Recurrent Diabetic Ketoacidosis: A phenomenological case study exploring the experiences of young women with Type 1 Diabetes Mellitus

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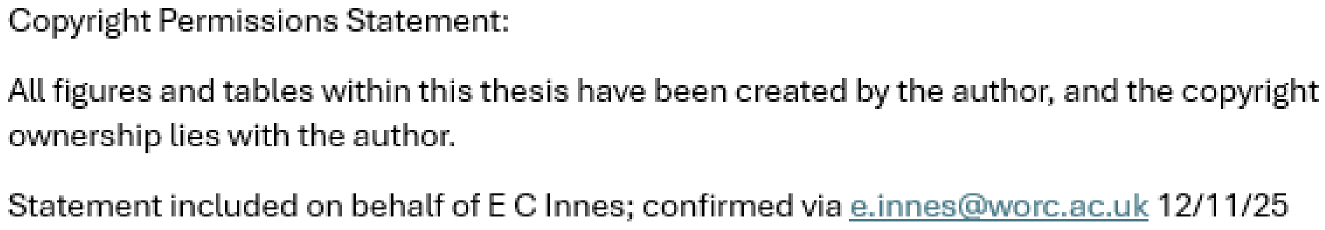
A thesis submitted in partial fulfilment of the University's requirements for the Degree of Doctor of Philosophy

University of Worcester

2024

Contents



Abstract

Introduction

Type 1 diabetes mellitus (T1DM) affects approximately 400,000 thousand of the United Kingdom's population and is characterised by an absolute lack of endogenous insulin production. Management requires complex decisions to be made on a daily reoccurring basis, and levels of distress and burden are unsurprisingly well documented across this population. If supplemental insulin is insufficient, the person will rapidly develop hyperglycaemia and, if uncorrected, diabetic ketoacidosis (DKA). This is a life-threatening acute complication often necessitating admission to an intensive care unit, with an increased risk of death. Despite DKA's impact on those with T1DM, the experience of developing and living through it has not yet been reported.

Methods

Five young women were recruited and interviewed, with nine semi-structured interviews completed over fifteen months. A phenomenological case study approach to analysing and interpreting interviews was utilised. Phenomenology aims to capture the uniqueness of experiences and phenomena. Drawing upon Merleau-Ponty’s (2014) philosophy by exploring the embodiment of experience and how individuals make sense of or perceive events over time. Analysis and philosophical interpretation are presented thematically to form the case study of recurrent DKA.

Findings

In total, seven themes were developed. Despite the initial questions remaining the same for both rounds of interviews, the themes differed over time. The themes for the first interviews were: 1) Diabetes is constantly on my mind; 2) The shaming and the blame; and 3) Fighting to stay alive. Four themes were developed from the second interviews**;** 4) Watching it constantly; 5) I feel really broken; 6) The importance of others and 7) I feel really broken.

Participants were profoundly affected physically and psychologically by having developed DKA, the legacy of which lasted beyond the initial hospital admission. They reported the overwhelming experience of being in DKA and having to give their bodies over to others to provide hospital treatment. There was a battle between the body and the mind both during the daily management of diabetes and during DKA which resulted in a disassociation between body and mind.

Conclusion

The case study highlights the fear of experiencing recurrent DKA. There were periods when the burden of daily diabetes management was overwhelming, and participants just wanted the normality of their old bodies back without diabetes. During these times, there was an internal battle between the mind's rationality and the body's experience. Still, these were inextricably intertwined, leading to the inability to prevent DKA from reoccurring. Participants felt blamed by health care professionals when DKA developed, causing delays in accessing emergency care. Using a phenomenological method in this case study provided the understanding that DKA was an embodied, temporal and corporeal experience for the young women in this case of recurrent DKA.

Acknowledgements

Completing this PhD thesis would not have been possible without the support of many others on this journey.

To the participants, Adele, Chloe, Laura, Mary and Phoebe (pseudonyms used), who freely shared their time and experiences of Diabetic Ketoacidosis and living with type 1 diabetes. Your candid honesty has provided invaluable information about the lived experience of DKA, without which this research would have been impossible. I sincerely thank you.

Associate Professor Theresa Mitchell, Professor Yvonne Thomas and Professor Eleanor Bradley were my supervisors. Your wisdom and critique regarding the research have challenged my thinking and enabled me to grow and develop as a researcher and nurse. I will miss our supervision sessions on Teams first thing in the morning or late in the evening in New Zealand to accommodate the difference in time zones! Thank you to Dr Ros Weston, who has supported me with PhD transfer and the mock viva.

To my husband Scott, sons Tom and Adam, and parents Mary and Richard, who have put up with me studying during evenings and weekends and being distracted from the rest of family life. Your support and belief in what I could achieve have been invaluable. I look forward to becoming present again and spending more time with you all. Thank you to Katherine Crompton for helping me format.

With the support of Ellie, a fellow PhD student now Dr. Hill, our study sessions were always beneficial in keeping the momentum to reach completion. Dr. Janice Clarke encouraged me to undertake the PhD and listened to me discuss the research. Finally, to my colleagues at work who supported and encouraged me over what must have felt like an eternity.

Glossary of terms

Blood glucose monitoring: A test completed to measure the glucose levels in a small sample of capillary blood.

Continuous glucose monitoring: Glucose measurement from interstitial fluid

Continuous subcutaneous insulin infusion (CSII): Insulin is delivered continuously by an insulin pump via a cannula into the subcutaneous tissue.

DAFNE: Dose Adjustment for Normal Eating is a validated structured diabetes education course for type 1 diabetes.

Diabetes: A disorder of the carbohydrate, fat and protein metabolism.

Diabetic Ketoacidosis: Develops when insufficient insulin is circulating to transport glucose into the cells. Diabetic Ketoacidosis causes raised glucose and ketone levels, which cause the blood's acidity (pH) to fall below the norm of a pH <7.33. This causes acidosis and severe dehydration, which can be life-threatening.

Diabetes Specialist Nurse (DSN)- A nurse who will have completed post-graduate education specialising in diabetes.

Hypoglycaemia: Clinically classed as a glucose level below 4 mmol/L. Symptoms experienced may include shaking, sweating, tiredness, difficulty concentrating, and headache.

Ketones: Produced when there is insufficient circulating insulin as a result of breaking down fat and protein to utilise alternative energy supplies. Ketones change the acidity of the blood, leading to diabetic ketoacidosis in type 1 diabetes.

Insulin: Insulin is a hormone required to facilitate the transfer of glucose into the cells.

NHS: National Health Service is a publicly funded service free at the point of access.

Type 1 diabetes: An autoimmune or genetic condition that results in the absence of insulin excretion, raised glucose levels and the production of ketones.

Type 2 diabetes: Characterised by insulin resistance resulting in elevated glucose levels. Causation can be genetic and environmental.

Chapter 1 Background context

1.1 Introduction

In this introductory chapter, I will define the purpose and rationale underpinning this doctoral study which was designed to investigate the lived experience of recurrent diabetic ketoacidosis (DKA) through a phenomenological case study. Recurrent DKA has not previously been explored from the perspectives of those with lived experience despite their increased risks of morbidity and mortality.

1.2 Defining diabetes

Diabetes is an endocrine system disease with glucose and insulin dysregulation (Holt *et al.,* 2017). The hormone insulin is secreted via the beta cells in the pancreas in response to glucose levels; this process either becomes impaired, as occurs in Type 2 diabetes mellitus (T2DM) or abruptly declines, as in Type 1 diabetes mellitus (T1DM) (Holt *et al.,* 2017*;* DiMeglio, Evans-Molina and Oram, 2018). Whilst both T1DM and T2DM come under the umbrella term ‘‘diabetes,’’ aetiology and subsequent clinical management differ. Worldwide, the increasing rate of diabetes has been classed as a public health epidemic by the World Health Organisation (WHO) (WHO, 2018). Globally, the number of people diagnosed with diabetes continues to rise exponentially, with 8.4 % of adults now having a diagnosis of diabetes (WHO, 2018). National Health Service Digital (NHS Digital) reported in the National Diabetes Audit in England for years ending 2020-2021 that 270,935 people had a diagnosis of T1DM, equating to a rise of 22,695 since the 2017-2018 data (NHS Digital,2023). The reasons for the increasing prevalence of T1DM are not yet fully understood. Neither the National Institute of Health and Clinical Excellence [hereafter NICE], (NICE, 2022) nor the National Health Service (NHS) Digital (2022) reported on the difference between males and females diagnosed with T1DM. However, males have a higher prevalence of T1DM than females (Gale & Gillespie, 2002; Mauvais-Jarvis, 2017; Östman *et al.,* 2008). Tatti and Pavandeep's (2022) review adds a note of caution that while this is true for Europeans the same gender split cannot be extrapolated to people from African or Asian backgrounds. Diabetes has been calculated to ‘‘directly cause 1.5 million excess deaths worldwide annually’’ (WHO, 2018).

The relative prevalence of diabetes classification is broadly 90% T2DM and 5-10% Type 1 (Holt *et al.,*2017). Other sub-classifications of diabetes are beyond the scope of this thesis. As DKA primarily occurs in the T1DM population, this work will focus solely on those with T1DM; however, it is important to outline the varying aetiology and treatment modalities for each diabetes type. T2DM usually presents later in adulthood but can develop in late childhood (DeFronzo, *et al.,* 2015; Holt *et al.*, 2017). The causation of T2DM is varied and includes a genetic component and increased risks of glucose dysregulation that occur with age and central abdominal obesity. In T2DM, insulin continues to be produced by the beta cells in increasing levels, but due to insulin resistance, the transport of glucose into the cells is incomplete, causing higher levels of circulating insulin (DeFronzo *et al.,* 2015; Holt *et al.*, 2017).

In contrast, T1DM is classified as an autoimmune condition that destroys pancreatic beta cells (DeFronzo, *et al.,* 2015; Holt *et al.*, 2017; Hull and Khan, 2015; Levey, 2016). T1DM is more commonly diagnosed in childhood and younger adults but can occur at any age across the lifespan (Levey, 2016). Once the beta cells are destroyed, glucose levels rapidly rise. There is an acute onset of osmotic symptoms such as polydipsia (thirst) and polyurea (excess urination), lethargy and weight loss which, in some instances, will result in DKA at the point of diagnosis (DeFronzo, *et al.,* 2015; Hull and Khan, 2015; Holt *et al.*, 2017). Diabetic Ketoacidosis (DKA) develops when glucose levels rise excessively due to a lack of circulating insulin. This reflects an acute, life-threatening complication of T1DM (DeFronzo, Ferrannini & Zimmet 2015; Farsani, Brodovicz and Soleymanlou, 2017 pp. 789-803).

Due to the abrupt failure of the beta cells to produce insulin, the essential treatment for T1DM is the replacement of endogenous insulin. This is administered via subcutaneous (s/c) injections, s/c infusion, or intravenous infusion when acutely unwell and in cases of DKA. The dose of insulin is rarely fixed, requiring adjustment according to dietary intake, activity levels, current glucose level and illness. The responsibility of enacting this process is handed to the person with T1DM once they have received initial education from the diabetes health care professionals (HCP) (NICE, 2022; Markowitz, Garvey and Laffel, 2015). Diabetes self-management (DSM) requires perpetual decision making, mathematical literacy and anticipatory behaviours to counteract rapidly changing glucose levels, which are burdensome (Speight *et al.*, 2020).

In addition to the immediate requirement to inject insulin to feel well and maintain physiological homeostasis, there are longer-term goals of treatment to reduce the risk of developing complications such as cardiovascular disease (DCCT,1993). Home monitoring of glucose levels via finger prick glucose testing or a continuous glucose sensor enables real-time changes to be made to insulin doses. In addition, surveillance is offered at clinic appointments, assessing blood pressure, renal function, cholesterol, and glucose control via an HbA1c blood test, which measures the glucose levels over the past two to three months, leading to a judgement to be made regarding the quality of diabetes control during this period (Barnard & Holt *et al.* 2017, p. 319).

1.3 Diabetic ketoacidosis

Several thresholds must be exceeded to diagnose DKA, as illustrated in Figure 1 below (NICE, 2022; JBDS, 2023).

Diagnostic criteria for diagnosing DKA

Diagnostic criteria for DKA

- Glucose ≥ 11mmol/L
- pH < 7.3
- Bicarbonate (HC03) ≤16mmol/L
- +2 ketones or ≥3mmol/L

Figure 1.

The person living with T1DM needs to develop the ability to differentiate between common acute illnesses such as colds, influenza, norovirus, and the early symptoms of DKA. These early symptoms may present as increased thirst, urination, and lethargy. Vigilant monitoring of glucose and ketone levels is essential for early signs that DKA may be developing. This information can be used to make decisions regarding corrective insulin doses, which should significantly reduce the risk of subsequent DKA (JBDS, 2023). It is essential to note that even these actions in severe intercurrent illness are not always sufficient to mitigate DKA development.

The increased mortality rates for people admitted to hospitals with DKA in the UK are reported to range between 1 and 5 % (Gibb, Teoh, Graham & Lockhart, 2017; Misra & Oliver, 2015). Reflecting on my clinical experience, I vividly remember several young patients who died with recurrent DKA. These were people whom I had got to know during their previous admissions and outpatient appointments. Their deaths were poignant as they were young adults, and there was no obvious explanation as to why DKA had occurred again, as both were knowledgeable regarding sickness management and hyperglycaemia. Their deaths caused me to reflect on what additional factors the diabetes team were unaware of that may have contributed to their deaths.

The underlying causation of DKA is reported as variable, but DKA is commonly attributed to high glucose levels that may be caused by infection, myocardial infarction, newly diagnosed diabetes and self-management issues such as omission of insulin either by missing sub-cutaneous injections or insulin pump failure (Kitabchi, Umpierrez & Murphy 2015 pp. 799-803; Moffett *et al.*, 2013; Yan *et al.*, 2017; Flores *et al.*, 2020). Gibb *et al.* (2016) found in a retrospective Scottish cohort study that multiple admissions for DKA increased the mortality risk to 23.4% over a six-year follow-up period; however, even for those with a single episode of DKA, there was a 5.2% risk of death. The risk of death increased for each admission with DKA; the population in the study by Gibb *et al*. (2016) was not dissimilar to the two patients I referred to and reflected on earlier in this chapter.

