level of transparency regarding sample sizes and the underlying arguments for these (Carlsen & Glenton, 2011; Sim, Saunders, Waterfield & Kingstone, 2018; Mason, 2010). Rule of thumb estimates tend to be largely used, and ‘saturation’ is the prevailing concept for determining sample size in qualitative studies (Malterud, Siersma & Guassora, 2015). Saturation is defined as reaching a point in data collection/analysis where no new information is discovered, suggesting data collection may cease (Faulkner & Trotter, 2017). However, this term is closely tied to a specific methodology (Grounded Theory) and is inconsistently used in the literature. Malterud et al. (2015) suggest the concept of information power to guide adequate sample size – this concept suggests the more information the sample holds, relevant to the actual study, the smaller the number of participants are required.

Malterud et al. (2015) suggest sufficient information power depends on: (a) The aim of the study; (b) Sample specificity; (c) Use of established theory; (d) Quality of dialogue; and (e) Analysis strategy. Therefore, a study will require fewer participants when the study aims are narrow, if the participants recruited are specific for the study aim, if the study is supported by a theoretical basis, if the interview dialogue is strong, and if the analysis includes in-depth exploration of the data. Taking the above information into account, planned recruitment for study 2 (one-to-one interviews) aimed for a sample of 12-15 participants in each group (T1DM/T2DM). This is also supported by Braun and Clarke (2013), who recommend samples of 6-12 participants for interview projects. One of the aims of Study 3 (qualitative questionnaires) was to investigate findings from previous studies in a broader sample, to examine how study 2 themes and patterns expressed in a larger dataset, and so planned sample size was roughly *n*=100. TA can be used to analyse small and large datasets; current guidelines are varied (e.g., 2 – 100, Braun & Clarke, 2016; Fugard & Potts, 2015), where sizes of 10-50 are recommended for participant-generated text. Considering the importance of information power, and breadth versus depth, (e.g., looking at two diabetes groups) I have opted to collect a larger sample (n=100).

### *5.4.2 Interviews – Unstructured, Semi-Structured and Structured*

Semi-structured interviews are one of the most common methods of data collection in qualitative healthcare research and are used to explore the views and lived experiences of individual participants (Dejonckheere & Vaughn, 2019). There are three categories of research interviews: structured, semi-structured and unstructured; unstructured interviews are more guided conversions (Whiting, 2008; 2014), whereas structured interviews consist of a question set with little to no deviation (Gill et al., 2008). Semi-structured interviews typically follow a set of predetermined questions (i.e., interview guide) but with additional verbal prompts to investigate further dialogue, if appropriate (Gill et al., 2008). It is a guided and flexible approach, and best suited when investigating novel themes/issues where there is already some knowledge of the research topic (Whiting, 2014). This applies to this thesis, which is investigating the model from study 1, underpinned by a thorough literature review. Additionally, interviews allow for establishing trust and rapport, which is especially important when discussing sensitive topics, such as weight management, lifestyle difficulties, health conditions, which are all relevant in the domain of diabetes research (Dejonckheere & Vaughn, 2019). Lastly, the flexibility of this method allows for probing of information, which is effective in exploring important concepts outside of the direct research questions (i.e., inductive themes). Semi-structured interviews were therefore chosen as the most appropriate method for data collection in study 2.

### *5.4.3 Analytical Strategy: Reflexive Thematic Analysis*

Reflexive Thematic Analysis (TA) is described as a cluster of approaches, with the aim of systematically identifying, analysing and making sense of patterns across a dataset (Braun & Clarke, 2006; 2021). TA is a widely applied method for analysing qualitative data in health research fields (Campbell et al., 2021), and is effective in understanding perspectives and experiences of both patient and healthcare providers, to inform interventions and clinical guidelines. Reflexive TA (as outlined by Braun & Clark, 2006; 2012) has been chosen as the most appropriate method of analysis in studies 2 and 3 for several reasons. First, TA is not atheoretical, but it is not restricted to a particular 'inbuilt' framework, which is the case for other qualitative methods such as Interpretative Phenomenological Analysis (IPA), grounded theory or discourse analysis. This flexibility will allow for a broader examination of topics (i.e., lived experience of model in study 1 and other pertinent factors in the data, e.g., healthcare or intervention experiences), relative to IPA which was initially considered for analysis. Recommended sample sizes of TA and IPA were also considered when deciding the analytical method. Smith et al., (2009, p.56) suggest "there is no right answer to the question of sample size" in IPA research. However, due to IPA's idiographic focus smaller samples are commonly used, with default suggestions of 3 for undergraduate/Master's level study and 4-10 advised for doctorates. In some cases, single participant studies can be justified if sufficiently detailed/rich (Smith, 2004). In contrast, TA has less of an idiographic focus than IPA, and would be more appropriate with larger samples and more focus on patterned meaning across the dataset (Langdridge, 2007; Larkin et al., 2006; Smith et al. 2009). Samples of 6-10 are recommended by Braun & Clarke (2013).

The analytic focus of studies 2 and 3 are more suited to reflexive TA, compared to IPA. For example, Braun and Clarke (2020) recommend using TA over IPA in the following circumstances: 1) When analytic focus is solely on identifying themes across the dataset, rather than on the unique features of individual cases (i.e., which is the case with examining the proposed model and interactions between psychological variables in studies 2 and 3); 2) When there is a need for the research to have actionable outcomes, with implications for practice (i.e., this PhD aims to produce tangible recommendations for future research including interventions); and 3) when the analytic interest lies in how personal experiences are located within wider socio-cultural contexts (e.g., education and stigma within diabetes and non-diabetes populations). Ultimately, reflexive TA is more aligned with the analytic focus; the process outlined by Braun and Clarke (2006; 2012) provides a systematic TA guide which is followed in studies 2 and 3 (see chapters 7 and 8 respectively, for specific details).

## 5.5 Ethics and Informed Consent

Ethical approval was obtained for all research studies conducted within this PhD; approval was granted by the University of Central Lancashire Science Ethics committee. No ethical concerns or issues were raised whilst conducting these studies, and all participants were provided with informed consent. Consent was obtained via electronically signed consent forms, or online through questionnaire completion and submission. All consent forms and research data (e.g., raw data, interview transcripts) were stored on a password-protected laptop only accessible by the researcher, and names/any identifying information (e.g., locations) were replaced with pseudonyms or generic terms to protect participant anonymity. All participants were debriefed on completion of a study and were aware that data may be anonymously used within the thesis or research publications/conferences.

NHS ethics would be required to recruit participants through the NHS, and applications can take approximately 2 months (Health Research Authority, 2024). Due to time constraints of the PhD and accounting for interruptions at the time of study 3 planning, it was decided not to apply for NHS ethics and to try and recruit through the same methods as for study 2. In retrospect, it would have been useful to have applied for NHS ethics, and this will be taken into account for future research.

## 5.6 Recruitment and Sampling

For each study, opportunity and snowball sampling were used to recruit participants. No processes to ensure sample diversity were used due to the main concern of achieving planned numbers with tight deadlines for data collection (due to interruptions, e.g., family bereavement, and problems focusing). This is acknowledged as a limitation of the sampling as the studies need to have a more diverse and representative sample. In future research, stratified sampling will be used to counter this.

# Chapter 6: Study 1. Exploring the interplay of psychological states and diabetes outcomes, and the mediating effect of resilience: A structural equation model in adults with type 1 and 2 diabetes

## 6.1 Chapter Structure

This chapter describes study 1; SEM was used to test a model developed from the literature review in chapters 2-3. This study had three aims: (a) to examine associations between mood states (exogenous variables: anxiety and fatigue) and diabetes outcomes (endogenous variables: diabetes distress and cognition); (b) explore whether resilience mediated the association between mood states and diabetes outcomes; (c) to assess whether individuals with 1 and type 2 diabetes differ in relation to covariances amongst the afore-mentioned variables. Sections will appear in the following order: Abstract, Introduction, Method, Results, Discussion and Conclusions. See Appendix 1 for a copy of the published study.

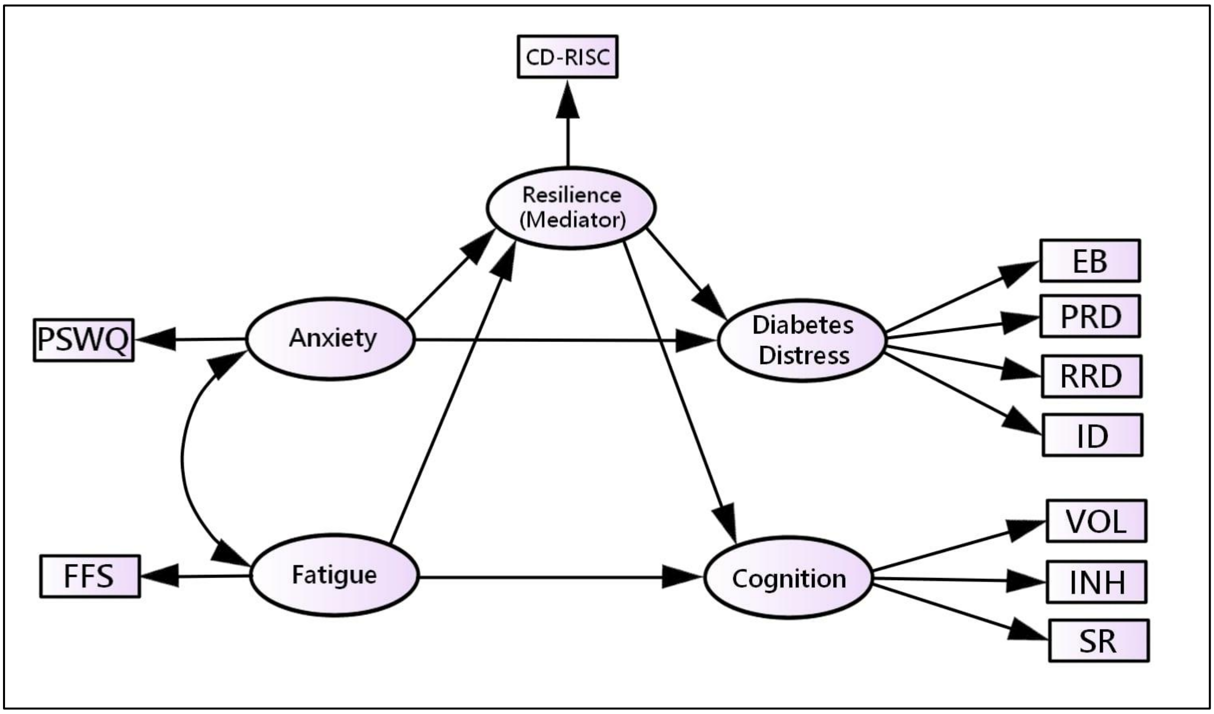
## 6.2 Introduction

The two main classifications of diabetes are T1DM and T2DM, and whilst they share clinically similar symptoms, the aetiology of the disorder types differs significantly (Zaccardi et al., 2016). Both have a strong genetic component (Zaccardi et al., 2016), and inadequate long-term self-management is associated with greater risk of serious acute complications (e.g., coma) and chronic (e.g., cardiopathy, sexual dysfunction, retinopathy, nephropathy, limb loss) (NHS, 2021). Approximately one third of people with T2DM, and two thirds of people with T1DM do not achieve the target glycated haemoglobin (HbA1c) levels (NHS, 2021). Glycated haemoglobin is considered the ‘gold standard’ for predicting micro- and macrovascular complications related to diabetes, across 5-10 years (Klein & Buse, 2020). Therefore, achieving target HbA1c levels are important in maintaining good long-term cardiovascular health and preventing complications (see chapter 1). The constant demands of living with diabetes can also take a significant psychological toll, with many individuals experiencing distress, depressed mood, anxiety, fatigue and reduced quality of life (Wylie et al., 2019; Robinson et al., 2018). The rising burden of diabetes globally is a major health priority, placing increased demands on patients, carers, health systems and society (Forouhi & Wareham, 2019).

Identifying and understanding the key psychological factors that contribute to diabetes management and outcomes is therefore a key priority.

Existing literature shows individuals with either T1DM or T2DM suffer from high levels of anxiety and fatigue, with diabetes distress and executive functioning (EF) issues (Fritschi & Quinn, 2010). Diabetes distress and EF issues are positively associated with each other, and with anxiety and fatigue (Ba et al., 2021; Fritschi et al., 2012; Fritschi & Quinn, 2010; Goendorp et al., 2014; Griggs & Morris, 2018; Hidayat et al., 2020; Hill et al., 2013; Menting et al., 2016; Nguyen et al., 2020; Pietrzak et al., 2012; Raffield et al., 2016; Shaban et al., 2009). Resilience is an increasingly important factor in diabetes self-management because resilience can be taught through intervention (Katcham et al., 2020; Wang et al., 2021). In particular, resilience interventions have been used to target glycaemic control, self-management behaviours, and diabetes distress to improve health outcomes (de Wit et al., 2020). For example, significant improvements in hbA1c have been found in both type 1 and 2 diabetes at 6 months post- resilience intervention: -0.68%/7.4 mmol/mol (Dubois et al., 2020) and 0.5%/3.9mmol/mol (Pyatak et al., 2018). See Wu et al., (2023) for a systematic review. Resilience is defined as the capacity to adapt and maintain psychological and physical 'wellbeing' in the face of adversity (Terte et al., 2014), and has been found to correlate negatively with anxiety, fatigue, diabetes distress and cognitive dysfunction (Frazao et al., 2018; Hood et al., 2018; Murdock et al., 2016; Ruiz-Aranda et al., 2020; Santos et al., 2013; Scott et al., 2020; Terte et al., 2014; Vemuri et al., 2019; Wang et al., 2017; Wang et al., 2021; Yi-Frazier et al., 2015). These patterns of associations suggest that resilience may act as a mediator (Hayes, 2022), but not a moderator; research suggests a causal relationship between anxiety/fatigue and resilience, and resilience and diabetes distress/cognition, therefore resilience cannot theoretically be a moderator variable (Hayes, 2022). Studies have yet to explore the role of resilience in conjunction with anxiety, fatigue, diabetes distress and executive dysfunction simultaneously, within one model; this is the focus of the present research and is depicted within Figure 3:

**Figure 3:** *Proposed Structural Model: Psychological States (Anxiety/Worry, Fatigue), and Diabetes Outcomes (Diabetes Distress, Cognition), with Resilience as Mediator*



***Key**: PSWQ (Penn State Worry Questionnaire); FFS (Flinder's Fatigue Scale); CD-RISC (Connor-Davidson Resilience Scale), DDS (Diabetes Distress Scale, using four subscales: Emotional Burden, Physician Related Distress, Regimen Related Distress, Interpersonal Distress); DEX (Dysexecutive Questionnaire, using three subscales: Volition, Inhibition and Social Regulation).*

**Fig 3** The proposed structural model shows association pathways between predictor variables (Anxiety, Fatigue) and Diabetes Outcome variables (Diabetes Distress, Cognition), mediated by Resilience. The boxes indicate the measures used to assess their respective variable.

Existing literature suggests direct associations between anxiety (predictor) and diabetes distress and cognition (outcomes), and between fatigue and cognition. There is still little research to suggest a direct link between fatigue and diabetes distress (Fritschi & Quinn, 2010). Park et al. (2015) found the relationship between fatigue and diabetes distress was mediated by diabetes symptoms, suggesting the relationship may be an indirect one, and is reflected as such in the proposed model (see Figure 3).

Winkley et al. (2020) suggests future research should focus on underlying theories, rather than replicating existing psychological models that usually deliver small effect sizes. Since theory-based interventions are more likely to produce longer-lasting and larger effects than those without (Zhao et al., 2017), this supports the need to focus more on the underlying mechanisms, with a focus on the psychosocial effects of living with and managing diabetes (Wylie et al., 2019). Therefore, the overall aim was to formulate and test an original model, based on a review of existing literatures, that could be used to provide guidance for those designing interventions for T1DM and T2DM groups. More specifically, the study aims were to: (a) explore whether resilience mediated the association between psychological states and diabetes outcomes, and (b) to assess whether T1DM and T2DM diabetics differ in relation to covariances amongst the afore-mentioned variables.

Based on the above literature (see also chapters 2-3), the hypotheses for the proposed structural model are as follows:

Direct relationships will be:

- **$H_1$ –** Anxiety/Worry will be positively related to Diabetes Distress

  *(Hill et al., 2013; Menting et al., 2016; Nguyen et al., 2020)*
- **$H_2$** – Anxiety/Worry will be negatively related to cognition

  *(Murdock et al., 2016; Pietrzak et al., 2012; Raffield et al., 2016; Shaban et al., 2009)*
- **$H_3$** – Fatigue will be negatively related to cognition

  *(Goendorp et al., 2014; Griggs & Morris, 2018; Hidayat et al., 2020; Menting et al., 2016)*

The mediating relationships will be:

- **$H_{4, 5, 6,7}$** – Anxiety and fatigue will predict diabetes outcomes of distress and cognition, and these relationships will be mediated by resilience

  *(Frazao et al., 2018; Hood et al., 2018; Murdock et al., 2016; Ruiz-Aranda et al., 2020; Santos et al., 2013; Scott et al., 2020; Terte et al., 2014; Vemuri et al., 2019; Wang et al., 2017; Wang et al., 2021; Yi-Frazier et al., 2015).*

## 6.3 Method

### *6.3.1 Design*

A correlation design was used to investigate the strength and direction of associations between the following variables in people with T1DM and T2DM: anxiety, fatigue, diabetes distress, cognition and resilience (as a potential mediator).

### *6.3.2 Participants*

Adults in the UK with T1DM (n = 129) and T2DM (n = 178) were recruited via diabetes support groups, local newspaper advertisements and social media advertisements. Participants completed an e-survey, created using the platform Qualtrics. Exclusion criteria included people below the age of 18 years, those with diabetes that is not T1DM/T2DM, and those who failed to state diabetes type. The desired sample size was 200, and this was achieved.

Both T1DM and T2DM groups were mostly female (gender) (77.5% and 79.2%, respectively), with mean ages of 432.41 (*SD = 178.99)* and 663.99 (*SD = 129.65)*, and were white British (80.6% and 72.5%, respectively). T1DM durations ranged from 5 - 960 months (80 years), whereas T2DM ranged from 1 – 444 months (37 years). Average diabetes durations were 235.71 (T1DM), 97.08 (T2DM), and average HbA1c levels were 62.11 mmol/mol (T1DM) and 62.271 mmol/mol (T2DM).

Table 4. Means (and Standard Deviations) for Participant Classification Information and Demographics

| | **Type 1 (N=129)** | **Type 2 (N=178)** | **Total (N=307)** |
|---|---|---|---|
| | Male (27) Female (100) | Male (36) Female (141) | |
| **Age*** | 36.03 *(14.92)* | 55.36 *(10.78)* | 47.24 *(15.86)* |
| **Diabetes Duration*** | 19.64 *(14.93)* | 8.07 *(7.11)* | 12.93 *(12.46)* |
| **HbA1c**** | 62.11 *(17.01)* | 62.271 *(18.68)* | 62.204 *(17.93)* |
| ***Ethnicity (see 2021 Census)*** | | | |
| **White** | 128 | 173 | 299 |
| **Black, Black British, Caribbean or African** | - | 1 | 1 |
| **Mixed, or Multiple Ethnic Groups** | | 1 | 1 |
| **Asian/Asian British** | 1 | 3 | 4 |
| **Other Ethnic Group** | - | - | - |

**Age and Diabetes Duration measured in years*
*** Measured in mmols/mol (International Federation of Clinical Chemistry units; IFCC).*

### *6.3.3 Sample size Requirements for Structural Equation Modelling*

The desired sample size was n=200, which was achieved for this study. See also chapter 5 for detailed rationale.

### *6.3.4 Materials and Procedure*

Participants were provided a link to an anonymous survey, first directing them to the study participation information sheet. Consent was confirmed through completing and submitting the questionnaires. Any participants who did not submit at the end of the survey were deemed to have withdrawn and their data was not used.

### *Anxiety/Worry (Psychological State Latent Variable)*

Anxiety/worry was assessed using the Penn State Worry Questionnaire (PSWQ; Meyer et al., 1990), a 16-item single factor scale that is considered the ‘gold standard’ for measuring unspecific worry. Scores range between 16 and 80, with a higher score indicating higher anxiety. Internal consistency (Cronbach’s alpha) for this sample was .97 and .98 for T1DM and T2DM groups, respectively.

### *Fatigue (Psychological State Latent Variable)*

Fatigue was measured using Flinder’s Fatigue Scale (FFS; Gradisar et al., 2007), a 7-item single factor scale measuring daytime fatigue (e.g., frequency, severity), often associated with insomnia. Six items use a 5-point Likert scale, and item 5 uses a multiple item checklist. Scores range between 0-31, with higher scores indicating greater fatigue. Internal consistency for this sample was .92 and .90 for T1DM and T2DM groups, respectively.

### *Diabetes Distress (Diabetes Outcome Latent Variable)*

Diabetes-specific Distress was assessed using the Diabetes Distress Scale (DDS; Polonsky et al., 2005), a 17-item, 4-factor measure consisting of emotional, physician, regimen and interpersonal distress subscales (overall and subscale scores were used in correlational analyses, but only subscales were used in the SEM). Scores range between 17-102, where higher scores indicate greater distress. Items relating to their respective factor are averaged, where a mean score of 3 or higher indicates moderate distress, worthy of clinical attention. Internal consistency for this sample was .94 and .95 for T1DM and T2DM groups, respectively.

### *Cognition (Diabetes Outcome Latent Variable)*

Cognition/EF was assessed using the Dysexecutive Questionnaire (DEX; Wilson et al., 1996), a 20-item, three-factor measure consisting of volition, inhibition and social regulation subscales. Scores range between 0-80, with higher scores indicating greater problems with EF. Internal consistency for this sample was .88 for T1DM and T2DM groups.

### ***Resilience (Mediator Variable)***

Resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC; Connor & Davidson, 2003), a 25-item single factor scale, where resilience is defined as the capacity to adapt and maintain psychological and physical wellbeing in the face of stress, adversity or trauma. Scores range between 0-100, where higher scores indicate greater resilience. Internal consistency for this sample was .95 for T1DM and T2DM groups.

### *6.3.5 Data Analytic Strategy (SEM)*

Structural equation modelling was chosen for analysis as it is a flexible method that can be used to explore relationships between latent variables (Boateng, 2018), using AMOS (version 27). Two psychological state latent variables (anxiety and fatigue) were categorised as predictor variables. A third latent variable was resilience (mediator variable). Two diabetes outcome latent variables (diabetes distress and cognition) were categorised as outcome variables. Figure 3 shows the operationalisation of exogenous, endogenous and mediator variables. As recommended in SEM literature (Boateng, 2018), an alternative model was also tested, whereby diabetes distress was incorporated as an exogenous variable rather than endogenous, based on existing literature findings (Park et al., 2015).

The Maximum Likelihood (ML) chi-square statistic was used to evaluate the measurement and structural models, as it is considered to be computationally more thorough; it assumes multivariate normality among the observed variables, which leads to more efficient inferences (Boateng, 2018). ML allows for the acquisition of estimates of the unknown parameters, such that the values obtained maximise the likelihood that the phenomenon described by the model produced the data that was actually collected. However, since this is sensitive to sample size, the normed chi-square ($\chi 2$ /df) was also used alongside several other indices to assess model fit, including: comparative fit index (CFI), Tucker-Lewis index (TLI), incremental fit index (IFI), root mean square error of approximation (RMSEA) and standardised root mean square residual (SRMR). Hu & Bentler (1999) suggested acceptable cut-off criteria indicative of good model fit are >.95 (CFI, TLI, IFI). However, given the exploratory nature of this study, it was decided best to use more conservative criteria, indicative of moderate fit. Therefore, the following cut-offs for acceptable model fit were used: $\chi^2$/df 1-5; CFI, TLI and IFI >.90; RMSEA ≤.06 - .08; and SRMR ≤ .08 (Hu & Bentler, 1999; Schreiber, 2008). Standardised regression weights were used to interpret direct effects, and bias-corrected bootstrap confidence intervals technique was used to assess the significance of standardised indirect effects.

## 6.4 Results

### *6.4.1 Preliminary Analyses*

Data were examined for missing values, outliers, and normal distribution. Missing value analysis for validated measures were <5%, missing variables at random (Little's MCAR test: Chi-Square = 42895.414, df = 42606.00, Sig = 0.161). Missing values were replaced using person mean substitution by scale/subscale. Outlier detection revealed seven univariate outliers that were dealt with using winzorising (replacing the closest legal value for the scale/subscale; see Kwak & Kim, 2017), and five multivariate outliers were removed. Given the large sample size (N > 300), distribution shape/skewness and kurtosis were used to determine normality (Field, 2009; Hae-Young, 2013). Mean and *SD* values were calculated for all variables recorded, separately for T1 and T2 groups, and independent samples t-tests, Pearson's correlations and SEM analyses were then run separately for each diabetes group. See Appendix 8 for the table of means and SDs. See figure 4 below for a consort diagram detailing information drop out and uptake.

**Figure 4.** Consort diagram

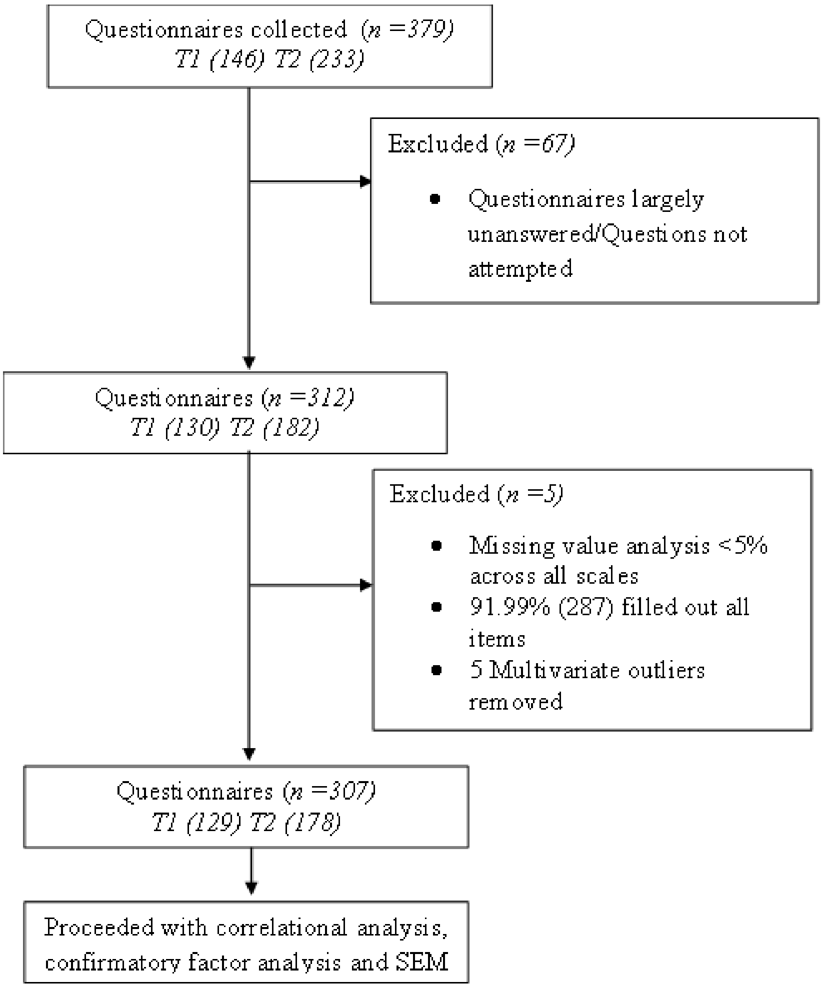


**Fig 4**. consort diagram detailing information drop out and uptake throughout the data collection process, and missing value analysis before proceeding with correlational and SEM analyses.

### *6.4.2 Correlational Analyses*

Pearson’s correlations were conducted to examine **a)** the relationship between psychological states (anxiety, fatigue) and diabetes outcome measures (diabetes distress, cognition), **b)** multicollinearity i.e., high correlations between indicators of psychological state latents and indicators of the outcome measures with each other, and **c)** the potential for a mediating relationship of resilience between psychological states and diabetes outcomes. These correlations were undertaken for T1DM (N=129) and T2DM (N=178) diabetes groups separately. Effect sizes (*r* values) were deemed to be small, medium, or large if they were .10, .30, or .50, respectively (Cohen, 1988).

## Table 5. Correlations (*Pearson's r)* between Mood States, Resilience and Diabetes Outcomes in T1DM and T2DM Groups

| | PSWQ | FFS | DDS_TOT | DDS_EB | DDS_PRD | DDS_RRD | DDS_ID | DEX_TOT | DEX_VOL | DEX_INH | DEX_SR | CDRISC |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| PSWQ | - | .41$^{**}$ | .57$^{**}$ | .59$^{**}$ | .32$^{**}$ | .54$^{**}$ | .38$^{**}$ | .44$^{**}$ | .55$^{**}$ | .34$^{**}$ | -.03 | -.52$^{**}$ |
| FFS | **.46**$^{**}$ | - | .49$^{**}$ | .49$^{**}$ | .37$^{**}$ | .33$^{**}$ | .43$^{**}$ | .30$^{**}$ | .41$^{**}$ | .18$^{*}$ | .07 | -.34$^{**}$ |
| DDS_TOT | **.49**$^{**}$ | **.50**$^{**}$ | - | .88$^{**}$ | .74$^{**}$ | .86$^{**}$ | .81$^{**}$ | .41$^{**}$ | .48$^{**}$ | .31$^{**}$ | .15 | -.51$^{**}$ |
| DDS_EB | **.53**$^{**}$ | **.50**$^{**}$ | **.89**$^{**}$ | - | .48$^{**}$ | .70$^{**}$ | .64$^{**}$ | .43$^{**}$ | .48$^{**}$ | .35$^{**}$ | .09 | -.50$^{**}$ |
| DDS_PRD | **.24**$^{**}$ | **.32**$^{**}$ | **.80**$^{**}$ | **.60**$^{**}$ | - | .47$^{**}$ | .53$^{**}$ | .29$^{**}$ | .29$^{**}$ | .22$^{*}$ | .14 | -.30$^{**}$ |
| DDS_RRD | **.42**$^{**}$ | **.48**$^{**}$ | **.87**$^{**}$ | **.71**$^{**}$ | **.53**$^{**}$ | - | .59$^{**}$ | .35$^{**}$ | .43$^{**}$ | .30$^{**}$ | .12 | -.50$^{**}$ |
| DDS_ID | **.47**$^{**}$ | **.39**$^{**}$ | **.84**$^{**}$ | **.71**$^{**}$ | **.59**$^{**}$ | **.65**$^{**}$ | - | .25$^{**}$ | .32$^{**}$ | .09 | .15 | -.34$^{**}$ |
| DEX_TOT | **.45**$^{**}$ | **.46**$^{**}$ | **.42**$^{**}$ | **.43**$^{**}$ | **.19**$^{*}$ | **.44**$^{**}$ | **.35**$^{**}$ | - | .85$^{**}$ | .83$^{**}$ | .61$^{**}$ | -.50$^{**}$ |
| DEX_VOL | **.48**$^{**}$ | **.59**$^{**}$ | **.51**$^{**}$ | **.53**$^{**}$ | **.27**$^{**}$ | **.50**$^{**}$ | **.42**$^{**}$ | **.82**$^{**}$ | - | .58$^{**}$ | .37$^{**}$ | -.58$^{**}$ |
| DEX_INH | **.32**$^{**}$ | **.31**$^{**}$ | **.23**$^{**}$ | **.25**$^{**}$ | **.07** | **.29**$^{**}$ | **.16**$^{*}$ | **.82**$^{**}$ | **.51**$^{**}$ | - | .46$^{**}$ | -.28$^{**}$ |
| DEX_SR | **.13** | **.14** | **.18**$^{*}$ | **.20**$^{**}$ | **.10** | **.17**$^{*}$ | **.15**$^{*}$ | **.61**$^{**}$ | **.34**$^{**}$ | **.44**$^{**}$ | - | -.18$^{*}$ |
| CDRISC | **-.47**$^{**}$ | **-.44**$^{**}$ | **-.47**$^{**}$ | **-.46**$^{**}$ | **-.27**$^{**}$ | **-.45**$^{**}$ | **-.39**$^{**}$ | **-.41**$^{**}$ | **-.53**$^{**}$ | **-.16**$^{*}$ | **-.23**$^{**}$ | - |

Type I = top half of matrix, **Type II = bottom half of matrix**
$^{**}$ Correlation is significant at the 0.01 level; $^{*}$Correlation is significant at the 0.05 level.

**Key:**
**Psychological States: PSWQ** (Measuring Anxiety); **FFS** (Measuring Fatigue).
**Resilience: CD-RISC** (Measuring Resilience).
**Diabetes Outcomes: DDS** (Measuring diabetes distress); **EB** (Emotional Burden); **PRD** (Physician-Related Distress); **RRD** (Regimen-Related Distress); **ID** (Interpersonal Distress); **DEX** (Measuring Cognitive dysfunction); **VOL** (Volition); **INH** (Inhibition); **SR** (Social Regulation).

**T1DM Correlations:** All psychological state and diabetes outcome variables were significantly positively correlated, except from the cognition (social regulation only) values. Correlations between components of diabetes distress, anxiety, fatigue and cognition were significant and typically moderate in strength. All psychological state and diabetes outcome variables were significantly negatively associated with resilience values, and typically moderate to strong in strength.

**T2DM Correlations:** All psychological state and diabetes outcome variables were significantly positively correlated, except from the cognition (social regulation only) values, as in T1DM. Correlations between components of diabetes distress, anxiety, fatigue and cognition were significant and typically moderate in strength. All psychological state and diabetes outcome variables were significantly negatively correlated with resilience values, and typically moderate to strong in strength.

### *6.4.3 Measurement Models: Confirmatory Factor Analysis (CFA)*

#### ***Factor loading, and Reliability and Validity***

Using a factor loading of at least .40 (Boateng, 2018), 6 items were deleted and excluded from the analysis. To assess the reliability and validity of scales used, Composite Reliability (CR) and Average Variance Extracted (AVE) values were calculated, and all scales met acceptable cut-off values for Cronbach's alpha (>.70) and CR (>.60), demonstrating adequate reliability (Hair et al., 2010). See Appendix 9 for the table of full CFA measurements for model 1 in T1DM and T2DM groups.

#### ***Multigroup CFA: Model Fit Statistics, T1DM and T2DM Groups***

Pearson's correlations were conducted between the latent variables in both diabetes groups; all correlations between psychological states, resilience and diabetes outcomes were significant, with no evidence of multicollinearity ($r \leq .90$). Fit indices are presented in Table 6; All indicators loaded onto their respective factors (>.40), and each scale achieved acceptable values in ≥3 fit indices. This suggests the data is suitable for SEM analysis.

Table 6. Confirmatory Factor Analysis Fit Indices (Chi Square, CFI, IFI, TLI, RMSEA and SRMR) in T1DM and T2DM Groups

| **Scale** | $\chi^2/df$ **(≥ 1 to 5)** | Comparative Fit Index (CFI; ≥ **0.90)** | Incremental Fit Index (IFI; ≥ **0.90)** | Tucker-Lewis Index (TLI; ≥ **0.90)** | Root Mean Square Error of Approx. (RMSEA; **≤.06 - .08)** | Stand. Root Mean Square Residual (SRMR; ≤ **.08)** |
|---|---|---|---|---|---|---|
| DDS | **2.33(p<.001)** | **0.93** | **0.93** | **0.91** | **0.07** | 0.16 |
| PSWQ | **4.06(p<.001)** | **0.90** | **0.91** | 0.89 | 0.10 | **0.07** |
| FFS | **2.50(p<.001)** | **0.98** | **0.98** | **0.97** | **0.07** | **0.06** |
| DEX | **1.88(p<.001)** | **0.94** | **0.94** | **0.92** | **0.05** | **0.07** |
| CD-RISC | **2.15(p<.001)** | 0.89 | 0.89 | 0.88 | **0.06** | **0.07** |

**Key:** ***Psychological States:*** **PSWQ** (Penn State Worry Questionnaire); **FFS** (Flinder's Fatigue Scale). ***Resilience:*** **CD-RISC** (Connor-Davidson Resilience Scale). ***Diabetes Outcomes:*** **DDS** (Diabetes Distress Scale); **DEX** (Dysexecutive Questionnaire)

### *6.4.4 Structural Models*

A diagrammatic representation of the structural model (for T1DM and T2DM) is presented in figures 4 and 5. This shows the standardised path coefficients, significance levels and $R_2$ values, which indicate the amount of variance explained by the independent variables. The values of fit statistics for the structural model were all found to be within acceptable limits: $\chi^2$ (Chi-Square) = 139.905, $df$ = 58, and $\chi^2/df$ ratio = 2.41, CFI = .94, IFI = .94, TLI = .90, RMSEA = 0.07, and SRMR = 0.07.

**Figure 5.** *Structural Model for T1DM*

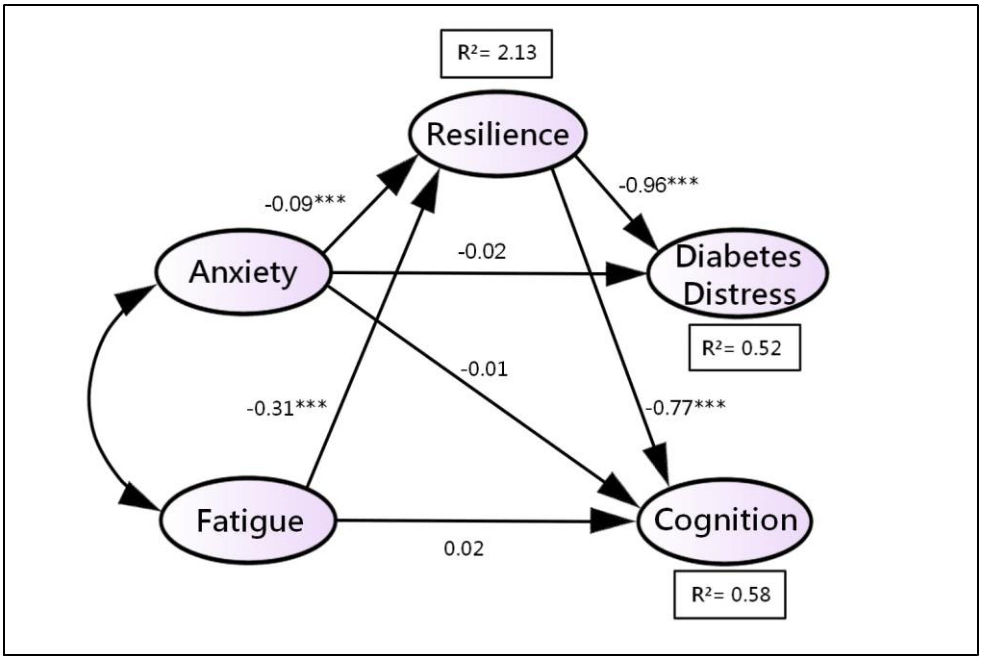


**Fig 5** The structural model shows pathway coefficients between predictor variables, resilience, and diabetes outcome variables in the T1DM group. All indirect pathways (i.e. involving the mediator) were significant, and direct pathways were non-significant) *** *p = <.001, *** *p = < .05.*

**Figure 6.** *Structural Model for T2DM*

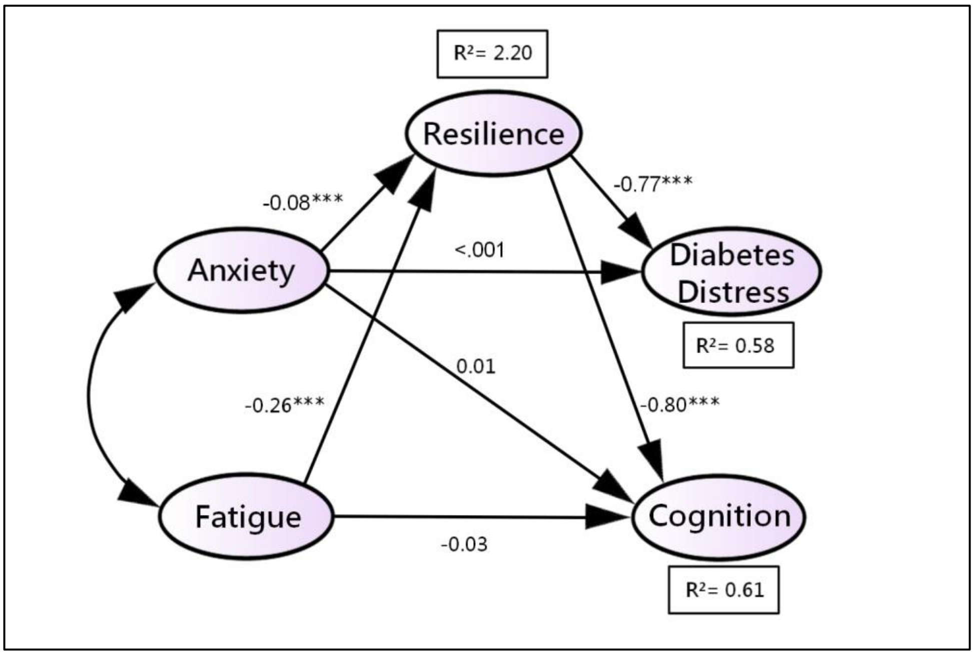


**Fig 6** The structural model shows pathway coefficients between predictor variables, resilience, and diabetes outcome variables in the T2DM group. All indirect pathways (i.e. involving the mediator) were significant, and direct pathways were non-significant) *** *p = <.001, *** *p = < .05.*

The results of initial hypotheses tests for each path in the structural model are summarised in table 7.

Table 7. SEM results for T1DM and T2DM groups, showing standardised coefficients, t-values, and significance

| **Hypothesised Path** | **Standardised Coefficients, β** | ***t* (C.R.)** | ***p*** | **Hypothesis** |
|---|---|---|---|---|
| ***Direct Relationships*** | | | | |
| **$H_1$** Anxiety/Worry → Diabetes Distress | -0.02 **(0.01)** | -1.59 **(-0.07)** | .112 **(.942)** | Not Supported |
| **$H_2$** Anxiety/Worry → Cognition | -.01 **(0.01)** | -0.90 **(0.98)** | .369 **(.325)** | Not Supported |
| **$H_3$** Fatigue → Cognition | .02 **(-0.03)** | 0.64 **(-1.00)** | .525 **(.317)** | Not supported |
| ***Paths in the indirect/ Mediating effect*** | | | | |
| $H_4$ Anxiety/Worry →Resilience | -0.09 **(-0.08)** | -5.21 **(-6.18)** | <.001 **(<.001)** | Supported |
| $H_5$ Fatigue → Resilience | -0.31 **(-0.26)** | -4.12 **(-5.85)** | <.001 **(<.001)** | Supported |
| $H_6$ Resilience →Diabetes Distress | -0.96 **(-0.77)** | -6.26 **(-6.56)** | <.001 **(<.001)** | Supported |
| $H_7$ Resilience → Cognition | -0.77 **(-0.80)** | -5.21 **(-5.79)** | <.001 **(<.001)** | Supported |

*T1DM: Chi-Square = 139.905, df = 58, p<.001, n=129;* ***T2DM: Chi-Square = 139.905, df = 58, p<.001, n=178***

### *SEM: T1DM*

Findings were similar for T1DM and T2DM. As shown in table 7, hypotheses 1, 2 and 3 were non-significant and therefore unsupported. However, hypotheses 4, 5, 6 and 7, which are part of the indirect effect were all supported: anxiety and fatigue had a significant negative influence on Resilience, and Resilience had a significant negative influence on Diabetes Distress and Cognition.

To confirm the presence of mediation, bootstrapping was used to calculate direct and indirect effects in T1DM. Results confirmed a mediating effect of resilience on the relationships between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in T1DM:

**Table 8. Mediation Analysis in T1DM**

| Hypothesis | Direct Effect | Indirect Effect | Result |
|---|---|---|---|
| Anxiety→Res→D.Distress | -.018 (ns) | .086** | Mediation |
| Anxiety→Res→Cognition | -.007 (ns) | .069** | Mediation |
| Fatigue→Res→D.Distress | n/a | .299** | Mediation |
| Fatigue→Res→Cognition | .023 (ns) | .240** | Mediation |

****=p<.001, **=p<.05*

### *SEM: T2DM*

For T2DM, hypotheses 1, 2 and 3 were non-significant and therefore unsupported. However, hypotheses 4, 5, 6 and 7 were all supported: anxiety and fatigue were found to have a significant negative influence on resilience, and resilience has a significant negative influence on diabetes distress and Cognition.

To confirm the presence of mediation, bootstrapping was used to calculate direct and indirect effects in T2DM. Results confirmed a mediating effect of resilience on the relationships between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in T2DM:

**Table 9. Mediation Analysis in T2DM**

| Hypothesis | Direct Effect | Indirect Effect | Result |
|---|---|---|---|
| Anxiety→Res→D.Distress | -.001 (ns) | .059** | Mediation |
| Anxiety→Res→Cognition | .008 (ns) | .061** | Mediation |
| Fatigue→Res→D.Distress | n/a | .201** | Mediation |
| Fatigue→Res→Cognition | .026 (ns) | .209** | Mediation |

****=p<.001, **=p<.05*

### *Model Comparisons*

The above SEM model was used as a baseline comparison, and non-significant pathways were consecutively constrained to zero to confirm whether eliminating non-significant pathways results in a more parsimonious final model (Boateng, 2018). The paths of $H_{1\text{-}3}$ were consecutively constrained in models 1, 2 and 3, after which a full mediation model was tested in model 4; all direct paths from psychological states to diabetes outcomes were constrained to zero, leaving only indirect paths (see table 10).

Table 10. Fit Statistics of Alternative Model Comparisons for T1DM and T2DM

| Model | $\chi^2$ | df | $\Delta\ \chi^2$ | $\Delta$df | $\chi^2$/df | CFI | RMSEA | SRMR |
|---|---|---|---|---|---|---|---|---|
| **Base model (see Fig 3)** | *139.905* | *58* | - | - | *2.41* | 0.94 | 0.07 | 0.07 |
| **Model 1** | *142.843* | *60* | *2.938*** | *2* | *2.38* | 0.94 | 0.07 | 0.07 |
| **Model 2** | *141.464* | *60* | *1.559*** | *2* | *2.34* | 0.94 | 0.07 | 0.07 |
| **Model 3** | *141.580* | *60* | *1.675*** | *2* | *2.36* | 0.94 | 0.07 | 0.07 |
| **Model 4** | *146.908* | *64* | *7.003*** | *6* | *2.30* | 0.94 | 0.07 | 0.07 |

**p<0.001, *p<0.05

*Model 1: The path of Hypothesis 1 (**$H_1$** Anxiety/Worry → Diabetes Distress) was constrained to zero.*

*Model 2: The path of Hypothesis 3 (**$H_2$** Anxiety/Worry → Cognition) was constrained to zero.*

*Model 3: The path of Hypothesis 4 (**$H_3$** Fatigue → Cognition) was constrained to zero.*

*Model 4: The paths of hypotheses 1,2 & 3 were constrained to zero.*

Model 4 is the most parsimonious solution; the non-significant pathways have been eliminated without negatively impacting the model fit statistics, and therefore model 4 was used as the final structural model (see figure 4). Multigroup analysis of Model 4 revealed no significant differences between T1DM and T2DM groups ($\chi^2 = 8.68$, $p = .730$), suggesting the model is appropriate to both groups.

In summary, structural equation modelling identified a significant mediational effect of resilience on psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition), in both T1DM and T2DM.

**Figure 7**. *Final Structural Model for T1DM and T2DM*

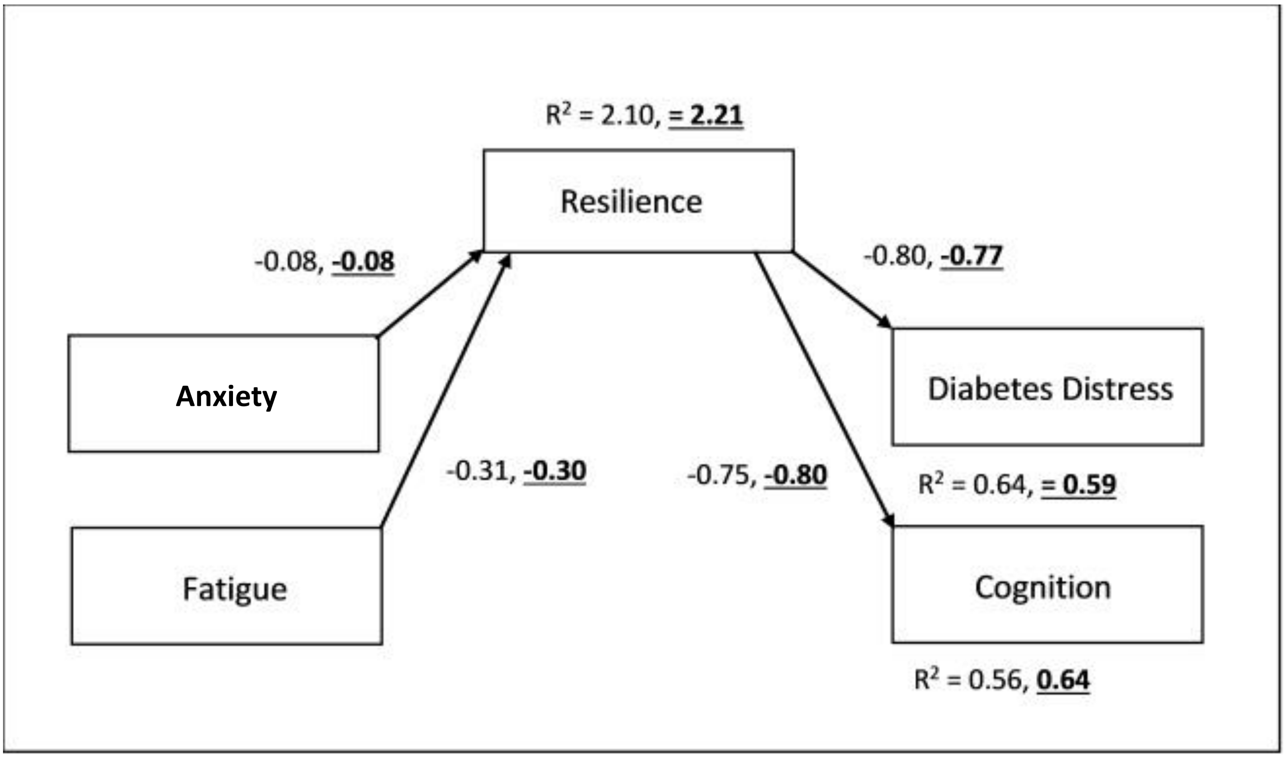


**Fig 7** This shows the most parsimonious model, with all non-significant paths removed. All indirect pathways (i.e., involving the mediator) were significant at the *p* <.001 level. Standardised beta coefficients are provided for each pathway, indicating effect strength and direction of each predictor variable on outcome variable, and $R_2$ values indicate the amount of variance explained by the independent variables (T2DM values are formatted in bold, underlined).

### *Alternative Model Testing*

An alternative model was tested (as recommended in the literature; Vandenberg & Grelle, 2009), whereby diabetes distress was incorporated as an exogenous variable rather than endogenous. There is strong evidence for an association between diabetes distress and resilience in the literature (see chapters 2, 3), however a number of studies categorise diabetes distress as a prevalent emotional/mood state, with glycaemic control/self-management efficacy as the outcome variables (Berry at al. 2015; Dieter & Laurer, 2017; Fisher et al., 2010). Often in research studies, diabetes distress is measured alongside other mood states (e.g., depression; there is a lot of symptom overlap) and as such, it would be insightful to investigate whether diabetes distress would be better placed on the left in the SEM as a mood state variable.

This model was rejected due to poor fit. Fit indices yielded a poorer model fit compared to the initial model: $\chi^2$ (Chi-Square) = 172.606, df = 60, and $\chi^2$/df ratio = 2.877. Comparative Fit Index (CFI) = 0.913, Incremental Fit Index (IFI) = 0.915, Tucker-Lewis Index (TLI) = 0.87; Root Mean Square Error of Approximation (RMSEA) = 0.08, and Standardised Root Mean Square Residual (SRMR) = 0.091.

For the T1DM group, hypotheses 1, 2, 3, 4, 5 and 7 were non-significant and therefore unsupported. Hypothesis 6, which is part of the indirect effect was supported (β= -.414, t = -1.96, *p* =.050), suggesting fatigue had a significant negative effect on resilience. Mediation analysis revealed no significant effects.

For the T2DM group, hypotheses 1, 2, 3, 4 and 7 were non-significant and therefore unsupported. Hypotheses 5 and 6, which are part of the indirect effect were supported (β= -.059, t= -2.54, *p* = .011; β= -.218, t=-3.09, *p* = .002, respectively), suggesting a significant effect of anxiety and fatigue on resilience. Mediation analysis revealed significant indirect effects of anxiety (-.156, *p* =.001) and fatigue (-.578, *p* =.001), suggesting resilience mediated the relationship between both anxiety and fatigue, and cognition.

Multigroup analysis revealed no significant differences between T1DM and T2DM groups ($\chi^2$ = 2.33, *p* = .507), suggesting the alternative model is appropriate to both groups.

## 6.5 Discussion

This study was the first to test a model whereby psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) are mediated by resilience, in both T1DM and T2DM groups. Preliminary correlations between predictor and outcome variables were as expected, based on past evidence (Fritschi & Quinn, 2010; Griggs & Morris, 2018), in both T1DM and T2DM. All psychological state and diabetes outcome variables were significantly negatively associated with resilience, laying the groundwork for SEM. The proposed structural model achieved an acceptable model fit with no significant differences between diabetes type, suggesting the model was appropriate for both T1DM and T2DM groups.

For both T1DM and T2DM groups, direct relationships within the model were not significant and therefore not supported. However, indirect paths demonstrating the mediating effect were all significant. Bootstrapping confirmed a significant mediating effect of resilience between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in both T1DM and T2DM. Additionally, the model supports an indirect relationship between diabetes distress and fatigue, which is similar to the findings of Park et al. (2015), although this study looked at resilience as a mediator variable rather than diabetes symptoms. Interestingly, Lasselin et al. (2012) also found data supporting higher rates of fatigue in T2DM compared to T1DM, however the SEM revealed no significant multigroup differences in fatigue.

Mediation research is necessary for advancement of psychological theory and clinical therapies (Windgassen et al., 2016). These findings confirm a novel model, that has the potential to inform future research and intervention design – although first these findings would need further confirmation in larger populations, including longitudinal support. These findings help to understand the underlying mechanisms of the model variables, which is necessary to try and improve education regarding diabetes self-management (i.e., improving disease prognosis and health outcomes). Resilience has also been found to play a protective role in the psychological states of other diseases, for example, protecting against: depression in adults managing cardiac disease (Ketcham et al., 2020);

psychological distress in cancer patients (Macia et al., 2022); and diabetes-specific distress in diabetes patients (Yi-Frazier et al., 2015), where each study found improved health outcomes with greater resilience.

Despite this, the pathways by which resilience acts as a protective factor are not well known in the context of these diabetes variables specifically (Ketcham et al., 2020; Yi-Frazier et al., 2015), which this study aimed to address. The mediating effect of resilience (in the context of anxiety/fatigue) can be utilised in early education interventions (e.g., conversion maps) to improve knowledge and management of diabetes outcomes (Defeudis et al., 2018), which can prevent serious diabetes complications (e.g., limb loss; Robinson et al., 2018). Resilience training would provide a protective measure against negative psychological states/disorders and help improve health outcomes; this would be widely applicable to other areas of life and managing other chronic diseases.

This study has several strengths. Structural Equation Modelling allows for investigation of complex relationships simultaneously and is able to measure unobserved variables using observed variables (accounting for error measurement, rather than treating them separately) (Boateng, 2018). Another benefit is that SEM performs well with a range of sample sizes, including ones smaller than that of this study (e.g., Sideridis et al., 2014; Wolf et al., 2013). Yet, it is important for future studies to confirm this model using a larger diverse sample. Although this study is cross-sectional rather than longitudinal, SEM allows one to test plausible ideas about the order of variables, and thus, this study identified anxiety and fatigue as psychological risk factors that can be mediated by resilience.

This study has several areas for further investigation. Comparisons of individual difference variables such as gender and ethnicity were not investigated, which is important for this model because findings have suggested gender and racial differences in diabetes management (McCoy & Theeke, 2019). For example, males report more problem-focused coping methods whereas females report more negative and emotion-focused coping styles. It is important also to note total samples for T1DM and T2DM groups were mostly female (77.5% and 79.2%, respectively), which is not representative in the current diabetes literature (Sattar, 2013). This could suggest that females are more likely to reach out to others regarding their diabetes, which has significant implications in both healthcare and research settings. Gender differences were not analysed due to multi-group requirements in SEM; i.e., double the sample size would be needed within each group (T1 and T2) to meet sample size requirements (see Cheah et al., 2023). Therefore, it is important to confirm these results in a larger, more representative population regarding gender split, to ensure reliability of findings. Additionally, the sample recruited was advertised for adults living in Northwest England, although there were no other procedures in place to ensure this sample was strictly from the Northwest. This means the sample from this study is not representative of Northwest UK, but a more generalised UK sample.

## 6.6 Conclusions

This study showed resilience mediates the relationship between anxious and fatigued psychological states and diabetes distress and cognition in adults with T1DM and T2DM. It is recommended those devising interventions for people with T1DM and T2DM target resilience as a potential psychological mechanism; specifically, to offset problems with diabetes distress and cognition, as a consequence of anxiety and fatigue. This could help improve health outcomes and quality of life in people with this lifelong condition, which in turn can positively impact mental health and wellbeing.

# Chapter 7: Study 2. A qualitative examination of the model developed in study 1: psychological states, resilience, diabetes outcomes and interventions in T1DM and T2DM

## 7.1 Structure of Chapter

This chapter describes study 2; Reflexive Thematic Analysis was used to qualitatively explore the model from study 1, in an attempt to further understand the model constructs in context of lived experience, e.g., how resilience interacts with anxiety, fatigue, diabetes distress and cognition in individuals' daily lives. Also, to investigate other prevalent themes outside the model. Deductive and inductive findings were used to inform study 3. Structures will be presented in the same order as study 1.

## 7.2 Introduction

Living with the constant demands of diabetes can take a significant psychological toll, and as a result many individuals experience distress, depressed mood, anxiety, and fatigue (Ducat et al., 2015; Wylie et al., 2019). The presence of these psychological issues can exacerbate and accelerate adverse diabetes complications (e.g., limb loss, cardiopathy, neuropathy), and are significantly associated with reduced self-care activities, poorer glycaemic control and thus, quality of life (Berry et al., 2015; Robinson et al., 2018; Smith et al., 2018). The rising burden of diabetes globally is a major health priority, placing increased demands on patients, carers, health systems and society (Forouhi & Wareham, 2019), and so identifying the key psychological factors that contribute to diabetes management and outcomes is a priority (Wylie et al., 2019). Resilience has been correlated with greater health behaviour adherence and reduced mortality in T1DM and T2DM (Massey et al., 2019), and as such, resilience is a key factor in a range of intervention studies (Massey et al., 2019). Resilience is defined as the capacity of a dynamic system to withstand or recover from significant challenges/adversity (Van der Hallen et al., 2020), and can be conceptualised as mental health in relation to stressor load (Chmitorz et al., 2018). Generally, literature supports resilience as a dynamic process that accounts for both internal (e.g., epigenetics, personality traits, beliefs, self-efficacy) and external factors (e.g., social support, financial and environmental resources including stability/access to these). For example, increased resilience is associated with more resource-rich and stable environments (Hobfoll et al., 2015; Chmitorz et al., 2018).

Existing literature shows individuals with either T1DM or T2DM suffer from significantly higher levels of anxiety, fatigue, diabetes distress, and executive functioning difficulties compared to a non-diabetes population (see chapter 2 for a literature review), and these factors are all interrelated and have been found to correlate negatively with resilience (Frazao et al., 2018; Hood et al., 2018; Murdock et al., 2016; Ruiz-Aranda et al., 2020; Santos et al., 2013; Scott et al., 2020; Terte et al., 2014; Vemuri et al., 2019; Wang et al., 2017; Wang et al., 2021; Yi-Frazier et al., 2015). Subsequently, the progression of symptomology in chronic diseases such as diabetes can be related to resilience, where lower resilience levels have been correlated with maladaptive coping strategies (i.e., emotional avoidance coping such as denial, wishful thinking), higher levels of diabetes distress, poor glycaemic control and reduced quality of life, in both T1DM (Yi-Frazier et al., 2010 & 2015) and T2DM (Pesantes et al., 2015; Wilson et al., 2017). Qualitative research (Skegdell et al., 2021) found adults utilised protective factors associated with resilience in three main ways to manage their diabetes: 1) Social strategies: seeking tangible interpersonal support from family and emotional support from friends and healthcare providers; 2) Cognitive strategies: appraisal and believing one can live a normal life with T1DM; and 3) Behavioural strategies: proactive planning, flexibility in routine, balancing diabetes/non-diabetes activities, and utilising technologies to support diabetes management. These protective factors may explain pathways through which resilience may mediate/facilitate good diabetes self-management and engaging with associated challenges.

A recent review (de Wit et al., 2020) of the past 25 years' research in diabetes identifies several gaps in resilience; A number of observational studies have been carried out into resilience and diabetes, however they rarely addressed the nature of the adversity e.g., diagnosis, living with the condition, comorbidities, socioeconomic factors. Additionally, only a component of resilience tends to be operationalised (e.g., self-efficacy), often statistically identified from non-validated questionnaire data, rather than using a comprehensive resilience scale, such as the Connor-Davidson Resilience

Scale (2003) (Hadj-abo et al., 2020). There is even less qualitative resilience research in both T1DM and T2DM populations (e.g., Wilson et al., 2017; Skegnell et al., 2020). In order to address this gap, systematic reviews of resilience in chronic diseases recommend future studies should employ more integrative methods (i.e. mixed methods) to further understand the concept of resilience (Kim et al., 2019), which is what the current study aims to do.

The model in study 1 was the first to test a psychological model where resilience mediates anxiety and fatigue, and diabetes distress and cognition. Combining the findings with qualitative follow up will provide further understanding than a single method approach, by providing a more holistic picture (Guest & Fleming, 2015; Wasti et al., 2022). Due to the complex and multifactorial nature of diseases such as diabetes, no single research method is superior; an integration of quantitative and qualitative approaches is considered the most effective for gaining a more comprehensive understanding of the research issue (Creswell & Plano Clark, 2017; Kaur, 2016; Holloway & Wheeler, 2010).

This study aimed to qualitatively investigate the model in study 1, using a deductive and inductive hybrid approach (i.e., starting with a deductive approach and remaining open to inductive themes throughout data analysis), to understand the lived experience behind and outside of the model constructs. More specially:

(a) To examine the lived experience of relationships between anxiety/fatigue and resilience
(b) To examine the lived experience of relationships between resilience and cognition/diabetes distress
(c) To identify other important aspects of living with diabetes beyond those in model.

Specifically, the study will start with a deductive approach (in examining the lived experience behind the model variables), but remain open to inductive themes in identifying other important aspects of living with diabetes, beyond the model. The advantages to using a combined approach (if inductive themes do indeed emerge), is to further ensure voices of participants are valued and to create a more holistic understanding of the data (Proudfoot, 2023).  Examining the model qualitatively and observing the lived experience behind these model concepts will provide necessary insight for healthcare providers and intervention researchers.

## 7.3 Method

### *7.3.1 Design*

The study had a qualitative design using semi-structured individual interviews.

### *7.3.2 Participants*

Adults in the UK with T1DM (n = 12) and T2DM (n = 14) were recruited through purposive sampling via social media advertisements. Exclusion criteria included people under the age of 18, and those with diabetes other than T1DM/T2DM. Both T1DM and T2DM groups were mostly female (75.0% and 71.4% respectively), with mean ages of 46.00 *(SD=15.43)* and 55.29 *(SD=8.60)*, and were mainly white British (100% and 78.57% respectively). T1DM durations ranged from 14 – 56 years, whereas T2DM ranged from 2 months – 28 years. Average diabetes durations were 28.67 and 10.48 years respectively, and HbA1c levels were 57.09 and 72.83 mmol/mol, respectively.

Table 11 shows the recorded demographics of participants with T1DM and T2DM groups separately.

Table 11. Participant Demographics for T1DM and T2DM Groups

| Participant (pseudonyms) | Age (Years) | Gender | Nationality | Diabetes duration (Years) | HbA1c | Medication | BMI | Comorbidities/ Complications | BG Test (per day) |
|---|---|---|---|---|---|---|---|---|---|
| **Type 1 Diabetes** | | | | | | | | | |
| T1P1 [Amelia] | 21 | Female | WB | 16 | 44 | Insulin | Not known | None Stated | 4x |
| T1P2 [Gordon] | 32 | Male | WB | 15 | 80 | Insulin (Tresiba, Novorapid) | 25.8 | None Stated | 4x |
| T1P3 [Emma] | 47 | Female | WB | 45 | 60 | Insulin | 33 | Celiac, hyperthyroidism | 11x |
| T1P4 [Toni] | 47 | Female | WB | 42 | 65 | Insulin | 30 | Epilepsy, hypothyroidism | 4+ |
| T1P5 [Ross] | 62 | Male | WB | 56 | 51 | Insulin (Lantus/ Novalog),<br>Statin | 37 | Retinopathy (mild) | Many; CGM |
| T1P6 [Lesley] | 60 | Female | WB | 18 | 61 | Insulin (Basal/ Humalog) | Not known | None Stated | 5x |
| T1P7 [Danielle] | 55 | Female | WB | 18 | 55 | Insulin (Tujeo/ Novorapid) | Not known | None Stated | 8x |
| T1P8 [Jaqueline] | 53 | Female | WB | 35 | Not known | Insulin | Not known | Celiac,<br>Macular oedema | 4-6 x |
| T1P9 [Ben] | 23 | Male | WB | 14 | 59 | Insulin | 29.7 | None | 4-5x |
| T1P10 [Maisey] | 32 | Female | WB | 26 | 52 | Insulin (Levemir/ Humalog) | 20.3 | Diabetes-related Anorexia | 10+ |
| T1P11 [Maureen] | 53 | Female | WB | 32 | 53 | Insulin (Novorapid) | Not known | None Stated | 6-8 x |
| T1P12 [Sue] | 67 | Female | WB | 27 | 48 | Insulin,<br>Metformin | Not known | Kidney disease | 4-8 x |
| **Type 2 Diabetes** | | | | | | | | | |
| T2P1 [Theresa] | 52 | Female | WB | 15 | 48 | Metformin | 30 | Retinopathy,<br>Neuropathy | None |
| T2P2 [Martin] | 49 | Male | WB | 1 | 34 | Metformin | 17.2 | Retinopathy,<br>Anxiety | Once x wk |
| T2P3 [David] | 62 | Male | WI | 3 | 112 | Metformin<br>Canagliflozin | Not known | None | None |
| T2P4 [Tess] | 61 | Female | WB | 10 | 64 | Metformin<br>Insulin;<br>Levemir<br>Humalog | 27 | Myasthenia Gravis | 5x |
| T2P5 [Karen] | 48 | Female | WB | 12 | 83 | Metformin<br>Dapagliflozin<br>Liraglutide | 52 | High cholesterol,<br>Thyroid issues (corrected) | None |
| T2P6 [Kenny] | 53 | Male | WB | 1.5 | 46 | Metformin | 21.6 | None | 4-5x |
| T2P7 [Gail] | 65 | Female | WB | 9 | 55 | Metformin | Not known | Polymyalgia rheumatica | None |
| T2P8 [Dorothy] | 56 | Female | WB | 28 | 173 | Gliclazide<br>Sukkarto<br>Alma insulin | 29.6 | Neuropathy | None |
| T2P9 [Lynne] | 53 | Female | WB | 3 | 52 | Metformin | Not known | None | N/A |
| T2P10 [Donna] | 41 | Female | WB | 10 | 105 | Insulin | 22 | None | 3x |
| T2P11 [Michael] | 71 | Male | WB | 26 | 57 | Metformin<br>Bydureon | 30 | Neuropathy<br>Retinopathy | None |
| T2P12 [Rita] | 54 | Female | WB | 0.17 | N/A | N/A | Not known | Cancer<br>Peripheral Neuropathy | 1x six wks |
| T2P13 [Jayne] | 65 | Female | WB | 27 | Not known | Metformin | 35 | Asthma | 3x |

|  |  |  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  |  |  | Cataracts (diabetic caused) |  |
| T2P14 [Roseanne] | 44 | Female | WB | 1 | 45 | Metformin | Not known | None | 1x 2 wks |

***Key: WB [White British]; WI [White Irish] *All participants live in the UK***

Table 12 shows the means and standard deviations for age, diabetes duration and HbA1c levels for type 1 and 2 diabetes groups.

Table 12. Means and Standard Deviations for T1DM and T2DM Groups

|  | **Type 1 (N=12)** |  | **Type 2 (N=14)** |  | **Total (N=26)** |
|---|---|---|---|---|---|
|  | Male (3) | Female (9) | Male (4) | Female (10) |  |
| **Age*** | 46.00 (15.43) |  | 55.29 (8.60) |  | 51.00 (12.62) |
| **Diabetes Duration*** | 28.67 (13.63) |  | 10.48 (10.09) |  | 18.87 (14.55) |
| **HbA1c**** | 57.09 (9.76) |  | 72.83 (39.78) |  | 65.30 (29.33) |

**Age and Diabetes Duration measured in years*
*** Measured in mmols/mol (International Federation of Clinical Chemistry units; IFCC).*

### *7.3.3 Procedure*

Interviews were conducted online via Microsoft Teams. First, consent was given via electronically signed consent forms prior to the interview. Then, participants were provided a verbal description of the study brief (see Appendix 10) and given chance to ask any questions before proceeding with the interview. Interviews were carried out and recorded using an encrypted Dictaphone. Participants were provided a verbal debrief (see Appendix 10) and interviews were later transcribed. No transcription software was used due to personal preference and software inaccuracies with strong northern accents, colloquialisms, and spellings. By typing the transcripts out, it provided another opportunity to listen to the interviews again and ensure accuracy.

### *7.3.4 Interviews*

The lengths of each interview varied (mean = 32 minutes), with the shortest interview lasting 17 minutes, and the longest lasting 45 minutes. Two type 1 interviews were conducted via a written format due to participant blindness and anxiety. See Appendix 11 for the interview guide. A pilot study was not conducted, the implications of which are considered in the Discussion (see section 7.5). There are no clear guidelines regarding the inclusion and nature of pilot studies in qualitative research (e.g., see Malmqvist et al., 2019), and as a novice qualitative researcher alongside time constraints precluding a full pilot study, I opted to use the first interview as a learning opportunity (not excluded from data analysis), with the purpose of reflecting and guiding the interview schedule. For example: 1) how well the interviewee answered the questions, to assess whether the schedule and terminology were fit for purpose and 2) the skills of the interviewer, to identify potential areas for improvement to facilitate good quality interviews and 3) to identify any potential challenges/difficulties. Question changes were made in response to the first interview (see interview guide below) and the researcher addressed their difficulties with interview inexperience and social awkwardness/lack of confidence. This approach is reflected on in the Discussion (see section 7.5).

The interview guide was developed in three blocks: 1) demographic; 2) model components and relationships; 3) healthcare experiences. The demographic questions (Qs 1-8) were developed using the Diabetes Control and Complications Trial demographic items as a guide (see Nathan & DCCT/EDIC Research Group, 2014). This included the following items: gender, diabetes type, duration and age, HbA1c, comorbidities, BMI, how often they tested their BG levels, and how well participants generally felt they managed their diabetes on a scale 1-10. The model components and relationships questions (Qs 9-23) were derived from the model in study 1, and split into two parts. The first part examined mental health and model predictors/outcomes separately (e.g., anxiety, fatigue, cognition, diabetes distress), to understand what they meant to participants, and if they were present in their experience (and if so, to what extent). The second part examined what resilience meant to participants (and what role it played in their diabetes self-management), and the relationships of model variables in relation to resilience. For example, ‘Do you feel that your resilience has an impact on thinking abilities?’ The healthcare experiences questions (Q24 -25) were developed and added in response to the first interview where the participant had alluded to negative experiences that affected their attitudes and diabetes-self management. These questions examined interactions with healthcare providers and intervention experiences.

During the course of the study, questions 24 and 25 were added in as a result of the first interview, and questions 12 and 15 (i.e., ‘if you think back to before you were diagnosed how does your anxiety/fatigue compare to now’) were also added to facilitate deeper reflection regarding these topics, as sometimes participants contradicted themselves as they were working through the answers, suggesting further reflections might be needed (e.g., Lynne). Question 17 (i.e., ‘do you have any thoughts on the long-term effects of diabetes on thinking abilities’) changed position (i.e., would be added in at the end) as a result of how well the interview was going, as this was more a point of interest than directly related to the model (for example, Q22 asks directly about thinking processes in relation to resilience).

### *7.3.5 Data Analytic Strategy*

Semi-structured interviews were transcribed verbatim and subjected to a qualitative thematic analysis to address each participants’ lived experience of psychological states, resilience and diabetes management and outcomes. A deductive thematic analysis was conducted to address the first two research questions, and an inductive thematic analysis addressed the third. These thematic analyses (as described in chapter 5) followed the six stages of guidance as described by Braun and Clarke (2013): 1) Familiarisation with the data was gained through conducting the interviews and then reading and re-reading transcripts. Potential codes were noted in preparation for next stages. 2) Initial codes were generated systematically across both data sets, respectively. 3) Themes were identified by reviewing initial codes across both data sets, collating these into themes/subthemes based on how often they were presenting in the data, taking note of what they meant and how they were important to the participant’s experiences (e.g., healthcare experience identified as an inductive theme, with healthcare provider and service issues as subthemes). 4) These themes were reviewed by re-reading the coded transcripts, to ensure themes accurately represented the data, and a thematic map for the data set was generated (see results). 5) The entire dataset was re-read to identify and refine any additional themes, and to confirm the themes accurately represented the dataset overall. 6) Finally, appropriate extracts were selected to produce the final report, which are compared and contrasted with existing research findings. Quote selection adhered to Lingard’s (2019) guidance, where quotes should reflect strong patterns in the data, including discrepant examples, and distributed across participants fairly, to represent the dataset; this may mean using a second- or third-best example rather than quoting repeatedly from more articulate individuals.

## 7.4 Analysis and Results

### *7.4.1 Structure of Findings*

Results are presented in order of deductive findings and inductive findings, and the themes and subthemes within are described together for type 1 and 2 groups, unless findings are different. Table 13 demonstrates the breakdown of themes across the analyses. Specifically, the deductive analysis examined the lived experience in relation to model concepts found within study 1, whereas the inductive analysis aimed to identify other important aspects of living with diabetes that were not addressed in the development of the model. Findings will be discussed and compared against the literature in the discussion section.

The first overarching theme described is psychological states, to gain an understanding of what psychological issues participants are facing, and how these might interact with their daily lives and diabetes self-management. This is followed by the overarching theme of resilience, which explores how resilience might interact with the aforementioned psychological states, to understand the lived experience behind the model developed in study 1. Although diabetes management is not part of the model in study 1, it was included due the research discussed in chapters 2 and 3; i.e., the literature review suggests how the psychological variables are all known to have significant effects on each other and on diabetes management (e.g., HbA1c levels, self-efficacy, self-care behaviours). Study 2 is open to (and aims to) identifying factors outside of the model, and as such, it made logical sense to ask about diabetes management and coping methods in the context of resilience to examine this.

The inductive themes identified from the data were: 1) healthcare experiences and attitudes, which explored how participants felt about the quality and usefulness of the diabetes care they receive, in regards to interactions with health care providers and the healthcare system. The last theme identified examined education and intervention experiences, gaining an understanding of diabetes stigma, public and healthcare education perceptions and diabetes intervention feedback.

Table 13. Breakdown of Explored TA Themes

| **Thematic Analysis** | **Overarching Themes** | **Themes** | **Subthemes (if applicable)** |
|---|---|---|---|
| **Deductive** | Psychological States | *Mental Health*<br>*Anxiety*<br>*Fatigue*<br>*Cognition* | |
| | Resilience | *Role of Resilience in DSM*<br>*Resilience and Anxiety, Fatigue*<br>*Resilience and Cognition*<br>*Resilience and Diabetes Distress*<br>*Resilience and Coping styles* | |
| **Inductive** | Healthcare Experiences | *Healthcare Provider Interactions* | *-Lack of: support, continuity (T1 only)*<br>*-HCP attitudes and approaches* |
| | | *Healthcare System* | *-Lack of direction/help*<br>*-Variability in support* |
| | Education and Intervention Experiences | *Public and healthcare education (and stigma)*<br>*Interventions* | |

Below is a thematic map of the final themes for study 2, illustrating how themes and subthemes fit together.

**Figure 8**. Thematic Map of Final Themes (Study 2)

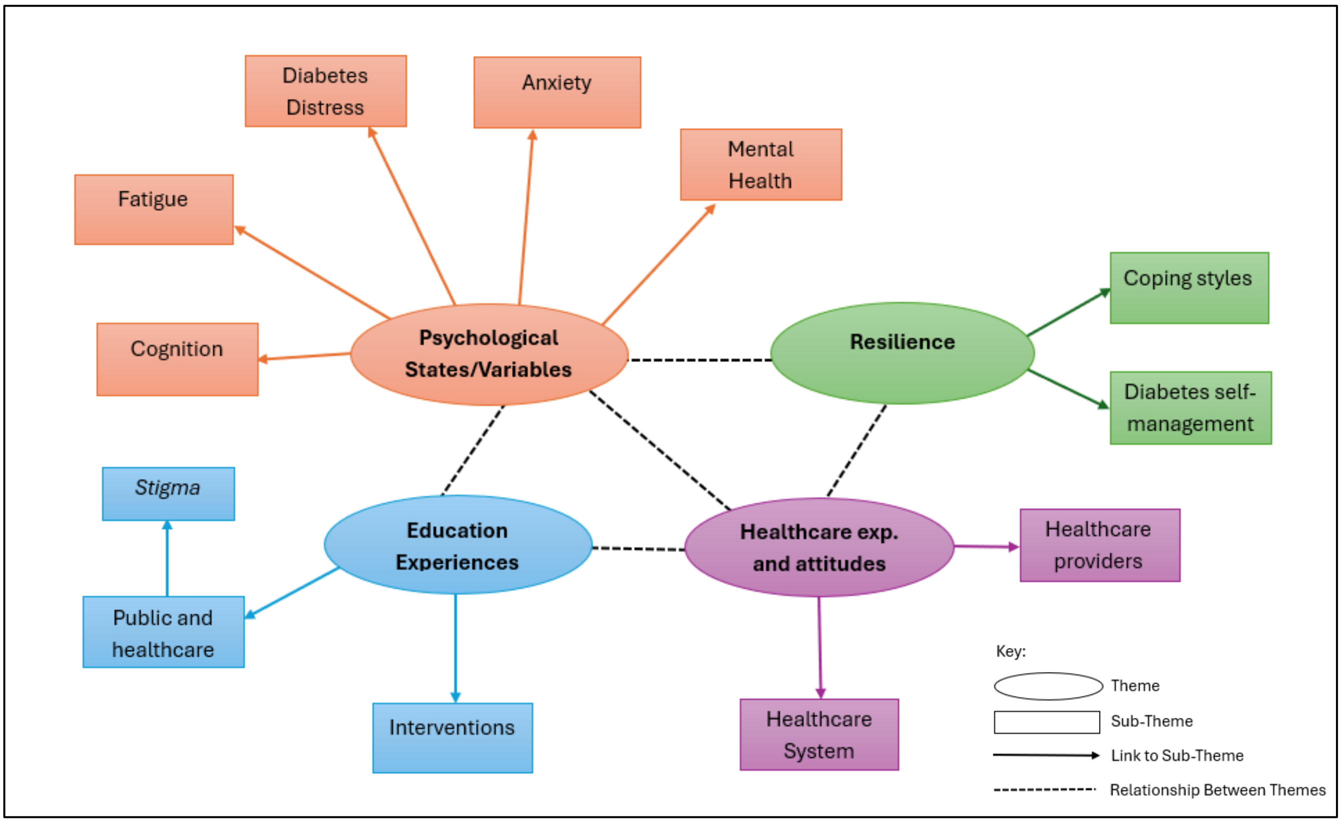


**Fig 8.** The final thematic map produced at the end of data analysis, representing the four candidate themes with their respective subthemes.

## *7.4.2 Overarching Theme 1: Psychological States*

This theme describes mental health difficulties in participants as a result of the diabetes, and explores how psychological difficulties might interact with their daily lives and diabetes self-management.

### *7.4.2.1 Mental Health*

Every participant in both groups identified and discussed negative effects of their diabetes on their mental health, such as depression, anxiety, fatigue and distress, with cases ranging from mild to severe, such as: worrying (e.g., David, T2P3), eating disorders (e.g., Maisey, T1P10), and attempted suicide (Jaqueline, T1P8). Some participants experienced particular difficulty with mental health around the time of diagnosis, feeling overwhelmed or 'singled out' (e.g., Michael, T2DM P11). Explanations as to how participants felt their diabetes affected their MH were exemplified by Danielle

(T1DM P7): *"It certainly regularly creates anxiety if my blood sugar rises or drops, especially if it drops after I went unconscious. Thanks to low blood sugar, I don't always recognise the signs. It certainly creates depression which can be very difficult to handle - especially because all the joy of eating has been sucked away now. I have to inject before every meal. Sadly, I now feel food is the enemy."* Additionally, Tess (T2DM P4) explains: *"I would say in some ways it has because there's always that negative connotation of 'I shouldn't be eating this or I shouldn't be eating that,' or I need to moderate what I'm eating, you know. And there's kind of all the bits that come with the diabetes, like the sweating and the tiredness and the sort of blurry vision, needing to pee all the time getting loads of infections, so I think there is a kind of a knock-on effect from being diabetic that just makes you feel maybe a bit low health wise, which then can have an effect on your mental health."* This is supported by existing research, (e.g., Stoop et al., 2019) where the burden of diabetes (e.g., food restriction, regimen adherence) can result in a variety of psychosocial difficulties, such as stress and depression. These responses demonstrate the interconnected nature of physical and psychological factors, which is especially important in diabetes self-management (Zabell et al., 2022).

Despite the interconnected nature of physical and psychological diabetes factors, the majority of participants described how their mental health was not considered sufficiently or at all in the context of their diabetes care. For example, Gordon (T1P2) stated: *" I definitely, I definitely think there's not enough done for the mental health side of having diabetes, in the NHS."* This is supported by Martin (T2P2), who also explained, "*I felt like I had to deal with the mental health side of things myself."* This supports research by Hadjiconstantinou et al. (2020), where both HCPs and patients acknowledged a lack of emotional and mental health support in UK primary diabetes care settings. Additionally, Kelly et al. (2023) found the majority of diabetes patients stated their diabetes team never approached the topic of mental health. Barriers to emotional support in Primary care can be explained by a lack of: training and knowledge, confidence to discuss these issues, and time constraints at appointments (Benton et al., 2023; Hadjiconstantinou et al., 2020).

Some participants elaborated further, describing how a lack of psychological help contributed to feelings of neglect and a loss of faith in healthcare providers. The majority of T1DM and T2DM participants felt that psychological effects of diabetes are not taken sufficiently into account at appointments, relative to biomedical issues (e.g., HbA1c levels). For example, Gordon (T1P2) explained, *"[healthcare providers] don't know what you've gone through. You might have a lot of problems and that. They just see what's on the screen in front of them. They have a quick read of your notes and then if your bloods are high or whatever, they'll probably give you a bollocking for it, and then that's about it." (Gordon, T1P2)*. This is also supported by Maisey (T1P10), who struggled with anorexia, yet doctors praised physiological health (HbA1c) over addressing psychological concerns: *"When my HbA1c reached non-diabetic level I was highly praised, despite me begging for help as I looked like a skeleton [anorexia; 32kgs]. I now no longer have faith in doctors or my diabetic team after my treatment. I have severe burn out after living with it for so long but can't have access to the NHS psychologist."* Existing literature supports these findings, for example, Kalra et al. (2018), found primary diabetes care (UK) focuses more on managing biometrics rather than integrating and providing emotional support. Zabell et al. (2022) also found this intense focus on physical outcomes rather than mental difficulties led to feelings of frustration and loneliness in diabetes patients, and had a detrimental effect on their diabetes management. Whilst health outcome factors such as HbA1c are important, this could suggest a more holistic view of diabetes care would beneficial and prevent people from losing trust in their healthcare providers. In contrast, a few participants reported being asked by their healthcare providers about their mental health and felt it was helpful, and reported generally more positive feelings towards healthcare providers and their healthcare (supported by Dambha-Miller et al., 2020). This could suggest a more holistic approach in appointments might benefit people with diabetes.

Additionally, when asked about how diabetes had affected participants' mental health, many spoke about the invisibility and hidden nature of diabetes, and the stress of achieving blood glucose balance alongside other life stressors/factors (e.g., childcare, work). This suggests these could be key factors affecting mental health when living with diabetes. For example, Emma (T1P3) explains: *"Because [diabetes] is not visible, people aren't actually aware of how, some days you just feel truly awful… It's like having its own full-time job, being diabetic, on top of being a mum. So it's quite stressful trying to* *get that balance."* (Supported by Theresa, T2P1). This can be explained through a large number of 'hidden' factors such as DD, anxiety and fatigue, that interplay with each other that can impact physical outcomes of diabetes (e.g., glycaemic control). Psychological difficulties especially often go unnoticed or unaddressed in diabetes primary care, which can lead to frustration and loneliness in patients (Kalra et al., 2018; Zabell at al., 2022). The hidden nature of diabetes is also related to stigma, where a lack of public and HCP education can lead to negative feelings and misconceptions about insulin injections, causes of diabetes, obesity, dietary restrictions and hypoglycaemic episodes (Liu et al., 2017). As stigma is also associated with anxiety (e.g., Browne et al., 2013), it is important to consider how living with a hidden chronic condition may affect MH in patients.

In summary, diabetes can have many effects on individuals' mental health, to varying degrees. Major stressors involve the hidden nature of diabetes, and achieving blood glucose balance alongside other life stressors. The majority of participants are not asked about their mental health as part of their diabetes care, suggesting an area for improvement in the context of diabetes care; this is consistent with current literature findings (Diabetes UK, 2019; Speight et al., 2000).

#### *7.4.2.2 Anxiety*

Experiences of diabetes-related anxieties were reported across all participants at varying severities, with mild to severe cases described (based on their experiences and descriptions). However, the types of anxieties typically presented differently between T1DM and T2DM groups. T1DM participants reported more anxieties regarding fear of hypoglycaemia, and T2DM participants reported more regimen-related anxieties, such as managing diet and glucose levels. This is supported by existing research (Fischer et al., 2015; Perrin et al., 2017; Schmidt et al., 2018; Wardian et al., 2018).

An overview of T1DM responses identified factors such as: diabetes complications (especially sight and limb loss; Gordon, T1P2), medication (e.g., calculating correct insulin dosage, Ross, T1P5), carrying required equipment, facing stigma (e.g., injecting in public; Danielle, T1P7), long-term health uncertainty, and the most reported anxiety was fear of hypoglycaemic episodes. Participants' descriptions of anxiety followed similar patterns, typically characterised by overthinking, uncertainty of the future, frustration and panicking. An exemplifying response was by, Toni (T1P4), who explains her fear of hypoglycaemia: *"I suffer with what we call hypo anxiety. So because I don't get any warning signs with, where my sugar levels drop…I'm not aware when my sugar levels are low, so that's like the anxiety that it's not like normal anxiety that a normal person would get." (Toni, T1P4).* Additionally, Amelia (T1P1) explains how she is always experiencing anxiety: *"I've just always had [anxiety] on my mind. Never not had it…Definitely a lot of health anxiety around being diabetic and, the consequences of not controlling…My eyes and the risks of high blood sugars and eye health is definitely a hundred percent top of my list of worries."*

An overview of T2DM responses identified factors such as: diabetes complications, medications (e.g., fear of becoming insulin-dependent), long-term health and managing blood glucose levels. However, in contrast to the T1DM group, anxieties were less immediate and more concerned with long-term complications. Participant descriptions of anxiety were typically characterised by overthinking, inward nervousness, fear regarding the future, agitation and sleeplessness. An exemplifying response was from David (T2P3), who stated: *"Anxiety is probably a few different factors erm, inward fear, sort of nervousness, sort of being uncertain as to where this is gonna lead me, where my path leads. The fear, that inward fear that this isn't redeemable…And one of my main fears is that ultimately I might have to go onto insulin, and that's something that I want to avoid at all costs." This is supported by Martin (T2P2) who explained how diabetes made his anxiety worse: "I've always been quite a fidgety sort of person and um, the diabetes and the worry that came on with that just made it worse. So I became very, very nervous about everything."*

Another interesting contrast between diabetes groups was noting the patterns of when anxiety occurred; for example, T1DM participants generally reported an increase in anxiety since diagnosis (e.g., Jaqueline T1P8), but participants who were diagnosed younger experienced anxiety increase when growing older and reaching adulthood. This could be explained through parents taking responsibility for managing their child's diabetes (Aalders et al., 2021), which is demonstrated by Ross (T1P5): *"When I got older I had to be totally responsible myself for watching my blood sugars and so forth. And at that point, that's when more of my anxieties occurred cause there's nobody* *watching out for you."* (See also Maisey, T1P10). However, five T2DM participants described feeling more overwhelmed and anxious around the time of diagnosis (e.g., Martin T2P2), although this remained consistent for others in the long-term (e.g., Karen T2P5).

Additionally, participants explained how feelings of anxiety would contribute to maladaptive (i.e., emotional-avoidant, or potential safety) behaviours such as emotional eating or avoidance, and this would negatively impact their diabetes self-care (e.g., Emma, T1P3). Also, Karen (T2P5) stated: *"I get anxious 'cos my sugars are high, anxiety makes me want to eat, so I eat, so my sugars get higher, so my diabetes gets worse. So my anxiety doesn't get any better and I think you end up in the vicious cycle."* This suggests anxiety can contribute to maladaptive coping behaviours and negatively impact glycaemic control, which is supported by existing findings (e.g., Sultan et al., 2007; Zeiton et al., 2023). Another issue commonly linked to anxiety was avoidant behaviours, such as not wanting to know HbA1c levels. For example, Lynne (T2P9) stated*: "I think there is, there must be a level of anxiety there and it's just coming out in the, in this kind of like let's sort of like, 'let's forget that it actually exists' kind of manner."* Supporting this, Martin (T2P2) and Kenny (T2P6) also avoided looking up diabetes complications (including cognitive) due to anxiety about their health, suggesting anxiety could hinder potential diabetes health education, and therefore, diabetes health outcomes. This is important as a lack of health education is associated with poorer diabetes self-management (Balogun-Katung et al., 2021).

Four T2DM participants (e.g., Karen T2P5, Gail T2P7) had not thought of anxiety being related to diabetes, or had initial difficulty identifying whether they experienced anxiety or not, amending their answers after reflection. This could suggest they might not have considered this topic before, or might not have realised the behaviours they were exhibiting were possibly indicative of anxiety: *"when I look back retrospectively, I didn't see it as anxiety. I just saw it as high adrenaline." (Karen, T2P5)*. This could suggest that some individuals might not be aware of potential interactions between anxiety and diabetes, or of the less obvious symptoms that might indicate anxiety (e.g., procrastination in collecting medicine), as suggested by Lynne (T2P9). Gail (T2P7) suggests the lack of awareness of anxiety could be because healthcare providers do not link them together: *"I most probably wouldn't* *have thought of it in that way because everybody like a doctor, what treats them separately, it's almost like diabetes is something that's in your body. And anxiety is something that's in your head and they, they don't particularly link them. And so, I've kind of never put them together."* This is supported by existing research in UK patients and HCPs, where HCPs were reluctant to address emotional and psychological issues due to a lack of knowledge, confidence and appointment time, and patients expressed a clear need for emotional support from HCPs in primary care (Dambha-Miller et al. (2020) (see also Litterbach et al., 2020). The lack of MH education and discussion in appointments and structured education courses may explain why patients might not link psychological and biological aspects of diabetes together. Poor diabetes education is associated with significantly poorer glycaemic control (Velázquez López et al., 2023), and so there is a need to incorporate MH and psychological education into interventions and primary care (Zabell et al., 2022). The implementation of anxiety education into diabetes interventions may benefit individuals who might not realise they are experiencing anxiety, or as a preventative measure for those newly diagnosed who might be more prone to affective disorders. Understanding that anxiety is malleable and amendable to change (e.g., through resilience building) may help improve optimism or positive reframing for moving forward.

In summary, anxiety seems to be a key factor in the lived experience of diabetes; both diabetes groups described various experiences of anxiety ranging from mild to severe, but more immediate and hypo-based anxieties were described across T1DM participants. Experiences of anxiety were linked to other factors such as fatigue and maladaptive behaviours, which appeared to negatively impact self-care.

#### *7.4.2.3 Fatigue*

Diabetes-related fatigue was reported in most of the T1DM sample (10/12) and over half of the T2DM sample (8/14). Across both groups, responses suggested fatigue is a prevalent factor of diabetes, and generally resulted from hypoglycaemia, hyperglycaemia, anxiety or sleeplessness (from excessive glucose monitoring). From those who reported issues, T1DM and T2DM participants explained their fatigue was particularly invasive, in that it hindered their ability to carry out daily tasks (e.g., diabetes self-care and daily chores such as cooking and shopping, e.g., Donna, T2P10), and motivation to manage their diabetes (e.g., correcting high sugar levels). This is exemplified by

Amelia (T1P1), who explains: *"High blood sugar, that's just instant, instant fatigue for me personally. I can just be utterly… just like don't want to do anything. I don't even want to fix the blood sugar that's wrong. I'll just want to sit and… I don't even want to sleep with fatigue. It's not even a sense of sleepiness, it's just, yeah. Pure exhaustion."* This is also supported by Karen (T2P5), who states: "*Fatigue affects my life desperately. I think I miss out on a lot. And it's the tiredness that you can't… you cannot work through. You just can't. So yes, it does impact on my life desperately, and I don't like it, I don't like how much I'm sleeping, I want to have more of a life, and I just can't, I get behind with everything. Do you think I want to be sleeping through my daughter's childhood? No, I don't." (Karen, T2P5)* Both of these responses appear to suggest a strong impact on quality of life, and this is supported by existing research (Fritschi & Quinn, 2010; Darwish et al., 2018; Nefs et al., 2015). Fatigue is a prevalent issue in both types of diabetes and results support existing literature, including the reasons for fatigue (Jensen et al., 2017; Romadlon et al., 2022). Additionally, worse fatigue was described by T2DM participants who had higher HbA1c levels (i.e., more uncontrolled diabetes) or ate the wrong foods, for example, Gail (T2P7) stated: *"When I'm eating the wrong foods, that I am slower, more tired, more sluggish. So, I would say yes, I think if I stick to what I should be doing, then the fatigue isn't as bad."* These findings are consistent with the literature (Park et al., 2015), where increased fatigue has been significantly associated with higher HbA1c levels, via diabetes symptoms, depression and diabetes distress. It is also important to note that assessing the impact of fatigue alone was difficult for some participants due to comorbidities such as Cancer (Rita, T2P12) or Myasthenia Gravis (Tess, T2P4), and psychological comorbidities such as anxiety (Martin, T2P2). He stated: *"I wasn't quite sure whether [fatigue] was physically caused by diabetes, or caused by the worry of having it."* This is important because research suggests significant positive associations of fatigue with both, diabetes and anxiety independently (Romadlon et al., 2022). Therefore, to alleviate further potential worry and fatigue, integrating psychological education into primary care settings and structured education would be beneficial (Benton et al., 2023).

Additionally, most T1DM participants who were diagnosed in early adulthood/adulthood recalled a significant increase in fatigue levels from pre- to post-diagnosis (e.g., Gordon T1P2; Danielle T1P7), whereas those diagnosed as children were generally unable to make comparisons (e.g., Emma T1P3; Toni, T1P4). Ross (T1P5), who was diagnosed as a child remembers feeling fatigued but felt this was physiological rather than psychological, due to being unable to psychologically conceptualise fatigue as a child (i.e., a child may not understand psychological implications of fatigue or other mood states in the same way as an adult might). In comparison, T2DM participants described feeling more fatigued particularly at and post-diagnosis (e.g., Martin, T2P2; Michael T2P11).

In summary, fatigue is another psychological state which is prevalent and often debilitating in both diabetes groups. It seems to occur more in those who have higher HbA1c (i.e., less controlled) (Park et al., 2015) and can impact participants' quality of life greatly. Participants generally make clear distinctions between sleepiness and fatigue, and can be caused by a range of factors such as blood sugar levels, anxiety, and poor sleep (Fritschi & Quinn, 2010).

#### *7.4.2.4 Cognition*

Findings regarding cognition were similar across both groups. The majority of T1DM (8/12) and T2DM (8/14) participants were either unsure about the cognitive effects of diabetes, or had not considered it. Remaining participants described difficulties with memory and/or decision making but some were still not certain. Only four participants across both samples were aware of an established research association between diabetes and cognitive impairments/links to dementia (Emma T1P3, Toni T1P4, Danielle T1P7, and Gail T2P7), and two participants expressed notable worry regarding potential effects on cognition (Emma T1P3, Theresa, T2P1). Participants that did report cognitive impacts typically described how low blood glucose levels and hypoglycaemic episodes negatively impacted concentration (e.g., brain fog), memory and decision-making skills. For example, Danielle (T1P7) explains: *"If my blood sugar is low, I will find my concentration levels are shot and will make silly decisions. Almost like brain fog people describe or baby brain. It is scary and you start to worry if it is Alzheimer's or related to the diabetes – I didn't realise until recently that the two are related."* Supporting this, Tess (T2P4) explains the impact of diabetes on decision-making and impulsivity: *"I think sometimes my thoughts are foggier, I don't think as clearly, erm, it's interesting, when your blood sugar is low you definitely don't make such good decisions as you would if your blood sugar's* *in the normal range. I tend to be a little bit more impulsive if I've got a low blood sugar, and I think when my blood sugar is high and I'm tired I'm more likely kind of, not* **not** *to care, but to take less care, erm, with a decision so I think it does have an effect on the thinking processes."*

These responses are concordant with existing research, which reports clinically significant associations between diabetes (T1DM and T2DM) and cognitive impairment through attention, inhibition (i.e., impulsivity), and memory deficits (e.g., Abo-Hadj et al., 2020; Palta et al., 2014; van Duinkerken & Ryan, 2020). Executive functions are essential in planning behaviours (Carlson et al., 2016) and so are important to understand in the context of diabetes self-management. Due to the uncertainty or worry in some participants, and cognition being correlated with other factors such as diabetes distress, it may be a good topic to integrate into structured education. For example, one component of executive dysfunction is inhibition, which is associated in diabetes populations (van Duinkerken & Ryan, 2020), and those who have lower inhibition are more likely to attend anxious thoughts and have difficulty attentionally shifting from those thoughts (Martel et al., 2007). Therefore, informing participants of this may enable more effective coping strategies to deal with these psychological difficulties. Whilst cognitive problems do not seem to affect every participant, those who do experience them may benefit from understanding the potential interplay of cognition with diabetes and other psychological correlates as part of structured education.

Additionally, several T1DM (5) and T2DM (3) participants were usure whether cognitive effects (e.g., memory) were due to their diabetes or age. For example, Michael (T2P11) stated: *"It never occurred to me that it might be diabetes that's causing me to forget things, I put it down to old age."* Gail (T2P7) also felt her thinking processes had *'slowed up'* and was a source of worry for her, demonstrating a potential benefit of including cognitive effects of diabetes in diabetes education (as this will allow engagement with the problem). Given the severity of cognitive deficits are positively associated with younger diabetes onset age and longer diabetes durations (Brands et al, 2005; Shalimova et al., 2019), it is worth considering if this could be integrated into structured education, so patients might be able to identify problems they might be having as linked to their diabetes. Lastly, three T2DM participants (all recently diagnosed) deliberately avoided researching cognitive effects (e.g., Kenny, P2P6), due to anxiety regarding future complications. This suggests an effect of anxiety on cognition and therefore care behaviours.

In summary, both diabetes groups' responses were mixed; most participants had not considered cognitive effects of diabetes or were unsure, and others reported cognitive problems that are commonly reported in the diabetes literature. This could suggest cognitive issues are not generally significant experiences in these participants' lives, or it could be that individuals may be experiencing cognitive issues and are unaware. These findings could suggest a potential benefit of education in those who might be experiencing cognitive effects from diabetes but are unaware, although more research is needed to confirm this.

### ***7.4.3 Overarching Theme 2: Resilience***

This theme describes the lived experience behind the model concepts (see study 1), and how resilience might influence psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in participants. Coping styles are also considered in the context of resilience.

#### *7.4.3.1 Role of Resilience in Diabetes Self-Management*

Definitions of resilience were very similar across both groups, centred on remaining positive, persevering obstacles, and being able to bounce back and living a normal a life despite the diabetes. All participants across both groups described how resilience was important in their diabetes self-management, except for Dorothy (T2P8), who had "*Never given it much thought to be honest. Just got on with it.*" More specifically, recurring themes found across both groups centred on feelings of strength (e.g., Lesley, T1P6); perseverance (e.g., Theresa T2P1); the ability to live a normal life despite the diabetes (e.g., Sue T1P12); reframing/attribution (e.g., Karen, T2P5); coping with stress (e.g., Michael T2P11); and acceptance (e.g., Gordon, T1P2). A point of interest was how only three participants across both samples made direct reference to social support when answering what resilience means to them (Amelia T1, Karen T2; Gail T2). For example, *'asking for help when you need it as well. Actually showing you want support in order to keep doing what you're doing"* (Amelia, T1P1). Given how it is an established correlate in the literature (see chapter 3), it might be expected to have seen more of this in definitions surrounding resilience. Other unique definitions mentioned ‘taking advice from the experts’ (Martin, T2P2), and “not being brave or hiding your pain, but showing those things and carrying on regardless,” (Maisey, T1P10).

Overall, themes were consistent across participants, resilience was important in: 1) coping abilities, these allowed participants to engage in self-management behaviours and managing setbacks such as a high-blood sugar readings*;* 2) accepting that diabetes is a chronic illness and to not expect immediate changes; and 3) managing feelings of anxiety through reframing situations more positively and to not give in when managing diabetes becomes overwhelming. For example, Emma (T1P3), *“So that kind of waking up this morning with a higher blood sugar, knowing that within a couple of hours I will feel better. It's that, that's the, the resilience part as well, isn't it? Knowing that if I do this now in two hours, I will feel better and if I do not feel better, I will do this. I... you know, it's that kind of having, I guess, resilience. You need a bit of a plan to bounce back don’t you?... I think that's part of the resilience technique, isn't it, that I have things to go to if things aren't so great.”* This is supported by David (T2P3) who states: *“Resilience for me is the ability to cope, and be able to bounce back, erm, face what's ahead and embracing it and taking steps to either improve or change the situation for the better.”* These findings support existing research where increased psychological resilience can promote more effective (i.e., adaptive) self-management behaviours and is associated with significantly higher HbA1c levels in T1DM and T2DM (Luo et al., 2019; McGavock et al., 2018; Skegdell et al., 2021). This can be explained through resilience providing more available resources and therefore adaptability to stressors such as diabetes self-management (Zhang et al., 2022). In summary, resilience plays an important role in both diabetes groups regarding self-management. Although resilience was important to almost every participant, psychological concepts such as this are not covered in structured education or discussed in primary care (Benton et al., 2023).

### *7.4.3.2 Resilience, and Anxiety and Fatigue*

Findings were similar across both groups. Almost all participants (11/12 and 13/14 in T1DM and T2DM, respectively) described how resilience helped to manage and/or reduce feelings of anxiety or fatigue in several ways, such as: reassuring anxious thoughts (e.g., Ross, T1P5); optimism and establishing available resources to cope (e.g., Emma, T1P3); persevering despite anxiety and fatigue (e.g., Ben, T1P9); and allowing participants to work out more ways of coping with anxiety and fatigue (e.g., Kenny, T2P6). Resilience and these behaviours allowed participants to engage more with diabetes self-management behaviours (e.g., exercise), which can lead to improved glycaemic control and health outcomes (Torabizadeh, Poor, Shaygan, 2019). For example, Danielle (T1P7) explains: *"I am a very resilient person and, to be honest, I find I push myself. My resilience is what makes me stop my anxiety in its tracks, and perhaps what enables me to do my walk when it literally feels as if having root canal and a filling that touches a nerve would be more pleasurable than walking or eating."* This is supported by Martin (T2P2) who stated: *"I was ready to give in to it all, but resilience said you got to keep on going with this, it's the only way to get rid of this, put it into remission, so that kind of got me out of my sleeping all the time… And I do have an enormous [inaudible] more energy, and that I think has helped with the resilience, so yeah I think the physical change has affected the mental way of dealing with things as well."* These findings suggest resilience plays a key role in how participants think and feel (i.e., cognitive appraisal and emotional regulation), and how they might cope with feelings of anxiety and fatigue to improve diabetes-management (supported by Wilson et al., 2017).

More specifically, eight participants provided examples of how resilience, anxiety **and** fatigue might interact with each other. For example Amelia (T1P1) describes: *"I think the sort of relationship between resilience and anxiety and fatigue is… they all come hand in hand, and…You're kind of anxious about the fact you, you know, something might be going wrong, but then your resilience kicks in and you have to keep going, but then it's so exhausting, so your fatigue kicks in. So I just think it is, you're very much in a nice little triangle, I suppose, when you look at them like that."* This is also supported in the T2DM samples, where Karen (T2P5) describes: "*Resilience has a big impact on your anxiety and your fatigue. Because depending on how resilient you are, I think the scales slide in the* *opposite direction, for example your anxiety and fatigue would be at 10 if your resilience is at 1."* These responses suggest associations between resilience and anxiety/fatigue, and between anxiety and fatigue themselves. Karen's (T2P5) response was particularly insightful as she described an indirectly proportional relationship between resilience and anxiety/fatigue, which is supported by existing research. For example, significant associations have been found between higher resilience and lower anxiety (Ruiz-Aranda et al., 2020; Santos et al., 2013) and fatigue (Wojujutari et al., 2019), in T1DM and T2DM populations.

In contrast to those who described how resilience helped them, eight participants explained the difficulty of being resilient when anxiety and fatigue levels are high (e.g., Maureen, T1P11), which could be explained through lower resilience levels. For example, resilience has been found to protect against negative emotional states (e.g., anxiety) in diabetes patients following trauma (Makai, Ratvai, Veszely, Pethes et al., 2019). Additionally, thirteen participants (e.g., Michael T2P11, Ross T1P5) felt being resilient individuals prevented them from struggling with anxiety and fatigue, supporting a protective effect of resilience. Collectively, these findings provide some support for a mediating effect of resilience between psychological states (anxiety/fatigue), as reported in the model from study 1. However, it is important to consider resilience could ease anxiety/fatigue, but to perhaps varying degrees across individuals; some participants felt that resilience helped reduce anxiety but not fatigue or vice versa, for example, Toni (T1P4).

Additionally, participant responses were consistent with existing bi-directional associations found between anxiety and fatigue (e.g., Romadlon et al., 2022). For example, Emma (T1P3) states: *"with anxiety it feels like you have to be fixed in something or you have to perform and then, but you're just so tired and you can't do it. But then you're getting anxious about the fact you're not doing anything."* In support, Dorothy (T2P8) stated: "*If you're tired you're gonna get anxious more, you're not gonna put so much [effort] in, you're gonna have that 'ughh I just can't be bothered' attitude."* Participants generally felt this association between anxiety and fatigue was *"a consequence of the diabetes, and the two sort of work hand in hand." (David T2P3).* This also provides some support for the respective associations in the model from study 1.

In summary, findings from both diabetes groups provide some support for the model in study 1, although resilience may affect people at different levels, or it may not be as prevalent a factor in some people's diabetes self-management. As research supports associations between resilience and diabetes-related psychological correlates (e.g., diabetes distress; see chapters 2 and 3), it is important to consider current resilience-based education and interventions for improving diabetes self-management (Wilson et al., 2017).