NHS diabetes care in the United Kingdom (UK) is underpinned by the NICE, (2022) guidance; many areas of diabetes management are covered, including sick day rules education, which encompasses the effects that illness has on both blood glucose and ketone levels, how to correct blood glucose, if elevated, with additional units of insulin, and when to access urgent medical care (JBDS, 2023; NICE, 2022). This education is given during diagnosis and periodically at clinic appointments, during structured diabetes education and following admission for DKA (NICE, 2022; JBDS, 2013).

Over the past two decades, there has been a plethora of studies examining morbidity, mortality and perceived causes of DKA (Watts, O'Hara and Trigg, 2010; Fritsch *et al.*, 2011; Chafe *et al.*, 2015; Gibb *et al.*, 2016; Farsani, Brodovicz and Soleymanlou, 2017; Semenkovich, *et al.,* 2019). These studies showed a correlation between HbA1c level and the development of DKA and poorer long-term outcomes. The conclusions suggest the risk of DKA perpetuates even after the initial episode resolves. In a group of young adults, DKA in the preceding four years was a predictor for subsequent DKA and higher HbA1c levels (Hodnekvam *et al.*, 2023). Higher prevalence rates for DKA have been attributed to being female (Weinstock *et al*., 2013; Cooper *et al*., 2016). Butalia *et al.*, (2013), however, found limited differences in the gender differences of those admitted with DKA but did report increased admissions for those with elevated HbA1c levels, gastroparesis and a short duration after being diagnosed with diabetes.

People with T1DM who develop recurrent DKA have poorer long-term outcomes, including an increased risk of death (Gibb *et al.*, 2016; Farsani, Brodovicz and Soleymanlou, 2017; Yan *et al.*, 2017). The prevalence of DKA and poor outcomes warrants further exploration of causation beyond the physical causes of insulin omission to consider the psychosocial circumstances of individuals and the illness trajectory of living with T1DM. This will further the understanding of how people with T1DM manage their diabetes on a daily basis and during times of acute illness.

1.4 Rationale for the study

Starting this doctoral journey was many years in the making. Over my time as a Diabetes Specialist Nurse (DSN), I had reflected on the patients I had met and nursed and I felt a nagging uncertainty that there was more to DKA than I had read in textbooks. Following a move into an academic role, I knew this was the area I wanted to research further. Most of my clinical nursing career has been spent in the speciality of diabetes. I have always approached my nursing practice with curiosity, wanting to improve the experience and outcomes of those with diabetes. For example, I developed a DKA care pathway for my BSc Independent Study; content for the ‘Think Glucose’ project as part of a national team with the National Health Service (NHS) for Innovation and Improvement (NHSII, 2010); and co-authored a paper on ‘‘Recurrent diabetic ketoacidosis after changing pan devices’’ (Bhardwaj, *et al*., 2006). As my thinking deepened, I wanted to understand more about why some patients experienced repeated admissions due to DKA and to interrogate further what was happening to patients before their hospital admission and after they were discharged home. As I approached this research, I increasingly realised that some people fall through the gaps of traditional diabetes care by either not accessing appointments or not being able to apply their knowledge of how to manage hyperglycaemia. Previous conversations with those admitted in recurrent DKA, who were able to recount the steps of sickness management, would suggest that current care is not meeting their needs. Current literature would support this view (Butalia *et al.*, 2013; Cooper *et al.*, 2016; Gibb *et al.*, 2016; Brandstaetter *et al.*, 2019).

The delivery of NHS diabetes care has become increasingly standardised since the publication of the National Service Framework for Diabetes in 2002 and the NICE Type 1 Guidance (first published in 2015 and updated in 2022), which recommends a structured education programme six months post-diagnosis to support those living with T1DM to independently manage their condition. Access and uptake of education vary. NHS Digital (2018) reported that only 50% of people were offered structured education, and previous studies suggest that uptake of education is limited (Horigan *et al*., 2017; Heller *et al*., 2020). Diabetes UK, a national diabetes charity, highlight diabetes education as reflecting a missed opportunity (Chafe *et al.*, 2015; Diabetes UK, 2015; Horigan *et al.*, 2017). Coates *et al*. (2018) conducted a qualitative study which was designed to investigate the reasons for non-attendance at diabetes education sessions, reporting that finding time to attend and the lack of HCP enthusiasm during referral were key factors in the failure to take up the offer of a place. Even without attendance at a structured education course, sickness management education is a rudimentary element of initial diabetes care and education, yet some people living with T1DM repeatedly develop further episodes of DKA (Gibb *et al.*, 2016; Dhatariya, Skedgel and Fordham, 2017; NICE, 2022).

Research in this area has largely relied on the economic and outcome data from DKA admissions. However, the rates of DKA mortality remain stubbornly consistent, correlating with reflections on my own nursing experiences. Therefore, this work is designed to create new knowledge by providing additional insights into the pathology of recurrent DKA from a fresh perspective; the lived experiences of those who have developed recurrent DKA.

1.5 Introduction to the Phenomenological Case Study

Underpinning this research is the philosophy of Phenomenology. A phenomenological case study will be employed to explore the experience of participants with recurrent DKA, what they felt was happening to their bodies during such times, and how they situated their episodes of DKA within the context of their lives and social constructs. Merleau-Ponty's (2014) philosophy frames the research, notably the ''Phenomenology of Perception.'' A close examination of how T1DM is assimilated into the lives of people living with T1DM, including the interplay between the physical and psychological experiences encountered within their changed lives, and how their experiences of DKA link to their experiences of living with T1DM will help us to further understand how patients with recurrent DKA attribute meaning to their experiences. Phenomenology enables me, as a doctoral researcher, to develop an understanding of the body in DKA from a different perspective. During the development of DKA, the body experiences physiological changes. The research aims to further understand the experiences and perceptions of the changes that result in DKA, in the participant's own words. Phenomenology can be used to aid understanding of DKA from the lived perspective and how this can be incorporated to inform the future practice of diabetes specialist nursing. For instance, the DSN can draw upon a different body of knowledge to inform their education and care for those with recurrent DKA. Utilising prior knowledge is, according to Crowe *et al*., (2011), a critical element of case study methodology. Drawing upon the rich findings from five participants with some bounded characteristics will enable recurrent DKA in young women to be studied in-depth, enhancing our understanding of the experience of DKA for those living with T1DM (Crowe *et al*., 2011; Heale and Twycross, 2018; Sandowoski, 2011).

1.6 Contribution to Knowledge

Research has focused on reporting the morbidity and mortality rates, plus the economic costs of developing DKA in T1DM. It has offered a minimal understanding of what it is like to develop DKA from the experience of those with T1DM. Following exhaustive literature searches, which were repeated in 2023, I could not locate any studies that directly captured the lived experience of recurrent DKA. Without this, it is difficult to understand whether current care provision is sufficient to meet the needs of this group, who carry a significant burden of morbidity and mortality. This study will fill this gap, generating new knowledge and making an important contribution to evidence that underpins clinical practice and diabetes education provision in the UK.

1.7 Chapter summary

This chapter has set the scene for the study and drawn attention to the gap in the current literature regarding the experience of recurrent DKA. Importantly, it also demonstrates the gravity of recurrent DKA and the higher prevalence of morbidity and mortality in a predominantly young population.

As a doctoral researcher working in academia, it is essential for me to interrogate and, where necessary, to challenge the status quo that exists for the delivery of care. The link between academia, research and clinical practice is essential to ensure the nursing profession can be supported to deliver care based on the best available evidence. As this research will highlight, where knowledge does not already exist, nurses should utilise methods to capture and develop what is known about complex areas such as recurrent DKA. Completion of research can aid the development of nursing practice, and for this study, the findings that illustrate what people with T1DM experience when they have DKA will be important for diabetes care.

Chapter 2 Literature Review

2.1 Chapter overview

This chapter contains a narrative literature review that summarises research conducted to understand the experiences of people living with type one diabetes mellitus (T1DM). The chosen methods for the narrative literature review will be discussed in the context of the underpinning theoretical frameworks. The findings from the narrative literature review will be presented thematically.

2.2 Background and Context

2.2.1 Socio-determinants of Health in Type 1 Diabetes Mellitus

The health, well-being, and life expectancy of our population are impacted by social factors such as finance, employment, housing, education attainment, and physical and social environments. These individual elements are known collectively as the social determinants of health (WHO Regional Office for Europe, 2014; Public Health England, 2017; Marmot, 2020). These social determinants of health can disproportionately affect a person's longer-term health and well-being, reducing both quality and longevity of life (Marmot, 2010, 2020).

Managing and living with T1DM is complicated. In T1DM, if glycaemic control remains at sub-optimal levels for prolonged periods, this is known to increase the risk of micro and macrovascular complications in addition to neuropathy (Diabetes Control and Complications Trial Research Group *et al.*, 1993; Marmot, 2009; World Health Organisation, 2010; Apperley and Ng, 2017; Diabetes UK, 2023). Where there is consistent social support from family members or significant others, it can have a positive impact on diabetes self-management strategies; if present, those with T1DM are more likely to reach therapeutic targets for glycaemic control and reduce the risk of diabetes complications (Walker *et al.*, 2015; Apperley and Ng, 2017; Willers *et al.*, 2018).

In line with this, it is well documented that family support can help prevent hospital admissions for DKA, but this depends on family/significant others' support being available (Hill *et al.*, 2015; Apperley and Ng, 2017; Hill, Ward and Gleadle, 2019). Income can be a predictor of avoidable diabetes hospital admissions, with higher rates for patients with a lower socioeconomic status (SES) (Apperley and Ng, 2017; James *et al.*, 2021). Several studies report a link between increased DKA admissions in those that have lower socioeconomic status, educational attainment, having been prescribed anti-depressants, difficulty self-managing T1DM, and poor glycaemic control as measured by Haemoglobin A1c (HbA1c) levels compared to those without DKA admissions (Farsani *et al.* 2017; Gibb *et al.*, 2016; Fritsch *et al.*, 2011 & Watts, O'Hara & Trigg, 2010).

Despite the importance of social determinants, including SES, specialist diabetes teams do not consistently consider how diabetes care needs may contextually differ, or adapt their approach as appropriate for the individual within their social context (Chen *et al.*, 2015; Apperley and Ng, 2017; Seear *et al.*, 2019). The UK is not unique in having guidelines for managing T1DM that ensure consistency in offering evidence based care to the diabetes population. However, this means that those who may require additional support are not always accounted for (NICE, 2022; Wylie *et al.*, 2019) and studies have called for further support to help HCPs consider how to support patients to manage the complexity of living with T1DM at the point of diagnosis and regularly post-diagnosis (Harris *et al*., 2018; Fazeli Farsani, Brodovicz and Soleymanlou, 2017; Gibb *et al.*, 2016; Fritsch *et al.*, 2011; Hill *et al.*, 2015; Apperley and Ng, 2017; Hill, Ward and Gleadle, 2019). Early identification of those with T1DM who face social and economic challenges is essential, given the importance of these particular social determinants as risk factors for recurrent DKA (Cooper *et al.*, 2016; Everett and Mathioudakis, 2019; Forbes *et al.*, 2020).

2.2.2 **Diabetes distress**

T1DM occurs abruptly, and being diagnosed with T1DM has been noted to evoke significant feelings of distress (Ng *et al.*, 2022). Once diagnosed, there is the requirement to adjust quickly to a new, often less carefree, way of life (Phillips, 2017 pp. 319-322; Holmström Rising and Söderberg, 2022). Patient experiences at diagnosis have been suggested to follow the five stages of the Kubler-Ross (1969) grief cycle (Dunning, 2020, p. 471).

- Denial and isolation
- Anger
- Bargaining

- Depression
- Acceptance

Within healthcare practice, the five stages of grief are rarely acknowledged for those who have no immediacy of dying (Hill *et al.*, 2015; Fraser, 2020). There is currently pressure on the provision of psychological wellbeing services within the NHS. NHS referrals to services designed to help patients adjust to a diagnosis have focused on support for patients referred via oncology or palliative care services. There is little equivalence in UK adult diabetes services, with a limited offer relating to psychological care as part of routine diabetes care. Despite the efficacy of such interventions in reducing diabetes related morbidity, there continues to be a separation in health care provision, treating the physical or the psychological, but rarely in tandem (Winkley *et al.*, 2006; Hagger *et al.*, 2016).

The impact of a diagnosis of T1DM has been identified as ‘‘life changing,’’ demonstrating the psychological impact of this condition (Hill, Ward and Gleadle, 2018). At the point of diagnosis, changes occur that impact every aspect of life, including feelings about their body, their everyday routines, personal identity and how others perceive them (Holmström Rising and Söderberg, 2022). Type 1 diabetes is most frequently diagnosed in children and young adults (DiMeglio, Evans-Molina and Oram, 2018). Self-managing T1DM requires a significant transformation in daily activities and psychological adjustment not only for the young adults but also for their family, friends and teachers (Holmström Rising and Söderberg, 2022).

Adolescence can be a challenging life stage to navigate, more so when complicated by a diagnosis of T1DM (Whittemore, 2010; Sperling*, et al.*, 2014). Chilton and Pires-Yfantouda (2014) grounded theory study reported acceptance as a staged process in adolescents with T1DM. The time required to adapt to the diagnosis was frequently inhibited if the social support was diminished. Similarly, Harazneh, Malak & Ahmad (2024) reported a significant burden in self-management which also impacted the acceptance of a T1DM diagnosis. Such difficulties have a continued adverse effect on the efficacy of self-management and can lead to maladapted behaviours in young people with T1DM (Whittemore, 2010; Jaser *et al.*, 2012; Rewers *et al*., 2014).
The abrupt life change once T1DM is diagnosed is not always fully acknowledged in health care provision; psychological care forms part of the paediatric diabetes best practice tariff, with annual documented assessments and referrals as necessary, but it

is not yet routine for adult diabetes care (NHS England, 2022). In 2015, 76% of adults with diabetes in the UK did not have routine access to psychological care (Diabetes, UK, 2015). The current NICE (2022) Type 1 management guidelines only refer to ‘‘psychological care’’ on four occasions. This starkly contrasts the Australian T1DM guidelines, which refer to ‘psychological’ on 157 occasions (Australian Pediatric Endocrine Group-Australian Diabetes Society *et al.*, 2011). The consensus guidelines for the diabetes associations of both Europe and America now provide a significant focus on psychological care, reporting that the stages of diagnosis and development of diabetes complications are vital points that increase the risk of substantial diabetes distress (Holt *et al.*, 2022).

Diabetes distress is defined as the psychological impact that living with T1DM has on everyday life, such as interactions with food, activity, social activities and significant others (Polonsky, *et al*., 2005; Joensen, Almdal and Willaing, 2016; Jones *et al.*, 2016; Dennick, Sturt and Speight, 2017; Hessler *et al.*, 2017). It is enduring and permeates through an individual's life (Dennick, Sturt and Speight, 2017; Due-Christensen *et al.*, 2019). Having T1DM can cause guilt, with many feeling a sense of failure by not being able to achieve the glycaemic targets discussed with their diabetes team; parameters for these targets originate from research trials and national guideline advisory groups (Diabetes Control and Complications Trial Research Group *et al.*, 1993; Sturt *et al.*, 2015; Joensen, Almdal and Willaing, 2016; Litterbach *et al.*, 2020; Hernar *et al.*, 2021).

Diabetes distress can be differentiated from the experience of clinical depression caused by diabetes. However, if not addressed, distress can lead to a depressive illness developing (Fisher *et al.*, 2012; Balfe, Doyle, *et al.*, 2013). It is easy for clinicians to overlook or miss signs of distress and assess instead for symptoms of depression, the prevalence of which is estimated to be between 10-20% in the T1DM population (Barnard, Skinner and Peveler, 2006; Fisher, Gonzalez and Polonsky, 2014; Dieter and Lauerer, 2018).

Moreover, the tools available to define diabetes distress are varied, and no one tool is used consistently (Fisher *et al.*, 2012; Hilliard *et al.*, 2018). Dennick, Sturt, and Speight (2017) aimed to define the term diabetes distress using a narrative review of participants' experiences to develop a ‘‘conceptual model.’' Reviewing the current questionnaires for assessing diabetes distress, they identified fifty-three potential scales, concluding that there is both inconsistency and variance regarding what elements of distress and psychological well-being are under evaluation (Dennick, Sturt and Speight, 2017). This may raise questions regarding the appropriateness of assessing distress using a questionnaire, which is frequently completed alone. Language is essential in diabetes care and is known to be valued in interactions with healthcare professionals. Yet, Dennick, Sturt, and Speight (2017) found that the wording of such questionnaires could also evoke guilt and distress in participants with questions about such behaviours as blood glucose monitoring, which HCPs play an active role in assessing (Lloyd *et al.*, 2018). The lack of psychological education for diabetes teams and challenges in selecting a Patient Reported Outcome measure (PROM), may impede their routine use in diabetes clinics. Even where HCPs identify distress, there is limited direct guidance for them to follow to support individuals or onward referral routes (Sachar, Willis and Basudev, 2020; NICE, 2022). This is seemingly a missed opportunity given that earlier tailored intervention has, in small sample sizes, shown efficacy in reducing the recurrence of DKA (Garrett *et al.*, 2023; Hart *et al.*, 2024).

Those living with T1DM are, at a minimum, invited to attend appointments to assess their diabetes and complete the eight diabetes care processes (NICE, 2022; NHS Digital, 2022). The eight care processes stipulated include measuring ‘‘HbA1c, Blood Pressure, Serum Cholesterol, Serum Creatine, Urine Albumin/Creatine Ratio, Foot risk Surveillance, Body Mass Index, and Smoking history’’ (NHS Digital, 2022). For many with T1DM, this ‘annual review’ focuses on evaluating the bio-medical markers of diabetes management such as HbA1c, cholesterol and kidney function, which verifies to the clinician the impact of home diabetes management and if further escalation of treatments is required. There is little emphasis on the aspects of care that are the priority for the patient, such as distress (Diabetes UK, 2017; Litterbach *et al*., 2019; Hendrieckx *et al*., 2020). This may explain why only 80% of patients achieved all the tests in the most recent audit (NHS Digital, 2022). The funding for primary care partly drives this focus on measuring the eight care processes (NHSE, 2017; Forbes *et al.*, 2017). In the UK, primary care has specific targets for glycaemic control contained within the Quality and Outcomes Framework, with GP practices receiving funding dependent on the percentage of patients with diabetes reaching an HbA1c target of 58 mmol/mol or below (NHSE, p.12, 2020).

The value of such episodes of care cannot be underestimated; during the Covid-19 pandemic, many of these routine care processes ceased. Subsequently, an excess of 7000 diabetes-related deaths have been reported in the UK since the pandemic began in 2020; these are not from Covid-19 itself but missed opportunities to optimise diabetes control (Iacobucci, 2023; Diabetes UK, 2023). This was not unique to the UK, with the USA also reporting an increase in excess deaths with middle aged and adults from non-Caucasian backgrounds adversely affected (Lv *et al.*, 2022). Therefore, it is easy to see why clinicians were focused on achieving glycaemic control as close to physiological normal for their patients based on the original outcome evidence provided regarding reduction in both micro and macrovascular complications reported by the DCCT group in 1993 (Diabetes Control and Complications Trial Research Group *et al.*, 1993; Holman *et al.*, 2020; Fedeli *et al.*, 2022; Lv *et al.*, 2022). Given the burden of premature mortality from diabetes after the Covid-19 pandemic, it will be essential for healthcare systems to level back up from the delays caused by missed diabetes care, ensuring that all people with diabetes can access regular appointments (Fisher *et al.* 2020; Mohseni *et al*., 2021; Khunti *el al*., 2022; Diabetes UK, 2023).

The HbA1c level can be viewed as a predictor of the development of DKA and longer-term chronic micro and macrovascular complications (DCCT, 2003; Govan *et al.*, 2011, 2012; Bradford *et al.*, 2017). Clinical conversations to support improving HbA1c levels whilst well intentioned and utilising research evidence can invoke a sense of guilt or failure regarding individuals with T1DM despite this not being clinicians' intention, perpetuating diabetes distress (Kibbey *et al.*, 2013; Lloyd *et al.*, 2018; Hill, Ward and Gleadle, 2019; Dickinson, Guzman and Wooldridge, 2023). This raises questions about how HCPs navigate from utilising research findings to prevent excessive morbidity and mortality whilst not causing undue additional distress to those living with T1DM (Skinner, Joensen and Parkin, 2020).

Hendrieckx *et al.*, (2020) examined the willingness and frequency of adults with diabetes who need to speak about diabetes distress during a clinical appointment. This was a non-selected or convenience sample that included both T1DM and Type 2 diabetes mellitus (T2DM) data analysis separated the results according to type of diabetes. In the T1DM group, 51% reported being asked about their wellbeing living with diabetes and if they wanted to talk about it. There may be cultural and organisational differences as this study was completed in Australia; whilst there remains significant room for improvement, the Australian emphasis on psychological care in the national T1DM guidance should continue improving access to this neglected care element (Hendrieckx *et al.*, 2020).

The first outward signs of diabetes distress may be the subsequent failure to attend additional clinic appointments, individuals avoiding what they perceive will be criticism of how they manage their diabetes (Brewster *et al.*, 2020). In 2017, the American Association of Diabetes Educators and the American Diabetes Association produced consensus statements about language in diabetes care (Dickinson *et al.*, 2017). This provides similar content to the NHS Diabetes report Language Matters, a document co-created with people living with diabetes and professional groups regarding the phrasing they found acceptable when discussing diabetes (Lloyd *et al.*, 2018; NHS England, 2018). All three consensus reports from the UK, the United States, and Australia provide similar suggestions to clinicians regarding language. The critical challenge is for healthcare commissioners and providers to consistently adopt these recommendations by clinical staff to avoid the harm that inappropriate language can cause to those living with T1DM (Dickinson *et al.*, 2017; Dunning, Speight and Bennett, 2017). A wrongly made comment can have a long-lasting detrimental effect on subsequent diabetes management and future relationships with diabetes HCPs (Dickinson, Guzman and Wooldridge, 2023).

Additional research is required to determine the interplay between the underlying causes of diabetes distress and the risks this poses to the development of recurrent DKA in susceptible patients. The importance of language and the feelings that this evokes in PWD when clinical encounters are perceived to be judgemental and non-therapeutic, leading to insulin omission, also warrant further investigation.

2.2.3 **Engagement with diabetes health care professionals**

HCPs are a crucial element in providing diabetes care to those living with T1DM. Their role is to support the individual in managing T1DM to improve their quality of life and reduce the risk of acute and chronic complications; in England, diabetes care is delivered based on guidance from NICE’s (2022) Type 1 diabetes guideline. The interaction and acceptability of engagement with diabetes care settings and HCPs is a critical element of diabetes care, with the outcomes of consultations having a lasting effect on how diabetes can be subsequently managed (Kibbey *et al.*, 2013; Hill, Ward and Gleadle, 2019; Skinner, Joensen and Parkin, 2020). Despite the importance of care, Diabetes UK (2015) estimated that just three hours per year are spent with an HCP for those living with diabetes (NHSE, 2018). However, there is no stipulation of the expected time required to self-manage diabetes in the NICE (2022) T1DM guidelines. In stark contrast to this time is the estimation by diabetes educators in America that an adult managing diabetes requires four hours daily of self-care activities (Shubrook *et al.*, 2018). These activities can include meal planning, monitoring of glucose levels, administration of insulin, the dose of which is calculated from current glucose, planned food intake and activity levels. The impact of this extra time spent away from usual daily activities such as work is not always fully acknowledged (Hansen *et al.*, 2018). Diabetes HCPs are essential in supporting those with T1DM to accept and adapt to their condition (Beran, 2014; Hirjaba *et al.*, 2015; Dunning, Speight and Bennett, 2017; Simms, Baumann and Monaghan, 2017).

Diabetes Specialist Nurses (DSNs) are an integral part of the diabetes team for patients with responsibilities, including supporting patients in managing and living with diabetes. The body is irrevocably changed following the development of T1DM, but clinicians and educators do not always acknowledge the importance of how a condition such as T1DM affects the body (Draper, 2014; Harrison, Kinsella and DeLuca, 2019; Keller, 2020). In the development of diabetes, where there are abrupt internal changes to the body affecting the storage of carbohydrates, fat, protein and cellular energy production but little to see externally, there is limited focus on these other more abstract aspects of diabetes care as the urgent priorities are to educate about insulin, glucose levels, diet, and exercise (Lim and Taylor, 2017, pp.305-309). Yet patients frequently feel there is far too much focus on these elements of practical tasks and less on how they are managing to live with diabetes (Johansson *et al.*, 2016; Due-Christensen *et al.*, 2019; Ndjaboue *et al.*, 2020). For some, attendance at the diabetes clinic not only evokes feelings of distress regarding living with diabetes but also a feeling of little value of the benefits of attendance due to the transient relationships with HCPs (Lawson *et al.*, 2005; Ndjaboue *et al.*, 2020; Berkovic *et al.*, 2022).

Hill *et al.'s* (2015) grounded theory study investigating a young adult cohort with both T1DM and end-stage renal failure reported it is not the access to diabetes care itself that is the issue for young adults with T1DM but the acceptance of attending diabetes services themselves. This correlates with poor engagement in attending diabetes appointments for those who have experienced recurrent DKA despite repeated attempts by diabetes clinicians to engage with them (Cooper *et al.*, 2016; Brewster *et al.*, 2020). Forbes *et al.* (2020) articulated this ''as putting the pieces together.'' Discharge home after admission for DKA does not necessarily enable a person to resume their life with diabetes again. There are complex elements to address, often whilst feeling the aftereffects of having had DKA and the impact this causes on both the body and mind.

Interactions with HCPs are important in how PWDs subsequently manage their diabetes. Within the clinical contacts, the choice of words and behaviours is instrumental for PWDs to build a therapeutic relationship with their HCPs (Hynes *et al.*, 2016). Where such interactions are perceived to be absent or negative, they can have a profound impact on the individual, impacting their attendance and engagement with future diabetes care (Brewster *et al.*, 2020).

2.2.4 **Structured diabetes self-management education**

In 2003, NICE mandated the delivery of diabetes self-management education (DSME) in England (NICE, 2022). DSME aims to give individuals with diabetes the knowledge and skills to successfully self-manage their T1DM independently from the HCPs (Holt *et al.*, 2022). In T1DM, this refers to the commissioned courses Dose Adjustment For Normal Eating (DAFNE) and Bournemouth Type 1 Intensive Education (BERTIE) in adults with T1DM (DAFNE Study Group, 2002; Humayun *et al*., 2018). DSME courses are led by specially educated diabetes clinicians, often in small groups of 6-8 participants. Delivery methods can vary between in person or a blended online approach to delivery. They focus on carbohydrate counting and insulin dose adjustment, aiming to enable increased flexibility. Overall, this strategy is effective at reducing HbA1c levels at 12 months (Humayun *et al.*, 2018). In addition, education is also provided to manage sexual health successfully, hypoglycaemia and hyperglycaemia, including sickness management. Participants also report increased quality of life scores and find peer support beneficial (Sanders *et al.*, 2018; Heller *et al.*, 2020). DSME is effective in reducing both HbA1c and the occurrence of acute complications such as DKA and hypoglycaemia (DAFNE Study Group, 2002; Hopkins *et al*., 2012; Keen *et al*., 2012; Kruger *et al*., 2013; Elliott *et al*., 2014).

Access to structured education is not always equitable and depends on local healthcare organisational delivery. In addition to this are the challenges with attendance from time away from other activities such as work; health literacy levels can also deter attendance, with maths skills being reported as a reason for non-attendance (Harris *et al*., 2019). There are also some differences reported in a systematic review of international studies examining the uptake of structured education by Horigan *et al*.