### *7.4.3.3 Resilience and Cognition*

Findings were similar across both groups; the only noticeable difference was a wider range of answers in the T1DM sample, and answers centred around processes such as decision making, planning and appraisal, all of which are associated with executive functions (Carlson et al., 2016). Most participants (eighteen) explained how having good resilience helped them to: make better and more decisive decisions (e.g., Ben T1P9); finding different ways of adapting to and coping with problems (e.g., Theresa, T2P1); attain a positive attitude (e.g., Tess, T2P4); cognitive attribution and reframing (e.g., Amelia T1P1; Karen T2P5); remembering things (e.g., Lesley T1P6); and planning (e.g., Michael, T2P11). Supporting this, Ben (T1P9) explains how resilience aids decision making and persistence: *"If I didn't have the resilience I do, I probably wouldn't be able to make the sort of choices I do, it'd be easy to go down, like a less sort of friction road, if you will."* Additionally, Michael (T2P11) explains how resilience helps in planning and adapting to problems: "*it's really what you interpret resilience as, but like I just explained choosing the right foods to eat is part of the planning and I plan what we are going to eat and what we buy, I always go with my wife shopping so we sort of plan it together, yes I think that is being resilient, it's adapting to the problem and the problem is diabetes."* These findings suggest several ways in which resilience could facilitate improved cognition (i.e., thinking processes, decision making) across participants. Factors such as adaptive coping, appraisal, self-efficacy and optimism are core constructs of resilience (Terte et al., 2014), and resilience has been significantly and positively correlated with cognitive function in adults with T1DM and T2DM (e.g., Frazao et al., 2018; Hadj-Abo et al., 2020). Also, resilience has been found to improve cognition in diabetes through improving cognitive appraisal of the difficulties of living with diabetes (Esenkova, 2021). Whilst participant responses provide some support for an association between resilience and cognition in diabetes, it is hard to ascertain whether this supports a mediating effect of resilience.

It is important to note ten participants across both groups were somewhat unsure of the effects of resilience on cognition, struggling with the question at times (e.g., Toni T1P4). In the interview cognitive processes were referred to as ‘thinking processes,’ although these concepts are quite abstract; it is likely not everyone will have heard or used these terms, which may have an impact on how they answered. It may be that participants did not understand some of the concepts being discussed, especially regarding thinking processes compared to affective states (e.g., anxiety). This might explain why some participants did not answer the question directly or sometimes trailed off (even after the researcher prompted clarification), making it hard to ascertain the involvement of resilience on cognition (e.g., Gordon T1P2, Dorothy T2P8, Sue T1P12).

Generally, resilience seemed to facilitate better decision-making and planning skills, which are associated with improved diabetes self-care and health outcomes (see chapter 3). Findings provide support for an association between resilience and cognition, although this is not true for all participants.

#### *7.4.3.4 Resilience and Diabetes Distress*

Findings were similar across groups. Most participants (fifteen) across both groups described positive situations where sufficient or good levels of resilience helped manage or ease feelings of diabetes distress. Participants explained these via several mechanisms, the most common was allowing participants to rationalise feelings of destress and talk oneself out of them. For example, Emma (T1P3) states: *“I think, yeah, cos you talk yourself out of being distressed. Well, I do. It's, you know, and, and sometimes you just have to sit with the unhappy, distressing feelings. And kind of finding the root cause of them.”* Supporting this, Danielle (T1P7) explains: “*I’m resilient enough that I can talk myself into a better mood, whether that be through walking, eating I confess, something I love or simply positive affirmations and or relaxation. This has a huge impact on any feelings of distress - for the better.”* An explanation for these findings could be that resilience facilitates greater emotional control, allowing better regulation of negative emotions (Coccaro et al., 2021), such as diabetes distress. This is supported by existing research, where resilience has been positively associated with adaptive coping methods, more effective diabetes self-care behaviours, and decreased diabetes distress levels (e.g., Wang et al., 2017; Yi Frazier et al., 2015). Resilience intervention studies further support this and have shown significant reductions in DD in T1DM and T2DM groups (Hood et al., 2018; Scott et al., 2020).

Participants also described specific ways in which they felt resilience affected DD levels. For example, facilitating a positive mindset, which allowed Jaqueline (T1P8) to work through feelings of distress and denial. This helped her to engage with self-care behaviours after a period of ignoring them. Toni (T1P3) described resilience as stubbornness which allowed her to take control of the diabetes distress and not let it '*dictate or ruin her life*.' Martin (T2P2) described resilience as feelings of determination, which helped him to adhere to medication and self-care regimes such as BG testing and exercising. Lastly, Gail (T2P7) felt resilience helped her bounce back to a mentally healthier place more quickly, in the context of diabetes distress. Resilience could be described as a protective factor against DD (see chapter 3), and this was supported by Michael (T2P11) and Lynne (T2P9). For example, Michael stated: "*Well it might be because I am resilient that it doesn't affect me. If you were a bit unable to cope then you could get very stressed about it."*

In contrast, a few participants explained that resilience did not affect their feelings of DD, but instead helped them to cope/manage with high levels of DD without being overwhelmed, or finding acceptance/peace concerning this. For example, Maisey (T1P10) stated: *"No [Resilience did not affect DD levels]. I have been more distressed than words can say, especially when I was in the grips of my anorexia and it has caused severe trauma but it didn't affect how strong I was or how resilient I was. It didn't make the distress easier to cope with, but the distress didn't break my resilience either. If that makes sense."* In addition, Rosenna (T2P14) explained: *"I don't think it's necessarily a case of improving [DD] if you have resilience. I think sometimes things do stay bad, and there's no improvement, but, you know, you find your acceptance and peace after the situation."* This suggests that whilst resilience may still play an important part in coping with the stressful situations, it may not necessarily alleviate DD related symptoms people experience, and therefore resilience does not affect everyone in the same way. It is also important to consider that people's experiences and comorbidities might shape their resilience levels and how they appraise diabetes distress, for example, Rita (T2P12) was also diagnosed with cancer before diabetes and when asked whether she felt resilience had any effect on diabetes distress she responded with: *"to be honest because of what I have been through, no. To my mind what I already had is so extreme that anything else is fairly minor."* This is important because it demonstrates the individualistic nature of resilience and possible diabetes distress thresholds based on personal experience. This has implications for examining effects of resilience across participants and in healthcare and education. Additionally, as with the previous section (7.4.3.3) on resilience and cognition, a few participants were unsure of the term DD, this could be because DD is a less conceptually understood term in comparison to anxiety or fatigue. This has implications for education in HCPs and patients, and research suggests more discourse on psychological effects of diabetes is needed (Benton et al., 2023; Zabell et al., 2022).

In summary, the findings provided insight into how resilience might affect DD; resilience appeared to facilitate better management of DD, although this was not the case for everyone. This provides some support for the model in study 1, which has implications for diabetes self-care and interventions.

#### *7.4.3.5 Resilience and Coping Styles*

Findings were mostly similar across both groups. Coping behaviours described by participants who felt they had good resilience (established by them acknowledging this in the interview) were typically indicative of adaptive (i.e., emotion-approach and problem-focused) coping methods. For example: planning/organisation of meals, equipment, calculating insulin, reminders for medication or activities *(e.g., Gordon T1P2; Tess T2P4),* positive attributes and reframing *(e.g., Danielle T1P7; Rita T2P12*), recording blood sugar readings *(e.g., Lesley T1P6; Donna, T2P10),* exercise or relaxation techniques *(e.g., Amelia T1P1; Martin T2P2),* and frequenting diabetes blogs and forums for support *(e.g., Maureen T1P11).* For example, Jaqueline (T1P8) explains how she seeks social support as a coping method: *"Going on a diabetes blog helps because you're speaking to other people who understand,* *you know, cause they're going through the same rigmarole every day. That's quite helpful."* Additionally, Theresa (T2P2) explains how she sought immediate action following diagnosis: "*I came straight home, I joined a gym. I went straight from the diagnosis of that high level, straight to the gym from where I was, um… and dealt with it that way." And that's how I just deal with it. Action, get on with it, and it was them as well as me, and as well as the nurse all going 'come on, something's got to happen.' Cos they gave me the horror stories about it…"* These responses demonstrate problem-focused coping methods, which involves behavioural activities to remove or reduce the stressor (Hapunda, 2022; Skegdell et al., 2021), for example, planning and adhering to an exercise regime to improve glycaemic control. Research suggests problem-focused coping is the most effective coping method by individuals living with a chronic disease (e.g., cancer, diabetes), to reduce stressors (Bakan & Inci, 2021). This can be explained through associations with increased self-efficacy and increased resilience, which is supported in existing research (e.g., Torabizadeh, Poor, & Shaygan, 2019; Wilson et al., 2017).

Interestingly, feelings of good resilience were less consistent across the T2DM group; participants who felt they had poor resilience tended to describe behaviours more indicative of maladaptive coping styles (e.g., emotional-avoidant coping). For example, Karen (T2P5) stated her resilience was one out of ten, did not test her blood glucose levels and suffered from severe anxiety and fatigue, and she described maladaptive coping behaviours such as emotional eating in response to anxiety: *"I get anxious cos my sugars are high, anxiety makes me want to eat, so I eat, so my sugars get higher, so my diabetes gets worse. So my anxiety doesn't get any better and I think you end up in the vicious cycle."* Collectively, these findings are supported by existing research (e.g., Indelicato et al., 2017; Knowles et al., 2020), where maladaptive coping and poorer self-efficacy are associated with greater anxiety symptoms. Additionally, emotional-avoidance coping behaviours due to feelings of worry or stress were frequently reported, for example, avoiding collecting medication (Lynne, T2P9), avoiding blood glucose testing due to worry of high levels specifically (David, T2P3; Dorothy T2P8), and avoiding taking tablets (Theresa, T2P1). Although emotional avoidance coping may ease short-term stress for some, it could contribute to longer-term health anxiety, which is associated with poorer diabetes self-management and glycaemic control (Wilson et al., 2017. See also section 3.2 for a discussion of coping and safety behaviours). However, behaviours such as excessive blood glucose testing, or comfort eating could be evidence of a safety behaviour which shares overlap with emotion-focused coping behaviours (see section 3.2). Safety behaviours can facilitate/perpetuate rigidity, threat perception and avoidance of feared situations, whereas coping behaviours facilitate flexible approach of feared situations; therefore, it is important to understand the function and motivation of the behaviour, and individual context of the experiences (Hoffman & Chu, 2019). Emotion-focused coping strategies aim to manage and reduce the intensity of negative emotions (e.g., anxiety, diabetes distress) caused by a stressful situation, in this case managing a chronic disease (Hapunda, 2022). Emotion-avoidance coping styles (e.g., denial, avoidance, wishful thinking) are typically categorised as maladaptive, and are associated with poorer glycaemic control and higher levels of emotional distress (e.g., anxiety, depression) (Burns et al., 2016; Knowles et al., 2020). This can be explained as emotional strategies do not address the source of emotional distress.

In summary, more adaptive coping styles were reported in those who felt they were resilient and managed their diabetes well, and more maladaptive coping styles were reported in those who felt less resilient and not in good control of their diabetes. This supports existing research (e.g., Ruiz-Aranda et al., 2020; Wilson et al., 2017; Yi-Frazer et al., 2008). These findings also provide some support for Adu et al. (2019), who found higher rates of self-efficacy and coping in T1DM patients than T2DM. This could be explained by diabetes duration, and on average T2DM patients are diagnosed later in life, requiring behavioural changes at later life stages.

### *7.4.4 Overarching Theme 3: Healthcare Experiences and Attitudes (Inductive)*

This theme describes healthcare experiences and attitudes expressed by the participants, in order to examine their feelings and experiences regarding their diabetes care. This overarching theme is split into two themes (healthcare provider interactions and healthcare system).

#### *7.4.4.1 Healthcare Provider Interactions*

**Lack of Support**

For the T1DM sample, views on healthcare providers appear to be varied among participants. Only three participants were ‘satisfied’ or ‘happy’ with their care throughout, two had very negative experiences (described as ‘appalling’ and ‘abysmal’), and the rest had mixed experiences. In comparison, six T2DM participants expressed more negative/very negative views of healthcare experiences, with 4 expressing mixed views, 3 good/satisfied, and 1 neutral. A strong theme repeating across both samples was a lack of diabetes support, particularly emotional and psychological. Participants across both groups felt healthcare providers generally do not care, nor do they ask about mental health or moods, and participants explained this can make it difficult for people to open up to healthcare providers.

The majority of participants (nineteen) explained quite despondently how they felt at times ignored or neglected, and this appeared to affect their perception of HCPs. Participants in the T2DM sample appeared to speak more strongly and with more frustration, especially concerning the time around diagnosis (e.g., Kenny, T2P6) with several participants wondering if their blood glucose would be better controlled with sufficient healthcare support (e.g., Tess, T2P4). As an example, Lesley (T1P6) states: *“You don’t get backup, or they’re not interested, nothing whatsoever, the diabetic nurse at my doctors is- she’s not very good, full stop.”* Additionally, Martin (T2P2) explains feeling unsupported at the time of diagnosis, which is a critical time: *“The doctor was quite abrupt, last year when we were recovering from covid crisis and all the doctors were overworked, and so… He phoned us, ‘we’ve got your blood tests a month ago, but I think somebody’s forgot to phone you, and you’re diabetic by the way.’ And that was not helpful…The doctor I thought was hopeless – the fact he waited so long to tell me [the diagnosis] and then wasn’t very helpful or friendly, just gave me the news and said, ‘oh I’ll put you on the list, somebody will be in touch,’ and that was it.”* These findings can be explained through several barriers which participants highlighted, for example: HCPs being overworked (e.g., Theresa, T2P1), pressure on the NHS system (e.g., Tess, T2P4) insufficient knowledge (e.g., Emma, T1P3), or not believing/listening to patients’ problems, such as difficulties with medication (e.g., Danielle, T1P7; Donna, T2P10). These findings are supported by Hadjiconstantinou et al. (2020), a UK-based study, where both HCPs and patients identified main barriers to emotional support: 1) lack of HCP confidence to address these issues, 2) lack of HCP training/knowledge, and 3) time constraints in appointments. Additionally, Dambha-Miller et al. (2020) found that GPs repeatedly emphasised optimal diabetes care (including emotional support) is not achievable due to unmanageable workloads, and there was an expressed need for greater funding and workforce support. Emotional support is insufficient and rarely discussed in diabetes appointments (Zabell et al., 2022), and so this is a target area to improve patient care.

Conversely, participants from both groups who expressed satisfaction with their care referred to their care being holistic (e.g., Amelia, T1P1), caring (e.g., Ross, T1P5) and compassionate (e.g., Roseanne, T2P14), and it made a difference to feeling supported and their self-care. For example, Karen explained how it makes her feel valued as a patient: *"[Her consultant says] Please don't leave your appointment, please wait for me because I want to see you.' And just those words, 'I want to see you,' make a difference… So definitely I feel valued, and I feel like he's helpful."* Additionally, Amelia explained how her HCPs would ask her how she was feeling (emotionally), rather than focusing just on physical diabetes symptoms. This could suggest a more holistic approach (i.e., inclusion of emotional support) could contribute to greater diabetes healthcare satisfaction, which is recommended by several research papers (e.g., Dambha-Miller et al., 2021; Hadjiconstantinou et al., 2020; Zabell et al., 2022). Additionally, a few participants (e.g., Dorothy, T2P8) felt due to a lack of support that her issues were ignored, and this prevented her from seeking out further help for problems such as neuropathy. These findings suggest expressed care from HCP's can have an impact on how supported patients feel, which has been associated with self-care efficacy in the literature (e.g., Chan et al., 2020).

Additionally, there seems to be a lack of support for HCPs who are also diabetes patients themselves. In this study, there were two participants (Emma, T1P3; Tess T2P4) who also worked as HCPs (not diabetes-related). Tess (T2P4) described how because of her occupation, it appeared she was expected by other nurses to have more knowledge than someone who was not a nurse: *"They sent me to the* *specialist nurses who basically left me to get on with it, you know, there was no real guidance, they just sort of said you know, you're a nurse, almost like have a guess at how much insulin you need. So, I don't feel that the care has been great. So yeah, I kind of wonder if there was sort of better support whether my diabetes would be a little bit better controlled."* Although this is a small proportion of the entire sample, it is still important to consider as it may be a valid barrier for some people in receiving optimal diabetes care. Although Emma (T1P3) did not describe the same assumptions from her diabetes HCPs, she explained: "*I don't think there's enough knowledge, even with other nurses, of the impact of diabetes. So I'm super nice to my diabetic patients cos obviously I can understand… Because you tend to find the people who go to be diabetes nurses aren't… They're a bit older, so they've been in nursing for a while. And they kind of, a lot of them feel that they know everything."* This also supports the findings of Benton et al. (2023), who conducted interviews with UK diabetes HCPs, and found lack of knowledge, relationship between services, lack of time in appointments and stigma were the main barriers for HCPs in providing effective emotional support (see also Dambha-Miller et al., 2020).

In summary, most participants across both groups felt unsupported, especially psychologically and emotionally from their HCPs. Those who described positive experiences described HCP interactions that felt caring, compassionate and were holistic regarding both physical and emotional impacts of diabetes.

### Continuity (T1DM only)

One issue identified that was specific to the T1DM group was continuity amongst their HCPs. Several participants described seeing a different HCP across appointments, and explained how this affected their ability to form a rapport with the HCP, making it harder for them to open up about sensitive topics such as mental health. For example, Gordon (T1P2) explains: *"Even at the appointments it's not like you're seeing the same person over and over again… You can't build that rapport with them."* Additionally, Sue (T1P12) supports this by saying, *"You keep seeing different [HCPs] and they all have different opinions about it."* In contrast to these responses, Ben (T1P9) describes how beneficial it has been having access to the same HCP across appointments, especially regarding opening up about sensitive topics: *"I've grown quite accustomed to having them around and I'm used to the way they do things, and it's easy to talk to them about problems that I might not really want to talk to people about."* These findings can be explained through continuity and developing trust in the HCP, and criticisms of a lack of continuity have been expressed by other UK diabetes patients (see Dambha-Miller et al., 2020). This is important as care satisfaction has been positively associated with trust in HCPs (Orrange et al., 2021), and so is an important area to target when improving diabetes care. Benton et al. (2023) argues facilitating trust and a safe relationship between the HCP and their patient is imperative, and a way to do this could be to improve and ensure consistent HCP and informational continuity (Husdal et al., 2021). One explanation as to why this theme was present in the T1DM group and not T2DM could be that typically T1DM patients are diagnosed younger and have experienced longer diabetes durations compared to T2DM patients of the same age.

### HCP's Attitudes and Approaches/Assumptions

An attitude can be defined as a psychological tendency to respond to a particular entity/concept in a positive or negative way (DiMartino & Zan, 2010). The majority of participants across both groups spoke strongly about how negative HCP attitudes and approaches made them feel unsupported, and negatively affected the way they viewed their HCP and their diabetes care. One problem identified was participants were frustrated with insensitive attitudes towards them. For example, HCPs being rude or not believing the participants' medication/regimen adherence due to assumptions regarding symptoms such as high blood glucose levels. Donna (T2P10) describes a relevant experience: *"The Doctor was accusing me of not taking my medication because my blood sugar was so so high, so he really did make me feel like I was totally unsupported."* Additionally, Donna was also not believed when she had taken a fasting blood glucose test and went to the doctor for help, " he *was laughing at me and went, 'do not be stupid, you've not presented to me with feeling unwell on this that and the other'"* In this case, Donna's fasting blood sugar levels were 12.5 (normal 4-7mmol) and she was later diagnosed that day. Additionally, Lynne (T2P9) describes a similar situation: *"I had a whole host of muscular skeletal issues and i've damaged my neck, and erm, and my hip had started playing up and she [HCP] said "oh you haven't been doing exercise and you haven't been walking" and i'm* *like i'm out walking all the time, I live in the middle of, you know, the country side…"* Examining Donna's case above, high blood sugar levels are not sufficient to make a judgement on whether a patient is taking their medication, as diabetes is a progressive disease and blood glucose levels can fluctuate unpredictably and without any obvious cause (Hirsch & Gaudiani, 2021; Speight et al., 2012). Supporting this, Litterbach et al. (2020) found a prevalent complaint among people with diabetes in the UK was wanting their HCPs to understand that negative judgements, assumptions and perspectives are unhelpful and unwanted. A possible explanation for negative assumptions and attitudes in HCP's could be a lack of education/training and confidence to address such issues (Benton et al., 2023; Hadjiconstantinou et al., 2020).

Another problem identified by participants was HCPs criticising in an unhelpful and/or unconstructive manner. For example, focusing too heavily on severe complications to elicit behavioural change (e.g., limb loss, organ failure), or criticising based on a 'textbook version of diabetes,' which led to a great deal of frustration expressed by participants. Specifically, participants faced resistance when trying to explain how their diabetes would respond. For example, Maisey (T1P10) spoke strongly about her experience: *"They [HCPs] are always making you feel like you're not doing good enough. Criticising, telling you you're wrong because you don't fit the textbook version of diabetes. All the constant, "you'll end up losing…" or "your X, Y or Z will fail." I know they have to make sure you are aware but I've had it since I was 6… I know the score! Everyone has to be their own version of diabetic. When we all have different bodies and different realities of living with it."* This is also supported by Dorothy (T2P8) who expressed: *"But nobody is bothered to say "Oh, let's look at this." You know? I say it and people say 'nope, nope. You're wrong. It doesn't do that.' It does. I know my diet so because people are sort of 'put me in the box' as a stereotype, i've gone, 'Right, you treat me like that I'll do my own thing. "And I think my biggest thing is the medical profession needs to wake up and realise, that diabetes is not a one size fits all."* These findings suggest a lack of holistic understanding, and at times, a lack of compassion and support. Other UK studies report similar findings, where HCPs and diabetes patients acknowledge a lack of emotional support, and too much focus is placed on physical symptoms, as opposed to emotional understanding (Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020). Litterbach et al. (2020) also found that UK diabetes patients wanted more understanding that they are well versed in their own diabetes, rather than being compared 'textbook' expectations. These findings could be explained through a lack of HCP knowledge/training and confidence, which has been found in several studies (e.g., Benton et al., 2023; Hadjiconstantinou et al., 2020).

Additionally, several participants explained 'blinkered approach' issues in HCPs, where Lynne (T2P9) for example, described a patient at her local practice who had to formally complain; the doctors were telling her to lose weight despite being severely underweight, to achieve better HbA1c levels: *"I encountered a lady once who was skin and bones and she was saying she had to put a complaint in to her own surgery because she was losing weight and she had developed diabetes and the local GP that she saw said to her "you need to lose weight" and she's like "wha- look at me", i'm like well I see it, I think it's… it's sometimes they can be very blinkered erm…In their approach rather than looking at the wider picture."* Interestingly, this somewhat mirrors what Maisey (T1P10) went through, where she was praised for achieving good HbA1c levels, but was severely underweight from diabetes-related anorexia. These findings suggest a more holistic and sensitive approach would benefit patients' care experiences. This is supported by Tierny et al. (2017), where compassionate and understanding approaches are essential part of developing a healthy HCP-patient dynamic, and are recommended as part of good care practices. Participants also expressed a need for HCPs to understand that their diabetes is individual to them, and wanted them to "*Treat every single diabetic as an individual and you listen to them. You don't go from a book, you listen to that person" (Toni, T1P5).* This is also supported by Emma (T1P3) who stated: *"My daughter's diabetes is so, so different to my own, which it's not just a one size fits all really. And that's what I find so interesting when I'm looking after patients as well. It truly is an individual disease, isn't it? I don't think I've ever met another diabetic who's the same as me."*

In summary, participants expressed unhappiness and frustration with HCPs attitudes and assumptions, and expressed a need to be understood as an individual rather than being compared to textbook expectations of diabetes. This can lead to patients feeling unsupported, which is associated with poorer self-care efficacy and self-management behaviours (Chan et al., 2020). Improving education within healthcare settings may address these issues, improving identification of emotional difficulties and reduce stigmatisation within and outside of healthcare settings (Benton et al., 2023).

### *7.4.4.2 Healthcare System*

**Lack of Direction/Help**

Several participants (eleven) across both groups expressed frustration at a general lack of direction from the healthcare system, in particular with informational help, and accessing diabetes-related psychological help, very much feeling ‘left to [their] own devices’ (Emma, T1P3), which caused which caused quite significant stress in some participants (e.g., Maisey, T1P10). For example, Amelia (T1P1) stated: *“It almost sounds unfair to say, but nobody was particularly helpful. It was very much they give you a call and I think they just needed to tick off that they'd checked in.”* These thoughts are echoed by Emma (T1P3), who explained: *“It is me having to do all the work, you know, that wasn't automatically help given to me. I had to go ask for it. So that's quite stressful as well, because you don't know who to ask for what, It's not actually explained… So imagine if somebody wasn't even in the system, like working in the NHS to be aware of that process - they may just go, oh, okay, never mind. And just carry on…and not get sorted. I just find that really frustrating.”* It is important to mention the last response was from Emma, who works as works as a NHS nurse, and despite working in the NHS, still found it very hard to access help and to know who to ask. These responses suggest that signposting regarding accessing help is poor, and should be considered in improving diabetes care.

Participants from the T2DM group were noticeably more frustrated and angry than that of the T1DM group with the lack of direction and help from the NHS; this could be because T1DM is usually diagnosed younger and people diagnosed under 18 have more frequent appointments, and also children appear to have an easier time adapting to diabetes with parental support (whereas independent adults carry sole responsibility for their diabetes management). Participants felt very much left to their own devices, especially at the time of diagnosis, which caused quite significant stress in some participants. For example, Kenny (T2P5) stated: *"Because I've looked after myself, something's gone wrong, I would at least like to know what it is, and at the moment I don't even know if there's something wrong with my pancreas, or if I've become insulin resistant over a long time just because of stress and all that kind of stuff, and it saddens me that no one will tell me unless I go private, and that sucks… That really, really sucks…It's very much, here's your testing kit, here's some medication, we might change the medication to see what works better, off you go, see you. Come back if you're really sick and we will deal with the problems…"* Additionally, these thoughts are mirrored by Jayne (T2P13) who states: *"I've not really had a lot of information in all these years on diabetes from anybody at the doctors. It's almost like you've got it, off you go." (Jayne, T2P13)*

Furthermore, participants often described how waiting times between appointments are insufficient for their care needs (e.g., Gordon, T1P2), and changing appointments means they would not get another for a significant period of time (e.g., six months; Theresa, T2P1). Also, available time during appointments with the HCP is insufficient, and this is acknowledged by patients and HCPs in UK-based research (Benton et al., 2023; Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020). Several participants have stated they have found diabetes UK or other self-help resources more helpful than the NHS regarding their education *(e.g., Theresa, Kenny, Michael* for further detail). This suggests current education within the care system is insufficient (supported by Benton et al., 2023; Zabell et al., 2022).

### Variability of support

Findings were similar across both groups, where five participants in particular expressed frustration with the variability of primary care support across locations and care teams (e.g., Danielle, T1P7; Donna, T2P10), and the discrepancies between primary and secondary care support, where comparatively poorer experiences were reported in primary care settings such as GP practices (e.g., Lesley, T1P6; Tess T2P4). For example, Danielle explains how a difference of care team was life changing: *"Two years ago I'd give the health care team 0/10. I got no help from them whatsoever. Then I was swapped to a different team and they changed my life… It wasn't that I had changed what I was eating so much as I had learned from the dietician and had the support I had been craving all* *along."* Supporting this, Dorothy exclaimed: *"I hate the diabetes care in this country, I've asked for one of these things that go on your arm (continuous glucose monitor) so you can scan by your phone; [location] don't fund it so I got no chance of doing it, now if I have it privately, It's £150 a month. Well it sucks because, if you come from [location], you can have it. Why is diabetes a lot like cancer treatment? Why is it a postcode lottery?"* These responses demonstrate dissatisfaction with the variability of diabetes care support, improvements to the consistency of healthcare locations might improve patient care experiences, quality of care and engagement with services as a result. Danielle's responses above particularly shows how important feeling supported is in aiding diabetes self-care (supported by Chan et al., 2020). Existing research supports these findings and acknowledges primary diabetes care is suboptimal, with significant differences in care measures across location (Acharya et al., 2019; Dambha-Miller et al., 2020). These differences could be explained through regional differences in healthcare/funding, which is supported by the British Medical Association (2023); significant differences in per person healthcare spend can result in differences in care, and regions with lower levels of health may receive more funding. These findings are important because they have clinical relevance; Dambha-Miller et al. (2021) found more positive primary care experiences were associated with significantly lower HbA1c levels, and significantly more likely to achieve diabetes remission after 5 years. Although these patients were T2DM, it demonstrates a positive impact on glucose control. Therefore, it is important for primary care practitioners to deliver consistent and optimal patient care across the UK.

### *7.4.5 Overarching Theme 4: Education and Intervention Experiences (Inductive)*

This theme describes participants' attitudes regarding diabetes education and interventions, to understand the lived experience of their diabetes care, and to gain insight into recommendations they feel would be beneficial to individuals with diabetes. This overarching theme is split into two themes (diabetes education and diabetes interventions), and are presented separately by diabetes type. This is to adequately reflect the more nuanced differences captured in these inductive themes, for example, stigma and intervention recommendations specific to T1DM and T2DM.

### *7.4.5.1 Public and Healthcare Education*

The perceived low level of diabetes education within a public and healthcare setting appears to be another prevalent frustration/difficulty in T1DM participants; they recounted experiences where they have experienced either/both, and in most cases has led to a feeling of stigma. For example: individuals with T1DM being confused with T2DM by the public (e.g., Jaqueline, T1P8) and being told not to eat sugar during a hypo, or not understanding the impacts of fatigue in a hidden illness (e.g., Danielle, T1P7). Also, the stigma of being berated for needing to inject or eat sugary foods (to correct low sugar levels) in public settings (e.g., theatres; Danielle T1P7). This appeared to create feelings of unease and exhaustion, which might be mitigated by improving public education. Additionally, participants talked about the unfairness of stigma in workplace environments, where they would be compared to other diabetics in terms of needing time off for sickness or fatigue (e.g., Gordon, T1P2). This tied in with the individuality of diabetes, where participants would often express that every diabetic is different. For example, Gordon (T1P2) stated: *"Work don't really understand, 'cause they were comparing me to a couple of other diabetics 'cause they're asking, well how come these [other diabetics] aren't having days off? ...Every diabetic's certainly different."*

Additionally, Emma (A NHS nurse; T1P3), discussed how she felt alongside a lack of education of the general public, there was a lack of healthcare education among other nurses, and that the level of education given to a general nurse is not sufficient when considering the high rates of diabetes: *"As a general nurse, I had, a lecture which was maybe two hours, and a couple of hours teaching session in my three years of nurse training. So that shows you how poor, and that's the education in people in healthcare, let alone, if you're brand new, newly diagnosed… Quite often I ask people, have you been given education on what foods are good? Have you been given education on, you know, how your medication works? And quite a lot of people haven't...Which I find quite hard because these people are housebound as well... and it's how do you get that education out to people? Really, there's not been a huge amount."* These feelings were also echoed by *Toni*, who works for Diabetes UK. In summary, these findings suggest a lack of perceived education in public, work and educational settings that may be contributing to feelings of stigma, and increasing education overall may be beneficial to easing feelings of stigma (Benton et al., 2023; Dambha-Miller et al., 2020; Liu et al., 2017).

T2DM Findings generally mirrored that of the T1DM group; The perceived low level of diabetes education within a public and healthcare setting seem to be another frustration/difficulty in participants; they recounted experiences where they have experienced either/both, and it has led to a feeling of stigma, e.g., weight loss, lifestyle and fatigue. For example, Donna (T2P10) and Karen (T2P5) describe how upsetting it is to feel so fatigued, and people do not understand since diabetes is a hidden illness, which can lead to feelings of embarrassment: *"I just feel so wiped, I feel tired,' And [people are] like, 'yeah but you've had a relaxing day.' …But you've not actually done anything, and then it kind of does make you feel quite a bit embarrassed, and then it's like, well are they right? Do I seem lazy?" (Donna, T2P10).* A specific frustration within the T2DM group was if the participant already followed a healthy lifestyle. Participants, in particular Kenny (T2P6), Rita (T2P12) and Lynne (T2P9), explained how the public misconception of a T2 diabetic was upsetting: *"This assumption that if you have got it you must be fat and eat sort of eat loads of crisps and biscuits and never exercise and all that, because those people who do that have been able to turn it round and it is really unfortunate that those of us who haven't got those lifestyle things still have diabetes…It feels like victim blaming and the truth is if you have not done any of these unhealthy things and you still have diabetes, you kind of feel like a stigma" (Rita, T2P12).* This suggests that public education could be improved and might reduce some of the stigma people are feeling. This ties into feelings of healthcare education, where Kenny (T2P6) expressed annoyance at the nurses being unable to advise for someone who already has a healthy lifestyle: *"I run a lot and I cycle a lot, and I was saying, you know right, what do I do if I'm out for, you know, eight hours, ten hours something like that, what do I eat? And they're very much, 'eh I don't know,' So, it feels like they're kind of geared up to people who have a bad diet for most of their lives, and they're trying to kind of nudge them, on… But for someone who eats fairly healthily anyways, and may need to adjust for my specific circumstances, there's no help."* Additionally, Lynne (T2P9) describes how she feels public healthcare is poor and her nurse explained *"[Lynne] was the only person she actually encountered who knows what a carbohydrate* *is."* This could suggest a lack of diabetes- and food-based education in the general public. Furthermore, Tess (T2P4) feels healthcare education is not great since she had "*no real guidance"* from the specialist nurses regarding insulin dosages.

To summarise, the stigmatisation described by T1DM and T2DM participants are supported by Liu et al. (2017), who conducted a survey of 12,000 individuals with T1DM and T2DM. A lack of HCP knowledge/training and stigma have been identified as main barriers to providing emotional support for individuals with diabetes (e.g., Benton et al., 2020; Litterbach et al., 2020), and so these are key areas to consider in improving diabetes care. The lack of education in patients and public could be due to poor uptake rates of diabetes educational courses, which is supported in the literature (Reeves et al., 2023; Whicher, Holt & O'Neill, 2020). Future research should focus on how to improve intervention attendance rates in patients and improving educational training in HCPs (i.e., psychosocial/emotional challenges of diabetes).

### *7.4.5.2 Interventions*

Intervention attendance for the T1DM group was 58%; this included DAFNE, carb counting courses, and related seminars, *(e.g., Maureen – menopause and anxiety in type 1 diabetes*) where every participant reported course satisfaction and found it useful. However, several criticisms of current interventions were common across participants, such as the DAFNE course not being flexible (e.g., with work commitments). For example Amelia (T1P1) explains: *"I often get offered the DAFNE course for carb counting, um, but it's like, it's like a whole five days or like a whole 10 weekends or whatever it is, I feel like there should be other, other methods of being able to take part in those things without having to take such big chunks of time out of your life to sort it out."* This is supported by Horrigan et al. (2016) and Reeves et al. (2023), where one of the main reasons for poor uptake rates were practical difficulties, related to financial or logistical factors (e.g., fitting the course in around other commitments). Additionally, several participants expressed wanting to see more information on support/local community support groups, for example, Gordon (T1P2) stated he *'did not know they existed.'* This suggests signposting within healthcare settings are poor, which has been supported by Benton et al. (2023). They found NHS diabetes HCPs expressed frustration with the disconnect between health services, and a lack of knowledge on available pathways and referring between services. As such, trying to signpost patients becomes very difficult.

Additionally, six participants expressed frustration at the lack of variety in educational interventions, particularly regarding a lack of mental health consideration. Courses such as DAFNE and DESMOND are available (for T1DM and T2DM respectively), but these focus on the physical management of diabetes and do not cover mental health or emotional factors of diabetes. For example, Toni (T1P4) explains:*"There's absolutely sod all out there, I'm sorry to say it. As, as a person with diabetes and a mother with two type one diabetics and my father's type two… The only thing out there is the Katie course or the DAFNE, the Derek course for type twos. There's nothing out there for mental health.."* These feelings are supported by Ben (T1P9): *"There's no actual like, proper stuff in place to check on your mental health."*

Lastly, Ross (T1P5) suggests teaching resilience to clinicians who treat diabetes; he explains the limits which individuals place on themselves could hinder navigating obstacles, including managing diabetes, therefore teaching resilience to clinicians and subsequently patients, helps to manage problems and push past limits: *"In my mind, I think [resilience] should be taught to, to clinicians because I think a lot of the care, especially with children is, if you're a parent and you lock your kid into a glass box, your kid is gonna be in a glass box the rest of his life."* This is also recommended by Benton et al. (2023) and Hadjiconstantinou et al. (2020), who suggest a key area for diabetes care improvement is training and educating HCPs in psychological/emotional factors associated with diabetes, to ensure patients are provided with the emotional support and education they need for optimal self-care. Given that resilience is a mediator of psychological factors such as anxiety, fatigue and DD (see Chapter 3) it would be a good topic to incorporate into existing education interventions such as DAFNE and DESMOND.

For the T2DM group, intervention attendance group was 36%; this included DESMOND, carb-counting courses or related seminars (e.g., dietician advice). Only one participant found the DESMOND course useful (David, T2P3). Although comments regarding the courses only came from a small number of participants, similar arguments were made. For example, finding the courses unhelpful due to a lack of host engagement, and information being too basic: *" I attended the first one… but I found it really unhelpful. It was just equal grumbling about various side effects and so on… and other people were just chiming in with ideas and the woman organising it, the woman hosting it didn't really contribute anything despite being… She was meant to be the expert. So I give up after one session because it wasn't helpful. It's… It was also for people with type 1 diabetes as well, which needs handling differently" (Martin, T2P2).* These thoughts were mirrored by Tess (T2P5) who explained: *"Oh god when I was first diagnosed, they sent me on a carb counting course which was the most excruciating and painful thing I've ever done. There were about ten of us and they hadthis plastic play food and, you know, to be fair I come from a nursing background and I would say that there was quite a mix of people but the majority of them were, and this sounds derogatory and I don't mean it that way, but I think you know what I mean, the majority of them were Sun readers, so they didn't realise that you know, it wasn't just sugars that, you know, carbs were part of the issue. You know, and there was this guy sitting there saying you know 'well I only like full fat Coke and I like my Mars bars and I have 3 mars bars a day and I'm not going to change' and I just thought 'Oh God.' And they had us sort of picking up these little bits of plastic food and we were supposed to say you know, have they got any carbohydrate in them and I just thought, you know this is not… I didn't find it helpful I actually found it really frustrating."* These findings suggest that there might be a range of diabetes knowledge levels between people on the education courses, with some participants finding those that find the information too basic or not specific enough. To prevent frustration or discouraging further attendance, perhaps implementing screening of the patients' prior knowledge before interventions could be beneficial, so that those who already understand certain concepts can build on their existing knowledge, rather than feeling frustrated. And conversely, those who lack understanding of more basic concepts (e.g., understanding carbohydrates are sugars) will not feel rushed or overwhelmed in sessions.

Additionally, Tess (who worked as a nurse, T2P4) also explains how she feels the manner in which things are presented to newly diagnosed patients is important, and it would be better to reframe things in a way where alternatives are presented as positives, not as restrictions (also supported by Michael, T2P11): *"Like that there can be positives, like what could you have instead of a juice or whatever, but, kind of trying to look on it in that way rather than you can't have this you can't have that, you're diabetic…I think that kind of education bit in the beginning is actually really important."* Participants also expressed they would like to see some form of integrating mental health help into educational courses (e.g., Roseanne), to better understand the reality of living with diabetes and their individual needs in managing diabetes. For example, Martin (T2P5) explains: *"I think I would have appreciated more mental health help, more specialised things, I didn't really think I needed anything else, but perhaps the mental health thing would be… I think if it was more my situation than a general one."* Lastly, Michael (T2P11) explained how he struggles to compare his lived experience to other diabetics because he has *"never sat down or discussed with other diabetics."* This suggests interventions may benefit from signposting more about support groups that are available, especially when signposting and understanding of pathways between health services is poor in care settings (see Benton et al., 2023).

To summarise, intervention attendance rates were lower in the T2DM group than T1DM, which is in line with existing research (Whicher, Holt & O'Neill, 2020). Notable comments regarding interventions were logistical difficulties, course content (e.g., too basic), and noting the lack of mental health content in current education courses. Some participants expressed incorporating MH or resilience into current courses would be helpful. However, as only a small number of participants could comment on interventions from prior experience, the findings should be generalised with caution.

## 7.5 Discussion

This is the first study to qualitatively investigate a model where resilience mediates psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition), in both T1DM and T2DM adults. There is also a lack of UK studies examining healthcare experiences in relation to the psychological impacts of living with diabetes, especially in T1DM. The findings provided insight into the lived experience of the model from study 1, providing some support for the associations and mediating effect of resilience, between psychological states and diabetes outcomes. Additionally, findings provided insight into diabetes care perceptions and experiences, and diabetes education and interventions; all of which are relevant to informing interventions and health outcomes. The findings are discussed in relation to the research questions below and will discuss T1DM and T2DM groups together unless there were differences in patterns of findings.

The first research question was to examine the lived experience of relationships between psychological states (i.e., anxiety, fatigue) and resilience. Mental health was also discussed. Generally, anxiety seemed to affect all participants but appeared to vary (based on accounts) from mild to severe, whereas fatigue seemed less of a widespread problem and did not affect every participant, but cases discussed were usually invasive and severe (also accompanying hypoglycaemic events). Fatigue was also reported more in those with more uncontrolled HbA1c levels, which supports existing research (Park et al., 2015). Participants described how anxiety and fatigue brought on feelings of distress, through emotional eating, over worrying, or a lack of motivation to engage with self-care behaviours (e.g., physical exercise). Participants explained a number of methods in which resilience interacted with anxiety and fatigue, (e.g., engaging with self-care behaviours, adopting more adaptive coping, positive appraisal); this allowed participants to push through feelings of anxiety and fatigue and prevent or lessen the negative outcomes as a result. This supports the idea that resilience provides a means of accessing more resources, to help individuals cope with stressors (see Chapter 3). Additionally, the majority of participants are not asked about their mental health as part of their care, and in some cases led to a loss of trust in healthcare providers through feeling unsupported, or feeling that help was inaccessible. The lack of mental health support could be explained by: 1) lack of HCP confidence to address the issues; lack of HCP training/knowledge; 3) time constraints in appointments; 4) unmanageable workloads and lack of funding (Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020). Participants who were asked about their mental health in appointments described more satisfaction with their diabetes care teams, suggesting a more holistic approach in diabetes appointments may benefit patients and help them feel more supported (supported by Benton et al., 2023; Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020). Additionally, participants highlighted that key stressors underlying mental health and diabetes were related to the hidden nature of diabetes and achieving blood glucose balance alongside life stressors. These factors subsequently associate with stigma surrounding both diabetes types (Liu et al., 2017).

The second research question was to examine the lived experience of relationships between resilience and cognition/diabetes distress. Generally, resilience seemed to facilitate better decision-making skills (e.g., planning, reframing, appraisals of situations) which is associated with improved self-care efficacy and health outcomes in the literature. Resilience also seemed to reduce and/or manage feelings of diabetes distress. Findings provide potential support for the lived experience of the model in study 1, although this did not apply to all participants. Additionally, participants were generally unsure, or had not considered long-term cognitive effects on diabetes, which could suggest it is not a problem experienced by participants, or that individuals were unaware of that as a potential issue. It is also a relatively abstract concept compared to anxiety or distress, therefore may be harder to think about in the interview. Others reported cognitive problems that are commonly reported in the diabetes literature (e.g., poorer memory, attention, decision-making and increased impulsivity (see Chapter 3). These findings could suggest a potential benefit of education in those who might be experiencing cognitive effects from diabetes but are unaware, although more research is needed to confirm this.

The last research question was to investigate other prevalent themes (healthcare attitudes/perceptions and diabetes education/interventions). Although not everyone evaluated their care experiences negatively, the majority of participants were dissatisfied or had mixed views regarding healthcare provider interactions and healthcare systems. Namely, a lack of: support and direction (especially after diagnosis in type 2), continuity (T1DM only), poor attitudes, inconsistencies in support across location and system (i.e., primary and secondary care). These factors support existing literature (e.g., Dickinson et al., 2017; Speight et al., 2020; deWit et al., 2020) and appeared to contribute to a lack of trust and confidence in healthcare providers. These findings identify several areas to consider for improvement, regarding the implementation of care in diabetes patients.

There were a number of findings regarding diabetes education and interventions. First, ten participants across both types described feeling distressed due to stigmatisation, in particular, T2DM participants talked about being blamed for bringing the condition upon themselves, and T1DM participants talked about being wrongly associated with T2DM (e.g., being told they should not be eating sugar despite a hypoglycaemic episode), and needing to take medicine in public settings. These findings are concordant with that of existing literature (deWit et al., 2020; Jaser, 2011; Eilander et al., 2017). Also, both groups described feeling stigmatised in relation to fatigue, which was assumed to be laziness. Additionally, eight T1DM and T2DM participants, including nurses in both groups, felt that education levels were not only low in public, but in healthcare providers generally (supported by Litterbach et al., 2020; Dambha-Miller et al., 2020). One participant talked about how her training was only a few hours long, and current education was insufficient given how widespread and serious diabetes is. Some T2DM participants also expressed a need for better education and guidance from healthcare providers when they already had healthy, active lifestyles. The above findings suggest a further research need in healthcare and public education, with perhaps a focus on whether psychological effects of diabetes are integrated into this. This will be considered in study 3.

Additionally, intervention course uptake was low in T1DM and T2DM groups (58.3% and 35.7%, respectively) and in line with current UK findings, where higher rates are reported for T1DM. Whilst the data is not generalisable in this way, it can help to see if the sample is a fair representation of the population. Uptake rates of structured education in the UK are also poor in both diabetes types; forty-nine per cent of people with T1DM were offered structured education, but only 7.6% attended; the corresponding figures for T2DM were 90% and 10.4%, respectively (Whicher et al., 2020). This suggests a need to increase uptake of structured education in the UK. T1DM participants in this study generally reported good satisfaction with interventions, although recommendations such as more varied resources, and integration of mental health into current interventions were made. Intervention satisfaction in the T2DM participants was generally poor, although it is hard to make conclusions as only a small number of participants had experience with interventions. Key criticisms included lack of engagement, poor or basic content, and lack of mental health and resilience integration. Findings suggest interventions could benefit from screening prior knowledge levels and including mental health and resilience-based content, that would allow patients to cope better with the demands of diabetes and apply resilience to their situations. A last notable finding was that five participants commented on previously not being introspective, and how having the conversations in the interview had helped them to make more sense of how their diabetes was affecting them. This suggests having these conversations may be useful for certain people and encourage these discussions in health-based settings, and is recommended by a range of research (e.g., Zabell et al., 2022)

This study had several strengths. First, the originality of the study addresses a gap in the literature which has clinical applications in informing interventions. Additionally, the inclusion of both T1DM and T2DM participants as independent groups, whereas studies typically look at only one, or both as a singular group. This allows for a better insight of potential group differences and comparisons. Additionally, semi-structured interviews allowed for flexible exploration of the research questions and associated themes. Lastly, although the inclusion of HCPs was not planned for in this study, two participants (Emma, T1P3; Tess, T2P4) worked as nurses but also had diabetes, experiencing both ‘sides’ of healthcare. This dual role as both patient and healthcare provider could have influenced participants’ responses through unique perspectives or biases. For example: 1) some individuals may have enhanced empathy and a nuanced patient understanding due to dual roles and potentially advocate for more patient-centred care approaches (especially if they have their own personal struggles with healthcare systems and/or guidelines). However, depending on situational/individual factors this could also present as negative attitudes and views of the system;  2) their dual role may allow for unique systemic insights and knowledge, allowing them to evaluate the healthcare system on a deeper level compared to non-healthcare professionals; 3) credibility bias in self-reporting, where individuals may under-report their own challenges or non-compliance (e.g., medication adherence) due to social desirability, which could contrast with more honest responses from participants who do not work as healthcare providers; and 4) potential contradictions in responses from advocating guideline advice as a healthcare provider but personal struggles with these. While it is important to consider sources of bias, the view taken in this thesis is that these dual roles offer unique and rich perspectives that are important in understanding lived experience (i.e., by providing a more layered, blended personal experience with professional insight). However, it is important to acknowledge they were asked the same questions as other participants, and their views were in line with existing research with HCPs, for example, acknowledging there is not enough emotional/mental health support for patients and identifying the same barriers to providing this support, such as lack of training and education (Benton et al., 2023; Dambha-Miller et al., 2023; Hadjiconstantinou et al., 2020).

The study is not without limitations; an important factor to recognise is that both groups were mostly female and so findings may be less generalisable to males with diabetes. This could be explained as females are more likely to reach out regarding their diabetes, and higher ratios of females to males are seen in some recent studies (e.g., Torabizadeh et al., 2019). Another limitation is two of the participants completed a written form of the interview due to severe anxiety (Maisey, T1P10) and blindness and anxiety (Danielle, T1P7). Although they were asked to provide as much detail as possible in their answers, their data will have less detail in them than the other participants. Another limitation is the questions relevant to the model from study 1 grouped anxiety and fatigue in relation to resilience, which should be avoided in future, as it would prevent participants from answering about both collectively, which makes it harder to ascertain which factor they were talking about. Anxiety and fatigue were grouped because they were both predictor and bi-directional variables, and so the researcher wanted to understand how these would react within people’s experiences. In retrospect, this decision was made by an inexperienced qualitative researcher, and so questions examining variables will be planned more carefully in future research.

Another important consideration of the study was the difficulty of ascertaining the influence of comorbidities in behaviour. The lack of controlling for comorbidities can potentially reduce the validity of study data. However, comorbidities are very common in diabetes populations (e.g., Nowakowska et al., 2019), and so to exclude on that basis would risk not understanding what a large number of individuals are dealing with in relation to the model in study 1. Additionally, high numbers of comorbidities emphasise the need for patient-centred/individualised healthcare, which is also supported in studies 2 and 3, and existing research (e.g., Benton et al., 2023). Another consideration was the length of interviews; interviews typically lasted 30-40 minutes, however one interview (Kenny) only lasted 17 minutes. This was due to the participant's concise nature; Although this can limit the level of detail in answers, the researcher felt this did not significantly compromise the insightfulness/richness of what was said. Additionally, the model factors were examined separately as part of theme 1; this could limit understanding of the SEM model, but the psychological variables are already well established within the research (see Chapter 2). What is not understood is how these variables interact with one another at the same time and how resilience might mediate them (which is what theme 2 aimed to address). Therefore, I made a pragmatic decision to look at relationships separately first, allowing me to piece together a better idea of how resilience might (or might not) be acting as a mediator in these variables and how each relationship is experienced through the participants. Lastly, it is important to acknowledge that no pilot study was conducted, potentially reducing rigour and making it less likely to identify potential issues/difficulties e.g., with the interview questions. Although the researcher made sure to iteratively examine interviews throughout in the context of the interview schedule, a lack of piloting may have increased the chance of bias in the analysis stage. The experience from this research process has led to clear understanding of the value of conducting pilot studies, which will be considered going forward.

## 7.6 Reflective Summary

This section will briefly consider how my characteristics as a researcher may have influenced my interpretation and work throughout study 2 (for a more in-depth and wider discussion, see Chapter 9). Then, other reflective aspects of the study will be considered (e.g., how I avoided bias, participant interpretations that stood out to me). Firstly, the biggest challenge was that I had no prior qualitative experience, only quantitative. This required shifting paradigms from an objective numbers-focused approach to a more subjective narrative-focused approach. I found it very hard to adapt and embrace to subjectivity, and it hindered my analytic interpretation a lot in the beginning. I tended to focus too heavily on objective patterns (i.e., how many people said the same thing) as to the subjective patterns (i.e., why they were saying the same thing). As a result my analysis was too descriptive; however I worked closely with the supervisory team to develop my skills and arguments throughout (e.g., considering contrasting information and being open to this). Additionally, I also hold particularly passionate views about the NHS, and as a result of my poor experiences with accessing mental health help (and the NHS's current state) I may have fixated more closely on the problems discussed rather than the positives in interviews. However, I did try to ground myself and work on this as part of my growth as a reflective researcher.

Another reflective consideration was how to avoid bias, ensure objectivity and develop good quality arguments. To do this I worked closely with the supervisory team throughout the analysis, one of who is an expert in qualitative data and thematic analysis (the other supervisors also had experience in qualitative data and health research). For example, after I began coding the transcripts, we all met via Teams to ensure consistency and quality in my work. The same applied with checking my themes/subthemes and my analysis as I developed it. Feedback in my work was very useful as it pinpointed where my arguments were not being objective enough (e.g., deductive analysis not supported with research) or if I was being too objective on subjective issues (to the point of missing what participants were saying). The team periodically reviewed my work. Additionally, As this was a qualitative study, it is harder to ascertain evidence of a mediating effect. However, steps were taken to try and facilitate this. For example, paying close attention to participants' narratives and how they explained relationships between predictors and resilience, and resilience and outcomes; at the same time remaining open to contrasting data throughout the research process. Also, acknowledging the potential for bias as a quantitative researcher. Ultimately, resilience played a key role in diabetes management for all but one participant who was unsure; participants referenced a range of examples of resilience indirectly aiding psychological difficulties such as anxiety, fatigue, cognitive difficulties, and distress. Many described pathways that are supported in the literature e.g., resilience helps to manage stress through cognitive appraisal and emotional regulation (see section 3).

Regarding the interview schedule, I feel the questions were generally appropriate for the population, and only on occasion would I have to use prompts. The only term that caused slight confusion was diabetes distress (i.e., not knowing the difference between diabetes distress and stress). Some of the retrospective questions occasionally provided difficulty - this question was asked with the understanding that it may be hard to remember for some participants who were diagnosed a long time ago (especially some individuals with type 1). I felt it was a good question to ask as it helped participants reflect further on their anxiety levels and how this may have changed over the years and for what reasons. Additionally, as fatigue is a psychobiological state of body and mind, some participants may have struggled to distinguish between non-diabetes related and diabetes related fatigue. However, to control for this: 1) The questions clearly asked about diabetes-related fatigue. If participants were unsure of what fatigue was, prompts and explanations were discussed; and 2) Before and after comparisons of fatigue were asked to help facilitate reflection on diabetes-specific symptoms. A main issue was that they had never thought of it in this depth before, with participants often remarking that no healthcare professional had asked them about fatigue or causes of fatigue in context of their diabetes.

Lastly, five participant interpretations of anxiety stood out to me, particularly regarding how visceral some quotes felt, for differing reasons. For example, Karen described anxiety as *'being on a cliff edge, hanging on with my fingernails. Or… I'm treading water, I'm not able to swim…I'm not sinking quite, but I'm gonna wear out very, very soon and I'm going to either drown or just float.'* Additionally, David interpreted anxiety as: '*that inward fear that [diabetes] isn't redeemable... that I may have done untold damage on the inside.*' Both of these quotes made me feel quite existential and empty, as living with chronic health anxiety must be very daunting. In addition, I found Gordon's description of anxiety quite harrowing, where he explains having intrusive thoughts of him with no legs. These interpretations made me feel empathic for someone who might be experiencing health anxiety for a chronic, progressive disease. Other notable interpretations of anxiety involved the fear of going to sleep (e.g., Jaqueline), and the inescapable nature of chronic anxiety (e.g., 'always bubbling under the surface,' Tess).

## 7.7 Conclusions

This study provided insight into the lived experience of the model from study 1, and provided some support for the mediating effect/associations of resilience between psychological states and diabetes outcomes. Resilience appeared to be an important factor across both groups regarding diabetes self-management, generally helping to manage and/or minimise psychological difficulties such as anxiety, fatigue, and distress. Additionally, inductive findings provided insight into diabetes care perceptions and experience, and diabetes education and interventions; the majority of participants felt they were not receiving the emotional help or feeling sufficiently supported by the system or their diabetes HCPs. Further investigation into the inductive factors is needed to inform intervention and education recommendations.

# Chapter 8: Study 3. A qualitative examination of resilience, diabetes education and intervention experience in adults with T1DM and T2DM diabetes.

## 8.1 Chapter Structure

Chapter 8 describes the third study, which qualitatively explored the findings of studies 1 and 2, but in a broader sample. This study used questionnaires (closed and open questions, based on findings from study 2), to explore significant issues such as resilience education, mental health support and intervention and healthcare experiences from patients to help compile recommendations for future intervention design. To avoid repetition, the introduction will focus on introducing/contextualising inductive themes from Study 1.

## 8.2 Introduction

Self-management is the foundation of diabetes care and requires ongoing vigilance and multiple daily self-care tasks (e.g., blood glucose monitoring, regimen and medicine adherence, planning, counting carbohydrates) (Benton et al., 2023). The burden of self-care is psychologically demanding, and those with diabetes are at significantly higher risk of psychological distress and mental health problems compared to individuals without diabetes (Robinson et al., 2018; Wylie et al., 2019). Interventions are especially important considering individuals with diabetes spend an average of three hours with a healthcare professional per year, therefore must manage their diabetes the rest of the year themselves (Wicher, O’Neill & Holt, 2020). Therefore, their education and health literacy is crucial for adequate diabetes management (Balogun-Katung et al., 2021). In healthcare, an intervention is defined as any activity undertaken with the aim of improving health via preventing disease, reducing the severity or duration of an existing disease or restoring lost function (Smith et al., 2015). These activities can range from (but are not limited to): health education, behavioural change strategies, health planning, and self-management methods (Smith et al., 2015).

Diabetes education is a core component of diabetes treatment, where the goals of this are to provide knowledge and skills (e.g., awareness of cardiovascular complications and how to avoid them), increasing motivation to engage with therapeutic recommendations, improving psychological resilience and health outcomes/quality of life (Stotz et al., 2023; Wicher, O'Neill & Holt, 2020). Diabetes education interventions are associated with positive health outcomes, such as improved HbA1c levels, healthcare engagement and fewer complications (see section 4.3). However, despite these education courses being positively received and clinically effective, course uptake in the UK is low. For example, A National Diabetes Audit Report (2019) found that while 49% of those with T1DM were offered structured education, only 7.6% attended. Corresponding data for T2DM were 90% and 10.4%, respectively. Uptake rates of structured diabetes education is poor, and the NHS spends approximately £10 billion a year on diabetes, 80% of which is spent treating complications. This suggests more should be done to target improving structured education as a preventative measure against complications and poorer health outcomes (Whicher et al., 2020). A common criticism of these courses and structured education as a whole is the lack of emotional/psychological information (Diabetes UK, 2019; Primary Care Diabetes Society, 2018).

DAFNE is the leading structured skills-based education course for adults with T1DM, enabling patients to self-manage their diabetes (DAFNE, 2013). The original pilot study (Amiel et al., 2002) found significant improvements in treatment satisfaction, psychological wellbeing and quality of life after 6 months compared to those without DAFNE attendance. These findings were replicated in other longitudinal studies, where significant reductions in anxiety, depression, distress and HbA1c were found after a year (Hopkins et al., 2012). Conversely, DESMOND is the leading structured education course for adults with T2DM, providing patients with the skills and education to manage their diabetes. The original study (Skinner et al., 2002) administered DESMOND in 236 individuals with T2DM, and significantly found reduced and lower HbA1c levels after 3 months. Illness beliefs also significantly improved, and participants felt more able to control their diabetes. Longitudinal research has also found significantly reduced diabetes-distress, and improved self-efficacy after 8 weeks (Hadjiconstantinou et al., 2021), and significant reductions in HbA1c levels after 12 months (Chatterjee et al., 2018).

The DAWN2 study (Stuckey et al., 2014) is one of the largest to qualitatively investigate psychosocial experiences of type 1 and 2 diabetics' negative emotions/experiences and adaptive ways of coping with these (n=1,368 and 7,228, respectively; across 17 countries). The two main negative themes associated with diabetes were: 1) anxiety/fear (e.g. worrying about diabetes complications or hypoglycaemia), tiredness and negative moods/feelings of hopelessness; 2) discrimination at work and public misunderstanding of diabetes. The two main themes for adaptive coping were identified as: 1) having a positive outlook and sense of resilience, and 2) receiving psychosocial support through family, friends and healthcare professionals. This study demonstrates how resilience can be useful in overcoming negative experiences, which has implications for diabetes self-management. Additional findings that are important to consider, were the need to better inform and support people with diabetes, especially the newly diagnosed, and to increase public knowledge of diabetes to reduce discrimination.

Despite national and international guidelines recommending regular screening, up to 45% of cases of mental disorders go undetected among people with diabetes (Benton et al., 2023). Therefore it is important to consider what the facilitators and barriers are to providing/recieving mental healthcare. To my knowledge, there were only four appropriate UK-based studies that directly examined emotional support from NHS HCPs and/or diabetes patients (see Benton et al., 2023; Berry et al., 2020; Dambha-Miller et al., 2023; Hadjiconstantinou et al., 2020. Hadjiconstantinou et al., 2020). found both HCPs and patients identified the following barriers: 1) lack of HCP confidence to address these issues; 2) lack of HCP training/knowledge; 3) time constraints in appointments, and 4) stigma (Benton et al., 2023). Facilitators included education, communication, and appropriate tools/services for referral. Additionally, Dambha-Miller et al. (2020) found that GPs repeatedly emphasised optimal diabetes care (including emotional support) is not achievable due to unmanageable workloads, and there was an expressed need for greater funding and workforce support. Emotional support is insufficient and rarely discussed in diabetes appointments (Zabell et al., 2022), and so this is a target area to improve patient care. There is a lack qualitative resilience research in both T1DM and T2DM populations (e.g., Wilson et al., 2017; Skegnell et al., 2020), which this study aims to address.

This study will qualitatively build upon study 2, by using deductive reflexive thematic analysis to examine the themes and patterns found across a larger dataset. This will help to further understand the inductive themes identified in study 2. Specifically, this study will address two research questions: 1) qualitatively investigate the lived experience behind the model constructs and relationships in study 1, but in a broader sample (i.e., psychological states, MH and resilience) and 2) further examine aspects of living with diabetes identified in study 2, that were not present in the model in study 1 (healthcare experiences, i.e., HCP interactions and healthcare system, and intervention/education experiences, i.e., direct experience, intervention recommendations, and public/healthcare education). See section 8.3, data analytic strategy for a list of constructs/themes guiding the analysis. These findings will help inform recommendations for healthcare providers and intervention researchers.

## 8.3 Method

### *8.3.1 Design*

The study had a qualitative e-survey design, using closed and open-ended questions.

### *8.3.2 Participants*

Adults in the UK with T1DM (n = 20) and T2DM (n = 33) were recruited using opportunity and snowball sampling via diabetes support groups (e.g., closed and open UK Facebook groups), local newspaper advertisements (e.g., castle view newspaper in Clitheroe) and social media advertisements (e.g., Facebook, Instagram). Participants completed an e-survey, created using the Qualtrics platform. Exclusion criteria included people below the age of 18 years, and those with diabetes other than T1DM/T2DM. Participants were not excluded if they had participated in either of the previous studies. Participants have been numerically coded in order of responses exported from Qualtrics, and sorted into T1DM and T2DM groups (e.g., T1DM P1, T2DM P1).

Both T1DM and T2DM groups were mostly female (75% and 70% respectively), with mean ages of 48.70 (*SD = 13.85)* and 56.91 (*SD = 8.65),* and were white British (95% and 100% respectively). Average diabetes durations were 19.79 (T1DM), 8.31 (T2DM), and average HbA1c levels were 70.46 mmol/mol (T1DM) and 65.96 mmol/mol (T2DM). Table 14 shows the means and standard deviations for age, diabetes duration and HbA1c levels for T1DM and T2DM groups.

Table 14. Participant Demographics, Means and Standard Deviations for T1 and T2DM Groups

| | **Type 1 (N=20)** | | **Type 2 (N=33)** | | **Total (N=53)** | |
|---|---|---|---|---|---|---|
| | Male (5) | Female (15) | Male (10) | Female (23) | Male (15) | Female (38) |
| **Age** *(Years)* | 48.70 *(13.85)* | | 56.91 *(8.65)* | | 53.81 *(11.50)* | |
| **DM Duration** *(Years)* | 19.79 *(15.53)* | | 8.31 *(8.61)* | | 12.27 *(12.75)* | |
| **HbA1c*** *(mmol/mol; IFCC units)* | 70.46 *(26.05)* | | 65.96 *(27.59)* | | 66.21 *(28.68)* | |
| **Ethnicity (see 2021 Census)** | | | | | | |
| **White** | 19 | | 33 | | 52 | |
| **Black, Black British, Caribbean or African** | 1 | | - | | 1 | |
| **Mixed or Multiple Ethnic Groups** | - | | - | | - | |
| **Asian/Asian British** | - | | - | | - | |
| **Other Ethnic Group** | - | | - | | - | |

** Only 35/53 participants knew and reported their HbA1c level (7 T1DM, 11 T2DM)*

**Key:** *Diabetes Mellitus (DM); HbA1c (glycated haemoglobin measure); International Federation of Clinical Chemistry Units (IFCC).*

### *8.3.3 Materials and Procedure*

Potential participants were provided a link to an anonymous survey, first directing them to the information sheet. For those who wished to proceed, consent was confirmed by completing and submitting the questionnaires.

A series of open-ended questions regarding knowledge and experiences on mental health, psychological correlates, resilience, education, care satisfaction and intervention experiences in the context of diabetes management were presented (see Appendix 14). Similarly to study 2, the interview guide was developed in three blocks: 1) demographic; 2) model components (i.e., mental health, psychological factors, resilience), and 3) interventions and care satisfaction questions. The demographic questions (Qs 1-8) were developed using the Diabetes Control and Complications Trial demographic items as a guide (see Nathan & DCCT/EDIC Research Group, 2014). This included the following items: whether they were a patient/HCP with diabetes (or both), gender, diabetes type, duration, age, ethnicity, HbA1c, and how well participants generally felt they managed their diabetes on a scale 1-10. The model components questions (Qs 9-14) were developed to investigate the deductive findings from study 2 (e.g., examining MH, role of resilience, psychological factors and education of these). The interventions and care satisfaction questions (Qs 15-22) were developed to examine the inductive findings of study 2. For example, asking about: intervention attendance and why they were/were not useful, what recommendations would participants suggest for interventions, frequency of appointments, and satisfaction of care and why.

### *8.3.4 Data Analytic Strategy*

A deductive thematic analysis was conducted to address both research questions described in the introduction. Deductive analysis was chosen due to the overall aim of this study – which was to examine inductive and deductive themes identified in study 2 across a wider dataset. Using inductive analysis would not have been appropriate for this, as it would require examining already established data.  These thematic analyses follow the six stages of guidance as described by Braun and Clarke (2013) as used in study 2 (see section 7.3). Table 15 details the constructs and themes from the findings of study 2, which provided an initial guide for the deductive analysis. Table 16 shows the final structure of themes after analysis was complete, to demonstrate development of themes.

Table 15. Constructs and Themes Analysis Guide

| Thematic Analysis | Overarching Themes | Themes |
|---|---|---|
| **Deductive** | Psychological States/ Mental Health | *Mental Health*<br>*Anxiety*<br>*Fatigue*<br>*Cognition* |
| | Resilience | *Resilience and Coping styles*<br>*Resilience interactions with psychological correlates above* |
| | Healthcare Experiences and Attitudes | *Healthcare Provider Interactions*<br>*Healthcare System* |
| | Education and Intervention Experiences | *Public and healthcare education (and stigma)*<br>*Interventions* |

## 8.4 Results and Analysis

### *8.4.1 Structure of findings*

Themes and subthemes that are similar between T1DM and T2DM groups will be discussed together and described separately where clear differences exist. The theme breakdowns are presented in Table 16. The first theme described is mental healthcare, which examines the accessibility of mental healthcare for patients with diabetes, and how HCPs approach the topic of mental health with their patients. Quality of care satisfaction is also examined. The second theme described is psychological correlates of diabetes, which examines the effect of diabetes on mental health, the role of resilience in diabetes self-management, and any experienced cognitive effects. The last theme described is education and interventions, which examines education from HCPs, specifically whether patients were informed of: 1) the role that resilience can play in diabetes self-management and the effects of this, and 2) the psychological effects of living with diabetes, such as anxiety, distress, fatigue, and impacts on thinking processes. This theme also examined whether this information helped participants, or how would it benefit them if they were informed. The remaining subthemes were intervention participation and experiences, and any recommendations participants had for improving current interventions (e.g., resilience and mental-health based interventions).

Table 16. Breakdown of Explored TA Themes

| **Overarching Theme** | **Themes** | **Subthemes (If type not stated, applies to both)** |
|---|---|---|
| **1. (Barriers to) Mental Healthcare** | *MH Accessibility* | *Limited Accessibility* |
| | *Approaches to MH* | *MH not raised* |
| | *Care Satisfaction* | *HCP-related issues; Service-related issues* |
| **2. Psychological Correlates** | *Impact on Mental Health (psych. states)* | *Psychological/Model correlates; Chronicity of DM; Social impact (T1); Difficulties understanding DM (T2)* |
| | *Effects on Cognition (functioning)* | *Memory and decision-making* |
| | *Role of Resilience in DSM* | *Persistence/overcoming adversity* |
| **3. Education and Interventions** | *Education from HCPs* | *Resilience education*<br>*Psychological effects education* |
| | *Intervention Experiences* | *Knowledge/Content; MH/Resilience recommendations; General intervention recommendations* |

**Figure 9.** Thematic Map of Final Themes

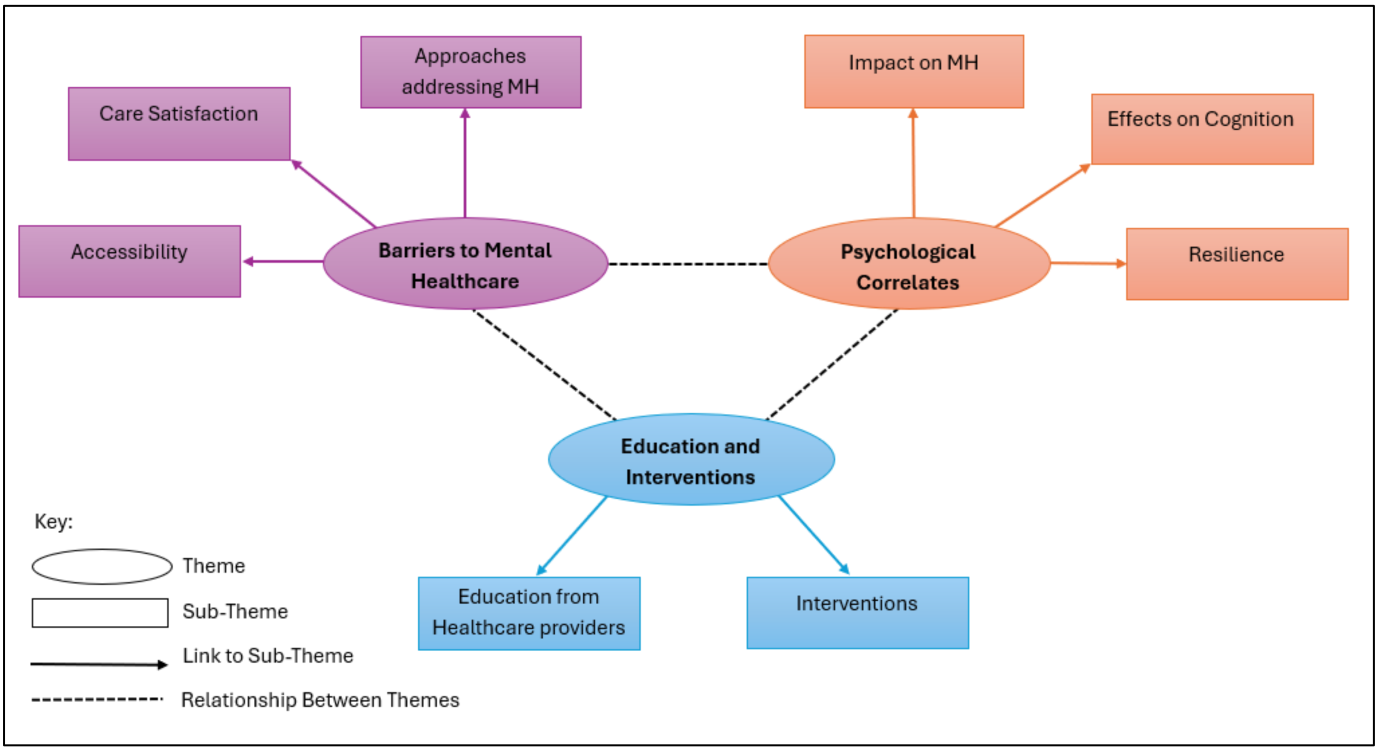


**Fig 9**. The final thematic map produced at the end of data analysis, representing the four candidate themes with their respective subthemes.

## *8.4.2 Theme 1: Mental Healthcare*

This theme discusses participants' feelings towards mental healthcare, specifically, the accessibility to mental healthcare as part of their diabetes care and whether they have been signposted to appropriate resources, how they feel their HCPs approach topics of mental health, and overall feelings towards their diabetes care satisfaction. This will help to identify potential strengths of, and issues with, current diabetes care.

### *8.4.2.1 Accessibility of Mental Healthcare Services*

***Limited Mental Healthcare Accessibility***

In response to the initial closed question, the majority of T1DM patients (14/20) stated they felt there was 'no' or 'hardly' any mental health help at all for diabetes patients, and none of the T2DM participants (0/33) reported mental healthcare to be an accessible part of their diabetes treatment. The responses across T2DM participants seem to be less varied and more negative overall compared to the T1DM sample, and overall, the majority of responses stated mental healthcare was either never discussed or offered, or feeling that there is no help available for diabetes specifically. However, a couple of participants felt the question was not applicable to them as they have never sought out help. Responses generally focused on the lack of integration between mental and physical diabetes care, for example T1DM P1 states: "*There is hardly, if any help for diabetes patients for their mental health."* This is also supported by T2DM P29: *"There is no support between mental health services and physical health services."*

Feelings among T1DM participants in relation to mental health accessibility are exemplified by T1DM P19: *"No, it is definitely not easily accessible and should be a routine part of outpatient clinics particularly in the secondary care hospital setting. I have been a diabetic for many years and I am seen in a hospital diabetes clinic and in all those years have never had access to mental health professionals within the clinic setting. This should be a routine part of diabetes management."* T1DM P19's statement in particular suggests mental healthcare is not easily accessible and needs to be more integrated as part of routine diabetes care, and is supported by Dambha-Miller (2020). It is important to acknowledge not all participants had this experience; a minority (5) reported good accessibility, but this difference could be explained through regional differences in healthcare/funding. This is supported by the British Medical Association (2023), where significant differences in per person healthcare spend can result in differences in care. Additionally, regions with lower levels of health may receive more funding. Despite this, the RightCare Pathway model (see Chapter 1) states mental healthcare should be clearly accessible to all patients if needed.

Feelings among T2DM participants in relation to mental health accessibility are exemplified by T2DM P28: *"I feel that if I could spend more time with some nurses or at least someone to give a bit more support it might ease my worries, I think it's just more physical problems with them, your levels fine, all ok, but no, my mind racing, upset, gets you down."* Whilst it is understandable HCPs are primarily focused on physical health and symptoms, mental health problems can become significant barriers to self-care behaviours (Robinson et al., 2018; Wylie et al., 2019). Additionally, participants felt that diabetes was not just a physical condition, but a psychological condition too. These findings support Zabell et al. (2022) and Stenov et al. (2020), where emotional and mental states strongly influenced diabetes self-care, yet dialogue from HCPs regarding this is infrequent and insufficient. A way to make mental healthcare more accessible might be ensuring HCPs are equipped to identify (not necessarily diagnose) potential MH difficulties and normalise signposting mental health support services across diabetes patients. Six participants who had diabetes for a relatively short time had not discussed MH with their HCPs; One recently diagnosed participant (T2DM P13) noted they had *"never been offered or had mental health support even suggested as linked to diabetes."* This is important as diagnosis is arguably the most important time for patients to learn about their diabetes (Whicher, O'Neill & Holt, 2020), and they had not been informed of any link between MH and diabetes. This should be a suggestion for future care practices. Generally, the data suggest more could be done to inform participants about the relationship between diabetes and mental health, and future research could focus on improving the integration and accessibility of mental health services/care into routine diabetes care (Speight et al., 2020; Zabell et al., 2022).

Other participants mentioned additional problems: not knowing mental healthcare for diabetes existed (T1DM P15), the length of waiting lists for access to mental health services (T1DM P10), difficulty accessing mental health services (T2DM P18), and a general lack of MH help for those with any chronic conditions (T2DM P31). This could suggest that whilst diabetes mental healthcare services are available, accessibility is not adequate due to factors such as service publicity/awareness of services and systems in place and waiting times until an appointment. Additionally, T1DM P10 felt having diabetes would not affect any mental healthcare they receive, and this could have ramifications on how likely patients are to reach out for MH help. Also, this is important to consider given the abundance of correlations between diabetes and clinically significant mental health difficulties, such as anxiety and diabetes distress (e.g., Mersha et al., 2022; Romadlon et al., 2022; Wibowo et al., 2022). This can, in turn, negatively affect diabetes management (Robinson et al., 2018; Smith et al., 2018) and increase potential strain on the NHS through complications and poor health (Whicher, O'Neill & Holt, 2020).

Conversely, five T1DM participants felt that mental healthcare was accessible, four of whom were positive about it. Out of the four who responded positively, two participants (T1DM P5; T1DM P14) did not actively seek out mental healthcare as they did not need it, but still felt it was accessible and they would receive help if they reached out. T1DM P15 contradicted themselves by saying mental healthcare was accessible but they had never received help "*as of yet due to only finding out about it*." The remaining participant with a positive response (T1DM P8) stated they "*have been fortunate to have taken part in a pilot study to have a psychologist which was extremely beneficial, and have been lucky enough to find diabetes nurses who understand living with diabetes is a balancing act."* This demonstrates access to mental healthcare can have positive effects on diabetes patients, although it can be noted that his language seems indicative of mental health care not always being accessible. It is important to note that the only participants who had anything positive to say regarding this had either not sought out mental healthcare, or in T1DM P8's case, they had been able to taken part in a pilot study with access to a psychologist. Conversely, one participant (T1DM P7) felt "*it is easily accessible at [their] local hospital but feel they don't help and wasn't offered anything else by another provider."* This demonstrates the importance of not just ensuring good accessibility, but ensuring accompanying quality of care. Additionally, they mentioned good accessibility, but only locally despite no other help from providers. Additionally, five T2DM participants stated they did not know if mental healthcare was accessible as part of their diabetes treatment – this could suggest that they have not been informed otherwise, or that it has never been an issue they have needed to seek out help for. However, Speight et al. (2020) does argue that more emphasis needs to be placed on mental healthcare in the context of diabetes, and this ideally should be discussed from diagnosis.

Another factor contributing to limited mental healthcare access was specific signposting; half of the T1DM participants (10/20) did not receive any signposting, whilst six were signposted by their HCPs, all of which were to Diabetes UK. One participant thought that if they did inquire, they would be signposted appropriately (T1DM P14). Four participants did not respond. It is important to acknowledge qualitative data cannot be examined in a quantitative way, however it is insightful to see many participants have not been signposted to external resources such as Diabetes UK. To improve

MH care accessibility, it may be important to signpost every participant to diabetes UK and also include a wider range of resources, perhaps MH based ones. As with the T1DM sample, the T2DM group discussed signposting in the context of limited mental healthcare accessibility; Nine participants were signposted by their HCPs, all of which were to Diabetes UK, apart from one participant who was referred to the DESMOND educational course. Over half the participants (19/33) stated they were not signposted to any resources by HCPs as part of their diabetes treatment. As with T1DM responses, it is insightful to see many participants have not been signposted to external resources such as Diabetes UK. To improve diabetes self-management, education and health outcomes, it may be important to a) signpost everyone consistently and b) signpost to a wider range of resources than just Diabetes UK at diagnosis, especially for MH services.

Overall, the T1DM and T2DM data suggests that accessibility to mental healthcare is generally poor, and if this is the case, it could mean people who need mental healthcare are not receiving it. This is important because long-term mental health conditions (e.g., anxiety, depression) are substantially associated with missed care appointments, premature all-cause mortality rates, and this was highest in those with a chronic physical and mental health condition (McQueenie et al., 2019). Given DM is comorbid with mental health difficulties, this may create difficulties in attending care appointments. Holman et al. (2021) found individuals with T1DM and T2DM (National Diabetes Audit for England and Wales) who attend fewer routine care procedures (e.g., retinal screening, foot examinations) have significantly higher mortality rates. This suggests the importance of ensuring clear and consistent accessibility to care (physical and mental) for those with diabetes, in order to attain better health outcomes. Integrating mental health into diabetes care is recommended (Sachar, Breslin & Ng, 2022; Zabel et al., 2022), and these findings support Hadjiconstantinou et al. (2020) who also found a lack of emotional support for diabetes patients in Primary care.

### *8.4.2.2 HCP Approaches to Mental Health*

***Mental Health not raised (or sufficiently) during appointments***

Most T1DM participants (14/20; 70%) and almost all T2DM participants (27/33; 81%) reported not being asked about their mental health at all during appointments, although most answers do not further clarify on why this might be the case. However, T1DM P1 states funding and self-referral as potential reasons: *"They used to [ask about MH] but not anymore. I think because there is so little funding and most of the time you have to self-refer now."* Additionally, T1DM P8 states: *"I don't think I am asked. I usually state where the two [diabetes and mental health] collide."* This is important because if a HCP does not ask about mental health, then it becomes the patient's responsibility to identify any problems, and they may not be aware of this or could dismiss an issue if they do not perceive any clinical significance. Whilst this may not be the case for every patient, it may act as a barrier to receiving appropriate care for some. These findings add further evidence for study 2 findings, where several participants also explained how they were less likely to open up to HCPs about mental health if the HCP did not ask. Qualitative research suggests building a rapport is essential for patients to feel comfortable and trust the HCP (Dambha-Miller et al., 2020), and so not asking the patient about MH coping could have negative implications for diabetes self-management and health outcomes. Additionally, T1DM P11 and P14 state being asked about MH, but MH is not addressed in appointments consistently, *"only very occasionally will one ask 'are you feeling any depression or other mental health concerns?'" (T1DM P14).*

Conversely, four T1DM participants mentioned MH being approached, but were instead unhappy with the assessment methods. One example, T1DM P3 mentioned *"In my yearly checkup I get asked standard questions about my mental health but that's it."* (They specified this is a preset questionnaire, e.g., 1-10 how do you feel you are controlling your diabetes). This raises some concerns; whilst mental health questions are being asked, these are possibly not adequate/detailed enough to gain sufficient insight into the participants' mental wellbeing and coping. T1DM P10 also states, "*They do a questionnaire then score you after the appointment. It's very simple and don't think this impacts the level of care I or others receive."* Whilst simplicity of tools might be perceived negatively, and whilst T1DM P10 cannot see the link between the test and care, that is not to say these are accurate statements. However, perceptions such as this might have an impact on how they respond in tests, which could have hidden ramifications. A suggestion for future diabetes care might to better inform patients about the links between tests and care. Another participant T1DM P7 states: *"They just ask how everything is. They don't push for details about anything that might've happened."* This suggests the participant might not see the link between the HCP's questions and mental health, if that was the intention. It could also suggest that specific signposting to the link between MH care and these assessments might help when asking patients about their diabetes. Understandably, time in HCP appointments is limited, so screening questionnaires/discussions will be brief, but perhaps encouraging HCPs to signpost patients to be aware of factors such as anxiety, fatigue, depression and distress would help patients who might not see the link between mental health and their diabetes care (Stenov et al., 2020).

T2DM answers typically centred more on feeling unsupported from HCPs placing too much focus on physical symptoms alone, rather than taking a holistic approach also integrating mental health. Increasing focus on physical symptoms (e.g., weight) in the context of psychological factors might provide more help and support to certain patients. For example, T2DM P17 who suffers from mobility issues states: *"Same questions, same highlighting of diet and exercise knowing I have poor mobility through arthritis."* In this case, it might be more effective to look at any mental health and coping mechanisms that might be affecting their diet (e.g., anxiety or depression). Supporting comments from T2DM P33 and P28 also emphasise the focus on physical symptoms where mental symptoms might need to be acknowledged. For example, T2DM P33 explained: *"I think more support is needed I just get told about my weight on every visit which gets me down no support is given I leave upset. I think if you feel like you're not a burden to society your mental health will improve."* This was further reinforced by T2DM P28: *"I think it's just more physical problems with them, your levels fine, all ok, but no, my mind racing, upset, gets you down."* T2DM P28's experiences suggest that if their glucose levels are fine then the HCPs perceive no further issues, but P28 is clearly struggling with the mental health aspect of managing diabetes (which can increase the burden of self-care behaviours, leading to poorer health outcomes; Wylie et al., 2019). This is supported by Litterbach et al. (2020), where a prevalent theme with diabetes patients (T1DM and T2DM) was wanting their HCPs to understand diabetes care is more than just HbA1c levels. Whilst managing physical symptoms are key in diabetes self-management, contextualising these through the lens of MH may provide more support for those struggling. This is supported through resilience intervention studies, that found reducing psychological stress (e.g., anxiety, diabetes distress) improved physical management and outcomes such as HbA1c levels, in T1DM and T2DM (Ruiz-Aranda et al., 2020; Ryan et al., 2020). This can be explained through reducing the mental burden of their diabetes, promoting better adherence to self-care. Research also suggests a mediating role of resilience between mental health difficulties (depression) and adherence to diabetes care (Rahimi, Jalali, Nouri & Rahimi, 2020).

Overall, the data suggests the majority of T1DM and T2DM are not asked about their mental health during appointments (supported by Zabell et al., 2022), and those that do commented on the lack of consistency and methods used in assessing mental healthcare (T1DM), and focusing too much on physical symptoms rather than integrating mental health. This is supported by Kalra et al. (2018), who found primary diabetes care (UK) focuses more on managing biometrics rather than integrating and providing emotional support. A possible explanation for this could be diagnostic overshadowing, where symptoms of one condition (e.g., anxiety, depression) is misattributed to an already diagnosed comorbid condition (e.g., diabetes), and is a current problem in diabetes care (Molloy et al., 2021; Nash, 2014). This can lead to mental health being disregarded in place of physical symptoms, as shown in the recent review by Hallyburton (2022). Ensuring HCPs are aware of this concept would help prevent this occurring. Whilst a few participants have described some positive experiences in how their HCPs have approached mental health topics, (e.g., T1DM P11), it does not appear to be consistent across participants. Not all diabetes patients will require help regarding mental healthcare, but research suggests mental health should be a more frequent topic of discussion in appointments, as a precautionary measure (Speight et al., 2020; Tabvuma et al., 2022).

### *8.4.2.3 Care Satisfaction*

T1DM responses regarding satisfaction of care were mixed; five participants were satisfied, six were dissatisfied with their care, three were mixed, one was unsure, and five did not answer the question. T2DM responses were still mixed but overall more negative than the T1DM sample; ten participants were satisfied, thirteen were dissatisfied, one was neutral, one was unsure, and four were mixed. Four did not answer. Examination of responses across both groups found themes relating to: HCPs (e.g., lack of knowledge, compassion, understanding), inconsistencies of care across care services and difficulties getting appointments.

***HCP-Related Factors***

T1DM and T2DM Participants identified similar factors related to healthcare providers that directly affected their care satisfaction, for example a lack of: information, perceived knowledge and support. These factors led to feelings of being alone in managing the condition, for example, T2DM P19 states: *"I really feel as if I have been abandoned. I have no idea whether I should do some things and not others. I have received more information from Diabetes UK but I had expected more tangible support from the NHS."* Supporting this, a more severe example was given by T1DM P6: *"My diabetes team wasn't providing the support I needed, and would pay comments that I wasn't taking my insulin, however I was and even was showing my mum every injection. After not long coming out another hospital stay the nurse told me I may well run in front of a bus as I have more chance surviving that. I got to the point I couldn't cope no more and took an overdose of nova rapid 85 units because I didn't see an end to how ill I was."* These statements show the importance of support in some individuals, and also suggests care satisfaction can be influenced by perceived knowledge of HCPs and how supportive they are. In T1DM P6's case, not only was the HCP unsupportive and (possibly) unprofessional, but it could be argued if they understood sufficiently how blood glucose levels fluctuate even with correct insulin use (e.g., diabetes can result in unpredictable blood sugar levels without any obvious cause; Hirsch & Gaudiani, 2021, Speight et al., 2012), then the HCP might not have made that assumption about their patient. Whilst assumptions about the HCP knowledge cannot be conclusively made, it is important for HCPs to understand and exhaust other avenues before blaming the patient. Diabetes literature also highlights insufficient knowledge of diabetes and mental illness among HCPs (Zabell et al., 2022), and may explain some of the HCP behaviour described by participants. This is supported by Hadjiconstantinou et al. (2020) who conducted focus group discussions in the UK with HCPs and diabetes patients. The main barriers to HCP support, especially emotional, were: lack of confidence, lack of training/knowledge, and appointment time constraints. A lack of HCP education is also a factor in therapeutic inertia (defined as a failure to initiate, modify or intensify treatments when goals are not being met; Lebeau et al., 2014), which may prevent patients from getting the help they need (Chew et al., 2023). This may explain why some patients are feeling unsupported with their mental health as part of their diabetes care. Additionally, T1DM P6 was not believed about taking her insulin, which is also a recurring comment in study 2 participants, and perhaps a more compassionate approach would provide feelings of support and satisfaction with their care. In support of this, T1DM P14 was satisfied with his care due to the compassionate nature of the HCPs. T1DM P17 also stated they were "*not listened to and their pain was not believed*," leading to feelings of stress. The patient-doctor relationship is important in establishing patient care satisfaction, and so HCPs should be aware of the ramifications of this (McInerny et al., 2022; Wens et al., 2005); A lack of trust in HCP are associated with missed appointments in individuals with diabetes (Sun et al., 2021), and as such has important implications for diabetes health outcomes in patients.

Feeling socially supported is a main component in resilience (Tan et al., 2019) and so patients who are feeling unsupported may not feel they have the tools or confidence necessary to optimise their diabetes self-management. Individuals displaying higher levels of resilience report significantly lower levels of anxiety, and healthier levels of psychological adaptation and function (Ruiz-Aranda, Mateo-Rodriguez, Olmedo et al., 2020), therefore feeling socially supported by healthcare providers could have a positive effect on diabetes self-management. Additionally, T2DM P33 states: *"I absolutely hate going to my doctors I feel unsupported and a failure."* This is concerning as feeling unsupported is one of the three main barriers to self-efficacy in health care, and self-efficacy is a fundamental concept in managing a chronic disease (Farley, 2020). It is also a core component of resilience (Connor & Davidson, 2003). Additionally, participants did not feel understood on the emotional side of living with diabetes (e.g., T2DM P27, P28) and adapting to diabetes: "*even with all the routine boxes being ticked, it doesn't help the way I feel, not being diabetic for a long time, then having to deal with it." (T2DM P28).* This is important for individuals with T2DM specifically, because they are typically diagnosed later in life than T1DM (Kolb & Martin, 2017), and may experience a harder time adapting to the diagnosis. Vanajan et al. (2022) suggests older individuals newly diagnosed with chronic health conditions experienced significantly more psychological disorders (e.g., anxiety, sleep disorders), decreased vitality and increased worries specifically regarding physical functionality, than younger individuals. To the author's knowledge this has not been specifically investigated in older diabetes populations. It is important to ensure HCPs understand the ramifications of patients feeling unsupported, as this can impact patient diabetes self-care behaviours (Farley, 2020). Diabetes literature also highlights insufficient knowledge of diabetes and mental illness among HCPs (Zabell et al., 2022). Focus group research with HCPs identified a lack of training and confidence as two main barriers in supporting individuals with diabetes, which may explain the participants felt largely unsupported (Hadjiconstantinou et al., 2020).

Other noteworthy points raised were dissatisfaction with being *"left to their own devices as they appear to know what [they] are doing,"* regarding diabetes management (T1DM P1). This is understandable from the HCP's perspective, but checking in with patients consistently during appointments may provide more feelings of support, despite perceived self-efficacy of patients. Additionally, HCPs' ability to recognise 1) individual requirements specific to the patient, and 2) that diabetes is a balancing act provide feelings of support and care satisfaction (T1DM P8) are important factors in helping patients feel supported (see Litterbach et al., 2020).

Overall, these data suggest the importance of compassionate and understanding approaches when dealing with MH in diabetes patients. Research identifies significant positive correlations between HCP trust and care satisfaction (e.g., Orrange et al., 2021), so it is important to consider how HCPs interact with their patients. These findings support existing literature, where diabetes patients have expressed wanting understanding regarding the emotional impact of diabetes, and that judgements and assumptions about them from the HCP are unhelpful (Litterbach et al., 2020). Additionally, the Sun et al. (2021) systematic analysis and identified HCP factors such as rudeness (e.g., T2DM P31) and a lack of communication and support (e.g., T1DM P2 & P6, T2DM P19) are associated with missed appointments, which are associated with poorer health outcomes in diabetes.

**Healthcare Service-Related Factors**

Another identified theme in both T1DM and T2DM groups was inconsistencies across care services (e.g., primary and secondary), where comparisons from GP practices to hospitals would be made, with higher care satisfaction from the latter. For example, T1DM P19 stated: "*Apart from no mental health support at the clinic I feel very satisfied but that may be because my diabetes is managed by a hospital consultant. When in past I have had input from GP practice I have not been very satisfied."* This is also supported by T2DM P20: *"Not [satisfied] from my GP practice but my Endocrinologist is very good. She has supported me in trying to reduce my Hba1c by undertaking the Newcastle Diet and listens to my concerns regarding medication for artificially reduced levels of cholesterol and BP readings because of the diabetes diagnosis."* These statements suggest inconsistencies across care services might impact patient care satisfaction, which is important because research shows this can negatively impact self-care (Whicher, O' Neill & Holt, 2020). Care dissatisfaction appeared to affect some of the participants significantly, where ultimately, they "*would have felt better not going to the appointments," (T1DM P15)* and T1DM P16 felt their main source of support was from their specialist dietician, rather than the diabetes care team. Some participants also noted "*following an abysmal service from [Location] Health centre that could have cost my life, [Location] medical have been amazing."* If what the participant is claiming is true, this is a worrying difference in health care consistency in primary care, and is also concordant with several participant accounts from study 2. Research supports this and acknowledges diabetes care in primary care is suboptimal, with significant differences in care measures across location (Acharya et al., 2019), and a possible explanation could be differences in regional funding. In contrast, T1DM P19's statement above suggests that feeling supported and listened to regarding their concerns contributes to better care satisfaction, which is supported by qualitative literature (e.g., Zabell et al., 2022).

Additionally, T1DM and T2DM participants identified experiencing difficulty in obtaining appointments and contacting HCP services in context of their care satisfaction. Answers typically focused on HCP services being too busy and waiting times creating difficulties, for example, T1DM P17 states: *"No not really [satisfied]. I have had to fight all the way. To get to see anyone. I have had to fight to speak to a pharmacist. I am a strong person, but if you aren't, it is hell."* This is supported by the experiences described by T2DM P11: *"I Don't have any professionals contact me even after having a blood test and receiving a text from doctors to book a ring back from diabetic nurse. When I call to book a ring back I'm told they are too busy, told this by doctors receptionist."* These reflections are important because positive associations have been found between care satisfaction and trust in HCPs (Orrange et al., 2021), and it is important to consider how the difficulty of obtaining appointments might affect the perceptions and feelings of patients; also how this might affect the likelihood of patients to reach out for help should they need it. This is reflected in Sun et al. (2021), where service-related factors such as longer waiting times and difficulty reaching staff via phone were associated with missed appointments in those with diabetes. Missed appointments are associated with poorer health outcomes, and so this should be an area for improvement, especially in Primary care services. A recent narrative review (McIntyre et al., 2020) examined 49 papers with a sample of over 23 million patients across several countries, with the largest amount of data from UK and Australia studies. It was found worsening waiting times are associated with patient dissatisfaction (Nottingham et al., 2018), poorer clinical outcomes (Moscelli et al., 2018; Reichert & Jacobs, 2018), increased costs (Ray et al., 2015) and increased patient anxiety (Lizuar-Utrilla et al., 2016). Worsening wait times are also associated with increased socioeconomic burden, since those with chronic diseases are more likely to spend time out of work. Given this, waiting times should be allocated via the most clinical need, although this is not the case and in fact, the socioeconomically disadvantaged are those who have to wait the longest (McIntyre et al., 2020).

Other service-related reasons for being dissatisfied with care were not being seen enough throughout the year, for example T2DM P5 states: *"Not particularly [satisfied] as I only see anybody once or twice a year unless I ask for an appointment."* This is also supported by T2DM P30, who was *"[not satisfied] and haven't been seen since diagnosis."* This participant has only been diagnosed for six months, which is arguably the most important time for education and healthcare appointments. This is supported by Dambha-Miller et al. (2020), where diabetes patients repeatedly expressed wanting to be seen more by their HCPs. Conversely, T2DM P2 states being satisfied and "*the care they give is as good as it can be but NHS is under great pressure and ALL the staff are 'Angels on earth.'"* T2DM P9 also feels satisfied *"apart from being able to discuss specifics."* The data collectively suggests a possible reason for mental health not being addressed in appointments could be because of time constraints and how busy HCPs are. This provides some insight into patients' perceptions of HCP care and mental health, however, it is important to acknowledge participants may also feel pressured to follow the discourse of overworked NHS staff, and may instead not provide an answer in line with how they really feel.

Overall, T1DM and T2DM data suggest inconsistencies across care services and factors such as waiting times impact patient care satisfaction, which can affect diabetes self-management, appointment times and health outcomes. In support, qualitative findings (Dambha-Miller et al., 2020) demonstrated NHS doctors and nurses 'reluctantly' acknowledged only minimum care standards could be maintained, and due to current NHS strain, aspirations for higher-quality care were unlikely. Chew et al. (2023) also acknowledges that 'a lack of consultation time' and 'busy clinics' contribute to suboptimal diabetes care, and is one factor in therapeutic inertia (Lebeau et al., 2014). This may explain why some patients are feeling unsupported with their mental health as part of their diabetes care, and highlights important areas for interventions and improvements to care implementation.

### *8.4.3 Theme 2: Psychological Effects*

This theme describes the psychological effects of living with diabetes in three contexts: 1) how diabetes impacted participants' mental health, 2) if they feel diabetes might have an effect on thinking processes such as memory and decision making, and 3) the role their resilience plays in diabetes management and whether they feel this is important.

### *8.4.3.1 Mental Health Impact*

**Psychological correlates**

Almost every T1DM (18/20; 90%) and T2DM (25/33; 75%) participant reported problems with their mental health as a result of their diabetes, with issues ranging from mild to severe difficulties, such as not taking insulin (T1DM P4), not eating (T1DM P5), severe depression and attempted suicide (T1DM P6, T2DM P16). Answers were examined in the context of the model in study 1 (anxiety, fatigue, diabetes distress, cognition), and other identified psychological factors were also noted (e.g., depression). Within the context of the model, anxiety/worry, and stress (indicative of diabetes distress) were described most frequently for both T1DM and T2DM samples. An exemplifying response was: *"It impacts my health as it causes a degree of health anxiety in that it is quite stressful thinking about foods to eat (carbohydrate counting and administering the correct dose of insulin and management of libre sensor readings with associated insulin administration). Also managing other potential related health issues associated with diabetes i.e., cholesterol management, BP management and kidney function can cause health anxiety" (T1DM P19)*. Another example was from T2DM P27: "*I struggle with anxiety and fatigue quite badly. Nobody seems to know how to cope with it."* As expected from study 2 deductive analyses and findings, anxiety, depression and stress were commonly reported in T1DM and T2DM participants, resulting from a number of factors such as health, side effects, food and social situations, which supports existing literature (Buchberger et al., 2016; Dennick et al., 2016; Dieter & Laurer, 2017; Santosh et al., 2019; Wibowo et al., 2022). Findings also support more specific aspects of these difficulties, for example, worries concerning complications of diabetes (e.g., cholesterol, kidney function) are rated as the most distressing aspect of T1DM and T2DM (e.g., T1DM P19), and more regimen-related distress (e.g., food restrictions) is reported in T2DM compared to T1DM populations (e.g., T2DM P8) (de Groot et al., 2016; Wardian et al., 2018).

Depression was not a part of the proposed model in study 1, although it is a well-established correlate of diabetes in both T1DM and T2DM (Snoek et al., 2018). Reasons for exclusion from the model is both depression (MDD) and DD are significantly associated with diabetes but there is frequent overlap between the two (Kamrul-Hasan et al., 2022), which can lead possible misdiagnosis of MDD in place of DD (Berry et al., 2015; Kamul-Hasan et al., 2022). See chapter 2.3.5 for more on this discussion. Responses from T1DM and T2DM participants explained how their diabetes-related depression led to maladaptive behaviours such as "*binging on chocolate and donuts.*" (T2DM P13). T2DM P25 explains they have depression due to DM limiting what they can eat and drink, which supports existing findings (Wardian et al., 2018). It is important to acknowledge that participants were not asked if their depression was clinically diagnosed, and so their responses may not be clinically based. However, the data strongly suggests diabetes can impact mental health and wellbeing through depression. T2DM P16 explained how an admin error left him living with diabetes unaware and untreated (and therefore uncontrolled), and experienced significant difficulties with depression: *"[MH impacted] Massively. My diabetes was diagnosed in 2018 but admin error meant they didn't tell me or treat it. Fast forward to 2022- suicidal, severe depression, left my wife and baby as I was so down. Absolutely devastating… Wasn't until the team at my new health centre got me in in april 2022 following a blood test that they told me my diagnosis and everything made sense." (see also T1DM P5).* This statement also has clinical implications and concerns for primary care, which unfortunately is supported by existing findings, where NHS-based HCPs acknowledge diabetes care is suboptimal (Dambha-Miller et al., 2020).

Fatigue was another model construct which was largely absent from the T1DM sample, but not T2DM. This supports existing findings, where fatigue is more of a prevalent problem in T2DM patients (Lasselin et al., 2012), especially those with uncontrolled HbA1c levels (Park et al., 2015). This is supported by T2DM P14, who stated: *"When my sugars are high I feel lethargic and unmotivated. I sleep a great deal and this makes me feel guilty and depressed."* The link between fatigue and depression is supported in the diabetes literature, especially those with high blood glucose levels (e.g., Esen, Esen & Demirci, 2022). Additionally, participants mentioned feeling 'tired' (e.g., T1DM P3) or '*drained*' (e.g., T1DM P6), but no direct reference to fatigue or lethargy is made, and so it is hard to conclude if this is fatigue, or tiredness, which is often conceptually obscured with 'sleepiness' (Shen et al., 2006; Skau et al., 2021). To clarify, tiredness/sleepiness is a feeling of temporary loss of energy which is a normal state following exertion or lack of sleep, and can be relived by rest/sleep. Conversely, fatigue is more persistent feelings of exhaustion or loss of energy that is not relived by rest/sleep. It is typically more debilitating and has more impacts on social life, work or ability to do everyday things (Shen et al., 2006) (see also chapter 2). Lastly, it is important to consider why fatigue was only prevalent in T2DM sample. Reasons could include: individuals with T2DM have higher rates of comorbid obesity, which is also associated with increased fatigue and sleep apnoea (Klobucar, 2024); T2DM is typically diagnosed later in life compared to T1DM, so age may play a part, and T2DM is typically characterised by insulin resistance, so glucose stays in the bloodstream rather than being used up by the cells (whereas T1DM is an absolute insulin deficiency; see chapter 1). In addition, it could be due to perceptions of fatigue being a physical condition, and not a psychological one, and/or affecting mental health. Concepts of feeling '*drained*,' and '*worn out'* were discussed in the context of how mental health was generally impacted (i.e., chronicity of DM), and so will be discussed more appropriately below.

### Chronicity of DM (and burnout)

Another prevalent theme across both groups was the chronicity of DM, and this may explain why certain mental health difficulties develop (e.g., anxiety, distress, cognitive fatigue). Participants described how living with a chronic disease impacted their mental health, and feeling tired and fed up with diabetes always being on their minds. For example, T1DM P3 states: *"[Diabetes] does affect your mental health. It's the first thing you think about when you wake up and the last thing you think about before you to sleep. I have to be my own nurse administrating injections, I have to be my own doctor ensuring I give the right dose of insulin to ensure I don't give too much or too little and kill myself. It's tiring."* This is further supported by T2DM P9, *"I hate having this illness, it's affected my eyes and legs and my mental state as there's not a moment when I'm not thinking about in terms of eating or with its physical symptoms."* The responses suggest a link between anxiety/worry and managing diabetes, which is supported in existing literature (Amiri & Behnezhad, 2019). This data highlights the constant, daily burdens that come with managing diabetes and adhering to self-care regimens, and how it can negatively impact one's mental health through feelings of worry, tiredness, and wanting a break from it. Additionally, other factors that caused stress or feeling worn down were self-care behaviours such as: insulin injections and finger-prick testing (T1DM P12), attempting to balance blood glucose levels, and getting hyper- and hypoglycaemic episodes under control (T2DM 24). These statements show how worries can be both about mental or physical factors of living with diabetes, and also how the burden of trying to maintain control of a chronic condition can affect MH. Additionally, T1DM P2 described feeling totally fed up with constant balancing of blood glucose levels, and experienced temporary relief via missing injections and not counting carbs. The relief of missing injections and counting carbs could be indicative of the pressure the participant is facing in their diabetes self-management, and regimen-related distress is a component of diabetes distress (Polonsky et al., 2005).

The reason this is important is sustained cognitive stress (e.g., anxiety, diabetes distress) of treatment and regimen adherence can lead to ‘diabetes burnout,’ which is defined as a combination of emotional and behavioural disconnection, through exhaustion and feelings of lack of control over their diabetes (Abdoli et al., 2020). Diabetes burnout is associated with, but distinct from, depression and DD, and can lead to completely ignoring diabetes self-care (e.g., stopping taking insulin injections, not checking blood sugars, not carb counting, and ignoring appointments) (Adboli et al., 2021). It could be diabetes burnout that T1DM P2 was describing, and other participants (e.g., T1DM P7) have directly stated experiencing burnout. Given the adverse impact this can have on diabetes self-management, there is a need to address burnout and associated factors (e.g., anxiety, DD) in order to improve care for people with diabetes. Although currently, there is a paucity of research into diabetes burnout and more research (especially longitudinal) is required to understand exact mechanisms between burnout and psychological factors such as DD (Adboli et al., 2021).

### Social Impact - Stigma (T1DM only)

A factor specific to the T1DM group is the effect of diabetes-specific stigma on mental health. In diabetes literature, commonly reported stigmatisations of T1DM include injecting in public, workplace discrimination, and limitations in travelling or attending social situations, which can in turn impact maintaining friendships/relationships (Liu et al., 2017). Participant responses tended to focus on the social aspect, for example, T1DM P5 explained: *“It has impacted on my mental health by* *having to change how I eat and go out make sure I have my pens with me and people watching you."* Additionally, T1DM P19 further explained: *"Having to do injections in public and explain why and how is very hard."* Feeling stigmatised can affect diabetes management directly, as patients may be less likely to use therapies/self-care behaviours that are apparent in public. Stigma is related to diabetes distress, and both are associated with worse patient outcomes such as HbA1c levels (Capistrant, 2019). Additionally, T1DM P6 also describes diabetes type-related stigma: *"TV always get the info wrong about type one and we tend to be judged for something we never had any control over."* Overall, the T1DM data suggests whilst stigma-based mental health issues do not affect everyone; they are a prevalent and potentially serious issue linked to living with diabetes. A way to overcome this would be through patient and public health education to minimise the misconceptions between and within the diabetes types, and help to improve empathy and understanding.

It is important to note that whilst stigma was also mentioned in the T2DM group, it was not prevalent enough to be considered a subtheme. This could be because of increased stigma levels for individuals who are on insulin therapy – for example, individuals might need to inject insulin before a meal in public (see T1DM P19 above). These findings are supported in the literature. For example, Liu et al., (2017) found significantly higher rates in type 1 diabetes (76%) than type 2 (52%), and those who experienced the lowest stigma were type 2 who were not on insulin (49%), in a survey of 12,000 people. Additionally, HbA1c levels were significantly associated with increased levels of stigma, illustrating how this can be a significant issue in diabetes outcomes.

### ***Difficulties Understanding DM (T2DM only)***

A factor specific to the T2DM group reported to affect MH, was difficulties understanding and confusion regarding T2DM, with some participants feeling scared or alone as a result. Most responses stated the confusion affects MH but do not state why; one reason given is lack of support. For example: *"Yes I feel like it has impacted my mental health I don't feel like there is much support and it's hard at times understanding foods that spike your blood sugars etc" (T2DM P33).* This is further supported by T2DM P7: "*Def. I feel alone and confused about what I can eat drink and do."* This confusion or lack of understanding could be indicative of a lack of education, (or signposting of educational resources), which is supported by theme 3 (Education and Interventions, 9.4.4). It could be that people struggle to reach out and ask for help, which is also supported by some participants who displayed passive coping styles (Yi-Frazer et al., 2008); For example, T2DM P11 stated: "*I just do what I think is right and hope a professional will contact me.*" Passive or avoidant coping styles are associated with poorer self-efficacy and resilience (Wilson et al., 2017), and coping skills training is associated with improved anxiety, stress and self-efficacy (Edraki et al., 2018).