(2017). Reporting on twelve international studies, two main reasons for non-attendance were practical, logistical reasons and the belief that a person with diabetes (PWD) would not gain any benefits. In the studies that recorded gender, males had a higher rate of non-attendance, which differs from Brewster *et al.'s* (2020) systematic review, which concluded no specific differences between males and females.

A benefit of DSME is the surveillance of graduates tracking longer-term outcomes such as HbA1c, psychological wellbeing and subsequent DKA admissions (Kruger *et al*., 2013; Humayun *et al*., 2018). Elliott *et al.'s* (2014) observational analysis shows a strong correlation with a minimal increase in HbA1c level by as little as one mmol/mol, resulting in a 6% increase in DKA occurrence. Such correlations between HbA1c level and recurrent DKA have been thoroughly documented in the literature, and the reductions achieved by attending DSME are noted to be clinically beneficial (Butalia *et al.*, 2013; Elliott *et al.*, 2014; Cooper *et al.*, 2016; Del Degan *et al.*, 2019).

Humayun *et al*., (2018) followed 542 BERTIE graduates' post-course attendance, reporting a 50% reduction in DKA admissions at one year post course attendance. However, an insufficient sample size of n=142 meant this was not statistically significant, with *p*=0.5271. Robust reductions in DKA admissions were reported from a multi-centre study evaluating DAFNE graduates from twenty UK diabetes centres, with a 64% reduction in DKA admissions at one year (Elliott *et al*., 2014). An important finding from this study was a 73% reduction overall in recurrent DKA across the study population (Elliott *et al*., 2014). Reporting the cost-effectiveness of DAFNE reporting on "quality-adjusted life years' (QALY) calculated at £14,400 per QALY'', making this impact more cost-effective over time. The key to sustaining the reduction in DKA occurrence will be the continued support of graduates by HCPs and significant others (Rankin *et al*., 2014; Campbell *et al*., 2018).

The complexities of managing T1DM can be easy for clinicians to underestimate, as diabetes self-management must be sustained often for many decades after diagnosis (Heller *et al*., 2020). Given these challenges, Lawton and Rankin (2010) observed DAFNE courses and interviewed participants to evaluate what it was regarding attendance that subsequently facilitated changes in diabetes self-management. The key finding was the additional support offered by peers on the course who had real-world experience living with T1DM. Similarly, Sanders *et al.'s* (2018) study of qualitative interviews reported 'In it together,' highlighted peer support during the course as an essential element to participants. Despite the efficacy of DSME in reducing HbA1c, QOL and DKA admissions, the results are difficult to sustain for PWD in the longer term. DSME is evolving in the UK with the development of the DAFNEplus course, which includes an additional 12 months of support (Hart *et al.*, 2024). Utilising interviews, Hart *et al.*, (2024) investigated the experience of 28 participants attending this enhanced program which had increased behavioural support embedded. Finding that it increased the confidence with self-management and access to HCPs. Additional research is required to establish the longer-term impact of behaviours that last longer than a few months. Currently, no specific structured education programs exist in the UK for those who have experienced recurrent DKA. Garrett *et al*. (2023) completed a single-centred clinical trial of 10 participants to evaluate if a mental health treatment, forty weekly psychotherapy sessions, was effective in reducing subsequent admissions, concluding that a randomised control trial is now justified, the results are not yet available and consideration will need to be given to how this will translate into real world interventions or if other supportive strategies should be developed. Effective long-term strategies remain to be developed for those with current DKA as this area remains a significant gap in the literature.

2.2.5 **Risk taking in Type 1 diabetes mellitus**

DKA frequently occurs in adolescents and young adults and is a valuable area to explore. Adolescence is a developmental stage during which young people can push boundaries and take risks as they develop their identity away from the family (The Science of Adolescent Risk-Taking: Workshop Report, 2011; Sawyer *et al.,* 2018). Frequently, this is the time that parent’s hand over responsibility for diabetes self-management activities (Wasserman, Anderson & Schwartz, 2017). Conversely, reduced family support is reported to correlate with an increased risk of DKA (Hopkins *et al.*, 2012; Forbes *et al*., 2020). Changes in support levels frequently coincide with adolescents poorly adhering to diabetes self-management activities, which increases the risk of hyperglycaemia and DKA (Kichler, Moss & Kaugars, 2012; Wasserman, Anderson & Schwartz, 2017).

Managing T1DM requires many decisions to be made regarding food, insulin, glucose levels and planned activities; these decisions are complex and, particularly during adolescence, can impact the ability of the PWD to adhere to diabetes treatment (Gonzalez, Tanenbaum, Commissariat, 2016). Potentially leading to poor self-management behaviours persisting into adulthood, with the potential for longer-term complications of diabetes (Goethals *et al*., 2020; Wasserman, 2020). However, the literature presents a concerning discourse about the prevalence of risk-taking among adolescents with T1DM compared to their peers without the diagnosis; those with T1DM are just as likely to participate in drug taking, sexual intercourse and consumption of alcohol (Scaramuzza *et al.*, 2010; Thurheimer *et al.*, 2016). Scaramuzza *et al.'s* (2010) study reported that females with T1DM had a statistically significant increased use of both recreational drugs and alcohol. With both acute and longer-term consequences, risk-taking behaviours among adolescents with T1DM are a significant concern (Tas *et al*., 2020). In a cross-sectional cohort study, elevated HbA1c was found to be associated with increased risk-taking behaviours, including disordered eating, in young people (Tas *et al*., 2020). A randomised control trial by Thomas *et al*. (2021) reported a significant increase in risk-taking behaviours, which can also perpetuate diabetes distress. Diabetes distress is linked with a reduction in optimal self-care behaviours (Masharani, Strycker, and Fisher, 2022). According to Lambert and Keogh (2015), distress caused by being different to peers may have a causal link to outcomes such as hyperglycaemia, further emphasising the urgency of addressing risk-taking behaviours in diabetes care. Non-adherence in itself can be viewed as a risk-taking behaviour, as the omission of insulin leading to the development of DKA can demonstrate distress (Goethals *et al*., 2020; Wasserman, 2022). Regardless of the underlying cause, the risk of DKA development is present in adolescents and young adults. Therefore, developing further understanding as to why insulin is omitted is essential, as omission can be caused by risky behaviours, both conscious and unconscious decisions to omit insulin doses, both predisposing to DKA development.

2.2.6 **Hyperglycaemia and women with Type 1 diabetes mellitus**

For women with T1DM, there are adverse mortality differences reported. Following a systematic review and meta-analysis of 200,000 patients, Huxley *et al.*, (2015) reported that there is a gender difference in T1DM mortality, and women had an increased risk of death by 37% compared to males with T1DM. In comparison to the general population, where males account for 75% of suicide deaths in people under thirty, there were no differences between deaths from suicide or accidents in the T1DM population, but women were more likely to have hyperglycaemia, correlating with other studies (Huxley, *et al*., 2015; Ata *et al*., 2023; Hodnekvam *et al.*, 2023; Iina *et al*., 2021; ONS, 2022). Hyperglycaemia can lead to the development of DKA in T1DM if insufficient insulin is administered to correct it.

Adolescence is a time when both significant hormonal physiological changes and developmental factors occur which are important to consider in the context of DKA development, especially in young women (Holman *et.al*., 2023). Insulin requirements and resistance increase during puberty, significantly heightening the risk of DKA development as HbA1c levels are more frequently also elevated at suboptimal levels (Iina *et al*., 2021). In females with T1DM, the risk of hyperglycaemia also varies according to the stage of the menstrual cycle, becoming increasingly prevalent in the luteal phase (Barata, 2013; Dey, Dasgupta & Roy, 2019).

Kordonouri *et al.*'s (2020) observational study of German children with T1DM found that HbA1c levels were elevated during adolescence, correlating with an increased risk of DKA development. Insulin requirements and resistance increase during puberty, resulting in more frequent attendance at ED with DKA for those under the age of 25. These findings underscore the importance of considering hormonal changes in the context of DKA.

There are variances between the sexes reported in the literature for the development of DKA. Barksi *et al.'s* (2011) cohort study investigated the characteristics of those admitted with DKA. Reporting that although DKA in young women had an increased prevalence, mortality rates were not significantly different. Other studies have established that HbA1c levels were higher in females than males with T1DM (Iina *et al*., 2021; Ata *et al*., 2023; Hodnekvam *et al.*, 2023). In addition, Ata *et al.'s* (2023) cross-sectional cohort study reported that females were increasingly likely to be readmitted with recurrent DKA. Hyperglycaemia can be viewed as a risk factor for the subsequent development of DKA. With increased risks for its development noted in the female adolescent population. Arguably, there are developmental and physiological differences that predispose some young women to the development of DKA, but most of this population do not develop such severe hyperglycaemia that leads to DKA. Further research in this area is warranted to develop an understanding of the perceptions of young women regarding the development of DKA.

In this section, I have provided contextual background to the challenges faced when living with T1DM. Several independent factors complicate matters for the individual, which may also affect the development of DKA and long-term cardiovascular complications. Living with T1DM is burdensome, yet individuals are expected to accommodate it into their personal and social worlds at the point of diagnosis with little consideration from HCPs as to how this might happen. These aspects compound how T1DM can be initially accepted, and the burden and distress of diabetes can persist for many years post-diagnosis. If appropriate, sensitive clinical care and the HCP's choice of language can improve this experience. These findings illustrate the importance of considering both social and psychological complexities that may be involved in the development of DKA, moving it beyond a condition that simply has its causation in the physical origins of insufficient circulating insulin (Gibb *et al.*, 2016; Dhatariya, Skedgel and Fordham, 2017).

2.3 Aims of the literature review

The primary purpose of this narrative review is to address the following question:

- *What do young people with Type 1 diabetes report about their experiences of living with diabetes and or diabetic ketoacidosis?*

2.4 Timeline for the literature search

The comprehensive literature search was completed in January 2023. The search was conducted utilising CINAHL, Psych info, Medline, and Web of Science databases. In health care, time limits are frequently placed on the publication dates for the literature selected for review. However, this narrative review investigates what is known about the experience of developing recurrent DKA. It necessitates a wide literature search not bound by traditional time constraints for the search strategy. Therefore, the maximum search times were run within the databases between 1975 and Jan 2023. Consideration was given to the changing landscape of diabetes management from a health delivery perspective, which may impact experience. For example, in the last decade, there has been an increasing focus on patient empowerment, structured DSME, and home technology usage, such as glucose sensors and insulin pumps.

2.5 Search strategy

The search strategy was developed using Boolean operators ‘AND’, ‘OR’, ‘NOT’, in addition to truncating words that had variable spelling, were used to build the specificity of the search terms, which is visually presented in Table 2. In addition, by using them, the search can identify relevant literature and sift out papers that do not meet the inclusion criteria (Aveyard, Payne & Preston, 2021, p.52).

2.6 Justification for the type of review

Aveyard, Payne and Preston (2021, p.1) define the literature review as an appraisal of the available research to enable meaning to be taken from it, to evaluate the quality of research. There are several ways to undertake a literature review depending on the research question being addressed (Booth, Sutton and Papaioannou, 2016; Aveyard, Payne and Preston, 2021). This review follows a narrative approach; identification and selection of the research for inclusion within this chapter are presented in the search inclusion strategy in Section 2.9. Findings from these studies will be presented thematically (Grant and Booth, 2009). Those studies that appeared to have some similarities to the research focus of developing ‘‘understanding the experience of developing recurrent DKA’’ invariably leant towards examining experience from a different contextual framework, exploring both the causation and the steps that participants could take to avoid future occurrences of DKA, in addition to analysing morbidity and mortality rates in recurrent DKA.

The absence of published literature regarding the experience of having DKA precluded the ability to complete a systematic review or a scoping review of the topic because it requires adherence to a methodological framework of data identification and presentation (Arksey and O’Malley, 2005; Levac, Colquhoun and O’Brien, 2010; Daudt, Van Mossel and Scott, 2013; Colquhoun *et al.*, 2014). Therefore, this literature review comprises several discrete sections linked to the experience of living with T1DM and any occurrence of DKA. This will enable the examination of relevant literature by utilising a systematic approach to identify research that includes biological, sociological, and psychological components of life with T1DM. The prevalence, economic costs, socio-economic, psychological burden, risks of morbidity and mortality have previously been discussed in Chapter One and the context of this chapter. Consequently, this literature review will focus on the experiences of living with T1DM.

The aim of this literature review was to identify what was already known about the experience of developing recurrent DKA; the search terms population (P), Intervention (I), Comparison (C), and outcome (O) used as the acronym PICO were not appropriate for this review as the search terminology leans towards quantitative methodologies

(Methley *et al.*, 2014). Using words such as comparison and outcome to explore the lived experience of T1DM is inappropriate. The intent is not to measure but to understand the lived experience. Instead, the SPIDER framework was adopted (see Table 1). SPIDER, comprises 'Sample (S), Population and Phenomena of interest (P & I), Design (D), Evaluation (E) and Research type (R)*'* (Cooke, Smith & Booth, 2012). The context of the search terms was developed from the research question and aims and is designed for use in identifying qualitative studies.

As part of the selection criteria for the inclusion of papers in this review, it was appropriate only to select qualitative reports that explored the experiences of living with T1DM (Aveyard & Payne; Dibley *et al.* p. 35*;* Booth, Sutton and Papaioannou (2016). Therefore, to understand what it is like to experience recurrent DKA, first, it is necessary to understand the experience of living with T1DM. Developing an understanding of the lifeworld of people living with T1DM is crucial as it will provide context to this research participants who both live with T1DM and have, in addition, experienced recurrent DKA.

2.7 Keyword search terms

Component	Explanation	Term
S- Sample	Subject under investigation	T1DM
P & I- Phenomena of interest	What is of interest?	Experience of DKA/recurrent DKA Impact of DKA on life
D-design	Methods	Interviews Phenomenological studies Thematic analysis Qualitative studies
E- evaluation	Understanding the experience of DKA	Living with T1DM, DKA Temporality and embodiment
R- Research type		Phenomenological studies Thematic analysis Qualitative studies

Table 1

2.8 Search terms

1.	Type 1 diabet* OR T1DM OR Insulin dependent diabet*	AND
2.	Experience* OR Perception* OR Attitudes OR View* OR Feeling* OR Lived experience*	AND
3.	Diabetic Ketoacidosis OR DKA OR Re* DKA OR Diabetic acidosis OR brittle diab*	NOT
4.	Type 2 diab* OR NIDDM	

Table 2

2.9 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Studies focusing on the experience of living with type 1 diabetes mellitus	Type 2 diabetes
Published in English	Participants under 12 years old
Peer reviewed	PAID questionnaire only
Qualitative design	Health care professionals

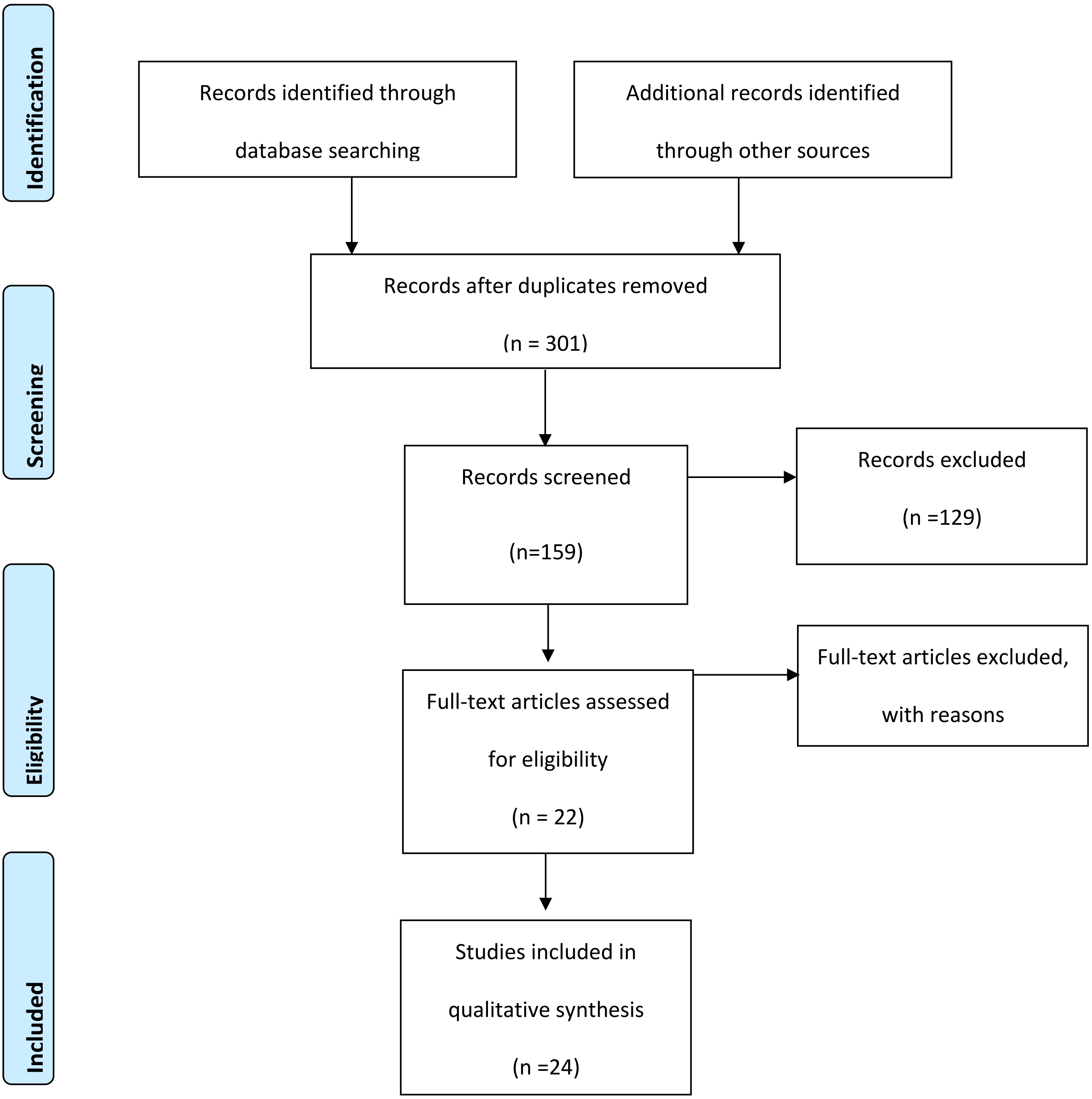
Table 3

A PRISMA diagram of the process is presented on page 27. This outlines the studies which were included and excluded once the criteria outlined in 2.9 were applied. Several studies only utilised questionnaires to collect participant data or analyse the completion of the Problem Areas in Diabetes (PAID) scale (Polonsky *et al.*,1995). PAID assesses the levels of distress that living with T1DM may entail. However, its purpose is not to explore experience in-depth. This visual representation enables the completed process to be clearly illustrated to the reader. Twenty-three studies were located that investigated the experiences of "living with Type 1 diabetes," eighteen of which have been published since 2015; this fits with the current ethos of patient-centred diabetes care in the UK, which is continuing to develop. In addition to the research papers included in the search, one piece of grey literature was included from 2012. Grey literature is defined as valuable to the research question but is not identified via the literature search or may not have been peer-reviewed before publication. The grey literature was an account of the experience of DKA written by Marple (2012) titled '*'Fire in my veins"* (Tillett and Newbold, 2006; Pappas and Williams, 2011).

Utilising the expertise of academic librarians was an essential element of developing the search strategy for this research (Aveyard, Payne & Preston (2021) pp. 47-48).

Booth, Sutton & Papaioannou, (2016, p.123). Several meetings were held with the academic librarian to ensure that the search strategy and subsequent selection of studies were systematic and replicable. A key process in conjunction with the librarians was the development of synonyms for the search strategy once initial searches failed to identify literature examining the experience of diabetic ketoacidosis. Thomas *et al.* (2023) state that for these occurrences, there is a need to broaden the search terms, and even though this is aimed at Cochrane systematic reviews, the guidance is valid for this literature review.

2.10 Prisma


Identification
Screening
Eligibility
Included
Records identified through database searching
Additional records identified through other sources
Records after duplicates removed (n = 301)
Records screened (n=159)
Records excluded (n =129)
Full-text articles assessed for eligibility (n = 22)
Full-text articles excluded, with reasons
Studies included in qualitative synthesis (n =24)

2.11 Quality Screening

The initial screening of studies excluded those that were quantitative in design or relied on a questionnaire such as the Problem Areas in Diabetes scale developed by Polonsky *et al.*, (1995). Such studies, whilst key for understanding the prevalence of distress, did not overtly investigate lived experience. Research that met the search terms included in Table 3.1 was screened for inclusion using a Critical Appraisal Skills Program (CASP) qualitative appraisal checklist for qualitative studies. A systematic process to assess studies for both inclusion and methodological quality enables studies that did not meet the inclusion criteria to be systematically rejected (Arksey and O’Malley, 2005; Lockwood, Munn and Porritt, 2015)

2.12 Data extraction table

Author	Year of publication	Title	Methodology	Findings
Abdoli, S., Hardy, L.R. and Hall, J.	2017	The complexities of "struggling to live life": The experiences of young adults with T1DM living in Appalachia	Qualitative Descriptive analysis n=9 Semi-structured interviews USA	Themes: • Struggle to adulthood • Daily struggle living with diabetes. • Desire to live life • Development of diabetes identity • Disruptions of diabetes • Pros and cons of diabetes technology Consistency of responses. There was also the view that diabetes can be positive
Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D. and Conroy, R.	2013	What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives'	Qualitative n=35 Semi-structured interviews Identified themes. Ireland	Diabetes distress was common. Themes: • Self-consciousness/stigma • Day to day management difficulties • Fighting the healthcare system • Concerns about the future • Pregnancy
Browne, J.L., Ventura, A., Mosely, K. and Speight, J.	2014	I'm not a druggie; I'm just a diabetic": A qualitative study of	Qualitative n=27 Semi-structured interviews Thematic analysis	The majority n=25 reported social stigma • Stigma by association (T2DM) • Blame • Negative social judgements and stereotyping • Exclusion • Rejection

Author	Year of publication	Title	Methodology	Findings
		stigma from the perspective of adults with type 1 diabetes.'	Australia	- Discrimination

Carlsund, Å. and Söderberg, S.	2019	Living with type 1 diabetes as experienced by young adults	Qualitative
			n=12
			Semi-structured interviews
			Content analysis
			Sweden
				There was variance in the responses reported as 'contradictory ways':
				Two main themes and five sub-themes:
				• Handling the situation
				  ◦ Managing daily life
				  ◦ Emotional roller coaster
				• Dealing with different opinions
				  ◦ General attitudes and concerns
				  ◦ Own views and apprehensions
				  ◦ Ignorance and lack of motivation

Chafe, R., Albrechtsons, D., Hagerty, D. and Newhook, L.A.	2015	Reducing episodes of diabetic ketoacidosis within a youth population: A focus group study with patients and families	Qualitative n=19 (14 Parents and five youths) Focus groups Themes Canadian	Four participants had experienced DKA previously; one described the unpleasantness of DKA. There were differences between rural and urban, with rural participants having additional fear due to their remoteness from the hospital Themes: • Difficulty in identifying DKA. • Variation in diabetes education • Information overload at diagnosis • Caregivers other than parents • Sense of crisis

Author	**Year of publication**	**Title**	**Methodology**	**Findings**
Cortright, D.	2021	*Unsung Heroes: The narratives of adults with type 1 diabetes.*	PhD thesis Qualitative n=8 Semi-structured interviews Narrative analysis USA	Utilising Campbell's (1973) mythological heroes' journey 'departure, initiation and return.' Narratives: • Memories about diagnosis • Pressure on relationships • Obstacles of diabetes
Fioretti, C. and Mugnaini, C.	2022	Living with type 1 diabetes mellitus in emerging adulthood: A qualitative study, *British Journal of Health Psychology*	Qualitative n=30 Autobiographical interview Inductive thematic analysis Italy	Five themes were a mix of positive and negative aspects of living with T1DM. • Intimate relationships • University life, work and plans for the future • Achievement of autonomy • The construction of an adult identity • Family planning
Forbes, T.H., Hodgson, J., Crespo, J., Jones, E. and Hardee, S.	2020	Putting the Pieces Together: An Exploration of Diabetes Ketoacidosis Readmissions	Grounded theory n=13 T1DM and n=6 support persons Semi-structured interviews USA	Examining factors linked to DKA readmissions. Occurring in three phases: home, hospital, and transition back to home. Themes: • Contextual life factors • Action strategies • Readmission triggers

Author	Year of publication	Title	Methodology	Findings
Fredette, J., Mawn, B., Hood, K. and Fain, J.	2016	Quality of Life of College Students Living with Type 1 Diabetes: A Qualitative View	Phenomenological- descriptive n=24 Semi-structured interviews Themes USA	College students. Three themes: • Planning ahead • Thinking positive • Seeking support
Habenicht, A.E., Gallagher, S., O'Keeffe, M.C. and Creaven, A.M.	2021	Making the leap and finding your feet: A qualitative study of disclosure and social support in university students with type 1 diabetes	Qualitative Semi-structured interviews Thematic analysis n=14 Ireland	They examined how college students disclosed T1DM. Three themes: • Disclosure as a measured process • The need for lived experience for proper understanding. • Personal growth and self-awareness
Rising-Holmström, M. and Söderberg, S.	2022	The lived experiences of young people living with type 1 diabetes: A hermeneutic study	Hermeneutic Phenomenology n=10 Sweden	Explore everyday life with T1DM. One overall theme: • Living a transformed and re-organised life

Author	Year of publication	Title	Methodology	Findings
Ingersgaard, M. Hoeeg, D. Willaing, I. Grabowski, D.	2021	An exploratory study of how young people experience and perceive living with type 1 diabetes during late adolescence and emerging adulthood	Qualitative n=19 Participatory workshops Thematic analysis Denmark	T1DM was paradoxical; it affected everything and nothing. Five themes: • Special rules during youth • Striving for autonomy • An uncertain future • Social support • Stigma and disclosure
Kruger, S., Deacon, E., van Rensburg, E. and Segal, D.	2021	Young adult women's meaning making of living with type 1 diabetes: towards growth and optimism	Phenomenological analysis (IPA0 n=6 Semi-structured interviews Thematic analysis South Africa	Three themes: • The process of reappraising life with diabetes • The development of diabetes as a lifestyle • Positive outcomes of living with diabetes
Markowitz, B., Pritlove, C., Mukerji, G., Lavery, J. V., Parsons, J.A. and Advani, A.	2019	The 3i Conceptual Framework for Recognizing Patient Perspectives	Qualitative n=33 In-depth interviews Narrative analysis Canada	The narrative analysis highlighted three distinct story types or lenses: • Ingrained • Intrusive • Inconspicuous

Author	Year of publication	Title	Methodology	Findings
		of Type 1 Diabetes during Emerging Adulthood		
Moffett, M.A., Buckingham, J.C., Baker, C.R., Hawthorne, G. and Leech, N.J.	2013	Patients' experience of admission to hospital with diabetic ketoacidosis and its psychological impact: An exploratory qualitative study	Qualitative n=4 semi-structured interviews Thematic analysis UK	Three themes were found: • Consequences of DKA • Recognising and managing DKA • Hospital experience
Mullan, B.A., Dzidic, P., Boyes, M., Hasking, P., Slabbert, A., Johnson, R. and Scott, A.	2020	The lived experience of young Australian adults with type 1 diabetes	Qualitative n=25 semi-structured interviews Thematic analysis Australian	The study focused on the navigation of health behaviours, eating out, alcohol and physical activity. Six themes: • Simple becomes complicated • Constant vigilance • Controlling the uncontrollable • Private becomes public. • Myths of the diabetic • Health moralism
Orben, K., Ritholz, M., McCalla, M. and Beverly, E.A.	2022	Differences and similarities in the experience of	Qualitative n=29 In-depth interviews	Three themes were identified: • Experiencing diabetes distress as a lack of control • Experiencing diabetes distress as a burden of constant management