This has implications for patient and HCP education, where interventions and structured education should be aimed at targeting coping skills (i.e., a factor of resilience), and ensuring HCPs are educated in the impacts of patient coping skills. Participants who display passive coping styles might need more direction and help, especially in asking for help. Research shows patient trust in HCPs is built on effective communication, compassion, and demonstrating effective competence and knowledge (Greene & Ramos, 2021). Unfortunately, qualitative studies have found a lack of diabetes HCP education, training and confidence in approaching emotional aspects of care with their patients (Dambha-Miller et al., 2020; Zabell et al., 2022; see also Chew et al., 2023). Linking back to the above data, if these T2DM participants are struggling to understand their diabetes, then HCPs need to work to ensure their patients understand their diabetes, and if not, signpost them to effective resources. A possible reason why individuals with T2DM might have struggled more with understanding diabetes is because typically T2DM is diagnosed later in life, compared to T1DM, which is typically diagnosed in childhood/young adulthood (where the child's parent takes responsibility for the diabetes and care behaviours). Additionally, there might be more difficulty understanding T2DM due to the differing aetiologies (e.g., insulin resistance and/or lack of insulin secretion) compared to absolute insulin deficiency (see chapter 1). This also caused frustration for participants like Kenny in study 2.

#### *8.4.3.2 Effects on Cognition*

Half of the T1DM participants (10/20) and felt diabetes affected their thinking processes, and two felt it did not. Three were unsure or had not thought about it enough and five participants gave no answer.

Just under half of T2DM participants (14/33) felt diabetes affected their thinking processes, 9 felt it did not, and 5 participants gave no answer. The remaining participants were either unsure or stated they were not aware of a link between diabetes and thinking processes (e.g., T2DM P5). The data suggests cognitive problems do not affect everyone, or significantly enough for it to be a recognisable problem. T1DM and T2DM participants talked about cognition as 'thinking processes' and described difficulties or changes indicative of memory or decision-making. For several participants, these problems often lead to feelings of worry or isolation. An exemplifying response is from T1DM P14: *"Diabetes obviously triggers neurological, circulatory, kidney and cardiac risks earlier in life and at higher severity that can affect memory and thought processes. In my own perception of all these, having T1 at a young age is like adding 25 years wear and tear on the body/brain over time, especially if good control is not maintainable. Memory and decision-making fall right in that path as well."* This is also supported by T1DM P17: *"If my sugars drop, I can't speak, I lose my cognitive ability. I worry about the long-term effects."* T1DM P17's response also demonstrates an example of how cognitive difficulties can lead to worry, which is supported in the literature (e.g., Raffield et al., 2016), and worry is also correlated with fatigue (e.g., Lock, Bonetti & Campbell, 2018), and DD (e.g., Fisher et al., 2018).

Considering how diabetes shares many psychological comorbidities, this cognitive strain could also contribute to burnout (Abdoli et al., 2020). To re-summarise, executive functions are the coordination of higher-order working memory, attentional and inhibitory processes, to achieve a goal; this is essential for diabetes management (Carlson et al., 2016; Miller & Wallis, 2009). In particular, larger effect sizes for cognitive decrements have been found in inhibitory control, memory and processing speed in the literatures for both T1DM and T2DM (e.g., Palta et al., 2014; see also chapter 2). T2DM P27 also states that they '*take a while to think about things and come up with an answers*.' This could be indicative of reduced processing speed, however, it is hard to conclusively determine without more detail, which is a limitation of surveys compared to interviews where the researcher can probe for clarifying information. Additionally, several participants talked about how diabetes was constantly on their minds, in some cases dominating their decision making – which may be indicative of cognitive inflexibility (i.e., shifting onto another topic) and inhibitory difficulties (Smolina et al., 2015; Warren, Heller, & Miller, 2021). For example, T1DM P5 stated: *"I find I'm constantly thinking about when my injection is due and eating,"* and T1DM P8 stated: "*[Diabetes] affects every decision and due to others' lack of knowledge or wanting to understand can be extremely isolating."* This last response especially indicates a level of strain from diabetes affecting thinking processes, and stigma and a lack of education in HCPs and public is a prevalent problem in healthcare (see Dambha-Miller et al., 2020). Feelings of isolation and not being understood are associated with burnout and poorer glycaemic control (e.g., Kalra et al., 2018) and therefore have implications for diabetes healthcare. Diabetes dominating thinking and constantly accommodating for diabetes (e.g., T1DM P18) might explain why chronic diseases like diabetes can contribute to the mental burden, fatigue, emotional problems, and burnout. Interestingly, T1DM P8 also identified being aware of the link between ADHD and diabetes, where a core symptom of ADHD is executive function difficulties (Welsch et al., 2021).

A response from T2DM 31, who works as a psychotherapist, made a particularly insightful comment into the ramifications of diabetes affecting mood and impulsivity, which is a component of inhibitory control: *"As a psychotherapist myself I do think that [diabetes] will affect your thinking process I also feel depending on mood can cloud a person's judgement into making unsafe choices for themselves for example we all like comforts but for a diabetic some comforts can be harmful to health."*
Additionally, T2DM P2 also stated: *"Yes I do [think diabetes affects thinking processes] now, but when I first had diabetes I just lived my life knowing I just had my tablets or insulin to take to make it all go away."* This response suggests a possible lack of understanding into the psychological effects of diabetes, where feeling that the medicine would be enough to 'make it all go away.' This could be a product of a lack of education in patients or HCPs (Dambha-Miller et al., 2020; Zabell et al., 2022), or people viewing diabetes as more of a physiological condition rather than a combination of physical and mental conditions. This provides further support for the need to improve mental health and emotional education in diabetes patients and HCPs.

Additionally, both groups reported difficulties or changes in memory processes, however these appeared to be more prevalent within the T2DM sample, often accompanied by uncertainty whether these changes were associated with diabetes or age. For example: T1DM 28 states: *"My memory has had a knock, used to be very quick to remember things, now I have to check things like did I lock that door? Could be age but funny it's started same time as my diabetes, really stresses me sometimes."* Additionally, T2DM P5 states: "*My memory is getting really bad but I didn't know diabetes could affect my memory. I have concerns about possible early-stage dementia for over a couple of years…My problem is more a case of getting names mixed up and totally going blank sometimes even with my own kids and grandkids names and struggle to remember what I did or ate yesterday that sort of thing and I constantly forget to do things like remembering to ring people or miss things like appointments and birthdays."* These responses suggest a level of uncertainty when considering if diabetes can affect memory, especially T2DM P5 (see above). It is important to consider whether these are age-related changes or due to the diabetes, although there is substantial evidence to suggest significant associations between memory function independent of age (Messier, 2005; van Duinkerken & Ryan, 2020). Due to participant uncertainty regarding diabetes and memory changes, it could suggest an area for education improvement regarding long-term cognitive effects of diabetes. This may ease worries and DD in diabetes patients, which are also related to improved glycaemic control (e.g., Trief et al., 2022). Additionally, regarding T2DM P28, it would be interesting to know if their memory changes started when they were diagnosed, or when the diabetes symptoms started. Again, this is a limitation of surveys in comparison to other methods such as interviewing, but it does suggest a possible link between memory and diabetes, which is concordant with existing literature.

Other notable points include, T2DM P9 felt "*overwhelmed is more accurate*" rather than diabetes affecting thinking processes. It could be argued that the process involving feeling overwhelmed could be better attributed to diabetes burnout, which stems from a feeling of loss of control over diabetes (Abdoli et al., 2021), however, diabetes burnout and executive function difficulties are both associated with affective disorders and emotional regulation (Warren, Heller & Miller, 2021). There is a complex interplay between cognition (EFs) and affective states. Also, P15 did "*not have [diabetes] long enough or see any deterioration in [their] health to consider*" whether diabetes affected thinking processes.

Overall, there appears to be a link between cognitive processes indicative of EFs in those with T1DM and T2DM. This is concordant with existing literature (e.g., van Duinkerken & Ryan, 2020; Palta et al., 2014). Both groups reported more memory changes/difficulties than decision-making, although problems described were almost always mild in nature. Although problems reported were not described as severe, the chronic nature of these difficulties may contribute to long term stress.
The uncertainty of the link between diabetes and cognition is concerning, given the amount of research supporting this and cognitive impairment has been associated with significantly higher HbA1c and chance of microvascular complications (Chaytor et al., 2019). Although not all participants reported cognitive difficulties/changes, it is still an important factor (affecting diabetes management) that could be taught to improve education levels to patients and HCPs.

### *8.4.3.3 Role of Resilience in DSM*

#### ***Persistence and Overcoming Adversity***

Both T1DM and T2DM responses were strongly in agreement that resilience plays an important role in diabetes self-management (16/20, 80% and 23/33, 70%, respectively). Remaining participants were either unsure about resilience or felt it was not applicable to them (no reasons supplied). In both groups, answers strongly centred around the concept of overcoming obstacles and persisting with self-care behaviours, such as regimen adherence (e.g., T1DM P7). An exemplifying response is: "*Type 1 diabetes is a DRAG. Resilience has been an important thing for me and while I have never put a name on it like that, I think I'm pretty good at it. I am lucky that my father (diagnosed T1 at age 33-34) engendered a "can do" attitude in me that helped me move through life with the disease as a "thing" but not the ONLY thing. For me resilience means understanding what the limits are on diet, activity and control, and then working with them to live life as normally as possible while still doing the right things to stay in good control" (T1DM P14)*. Additionally, this is supported by T2DM P19, who stated*: "I think [resilience] is really important…I need to be aware of the damage not taking care of my diabetes could do which might contribute to loss of sight, heart damage. I do my best but I will not allow diabetes to become the be all and end all of my life."* The data suggests resilience plays a crucial role in diabetes self-management, which is supported by existing literature. Observational studies have found increased resilience improved glycaemic control through promoting self-care behaviours in T1DM and T2DM populations (Luo et al., 2019; McGavock et al., 2018). Additionally, qualitative research (Kusnanto, Arifin & Widyawati, 2020) examined diabetes resilience in T2DM with controlled glucose levels, and found concepts such as adaptability, persistence, determination and self-agency (as a function of self-care behaviours) present in resilient individuals. Also, Skegdell et al. (2021) found cognitive and behavioural concepts such as: believing one can live a 'normal' life with diabetes, proactive planning to overcome challenges, balancing diabetes and non-diabetes activities and maintaining a regimen. Existing and current findings can be explained through higher resilience allowing for more effective perception and utility of resources to cope and adapt to stressors (Zhang et al., 2022).

However, it is interesting that very few participants directly mentioned the use of resilience for emotional regulation, which is established in many studies and contexts, and is associated with decreased: DD (Wang, Hsu & Kao et al., 2017), anxiety (Ruiz-Aranda et al., 2020) and fatigue (Wojujutari, Alabi & Emmanuel, 2019). The only affective state mentioned in the context of resilience was anxiety, where T1DM P19 stated: *"Resilience is definitely important. For example, if at times blood sugar control is abnormal through illness (covid is a good example) you have to keep trying to manage it back into control, which can be very anxiety provoking. It's easy just to think I've had enough and can't do this."* This suggests that trying to maintain control of diabetes can be a source of anxiety, and resilience can help achieve with persistence and not giving in. This supports existing findings (e.g., Ruiz-Aranda et al., 2020) and also supports the idea that resilience could mediate feelings of anxiety. This is also supported by T2DM P6 who stated: *"Due to mental health and severe anxiety I find I have problems with resilience for my diabetes."* The participant makes the link between anxiety and resilience, but may not understand that if their resilience were to be improved, it may ease their anxiety. These findings suggest participants may not be aware of how resilience may interact with other psychological and emotional states, and so could be an effective area of education for diabetes patients and HCPs (supported by Zabell et al., 2022).

In contrast to participants' acknowledging the strengths of resilience, T2DM P14 states: "*As a care leaver with a traumatic upbringing I have very little resilience which in turn makes coping with my diabetic journey very difficult."* This supports the idea that resilience can mediate diabetes self-management through coping. T2DM P16 also noted how resilience helped them to cognitively reframe (a factor of resilience) their situation in order to "*rebuild relationships and approaches to things*." Other notable responses (e.g., T2DM P19) acknowledged a lack of resilience awareness: "*Resilience is very important I would say as Diabetes is not well spoken about…Also having to battle with yourself sometimes is hard, especially when you are having a bad day."* This suggests resilience is useful but awareness of this concept is poor. In diabetes literature, understanding of mental health correlates of diabetes are not well understood (Zabell et al., 2022), and the same applies to resilience (Kusnanto, Arifin & Widyawati, 2020); it could be recommended to add resilience to existing structured education courses, so individuals with diabetes can understand the interplay (and benefits of) resilience with psychological states such as anxiety, fatigue, DD and cognition. HCPs could also benefit from learning about this, and may help in understanding possible symptoms of patients who might need mental health help. Increasing education and training in HCPs would also help to increase their confidence, which is recommended by Dambha-Miller et al. (2020) to improve diabetes patient outcomes.

Additionally, a couple of participants made statements that appeared to take a reductionist view of their situation with diabetes, dismissing the role of resilience. For example, T1DM P6 stated: "*with type 1 it's life or death doesn't matter if you're resilient or not, we don't have a choice in the matter we have to do it,"* and T1DM P3 stated: "*You have to be resilient the other option is dying."* Whilst it cannot be concluded with certainty that this is not an example of resilience, it reduces the situation to life or death; whilst this is understandable given the nature of diabetes, it appears dismissive of how resilience can actually help diabetes self-management. In an effort to cope, they might be reducing their situation in the absence of emotional context/considerations, which could lead to maladaptive coping mechanisms, such as emotional repression (Chen et al., 2023). Emotional repression, also known as cognitive avoidance, is defined as ignoring or minimising the emotional influence of a stressor (Prasertsri et al., 2011). This is important as repressive coping has been significantly associated with increased anxiety and depression in those with chronic pancreatitis (Chen et al., 2023) and reduced thalamic grey matter density (Gunther et al., 2022), contributing to worse mental health and poorer glycaemic control (e.g., Pesantes et al., 2015; Yi-Frazier et al., 2010 & 2015; Wilson et al., 2017). A holistic understanding of resilience would inform the difference between adaptive (e.g., problem solving) and maladaptive (e.g., emotional repression) coping styles, promoting better health outcomes.

Lastly, several participants expressed resilience being important but struggling with feelings of tiring or the difficulty of maintaining resilience (T2DM P27, T2DM P33). This could be due to not understanding resilience sufficiently in the context of diabetes (i.e., how resilience can interact or mediate certain psychological states such as anxiety). Interestingly, T2DM P31 who is a psychotherapist explained, "*resilience is like a rubber band. It stretches but doesn't break; I feel this is essential in maintaining understanding and wellbeing in managing diabetes."* This suggests resilience can be flexible depending on current stressors/circumstances, and is demonstrated through resilience interventions for those with T1DM and T2DM (e.g., Rausch & Weissberg-Benchell, 2018). Perhaps reiterating the flexible aspect of resilience may help some patients.

### *8.4.4 Theme 3: Education and Interventions*

This theme describes education and interventions, which examines education from HCPs, specifically whether patients were informed of: 1) the role that resilience can play in diabetes self-management and the effects of this, and 2) the psychological effects of living with diabetes (e.g., anxiety, distress, fatigue, and impacts on thinking processes). This theme also examined whether this information helped participants, or how would it benefit them if they were informed. The remaining subthemes were intervention participation and experiences, and any recommendations participants had for improving current interventions (e.g., resilience and mental-health based interventions).

### *8.4.4.1 Education from HCPs (or lack thereof)*

Diabetes education was explored in this broader sample, specifically, psychological and resilience-based education. In line with the previous study findings, almost all T1DM participants (17/20; 85%) and T2DM participants (32/33; 97%) explained their HCP had never discussed the role of resilience with them, in the context of diabetes self-management. Similarly, almost all T1DM (16/20; 80%) and T2DM (30/33; 91%) stated their HCP had never discussed psychological education with them, such as the effects of diabetes on anxiety, fatigue, or diabetes distress. This is a concerning proportion of the sample that are uninformed about the psychological correlates of diabetes, especially given lower health literacy levels are identified as psychological barriers to diabetes self-management activities, in particular those with comorbid MH difficulties (Balogun-Katung et al., 2021; Mulligan et al., 2018; Ronne et al., 2020). Therefore, improving education in patients may improve diabetes self-management. These findings are concordant with existing literature, where discussions of psychological and emotional effects of living with diabetes are infrequent (Dambha-Miller, 2020; Stenov et al., 2020; Zabell et al., 2022).

One explanation for this lack of education could be HCPs correlating good self-care behaviours and/or good HbA1c measures with high resilience, and therefore not feeling it necessary to approach the topic. However, this might not be the case. This is supported by T1DM P14: *"I do not think any clinician has ever approached me with being resilient as a topic, and fostering that mindset as a specific thing. Because I am compliant and not ignoring my self-care, they (in my opinion at least) believe I am resilient by knowing what to do and then doing it."* This can be problematic as resilience is multifaceted, and there are various coping styles; those that display maladaptive coping styles may be performing some self-care behaviours but not engaging with the emotions (e.g., repressive coping) and so HbA1c alone may not be a sufficient indicator of resilience. Additionally, another reason why HCPs are not addressing resilience could be explained by Hadjiconstantinou et al. (2020), where a lack of HCP training/education and confidence were key barriers to HCPs discussing psychological and emotional concepts of diabetes care. This is important as perceived lack of support from HCPs significantly contributes to elevated levels of DD (Berry et al., 2015). Even those who are managing their diabetes adequately may still benefit from understanding the concept of resilience, for example, when unexpected life stressors present and it becomes harder to manage diabetes self-care. Additionally, it is important that people are informed about resilience, so that they have the ability to communicate with HCPs should they experience any difficulties with this, and they understand how to 'bounce back' in a healthy way when facing difficulties. Especially given that almost every participant recognised resilience being important in diabetes self-management, not enough participants are being informed about resilience. Participants also reflected on *"having to work out what resilience was themselves"* (T2DM P31) and "*taking it for granted that you need to be so."* (T2DM P13). An interesting response by T2DM P2 was *"I have not been informed about resilience but life is tough and if you are going to live [with diabetes] you have toughen up."* It could be argued that this is support for resilience education, as mental toughness is not an interchangeable concept for resilience. Whilst mental toughness (i.e., a set of personal attributes that influence the manners in which challenges are approached) overlaps with components of resilience, resilience is a collection of both protective internal and external factors (e.g., personal, perceived social support) (Cowden et al., 2016; Fletcher & Sarkar, 2012). Therefore, mental toughness may not be a comprehensive enough concept to deal with psychological difficulties in the same way as resilience in diabetes self-management.

The impact of a lack of education in some participants had a clear impact on their MH. For example, some participants had described experiencing severe psychological and mental health difficulties, as a result of not understanding the symptoms they were experiencing: *"I think the mental health aspect is massive- I wanted to die and spent every day thinking about how to do it... I would stare into space for hours. My wife got so upset and it did so much damage to our relationship. It was such a relief to understand I'd been living with diabetes for 4 year but didn't know- and that the it can be really damaging to your mental health. People don't know this" (T2DM P16)*. This suggests a clear importance for individuals to understand what psychological effects are associated with diabetes, and so will be better prepared to identify symptoms and seek out appropriate help should they need it. Additionally, another participant explained that they had "*never been offered or had mental health* *supported even suggested as linked to diabetes*" (T2DM P13). This supports the idea that understanding of diabetes is important in self-management (Balogun-Katung et al., 2021) and may help encourage those to seek out related help. In support of this, both T1DM and T2DM participants described how understanding the psychological effects would benefit their resilience, mental health, confidence (i.e., self-efficacy) and overall understanding of diabetes. This includes physical and psychological understanding (e.g., effects of hypo/hyper episodes and anxiety, respectively). For example, T1DM P19 stated: *"The benefits of [psychological education] are that if you are more aware of these and have the input at clinic to understand these better then you can apply improvement techniques if suffering from for example fatigue and distress. Adapting to a life living with diabetes can be very difficult any input with these things would be beneficial in my personal view."* Another example was from T2DM P27 *"Might help deal with the fatigue I experience and ease my anxiety."*

Another helpful area to educate diabetes patients is the discussion of expected age-related changes and diabetes effects (e.g., T1DM P6) such as forgetfulness over time. This might help some patients identify problems with memory if they understand there is a link there. Another response (T1DM P3) commented on how both diabetic and non-diabetic individuals would also benefit from improved education: *"I think everyone would benefit from this. Sometimes you feel like you're the only person going through this. Non-diabetics don't understand how hard you have to work to control it."* This is important because there are stigmas surrounding both diabetes types (e.g., injecting insulin in public, the cause(s) of an individual's diabetes such as unhealthy diet), and a lack of public education can leave people with diabetes feeling isolated and not understood (Liu et al., 2017). Seeking ways to improve public education and in those with diabetes (especially newly diagnosed) is imperative. Targeting close families and friends of those with diabetes might be the best way to approach this. Overall, the data suggests participants would benefit from more information about co-morbid psychological difficulties that may occur with diabetes: anxiety and fatigue especially. Perhaps understanding these factors and how they can interact with resilience might provide context for the symptoms some patients are facing. Preventing psychological stress such as anxiety has been shown to improve diabetes self-management (e.g., Santosh et al., 2019), so would be beneficial to consider how patients are educated and to improve on this. Other participants support this by stating not enough information is given (T2DM P25) and *"any advice would be beneficial other than a prescription and offered a diet nurse"* (T2DM P13). Additionally, T1DM P24 currently works as a HCP and supported the need for a more holistic understanding of psychological and physical factors of diabetes management: *"More resilience/training needs to be available [in patients] as it isn't just knowing about diabetes and how to manage it, it's looking at the whole holistic approach with regards to wellbeing, mental health, emotional, and being able to control and manage the diabetes, and enjoy life without the worry."* In summary, the number of participants informed about psychological effects of diabetes were very low, and almost all participants clearly felt that more information would benefit them. Future recommendations could be to improve signposting and abundance of resilience resources in diabetes.

### *8.4.4.2 Intervention Experiences*

Intervention uptake and experiences will be discussed separately via diabetes type as there are different courses specific to diabetes type, and links to literature will be made at the end. Almost half of T1DM participants (8/20; 40%) of T1DM participants took part in a diabetes intervention course; all but one participant reported finding the course helpful. Almost all of these participants took part in the DAFNE course and reported positive experiences, and T1DM P8 took part in a pilot study where they were assigned a psychologist to help with self-management. These interventions benefitted participants through gaining control and improving knowledge. For example, T1DM P1 stated they found DAFNE 'very *helpful and it also helped me gain better control of my overall diabetes."* Additionally, T1DM P14 commented DAFNE was *"Helpful in gaining some insights on control, diet and overall T1 management. I have not attended one in many years, so the actual impact now is hard to define. I am sure however I gained some actionable tools from them."* One participant T1DM P8 took part in a psychology-based intervention, but found it "*extremely beneficial*." They also stated: *"I do believe more should be advised at the beginning for newly diagnosed people,"* which is supported by Whicher, O'Neill & Holt (2020) and Speight et al. (2020). This may be an area to improve on with regards to primary healthcare, and perhaps examining the symptoms of diabetes through a more psychological perspective would be beneficial to a lot of newly diagnosed individuals. P3 stated they would *"highly recommend DAFNE to all T1 diabetic I actually think it should be mandatory."* From this and other responses, DAFNE seems to be a very helpful aid for those with T1DM, however the addition of more psychologically based courses may vastly help patients who are struggling with their mental health.

Regarding the T2DM sample, only three participants (3/33; 9%) participated in a diabetes intervention course, and were asked a follow up question about their experiences. I have included each quote to better demonstrate experiences within the minority. T2DM P9 explained: "*There's only so much to learn and take in I feel and as it's an individual thing all that came out of my course was generic… I enrolled with a diabetes group, which was helpful to a point but I think it's a case of finding what's right or wrong for the individual."* This suggests that T2DM P9 found the course generic and not very applicable to them as an individual. They identify the individual nature of diabetes (i.e., how it varies between individuals; bodies can react very differently to the same foods), and so a more individualised approach to diabetes education (i.e., linking to personal experience and their situation) might be more beneficial in future intervention research. This was also a topic frequently mentioned from T1 and T2DM participants in study 2, with the context that this understanding is lacking from public and HCPs (Hadjiconstantinou et al., 2020; Zabell et al., 2022). Another participant (T2DMP11) stated: *I completed an online course for understanding diabetes which I sourced myself. Well it was very confusing and explained in detail how the body works with type 2 diabetes, I found it hard to understand and still learning daily. I did pass the course…I have completed a Desmond day, that is the only thing offered to me by my doctors surgery when diagnosed."* T2DM P11 states they completed and passed a T2DM online course, but still came away from it with gaps in understanding and struggling with some of the concepts covered. Perhaps language usage across courses could be reviewed, to ensure that layman-friendly language is used throughout. Lastly, T2DM P16 explained: *"My diabetes nurse had already covered the course content- so the course didn't cover anything new at that point. What it was useful for was it made me realise I had the body of a 60-year-old given I was significantly younger than all of the other participants and at the time, my glucose was* *significantly higher. It really hit home how bad my condition was."* It is positive to see T2DM P16 was already informed of educational course content from their HCP, and they found the intervention useful for giving a realistic understanding of how diabetes was affecting their body. It is important to acknowledge these are responses from only three participants, but it offers insight into course benefits and potential areas for improvement.

Overall, the data suggests a generally positive response to structured education courses in T1DM and T2DM individuals, but uptake appeared poor especially in the T2DM sample. These findings are supported by existing research, where structured education is received well (e.g., Chaterjee et al., 2018; McKnight et al., 2020), but uptake rates are poor; 7.6% and 10.4% for T1DM and T2DM, respectively (Whicher, O'Neill & Holt, 2020). This statistic is lower in newly diagnosed, at 2% and 6%, respectively (NHS England, 2017). Research suggests low uptake rates are due to two reasons: practical (e.g., financial, logistical) and perceived benefit (e.g., no perceived benefit, felt they had sufficient knowledge, denial or negative feelings towards education) (Horigan et al., 2016; Reeves et al., 2023). Future research should focus on how to improve intervention attendance rates to improve education levels and diabetes self-management in patients.

### *8.4.4.3 Intervention Recommendations*

***More Mental health and Resilience-based courses***

Both T1DM and T2DM participants were overwhelmingly supportive of wanting to see more mental health and resilience-based educational courses (e.g., in learning about active/passive coping styles, training resilience and applying that to their individual situations), and explained why they felt this would be beneficial. Answers strongly centred around either: the concept of raising more awareness of the psychological aspects of living with diabetes, or improving resilience/coping strategies. For example, T1DM P15 demonstrates the need for psychological awareness of diabetes: *"It's easy to give booklets out when you first get diagnosed, but it doesn't make it any easier sometimes. Living and coping with diabetes is never talked about, only eating habits and exercise etc."* This feeling was echoed by T2DM participants, for example: *"Yes there should be more [mental-health based courses]* *as how are newly diagnosed diabetics able to recognise signs, symptoms, the impact on mental health, life, family, day to day activities and what support is available." (T2DM P24).* Raising awareness is important in reducing stigma and helping those with diabetes feel more understood and less isolated (Liu et al., 2017). The psychological side to diabetes is discussed very rarely, if at all (Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020), and this would help patients to understand their symptoms and their diabetes more effectively (i.e., health literacy; Balogun-Katung et al., 2021).

Answers also centred around resilience; ideas such as improved coping strategies, improved resilience, and better adapting to changes of living with diabetes were described. One response exemplifying the focus on improving resilience/coping strategies was stated by T1DM P14: "*Certainly I think [resilience based educational courses] are of immense value and they should be promoted to people with diabetes. Knowing the tools to live with diabetes is the first step to being "resilient". Knowledge is power and that power lets you respond in good ways… With so many complexities in diabetes, certainly learning ways to manage the whole package is of value."* This feeling was echoed in the T2DM participants, where they stated resilience-based courses would be useful because "*When you feel supported and understand more you can put coping styles in place I feel that this would be massive. I think more people should be educated about diabetes"  (T2DM P33).* Participants T1DM P5 and T1DM P10 picked up on the issue of issues of learning to live and cope with diabetes, talking about people struggling "in denial" (T1DM P10) and how resilience-based courses could help "people to adjust to changes." T1DM P16 implies that resilience-based courses could have a significant impact when they said, "*I've stopped caring more than once and would like to find things easier it's exhausting.*" Other issues identified were allowing people to feel they are not alone (T2DM P31) and to prepare for the future (T2DM P22).

Another recurring and important point is that "*everyone has individual needs, one approach does not fit all"* (T1DM P19*).* Understandably, a lot of value is placed in physical outcomes, such as HbA1c levels. However, participants have reiterated across both study 2 and 3 that they want HCPs and the public to understand diabetes is not consistent across individuals or fitting with a 'text-book' description of diabetes. Psychological difficulties and stressors have been shown to indirectly impact self-care behaviours, so more emphasis on informing patients this might help them feel more informed and understood. This is exemplified by T1DM P8, who states: *"I do think [MH/Resilience based courses] are extremely important so people don't feel like a failure if their levels 'aren't textbook'. I think all health care professionals should have more training in diabetes and how they can support rather than judge and instruct."*

In summary, these responses suggest not enough emphasis is placed on the mental health/psychological aspect of diabetes; some do not feel there is adequate mental health related content in current education courses. Especially in T2DM P5's case where physical changes are hard to achieve (e.g., mobility restrictions), it is especially important that other coping and management methods are discussed and provided. Mood and psychological difficulties such as depression and anxiety can affect food intake, so would be more beneficial to increase education on underlying psychological factors of diabetes and how to manage these. T2DM P24's comment is important as it highlights the need for a holistic approach when educating people, i.e., to take into account the emotional, social and psychological things rather than just physical management.

### *Existing Intervention Recommendations*

One of the main criticisms across of current interventions across both T1DM and T2DM groups were the course language and presentation. For example, participants generally wanted information to be more layman friendly and easier to understand. T1DM P11 suggested: *"Maybe change of language so it's in laymen's terms and easier to understand."* This is supported by T2DM P19 who wanted courses to be *"more visual, easier to understand and very relevant."* However, some participants expressed the courses being too simple, for example: *"all that came out of my course was generic."* (T2DM P9). This is an important contrast to make, as what is easy for one person to understand could be too simplistic and possibly unengaging for someone else. A possible remedy to this could be to gauge and control for individual's prior knowledge, and perhaps assign courses non-beginners who might feel they need more information or information on a deeper level. This is supported by study 2 participants such as Kenny and Tess, who expressed frustration at the vagueness of information they received from HCPs and during interventions, respectively. Additionally, participants made reference to slow speeds of the course impacting their engagement, for example T2DMP19 stated: *"I learnt a few things but the speed of course delivery was too slow and I soon lost interest."* This reinforces the idea that courses need to be easy to understand and engaging to maintain interest, and perhaps could be examined to improve uptake rates.

Other comments made particular reference to language and delivery of the course. For example, T1DM P16 stated: "*Less patronising would be helpful. More understanding of the issues from living with it rather than 'you're not doing this right. Do it better."* This was echoed by T1DM P3, who stated: *"To be run by diabetics, nothing worse than be preached to by someone who read it in a book."* To address T1DM P3's response, it would be unreasonable to expect only those with diabetes to educate other individuals with diabetes, however perhaps HCPs or diabetes educators could review their approach to ensure they are informing from a place of understanding and compassion. They could also invite someone with a longer standing diagnosis of diabetes to come and speak to the group too. Overall, these responses suggest that language could be more layman-friendly, and sometimes a more compassionate response could be helpful to those who might be struggling. This is also supported throughout study 2.

Another recurring factor was improving on certain areas of knowledge, such as treatment options and respective side effects (e.g., T2DM P23), and long-term impacts of diabetes (e.g., T2DM P19). Another participant (T2DM P27) recommended improving diet knowledge as their health carer "*gave up*" when they said they were vegetarian, as "*she didn't know how to advise on the best foods etc."* This identifies potential areas for improvement regarding patient education. T2DM P14 and T2DM P31 also suggested the inclusion of CBT elements, which again touches on psychological topics and cognitive reframing as a way to help manage diabetes (see chapter 4). Another suggestion was to improve knowledge and understanding on physiological issues, such as: *"Understanding that Blood Sugars are so hard to control, no matter how hard you try"* (T1DM P15). This would be helpful for those that are struggling to manage their sugar levels, and help them to feel more understood. It might prevent patients feeling a sense of failure, and affecting their mental health.

Both T1DM and T2DM participants also expressed feeling the need for more educational courses in general for people with diabetes (e.g., T1DM P17), for the public and those caring for those with diabetes (e.g., T1DM P1), and especially for those who are newly diagnosed (e.g., T2DM P25). For example, T2DM P11 stated: *"Yes definitely [should be more courses]. I have completed a Desmond day, that is the only thing offered to me by my doctors surgery when diagnosed."* The needs for a wider range of courses was echoed by T1DM P17, who educated themselves as a result: *"Yes there should be more [education courses]. I have self-educated myself. I have used NHS sites and Diabetes UK. I do feel like it's a forgotten disease"* (T1P17). These responses suggest participants want more variety of courses available, but it is important to consider there are courses available, but uptake rates may be low. Research suggests this could be because of perceived need for the course (e.g., feeling their knowledge is already sufficient, or the course will provide little benefit), or practical barriers such as cost, interfering commitments and travel (Coningsby, Ainsworth & Dack et al., 2022). Therefore, ways to improve this might be to target the aforementioned factors (Coningsby, Ainsworth & Dack et al., 2022).

Another factor commented on was easier accessibility, including to those that do not have diabetes such as teaching it in schools (T2DM P26), and more advertising and letting those without diabetes attend (T2DM P28). Although letting those without diabetes attend educational courses would be unfeasible (due to cost, time, etc), it could perhaps be extended to those with close family or carers of someone with diabetes. Other suggestions were for online courses (T2DM P30; P27; P18) and face to face courses (T2DMP10; P9; P8), although courses are already available in these formats, which could suggest people do not know what is currently available/accessible, in which case more signposting could be used to raise awareness.

Overall, suggestions were made for including more emotional support, reviewing language and presentation of courses, and areas of knowledge to improve upon. It is important to acknowledge that only 8/20 T1DM participants and 3/33 T2DM participants attended intervention or education courses, so these comments may not be representative for the DM population as a whole. Additionally, although participants expressed want for a wider range of courses, it would also be wise to revise current course content and also consider including a wider range of information (e.g., including mental health aspects of living with diabetes) to provide a more holistic overview of living with and managing diabetes.

## 8.5 Discussion

This study aimed to investigate the lived experience of model 1 constructs in a broader sample, and to more closely examine inductive diabetes variables identified in study 2, in order to better inform interventions and diabetes care. This study explored issues such as resilience education, mental health support, and intervention and healthcare experiences from patients to help inform intervention recommendations.

The first overarching theme discussed was Mental Healthcare. The main findings from this were: 1) both diabetes groups felt there was no or hardly any help for MH for their diabetes; 2) MH is very rarely spoken about or signposted; 3) T2DM participants seemed more negative regarding lack of MH care; 4) responses strongly focused on a lack of integration of mental and physical diabetes care, with possible suggestions of lack of funding or HCPs being too busy as the reason for this; 5) care satisfaction was mixed among participants, but more negative in the T2DM sample, where participants felt unsupported in the MH side of diabetes. Difficulty obtaining appointments and inconsistencies across care services and locations were also reasons for dissatisfaction.

The second overarching theme was psychological correlates of diabetes. The main findings were that the vast majority both diabetes groups were affected by a range of MH and psychological difficulties as a result of living with diabetes, and although they did not affect every participant, it is an issue worthy of clinical attention. Participants reported mental wellbeing issues ranging from mild to severe (e.g., feeling down or anxious to severe depression and suicidal thoughts), therefore improving education of this to those diagnosed with patients would be a good first step in addressing the issue. In line with the model in study 1, anxiety, fatigue and diabetes distress were described most frequently, although depression was also commonly reported. Another main finding was that almost every participant felt resilience plays an important role in diabetes self-management through overcoming obstacles, persisting with self-care behaviours, and to help maintain control over diabetes and their blood sugars. Specific links between anxiety and resilience were made, providing insight into the lived experience behind these concepts. Lastly, cognitive problems did not affect every participant, or significantly enough for it to be a recognisable problem, but participants are generally identifying certain problems such as issues with memory or decision-making. This contributed to feelings such as anxiety and isolation. T2DM participants reported more memory-based problems than T1DM. Overall, responses collectively tied in with executive dysfunction, where problems with decision making and memory have been described, and are significantly correlated with individuals with diabetes, and also poorer blood glucose control.

The final overarching theme examined education and interventions. Although the data cannot make any statistical conclusions, it is interesting to see the participant rate for interventions was much lower in the T2DM sample (3/33, relative to 8/20 for T1DM), which is in line with existing findings (Whicher et al., 2020; see section 7.5). Psychological and resilience-based education in the context of diabetes was very low for both groups, despite almost all participants describing MH problems and how important resilience was to their diabetes self-management. Many participants across both groups expressed wanting to see more resilience and MH-based intervention/education courses, as it would help in a variety of ways: better understanding their symptoms, teach them better coping methods, easing psychological problems such as anxiety and fatigue, confirming if they were self-managing correctly, improving mental health and developing resilience levels. The psychological side to diabetes is discussed very rarely, if at all, and this is supported by existing UK research (Benton et al., 2023; Hadjconstantinou et al., 2020; Zabell et al., 2022). Therefore, providing more psychological education and resilience training to participants would help provide them with more cognitive tools to apply to their individual situations and stresses, and help them to understand their diabetes better. Additionally, recommendations regarding current interventions were: 1) to raise awareness of MH difficulties associated with diabetes; 2) needing to use more layman-friendly language; and 3) improving certain areas of knowledge, such as how diabetes can vary hugely across individuals, and blood sugars can be hard to control even when doing the right things.

Overall, these findings point to a significant need to increase psychological and MH-based education for diabetes patients, to help them feel supported, further understand and address their diabetes symptoms, and improve self-efficacy in managing their diabetes. It will help give patients an idea of what living with diabetes is like, not just from a physical perspective. Not all diabetes participants will require help regarding mental healthcare, but research suggests mental health should be a more frequent topic of discussion in appointments, as a precautionary measure (Speight et al., 2020). This may help ease stress on the NHS and improve patient and public education levels, so those with diabetes can self-manage better independently (e.g., being able to self-identify when they need to seek MH help etc).

This study had several strengths. First, the use of the survey design allowed a larger scale examination of variables identified in study 2. Findings of this study strongly supported studies 1 and 2, and was able to provide more detail and understanding into the lived experience of diabetes, and the psychological and healthcare challenges that might accompany this. Additionally, as with study 2, the inclusion of both T1DM and T2DM participants as independent groups, whereas studies typically look at only one, or both as a singular group. This allowed for a better insight of potential group differences and comparisons. There is also a paucity of UK-based research into emotional support and healthcare experiences in T1DM compared to T2DM (see Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020), which this study addresses in detail.

This study is not without limitations. First, the inclusion of HCPs was planned, but recruitment issues caused difficulties with this. Ultimately, these data were disregarded, and this decision was based on two factors. The first being a lack of data richness due to the nature of the study (i.e., questionnaire-based qualitative data, examining study 2 findings across a wider population). Therefore, with only 4 HCPs recruited and with 2 of these participants having questions missing, the data were not sufficient to run a thematic analysis on. The second factor was the lack of feasibility given the time constraints of the PhD submission date. Additionally, the sample size was n=53 due to recruitment difficulties, although originally planned for n=100. Despite this, clear themes could be seen throughout data analysis, and the participant sample was still within recommended guidelines (i.e., 10 to 50 for participant generated text. Fugard & Potts, 2015; Braun & Clarke, 2016). Considering the sample demographics, respondents were largely female in both groups, which means the findings may be less representative of male participants. Another limitation is that participants who took part in the second study were not actively excluded from this study, and due to the anonymity of the data, it is impossible to tell if these participants took part in the prior study. If this was the case, it would limit the representatives (and therefore generalisability) of the findings. Another major limitation was that due to the staggered overlap between studies 2 and 3; Analysis writeup for study 2 was well underway whilst study 3 data collection began. Whilst study 2 partially informed study 3 (i.e., the deductive and indicative themes, allowing me to develop questions) the study was not yet finished at the time, so I could not address weaknesses specific to study 2. This will be considered in any future work. Another major limitation was the lack of recording comorbidities for each participant, which will have reduced the validity of my data because it means there are no comorbidities to provide context to the individual experiences described. This will be addressed in research going forward. Lastly, as this is a questionnaire study, it is important to acknowledge the limitations in not being able to ask follow-up questions to interesting points, and individuals with negative experiences (i.e., disgruntled patients) who may be more likely to respond. However, understanding the problems is the most effective way to improve healthcare and so this is not entirely a weakness of the study.

The findings have several implications for the model in study 1. For example, certain factors were absent from one group and not the other, for example stigma (T1DM) and fatigue (T2DM). See respective analysis for explanation of results. This also contrasts findings from study 2, where stigma and fatigue were both themes in T1DM and T2DM groups. A recent meta-analysis (Guo et al., 2023) found no significant type differences for stigma and diabetes distress in T1DM, which supports studies 1 and 2, but not 3. The mixed findings could indicate a validity issue in my model, and perhaps there are variables that could better explain relationships between model constructs (see Chapter 9, general discussion for further examples of this). Perhaps it would be more appropriate to design more nuanced models between diabetes types, rather than broad constructs as I have done in study 1 (e.g., looking at stigma or burnout in place of anxiety and fatigue, respectively).

## 8.6 Reflective Summary

This section will briefly consider how my characteristics as a researcher may have influenced my interpretation and work throughout study 3 (for a more in-depth and wider discussion, see Chapter 9). Then, other reflective aspects of the study will be considered (e.g., reflecting between study 2 and 3, e.g., analysis approaches, how I avoided bias). As a reflexive researcher at this point in the PhD, I feel I did a much better job at interpreting and assimilating quotes into a narrative, but I still struggled with a ‘quantitative’ mindset that I described in the study 2 reflective summary. I also hold particularly passionate views about the NHS, and as a result of my poor experiences with mental health help (and the NHS’s current state) I may have fixated more closely on the problems discussed rather than the positives in interviews. However, I did try to ground myself and work on this as part of my growth as a reflective researcher. Also, considering my personal experiences at the time of data analysis I had been in a very difficult situation caring for a terminally ill family member with cancer. I think this made me more empathetic to participants who were describing difficulties living with a chronic and progressive disease, alongside difficulties with mental health. I could especially relate to feelings of being run down, depression and anxiety. I do think my situation helped foster feelings of resilience, which helped in relating to and interpreting participants’ experiences.

Reflecting on the analysis process for studies 2 and 3, I followed the same iterative steps from Braun and Clarke (2006;2013), however there were differences in the way I approached things. First, study 2 utilised a combination of deductive and inductive analysis, which meant I had to remain as free from preconceived ideas for factors outside the model – which admittedly is hard as a researcher with hours of reading literature in this field. The way I facilitated this was considering how to remain free of bias and ensure objectivity for effective data-driven research (explained below). I felt study 2 was more time-consuming as it was incorporating a combination of approaches, and the inductive analysis especially required a high level of immersion with the data. In comparison, I felt study 3 leaned more towards my quantitative nature, where I was examining for themes/patterns across a wider dataset. However, for study 3 analysis I needed to develop a different set of skills in working with questionnaires and participant-generated text, as opposed to one-to-one interviews. I also found it took longer to design the questions due to being aware that I would not be able to ask participants any follow up questions. Therefore, I was careful to include clear instructions such as ‘please explain why you feel this way.’

Another reflective consideration was how to avoid bias, ensure objectivity and develop good quality arguments. To fully address bias, it must be considered in the context of the analytical approach. The supervisory team agreed deductive analysis was most appropriate for study 3, as the main aim was to examine study 2 findings across a broader population, and therefore the rationale needed to be theory driven. There are several potential issues associated with deductive approaches, which may influence the thematic analysis through bias. A deductive approach is guided by pre-existing theory or concepts, which can predispose one to looking for evidence that supports expectations. This could lead to confirmation bias (i.e., confirmation of pre-existing hypotheses), selective coding (i.e., coding in a way that fits preconceived categories rather than being open to the narrative), and reduced reflexivity (i.e., reducing openness to alternative interpretations). All of these could lead to overlooking nuances within the data, potentially oversimplifying participant experiences and reducing analysis objectivity. I took several steps to mitigate these issues: 1) Keeping a reflexive journal, to document and question assumptions, feelings, theoretical bias, and decision-making to critically examine how these may influence the analysis (see Appendix 17 for an example); 2) Iterative reviewing of narratives ensures that interpretations remain grounded in participant narratives rather than preconceptions, and prevent themes from being settled on too early; 3) Ensuring I was open to contrasting data or alternative explanations throughout, which is especially important in deductive analyses to avoid confirmation bias; 4) verifying data with other findings (i.e., triangulation) to see if other sources refuted or supported interpretations (e.g., barrier’s to participant’s MH care, which could influence the confidence of my arguments; and 5) collaborative analysis - where I worked closely with the supervisory team, one of who is an expert in qualitative data and thematic analysis (the other supervisors also had experience in qualitative data and health research). This allowed things that were missing, or insufficiently considered/explained to be addressed. The team would also check the quality of my coding and themes, and helped to spot and reduce bias where I may have been struggling (i.e., first adapting away from a ‘quantitative’ mindset).

## 8.7 Conclusions

This study examined the lived experience of model 1 constructs in a broader sample, and further examined the inductive diabetes variables previously identified in study 2 (diabetes healthcare experiences, and diabetes interventions/education). Both groups felt largely unsupported with the psychological/mental health aspects of living with diabetes, and felt that MH accessibility in NHS healthcare settings were poor. Healthcare satisfaction was generally poor, and it was clear that the majority of participants were affected by psychological difficulties, matching those examined in study 1 (largely anxiety, fatigue, and diabetes distress). Overall, findings suggest a substantial need to integrate mental health support and psychological/resilience education into primary care settings and interventions. This could have benefits for diabetes self-efficacy and improve health outcomes.

# Chapter 9: General Discussion and Directions for Future Research

## 9.1 Chapter Structure

First, the overall findings of the thesis are discussed, and the proposed model will be outlined. Next, the strengths and limitations of the thesis are discussed, followed by a reflective discussion regarding the qualitative research throughout the thesis. The chapter is concluded with directions for future research and final statements.

## 9.2 Overall Findings and Current Proposed Model

The overall aim of this research was to develop a novel model based on a thorough review of existing literatures, that could be used to provide guidance for intervention design in T1DM and T2DM. Findings revealed significant associations between psychological states (anxiety, fatigue), and diabetes outcomes (diabetes distress, cognition), and resilience significantly mediated indirect relationships between these variables. This suggests resilience is a key factor in diabetes self-management, and therefore would be a necessary target for interventions. Qualitative findings explored the lived experience of the model relationships, and identified key areas, such as education, resilience, and mental health, that could be targeted to help inform interventions (e.g., integration of mental health into primary care, and recommendations for HCPs to improve education and skills in the emotional aspects of diabetes management).

Specifically, study 1 (SEM model) confirmed expected positive associations between psychological states (anxiety, fatigue) and diabetes outcome variables (diabetes distress, cognition) (e.g., Fritschi & Quinn, 2010; Griggs & Morris, 2018), and each variable significantly negatively associated with resilience in both T1DM and T2DM groups. The proposed structural model achieved an acceptable model fit and was appropriate for both groups; direct relationships were not significant and therefore not supported, although indirect paths indicating mediation from predictors (anxiety, fatigue) to diabetes outcomes (diabetes distress, cognition) through resilience were all significant and supported. Additionally, the model supports an indirect relationship between diabetes distress and fatigue, which supports the findings of Park et al. (2015), although this thesis examined resilience as a mediator variable rather than diabetes symptoms. These findings suggest interventions should target resilience as a potential psychological mechanism to offset difficulties with diabetes distress and cognition, as a result of anxiety/worry and fatigue. This could improve health outcomes (both physical and mental) and quality of life in people with diabetes.

Study 2 (deductive and inductive thematic analyses; interview study) provided insight behind the model constructs from study 1, and appears to provide some support for a mediating effect of resilience between psychological states and diabetes outcomes. Anxiety seemed to affect all participants, with varying severities (mild to severe, based on participant descriptions) whereas fatigue seemed to affect relatively fewer participants, but cases discussed were more severe and hindered daily functioning (e.g., chores such as cooking, cleaning). Fatigue was reported more in those with uncontrolled HbA1c levels (above 48mmol), which is concordant with existing research (Park et al., 2015). Feelings of anxiety and fatigue contributed to feelings of distress through emotional eating, over-worrying, or a lack of motivation to engage with self-care behaviours (e.g., physical exercise). Participants described various mechanisms indicating how resilience might interact with anxiety and fatigue, where individuals displaying more resilient behaviours (e.g., engaging with self-care behaviours, using adaptive coping, positive appraisal) felt it helped them to manage and/or reduce feelings of diabetes distress. This could be explained through resilience facilitating better decision-making skills (e.g., planning, reframing, situational appraisals), which is associated with improved self-care efficacy and health outcomes in the literature (see chapters 2-4). Regarding cognition, most participants were generally unsure or had not considered long-term cognitive effects of diabetes, which could suggest it is not a problem experienced by participants, or that individuals were unaware of that as a potential issue. However, a minority described problems with memory, attention, decision making and increased impulsivity. These findings suggest a potential area for education surrounding cognitive effects in diabetes. Additionally, an important problem raised was the lack of mental health integration in diabetes care, which in some cases led to a loss of trust in healthcare providers through feeling unsupported, or feeling that help was inaccessible. Participants who were asked about their mental health in appointments described more satisfaction with their diabetes care teams, suggesting a more holistic approach in diabetes appointments may benefit patients and help them feel more supported. Additionally, participants highlighted that key stressors underlying mental health and diabetes were related to the hidden nature of diabetes and achieving blood glucose balance alongside life stressors.

Study 2 also identified and examined other important aspects of living with diabetes beyond those in the model, such as patient perceptions and attitudes towards healthcare, and diabetes education/interventions. Participants were generally dissatisfied or had mixed views regarding healthcare provider interactions and healthcare systems. Namely, a lack of support and direction (especially after diagnosis in type 2); continuity with same HCPs (type 1 only); poor HCP attitudes (e.g., not believing patients, comparing to 'text-book diabetes'); area funding allocation; and feedback language in healthcare assessments. These factors support current literature (e.g., Dickinson et al., 2017; Speight et al., 2020; deWit et al., 2020) and appeared to contribute to a lack of trust and confidence in healthcare providers. Regarding education levels, both T1DM and T2DM (including nurses in both groups) felt that education levels were too low in both the public and healthcare providers. This appears to contribute to stigma, which was a prevalent theme among both groups leading to feelings of distress. For example, being blamed from bringing diabetes upon themselves (T2DM), being wrongly associated with type 2 (T1DM), and being judged for experiencing severe fatigue (both types) (supported by Liu et al., 2017). Participants also expressed a need for better education and guidance from healthcare providers (e.g., when they already had healthy, active lifestyles). Key criticisms of current interventions included: a lack of engagement, poor or basic content, restrictive approaches, and lack of mental health and resilience integration. Several participants recommended the inclusion of more mental health and resilience-based interventions, that would allow them to cope better with the demands of diabetes and apply resilience to their situations.

Study 3 (deductive thematic analysis; online survey) aimed to further examine the lived experience behind the model constructs in study 1, but in a broader sample, and to more deeply examine the inductive aspects of living with diabetes not present in the model (identified in study 2). Findings confirmed those of study 2, providing some support for a mediating effect of resilience between psychological states and diabetes outcomes, and further explored mental health, diabetes care, psychological correlates (including resilience), and education and interventions. The first overarching theme discussed was Mental Healthcare (MH). The main findings from this were: 1) both diabetes groups felt there was no or hardly any help for MH for their diabetes; 2) MH is very rarely spoken about or signposted; 3) T2DM participants seemed more negative regarding lack of MH care; 4) responses strongly focused on a lack of integration of mental and physical diabetes care, with possible suggestions of lack of funding or HCPs being too busy as the reason for this; 5) care satisfaction was mixed among participants, but more negative in the T2DM sample, where participants felt unsupported in the MH side of diabetes. Difficulty obtaining appointments and inconsistencies across care services and locations were also reasons for dissatisfaction.

The second overarching theme was psychological correlates of diabetes. The main findings were that the vast majority of both diabetes groups were affected by a range of MH and psychological difficulties as a result of living with diabetes, and although they did not affect every participant, it is a prevalent issue worthy of clinical attention. Participants reported issues ranging from mild to severe (e.g., feeling down, suicidal thoughts), therefore improving education of this to those diagnosed with diabetes would be a good first step in addressing the issue. Considering the model in study 1, anxiety, fatigue and diabetes distress were described most frequently, although depression was also commonly reported. Another main finding was that almost every participant felt resilience plays an imported role in diabetes self-management through overcoming obstacles, persisting with self-care behaviours, and helping to maintain control over diabetes and blood sugars. Specific links between anxiety, fatigue, stress, and resilience were made (e.g., being resilient helped cope with feelings of anxiety, fatigue and stress), providing insight into the lived experience behind these concepts. Lastly, cognitive problems did not affect every participant, or significantly enough for it to be a recognisable problem, but some participants identified difficulties with memory or decision-making which contributed to feelings such as anxiety and isolation. T2DM participants reported more memory-based problems than T1DM, however. Overall, responses collectively tied in with executive dysfunction, where problems with decision making and memory have been described, and are associated with individuals with diabetes, and also poorer blood glucose control.

The final overarching theme examined education and interventions. Participant rate for interventions was much lower in the T2DM sample (3/33, relative to 8/20 for T1DM). Psychological and resilience-based education for those with diabetes was uncommon, despite almost all participants describing MH problems and how important resilience was to their diabetes self-management. Many participants across both groups strongly expressed wanting to see more resilience and MH-based intervention/education courses, as it would help in a variety of ways: teaching them to better understanding their symptoms, teach them better coping methods, easing psychological problems such as anxiety and fatigue, confirming if they were self-managing correctly, improving mental health and developing resilience levels. Participants described how the psychological side to diabetes is rarely discussed, if at all, and they felt providing more psychological education and resilience training to participants would help provide them cognitive tools to apply to their individual situations and stresses, and help them to understand their diabetes better (supported by Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020). Additionally, participants' main recommendations regarding current interventions were: 1) to incorporate MH and resilience-based knowledge to provide a more complete understanding of living with diabetes; 2) needing to use more layman-friendly language; and 3) integrating certain areas of knowledge to both HCPs and patients (e.g., blood sugars can change unpredictably even when taking correct medicine, diabetes will not react the same across individuals, and that diabetes is more than just HbA1c levels), that will help to alleviate stigma.

Collectively, the qualitative findings from this thesis map onto existing findings; the most prevalent complaint among people with diabetes is a lack of emotional support to address the psychosocial aspects of living with diabetes (Benton et al., 2023; Dambha-Miller et al., 2020). Additionally, UK HCPs acknowledged that daily emotional challenges are more accepted for other long-term conditions (e.g., Cancer, Parkinson's) within NHS services, and this needs to be normalised for diabetes (Hadjiconstantinou et al., 2020). The thesis findings identified the same barriers and difficulties described by people with diabetes within NHS care settings, such as: a lack of support and understanding from HCPs; negative attitudes and assumptions from HCPs; wanting their HCP to understand potential barriers to self-management, and feeling more than just their HbA1c levels (see Hadjiconstantinou et al., 2020; Litterbach et al., 2020). In existing literature, these barriers are supported and acknowledged by NHS HCPs (Benton et al., 2023; Berry et al., 2020; Dambha-Miller et al., 2023; Hadjiconstantinou et al., 2020), and can be explained through a lack of HCP knowledge/training, confidence in addressing emotional issues and time constraints in appointments. To my knowledge, there were only four appropriate UK-based studies that directly examined emotional support from NHS HCPs and/or diabetes patients, and the findings discussed in those papers support the qualitative findings described in studies 2 and 3 (see: Benton et al., 2023; Berry et al., 2020; Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020).

Overall, these findings point to a significant need to incorporate psychological and MH-based education into interventions for diabetes patients, to help them feel supported, further understand and address their diabetes symptoms, and improve self-efficacy in managing their diabetes. Doing this will help improve understanding of what living with diabetes is like holistically, rather than from only a physical perspective. Not all diabetes participants will require help regarding mental healthcare, but research suggests mental health should be a more frequent topic of discussion in appointments, as a precautionary measure (Speight et al., 2020; Zabell et al., 2022). This may relieve some stress on the NHS by preventing psychological difficulties worsening without the appropriate help, preventing the likelihood of serious complications due to burnout, etc. Additionally, it could improve patient and public education levels, so those with diabetes can self-manage better independently (e.g., being able to self-identify when they need to seek MH help etc).

## 9.3 Strengths and Limitations

This research makes an original contribution to the literature, being the first to examine psychological states (anxiety, fatigue) and diabetes outcomes (cognition, diabetes distress) simultaneously, furthering understanding of the multifactorial relationships between diabetes and psychological correlates. Additionally, this is complemented by qualitative examination, and there is a paucity of research regarding emotional aspects of diabetes, especially in T1DM populations. A strength of the thesis is integrating both quantitative and qualitative methods to gain a comprehensive understanding of the issues (Creswell & Plano Clark, 2017; Wasti et al., 2022). Both quantitative and qualitative findings can contribute to clinical practice, and can be used to inform health care policies and interventions (Rapport and Braithwaite, 2018).

Another strength is using SEM as it allows for investigation of complex relationships simultaneously and is able to measure unobserved variables using observed variables (accounting for error measurement, rather than treating them separately) (Boateng, 2018). Another benefit is that SEM performs well with a range of sample sizes, including ones smaller than that of this study (e.g., Sideridis et al., 2014; Wolf et al., 2013). However, it is important to note Fritz and MacKinnon (2007) argue estimated sample sizes needed to detect a mediational effect (.80 power) differ depending on the indirect effect sizes. In study 1, the ‘anxiety-diabetes distress’ and ‘anxiety-cognition’ pathway values are ‘small-large’ for both diabetes types, which requires a sample of 385; therefore, these sample sizes have not been met (n=307). However, the ‘fatigue-diabetes distress’ and ‘fatigue-cognition’ pathway values are ‘small-medium large’ for both types, requiring a sample of 118. These sample sizes have been met and so the sample is adequate to detect mediational effects. This could be considered for future research, and larger sample sizes as part of a longitudinal replication would be best to ensure adequate power. Additionally, structural equation modelling allows one to test theoretically plausible ideas about the order of variables, and thus, this study identified anxiety and fatigue as psychological risk factors that can be mediated by resilience.

Another strength of the thesis was the use of a comprehensive and validated resilience scale in the quantitative research, whereas the resilience literature tends to operationalise resilience as only one construct of resilience (e.g., self-efficacy), or is typically identified from non-validated questionnaire data (see Hadj-abo et al., 2020; Hosseini et al., 2021; Yifrazier et al., 2010). All other scales used as part of the quantitative study used were reliable and validated (see chapter 5). Additionally, it is a strength that with each study T1DM and T2DM are in separate groups; they have clinically different aetiologies, and should be treated as such, although this is not always the case in existing literature and they are often grouped together and/or not defined (Speight et al., 2020).

The model, and the current research are not without limitations, however. One of the main limitations of using SEM and mediation analyses is the use of cross-sectional data, and so inferences cannot be made about these findings over time; therefore, there is a need for future work to confirm if this model replicates in longitudinal design. Additionally, whilst the fit indices for model 1 satisfied adequate cut-offs, the model fit could be improved. Other psychological variables, not included in the present model, could be considered in future SEM models, such as personality traits (e.g., neuroticism). Research suggests higher levels of neuroticism in diabetes are positively correlated with affective disorders (depression, anxiety), lower regimen adherence and diabetes self-management (Novak, Anderson & Johnson et al., 2017). Specifically, neuroticism can predict significantly problematic coping strategies such as wishful thinking and withdrawal which are emotion-avoidance behaviours. Whereas traits like Extraversion/conscientiousness predicted more problem-solving behaviours (Connor-Smith & Flaschbart, 2007). It is also significantly associated with anxiety, fatigue, diabetes distress and cognitive flexibility (e.g., Bianchi et al., 2018; Huang et al., 2021; Latzman & Masuda et al., 2013) so could be considered as a potential mediator for modelling in diabetes. Another example could be coping. Other factors generally that could be considered could be stigma, illness perception or trauma. Path analyses studies have shown neuroticism is a significantly strong predictor of less adaptive psychological functioning both directly and through diminished resilience (Kocian, Kavcic & Avsec, 2021), and so may be useful to investigate in diabetes contexts.

Additionally, comparisons of individual difference variables such as gender and race were not investigated, which is important for this model because findings have suggested gender and racial differences in diabetes management (McCoy & Theeke, 2019). For example, males report more problem-focused coping methods whereas females report more negative and emotion-focused coping styles. Study samples (1-3) were mostly female (70-79% in both T1DM and T2DM groups) and almost all White British, which is not representative in the diabetes literature (Sattar, 2013); this could suggest that white British females are more likely to reach out to others regarding their diabetes, which has significant implications in both healthcare and research settings. It is important to confirm these results in a more representative population regarding gender split, to ensure reliability of findings. Additionally, future work replicating these findings should control for HbA1c levels, since controlled HbA1c levels are associated with fewer psychological problems (e.g., anxiety, fatigue, distress) and better health outcomes.

Another limitation is participants who took part in the second study were not actively excluded from the third, and due to the anonymity of the data, it is impossible to tell if these participants took part in the prior study. If participants took part in both studies, it could limit the representativeness of the data, which would reduce the generalisability of the qualitative findings. If the studies were replicated, participants would be screened to see if they previously took part and appropriate exclusions would be made. Another major limitation was the lack of recording comorbidities for each participant in study 3, which will have reduced the validity of the data since there were no comorbidities to provide context to the individual experiences described. This will be addressed in research going forward.

## 9.4 Reflexive Section

### *9.4.1 Reflective Summary*

Reflexivity is a process of evaluating how identities, expectations, biases and expertise might influence a researcher and how they might shape their research, both positively and negatively (Finlay, 2003; Sabnis & Wolgemuth, 2023). I have used guidance from Sabnis & Wolgemuth’s review (2023) to consider how the above factors might have influenced the way I have collected, analysed and reported data, and to reflect on this process.

I am a PhD student with a BSc in Neuropsychology, and my BSc dissertation was entirely quantitative and focused on brain imaging. I completed statistics modules as part of the Master’s course at UCLan to help bridge the gap between BSc and PhD levels. The only qualitative experience I had prior to the PhD was a qualitative module and written report as part of my BSc. Due to this, I was a relative novice in qualitative research which presented several challenges throughout studies 2 and 3. For example, I had a tendency to perceive things in a quantitative way, which hindered my ability to really ‘listen’ and understand what the participants were saying. I also felt more inclined towards deductive over inductive analyses, although I took care to ensure study design was based on addressing study aims and not preferences. At first I found it very hard to embrace subjectivity and shift my way of thinking from a primarily numbers-focused approach to a more subjective and narrative approach. As a result, my analyses were more descriptive than analytic, and after several iterations I managed to improve how I incorporated research findings and analysis throughout the findings. Initially, I particularly struggled with categorising quotes into themes, and at times felt very overwhelmed with the amount of data to process, but I feel much more confident with qualitative research now. Additionally, as a result of my neuro/cognitive background, I may have had a tendency to focus more on cognitive difficulties described by participants. As such I may interpret things differently to a researcher with more experience in resilience for example, who might be more interested in other areas (e.g., coping styles).

Considering my personal background, I have two close family members that have diabetes, one with T1DM and one with T2DM. I feel these experiences with them have given me knowledge and allowed me to empathise closely with the participants and the struggles they described. Additionally, I have prior experience (and difficulty) trying to access mental health services within the NHS, so I may have had a tendency to empathise more with the patients than the HCPs, who also have difficult situations to deal with. This could have impacted the way I interpreted problems described by participants. I also recognised that I had to be careful and not influence participants through my own emotional feelings and reactions, when some described particularly harrowing situations (i.e., feelings of suicide etc). I also hold particularly passionate views about the NHS, and as a result of my poor experiences with mental health help (and the NHS’s current state) I may have fixated more closely on the problems discussed rather than the positives in interviews. However, I did try to ground myself and work on this as part of my growth as a reflective researcher.

Considering my personal beliefs, I place high value in personal autonomy and accepting personal responsibility; I had a lot of difficulty when participants described not wanting to bother taking steps to care for themselves entirely because of the way HCPs had treated them. Whilst HCP input and understanding is very important, I found it frustrating when people exhibited such apathy and external loci of control. However, I reflected on this by looking at other experiences they had described and realising it may be from burnout, or a range of other things; I realise it is important to come from a place of understanding and open mindedness and learning to emotionally regulate myself – that way I can interpret the data avoiding as much bias from my own personal beliefs as possible. Considering my personal experiences at the time of data analysis (study 3) I had been in a very difficult situation caring for a terminally ill family member with cancer. I think this made me more empathetic to participants who were describing difficulties living with a chronic and progressive disease, alongside difficulties with mental health. I could especially relate to feelings of being run down, depression and anxiety. I do think my situation helped foster feelings of resilience, which helped in relating to and interpreting participants' experiences.

Additionally, I have recently received a diagnosis for AuDHD (autism and ADHD) and in learning about these, a lot of my behaviours make more sense, which I do feel affects the way I interpret things compared to someone who does not have these difficulties. For example, I found qualitative data very overwhelming to work with, and I have a tendency to infer things very literally. This made it difficult to interpret the subjectivity of topics and I had a tendency to try to quantify/seek patterns in things a lot. To mitigate these difficulties, I did a lot of reading surrounding reflexive research, qualitative methods, and reading examples of previously published work. I also worked with the supervisory team closely to identify mistakes in my reasoning and interpretations throughout my work.

Participants often described personal issues (e.g., suicide, depression) that were emotionally laden, so I also made a conscious effort to remain objective about the situation and be mindful of my reactions. In order to take care of my own mental health and ensure these stories were not affecting me, I utilised several coping methods. These included reaching out to people (e.g., friends and family) for support and a chat if I was feeling down/overwhelmed, and utilising grounding exercises and CBT techniques which I have previously learnt from a therapist. I was also mindful of the importance of taking a rest when I felt burnt-out, such as going for a walk or taking time to enjoy my hobbies (e.g., violin, drawing). Additionally, I used reflexive diary entries to help me process how I felt or to 'vent' about difficult topics (e.g., frustrations, empathy) and I also made conscious effort to look into my own mental health issues that might have been compounding stress from the PhD (e.g., ADHD). Through this and working towards getting a diagnosis, I better understood how to manage my difficulties more effectively, and ensure my stress was not affecting my ability as a qualitative researcher.

Lastly, I found the process of carrying out qualitative research very rewarding. Many of the participants expressed significant gratitude that someone was taking the time to investigate further into their experience of diabetes, and it gave them a chance to feel heard (especially those who did not feel supported from their HCPs). This research really helped me to: 1) appreciate more of what individuals with diabetes go through, and the burdens of living with this chronic disease, and 2) appreciate personal growth and perspective shift in understanding the value and nuance in qualitative research.

### *9.4.2 Reflecting on Study Design*

The qualitative findings have been insightful in informing nuanced differences between participant groups. For example, in study 3 certain factors were absent from one group and not the other, for example stigma (T1DM) and fatigue (T2DM). This also contrasts findings from study 2, where stigma and fatigue were both themes in T1DM and T2DM groups. A recent meta-analysis (Guo et al., 2023) found no significant type differences for stigma and diabetes distress in T1DM, which supports studies 1 and 2, but not 3. The mixed findings could indicate a validity issue in my model, and perhaps there are variables that could better explain relationships between model constructs (see Chapter 9, general discussion for further examples of this). Perhaps it would be more appropriate to design more nuanced models between diabetes types, rather than broad constructs as I have done in study 1 (e.g., looking at stigma or burnout in place of anxiety and fatigue, respectively). Due to the research of Lasselin et al., (2012) and Park et al., (2015), I think it would be best to run the initial model longitudinally, using the MFI fatigue scale, and control for HbA1c levels to see if this if this can elucidate the findings further regarding variables such as fatigue.

I feel I now have a much more thorough understanding of the research design process, and there are several things I would change. Firstly, I would have conducted a systematic literature review, after the scoping review. Although there may be some difficulty with lack of research in some areas more than others (e.g., cognition), it would ensure more rigour in my methodology. For study 1 measures, I would use the shortened CD-RISC 10 over the CD-RISC 25, as it is psychometrically robust, but reported rates of convergent validity are better. This would allow me to include a more comprehensive measure of fatigue (e.g., MFI) without significantly increasing participant burden. I would also put in place diversity measures (i.e., using stratified sampling) to improve the diversity, and therefore generalisability, of the sample (including gender ratios). Individual differences such as gender and ethnicity would be investigated and I could also try other variables such as coping as mediator to see if it better explains the model (i.e., improved explained variance). Additionally, it might have been more effective to have planned for a longitudinal follow up of the model whilst controlling for HbA1c and gender – I could have done this through having study 1 as the systematic review, study 2 as the proposed model testing, and study 3 could have been a 6-month follow up of the model. This would also allow for qualitative follow up post-doctorate.

For study 2, I would separate out anxiety and fatigue in relation to resilience questions, to improve consistency, as with the cognition/diabetes distress questions. As with study 1, I would also use stratified sampling to ensure a more diverse sample. For study 3, I would ensure that no participant in study 2 participated in the third. I would also ensure that the third study explicitly addresses the limitations of the second (the reason for this is that studies 2 and 3 were staggered, and data collection was overlapping during study 2). I would also ensure that information on co-morbidities were recorded; even if participants are not excluded on the basis of comorbidities, it is still important information for context and understanding their experiences. Lastly, I would apply for NHS ethics well in advance to counter the problems experienced with healthcare provider recruitment.

### *9.4.3 Reflecting on the Process of doing a PhD*

The initial stages of the PhD involved collecting data via home visits, testing executive function tasks of in individuals with type 2 diabetes. There were practical and experimental challenges (e.g., 2 separate home visit sessions, researcher could not drive at the time, older participants were struggling with computerised tasks), and so the direction of the PhD changed quite abruptly. I have kept this brief as it is not the focus of the current PhD, but felt important to mention as it taught me about barriers and facilitators to conducting research (i.e., what sounds good in planning may not reflect as such in real life), learning to adapt to research as a dynamic process, and regaining confidence in my work from abrupt and significant changes.

Over the course of my PhD I have learnt many research-specific and transferable skills, building upon the skills/foundations developed during my BSc. Although this had admittedly been a big jump from not having done a masters, I can feel and see the progress I have made - I can easily identify the problems with my thesis and know how to improve for future research. I feel the PhD has helped me grow as a person, understanding and appreciating the research process as a whole, and developing empathic and holistic perspectives; I am not just working with numbers but individual people who are managing a chronic disease daily. This PhD has helped me to understand living with diabetes on a level I would not have if not for this research.

Additionally, I have developed several research-based skills, such as: performing EFA/CFA and SEM analyses, conducting reflective thematic analyses (and so expanding my understanding of mixed-methods research and why that is useful), experience of publishing research, and improving critical thinking and academic writing skills. I also have improved at my ability to assimilate information together to form strong arguments. To supplement my understanding (from going straight onto a PhD from BSc), I also took part in the master's level statistics and assessment modules (e.g., PS4700), and I feel a lot more confident with statistics in general now. I  have also developed technical skills such as learning how to use software such as E-prime, AMOS, further consolidating knowledge of SPSS, and I completed safeguarding and first aid training courses.

The PhD also allowed me to develop interpersonal skills such as teaching, confidence in presenting and science communication (i.e., conveying complex topics/ideas at a layman level). This helped develop my confidence and psychological knowledge, and I used the opportunity to present at postgraduate research conferences at the university. Lastly, doing the PhD has unquestionably helped develop my time management/planning skills, and especially my resilience skills – the drive and determination to keep going, regardless of challenges. Ultimately, my PhD has provided me with a collection of valuable skills and opportunities that I will carry with me throughout my career, helping me to be a better researcher.

## 9.5 Directions for Future Research and Clinical Implications

This section will outline the final recommendations compiled from the findings discussed throughout the thesis, linking to their respective study findings and existing literature.

### *9.5.1 Recommendation 1: Developing Theoretical-Based Interventions*

Supported models are important in understanding complex processes and guiding clinical applications (Mathiesen et al., 2019), and systematic reviews highlight a gap in the literature for theory and evidence-based interventions in T1DM and T2DM (Chew, et al., 2017; Winkley et al., 2020; Zhao et al., 2017). Future research should ensure an empirically theoretical basis to develop novel treatments, rather than replicating existing psychological models that typically deliver small effect sizes (Winkley, Upsher, Stahl et al., 2020; Oyedeji et al., 2022). This thesis addresses the research gap by developing a statistically supported model to understand the interplay between psychological states and diabetes outcomes simultaneously, and how resilience can mediate these. However, there is still more to explore, and other variables could be considered to further address this research gap, such as but not limited to: stigma, illness perception, coping, and personality traits e.g., neuroticism).

### *9.5.2 Recommendation 2: Incorporating Mental Health and Psychological Education Support in Primary Care and Interventions*

Qualitative findings from studies 2 and 3 strongly suggest the need for education and support improvements in mental health and the psychological correlates of diabetes. For example, mental health and psychological aspects of living with diabetes was rarely discussed with the participants, and some were not aware that the symptoms they were experiencing (e.g., anxiety, fatigue, cognitive problems) are associated with diabetes. Currently, HCP knowledge of MH in diabetes is insufficient, which has led to patients feeling unsupported (Zabell et al., 2022), and so there is a strong need to incorporate mental health and psychological support for those with diabetes (Dambha-Miller et al., 2020; Hadjiconstantinou Et al., 2020). Qualitative research in both patients and HCPs (including the UK) has identified several barriers to effective diabetes care, one being a lack of education, which can result in: 1) HCP's feeling unable to address mental health problems, and 2) low levels of health literacy, which is associated with reduced self-efficacy in individuals with diabetes, and poorer self-management and reduced glycaemic control (Balogun-Katung et al. 2021; Dambha-Miller et al., 2020; Farley et al., 2019).

To address the lack of education in both patients and HCPs, it is necessary to consider recommendations within the scope of what is feasible within the NHS, and rather than offering more appointments, it might be better to: 1) shift focus onto offering preventative intervention during appointments, and ensuring HCPs have training to identify and inform/recommend MH help for patients, and 2) implementing resilience- and psychological-based education into existing structured education interventions to help patients better understand their diabetes, and to better recognise if they need MH support. Some examples of this education could include:

- Psychological correlates of diabetes and their definitions, (e.g., anxiety, fatigue, DD),
- Aetiology of the correlates and the role resilience has been shown to play in these,
- Components of resilience and steps to encourage adaptive coping styles,
- Understanding correlates such as anxiety, fatigue, diabetes distress are multifactorial and amenable to change (giving patients hope)

The goal is to prevent or slow deterioration, and so understanding psychological correlates known to hinder diabetes management is essential. Participants were strongly in favour of seeing more mental health education within interventions, and providing more psychological education and resilience training to participants would help provide them cognitive tools to apply to their individual situations and stresses, and help them to understand their diabetes better and how it affects them. This would also allow people with diabetes to recognise/identify symptoms of psychological problems sooner and seek out the help they would need. A proactive approach to mental health needs, rather than a reactive approach, is essential for prevention of mental health, and promotion of wellbeing (Carbone, 2020), a possible suggestion for this would be to screen for psychological factors strongly associated with diabetes outcomes (e.g., HbA1c), such as diabetes distress (Asonye, 2023; Skinner et al., 2020). Early intervention is strongly recommended in mental health conditions to prevent deterioration, and focusing on mental health prevention will help reduce illness, save lives, promote resilience, reduce primary care workload and cost (Budd et al., 2021; Thomas et al., 2016). Therefore, an integration of education into primary care will help support both HCPs and diabetes patients, and improve health outcomes in a more proactive way (Dambha-Miller et al., 2020).

### *9.5.3 Recommendation 3: Addressing Care Approaches and the Need for a Holistic Understanding of Diabetes Management*

Participants across studies 2 and 3 felt MH was overlooked in place of physical numbers (e.g., HbA1c values) and whilst emphasis on physical diabetes outcomes is necessary, it should not be the sole focus (Jones, Vallis & Pouwer, 2015). This can be explained through a perceived state of risk, where a HCP might not perceive a patient to be at risk if they seem compliant in their care and have reasonable numbers. But as seen especially in study 2, participants sometimes engaged in actively dangerous self-care behaviours to maintain a ‘good’ HbA1c level. A HbA1c is not always indicative of healthy self-care behaviours and should not be considered as such. Participants also expressed the need for compassionate and holistic understanding from their HCPs. In particular, participants strongly expressed frustration and/or dissatisfaction with: 1) HCPs overlooking emotional wellbeing and focusing too much on HbA1c values, and 2) not understanding the individual differences between diabetes symptomology, e.g., that blood glucose levels can fluctuate without reason, and can be hard to manage even with appropriate self-care, and 3) HCPs provided untailored advice, (e.g., lose weight) and patients wanted more instructive support on how to achieve this. These findings were closely in line with Litterbach et al. (2020). Considering the thesis findings, and support from existing literature, awareness of the following factors needs to be emphasised to HCPs as part of their training: using non-neutral language (Dickinson et al., 2017); addressing attitudes that may be reflective of stigma (Benton et al., 2023); and a lack of knowledge and emotional support (Hadjiconstantinou et al., 2020). These factors can negatively impact patient care satisfaction, trust in HCPs, and feelings of support (Benton et al., 2023; Zabell et al., 2022).

Communication between individuals with diabetes and HCPs is a core factor of effective integrated care (Dickinson et al., 2017), and so it is essential for clinicians to recognise the impact of their care approaches on patients. It would be recommended to those designing interventions to educate HCPs and patients of this perceived state of risk and how to approach the topic of accessing psychological help should one need it. Good HbA1c values and good mental health/quality of life are not mutually exclusive, but if it seems a doctor is overly focused on numbers, then it could create anxiety or diminish the motivation to try (Litterbach et al., 2020). Another way to address these issues could be to implement education on this topic in the form of interventions to both patients and HCPs, to further understanding and provide validation/confidence for patients about the multifactorial nature of diabetes, especially psychological. Additionally, ensuring interventions present a holistic overview of diabetes is crucial in helping patients (especially newly diagnosed) understand diabetes from a mental/emotional perspective, not just a physical one (see recommendation 2).

### *9.5.4 Recommendation 4: Better Co-ordination of Diabetes and MH Care Areas, and Signposting.*

A major theme from participants across studies 2 and 3 was the feeling that '*there's not enough done for the mental health side of having diabetes, in the NHS,"* leaving many feeling '*unsupported,*' '*abandoned*' or '*lost*.' This is also supported in the literature; A lack of integration between care areas has left a split between MH service users who are then diagnosed with diabetes, and those with diabetes who develop comorbid MH difficulties, leaving both groups of patients without the support they need (Stenov et al., 2020). This is also supported in the Diabetes UK report 'Too Often Missing,' (2019) where care routes to emotional and psychological support for people with diabetes are not clear or consistent. Healthcare professionals also stated the pathways were in place were disjointed, confusing and did not exist in certain areas (Primary Care Diabetes Society, 2018). Additionally, a key barrier in HCPs identifying MH problems in diabetes patients is a lack of training and knowledge of relationships between healthcare services and what pathways/services were available (Benton et al., 2023). Both diabetes and MH-based HCPs need additional training to further understand available pathways and services for service users, and to strengthen collaboration between care areas to provide effective individualised treatment (Zabell et al., 2022). Additionally, Hadjiconstantinou et al. (2020) found that diabetes HCPs were reluctant to address emotional issues due to lack of training and confidence, with HCPs being worried that this might ‘*open a can of worms*,’ and were reluctant to use the word ‘depression’ in appointments due to a ‘taboo’ stigma behind it. Perhaps addressing these factors through motivational interviewing, listening skills, empathy training or counselling skills might enable diabetes HCPs to feel more confident and trained to address psychological issues, and collaborate more effectively with other care areas and services (e.g., Byrne et al., 2017). Overall, there is a strong need to improve links between care services in the NHS and accessibility to these, and improve patient signposting in order to provide diabetes patients with appropriate psychological support.

### *9.5.5 Recommendation 5: Considering Patient Recommendations for Interventions and Improving Uptake*

One of the main barriers to effective diabetes self-management is health literacy (Farley et al., 2019) as it is associated with increased self-efficacy in management behaviours and improved glycaemic control (Balogun-Katung et al., 2021). Therefore, structured education interventions are an important aspect of diabetes care. Findings from the thesis studies resulted in three main recommendations for existing interventions: 1) to include psychological/MH aspects of living with diabetes; 2) to use more layman-friendly language; 3) to provide more individualised and instructive advice, and 4) including certain areas of knowledge, such as how diabetes can vary hugely across individuals, and blood sugars can be hard to control even when doing the right things. Making these changes, especially regarding the inclusion of MH and resilience education, will help patients to better understand and identify their symptoms, enable more effective coping mechanisms, easing psychological stressors such as anxiety or fatigue and improving mental health. Despite course satisfaction with structured education (e.g., DAFNE, DESMOND) being generally good, reported uptake rates are poor in both T1DM and T2DM populations (Coningsby et al., 2022; Horigan et al., 2017; Whicher, O’Neill & Holt, 2020). Therefore, working on ways to improve uptake rates is also recommended to improve diabetes self-management and health outcomes. Research suggests this could be because of perceived need for the course (e.g., feeling their knowledge is already sufficient, or the course will provide little benefit), or practical barriers such as cost, interfering commitments and travel (Coningsby, Ainsworth & Dack et al., 2022). Therefore, targeting the aforementioned factors and improving content of existing courses is recommended (Coningsby, Ainsworth & Dack et al., 2022).

## 9.6 Concluding Statements

The current research developed a novel model that could be used to provide guidance for intervention design in T1DM and T2DM. Whilst the findings provided some support for the proposed model and relationships between model constructs, there is certainly more to understand about the psychological correlates of diabetes, and perhaps even other factors that might not be included that could strengthen the model (e.g., diabetes healthcare and interventions). The findings from the three studies suggest a significant need for resilience and psychological-based education in T1DM and T2DM patients, and more integration of mental healthcare into their diabetes care, through HCP training and effective patient signposting. The model in study 1 requires longitudinal replication, but provides an empirical foundation in understanding psychological states, resilience and diabetes outcomes. The integration of psychological education and resilience training will provide people with the skills to apply to their own individual stressors associated with their diabetes management.

In conclusion, a more preventative approach is needed for diabetes care in the form of emotional and psychological support. The main barriers to HCPs approaching topics of MH include: time constraints; lack of knowledge/training and confidence; and a lack of care service coordination, which is supported by current research (Benton et al., 2023; Dambha-Miller et al., 2020; Hadjiconstantinou et al., 2020). HCPs acknowledge that daily emotional challenges are more accepted for other long-term conditions within NHS services (e.g., Cancer, Parkinson's), and this needs to be normalised for diabetes (Hadjiconstantinou et al., 2020). There is a strong need to integrate psychological support into primary diabetes care and this is recommended through educational interventions and training, and interventions should be theoretically based. It would be more effective to target a mediator variable such as resilience rather than single factors in intervention studies (e.g., diabetes distress), which is typically the case. People with diabetes want to be understood and have expressed strong needs for emotional support and continuity in their diabetes treatment. These feelings were poignantly exemplified by a respondent in study 2:

> *"There's not enough information, there's not enough follow up, and it feels like the NHS will pick up the pieces when things go wrong further down the line. But until then, they don't care...It feels like the NHS is more about dealing with sickness and not dealing with health."*

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# 12. Appendices

**Appendix 1:** Published Study 1

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**ORIGINAL ARTICLE**

# A structural equation model in adults with type 1 and 2 diabetes: exploring the interplay of psychological states and diabetes outcomes, and the mediating effect of resilience

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**Abstract**

**Aims** Type 1 and 2 diabetes mellitus (T1DM and T2DM) can lead to emotional distress and cognitive impairments, often caused by psychological factors such as low mood or anxiety; yet, few studies have explored the theoretical mechanisms underlying these relationships and within one study. This study explored the relationships between psychological states (anxiety/worry, fatigue) and diabetes outcomes (diabetes distress, cognitive dysfunction), and whether resilience mediated the association between these in T1DM and T2DM.

**Methods** A sample of 307 UK adults with a clinical diagnosis of diabetes (T1DM = 129; T2DM = 178) completed a cross-sectional online survey, composed of six questionnaires. Associations between variables were investigated using Pearson's correlations and Structural Equation Modelling (SEM).

**Results** Psychological states were significantly correlated with diabetes outcomes, and resilience was significantly related to both psychological states and diabetes outcomes. The SEM model achieved an acceptable model fit with a significant mediating effect of resilience between psychological states (anxiety/worry, fatigue) and diabetes outcomes (diabetes distress, cognitive dysfunction), with no significant differences between diabetes type.

**Conclusions** We propose a new theoretical model of T1DM and T2DM that could be used to provide guidance for those designing interventions. These findings help to understand the complex nature of diabetes management, suggesting resilience could be a key factor in managing psychological states and diabetes outcomes.

**Keywords** Structural equation model · Diabetes mellitus · Resilience · Anxiety · Diabetes distress · Cognition

## Background

The two main classifications of diabetes are T1DM and T2DM, and whilst they share clinically similar symptoms, the aetiology of the disorder types differs significantly [1]. Both have a strong genetic component [1], and inadequate long-term self-management is associated with greater risk of serious acute complications (e.g., coma) and chronic (e.g., cardiopathy, sexual dysfunction, retinopathy, nephropathy, limb loss) [2]. Approximately one third of people with T2DM and two thirds of people with T1DM do not achieve the target glycated haemoglobin (HbA1c) levels [2]. The constant demands of living with diabetes can also take a significant psychological toll, with many individuals experiencing distress, depressed mood, anxiety, fatigue and reduced quality of life [3, 4]. The rising burden of diabetes globally is a major health priority, placing increased demands on patients, carers, health systems and society [5]. Identifying

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and understanding the key psychological factors that contribute to diabetes management and outcomes is therefore a key priority.

Existing literature shows both T1 and T2 diabetes suffer from high levels of anxiety and fatigue, with diabetes distress and executive functioning (EF) issues [8, 9]. Diabetes distress and EF issues are positively associated with each other, and with anxiety and fatigue [8–19]. Resilience is an increasingly important factor in diabetes self-management because resilience can be taught through intervention [27, 45]. Resilience is defined as the capacity to adapt and maintain psychological and physical 'wellbeing' in the face of adversity [6] and has been found to correlate negatively with anxiety, fatigue, diabetes distress and cognitive dysfunction [6, 7, 20–28]. These patterns of associations suggest that resilience may act as a mediator [29] but not a moderator; research suggests a causal relationship between anxiety/fatigue and resilience, and resilience and diabetes distress/cognition, therefore, resilience cannot theoretically be a moderator variable [29]. Studies have yet to explore the role of resilience in conjunction with anxiety, fatigue, diabetes distress and executive dysfunction simultaneously, within one model; this is the focus of the present research and is depicted in Fig. 1.

Existing literature suggests direct associations between anxiety (predictor) and diabetes distress and cognition (outcomes), and between fatigue and cognition. There is still little research to suggest a direct link between fatigue and diabetes distress [8]. Park et al. [30] found the relationship between fatigue and diabetes distress was mediated by diabetes symptoms, suggesting the relationship may be an indirect one, and is reflected as such in the proposed model (see Fig. 1).

Winkley et al. [31] suggest future research should focus on underlying theories, rather than replicating existing psychological models that usually deliver small effect sizes. Since theory-based interventions are more likely to produce longer-lasting and larger effects than those without [32], this supports the need to focus more on the underlying theoretical mechanisms, with a focus on the psychosocial effects of living with and managing diabetes [3].

Therefore, the overall aim was to formulate and test an original theoretical model, based on a critical review of existing literatures, that could be used to provide guidance for those designing interventions for T1DM and T2DM groups. More specifically, the study aims were to: 1) to explore whether resilience mediated the association between psychological states and diabetes outcomes, and 2) to assess whether T1DM and T2DM diabetics differ in relation to covariances amongst the afore-mentioned variables.

Based on the above literature, the hypotheses for the proposed structural model are as follows:

Direct relationships will be:

- **$H_1$**: Anxiety/worry will be positively related to diabetes distress [14–16]
- **$H_2$**: Anxiety/worry will be negatively related to cognition [17–19, 22]
- **$H_3$**: Fatigue will be negatively related to cognition [9, 12, 13, 15]

The mediating relationships will be:

- **$H_{4,5,6,7}$**: Anxiety and fatigue will predict diabetes outcomes of distress and cognition, and these relationships will be mediated by resilience [6, 7, 20–28]

## Method

### Design

A correlation design was used to investigate the strength and direction of associations between the following variables in people with T1DM and T2DM: anxiety, fatigue, diabetes distress, cognition and resilience (as a potential mediator).

### Participants

Adults in the Northwest UK with T1DM ($n = 129$) and T2DM ($n = 178$) were recruited via diabetes support groups, local newspaper advertisements and social media advertisements. Participants completed an e-survey, created using the platform Qualtrics. Exclusion criteria included people below the age of 18 years, those with diabetes that is not T1DM/T2DM, and those who failed to state diabetes type.

Both T1DM and T2DM groups were mostly female (77.5 and 79.2%, respectively), with mean ages of 432.41 ($SD = 178.99$) and 663.99 ($SD = 129.65$), and were white British (80.6% and 72.5%, respectively). T1DM durations ranged from 5—960 months (80 years), whereas T2DM ranged from 1 to 444 months (37 years). Average diabetes durations were 235.71 (T1DM), 97.08 (T2DM), and average HbA1c levels were 62.11 mmol/mol (T1DM) and 62.271 mmol/mol (T2DM).

### Sample size requirements for structural equation modelling

Guidance taken from Boateng [34] and Wolf et al. [35] was used to inform sample size; sample sizes of 100–200 are recommended, or at least 5 cases per model parameter. See also [35, 36] for SEM discussion with smaller sample sizes.

## Materials and procedure

Participants were provided a link to an anonymous survey, first directing them to the study participation information sheet. Consent was confirmed through completing and submitting the questionnaires. Any participants who did not submit at the end of the survey were deemed to have withdrawn and their data was not used.

### Anxiety/worry (psychological state latent variable)

Anxiety/worry was assessed using the Penn State Worry Questionnaire (PSWQ) [48], a 16-item single factor scale that is considered the 'gold standard' for measuring unspecific worry. Scores range between 16 and 80, with a higher score indicating higher anxiety. Internal consistency (Cronbach's alpha) for this sample was 0.97 and 0.98 for T1DM and T2DM groups, respectively.

### Fatigue (psychological state latent variable)

Fatigue was measured using Flinder's Fatigue Scale (FFS) [49], a 7-item single factor scale measuring daytime fatigue (e.g., frequency, severity), often associated with insomnia. Six items use a 5-point Likert scale, and item 5 uses a multiple item checklist. Scores range between 0–31, with higher scores indicating greater fatigue. Internal consistency for this sample was 0.92 and 0.90 for T1DM and T2DM groups, respectively.

### Diabetes distress (diabetes outcome latent variable)

Diabetes-specific distress was assessed using the Diabetes Distress Scale (DDS) [50], a 17-item, 4-factor measure consisting of emotional, physician, regimen and interpersonal distress subscales. (Overall and subscale scores were used in correlational analyses, but only subscales were used in the SEM.) Scores range between 17 and 102, where higher scores indicate greater distress. Items relating to their respective factor are averaged, where a mean score of 3 or higher indicates moderate distress, worthy of clinical attention. Internal consistency for this sample was 0.94 and 0.95 for T1DM and T2DM groups, respectively.

### Cognition (diabetes outcome latent variable)

Cognition/EF was assessed using the Dysexecutive Questionnaire (DEX) [51], a 20-item, three-factor measure consisting of volition, inhibition and social regulation subscales. Scores range between 0 and 80, with higher scores indicating greater problems with EF. Internal consistency for this sample was 0.88 for T1DM and T2DM groups.

### Resilience (mediator variable)

Resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC) [52], a 25-item single factor scale, where resilience is defined as the capacity to adapt and maintain psychological and physical wellbeing in the face of stress, adversity or trauma [6]. Scores range between 0–100, where higher scores indicate greater resilience. Internal consistency for this sample was 0.95 for T1DM and T2DM groups.

## Data analytic strategy (SEM)

Structural equation modelling was chosen for analysis as it is a flexible method that can be used to explore relationships between latent variables [34], using AMOS (version 27). Two psychological state latent variables (anxiety and fatigue) were categorised as predictor variables. A third latent variable was resilience (mediator variable). Two diabetes outcome latent variables (diabetes distress and cognition) were categorised as outcome variables. Figure 1 shows the operationalisation of exogenous, endogenous and mediator variables. As recommended in SEM literature [34], an alternative model was also tested, whereby diabetes distress was incorporated as an exogenous variable rather than endogenous, based on existing literature findings [30].

The maximum likelihood chi-square statistic was used to evaluate the measurement and structural models, but as this is sensitive to sample size, the normed chi-square ($\chi^2/df$) was also used alongside several other indices to assess model fit, including: comparative fit index (CFI), Tucker-Lewis index (TLI), incremental fit index (IFI), root mean square error of approximation (RMSEA) and standardised root mean square residual (SRMR). Hu & Bentler [37] suggested acceptable cut-off criteria indicative of good model fit are $> 0.95$ (CFI, TLI, IFI). However, given the exploratory nature of this study, it was decided best to use more conservative criteria, indicative of moderate fit. Therefore, the following cut-offs for acceptable model fit were used: $\chi^2/df$ 1–5; CFI, TLI and IFI $> 0.90$; RMSEA $\leq 0.06$—0.08; and SRMR $\leq 0.08$ [37, 38]. Standardised regression weights were used to interpret direct effects, and bias-corrected bootstrap confidence intervals technique was used to assess the significance of standardised indirect effects.

## Results

### Preliminary analyses

Data were examined for missing values, outliers and normal distribution. Missing value analysis for validated measures

**Table 1** Confirmatory Factor Analysis Fit Indices (Chi Square, CFI, IFI, TLI, RMSEA and SRMR) in T1DM and T2DM Groups

| Scale | $\chi^2/df$ (≥ 1 to 5) | Comparative Fit Index (CFI; ≥ 0.90) | Incremental Fit Index (IFI; ≥ 0.90) | Tucker-Lewis Index (TLI; ≥ 0.90) | Root Mean Square Error of Approx. (RMSEA; ≤ 0.06—0.08) | Stand. Root Mean Square Residual (SRMR; ≤ 0.08) |
|---|---|---|---|---|---|---|
| DDS | 2.33 ($p < 0.001$) | **0.93** | **0.93** | **0.91** | **0.07** | 0.16 |
| PSWQ | 4.06 ($p < 0.001$) | **0.90** | **0.91** | 0.89 | 0.10 | **0.07** |
| FFS | 2.50 ($p < 0.001$) | **0.98** | **0.98** | **0.97** | **0.07** | **0.06** |
| DEX | 1.88 ($p < 0.001$) | **0.94** | **0.94** | **0.92** | **0.05** | **0.07** |
| CD-RISC | 2.15 ($p < 0.001$) | 0.89 | 0.89 | 0.88 | **0.06** | **0.07** |

Key: *Psychological States:* PSWQ (Penn State Worry Questionnaire); FFS (Flinder's Fatigue Scale). *Resilience:* CD−RISC (Connor−Davidson Resilience Scale). *Diabetes Outcomes:* DDS (Diabetes Distress Scale); DEX. (Dysexecutive Questionnaire)

were < 5%, missing variables at random (Little's MCAR test: Chi-Square = 42,895.414, $df = 42{,}606.00$, $p = 0.161$). Missing values were replaced using person mean substitution by scale/subscale. Outlier detection revealed seven univariate outliers that were dealt with using winzorising, and five multivariate outliers were removed. Given the large sample size ($n > 300$), distribution shape/skewness and kurtosis were used to determine normality. Mean and *SD* values were calculated for all variables recorded, separately for T1 and T2 groups, and independent samples t tests, Pearson's correlations and SEM analyses were then run separately for each diabetes group.

### Correlational analyses

Pearson's correlations were conducted to examine **a)** the relationship between psychological states (anxiety, fatigue) and diabetes outcome measures (diabetes distress, cognition), **b)** multicollinearity i.e., high correlations between indicators of psychological state latents and indicators of the outcome measures with each other and **c)** the potential for a mediating relationship of resilience between psychological states and diabetes outcomes. These correlations were undertaken for T1DM ($n = 129$) and T2DM ($n = 178$) diabetes groups separately. Effect sizes (*r* values) were deemed to be small, medium or large if they were, 0.10, 0.30 or 0.50, respectively [39].

T1DM Correlations: All psychological state and diabetes outcome variables were significantly positively correlated, except from the cognition (social regulation only) values. Correlations between components of diabetes distress, anxiety, fatigue and cognition were significant and typically moderate in strength. All psychological state and diabetes outcome variables were significantly negatively associated with resilience values, and typically moderate to strong in strength.

T2DM Correlations: All psychological state and diabetes outcome variables were significantly positively correlated, except from the cognition (social regulation only) values, as in T1DM. Correlations between components of diabetes distress, anxiety, fatigue and cognition were significant and typically moderate in strength. All psychological state and diabetes outcome variables were significantly negatively correlated with resilience values, and typically moderate to strong in strength.

## Measurement models: confirmatory factor analysis (CFA)

### Factor loading, and reliability and validity

Using a factor loading of at least 0.40 [34], 6 items were deleted (see Appendix 3). To assess the reliability and validity of scales used, Composite Reliability (CR) and Average Variance Extracted (AVE) values were calculated, and all scales met acceptable cut-off values for Cronbach's alpha (> 0.70) and CR (> 0.60), demonstrating adequate reliability [40].

### Multigroup CFA: model fit statistics, T1DM and T2DM groups

Pearson's correlations were conducted between the latent variables in both diabetes groups; all correlations between psychological states, resilience and diabetes outcomes were significant, with no evidence of multicollinearity ($r \leq 0.90$).

Fit indices are presented in Table 1; all indicators loaded onto their respective factors (> 0.40), and each scale achieved acceptable values in ≥ 3 fit indices (see Table 1). This suggests the data are suitable for SEM analysis.

### Structural models

A diagrammatic representation of the structural model (for T1DM and T2DM) is presented in Figs. 2 and 3. This shows the standardised path coefficients, significance levels and $R_2$ values, which indicate the amount of variance explained by the independent variables. The values of fit statistics for the structural model were all found to be

**Table 2** SEM results for T1DM and T2DM groups, showing standardised coefficients, *t*-values and significance

| Hypothesised path | Standardised coefficients, β | *t* (C.R.) | *p* | Hypothesis |
|---|---|---|---|---|
| *Direct relationships* | | | | |
| $H_1$ Anxiety/Worry → Diabetes Distress | −0.02 (**0.01**) | −1.59 (**−0.07**) | 0.112 (**0.942**) | Not Supported |
| $H_2$ Anxiety/Worry → Cognition | −0.01 (**0.01**) | −0.90 (**0.98**) | 0.369 (**0.325**) | Not Supported |
| $H_3$ Fatigue → Cognition | 0.02 (**−0.03**) | 0.64 (**−1.00**) | 0.525 (**0.317**) | Not supported |
| *Paths in the indirect/ mediating effect* | | | | |
| $H_4$ Anxiety/worry → Resilience | −0.09 (**−0.08**) | −5.21 (**−6.18**) | < 0.001 (**< 0.001**) | Supported |
| $H_5$ Fatigue → Resilience | −0.31 (**−0.26**) | −4.12 (**−5.85**) | < 0.001 (**< 0.001**) | Supported |
| $H_6$ Resilience → Diabetes Distress | −0.96 (**−0.77**) | −6.26 (**−6.56**) | < 0.001 (**< 0.001**) | Supported |
| $H_7$ Resilience → Cognition | −0.77 (**−0.80**) | −5.21 (**−5.79**) | < 0.001 (**< 0.001**) | Supported |

T1DM: Chi−Square = 139.905, df = 58, $p<.001$, $n$=129; T2DM: Chi−Square = 139.905, df = 58, **$p$**<.001, **$n$**=178 (T2DM values are formatted in bold with brackets)

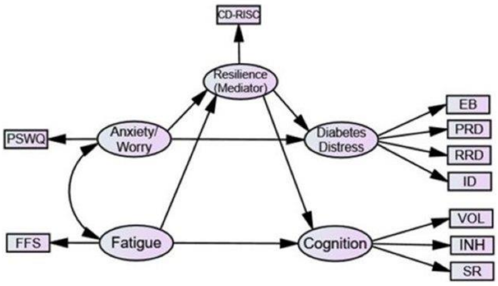


**Fig. 1** Proposed Structural Model: Psychological States (Anxiety/Worry, Fatigue), and Diabetes Outcomes (Diabetes Distress, Cognition), with Resilience as Mediator. *Key:* PSWQ (Penn State Worry Questionnaire); FFS (Flinder's Fatigue Scale); CD−RISC (Connor-Davidson Resilience Scale), DDS (Diabetes Distress Scale, using four subscales: Emotional Burden, Physician Related Distress, Regimen Related Distress, Interpersonal Distress); DEX (Dysexecutive Questionnaire, using three subscales: Volition, Inhibition and Social Regulation). The proposed structural model shows association pathways between predictor variables (anxiety, fatigue) and diabetes outcome variables (diabetes distress, cognition), mediated by resilience. The boxes indicate the measures used to assess their respective variable

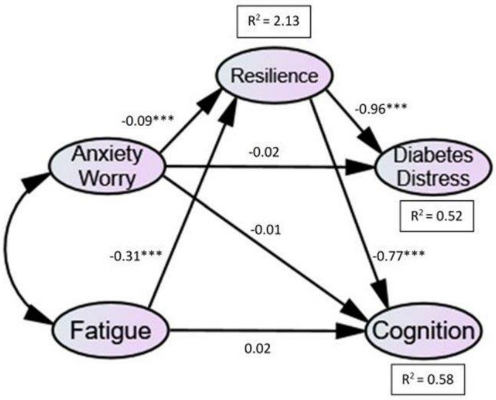


**Fig. 2** Structural Model for T1DM. The structural model shows pathway coefficients between predictor variables, resilience and diabetes outcome variables in the T1DM group. All indirect pathways (i.e. involving the mediator) were significant, and direct pathways were non-significant) *** *p* = < *0.001,* ** *p* = < *0.05*

within acceptable limits: $\chi^2$ (Chi-Square) = 139.905, $df$ = 58, and $\chi^2/df$ ratio = 2.41, CFI = 0.94, IFI = 0.94, TLI = 0.90, RMSEA = 0.07, and SRMR = 0.07.

The results of the initial hypotheses tests for each path in the structural model are summarised in Table 2.

### SEM: T1DM

Findings were similar for both T1DM and T2DM. As shown in Table 2, hypotheses 1, 2 and 3 were non-significant and therefore unsupported. However, hypotheses 4, 5, 6 and 7, which are part of the indirect effect were all supported: anxiety and fatigue had a significant negative influence on resilience, and resilience had a significant negative influence on diabetes distress and cognition.

To identify the presence of mediation, bootstrapping was used to calculate direct and indirect effects in T1DM. Results confirmed a mediating effect of resilience on the relationships between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in T1DM.

### SEM: T2DM

For T2DM, hypotheses 1, 2 and 3 were non-significant and therefore unsupported. However, hypotheses 4, 5, 6 and 7 were all supported: anxiety and fatigue were found to have a significant negative influence on resilience, and resilience

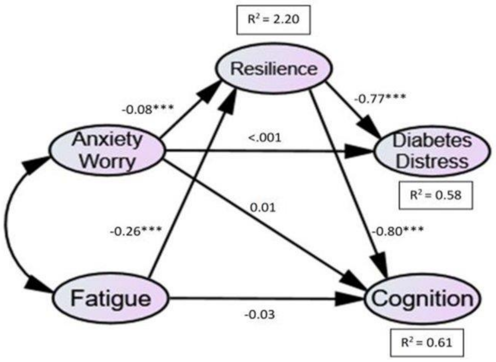


**Fig. 3** Structural Model for T2DM. The structural model shows pathway coefficients between predictor variables, resilience and diabetes outcome variables in the T2DM group. All indirect pathways (i.e. involving the mediator) were significant, and direct pathways were non-significant) *** *p* = *<0.001*, ** *p* = *<0.05*

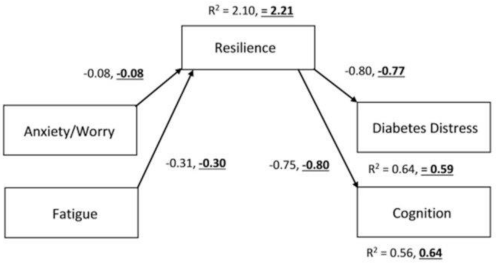


**Fig. 4** Final Structural Model for T1DM and T2DM. This shows the most parsimonious model, with all non-significant paths removed. All indirect pathways (i.e., involving the mediator) were significant at the $p < 0.001$ level. Standardised beta coefficients are provided for each pathway, indicating effect strength and direction of each predictor variable on outcome variable, and $R_2$ values indicate the amount of variance explained by the independent variables (T2DM values are formatted in bold, underlined)

has a significant negative influence on diabetes distress and cognition.

To confirm the presence of mediation, bootstrapping was used to calculate direct and indirect effects in T2DM. Results confirmed a mediating effect of resilience on the relationships between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in T2DM.

## Model comparisons

The above SEM model was used as a baseline comparison, and non-significant pathways were consecutively constrained to zero to confirm whether eliminating non-significant pathways results in a more parsimonious final model [34]. The paths of $H_{1\text{-}3}$ were consecutively constrained in models 1, 2 and 3, after which a full mediation model was tested in model 4; all direct paths from psychological states to diabetes outcomes were constrained to zero, leaving only indirect paths (see Appendix 6 for comparison table).

Model 4 is the most parsimonious solution; the non-significant pathways have been eliminated without negatively impacting the model fit statistics, and therefore, model 4 was used as the final structural model (see Fig. 4). Multigroup analysis of Model 4 revealed no significant differences between T1DM and T2DM groups ($\chi^2 = 8.68$, $p = 0.730$), suggesting the model is appropriate to both groups.

In summary, structural equation modelling identified a significant mediational effect of resilience on psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition), in both T1DM and T2DM.

## Alternative model testing

An alternative model was tested, whereby diabetes distress was incorporated as an exogenous variable rather than endogenous. This model was rejected due to poor fit.

Fit indices yielded a poorer model fit compared to the initial model: $\chi^2$ (Chi-Square) = 172.606, $df = 60$, and $\chi^2/df$ ratio = 2.877. Comparative Fit Index (CFI) = 0.913, Incremental Fit Index (IFI) = 0.915, Tucker-Lewis Index (TLI) = 0.87, Root Mean Square Error of Approximation (RMSEA) = 0.08, and Standardised Root Mean Square Residual (SRMR) = 0.091.

For the T1DM group, hypotheses 1, 2, 3, 4, 5 and 7 were non-significant and therefore unsupported. Hypothesis 6, which is part of the indirect effect was supported ($\beta = -0.414$, $t = -1.96$, $p = 0.050$), suggesting fatigue had a significant negative effect on resilience. Mediation analysis revealed no significant effects.

For the T2DM group, hypotheses 1, 2, 3, 4 and 7 were non-significant and therefore unsupported. Hypotheses 5 and 6, which are part of the indirect effect were supported ($\beta = -0.059$, $t = -2.54$, $p = 0.011$; $\beta = -0.218$, $t = -3.09$, $p = 0.002$, respectively), suggesting a significant effect of anxiety and fatigue on resilience. Mediation analysis revealed significant indirect effects of anxiety (-0.156, $p = 0.001$) and fatigue (-0.578, $p = 0.001$), suggesting resilience mediated the relationship between both anxiety and fatigue, and cognition.

Multigroup analysis revealed no significant differences between T1DM and T2DM groups ($\chi^2 = 2.33$, $p = 0.507$), suggesting the model is appropriate to both groups.