Author	Year of publication	Title	Methodology	Findings
		living with diabetes distress: A qualitative study of adults with type 1 and type 2 diabetes	Thematic analysis USA	• Understanding the value of social support in diabetes distress
Pinar, B. and Turan, T.	2022	Living with Type 1 Diabetes: A Qualitative Study	Phenomenology n=19 Semi-structured interviews Content analysis Turkie	Three themes: • Experience • Feelings • Perceptions
Scholes, C., Mandleco, B., Roper, S., Dearing, K., Dyches, T. and Freeborn, D.	2013	A qualitative study of young people's perspectives of living with type 1 diabetes: Do perceptions vary by levels of metabolic control	Qualitative n=14 Interviews Induction to thematic analysis USA	They examined whether perceptions varied according to glycaemic control. Four themes were similar in the high and low groups: • Family • People outside the family • Healthcare professionals • Knowledge about diabetes Differences between the two groups: • Illness perception • Parents • Self-care attitudes/activities

Author	Year of publication	Title	Methodology	Findings
Staite, E., Zaremba, N., Macdonald, P., Allan, J., Treasure, J., Ismail, K. and Stadler, M.	2018	"Diabulimia" through the lens of social media: a qualitative review and analysis of online blogs by people with Type 1 diabetes mellitus and eating disorders'	Qualitative n=11 Structured review of online blogs Thematic analysis International	Analysis of blogs with T1DM and an eating disorder Three key themes: • Different aspects of bloggers' relationship with insulin • Bloggers experiences of diabetes complications & DKA, in particular • Strategies for recovery and triggers for relapse
Visekruna, S., Edge, D.S. and Keeping-Burke, L.	2015	Being in balance": Self-management experiences among young women with type 1 diabetes	Phenomenology - descriptive n=9 Sem-structured interviews Thematic analysis Canadian	Five themes were identified: • Elusiveness of control • Dualism of technology • Forecasting and maintaining routines • Dealing with ups and downs • Interfacing with the health team

Author	Year of publication	Title	Methodology	Findings
Watts, S., O'Hara, L. and Trigg, R.	2010	Living with Type 1 diabetes: A by-person qualitative exploration	Qualitative n=4 By person (Case by case) Qualitative analysis of semi-structured interviews UK	Interview accounts are analysed for their stories: • Psychological conflict between pursuit and satisfaction of personal goals and aspirations
Willemse, M., Deacon, E. and Segal, D.	2018	Life stories managing chronic illness: Young adults' lived experiences with type 1 diabetes	Qualitative n=8 Participants told stories. Thematic analysis South Africa	Five themes: • Identity development • Personal control and subjective well-being • Social support • Health or carer • counselling & support • Futuristic goals

2.13 Selected studies

The research studies selected for this literature review used a qualitative methodology; most used thematic analysis to develop their themes, and the one piece of grey literature was an account of what it was to experience DKA. There is a predominance of studies from the USA, Scandinavia, and Australia, with only two being conducted in the UK; it is likely, therefore, that there will be some differences between the various healthcare systems that participants are required to navigate. Most study participants access insurance-based healthcare, which differs considerably from the UK NHS, which is free at the point of access (NHS Constitution, 2023). Access to insurance based care was complicated for the participants in Forbes *et al*., (2020), over half of whom had no healthcare insurance. Despite the structural differences in the organisation of health care settings, the experience of living with T1DM in the literature included many common themes. It highlighted the life-changing impact of a diagnosis of T1DM.

Completing this research is relevant because no studies directly explored the experience of developing DKA or recurrent DKA. The closest study was completed in the UK with in-patients who had DKA by Moffett *et al.*, (2013). This exploratory qualitative study investigated the experience of being admitted to a hospital with DKA and how this impacted the four participants psychologically. However, the cohort did not perceive insulin omission as the cause of DKA. Participants rarely specifically discussed DKA or complications in any format, correlating with the scarcity of literature researching the experience of developing DKA. The gravity of DKA with premature morbidity and mortality in a predominantly young T1DM population has been presented earlier; however, there was limited discussion by these participants regarding DKA.

2.14 Diagnosis and life afterwards

Six of the studies reported participants discussing how receiving a diagnosis of T1DM was for them a profound life changing event, whatever age diagnosis occurred (Scholes *et al.*, 2013a; Chafe *et al.*, 2015; Fredette *et al.*, 2016; Cortright, 2021; Holmström and Söderberg, 2022; Pinar and Turan, 2022). For many, this remained significant in the following years. Cortright (2021) defined this in his doctoral thesis as ‘going on a journey’ that involved significant changes to the order of life. Such a journey is far from smooth, and the day of diagnosis is memorable for many of the participants as there are following diagnosis, a multitude of diabetes-related activities required to manage T1DM (Kruger *et al.*, 2021; Holmström Rising and Söderberg, 2022).

Living with any chronic illness can be challenging, but a few long-term conditions require a multitude of daily decisions to be made. T1DM includes calculating insulin doses related to food intake, current and planned activity, and glucose levels just to feel well. The studies selected for this review consistently refer to the burden of living with T1DM and the impact it has on life (Balfe, Doyle, *et al.*, 2013; Visekruna, Edge and Keeping-Burke, 2015; Abdoli, Hardy and Hall, 2017; Willemse, Deacon and Segal, 2018; Carlsund and Söderberg, 2019; Ingersgaard *et al.*, 2021; Fioretti and Mugnaini, 2022; Holmström Rising and Söderberg, 2022). The participants' ages ranged from 12 to 28 in these studies; this did not change this perception of burden, which was consistently reported.

Carlsund and Söderberg's (2019, pp. 420-421) research using content analysis of the interviews of twelve adults with T1DM concluded two main themes, 'handling the situation' and 'dealing with different opinions.' These were subsequently subdivided further and included ''managing daily life'' and ''emotional rollercoaster,'' which were directly linked to the theme of ''handling the situation.'' Having diabetes was reported as stressful, not only having to perform diabetes related self-management activities but also how others responded to them (Abdoli, Hardy and Hall, 2017; Carlsund and Söderberg, 2019; Mullan *et al.*, 2020; Kruger *et al.*, 2021; Holmström Rising and Söderberg, 2022).

The self-management requirements of blood glucose testing and injecting insulin are taught at diagnosis. After that, clinicians expect that people with T1DM will incorporate this into their lives and adhere to treatment plans (NICE), 2022). Participants consistently reported that this was far from their reality; it is far more complex than merely following the instructions of the treatment plan. Various terms include an 'arduous' and a ''never ending challenge'' (Willemse, Deacon and Segal, 2018; Markowitz *et al.*, 2019). One theme Habenicht *et al*., (2021) identified is the 'need for lived experience for true understanding.' Events such as hypoglycaemia were felt not to be fully understood by family, friends, and HCPs unless they, too, had diabetes. The report stated that lived experience was critical in participants' experience to hold an authentic view regarding the realities of living with T1DM.

Living with T1DM requires planning to anticipate the requirements of access to insulin, food, and glucose monitoring on an enduring basis. This was reported by Holmström Rising and Söderberg, (2022, p. 2882) as a theme entitled ''living a transformed and reorganised life.'' After the diagnosis of T1DM, participants reported that they were 'living a governed life' caused by having a lifelong chronic disease, which meant they had no choice but to try and self-manage their diabetes. Having T1DM requires additional daily planning for participants when they are away from the home environment. There is a need to plan to ensure they have all the diabetes equipment they may need with them. This is reported as impacting upon spontaneity across the studies; rather than just being able to say yes to an unplanned activity, there is also the need to consider the impact this may have on their diabetes (Willemse, Deacon and Segal, 2018).

The perpetual need to weigh up independent factors such as activity levels, food, insulin injections and current glucose level was, on the whole, accepted as necessary, but the realities of achieving this were not always straightforward or successfully achieved (Fredette *et al.*, 2016; Mullan *et al.*, 2020). When this did not go to plan, it posed a different scenario of guilt and resentment about diabetes management and being different to others (Balfe, Doyle, *et al.*, 2013). This can manifest as a ‘‘why me’’ regarding having a diagnosis of T1DM (Kruger *et al.*, 2021). Markowitz *et al.*, (2019 p. 6) concluded as a theme that ‘my diabetes is like a weight, constantly weighing down on me.’ There is no respite from having diabetes, no day off from having to think about it. Other authors used differing versions of this theme, such as constantly having to think about diabetes management and how it reduces the spontaneity of life, as there is always the need to plan and keep the fact that they have T1DM at the forefront of their minds (Mullan *et al.*, 2020; Ingersgaard *et al.*, 2021; Orben *et al.*, 2022).

2.15 Loss of control

One of the participants in Watts, O’Hara and Trigg, (2010) reported that the very act of trying to ‘control’ diabetes meant that, inadvertently, the individual was being controlled by it. This is an interesting insight and maybe a way to offset the guilt experienced about managing T1DM. Drawing on the analogy that this is like being in a controlling relationship, you are at the mercy of the diabetes. Whereas the language used by participants in Ingersgaard *et al.*, (2021) study using workshops captured the feedback of one of the participants who also used the word ‘‘control’’ but in contrast, ‘‘because it does not control me, I must control it.’’ The words ‘good control, poor control, time in range or targets’ are frequently used by health care professionals (HCPs) to denote success with glucose management; in addition, such terms also refer to blood pressure and cholesterol results measured and reported against national standards. Frequently, participants also adopt these terms to articulate how they can live with and manage their diabetes (Cortright, 2021; Ingersgaard *et al.*, 2021).

Visekruna, Edge and Keeping-Burke's, (2015) phenomenological study of young women with T1DM explored the effect of menstruation on managing diabetes, including the impact on glucose levels. Participants reported an element of resignation that at stages of the menstrual cycle, they would be faced with significant hyperglycaemia, which in itself caused unpleasant feelings in addition to the risk of hypoglycaemia after insulin doses were significantly increased. Loss of control occurred regularly for these young women, but there was little that they could do to prevent these changes each month.

Watts, O’Hara and Trigg's (2010) research which explored living with T1DM reports that according to one participant, ‘‘diabetes won’t be beaten;’’ that there becomes an element of just having to get on with it. These views are not shared across the studies, with some participants also reporting that a diagnosis of T1DM can be beneficial to their long-term health (Abdoli, Hardy and Hall, 2017). Regular health checks, a healthy diet, and exercising were considered valuable compared to people without diabetes, who may not receive such reviews. Development of greater maturity and responsibility because of a diagnosis of T1DM was reported and seen as a positive consequence (Fredette *et al.*, 2016; Kruger *et al.*, 2021).

2.16 Social support and significant others

Developing personal relationships is a crucial life stage for adolescents and emerging adults, including those in this literature review. Still, many with T1DM choose to keep their diagnosis hidden away from others. The importance of social support was found to be valuable when navigating DKA (Moffett *et al.*, 2013; Forbes *et al.*, 2020). Participants repeatedly hid their diagnosis from others so they would not be viewed as sick or different to their peers. This perceived vulnerability extended to family members and potential partners, who were somehow less than perfect and, therefore, unsuitable for a long-term relationship. Choosing how to disclose the condition is carefully considered, and there still is a misconception that T1DM is contagious (Abdoli, Hardy and Hall, 2017). Once it is known that they have T1DM, there can also be the additional worry that others will focus on diabetes and not see them as a person (Browne *et al.*, 2014; Mullan *et al.*, 2020; Cortright, 2021; Habenicht *et al.*, 2021; Ingersgaard *et al.*, 2021). Whereby they become ‘the diabetic’ as opposed to the person with diabetes, and for the Turkish participants interviewed by Pinar and Turan, (2022), this was because they also felt shame about their diagnosis of T1DM.

Stigma was reported in several studies but not universally across the studies in this review. Scholes *et al*., (2013) investigated differences in perceptions of managing T1DM according to the level of glycaemic control. Two groups, one with a high HbA1c, 9.8% (mean), and the low group, HbA1c, 6.96 % (mean), reported that a greater sense of optimism prevailed in the high HbA1c group that a cure would be found for T1DM. Entirely why participants in Scholes *et al*., (2013) perceived this was not fully explained, nor is it possible to be confident, but it could be that there was a naïve view that regardless of HbA1c level, they would avoid the development of complications, holding onto hope for the future without T1DM as a way of coping with living with diabetes now. Scholes *et al*., (2013) provided additional insights into the perspectives of those with higher HbA1c levels. However, these perspectives differed for Markowitz's (2019) research participants, developing a 'conceptual framework recognising patient perspectives in emerging adulthood*.'* In contrast, those with a higher HbA1c, 9.6% (mean), were more likely to report distress, feeling that having diabetes was intrusive as it impacts ordinary life; this occurred in twelve of the thirty-three participants. It is important to remember that perceptions will vary by participants, and other variables, such as age and duration of diabetes, may also influence these views, which may change over time.

Many themes across both groups being examined for differences in perception according to HbA1c level shared a commonality, notably how others perceived them, including healthcare professionals (HCPs). Reporting that the tone consultations took with HCPs, such as lecturing about what they should or should not do to manage their diabetes, was frequently perceived as being negative, as if they were being told off (Scholes *et al.*, 2013). There is a correlation between diabetes and psychological distress reported by Garrett *et al.*, (2020), those who had struggled to adapt to their diagnosis of diabetes had the highest HbA1c levels in Scholes *et al.'s*, (2013) study.

2.17 Stigma

In the UK, people who have T1DM are protected by the Equality Act (2010). Yet many of the participants across the studies in this review found it difficult to disclose their diagnosis to others (Balfe *et al.*, 2013; Abdoli, Hardy and Hall, 2017; *et al.*, 2021; Kruger *et al.*, 2021). The term ''stigma'' was a common theme uncovered by researchers and significantly impacted how participants were able to incorporate and manage diabetes within the context of their lives.