## Discussion

This study was the first to test a theoretical model whereby psychological states (anxiety/worry, fatigue) and diabetes outcomes (diabetes distress, cognition) are mediated by resilience, in both T1DM and T2DM groups. Preliminary correlations between predictor and outcome variables were as expected, based on past evidence [8, 12], in both T1DM and T2DM. All psychological state and diabetes outcome variables were significantly negatively associated with resilience, laying the groundwork for SEM. The proposed structural model achieved an acceptable model fit with no significant differences between diabetes type, suggesting the model was appropriate for both T1DM and T2DM groups.

For both T1DM and T2DM groups, direct relationships within the model were not significant and therefore not supported. However, indirect paths demonstrating the mediating effect were all significant. Bootstrapping confirmed a significant mediating effect of resilience between psychological states (anxiety, fatigue) and diabetes outcomes (diabetes distress, cognition) in both T1DM and T2DM. Additionally, the model supports an indirect relationship between diabetes distress and fatigue, which is similar to the findings of Park et al. [30], although this study looked at resilience as a mediator variable rather than diabetes symptoms. Interestingly, Lasselin et al., [41] also found data supporting higher rates of fatigue in T2DM compared to T1DM, however the SEM revealed no significant multigroup differences in fatigue.

Mediation research is necessary for advancement of psychological theory and clinical therapies [44]. These findings confirm a novel theoretical model that has the potential to optimise intervention treatments and subsequently improve diabetes self-management (i.e., improving disease prognosis and health outcomes). Resilience has also been found to play a protective role in the psychological states of other diseases, for example, protecting against: depression in adults managing cardiac disease [45]; psychological distress in cancer patients [46]; and diabetes-specific distress in diabetes patients [7]; where each study found improved health outcomes with greater resilience. Despite this, the mechanisms by which resilience acts as a protective factor are not well known [7, 45], which this study aimed to address. The mediating effect of resilience (in the context of anxiety/fatigue) can be utilised in early education interventions (e.g., conversion maps) to improve knowledge and management of diabetes outcomes [47], which can prevent serious diabetes complications (e.g., limb loss) [4]. Resilience training would provide a protective measure against negative psychological states/disorders and help improve health outcomes; this would be widely applicable to other areas of life and managing other chronic diseases.

This study has several strengths. Structural Equation Modelling allows for investigation of complex relationships simultaneously and is able to measure unobserved variables using observed variables (accounting for error measurement, rather than treating them separately) [34]. Another benefit is that SEM performs well with a range of sample sizes, including ones smaller than that of this study [e.g., 35, 36]. Yet, it is important for future studies to confirm this model using a larger diverse sample. Although this study is cross-sectional rather than longitudinal, SEM allows one to test theoretically plausible ideas about the order of variables, and thus, this study identified anxiety and fatigue as psychological risk factors that can be mediated by resilience.

This study has several areas for further investigation. Comparisons of individual difference variables such as males and females and ethnicity were not investigated, which is important for this theoretical model because findings have suggested gender and racial differences in diabetes management [42]. For example, males report more problem-focused coping methods whereas females report more negative and emotion-focused coping styles. It is important also to note total samples for T1DM and T2DM groups were mostly female (77.5% and 79.2%, respectively), which is not representative in the current diabetes literature [43]. This could suggest that females are more likely to reach out to others regarding their diabetes, which has significant implications in both healthcare and research settings. It is important to confirm these results in a more representative population regarding gender split, to ensure reliability of findings.

## Conclusions

This study showed resilience mediates the relationship between anxious and fatigued psychological states and diabetes distress and cognition in adults with T1DM and T2DM. It is recommended those devising interventions for people with T1DM and T2DM target resilience as a potential psychological mechanism; specifically, to offset problems with diabetes distress and cognition, as a consequence of anxiety/worry and fatigue. This could help improve health outcomes and quality of life in people with this lifelong condition, which in turn can positively impact mental health and wellbeing.

**Appendix 2:** Participant Information Sheet and Debrief (Study 1)

## Thinking abilities, resilience, and blood glucose management in adults with type 1 & type 2 diabetes

### Information Sheet

The overall aim of this study is to see how mood states (such as anxiety, stress and fatigue) can affect wellbeing and how people manage their diabetes. Research suggests diabetes can impair certain thinking processes that are necessary in planning, reasoning and problem solving, and certain mood states can have negative effects on diabetes management. We are also investigating resilience, which is the capacity to cope with adversity and sources of stress, and managing diabetes can sometimes be stressful and challenging. We are very interested to see how people's resilience can influence their management of diabetes, and we want to see if resilience is related to mood states and thinking processes. The following questionnaires address several factors thought to influence diabetes management, and this study will help us to understand more about how mood, resilience and diabetes can influence self-management and wellbeing.

All participation is completely voluntary and you have the right to withdraw at any time without giving a reason. However, once participation has been completed it will not be possible to withdraw your data from the study as it is anonymous and so cannot be linked back to you. To withdraw, close the browser tab and delete the web-page from the browser history.

These questionnaires should take approximately 20 minutes to complete, however you can save your responses, close the questionnaire, and come back to it should you wish. All data gathered from this study will be kept strictly confidential and only the research team will be able to access it. If you have any questions before starting the questionnaire, please contact me using the details below. By clicking the 'next button' button below, you are providing consent to taking part in the study.

Email: RSPate@uclan.ac.uk
Tel: 07458933522

### Debrief

**Thank you for taking part in this study!**

The overall aim of this study was to see how thinking processes, such as memory and attention, can be affected by diabetes (both type 1 and type 2). These processes are important as they help us to plan, reason and solve problems. They are essential to our everyday abilities and help us perform our routine activities. Research suggests that diabetes can impair some thinking process, which can influence how we control some behaviours, and blood sugar levels can have a big impact on how people think and feel. We also wanted to see how people's resilience affects their management of diabetes, and see if resilience is related to thinking abilities. Research suggests higher resilience may lead to better management of diabetes, which could help protect against the effects that diabetes can have on our thinking processes. We do not know exactly how diabetes can impair some thinking processes, but it is thought that having consistently high blood sugar levels could affect the brain and these thinking abilities.

This is an important study to carry out, because there is very little research looking at these abilities, resilience and blood glucose management in both type 1 and type 2 diabetes. Existing research typically focuses on type 2 diabetes in people over 60 years of age. As a result, we do not know very much about how diabetes can affect thinking abilities, resilience and diabetes management. This study will help us to understand how diabetes impacts on thinking abilities across the lifespan and what influence resilience can have on thinking abilities and diabetes management.

All data will be treated as strictly confidential, and your data will be made anonymous. Therefore, once you have submitted the questionnaires, the data is no longer directly linked to you and as such your data cannot be removed from the study. If you decide to withdraw your data, you will not be penalised or disadvantaged in any way. If you would like to be sent a summary of the study findings, please ensure you have provided contact details so we can contact you.

If you have any further questions about the study, please contact us via the contact details below. None of the questionnaires used in this study are diagnostic and if you have any concerns about your health or mood, you should consult your local GP. You could also contact Diabetes UK if you have any concerns or questions, or if you would like to get in touch with your local diabetes support groups.

**Please click the 'next button' below if you wish to submit your responses.**

Diabetes UK website:
www.diabetes.org.uk

Diabetes UK Helpline:
0345 123 2399, Monday to Friday, 9am–6pm
Email: helpline@diabetes.org.uk

If you are unhappy or have concerns with any of the research, but do not wish to contact the research team, you can contact the University Officer for Ethics:
officerforrthics@uclan.ac.uk

**Appendix 3:** Penn State Worry Questionnaire (Study 1)

Rate each of the following statements on a scale of 1 (“not very typical of me at all”) to 5 (“very typical of me”) as to how you currently feel. Please do not leave any items blank.

| | Not at all typical of me | | | | Very typical of me |
|---|---|---|---|---|---|
| 1. If I do not have enough time to do everything, I worry about it. | 1 | 2 | 3 | 4 | 5 |
| 2. My worries overwhelm me. | 1 | 2 | 3 | 4 | 5 |
| 3. I tend to worry about things. | 1 | 2 | 3 | 4 | 5 |
| 4. Many situations make me worry. | 1 | 2 | 3 | 4 | 5 |
| 5. I know I should not worry about things, but I just cannot help it. | 1 | 2 | 3 | 4 | 5 |
| 6. When I am under pressure I worry a lot. | 1 | 2 | 3 | 4 | 5 |
| 7. I am always worrying about something. | 1 | 2 | 3 | 4 | 5 |
| 8. I find it easy to dismiss worrisome thoughts. | 1 | 2 | 3 | 4 | 5 |
| 9. As soon as I finish one task, I start to worry about everything else I have to do. | 1 | 2 | 3 | 4 | 5 |
| 10. I worry about everything. | 1 | 2 | 3 | 4 | 5 |
| 11. When there is nothing more I can do about a concern, I still worry about it. | 1 | 2 | 3 | 4 | 5 |
| 12. I have been a worrier all my life. | 1 | 2 | 3 | 4 | 5 |
| 13. I notice that I have been worrying about things. | 1 | 2 | 3 | 4 | 5 |
| 14. Once I start worrying, I cannot stop. | 1 | 2 | 3 | 4 | 5 |
| 15. I worry all the time. | 1 | 2 | 3 | 4 | 5 |
| 16. I worry about projects until they are done. | 1 | 2 | 3 | 4 | 5 |

**Appendix 4:** Flinder’s Fatigue Scale (Study 1)

We are interested in the extent that you have felt fatigued (tired, weary, exhausted) over the last two weeks. We do not mean feelings of sleepiness (the likelihood of falling asleep). Please tick the appropriate response in accordance with your average feelings over this two-week period.

**1. Was fatigue a problem for you?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Not at all | | Moderately | | Extremely |

**2. Did fatigue cause problems with your everyday functioning (e.g., work, social, family)?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Not at all | | Moderately | | Extremely |

**3. Did fatigue cause you distress?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Not at all | | Moderately | | Extremely |

**4. How often did you suffer from fatigue?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| 0 days/ week | 1-2 days/ week | 3-4 days/ week | 5-6 days/ week | 7 days/ week |

**5. At what time(s) of the day did you typically experience fatigue?** (Please tick box(es))

Early morning ☐

Mid-morning ☐

Midday ☐

Mid-afternoon ☐

Late afternoon ☐

Early evening ☐

Late evening ☐

**6. How severe was the fatigue you experienced?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Not at all | | Moderate | | Extreme |

**7. How much was your fatigue caused by poor sleep?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Not at all | | Moderately | | Entirely |

**8. Do you feel your fatigue/poor sleep is specifically related to your Diabetes?**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Not at all | | Moderately | | Entirely |

**Appendix 5:** Diabetes Distress Scale (Study 1)

Directions:

Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 17 items may have distressed or bothered you **during the past month.**

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, **not** whether the item is merely true for you. If you feel a particular item is not a bother or a problem for you, you would select 'not a problem.' If it is very bothersome to you, you might select 'a very serious problem.'

| | Not a Problem (1) | Slight Problem (2) | Moderate Problem (3) | Somewhat serious Problem (4) | Serious Problem (5) | Very Serious Problem (6) |
|---|---|---|---|---|---|---|
| 1. Feeling that diabetes is taking up too much of my mental and physical energy every day. | | | | | | |
| 2. Feeling that my doctor doesn't know enough about diabetes and diabetes care. | | | | | | |
| 3. Not feeling confident in my day-to-day ability to manage diabetes. | | | | | | |
| 4. Feeling angry, scared and/or depressed when I think about living with diabetes. | | | | | | |
| 5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes. | | | | | | |
| 6. Feeling that I am not testing my blood sugars frequently enough. | | | | | | |
| 7. Feeling that I will end up with serious long-term complications, no matter what I do. | | | | | | |
| 8. Feeling that I am often failing with my diabetes routine. | | | | | | |
| 9. Feeling that friends or family are not supportive enough of self-care efforts (e.g. planning activities that conflict with my | | | | | | |

| | | | | | | |
|---|---|---|---|---|---|---|
| schedule, encouraging me to eat the "wrong" foods). | | | | | | |
| 10. Feeling that diabetes controls my life. | | | | | | |
| 11. Feeling that my doctor doesn't take my concerns seriously enough. | | | | | | |
| 12. Feeling that I am not sticking closely enough to a good meal plan. | | | | | | |
| 13. Feeling that friends or family don't appreciate how difficult living with. | | | | | | |
| 14. Feeling overwhelmed by the demands of living with diabetes. | | | | | | |
| 15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes. | | | | | | |
| 16. Not feeling motivated to keep up my diabetes self-management. | | | | | | |
| 17. Feeling that friends or family don't give me the emotional support that I would like. | | | | | | |

**Appendix 6:** Dysexecutive Scale (Study 1)

This questionnaire looks at some of the difficulties that people sometimes experience. We would like you to read the following statements, and rate them on a five-point scale according to your own experience.

1. I have problems understanding what other people mean unless they keep things simple and straightforward.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

2. I act without thinking, doing the first thing that comes to mind.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

3. I sometimes talk about events or details that never actually happened, but I believe did happen.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

4. I have difficulty thinking ahead or planning for the future.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

5. I sometimes get over-excited about things and can be a bit ‘over the top’ at these times.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

6. I get events mixed up with each other, and get confused about the correct order of events.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

7. I have difficulty realising the extent of my problems and am unrealistic about the future.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

8. I am lethargic, or unenthusiastic about things.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

9. I do or say embarrassing things when in the company of others.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

10. I really want to do something one minute, but couldn’t care less about it the next.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Never | Occasionally | Sometimes | Fairly often | Very often |

11. I have difficulty showing emotion.

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |

Never Occasionally Sometimes Fairly often Very often

12. I lose my temper at the slightest thing.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

13. I am unconcerned about how I should behave in certain situations.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

14. I find it hard to stop repeating saying or doing things once I’ve started.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

15. I tend to be very restless, and ‘can’t sit still’ for any length of time.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

16. I find it difficult to stop myself from doing something even if I know I shouldn’t.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

17. I will say one thing, but will do something different.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

18. I find it difficult to keep my mind on something, and am easily distracted.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

19. I have trouble making decisions, or deciding what I want to do.

☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

20. I am unaware of, or unconcerned about, how others feel about my behaviour.

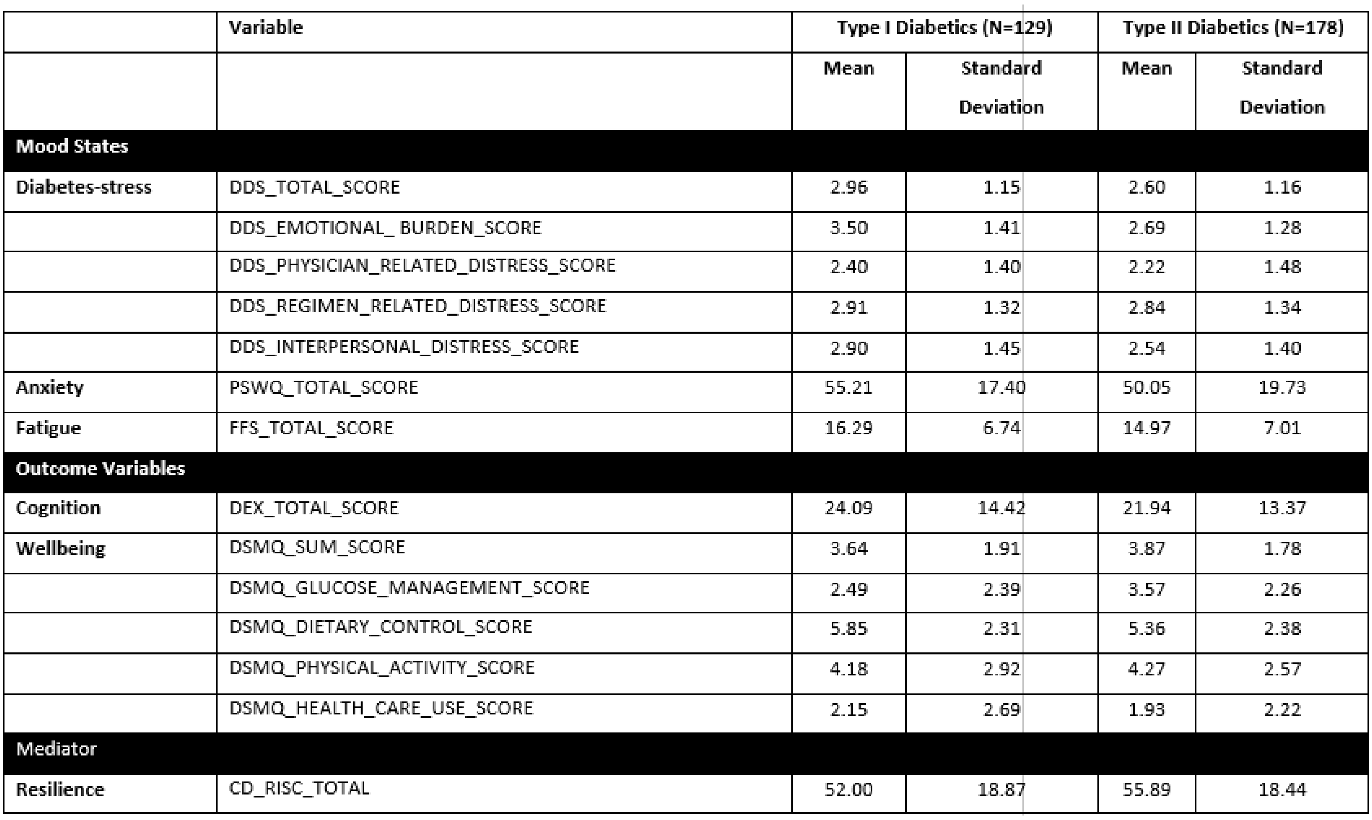
☐ Never ☐ Occasionally ☐ Sometimes ☐ Fairly often ☐ Very often

**Appendix 7:** Connor-Davidson Resilience Scale (Study 1)

Please indicate the extent to which each question applies to you over the past month.

| | Not true at all | Rarely true | Sometimes true | Often true | True nearly all of the time |
|---|---|---|---|---|---|
| 1. I am able to adapt to change | | | | | |
| 2. I feel I have close and secure relationships | | | | | |
| 3. Sometimes fate or God can help | | | | | |
| 4. I can deal with whatever comes my way | | | | | |
| 5. Past success gives me confidence for new challenges | | | | | |
| 6. I try to see the humorous side of problems | | | | | |
| 7. Coping with stress can strengthen me | | | | | |
| 8. I tend to bounce back after illness or hardship | | | | | |
| 9. I believe things happen for a reason | | | | | |
| 10. I give my best effort no matter what | | | | | |
| 11. I can achieve my goals despite obstacles | | | | | |
| 12. When things look hopeless, I don't give up | | | | | |
| 13. I know where to turn to for help | | | | | |
| 14. I can stay focused and think clearly under pressure | | | | | |
| 15. I prefer to take the lead in problem solving | | | | | |
| 16. I am not easily discouraged by failure | | | | | |
| 17. I think of myself as a strong person | | | | | |
| 18. I make unpopular or difficult decisions | | | | | |
| 19. I can handle unpleasant feelings | | | | | |
| 20. I act on a hunch | | | | | |
| 21. I have a strong sense of purpose | | | | | |
| 22. I feel I am in control of my life | | | | | |
| 23. I like challenges | | | | | |
| 24. I work to attain my goals | | | | | |
| 25. I take pride in my achievements | | | | | |

**Appendix 8:** Table of Variable Means and SD for unobserved (latent) and observed (measured) variables in T1DM and T2DM groups.



| | **Variable** | **Type I Diabetics (N=129)** | | **Type II Diabetics (N=178)** | |
|---|---|---|---|---|---|
| | | **Mean** | **Standard Deviation** | **Mean** | **Standard Deviation** |
| **Mood States** | | | | | |
| **Diabetes-stress** | DDS_TOTAL_SCORE | 2.96 | 1.15 | 2.60 | 1.16 |
| | DDS_EMOTIONAL_ BURDEN_SCORE | 3.50 | 1.41 | 2.69 | 1.28 |
| | DDS_PHYSICIAN_RELATED_DISTRESS_SCORE | 2.40 | 1.40 | 2.22 | 1.48 |
| | DDS_REGIMEN_RELATED_DISTRESS_SCORE | 2.91 | 1.32 | 2.84 | 1.34 |
| | DDS_INTERPERSONAL_DISTRESS_SCORE | 2.90 | 1.45 | 2.54 | 1.40 |
| **Anxiety** | PSWQ_TOTAL_SCORE | 55.21 | 17.40 | 50.05 | 19.73 |
| **Fatigue** | FFS_TOTAL_SCORE | 16.29 | 6.74 | 14.97 | 7.01 |
| **Outcome Variables** | | | | | |
| **Cognition** | DEX_TOTAL_SCORE | 24.09 | 14.42 | 21.94 | 13.37 |
| **Wellbeing** | DSMQ_SUM_SCORE | 3.64 | 1.91 | 3.87 | 1.78 |
| | DSMQ_GLUCOSE_MANAGEMENT_SCORE | 2.49 | 2.39 | 3.57 | 2.26 |
| | DSMQ_DIETARY_CONTROL_SCORE | 5.85 | 2.31 | 5.36 | 2.38 |
| | DSMQ_PHYSICAL_ACTIVITY_SCORE | 4.18 | 2.92 | 4.27 | 2.57 |
| | DSMQ_HEALTH_CARE_USE_SCORE | 2.15 | 2.69 | 1.93 | 2.22 |
| Mediator | | | | | |
| **Resilience** | CD_RISC_TOTAL | 52.00 | 18.87 | 55.89 | 18.44 |

**Appendix 9**: Full CFA Results for Measurement Model 1, Type I and II Diabetes Groups (TI= black, **TII= blue, bold)**

| **Conceptual Variable** *(and subscales)* | **Item** | **Factor Loading** | **t value (C.R.)** | **R$^2$ value** | **CR (Composite Reliability)** | **AVE (Average Variance Extracted)** | **Cronbach's alpha (α)** |
|---|---|---|---|---|---|---|---|
| **DDS** | Q1 | .79** **.80**** | Fixed **Fixed** | .621 **.637** | 0.968 **0.977** | 0.644 **0.716** | .935 **.951** |
| Emotional Burden (EB) | Q14 | .93** **.89**** | 12.436 **13.839** | .873 **.792** | | | |
| | Q8 | .87** **.85**** | 11.331 **13.011** | .760 **.725** | | | |
| | Q3 | .87** **.85**** | 11.308 **13.028** | .758 **.726** | | | |
| | Q11 | .70** **.74**** | 8.578 **10.868** | .495 **.554** | | | |
| Physician Related Distress (PRD) | Q4 | .81** **.91**** | Fixed **Fixed** | .653 **.823** | | | |
| | Q2 | .76** **.87**** | 9.114 **17.405** | .576 **.764** | | | |
| | Q9 | .84** **.88**** | 10.319 **17.555** | .714 **.770** | | | |
| | Q15 | .77** **.91**** | 9.269 **18.951** | .592 **.821** | | | |
| Regimen Related Distress (RRD) | Q6 | .86** **.91**** | Fixed **Fixed** | .731 **.828** | | | |
| | Q12 | .68** **.85**** | 8.432 **16.568** | .456 **.731** | | | |
| | Q16 | .86** **.78**** | 11.888 **13.902** | .739 **.615** | | | |
| | Q5 | .66** **.60**** | 8.157 **9.001** | .434 **.355** | | | |
| | Q10 | .69** **.90**** | 8.699 **18.841** | .477 **.817** | | | |
| Interpersonal Distress (IP) | Q17 | .87** **.88**** | Fixed **Fixed** | .754 **.768** | | | |
| | Q7 | .77** **.87**** | 10.197 **14.972** | .600 **.749** | | | |
| | Q13 | .85** **.84**** | 11.595 **14.348** | .724 **.711** | | | |
| PSWQ (Q8 removed) | Q5 | .898** **.911**** | Fixed **Fixed** | .807 **.831** | 0.971 **0.980** | 0.699 **0.769** | .971 **.980** |
| | Q7 | .869** **.929**** | 14.875 **21.816** | .756 **.862** | | | |
| | Q4 | .893** **.909**** | 15.860 **20.461** | .797 **.827** | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Q15 | .897** **.909**** | 16.073 **20.459** | .805 **.827** | | | |
| | Q14 | .882** **.911**** | 15.400 **20.589** | .778 **.830** | | | |
| | Q3 | .849** **.906**** | 14.077 **20.246** | .720 **.821** | | | |
| | Q13 | .877** **.897**** | 15.162 **19.691** | .768 **.805** | | | |
| | Q10 | .859** **.891**** | 14.457 **19.320** | .737 **.793** | | | |
| | Q11 | .835** **.896**** | 13.590 **19.659** | .697 **.804** | | | |
| | Q2 | .846** **.883**** | 13.976 **18.879** | .715 **.780** | | | |
| | Q6 | .829** **.873**** | 13.398 **18.337** | .688 **.762** | | | |
| | Q16 | .771** **.856**** | 11.630 **17.465** | .594 **.733** | | | |
| | Q9 | .765** **.789**** | 11.459 **14.628** | .585 **.622** | | | |
| | Q12 | .727** **.802**** | 10.509 **15.133** | .529 **.644** | | | |
| | Q1 | .715** **.772**** | 10.205 **14.020** | .511 **.596** | | | |
| FFS | Q1 | .902** **.908**** | Fixed **Fixed** | .814 **.825** | 0.925 **0.909** | 0.673 **0.632** | .916 **.899** |
| (Q7 removed) | Q2 | .883** **.911**** | 14.786 **18.916** | .779 **.829** | | | |
| | Q6 | .792** **.838**** | 11.877 **15.742** | .628 **.702** | | | |
| | Q4 | .828** **.764**** | 12.925 **13.188** | .685 **.584** | | | |
| | Q3 | .836** **.762**** | 13.175 **13.103** | .699 **.580** | | | |
| | Q5 | .659** **.521**** | 8.773 **7.527** | .434 **.271** | | | |
| **DEX** (3 factors) | Q8 | .706** **.722**** | Fixed **Fixed** | .498 **.521** | 0.915 **0.919** | 0.477 **0.489** | .881 **.882** |
| **DEX: Volition** | Q19 | .756** **.746**** | 7.641 **9.285** | .571 **.557** | | | |
| | Q10 | .627** **.778**** | 6.437 **9.669** | .393 **.606** | | | |
| | Q4 | .704** **.713**** | 7.174 **8.888** | .496 **.509** | | | |
| | Q18 | .748** **.776**** | 7.578 **9.646** | .560 **.603** | | | |
| **DEX: Inhibition** | Q9 | .666** **.687**** | Fixed **Fixed** | .444 **.471** | | | |
| | Q2 | .691** **.544**** | 6.654 **6.477** | .477 **.296** | | | |
| | Q17 | .707** **.813**** | 6.779 **9.146** | .499 **.661** | | | |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| | Q16 | .735** .632** | 6.997 7.431 | .541 .400 | | | |
| | Q15 | .610** .615** | 5.989 7.247 | .372 .378 | | | |
| **DEX: Social Regulation** | Q20 | .763** .682** | Fixed Fixed | .582 .465 | | | |
| | Q13 | .535** .639** | 3.892 5.112 | .286 .408 | | | |
| **CD-RISC:** | Q5 | .808** .756** | **Fixed** Fixed | .652 .572 | 0.955 0.950 | 0.504 0.477 | .954 .949 |
| Q9,18,20,3 removed | Q17 | .805** .744** | 10.644 10.380 | .648 .554 | | | |
| | Q4 | .788** .761** | 10.329 10.659 | .621 .580 | | | |
| | Q11 | .809** .734** | 10.723 10.214 | .654 .538 | | | |
| | Q23 | .704** .787** | 8.877 11.076 | .495 .619 | | | |
| | Q22 | .821** .696** | 10.957 9.619 | .674 .485 | | | |
| | Q7 | .770** .723** | 10.009 10.049 | .593 .523 | | | |
| | Q21 | .756** .719** | 9.770 9.985 | .572 .518 | | | |
| | Q24 | .730** .741** | 9.310 10.322 | .533 .548 | | | |
| | Q14 | .710** .737** | 8.977 10.266 | .504 .543 | | | |
| | Q8 | .710** .699** | 8.973 9.668 | .503 .489 | | | |
| | Q12 | .666** .728** | 8.274 10.122 | .443 .530 | | | |
| | Q25 | .682** .706** | 8.528 9.772 | .465 .498 | | | |
| | Q16 | .711** .641** | 8.995 8.763 | .505 .410 | | | |
| | Q19 | .751** .613** | 9.679 8.353 | .564 .376 | | | |
| | Q15 | .707** .634** | 8.927 8.669 | .499 .402 | | | |
| | Q6 | .613** .636** | 7.472 8.694 | .376 .405 | | | |
| | Q1 | .654** .607** | 8.086 8.256 | .427 .368 | | | |
| | Q13 | .549** .628** | 6.553 8.574 | .301 .395 | | | |
| | Q10 | .530** .613** | 6.295 8.350 | .281 .376 | | | |
| | Q2 | .527** .551** | 6.251 7.429 | .277 .303 | | | |

**p<.001, TI n=129, TII n=178.

**Appendix 10**: Participant Information Sheet and Debrief (Study 2)

# Information sheet for participants

## Study Title: Exploring the Relationships between Mood States, Diabetes Outcomes and Resilience in Type I and II Diabetes

### 1. Document Version Number and Date

V2.2, 24.09.2021

### 2. Invitation to participate

*We would like to invite you to take part in our research study; before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.*

### 3. What is the purpose of the study?

There are many things that can affect diabetes self-care, such as psychological states (e.g. anxiety, fatigue, resilience) and diabetes outcomes (e.g. diabetes distress, thinking processes). However, there is a lack of research that examined these together in order to understand the underlying relationships. We looked at these in our previous study, and wish to further examine these relationships. Having a good understanding of these are important for developing effective treatments and interventions, so we would like to hear about your experiences of living with diabetes.

### 4. Why have I been invited to take part?

We are looking to invite adults from the UK with a diagnosis of diabetes (type I or II) to take part in the study. The only requirements for participation are that you are over 18 (to provide informed consent), and fluent in English (due to the nature of the study).

### 5. Do I have to take part?

Participation is completely voluntary, and you can contact the researcher if you have any questions before deciding. Participants are free to withdraw from the study at any point, until one week after the completion of the study – this is because data analysis will begin, and it will not be possible to withdraw your data. You do not have to provide any reason for withdrawing from the study, and you will not be penalised in any way for doing so.

6. **What will happen if I take part?**

   The research will involve an online one-to-one interview with the researcher [Rosalind] that will last approximately 45 minutes. You will be asked a few short demographic questions to start (e.g. diabetes type, how long you have had diabetes for), and then several other questions about your diabetes, psychological mood states and diabetes outcomes. The interview will be conducted via videocall online, and only the audio will be recorded using an encrypted Dictaphone.

   (We will be using 'Microsoft Teams' to conduct the video call, if you are unsure of how to set up your devices for video calling, please let me know [RSPate@uclan.ac.uk], and I can help guide you through this).

7. **How will my data be used?**

   The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

   Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The University privacy notice for research participants can be found on the attached link:

   https://www.uclan.ac.uk/data_protection/privacy-notice-research-participants.php

Further information on how your data will be used can be found in the table below.

| | |
|---|---|
| How will my data be collected? | *Audio recordings of the interviews will be collected using an encrypted Dictaphone, provided by the University.* |
| How will my data be stored? | *The audio files (and resulting anonymised transcripts of these) will be stored on a password protected computer, that only the researcher will be able to access. Each transcript will be assigned by pseudonym and will not be linked to any personal data/ consent forms.* |
| How long will my data be stored for? | *Participant data and consent forms will be kept for a period of 5 years and then destroyed.* |
| What measures are in place to protect the security and confidentiality of my data? | *The audio data will be collected using an encrypted Dictaphone, and data will be stored on a password protected computer; both these devices are only accessible by the researcher.* |

| | |
|---|---|
| Will my data be anonymised? | *Yes - All data files will be assigned a pseudonym and will not be linked to any personal data/consent forms. Any identifying information such as names/ places mentioned in the interview will be changed to preserve anonymity. Only the researcher will have access to the original dataset.* |
| How will my data be used? | *Recordings will be transcribed and anonymised, and then recordings will be deleted. The anonymised transcripts will be kept for 5 years. It is intended that the data collected will be analysed, and overall findings be presented in scientific journals, and possibly presented at research conferences.* |
| Who will have access to my data? | *Only the researcher will have access to the data files. No information will be shared with any third-party organisations.* |
| Will my data be archived for use in other research projects in the future? | *All data will be stored securely for 5 years – and will only be used as part of this research project.* |
| How will my data be destroyed? | *After 5 years, all original data files collected will be destroyed/wiped from the password protected devices.* |

8. **Are there any risks in taking part?**

As this research is asking about your experiences with diabetes and psychological feelings such as anxiety, it may bring up sensitive topics that might be difficult to talk about. If you experience any discomfort during the interview (mental, emotional, or physical), please let the researcher know – you can take breaks at any point and as often as needed. In the case of any health-related or psychological concerns, we encourage you to contact your local GP/specialist care provider, or the other support groups listed at the end of this information sheet.

9. **Are there any benefits from taking part?**

Although there are no immediate benefits from taking part in this research, the findings from this study may provide further understanding into the relationships between psychological states/feelings and diabetes self-care. This could potentially help to improve intervention programs, and as a result, the quality of life in individuals living with diabetes.

10. **What will happen to the results of the study?**

It is intended that the results of this study will be published in scientific or medical journals, and you will not be identified/identifiable in any report or publication. When all participant data has been analysed and written up, a summary report will be made available should you wish to see it; if so, please email the researcher and you will be sent a copy once available [RSPate@uclan.ac.uk].

## 11. What will happen if I want to stop taking part?

Participation in this research is voluntary, and you can withdraw at any time without giving a reason by contacting the researcher [Rosalind; RSPate@uclan.ac.uk]. If you wish to withdraw, please note that data already collected can only be withdrawn up to one week after the interview. After this point, your data will be anonymised, and data analysis will begin; after this point it will not be possible to withdraw the data.

## 12. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting either the researcher [Rosalind, RSPate@uclan.ac.uk] or the director of studies [Dr Noreen Caswell, NCaswell1@uclan.ac.uk], and we will try to help. If you remain unhappy, or have a complaint which you feel you cannot come to us with, then please contact the Ethics, Integrity and Governance Unit at: *OfficerForEthics@uclan.ac.uk*.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

## 13. Who can I contact if I have further questions?

**Contact details of investigatory team:**

**Director of Studies:**
Dr. Noreen Caswell, NCaswell1@uclan.ac.uk,

School of Psychology and Computer Science,

University of Central Lancashire,
Preston, PR1 2HE.

**Researcher [PhD student]:**

Rosalind Pate, RSPate@uclan.ac.uk,

School of Psychology and Computer Science,

University of Central Lancashire,

Preston, PR1 2HE.

**Helplines and Support Groups:**

**Diabetes UK:**

- **Email:** helpline@diabetes.org.uk
- **Finding your local support group:** https://www.diabetes.org.uk/how_we_help/local_support_groups
- **Confidential Helpline:** 0345 123 2399, Monday to Friday 9am – 6pm.

**Samaritans:**

- **Website:** https://www.samaritans.org/ **Call free on** 116 123

# Debrief Statement

Thank you for taking part in this study. This research is investigating the underlying relationships between psychological feelings/states and diabetes outcomes in adults with type I and II diabetes. In our previous study, we found data to suggest that resilience can have a positive impact on psychological feelings and outcomes, that would normally have a negative effect on diabetes self-care. Therefore, resilience would be a key factor to examine for improving mental wellbeing. There is a lack of research looking at these relationships together, so that is why we wanted to hear your experiences about living with diabetes.

You have the right to withdraw from the study up until one week after the interview has taken place; after this point analysis of the data will begin. The anonymous results derived from all participants, and the report derived from them, may be presented to relevant people at conferences and within a peer reviewed journal article.

**What if I need support over the issues raised?**
If you have been affected by any of the issues raised and would like some free, confidential advice or somebody to talk to, the following services are available:

- ***Your registered GP/healthcare professional***
- ***Diabetes UK***
  Email: helpline@diabetes.org.uk
  Finding your local support group:
  https://www.diabetes.org.uk/how_we_help/local_support_groups

  Confidential helpline: 0345 123 2399, Monday to Friday, 9am to 6pm.

- ***Mindsmatter***
  Website: https://www.lscft.nhs.uk/mindsmatter2-contact-us-self-referral
- ***Samaritans***
  Website: https://www.samaritans.org/
  Call free on 116 123

***For more support and help, visit the NHS website:***

***https://www.nhs.uk/every-mind-matters/urgent-support/***

You can also contact:

The Project Lead:

Dr. Noreen Caswell, UCLan, Darwin Building Room 118, Preston, PR1 2HE.

Email: ncaswell1@uclan.ac.uk

Other Researcher: Rosalind Pate, RSPate@uclan.ac.uk

If you would like to speak to someone external to the project, please e-mail the officerforethics@uclan.ac.uk

**Appendix 11:** Semi-Structured Interview Questions Guide (Study 2)

## Demographic Questions

1. What is your gender?
2. What type of diabetes do you have?
3. What age were you diagnosed with diabetes, and how long have you had diabetes for?
4. Do you know your current/last HbA1c level?

    *If yes, then:*

    *What was your last measurement?*

5. What medications do you take (if any) to treat your diabetes?
6. Do you know your BMI? (if not known this is okay).
7. How often do you test your blood sugar levels?
8. On a scale of 1-10, how well do you feel you manage your diabetes? (Where 1 is very poorly, and 10 being very well).

## Mood States and Diabetes Outcomes

9. Has living with diabetes had any impact on your mental health?

    *If yes, then:*

    *What sort of impacts have you had? (e.g. Anx/dep/stress)*

    *How often do you feel these impacts?*

    *How severe are they?*

    *What would you say is the worst impact and why?*

10. How would you describe anxiety?
11. Do you experience anxiety that you feel is related to your diabetes?

    *If yes, then:*

    *How often do you feel anxious?*

    *How severe is it?*

    *Could you give an example of something about your diabetes that*

    *makes you worry the most?*

12. If you think back to before you were diagnosed, how does your anxiety compare to now?
13. How would you describe feelings of fatigue, related to your diabetes?
14. Do you experience diabetes-related fatigue?

    *If yes, then:*

    *How often do you feel fatigued?*

    *How severe is it?*

    *When during the day is your fatigue the worst?*

15. If you think back to before you were diagnosed, how would your fatigue levels compare to now?
16. Does your diabetes affect your ability to carry out daily tasks?

*If yes, then:*

*Could you give an example of some of these tasks and how your diabetes impacts these?*

17. Do you have any thoughts on the long-term effects of diabetes on thinking abilities/processes?
    *(If unsure, prompt: e.g., memory or decision making)*

    *If yes, then: please could you give some examples of these? Or any related issues that have prompted you to think about this?*

**Resilience Questions**

18. How would you define resilience?
    *(if unsure, or give incorrect answer, then prompt: 'some researchers define resilience as the ability to overcome adversity/trauma and bounce back')*

19. Do you think resilience is important in managing your diabetes?
    *If yes/no, then:*

    *Why? Could you provide any examples?*

20. Do you have any coping methods/strategies to help you deal with the demands of diabetes?
    *If unsure, then:*
    *(prompts: such as behavioural or mental strategies for reducing stress/upset/worry)*

21. We were talking earlier about anxiety and fatigue; do you feel your resilience might have an effect on these?
    *If yes/no, then:*
    *Can you explain why you feel this?*

22. Do you feel that your resilience has an impact on thinking abilities? (e.g. memory or decision making?)
    *If yes/no, then:*
    *Can you explain why you feel this?*

23. Do you feel that your resilience has an effect on feelings of distress?
    *If yes/no, then:*
    *Can you explain why you feel this?*

**Satisfaction with diabetes care specialists**

24. How do you feel about your interactions with your diabetes healthcare specialists? (Diabetes Nurse, etc).
    *If unsure then:*
    *Prompt – do you feel they are informative, helpful and encouraging about managing diabetes?*

    *If yes/no, then:*
    *Ask for further clarification – why do you feel this way?*

25. Have you taken part in any interventions (e.g., education courses) as part of treatment for your diabetes?

**Appendix 12:** Excerpts of Coding and Thematic Analysis (Study 2)

| *Transcript* | *Initial Coding* | *Abstract Coding* |
|---|---|---|
| **[Tess, F, T2P4]**<br>**R:** Ok so if I can start by asking you some demographic questions just like when you were diagnosed things like that and then I'll move on to the rest of the interview if that's okay.<br>**T:** Yes<br>**R:** So what type of diabetes do you have?<br>**T:** Type 2 diabetes.<br>**R:** And what age were you diagnosed with Type 2<br>**T:** I was probably about 51.<br>**R:** Do you mind if I ask how long you've had it for?<br>**T:** about 10 years.<br>**R:** And do you know your current or last hba1c level? It's fine if you don't.<br>**T:** Yeah I can tell you I'm, I’ve been wearing a Libre 2 because I am using steroids and they're, they've had major effects on me. So today it's 8[DCCT%]/64[mmol/mol]. | *Demographics:*<br>*Female,*<br>*Type 2,*<br>*Duration: 10 years*<br>*HbA1c: 64*<br>*Medication: Metformin, Levemir insulin, Humalog*<br>*BMI: 27*<br>*Co-morbidities:* myasthenia gravis | |

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| **R:** Okay, thank you. And what medication, if any, do you take to treat your diabetes?<br>**T:** Metformin 1G slow release twice a day, and I take Levemir insulin twice a day and Humalog 3 times a day.<br>**R:** Okay, and do you know your BMI? Again, if not it's okay.<br>**T:** It's about 27 I think...<br>**R:** And on a scale of 1 to 10 how well do you feel you manage your diabetes where one is very poorly and 10 being very well? | | |
| **T:** Probably about 6 at the moment, because of all the steroids I'm taking.<br>**R:** Yeah. | *6/10; would be higher but steroids are having an effect* | *Diabetes self-management* |
| **T:** It was a lot better than that, I'd almost got that I'd stopped the insulin, I'd lost a load of weight back in August, and I would have said 10 then. But since I've been on insulin 5 times in the day…Not been so good.<br>**R:** Mhmm, yeah. And so has living with diabetes had any impact on your mental health? | *Self-management was better,*<br>*Almost stopped the insulin,*<br>*Lost lots of weight in August,*<br>*Since been on insulin 5 times a day, impacted health negatively.* | *Diabetes self-management*<br>*Medication* |
| **T:** I would say in some ways it has because there's always that negative connotation of I shouldn't be eating this or I shouldn't be eating that, or I need to moderate what I'm eating, you know, most of the time you can make healthier choices but then sometimes you just don't feel like it. [Yeah]. And there's kind of all the bits that come | *Affected mental health in some ways,*<br>*Negative connotation of what she shouldn't be eating, or moderating,*<br>*Able to make heathier choices most of the time, but then sometimes you just don't feel like it.* | *Mental health*<br>*Stigma (eating)* |

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| with the diabetes, like the sort of, the sweating and the tiredness and the sort of blurry vision, needing to pee all the time getting loads of wee infections, so I think there is a kind of a knock-on effect from being diabetic that just makes you feel maybe a bit low health wise, which then can have an effect on your mental health. | *And symptoms of diabetes; sweating, tiredness, blurry vision, needing to urinate all the time, water infections,*<br>*Knock on effect from being diabetic that makes you feel low, and can negatively affect mental health.* | *Diabetes symptoms*<br>*Mental health* |
| **R:** Yeah. Erm, so have you had any issues with anxiety, depression, stress as a result of the diabetes? | | |
| **T:** I think not specifically as a result with the diabetes, I mean I try really hard, both my parents had, my mum's still alive, have a long history of depression and anxiety, so I've tried really hard through my life to kinda look half-full, rather than half empty. And I have to work very hard on that. So I would say you know there are days when I feel a bit fed up, but I wouldn't say it was specifically down to the, the diabetes. I think it can be stressful, again back to the sort of 5 lots of insulin a day, I've done the odd thing like giving the wrong Insulin at bedtime and given the like a big dose of short acting rather than long acting you know, just trying to stay on top of you know remembering to take the insulin out with you at lunch time because I wasn't used to doing that. You know, those things are quite frustrating and stressful. | *Doesn't experience anxiety as a direct result of diabetes,*<br>*Parents have a long history of depression and anxiety,*<br>*And so tried hard to be optimistic,*<br>*There are days where she feels a bit fed up,*<br>*But not specifically down to diabetes.*<br>*It can be stressful, especially with 5 lots of insulin a day,*<br>*Given the odd wrong insulin dose at bedtime,*<br>*And given the wrong type (short/fast acting).*<br>*Trying to stay on top of remembering to take insulin with you at lunch,*<br>*Quite frustrating and stressful.* | *Anxiety*<br>*Diabetes self-management*<br>*Difficulties* |
| **R:** Yeah. So I know you said that you don't really get impacted by… sorry, by things like anxiety very much, but how would you describe anxiety for yourself? | | |
| **T:** I'm a forward thinker and planner so if I was going somewhere i'd maybe start thinking about it a day or two beforehand making a list reminding me what take; You | *Forward thinker and planner,*<br>*Thinks about trips a day or two ahead, making lists of what to take.* | *Anxiety* |

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| know, making sure that I've got it, maybe taking some spare, spare needles or something. It's always in the back of your mind, you may wake up in the night, think about it. Erm, but not, I'm not kind of crippled by anxiety or, you know, can't do things because of anxiety or anything like that. But I suppose it's kind of… its bubbling under the surface. | *E.g., spare needles*<br>*Thoughts always in the back of your mind,*<br>*Not crippled by anxiety, but it's bubbling under the surface.* | *Anxiety* |
| **R:** Yeah. And so, again I know you don't experience it much but just for the sake of asking a question, before you were diagnosed with diabetes do you feel like there's been a difference in anxiety levels compared from then to now? | | |
| **T:** No not really no. | *No difference in anxiety levels before/after diagnosis.* | *Anxiety* |
| **R:** Okay, so the next thing I want to ask is do you experience fatigue that you feel is related to your diabetes? | | |
| **T:** That's hard to tell cos i've got myasthenia gravis as well, and the muscles get very tired and I need to rest more. I mean that's really only been since October. I would say if my blood sugars aren't well controlled in the evening, and they've been a lot worse in the evenings because of the steroids; the kind of build-up on the steroids. I tend to get very sort of sleepy and tired. I'm aware that I kind of tire very quickly when I'm doing, doing jobs. But a lot of that is probably down to the myasthenia. | *Hard to tell if diabetes or MG causes fatigue,*<br>*Muscles get very tired and need more rest,*<br>*Only since October (2021).*<br>*If blood sugars aren't controlled, also made worse by steroids, she gets very tired and sleepy. (Supports Park et al., 2015).*<br>*Tires very quickly when doping jobs.*<br>*But probably a lot down to the MG.* | *Fatigue*<br>*Fatigue* |
| **R:** Yeah. How would you describe feelings of fatigue related…What I mean, I know it's hard to tell because of | | |

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| the Co-morbidity, but how would you describe fatigue for you because I know it's different for everyone. | | |
| **T:** A kind of overwhelming sense of tiredness. Just, you, you're kind of doing something and you're thinking God, i've really got to finish this or I've got a sit down. Erm, in the evenings I can feel my eyes getting heavy and just needing to sit down and shut my eyes. And what I tend to do if I'm watching TV is do another activity like something on the iPad or a craft to keep me awake. Erm, sometimes your arms and legs just feel a bit like lead, erm, we, we live in a bungalow but we have a bathroom with a bath upstairs, and if I want a bath, you know kind of, I can get up the first maybe 8 stairs, but then the last 4 is like climbing Everest. But I think again that's probably more myasthenia related than the diabetes. Everything just feels like an effort, when just, I used to be somebody who would just do do do, keep going, and I've run out of steam a lot sooner than I used to. | *Fatigue is overwhelming sense of tiredness.*<br>*Doing something and needing to stop.*<br>*Can feel eyes getting heavy in evenings,*<br>*Needing to sit and shut eyes.*<br>*Will watch TV or do crafts to stay awake.*<br>*Arms and legs sometimes feeling like lead.*<br>*Lives in a bungalow, bathroom upstairs,*<br>*If wanting a bath, can manage first 8 stairs, but last 4 are like climbing Everest.*<br>*Probably more the MG than diabetes.*<br>*Everything requires an effort,*<br>*Used to be somebody who would do and keep going, but now tires much sooner.* | *Fatigue*<br>*Cause of fatigue* |
| **R:** Yeah. And do you feel, so, do you feel the anxiety and fatigue might be related? Or do you not feel like there's any effects, erm, for example, if you're more fatigued do you feel more prone to anxiety, things like that? | | |
| **T:** I don't think so. I mean I might feel a bit more irritated that I haven't completed a job, you know or, you know see something that needs doing and don't feel like doing it and feel more irritated by it, but I don't think there is for me, no. | *Doesn't think anxiety and fatigue are related. Feels irritated at jobs that need doing and she doesn't feel like doing.* | *Anxiety and fatigue* |
| **R:** Mhmm. Thank you and… Sorry, i've read these questions so many times like, my eyes go square every so often. Erm, sorry. Where's it gone…Yes, erm does your | | |

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| diabetes affect your ability to carry out daily tasks, so that could be any of your daily jobs? | | |
| **T:** No I don't think so. | *Diabetes doesn't affect daily tasks.* | *Diabetes self-management* |
| **R:** And do you have any thoughts on long-term effect of diabetes on thinking processes so for example, memory or decision making? [Pause]. Sorry I know it's not an easy question. | | |
| **T:** I know, i'm, I was kind of thinking about that, I think sometimes my thoughts are foggier, I don't think as clearly, erm, it's interesting, when your blood sugar is low you definitely don't make such good decisions as you would if your blood sugar's in the normal range. I tend to be a little bit more impulsive if I've got a low blood sugar, and I think when my blood sugar is high and I'm tired I'm more likely kind of, not ***not*** to care, but to take less care, erm, with a decision so I think it does have an effect on the thinking processes. I do a lot of word games because I'm limited physically with what I can do and If my blood sugar is kind of gone very high, say after meal, may be sort of say, 16 plus, I can see that I don't function as well as when it's in the normal range. | *Thinks that sometimes thoughts are foggier with diabetes, not thinking clearly,*<br>*Low blood sugar leads to poorer decision-making skills, compared to normal range.*<br><br>*Tends to be more impulsive with low blood sugar,*<br>*High blood sugar and tiredness leads to less care with decisions.*<br>*Diabetes does affect thinking processes.*<br>*Does lots of word games and doesn't function as well when blood sugar is high. (Compared to normal range).* | *Cognition* |
| **R:** Yeah. Erm, and so this next set of questions is about resilience, so, how would you define resilience? And this isn't about having a correct answer it's about seeing what it means to you. | | |
| **T:** Hmm. I think for me, this last couple of years, with all the sort of health issues i've had, it's kind of got me looking at things in perspective and making the best of | *Health issues have made her look at things in perspective,*<br>*Making the best of the situation she has,* | *Resilience* |

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| the situation that you have. Erm, I've got a group of friends I did my nurse training with and they're always saying, you know, they feel I've been very resilient and just sort of dealt with what's come along you know, something comes along and you have to kind of think about it and then you have to almost like reframe it. Put it into the best, best way that you can for you. Erm, i've had a whole load of health issues this week and somebody said you know, it can't get any worse, and I messaged back and I said you know it can. You know I've got chronic health issues but I'm not dying, I'm not in pain, you know, and if you can reframe it, it really makes a huge, a huge difference rather than sort of poor me feeling sorry for yourself. So looking, looking at the, the best way that you can deal with what…What's coming your way really, I suppose.<br>**R:** Yeah. And do you think resilience is important in managing your diabetes? And if yes or no could you try and give examples? | *Group of friends who she did nurse training with – always commenting on her resilience, Feel she's very resilient and dealt with things,*<br>*Something happens and you have to reframe it, making it the best way you can for you.*<br>*Had a load of health issues and somebody said 'it can't get any worse,' she messaged back disagreeing.*<br>*Her outlook – she's not dying and not in pain, so reframing it makes a huge difference rather than feeling sorry for herself.*<br>*So resilience is looking at the best way you can deal with what's coming your way.* | |
| **T:** Yeah I think it is I mean, you know, you could just feel sorry for yourself and say oh... You could make it a very negative thing 'I can't do this, I can't do that' you know, you can do everything in moderation, you can adapt your diet, I mean it was good opportunity for us to look at what we're eating and say what can we try and do. I've discovered all sorts of new foods, so things like konjac noodles which got no calories in at all, or Konjack pasta. Which you know, which is one way of cutting down on carbs, erm, you know, we eat a huge amount of fruit and vegetables anyway, but you know, we've tried a load more new recipes that maybe we wouldn't have tried | *Resilience is important in managing diabetes*<br>*You could feel sorry for yourself and make it a negative thing,*<br>*You can do everything in moderation,*<br>*Adapting diet was good opportunity to reassess what she was eating and what she could change.*<br>*Discovered new foods like Konjack noodles.*<br>*A good way of cutting down carbs,*<br>*She eats a huge amount of fruit and veg,*<br>*But tried a lot of new recipes they wouldn't have otherwise tried.* | *Resilience*<br>*Diabetes self-management* |

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| over the years. I mean, back in August as I said, I'd lost loads of weight and I was really exercising a lot more, I kind of got to a where I was feeling well enough to sort of tackle the diabetes, and I've got my, erm, insulin down to, you know, minimal amount, and then unfortunately, you know these other health issues came along, but i'm hoping that as they get my myasthenia under control I can go back, you know, to doing that again. So yeah, I think there are…You got to kind of look at what's the positives that come out of it because you could end up feeling very miserable otherwise. | *Lost a lot of weight in August,*<br>*Was exercising more,*<br>*Got to a point of feeling well enough to tackle diabetes; got insulin to minimal amount,*<br>*But other health issues came along,*<br>*Hoping to get MG under control,*<br>*So she can go back to controlling diabetes.*<br>*You have to look at the positives that come out of your situation, or you could feel very miserable otherwise.* | *Diabetes self-management* |
| **R:** Yeah. Sorry I keep getting lost sorry, erm and do you have any coping methods or specific strategies to help you deal with the demands of diabetes? [Pause]. Erm so I know some people might like plan everything that they're gonna have, things like that… | | |
| **T:** I've got alarms on my phone to remind me about the extra insulin. The morning is not too bad because I was doing that anyway, but, I've kind of, I've got an alarm for lunchtime supper and erm, before bed, so, that has been, kinda, quite a good help [laughs]. I'll try and think about, you know, plan ahead with what I'm going to eat maybe the day before, or certainly in the morning think about what i'm gonna have for supper, what i'm gonna have for lunch. I kind of plan out some snacks, erm… I'm on quite a high dose of steroids so I'm ravenous. All I can think about is, is food, erm, but I know that things like, if I have a cooked breakfast, so like this morning I've had a couple of boiled eggs, or you know yesterday I had egg and bacon, I'm much better because I'm fuller and my blood sugar is more even through the day, where is if I | *Has phone alarms to remind about insulin,*<br>*Morning isn't bad as she does this anyways,*<br>*But alarms are needed for lunch, supper and before bed.*<br>*Useful coping method.*<br>*Will plan ahead with what to eat the day before,*<br>*Plans out snacks,*<br>*On a high steroid dose so ravenous,*<br>*All she can think about it food,*<br>*Cooked breakfasts keep her fuller for longer,*<br>*And blood sugar is more even through the day,* | *Diabetes self-management*<br>*Coping methods* |