Stigma regarding T1DM does not just arise from contacts of those with T1DM, but it is frequently reported in the media, with particular distress caused by linking T1DM with type 2 diabetes (T2DM). Such reporting can include the misconceived belief that T1DM is caused by eating too many sweets or by poor lifestyle choices rather than its origins as an autoimmune disease, with T2DM also stigmatised as a self-inflicted condition despite its varying aetiology (Browne *et al.*, 2014; Ingersgaard *et al.*, 2021).

Moral judgement was also used by those living with T1DM to judge those with T2DM regarding what are perceived to be lifestyle choices. Balfe *et al*. (2013, p.5) reported, ‘‘We do not have a choice, the majority of Type 2’s have a choice, and they choose not to do what they should be doing*…*’’ Stigma is not unique to those with T1DM. Still, the fear of it can result in carefully considering how or if they will disclose having T1DM. Striving to manage their narratives on their own terms to be viewed as not different does, in some cases, give back a degree of control to the individual. Yet, in contrast, Browne *et al.* (2014) reported a participant who used equally derogatory language to describe type 2 diabetes as ‘the fat lazy type,’’ despite the awareness of how others stigmatised them because they had diabetes.

Choosing when or if to disclose their diagnosis of T1DM to avoid stigma can be problematic at the different stages of life, with school, university, work and personal relationships and critical moments such as new employment requiring calculated decision making. Moral judgement by others who know of the diagnosis of T1DM was experienced by participants, with decisions made about their choices of food and drink (Mullan *et al.*, 2020; Orben *et al.*, 2022). Participants felt that the comments about their food and drink choices and whether they were allowed to eat something particular, such as foods containing sugar, were particularly intrusive and judgemental (Scholes *et al.*, 2013; Mullan *et al.*, 2020; Orben *et al.*, 2022). This invariably stems from ignorance, a case in point being a participant in Orben *et al.* (2022) qualitative study exploring themes of distress, who, having just started school, was ‘‘not allowed” birthday cake, being given sugar-free chewing gum instead. This memory has impacted and stayed with them, causing a sense of embarrassment for many years afterwards as they were made to feel different, even though initially, this gift of chewing gum was well intentioned.

Sharing their diagnosis of T1DM can be limited because of the perceived reactions of others, and the desire to fit in with their peers can mean that blood glucose monitoring and insulin injections are hidden from others or omitted altogether. Frequently, studies reported that there was an element of subterfuge involved in testing blood glucose out of sight, even using a bag to shield the process or not wanting to scan a glucose sensor in the vicinity of others (Markowitz *et al.*, 2019; Habenicht *et al.*, 2021). Diabetes technology in the UK is revolutionising current clinical management. Yet, for some, this external insulin pump is a perpetual reminder that they have diabetes (National Institute for Health and Care Excellence (NICE), 2022). These devices can also advertise to others that there is something different, and even if they want to keep their diagnosis hidden, it can remove this choice and decision entirely from the control of the individual (Mullan *et al.*, 2020).

In their analysis of emerging adults living with T1DM, Fioretti and Mugnaini, (2022) found that participants could assess the interest that prospective partners and friends took in their diagnosis of diabetes. They used it as a marker of sincerity and commitment to help them determine if it was worth the time and effort of further developing the relationship. Linking with the stigma experienced by others, they are developing elements of being guarded about starting new relationships.

2.18 Diabetes distress

The morbidity caused by diabetes distress has previously been discussed in the introduction to this thesis. Given the prevalence of distress, it is a common theme across the studies in this literature review (Balfe, Doyle, *et al.*, 2013; Carlsund and Söderberg, 2019; Cortright, 2021; Ingersgaard *et al.*, 2021; Kruger *et al.*, 2021; Orben *et al.*, 2022). Being diagnosed with T1DM is life changing, and once initial osmotic symptoms at diagnosis resolve, it must be managed as a lifelong chronic condition, unless in the rare occasion that pancreas or islet cell transplantation occurs.

The day of diagnosis remains a clear dividing point as they look back to life before and after the event as the start of this distress. Many can remember the actual date of diagnosis; it is ingrained in their minds, and on social media, there is the phrase ‘diaversiary’ that is used to denote how long someone has lived with diabetes, but not as a cause for celebration (Holmström Rising and Söderberg, 2022). Many people continue to have strong feelings, which have been described as ‘‘fear, shock and denial’’ regarding their diagnosis (Pinar and Turan, 2022). Given that many participants were diagnosed in childhood across the studies, the recollection of the experience demonstrates how burdensome T1DM can be for individuals, with the experience lasting for many years. Some also remember and pick up upon the fear experienced by a parent at diagnosis Holmström Rising and Söderberg, 2022). Those who were able to accept and come to terms with their diabetes were more likely to find positives in having the diagnosis and incorporating it as part of ordinary life (Cortright, 2021; Kruger *et al.*, 2021). It would appear that those who can accept and incorporate T1DM into their lives can positively impact subsequent glycaemic control and general longer-term wellbeing (Scholes *et al.*, 2013; Fredette *et al.*, 2016).

Across the studies in this review, participants regularly discussed that having T1DM was distressing, occupying both time and thought (Markowitz *et al.*, 2019) and noting that those whose predominant theme was ‘‘an intrusive lens’’ were more likely to feel distressed about having their diabetes. This distress can adversely affect how diabetes is managed long-term, correlating with higher HbA1c levels (Scholes *et al.*, 2013). Prolonged hyperglycaemia is known to increase the risk of acute diabetes complications such as DKA, in addition to the chronic complications of vascular and neuropathic disease that can manifest following sustained high glucose levels (DCCT,1993). Perpetuating anxiety that festers away at individuals as it is ever present, ‘‘a weight constantly weighing down on me,’’ (Markowitz *et al.*, 2019).

Regardless of glycaemic control, participants across many of the studies reported distress that developed at the point of diagnosis, which continued long term. This distress is not just confined to the person with T1DM but also affects significant others in their lives; for the studies that specifically investigated DKA, diabetes distress perpetuated among participants (Moffett *et al.*, 2013; Chafe *et al.*, 2015; Forbes *et al.*, 2020). The psychological burden is enduring, and participants reported higher levels of depression Forbes *et al.*, (2020).

2.19 Diabetic ketoacidosis

There was limited research regarding the experience of DKA. Three studies were located from the search that explicitly had the words diabetic ketoacidosis in the title (Moffett *et al.*, 2013; Chafe *et al.*, 2015; Forbes *et al.*, 2020). Despite high mortality rates in a predominantly young population, participants in the studies included in this literature review rarely discussed DKA, nor have researchers chosen to investigate the phenomena of DKA further from the perspectives of those with lived experience. Indeed, there is infrequent discussion of hypoglycaemia or other longer-term complications by participants across the studies. The reasons for this are not immediately apparent; it could be that the participants interviewed across the studies have not experienced DKA, and therefore, it does not have the immediate concern as an acute diabetes complication of T1DM. Yet even the experience of low blood glucose in hypoglycaemia, the most common acute complication of T1DM, is not frequently discussed in the studies, suggesting that this is not a concern for many participants.

The limited reference to DKA in the studies in this literature review may arise from the possibility that it is difficult to engage and recruit participants who have experienced DKA. Moffett *et al.*, (2013) reported extreme difficulty recruiting participants in a study that examined 'the experience of admission to hospital with DKA.' From a potential population of forty people, only four of the eligible study population agreed to be interviewed. Noting that engagement with the diabetes team can be challenging in the recurrent DKA population once they have left the hospital. In addition, recruitment was challenging as the researchers did not have ethical approval to contact potential participants directly. I encountered similar challenges in recruiting for this doctoral research, using Twitter to reach participants. Despite the recruitment tweet being viewed over 17,000 times, following the selection criterion, only five respondents met the inclusion criteria.

The closest study to exploring the experiences was conducted on in-patients with DKA by Moffett *et al.,* (2013) titled ''Patients'' experience of admission to hospital with diabetic ketoacidosis and its psychological impact: An exploratory qualitative study.' This was a UK single centre-based study. Four of the forty invited participants opted to participate, highlighting the challenges of collaborating with a cohort of participants from the T1DM population who had experienced DKA. Moffett *et al.* (2013) focused on exploring the experience of being admitted to a hospital in DKA and the admission itself. It is not reported if any of the participants had previously been diagnosed with DKA. However, the findings provide a valuable foundation of knowledge for others to further research and develop understanding.

Other studies outside this review report that self-management errors account for many admissions (Dhatariya, Skedgel and Fordham, 2017; Yan *et al.*, 2017). This echoes participants in Moffet *et al.'s* (2013) study, which provided three distinct themes, one of which was the difficulties in 'recognising and managing DKA.' This echoes the fear experienced by young people with diabetes and their families in Chafe *et al.'s* (2013) focus groups in recognising the development of DKA. Challenges are reported in being able to take appropriate action, and from the outsider (HCP) looking ''in,'' the obvious steps of insulin administration, blood glucose, and ketone monitoring may be missed; I have discussed this previously as a sense of frustration in Chapter One. Yet it is apparent for Moffet *et al.'s* (2013) participants that insulin omission was not seen as a cause of DKA, and the impact of other elements such as ''intercurrent illness, lifestyle and psychological state'' were believed to hold more significance in the subsequent development of DKA by the participants.

2.20 The challenges of diabetes education strategies

As discussed in Chapter Two, T1DM impacts all aspects of an individual's life, and where available, support from others can be invaluable in navigating the challenges of living with T1DM. This correlates with the findings in Forbes *et al*.'s (2020) grounded theory study, where thirteen individuals with T1DM and six people who supported them were interviewed. Concluding from these interviews, managing T1DM at the point of DKA was like a ''puzzle'' requiring the ability to put ''the pieces together.'' Difficulties are reported in identifying the early symptoms of DKA, which are disparate pieces of the puzzle. Yet, there is the expectation by HCPs that people with diabetes can assimilate this complex clinical information and make complex decisions about what to do regarding their diabetes treatment. This is despite most HCPs needing to rely on the specialist diabetes team to support them with the complex management of DKA (Joint British Diabetes Societies for Inpatient Care, 2022 & 2023).

A common complaint from people with T1DM is the sheer volume of information given at the time of diagnosis, with minimal structure as to when this should be revisited (Chafe *et al.*, 2015). An example of the elements that are required to be covered can be found in the Type 1 Diabetes and Adults guidance published by NICE, (2022). Predominantly early T1DM education involves practical skills such as glucose monitoring, insulin injections and carbohydrate counting, hypoglycaemia and hyperglycaemia, and sickness management. These are complex elements for individuals without a health background to master. Given the urgency of the situation at the point of diagnosis, there is limited time to consider the health literacy of the person with newly diagnosed T1DM in the UK sickness management, and other elements of T1DM are revisited again in structured education programs and the annual refresher sessions (DAFNE Study Group, 2002; NICE, 2003; NICE, 2022).

Many study participants recollected that they were unaware of how to manage illness to prevent DKA. Even to the extent that they were unsure of the critical step of administering insulin and increasing the dose if blood glucose is elevated, it is not always easy to determine if this is another illness such as flu or DKA (Moffett *et al.*, 2013; Chafe *et al.*, 2015). The reasons for this occurring are unclear; HCPs will have, as part of the diabetes care plan, provided education and guidance about managing periods of sickness and very high glucose levels, including when to seek emergency advice. The studies cited here perpetuate the perception of being uninformed (NICE, 2022; Joint British Diabetes Societies for Inpatient Care, 2023).

The importance and urgency of DKA are discussed as part of education regarding sickness management and are stressed to patients. Yet two participants in Moffett *et al.'s (2013)* study felt no *urgency* from the health professionals they contacted, falsely implying that DKA is unimportant. This failure to rush may be due to the operating status of health care systems, in addition to the poor knowledge base of staff regarding the gravity of the situation, misconstruing that participants have self-inflicted the DKA, displaying elements of bias and stigma. Distance from the hospital was a key source of anxiety for the parents interviewed by Chafe *et al.'s*, (2015), and whilst the rurality of Newfoundland and Labrador in Canada is not typical, many patients living in parts of the UK will have journeys above an hour to reach a district general hospital for treatment.

2.21 Support from others to manage diabetic ketoacidosis

Support from others to help manage early DKA was valued by the participants in Moffet *et al.'s (2013)* study, but this support is not universally available across studies. There are some differences between a state funded health system, as experienced by Moffett *et al.'s* (2013) National Health Service (NHS) participants and the insurance-based health care system of Forbes *et al.*, (2020), in which sixty-two % of participants were unable to identify their insurance provider. Seven had no easily identifiable person who provided support. The assistance of others is highlighted as necessary in daily living with diabetes, even though it may sometimes feel unwarranted (Moffett *et al.*, 2013; Ingersgaard *et al.*, 2021). A theme identified by Forbes *et al.*, (2020) arose from these supporters, finding that despite their best intentions, they could not always link the individual's symptoms to the subsequent DKA development. Ultimately, those who could draw upon a supporter reported that this person could be an advocate connecting them and the HCPs, reducing the likelihood of subsequent admissions (Moffett *et al.*, 2013; Forbes *et al.*, 2020). To an extent, this is the role that the DSN takes on with the ward team and the patient, but such support is transient to the individual with T1DM.

2.22 Lived experience of diabetic ketoacidosis

Staite *et al.'s*, (2018) qualitative review examining online blogs for those with T1DM and eating disorders whilst not specifically researching DKA reports valuable insights into experiencing DKA in this patient population. Insulin omission is known to facilitate weight loss, and thereby, the intentional omission can be correlated to eating disorder behaviours. Studying an international cohort of eleven online blogs, permissions were sought from the authors to be included in the research. Online support and the use of social media to connect with others is a growing trend amongst those with T1DM. Across the participants, DKA was commonly written about. For some, it had become entrenched in their everyday life, so they continued to try and function, with one participant stating, ‘‘…was walking to and from work every day in severe acidosis, but I kept at it’’ (Staite *et al.,* 2018, p.133), the need to keep functioning was also discussed by Marple (2013).