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| have cereal I seem to digest it quite quickly, you know even porridge, and then about 11 o'clock I'm rooting for food. I'm limited with the exercise I can do, I can only walk about 30 to 50 yards at the moment, so I'm kind of just starting to think about what exercise I can try to, you know, help erm lose some of the weight that I've put on with the steroids. So yeah, that I mean there is some planning there. | *But digests cereal/porridge quickly and rooting for food by 11 o' clock.*<br>*Physically limited,*<br>*Can only walk ~30-50 yards,*<br>*Trying to think what exercise she can try to help lose weight that steroids have put on.*<br>*Planning is used.* | *Diabetes self-management* |
| **R:** And we were talking earlier about anxiety and fatigue, do you feel the resilience has an effect on this because you come across a very resilient person and I'm trying to figure out whether that is the reason why people might not feel anxiety or fatigued as much as someone who's say, not very resilient and not looking after things. Erm, do you feel this is the case with you? [Pause]. Sorry I know it's like a difficult question… [crosstalk]. | | |
| **T:** No, no… I think resilience has a really important part to play in how you, how you feel, and I look at my mum's who is not resilient, and I ring her, I dunno two or three times a day and she moans the whole time, 'oh i've got this pain,' 'i've got that pain,' you know. How you feel mentally in yourself makes a huge difference as to how you perceive what's going on in your body. You know, I might feel the pain as one where is my mum might feel it as five and it's the same pain, but it's kind of a lot of it is how you perceive it, and I think if you're anxious and worried about yourself then, I mean having I would say I do…You know I'm a Googler, I think that's the sort of the nursing bit in me, I will look things up and I will think about them and what effect they are having, and kind of, you know, probably have a bit of a worry about it and | *Resilience has a really important part in how you feel,*<br>*Rings her mum who isn't resilient and she moans the whole time,*<br>*How you feel mentally makes a huge difference in how you perceive what's going on in your body,*<br>*She might feel pain as 'one' where her mum might feel the same pain as 'five';*<br>*same pain, but depends on perception.*<br>*She feels she has anxiety and worries,*<br>*She's a googler, [due to nursing],*<br>*She will look things up and what effects they are having,*<br>*Have a bit of a worry and then think about it,* | *Resilience, anxiety and fatigue*<br>*Mental health and perception* |

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| think about it…You gotta keep it in perspective, so I think resilience is actually really important and I think if you've got, if you've got that sort of…I suppose for me I've got my husband whose a really good support or somebody to talk to as well. I think if you've got somebody to bounce things off of then maybe your thoughts don't get out of control. It's very easy to go into a negative spiral I think it wouldn't take much, to sort of spiral round and say you know I don't feel well I can't do this, you know, and blame everything you know on diabetes. | *You have to keep it in perspective,*<br>*Resilience is important.*<br>*She has good support with Husband,*<br>*If there’s someone to bounce thoughts off, then your thoughts won’t get out of control.*<br>*Very easy to spiral negatively,*<br>*And to think ‘I can’t do this,’ and blame everything on diabetes.* | *Social support*<br>*Resilience* |
| **R:** Yeah. | | |
| **T:** But I think maybe having been brought up with two depressive parents and seeing what it was like, you know, it's been really important me not to, not to be like that. | *Being raised by depressive parents makes her acknowledge the importance of not being like that.* | *Upbringing* |
| **R:** Yeah. And just, I know this question might seem a bit samey but it's looking at something different, do you feel that resilience might impact on your thinking abilities such as memory or decision making? Like the more cognitive side of things. | | |
| **T:** Yeah, quite possibly because if you have a positive attitude, you're more likely to feel that you can do it and you're more likely to try something new. If you're kind of all worried and thinking ‘oh no I can't do this I can't do that’ then you are less likely to try just kinda thinking about that the cognitive side of it. [Pause]. | *Resilience has effect; a positive attitude is more likely to make you feel you can do it and try something new.*<br>*If you’re worried and thinking ‘I can’t’ than you are less likely to think about the cognitive side to it.* | *Resilience*<br>*Anxiety* |
| **R:** Sorry, I know they're not easy questions, but yeah, it’s really interesting hearing what different people's take on | | |

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| that is. And there's two more questions left if that's ok, so, how do you feel about your interactions with your diabetes healthcare specialists? Do you feel that they're informative and helpful or have you had negative experiences? | | |
| **T:** Well I was under the care of the GP until I ended up on the insulin in 5 times a day. They sent me to the specialist nurses who basically left me to get on with it, you know, there was no real guidance, they just sort of said you know, you're a nurse, almost like have a guess at how much insulin you need. So, I don't feel that the care has been great. The thing I struggle with most of all is how much long-acting insulin to have at night-time. So last night I obviously over did it because I had two hypos in the night, and then again when I woke up this morning, and It's just trying to get that balance right with what you eating and, you know, I seem to have gone up, I'm using an awful lot of insulin through the day compared to what I was, but you know the steroid specialist nurse from the mysatheania was saying is that the steroids turn off the adrenals, and so produce less of your own insulin, and therefore you need more and more to be given to you. So yeah, I kind of wonder if there was sort of better support whether my diabetes would be a little bit better controlled. And then I've had an ongoing issue with infections and things, and that kind of raises your blood sugar so as I said my Hba1c was below the normal cut-off back in April, and it's come and gone up quite a lot…not April, in August. So it's gone up quite a lot, and I kind of, I feel upset having worked so hard, it's kind of… and I've put all this weight on, but anyway. | *Was under the care of GP until being put on insulin 5x per day.*<br>*They sent her to specialist nurses who left her to get on with it, no real guidance,*<br>*Said she was also a nurse, have a guess at how much insulin she needs.*<br>*Doesn't feel care has been great.*<br>*She struggles most with how much LA insulin to have at night-time,*<br>*Last night overdid insulin as she had two hypos in the night and again in the morning.*<br>*Difficult getting that balance right with what she eats,*<br>*Using a lot of insulin compared to past,*<br>*But steroids for MG turn off adrenals and so produce less insulin,*<br>*Therefore needing more insulin.*<br>*Wonders if better support would have helped control her diabetes better.*<br>*Ongoing issues with infections, which can raise blood sugars, and so HbA1c has gone up quite a lot.*<br>*And feels upset at having worked so hard to bring levels back down and it's gone up, and she's put weight on.* | *Healthcare experience*<br>*Healthcare professional interaction* |

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| **R:** I imagine it's particularly frustrating with it being out of your control like that… | | |
| **T:** What you put in your mouth is in your control but it’s not very easy, and then there's kind of an interesting, there's a sort of self-destruct bit as well, where sometimes I think it's just better not to buy anything, we went away for a few days, I don’t know, a couple of months ago and I picked up a packet of 21 two finger Kit Kats, we were only away for 5 days and I ate most of them over that time. I'm usually, I'm usually pretty good but sometimes there's that little sort of self-destruct bit and you think I shouldn't be eating this, and you unwrap another one and stuff it in. | *What you put in your mouth is in your control,*<br>*But there’s a self-destruct component,*<br>*Sometimes it’s better not to buy anything,*<br>*Went away for a five days and bought 21 pack of kitkats, and ate most of them during that time.*<br>*Usually good with self-control but there’s that self-destruct component and despite knowing not to eat it, she eats more.* | *Diabetes self-management* |
| **R:** But they're so good though [both laugh]. Sorry and last question is have you taken part in any interventions or education courses as part of your treatment for diabetes, like learning how to manage… | | |
| **T:** Oh god when I was first diagnosed, they sent me on a carb counting course which was the most excruciating and painful thing I've ever done. There were about ten of us and they had this plastic play food and, you know, to be fair I come from a nursing background and I would say that there was quite a mix of people but the majority of them were, and this sounds derogatory and I don't mean it that way, but I think you know what I mean, the majority of them were Sun readers, so they didn't realise that you know, it wasn't just sugars that, you know carbs were part of the issue. You know, and there was this guy sitting there saying you know 'well I only like full fat Coke | *When diagnosed they sent her on a carb counting course; painful and excruciating.*<br>*About 10 people and plastic play food,*<br><br>*Comes from nursing background,*<br>*Quite a mix of people but majority of them were ‘sun readers.’*<br><br>*Other people didn’t realise it wasn’t just sugars; carbs were also part of the issue.* | *Intervention/education experience* |

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| and I like my Mars bars and I have 3 mars bars a day and I'm not going to change and' and I just thought Oh God. And they had us sort of picking up these little bits of plastic food and we were supposed to say you know, have they got any carbohydrate in them and I just thought, you know this is not… I didn't find it helpful I actually found it really frustrating.<br>**R:** Yeah… | *There was a man saying how he only likes full fat coke and mars bars, and was Resistant to changing that.*<br>*They had the participants picking up plastic food and assessing the carbohydrate content of the foods,*<br>*She didn't find this helpful, and really frustrating.* | |
| **T:** I just wanted to sort of get out that room as soon as possible, I didn't find it helpful at all. And then I had a session with a dietitian who was quite interesting but quite… I eat a lot of fruit and veg and she was saying well you know you can only eat 3 pieces of fruit a day, and really you shouldn't eat that much fruit. And I said 'well you know I think it's better to eat a piece of fruit than a chocolate bar,' better to eat piece of fruit than, you know a bag of crisps that have got fat in them and not good for my heart as well as carbs.<br>**R:** Yeah absolutely. | *Wanted to get out the room asap,*<br>*Didn't find it helpful at all,*<br>*Had a session with a dietitian,*<br>*She eats a lot of fruit and veg a day,*<br>*Dietician said to only eat 3 pieces of fruit per day, and to not eat that much fruit,*<br>*Thinks it's better to eat a piece of fruit than a chocolate bar,*<br>*or a bag of crisps that have got carbs and fat in them.* | *Intervention/education experience* |
| **T:** You know, she wasn't, she'd got her bit of script and I just thought actually this is not, this is not helpful either. So it's kind of difficult you know, yeah obviously you do need to limit fruit sugars but if you're going to eat something else that's worse you're better to have the fruit is my feeling.<br>**R:** Yeah absolutely. | *She got her bit of script,*<br>*And this is not helpful either.*<br>*It's difficult,*<br>*You need to limit fruit sugars, but if you're going to eat something worse, you're better off eating fruit.* | *Healthcare professional interaction* |

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| **T:** So no, that's the only education that i've had and as I said from the from the diabetic nurses it was very much you know just get on with it play with it, if you have too much insulin have something to eat, and if you don't have enough insulin take a bit more. I mean, I do wonder how people who haven't had much education cope. I've got, I've had older family members and i'm you know, I'm aware of people that I visited when I was working who were diabetic who were very, very poorly controlled and some of that is maybe not understanding the consequences of, you know, the complications of diabetes.<br>**R:** Yeah. I mean with you being from a nursing background like, that's really helpful actually because the whole point of my PhD is to look at interventions what's going wrong, what can we do better, how can we teach people to manage it better. And a study that I've done before this basically was looking at whether resilience affects all these things and so in some, in people who have lower Resilience they don't seem to be on top of their anxiety, fatigue diabetes, distress. So I am trying to figure out if maybe that's the thing that we need to teach people, that especially are less educated, in order just to sort of, not make them bury their heads and stuff like that. That's what I'm kind of thinking about but I'm not sure because obviously I don't have diabetes but it runs in my family so it's, I'm just trying to figure out what's best to recommend. | *That's only education she's had,*<br>*Diabetic nurses left her to get on with it, play with insulin levels, taken more if needed.*<br>*Wonders how people who haven't had much education cope with diabetes,*<br>*Had older family members and visited people when she was working, and their diabetes was poorly controlled,*<br>*Some of that is maybe not understanding diabetic complications.* | *Intervention/education experience* |
| **T:** I mean I think a lot of it is how… how it's presented to you right in the beginning you know, do you see it as a you know, you hear people say 'I've got a touch of sugar' | *A lot of [coping] is how it's presented to you in the beginning,* | *Diabetes education* |

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| you know, the kind of older generation or you know, ‘oh well everybody over 60 has got to have a bit of sugar’ so some of it is around how it's presented, you know there are very simple changes that people can make that you know, like I never drink juice. You know just being aware of things like you know juice, alcohol you know, little swaps that you can make, that make a difference to what your sugar levels are like. And, I think sometimes if you can present things like that that it… Like that there can be positives, like what could you have instead of a juice or whatever, but, kind of trying to look on it in that way rather than you can't have this you can't have that, you're diabetic. You know a lot of people will say well I can't have sugar and then they'll go and buy all these sugar-free things that still got loads of carbs in them but they don't realise it. So they sell these sugar free biscuits, but they're still full of carbs and actually they're possibly worse because they've got like rice flour and stuff that you know, send your sugar level up higher. So I think that kind of education bit in the beginning is actually really important.<br>**R:** Yeah, I really appreciate your input on that and yeah. Sometimes, again sometimes it's hard for me to ask someone who doesn't really understand the educational side of it so it is really really interesting to hear your thoughts on all of that. But no, that's all the questions I had and I just want to say thank you so much for helping me out.<br>**[Debrief].** | *The older generation sometimes refer to ‘a touch of sugar’ or ‘everyone over 60 has to have a bit of sugar,’*<br>*Presentation is important; very simple changes can be made, e.g. drinking juice,*<br>*Being aware of little swaps you can make like juice and alcohol, can make a difference to blood sugar levels.*<br>*Thinks if you present things like that as positives, e.g. what you can have instead of juice,*<br>*That’s better than looking at it restrictively, e.g. you can’t have this you’re diabetic.*<br>*A lot of people will say they can’t have sugar, and then buy sugar-free things that still are carb heavy without realising.*<br>*Sugar-free biscuits are full of carbs, and possibly worse because of e.g. rice flour,*<br>*That might spike sugar levels,*<br>*Thinks this kind of education in the beginning is really important.* |  |

**Appendix 13**: Participant Information Sheet and Debrief (Study 3)

# Information sheet for participants

**Study Title: Exploring Relationships between Psychological states, Resilience, Diabetes Outcomes, and Interventions and in Type I and II Diabetes**

## 14. Document Version Number and Date

V2.2, 6.9.2022

## 15. Invitation to participate

*We would like to invite you to take part in our research study; before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.*

## 16. What is the purpose of the study?

There are many things that can affect diabetes self-care, such as psychological states (e.g. anxiety, fatigue, resilience), diabetes outcomes (e.g. diabetes distress, thinking processes) and diabetes interventions. However, there is a lack of research that examined these together in order to understand the underlying relationships. We looked at these in our previous studies, and wish to further examine these relationships. Having a good understanding of these are important for developing effective treatments and interventions, so we would like to hear about your experiences of living with diabetes.

## 17. Why have I been invited to take part?

We are looking to invite adults from the UK with a diagnosis of diabetes (type I or II) and individuals with experience as a diabetes healthcare professional to take part in the study. The only requirements for participation are that you are over 18 (to provide informed consent), and fluent in English (due to the nature of the study).

## 18. What will happen if I take part?

The research will involve completing two questionnaires, the first being a demographic questionnaire (e.g. asking about diabetes type, how long you have had diabetes for, gender, ethnicity), and then the second questionnaire will ask about mental health, psychological states, resilience and diabetes interventions. Questions will be largely open ended, so completion time may vary (estimated around 20 minutes, depending on how much information you want to provide).

**19. Do I have to take part?**

Participation is completely voluntary, and you can contact the researcher if you have any questions before deciding. Participants are free to withdraw from the study at any point using the 'withdraw' button until after the submission of responses – this is because the data is anonymous and it will not be possible to withdraw your data. You do not have to provide any reason for withdrawing from the study, and you will not be penalised in any way for doing so.

**20. How will my data be used?**

The University processes personal data as part of its research and teaching activities in accordance with the lawful basis of 'public task', and in accordance with the University's purpose of "advancing education, learning and research for the public benefit".

Under UK data protection legislation, the University acts as the Data Controller for personal data collected as part of the University's research. The University privacy notice for research participants can be found on the attached link:

https://www.uclan.ac.uk/data_protection/privacy-notice-research-participants.php

Further information on how your data will be used can be found in the table below.

| | |
|---|---|
| How will my data be collected? | *Electronic copies of data will be collected via Qualtrics (host website).* |
| How will my data be stored? | *All data is anonymous and will be stored on an password-protected computer, that only the researcher will be able to access.* |
| How long will my data be stored for? | *Participant data will be kept for a period of 5 years and then destroyed.* |
| What measures are in place to protect the security and confidentiality of my data? | *All responses recorded on Qualtrics will be anonymous, and this data will be stored on a password-protected computer that will only be accessible by the researcher.* |
| Will my data be anonymised? | *Yes - All data files will be anonymous.* |
| How will my data be used? | *It is intended that the data collected will be analysed; overall findings will be written up as part of a PhD thesis, and possibly published in scientific journals.* |
| Who will have access to my data? | *Only the researcher will have access to the data files. No information will be shared with any third-party organisations.* |
| Will my data be archived for use in other research projects in the future? | *All data will be stored securely for 5 years – and will only be used as part of this PhD research project.* |

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| How will my data be destroyed? | *After 5 years, all original data files collected will be destroyed/wiped from the password protected devices.* |

### 21. Are there any risks in taking part?

As this research is asking about your experiences with diabetes and psychological feelings such as anxiety, it may bring up sensitive topics that might be difficult to talk about. If you experience any discomfort, you can take breaks at any point (there is no time limit once you start the questionnaires) or withdraw at any point up until submission should you want to. In the case of any health-related or psychological concerns, we encourage you to contact your local GP/specialist care provider, or the other support groups listed at the end of this information sheet.

### 22. Are there any benefits from taking part?

Although there are no immediate benefits from taking part in this research, the findings from this study may provide further understanding into the relationships between psychological states and diabetes self-management. This could potentially help to improve intervention programs, and as a result, the quality of life in individuals living with diabetes.

### 23. What will happen to the results of the study?

It is intended that the results of this study will be published in scientific or medical journals, and you will not be identified/identifiable in any report or publication. When all participant data has been analysed and written up, a summary report will be made available should you wish to see it; if so, please email the researcher and you will be sent a copy once available [RSPate@uclan.ac.uk].

### 24. What will happen if I want to stop taking part?

Participation in this research is voluntary, and you can withdraw at any time up until submission without giving a reason by pressing the 'withdraw' button on the webpage. After this point, your data will be anonymised, and it will not be possible to withdraw your data.

### 25. What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting either the researcher [Rosalind, RSPate@uclan.ac.uk] or the director of studies

[Dr Noreen Caswell, NCaswell1@uclan.ac.uk], and we will try to help. If you remain unhappy, or have a complaint which you feel you cannot come to us with, then please contact the Ethics, Integrity and Governance Unit at: *OfficerForEthics@uclan.ac.uk*.

The University strives to maintain the highest standards of rigour in the processing of your data. However, if you have any concerns about the way in which the University processes your personal data, it is important that you are aware of your right to lodge a complaint with the Information Commissioner's Office by calling 0303 123 1113.

### 26. Who can I contact if I have further questions?

**Contact details of investigatory team:**

**Director of Studies:**
Dr. Noreen Caswell, NCaswell1@uclan.ac.uk,

School of Psychology and Computer Science,

University of Central Lancashire,
Preston, PR1 2HE.

**Researcher [PhD student]:**

Rosalind Pate, RSPate@uclan.ac.uk,

School of Psychology and Computer Science,

University of Central Lancashire,

Preston, PR1 2HE.

**Helplines and Support Groups:**

**Diabetes UK:**

- **Email:** helpline@diabetes.org.uk
- **Finding your local support group:** https://www.diabetes.org.uk/how_we_help/local_support_groups
- **Confidential Helpline:** 0345 123 2399, Monday to Friday 9am – 6pm.

**Samaritans:**

- **Website:** https://www.samaritans.org/
- **Call free on** 116 123

**For more support and help, visit the NHS website:**

- *https://www.nhs.uk/every-mind-matters/urgent-support/*

# Debrief Statement

Thank you for your participation.

This research investigates the underlying relationships between psychological states and resilience in type 1 and 2 diabetes, and current intervention and care experiences. In our previous research, our findings suggest resilience can have a positive impact on psychological feelings and diabetes outcomes, that would normally have a negative effect on diabetes self-care. We wanted to look at current education and intervention experiences, to consider how to improve upon these using previous findings.

The anonymous results derived from all participants, and the report derived from them, may be published within a peer reviewed journal article, or presented at research conferences.

If you have any questions concerning the study please feel free to contact the researcher via RSPate@uclan.ac.uk, or the project supervisor at ncaswell1@uclan.ac.uk. If you have any concerns about the research that you wish to raise with someone independent of the research team, you can contact the University Officer for Ethics at (OfficerForEthics@uclan.ac.uk).

If you have been affected by any of the issues raised and would like some free, confidential advice or somebody to talk to, the following services are available:

- ***Your registered GP/healthcare professional***
- ***Diabetes UK***

  Email: helpline@diabetes.org.uk
  Finding your local support group:
  https://www.diabetes.org.uk/how_we_help/local_support_groups

  Confidential helpline: 0345 123 2399, Monday to Friday, 9am to 6pm.

- ***Mindsmatter***

  Website: https://www.lscft.nhs.uk/mindsmatter2-contact-us-self-referral
- ***Samaritans***

  Website: https://www.samaritans.org/
  Call free on 116 123

***For more support and help, visit the NHS website:***

***https://www.nhs.uk/every-mind-matters/urgent-support/***

**Appendix 14:** Question list (Study 3)

*Demographic Questionnaire:*

1. Please select which describes your situation
- *I am not a diabetes healthcare professional, but diagnosed with diabetes*
- *I am (or was) a diabetes healthcare professional, but do not have diabetes*
- *I am both a diabetes health professional and diagnosed with diabetes*

2. Which type of diabetes do you have? (T1/T2)
3. How long have you had diabetes for? (in years and months)
4. What is your gender? (leave open)
5. What is your age?
6. What is your ethnicity? (White, Mixed/Multiple ethnic groups, Asian/Asian British, Black African/Caribbean/British, Other ethnic group e.g. Arab). (*Ethnic Categories from the UK and Wales Census)*
7. What is your current or last average blood glucose level? (HbA1c, or other measurement where units are given). If not known, please state this.
8. On a scale of 1-10, how well do you feel you manage your diabetes? (Where 1 is very poorly, and 10 is excellent).

*Mental Health and Resilience:*

1. Please explain in as much detail as possible, whether living with diabetes has impacted your mental health?

2. Please explain whether you feel mental health care for your diabetes is easily accessible as part of your treatment.

3. Please explain how your diabetes healthcare providers approach/ ask about your mental health during appointments. If they don't, please state this.

4. **Resilience can be defined as the ability to overcome adversity and to keep going**. Please explain whether you feel resilience is important in managing your diabetes.

5. As part of your diabetes care, please explain whether you have been informed about the important role that resilience can play in looking after diabetes and how this affects you.

6. Have you ever been informed/taught about the psychological effects of living with diabetes as part of your diabetes treatment? **(e.g. anxiety, distress, fatigue, thinking processes)** [YES/NO]

    - If yes: How was this information helpful to you?
    - If no: How do you think you might benefit from learning about this?

*Interventions and care satisfaction Questions:*

7. Have you taken part in any education or intervention courses as part of your diabetes care? (E.g. DAFNE, DESMOND) [YES/NO]

        - [If previous answer is YES] Please describe your experiences of these courses – did you find them informative or useful, or were they unhelpful?

8. Please explain whether you feel there should be more educational courses available to those diagnosed with diabetes.
9. What recommendations would you suggest for current diabetes education courses/interventions to improve them?
10. Would you prefer to see more mental health-based and resilience-based education courses for people with diabetes? (e.g. learning about active/passive coping styles, components of resilience and how to train these – and how these are relevant to your individual situations of living with diabetes). If so, why?
11. Do you feel satisfied with the quality of care you receive regarding your diabetes? Please explain your answer.
12. Do you have any thoughts about whether diabetes affects thinking processes over time? (e.g. memory or decision making?) If so, please explain.
13. How satisfied are you with the frequency of your diabetes follow-up appointments? [Very dissatisfied, mostly dissatisfied, dissatisfied, neutral, satisfied, mostly satisfied, very satisfied]
14. Have you been signposted by your healthcare professionals to any websites in particular to help with your diabetes? If so, please list these.

## Healthcare Professional Questions:

1 What position in the diabetes healthcare service did/do you work as? (e.g. diabetes nurse, GP, consultant, podiatrist etc).

2 Did you feel the quality of your diabetes training was sufficient, helpful and high quality? [Yes/Could be improved]

- [If could be improved]: Please explain the ways in which improvements could be made.

3 As part of your diabetes healthcare training, were you taught about the psychological effects of living with diabetes? (e.g. anxiety, distress, fatigue, cognitive function) [Yes/No]

- [If yes]: Please explain whether you found this information useful in clinical practice?
- [If no]: Do you feel you would have benefited from doing so?

4 As part of your diabetes training, were you taught the differences between type 1 and 2 responses to psychological effects (e.g. anxiety, distress, fatigue, cognitive function). [Yes/No]

5 How would you describe your current knowledge of the NHS Diabetes Pathway? [Excellent/good/some knowledge/poor]

6 Do you feel the NHS diabetes pathway for patients takes mental health care sufficiently into account? Please explain.

7 Do you feel mental healthcare is easily accessible to those with diabetes ?
[Yes, somewhat, no]
  - Please explain your answer

8 Please explain whether you feel current education/intervention courses for diabetes patients are sufficient in helping them manage their diabetes.

9 What, if any, recommendations would you suggest to improve current diabetes intervention programmes? (This can be hospital settings, primary/secondary care, or community settings).

10 Please explain whether you think more awareness of resilience and resilience training would be beneficial to patients with diabetes?

11 As a healthcare professional, do you feel you have sufficient support and resources, to keep up with changes and advancing knowledge in the field? Please explain your answer.

12 Do you have any other comments regarding improving healthcare knowledge, patient care, interventions and education that have not yet been addressed? If so, feel free to detail in the box below.

## **Appendix 15:** Excerpts of Coding and Thematic Analysis (Study 3)

| | | |
|---|---|---|
| **P19**<br>**Demographics:**<br>Diabetes duration: 31 years<br>Gender: F<br>Age: 62<br>Ethnicity: White<br>HbA1c: 69<br>DSM: 8/10 | | |
| Q1. It impacts my health as it causes a degree of health anxiety in that it is quite stressful thinking about foods to eat (carbohydrate counting and administering the correct dose of insulin and management of libre sensor readings with associated insulin administration). Also managing other potential related health issues associated with diabetes ie cholesterol management, BP management and kidney function can cause health anxiety. | *Diabetes impacts MH, causes health anxiety,*<br>*Stressful thinking about foods to eat,*<br>*Carb counting and administering correct insulin,*<br>*Management of sensor readings,*<br>*Managing other related health issues,*<br>*Cholesterol, BP and kidney function can cause health anxiety.* | *MH impact* |
| Q2. No it is definitely not easily accessible and should be a routine part of outpatient clinics particularly in the secondary care hospital setting. I have been a diabetic for many years and I am seen in a hospital diabetes clinic and in all those years have never had access to mental health professionals within the clinic setting. This should be a routine part of diabetes management. | *MH care not easily accessible,*<br>*Should be routine part of clinics,*<br>*Especially secondary care settings.*<br>*Attended hospital clinics for years,*<br>*Never had access to MH professionals within clinic.*<br>*Should be routine part of diabetes management.* | *MH accessibility* |
| Q3. They do not ask about my mental health. | *HCPs do not ask about MH.* | *Addressing MH* |
| Q4. Resilience is definitely important. For example if at times blood sugar control is abnormal through illness ( covid is a good example) you have to keep trying to manage it back into control which can be very anxiety provoking. It's easy just to think I've had enough and can't do this. | *Resilience important in DSM,*<br>*When BG control is abnormal due to illness,*<br>*Have to keep trying to regain control,*<br>*Can be very anxiety inducing,*<br>*Easy to think she can't do this.* | *Resilience* |

| | | |
|---|---|---|
| Q5. I have never been informed about the important role of resilience in managing my diabetes . | *Never informed about resilience in DSM.* | *Education (resilience)* |
| Q6. No | *Not informed about psych effects of DM* | *Education (psych effects)* |
| Q7. The benefits of this are that if you are more aware of these and have the input at clinic to u detest and these better then you can apply improvement techniques if suffering from for example fatigue and distress. Adapting to a life living with diabetes can be very difficult any input with these things would be beneficial in my personal view . | *Benefits of knowing this information, if you are more aware,*<br>*You can apply better techniques,*<br>*If suffering with fatigue/distress.*<br>*Adapting to life with diabetes very difficult,*<br>*Any input to help this would be beneficial.* | *Education (benefits)* |
| Q8. No | *Not attended education courses.* | *Interventions* |
| Q9. N/A | *N/A* | |
| Q10. Yes I do feel there should be . This could only be a good thing especially if it helps people with blood sugar control in the long run " | *Feels there should be more education courses,*<br>*Good thing if it helps long-term BG control.* | *Intervention (recommendations)* |
| Q11. Easier access; A mix of courses/ interventions (eg group courses are good for some as people can listen to others experiences) but may not suit other people; On line may be good for younger diabetics but may not suit the older generation; One to one sessions; Mentors; Supervisors; Community based support groups; Easy access to specialist professionals if experiencing problems as often can not get appt at GP practices | *Recommends easier accessibility,*<br>*Mix of courses, group courses not suited to everyone,*<br>*Online good for younger people,*<br>*One to one sessions, mentors,*<br>*Supervisors, community-based support groups,*<br>*Easy access to specialist professionals,*<br>*As often cannot get appt at GP practice.* | *Intervention (recommendations)* |
| Q12. Yes definitely as everyone has individual needs one approach does not fit all. | *[Would like to see more res/MH based courses],*<br>*As diabetes is individual and one approach does not fit all.* | *Intervention (recommendations)* |
| Q13. Apart from no mental health support at the clinic I | *No mental health support at clinic,* | |

| | | |
|---|---|---|
| feel very satisfied but that may be because my diabetes is managed by a hospital consultant . When in past I have had input from GP practice I gave not been very satisfied. | *Apart from that, feels satisfied,*<br>*Perhaps because managed by consultant,*<br>*Not satisfied in past from GP practice.* | *QoC satisfaction,*<br>*Addressing MH* |
| Q14. Yes I do think it affects thinking processes over time / years. I have noticed as I get older that my memory and decision making has been affected somewhat. | *Diabetes affects thinking processes over time,*<br>*Memory and decision making affected with age.* | *Cognition* |
| Q15. Mostly Satisfied | *Mostly satisfied with follow up appt frequency* | *QoC satisfaction* |
| Q16. Diabetes uk | *Signposted to Diabetes UK.* | *Signposting* |

**Appendix 16:** Study Tables (Literature Review)

## Summary of studies examining anxiety, fatigue, diabetes distress and cognition in type 1 and 2 diabetes

**Key**
**Participant classification**: **T1** (type 1); **T2** (type 2);
**Physiological measures: BG** (Blood Glucose); **HbA1c level** (glycaemic control); **BGM** (Blood glucose monitoring results)

**Questionnaire Measures: PSWQ** (Penn State Worry Questionnaire); **FFS** (Flinder's Fatigue Scale); **DDS** (Diabetes Distress Scale); **DEX** (Dysexecutive Questionnaire); **CD-RISC** (Connor-Davidson Resilience Scale); **BDI** (Beck Depression Inventory); **MMAS** (Morisky Medication Adherence Scale); **BIS** (Barrat-Impulsiveness-Scale); **NFC** (Need for Cognition Scale); **DMSES** (Diabetes-Specific Self-Efficacy Scale); **DSM** (Diabetes Self-Management); **WY-RS** (Wagnild & Young's Resilience Scale); **STAI** (State Trait Anxiety Inventory); **DQoL** (Diabetes Quality of Life Scale); **DSC-R** (Diabetes-Symptom Checklist Revised); **BRIEF** (Behaviour Rating Inventory of Executive functioning); **DSMP** (Diabetes Self-Management Profile); **MSM** (Mastery of Diabetes Management); **DPSAAS** (Diabetes-Specific Parental support for Adolescent's Autonomy Scale); **DFCS** (Diabetes Family Conflict Scale); **LOT** (Life Orientation Test); RSE (Rosenberg Self Esteem Scale); **CIDS** (Confidence in Diabetes Self-Care Scale); **SMS** (Self Mastery Scale); **PAID** (Problem Areas in Diabetes Scale); **SCI** (Self Care Inventory); **DRSCA** (Diabetes-Related Self Care Activities); **PSS** (Perceived Stress Scale); **SAS** (Self-Rating Anxiety Scale); **FS-14** (14-item Fatigue Scale); **MUIS** (Mishel Uncertainty in Illness Scale); **PSQI** (Pittsburgh Sleep Quality Index);

**Analysis Methods: CFA** (Confirmatory Factor Analysis); **SEM** (Structural Equation Modelling); **ANOVA** (Analysis of Variance)

| Author(s) | Participants | Design | Variables | Type of Analysis | Key Findings | Evaluations | Justification for Study 1 |
|---|---|---|---|---|---|---|---|
| **Zhao, Suhonen, Katajisto & Kilpi (2018)** | **n=251 T2**<br>56% male,<br>Age range: 22-85 | Cross sectional | DRSCA<br>PSS<br>SAS<br>FS-14 | Hierarchical multiple regression analysis | Sig. correlations between anxiety and stress, and anxiety and fatigue. Female gender sig. more associated with stress and anxiety. Improved self-care activities correlate with lower stress. | +Original contribution to knowledge, especially fatigue<br>+Good sample size<br>-Did not include HbA1c measures, only self-management measures<br>-% variance in regression model was high, suggesting other factors need to be considered | Anxiety and fatigue correlated, anxiety and stress correlated |
| **Park, Park, Fritschi & Quinn (2015)** | **n=155 T2**<br>(110 female, 45 male)<br>Age range: 55 years | Cross sectional | DSC-R (fatigue)<br>HbA1c<br>DDS | Path Analysis; **Model** | Fatigue sig. related to glucose control only in those with high HbA1c (≥7%); this relationship is sig. mediated by | +Paucity of papers addressing association between DDS and fatigue, this confirms a sig. indirect association.<br>-Depression assessed by self-report rather than a validated scale<br>-Did not record comorbidities | Fatigue related to diabetes distress (outcome variable) |

|  |  |  |  |  |  |
|---|---|---|---|---|---|
|  | Controlled glucose: 85<br>Uncontrolled: 70 | Depression (self-report) | depression and diabetes distress. | -Did not test for gender effects in the model |  |

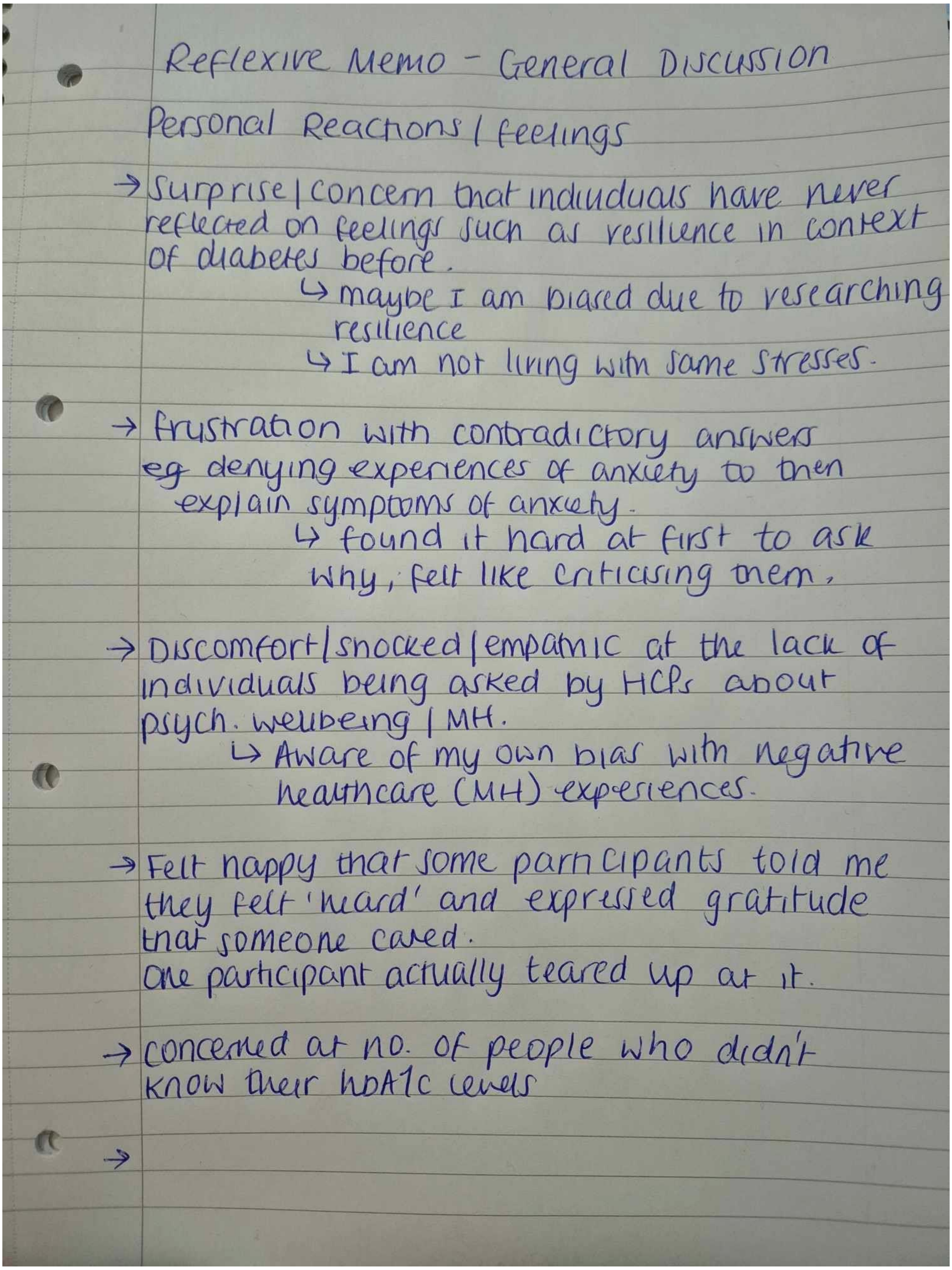
## Summary of Studies exploring the role of resilience in type 1 and 2 diabetes

| Author(s) | Participants | Design | Variables | Type of Analysis | Findings; Effect of Resilience | Evaluations | Justification for Study 1 |
|---|---|---|---|---|---|---|---|
| Wang, Wen, Kuang, Lin, & Cui (2021) | **n=205 T2**<br>(91 female, 114 male)<br>Age range: 18-60+ | Cross sectional | MUIS<br>PSQI<br>CD-RISC | Multiple Hierarchical Regression | Decreased mental resilience sig. correlated with poorer sleep quality and illness uncertainty. Resilience partially mediates sleep quality and illness uncertainty. | + Clinical application; Demonstrates need for further education to reduce illness uncertainty - could be combined with resilience interventions<br>+Demonstrates importance of resilience in sleep quality<br>-HbA1c not recorded | Resilience linked to poorer sleep quality, which is sig. associated with fatigue levels. |
| **Hadj-Abo, Enge, Rose, Kunte & Fleischhauer (2020)** | **n=77 T2**<br>(49 male, 28 female)<br>Age range: | Cross-Sectional | BIS<br>NFC<br>SDSCA<br>DMSES<br>HbA1c | Mediation Analysis; **Model** | Diabetes self-efficacy mediates NFC and DSM, which are implicated resilience factors. Shows link between resilience behaviours (cognition) and improved self-management and HbA1c. | +Studies examining impulsivity and glycaemic control are rare; no previous findings for these variables within one model.<br>+Implications for cost-effective screening<br>- Resilience factors were operationalised via need for cognition and impulsive personality traits, rather than direct scale use; however strong research supports this as a key component of resilience and findings have implication for PhD study 1 development. | Resilience linked to cognition (possible outcome variable), which affects HbA1c. |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
|  |  |  |  |  |  | . |  |
| **Rahimi, Jalili, Nouri & Rahimi (2020)** | **n=200 T2** (83 male, 117 female). Age range: 25-65+ | Cross-sectional | BDI<br>DDS<br>CD-RISC<br>MMAS<br>HbA1c | CFA; **Model** | Depression and treatment adherence are significantly mediated by resilience and diabetes distress. | +Inclusion of HbA1c in participant selection.<br>+No previous study investigated variables simultaneously.<br>-Sample from referred diabetes clinic, may not be indicative of T2 in Primary care. | Resilience possibly mediates anxiety as in depression, and linked to diabetes distress |
| **Rohan, Huang, Pendley, Delameter, Dolan, Reeves & Drotar (2015).** | **n=239 T1** & caregivers (130 female, 109 male) Age range: 9-11 | Longitudinal; 3 follow ups, every 12 months | HbA1c<br>BRIEF<br>DSMP<br>BGM<br>MDM<br>DPSAAS<br>DFCS | Longitudinal mixed effects logistic regression | Health resilience sig. predicts better diabetes self-management, more adaptive coping skills, and improved HbA1c levels. | + Three-year multisite longitudinal study<br>+Clinically relevant comorbid factors were included in predictive models as covariates<br>+First study to test predictive health resilience model in a large sample of paediatric T1 patients.<br>-Limited age range may not be representative of health resilience in other life stages<br>-Specific psychological states (e.g., anxiety and depression) were not examined | Resilience predicts better health outcomes and self-management in type 1. |
| **Ruiz-Aranda, Mateo-Rodriguez, Olmedo, Garcia, Enriquez & Martinez Brocca (2020)** | **n=30 T1** (9 male, 21 female) Age range: 20-58 years All had clinical reports of FoH | Cross-Sectional | WY-RS<br>BDI<br>STAI<br>DQoL<br>HbA1c | Mediation Analysis; **Model** | Sig. positive effect of resilience on anxiety and depression. Resilience was mediated by anxiety, not depression, and quality of life in T1 diabetes, suggesting the importance of resilience in improving anxiety and quality of life. | +Supports importance for resilience interventions, given that no programs include therapeutic and psych. Education strategies in T1 for management of FoH.<br>+Investigated both anxiety and depression<br>-Gender differences not examined<br>-Small sample size | Resilience related with anxiety and quality of life |
| **Yi, Vitaliano, Smith, Yi & Weinger (2010)** | **n=111 (63% T1, 37% T2)** 57% female. | Longitudinal; baseline and post 1 year | LOT<br>RSE<br>CIDS | SEM, repeated ANOVA | Higher resilience sig. predicted better HbA1c, and increased self-care | +Used SEM to confirm resilience measures<br>+Confirmed buffer effect of resilience | Resilience linked to diabetes |

| | | | | | |
|---|---|---|---|---|---|
| | Age range:<br>18-77 years | SMS<br>PAID<br>SCI<br>HbA1c | behaviours when facing increasing diabetes distress, suggesting buffering effect of resilience. | -Grouped type 1 and 2 together; need to be examined separately<br>- Although attrition rate analyses confirmed no sig difference, 23% of sample was still lost to follow up. | distress (where DDS is outcome variable) |
| | | | | | |

**Appendix 17:** Reflexive Diary Memos (General Discussion Points and Interview Notes for T2P8)



## Reflexive Memo – General Discussion

### Personal Reactions / feelings

→ Surprise / concern that individuals have never reflected on feelings such as resilience in context of diabetes before.
   ↳ maybe I am biased due to researching resilience
   ↳ I am not living with same stresses.

→ frustration with contradictory answers eg denying experiences of anxiety to then explain symptoms of anxiety.
   ↳ found it hard at first to ask why; felt like criticising them.

→ Discomfort / shocked / empathic at the lack of individuals being asked by HCPs about psych. wellbeing / MH.
   ↳ Aware of my own bias with negative healthcare (MH) experiences.

→ Felt happy that some participants told me they felt 'heard' and expressed gratitude that someone cared.
One participant actually teared up at it.

→ concerned at no. of people who didn't know their hbA1c levels

→

***Reflective Diary Entry #8 (T2DM P8)***

- *Worrying medication adherence – 15 units at night, but takes 4x per week (due to demanding job and forgetfulness).*

- *Avoidant behaviours – glucose testing (due to high levels disheartening her)*

- *Contradictory answers/possibly not thought out; Says no to diabetes-related to fatigue but had 10 days off with fatigue (after 100 hours overtime), but did not check her BG levels at all during this period. However, previously admitted she didn't want to check high levels, so how could she know? Should have followed up on this perhaps but did not want to cause distress or seem accusatory (i.e., how do you know if you didn't test?) Wanted to maintain consistency and avoid uncomfortableness, so carried on.*

- *Thoughts on LT cognitive processes; wonders if DM does affect, but avoids thinking about it because she feels other issues are ignored by HCPs, e.g., 'has no feeling in feet.'*

- *I've got no feeling in my feet now for about 6 years and everybody's gone 'oh that's diabetic neuropathy, you've just gotta live with it'… 'if that's the attitude the professionals are giving to me…then what is the point of, erm, not overly paying attention to it.'*

    - *She sounds apathetic – made me feel sorry for her, but I had complicated feelings because of her lack of care behaviours? External locus of control – she needs to motivate herself without depending on doctors.*
    - *I can relate to this feeling when seeking out mental health help for dermatillomania, and remember feeling crushed from HCPs lack of concern/condescension*
    - *But level of personal responsibility in diabetes care that one should acknowledge*
    - *Wanted to question, but again, felt very personal and worried questioning could shut down discussion*
    - *Perspective shift – I wonder if HCPs had said this in a matter of fact way, and possibly Dorothy inferred apathy/negativity?*
    - *I should/could have followed up on whether she addressed this with the HCPs?*

- *'Never given [resilience] much thought, just got on with it' feeling shocked/concerned with this statement given the avoidant care behaviours, and the fact she had never reflected on resilience.*
    - *Made me reflect on my own personal background – I have academic background in psychology and my own experiences with childhood trauma; perhaps feeling shocked about this is a by-product of my own circumstances? Normal levels might be different – some people may just not consider these factors in these ways? I will try to ground myself with comments such as*

*these. Maybe I need to be more empathic? More subjective and understanding in order to broach these topics – I am finding it hard to strike the balance between an objective academic approach and subjective nature of the research.*

- *Her diabetes does not react in a typical way – made me feel empathy, reinforces the idea that diabetes is an individual disease and not one size fits all, which is supported in the literature.*
- *But that, nobody is bothered to say "Oh, let's look at this." You know? I say it and people say 'nope, nope. You're wrong. It doesn't do that.' It does. I know my diet so because people are sort of 'put me in the box' as a stereotype, i've gone, 'Right, you treat me like that I'll do my own thing.' - experiencing resistance from HCPs about her diabetes – which is supported in literature. Made me feel sympathetic towards her about not feeling listened to.*
- *I hate the diabetes care in this country, I'm, I've asked for one of these, these things that go on your arm so you can scan by your phone; erm [Location] don't fund it so I got no chance of doing it, now if I have it privately, It's £150 a month. That su- well it sucks because, if you come from [location], you can have it. Why is diabetes a lot like cancer treatment? Why is it a postcode lottery? Made me feel existential about healthcare systems in the country, and I felt really bad for her. She sounded exasperated. Other participants have made similar comments about care and location differences.*
- *I remember getting frustrated with not having questions asked directly, I kept trying to redirect the conversation or follow up on points, but I had to ensure that this frustration did not come out in my tone or mannerisms or language. [possibly link to ADHD symptoms and being mindful of not rushing someone]*
- *I haven't got no… Yeah I've got no time for them, because I feel they've not taken the time to understand me. You know, when I say 'well the more exercise I do, the higher my sugar goes and they go 'well that's not right,' that's… and they think i'm a textbook and I've never been a textbook and my sugars have always run at about 12, 14. Always run high, you know?*
  *Noticing recurring theme of lack of support from HCPs – also made me think of there being two sides to every story, I felt sorry for both Dorothy and HCP's.*
- *Yeah… And…have you, have you ever had them ask about things like mental health and you know just everything as a whole? No, no. This is why I agreed to do this, 'cause I thought with my little simple- it might just help me get my head around my own situation and sort things out. – initial motivation to participate was to understand their own situation and talk about these things*

  *well, trouble is now when you say 'I'm phoning up about my diabetes' you have to see the "specialist nurse" who's not got diabetes. It's a bit like having a midwife who's never had a baby, you know?*

*Ethical considerations:*

*-Not knowing when to step in; wanting to advise but at the end of the day I am not there to provide any form of clinical guidance – but to listen to and hear their experiences. To comment on their diabetes management would feel inappropriate beyond the scope of the situation. However I do have difficult feelings when it comes to someone who seems to be displaying avoidant behaviours, their diabetes is very poorly controlled; I want to help but can't.*

*-I do wonder about the impacts of discussing with individuals things that they've never considered before in the context of their diabetes (i.e., did it encourage further reflection etc).*

*e.g.,*

*Emma, T1DM P3*

*Insight – felt she provided a lot of insight being both a HCP and a person with diabetes. Allowed her to be particularly empathic to those she cares for with diabetes.*

- *I don't quite feel like I've met my purpose in my life, like how I can help more people. But I think having talked to you that maybe there is that lack of knowledge that needs to be given. Hit me emotionally, felt like I'd provided help and insight to someone who also did the same for me.*

## 13. Glossary

**Anxiety:** *An affective disorder characterised by feelings of excessive fear and worry, that significantly impacts the occupational and social functioning of an individual.*

**Body Mass Index (BMI):** *A measure of body fat, calculated by dividing an individual's weight (KG) by their height in metres squared. A higher BMI is correlated with increased chance of long-term conditions such as T2DM and heart disease.*

**Cardiopathy:** *Disease of the heart.*

**Cognition:** *The mental process of acquiring knowledge and understanding through thought, experience and senses, and using this information to guide behaviour.*

**Confidence Interval:** *An interval estimate of an unknown population parameter; a confidence level of 95% indicates that 95% of the time the confidence intervals will contain the population parameter.*

**Confirmatory Factor Analysis (CFA):** *A statistical technique to verify the factor structure of a set of observed variables.*

**Diabetes Distress***: The significant and negative emotional response to coping with the demands of managing diabetes, including worry, frustration, discouragement and emotional burnout.*

**Effect Sizes (ES):** *The quantitative measure of the magnitude of differences between variables, i.e., the strength of the relationship.*

**Emotional Burden (ED):** *Emotional-related distress associated with the demands of living with diabetes (e.g., feeling overwhelmed).*

**Executive Function**: *Higher order, self-regulatory cognitive processes, such as working memory, attention and inhibitory processes, to allow the coordination of thought and action to achieve a specific goal (e.g., behavioural change).*

**Fatigue:** *An overwhelming and sustained feeling of exhaustion, that decreases one's ability to initiate and/or sustain attentional (mental fatigue) and physical activities (physical fatigue), including working effectively and functioning at a typical level in family or social roles.*

**Glucagon***: A hormone made by the pancreas, which triggers glycogen to convert back into glucose.*

**Glucose:** *A simple form of sugar known as a monosaccharide. It is a form of carbohydrate and the source of energy in cell function.*

**Glycogen:** *A stored form of glucose, typically in the liver and skeletal muscles.*

**Haemoglobin A1c (HbA1c):** *A measure of glycated haemoglobin (where glucose binds to haemoglobin in the bloodstream), to provide average blood sugar levels across 3-6 months.*

**Hyperglycaemia:** *An excess of glucose in the bloodstream.*

**Hypoglycaemia:** *A lack of glucose in the bloodstream.*

**Interpersonal Distress (ID):** *Interpersonal-related distress associated with the difficulties of living with diabetes (e.g., feeling that friends/family do not appreciate the difficulties of living with diabetes).*

**Mental Health:** *An individual's emotional and psychological well-being.*

**Model:** *A conceptual representation of a system of processes, ideas or events, to explain observable phenomena.*

**Nephropathy:** *Disease of the kidney(s).*

**Neuropathy:** *Nerve damage, often leading to pain, numbness or tingling in extremities.*

**Physician-Related Distress (PRD):** *Distress related to an individual's experience with their physician, as part of their diabetes healthcare (e.g., feeling their doctor does not take their diabetes-related concerns seriously enough).*

**Regimen:** *A prescribed course of medical treatment/diet/exercise to improve health.*

**Regimen-Related Stress (RRD):** *Distress related to an individual's regimen, as part of their diabetes management (e.g., feeling distressed from not being able to adhere to meal or exercise plans).*

**Resilience***: The capacity to adapt and maintain psychological and physical wellbeing in the face of adversity, through several attributes such as determination, personal strength, positive adaptation to stress, emotional regulation and supportive relationships.*

**Retinopathy:** *Disease of the retina.*

**Sexual Dysfunction:** *Recurrent problems with sexual desire, response/arousal, orgasm, and/or sexual pain.*

**Structural Equation Modelling (SEM):** *A combination of factor analysis and regression statistical techniques, that are used to examine a model of structural relationships between one or more measured variables and latent constructs.*

**T-Lymphocytes:** *A type of white blood cell that aids in immune responses and fighting infection.*

**Type 1 Diabetes Mellitus (T1DM):** *a chronic autoimmune disease characterised by the destruction of insulin-producing pancreatic beta cells, which prevents the body from producing sufficient insulin to adequately regulate blood glucose levels.*

**Type 2 Diabetes Mellitus (T2DM):** *a chronic disease caused by a result of insufficient insulin secretion and/or insulin resistance, which are strongly correlated with poor diet, sedentary lifestyle habits, and polygenic components (i.e., multiple associated genes).*