Participants had repeated episodes of DKA, which Staite *et al*. (2018) described as cyclical*.* This inevitably becomes burdensome, and for some participants, an element of despair is also recorded. Due to being left with other complications such as neuropathic (nerve) damage by the enduring hyperglycaemia they had experienced over time, such complications are forever and will not disappear however well blood glucose levels are subsequently controlled. Behaviours in recurrent DKA need to be considered and mitigated to reduce the likelihood of them becoming entrenched. In Visekruna, Edge and Keeping-Burke's, (2015) In a descriptive phenomenological study, one of the participants spoke of how she had to reduce her insulin doses ever so slightly just to function and still lose weight. In clinical diabetes care, scant attention is paid to the causes of DKA beyond insulin omission.

This review includes one piece of grey literature by Marple (2013) titled ‘‘Fire in my veins: A Story of Ketoacidosis.’’ This is a frank account of how DKA developed following emotional distress from a relationship breakup. Marple (2013) uses evocative language to explain how it felt to experience DKA, which is evocative, with the heaviness in her chest and her body on fire. Despite such grave symptoms, she attended work as her health insurance is dependent on her employment, and her boss stigmatises the fact that she has diabetes. This episode of DKA culminated in a five day long intensive care admission and the realisation that stress can have a profound impact on her diabetes management. There are similarities in how a participant in Chafe *et al*.’s (2013) focus group also described the experience of developing DKA and being in a hospital as unpleasant.

2.23 Discussion of the literature

In the twenty-three studies selected for inclusion across a range of continental settings and healthcare systems, there are many common themes and commonalities experienced by those living with T1DM. These studies have used several qualitative methods, most of which have distilled the interview data into themes that participants have experienced; given the geographical, cultural and societal differences that participants experience, there are similarities in themes, except for the anxiety regarding access to health care provision in those studies whose participants accessed insurance based health care (Forbes *et al.*, 2020).

The complexities and impact of living with T1DM were frequently discussed across studies (Balfe, Doyle, *et al.*, 2013; Visekruna, Edge and Keeping-Burke, 2015; Abdoli, Hardy and Hall, 2017; Willemse, Deacon and Segal, 2018; Carlsund and Söderberg, 2019; Ingersgaard *et al.*, 2021; Fioretti and Mugnaini, 2022; Holmström Rising and Söderberg, 2022). Despite being thoroughly documented in the research literature, acknowledgement of the burden of living with T1DM is yet to be consistently addressed by HCPs in their clinical interactions.

Frequently, participants in this literature review studies experienced significant diabetes distress. This is a different phenomenon from depression. Living with and managing T1DM is burdensome and impinges on all participants' lives; diabetes is always something that requires accounting for. There is a stigma stemming from having a diagnosis of T1DM, which impacted participants across many of the studies included in this review (Balfe, Doyle, *et al.*, 2013; Carlsund and Söderberg, 2019; Cortright, 2021; Ingersgaard *et al.*, 2021; Kruger *et al.*, 2021; Orben *et al.*, 2022). There is also a perceived stigma against those who have T2DM, so despite the commonality of the word ‘‘diabetes’’, those with T1DM do not want to have the stigma attached that they may have caused their diabetes, even though T2DM has a different aetiology to T1DM. Still, the lay population can misunderstand this differentiation in aetiology and this is often not acknowledged in media reports.

In the studies discussed in this literature review, there is little written about DKA or any of the other chronic complications of T1DM, even though much diabetes care and education is delivered to prevent such complications from occurring (Moffett *et al.*, 2013; Chafe *et al.*, 2015; Forbes *et al.*, 2020). So, although the risk of developing complications is omnipresent, they are not the pressing concern or experience of living with T1DM, as discussed across the studies in this literature review. DKA is described as an unpleasant experience (Chafe *et al.,* 2013; Marple, 2013). Chafe *et al., (2013)* and Forbes *et al*., (2013) reported uncertainty regarding recognising DKA*. From* Marple's (2013) account, it was evident that despite such severe symptoms, she was not immediately able to recognise that she had developed DKA.

2.24 Chapter Summary

Recurrent DKA in T1DM requires additional investigation and understanding. Despite advances in diabetes care, recurrent DKA continues to cause significant mortality in the T1DM population, which is predominantly under the age of 30. Although the prevalence and economic burden are well researched, the underlying reasons for insulin omission are not yet well documented, despite the significance of insufficient circulating insulin in causing DKA. Most cases of DKA occur in T1DM, with an increased risk of development during adolescence and young adulthood. During these stages, there are several compounding factors that increase the risk of developing DKA. For many, being diagnosed with T1DM is distressing and continues to be burdensome many years after the point of diagnosis. Managing the distress, in addition to the very regular interventions of glucose monitoring, food intake, and insulin administration, can be overwhelming, especially if social support was not present from others.

Findings from this review suggest that being diagnosed with T1DM was, for many, a traumatic event leading to long-term distress and burden. These feelings are extenuated when social support is limited. Frequently, participants reported support was crucial to help them facilitate successful self-management strategies and that this support was not just limited to significant others but also included the workplace and health care professionals.

The interactions with HCPs were also significant and could have an adverse effect on the person with T1DM. This warrants further exploration as it suggests that consultations could leave those with T1DM blamed for failing to achieve glycaemic targets, further adding to the burden felt. In some cases, this was significant enough to encourage participants to miss their subsequent diabetes appointments. In recurrent DKA, failure to attend routine appointments is high. This leads to a missed opportunity to intervene in the cyclical nature of recurrent DKA admissions. Although education on preventing DKA is routine at the point of admission, this does not necessarily result in stopping future admissions.

There remains a limited understanding of developing the acute complication DKA, as the participants infrequently discussed it as a concern in the studies regarding living with diabetes. Whilst insulin omission frequently causes DKA, the complexities behind why it is omitted are not fully understood, and those who develop DKA are frequently labelled as noncompliant with their treatment. It may also be possible that PWD who have had recurrent DKA are less likely to enrol in research studies if they are less likely to attend diabetes clinics. In the studies where participants did discuss DKA, the focus was on access to care and the unpleasantness of the situation. The most telling account came from Marples' (2012) first-hand narrative of her experience of recurrent DKA and the complex situation that precluded her from seeking treatment.

This literature review has highlighted a gap in the literature related to why some young adults with T1DM repeatedly develop DKA and a poor understanding of the experiences of young adults who develop recurrent DKA. The current available literature on DKA focuses on the burden on the health care system rather than on developing an deeper understanding of the perspective of lived experience, which could potentially reduce mortality from DKA. This doctoral research will address this gap in knowledge through a study which will investigate the experience of recurrent DKA, told through the lens of young adults with T1DM in the UK.

In Chapter Three, I will set the scene for the philosophical orientation of phenomenology for this case study underpinning this doctoral thesis.

Chapter 3 Philosophical Orientation

3.1 Introduction

The purpose of this chapter is to provide justification for the ontological and philosophical underpinnings of this phenomenological case study. An account of the evolution of phenomenology during the 20th Century with phenomenologists such as Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976) will be outlined. There will then be a focus on the philosophy of Maurice Merleau-Ponty (1908-1961) and his work on embodiment, temporality and corporeality, published in the Phenomenology of Perception (2014). This text will be used to explore how embodiment, temporality and corporeality are contextualised by participants in this phenomenological case study to aid the interpretation of their experiences captured during the interviews.

3.2 Ontology

It is important to qualify ontological positioning in qualitative research. As a social science researcher, I will present and discuss my ontological stance in relation to the doctoral study. Ontology is defined as the structure of being (Crotty, 1998). To ensure research is robust and adheres to a congruent way of being designed and conducted, phenomenological research should have the principles embedded throughout the study design (Taylor & Francis, 2013; Dibley *et al.*, 2020, pp. 153-155). Ontology scaffolds the entirety of the research process, providing a framework that comprises epistemology, methodology and methods (Hammond and Wellington, 2020, p.140). Several aspects of ontology are essential to acknowledge for this study. Firstly, the theoretical underpinnings of professional nursing education shape both my view and interpretation. The theoretical knowledge of how to treat DKA is based on previous clinical practice and outcomes rather than the perceived certainty of a randomised control trial or meta-analysis. Absent from theoretical knowledge, therefore, is what people with recurrent DKA experience during an episode and what nursing care is required.

Secondly, the philosophical underpinnings of Phenomenology and Merleau-Ponty's (2014) 'Phenomenology of Perception.' In T1DM, the impact of diagnosis and long-term physiological effects on the body are well documented in theoretical texts and research papers. However, this theoretical knowledge does not capture the experience of the individual who develops DKA. Nor is this experience something that can be measured to quantify. Therefore, Merleau-Ponty’s (2014) phenomenology offers the opportunity to create knowledge that captures the lived experience of recurrent DKA and how the body and the mind experience this. This chapter presents the philosophical underpinnings to contextualise the ontological positioning for this research investigating the lived experience of recurrent DKA.

3.3 Epistemology

Epistemology studies how we know what we know (Hammond and Wellington, 2020, p. 69). This thesis is mainly concerned with understanding the experience of recurrent DKA from participants' perspectives. The literature presented in chapters one and two highlighted the limited understanding of this experience.

Focusing on the construction of the lifeworld of those with T1DM and how participants chose to convey this information regarding their experiences of DKA during the interviews, enabled participants the opportunity to share both their experience of recurrent DKA and how this impacted their life with T1DM. The challenges and complexity of living with T1DM will be analysed and interpreted phenomenologically to create new knowledge about the experience of recurrent DKA and how this is sensed within the body.

Knowledge is a fundamental part of nursing practice. As a nurse academic, I am required by the nursing regulator to be able to practice evidence based care (Nursing and Midwifery Council, 2018). However, there is much that I and other HCPs do not know about recurrent DKA beyond that some individuals repeatedly present with the condition, use more NHS resources than others with T1DM, have poorer diabetes outcomes and an increased risk of premature mortality (Gibb *et al.*, 2016; Sperling, 2016; Dhatariya, Skedgel and Fordham, 2017; Garrett *et al.*, 2019). Unknown is why this may be the case with DKA occurring despite the remedial actions of structured diabetes education and the provision of insulin for injecting to ‘control’ blood glucose levels (DAFNE Study Group, 2002; Keen *et al.*, 2012; Misra, 2015). Professional ways of knowing are informed by research studies and theoretical frameworks; however, in the case of recurrent DKA, it is difficult to know with any certainty what the person experiences. This research addresses this deficit of what is known and develops increased understanding from the perspectives of those living with and experiencing DKA.

This work utilises a constructivist approach. It investigated the lived experience of participants who had DKA through their lens. External factors will shape their perceptions of their experiences. Participants will not all have the same experience even though physiologically their body will follow a particular path of biological disruption as the DKA develops; how this is felt or perceived both in the immediacy of the acute event of DKA and afterwards when they have time to reflect on the event (Bury,1982; Butalia *et al.*, 2013; Umpierrez and Korytkowski, 2016). There is no single truth available for the experience (Crotty,1998, p. 8).

3.4 Introduction to Phenomenology

This research investigated the lived experience of having had recurrent DKA. Such experience is individual and unique to that person, and the intention is not to generalise the individual's experiences but rather to explore each narrative to consider how each person's context and events impacted their experiences (Smith, 2018; Zahavi, 2020). Gadamer (2013, p. 4) criticises the need to establish ‘‘similarities,’’ being clear that phenomena will be different for individuals. This case study explores an individual's experience contextualised in their own world, creating an understanding of how events impacted the participants. Merleau-Ponty (2014) acknowledged that phenomenology has limitations as it will never provide a precise answer about the area under investigation; it is impossible to interpret the meaning of all phenomena entirely.

Phenomenology has evolved since the 1800s. Many European scholars have continued to add to and develop the philosophy, particularly during the first half of the 20th Century in France and Germany (Bakewell, 2017; Van-Manen,2020, pp. 1-6). During this period, Europe was experiencing a geo-political transition; this instability culminated in two world wars. Husserl (1859-1938), who is considered the founder of the phenomenological movement, was a Rector at Freiburg University in Germany (Smith, 2013). During the lead up to the Second World War, Husserl (1859-1938) lost both his right to lecture in Germany and publish new work due to his Jewish heritage. Ultimately, this led to his position at the university being removed from him (Zahavi, 2020). Husserl’s extensive phenomenological works were considered particularly important to society, and they were hidden before being smuggled out of Germany to Holland to ensure they survived intact for future scholars (Bakewell, 2017).

Initially a student of Husserl, Heidegger diverged from Husserl philosophically over the notion of bracketing, which Husserl advocated (Heidegger,1932, Smith, 2013). Bracketing is the requirement to set aside preconceived knowledge of the subject under investigation, a challenging feat (Thomas, 2005; Carman, 2009; Aagaard, 2017). Bracketing is exceedingly complex; other phenomenologists, such as Heidegger (1932), were unable to incorporate it in their interpretations of phenomenology (LeVasseur, 2003; Gearing, 2004). In the context of this study, bracketing would involve finding a way to forget all that I knew or had perceived about DKA from my clinical experience.

As a doctoral researcher, removing what I have learned from the experiences and clinical stories over the decades shapes my practice (Johnston *et al.*, 2017). The stories of previous patients with DKA contributed to both knowledge and understanding, which are intertwined with the researcher's role. Merleau-Ponty (2014) writes that the person analysing the experience themselves becomes involved in ‘‘perceiving’’ or making sense, even though they did not experience the situation firsthand, making such a thing as bracketing, in reality, impossible to achieve (Merleau-Ponty, 2014, p. 220).

Gadamer (2013) shared some philosophical commonalities with Merleau-Ponty (Earle, 2010). Both philosophers focus on being- in the world; however, how they view this situation differs. Gadamer (2013) focused on the hermeneutic circle and the words used to describe the experience, particularly ‘the prejudice,’ reviewing this throughout the research process (Honderich, 2005). The hermeneutic circle has an element of familiarity with nursing practice, sharing some commonality with the experience of reflective practice (Tuohy, *et al*., 2013). Whilst there are some elements of commonality between Gadamer (2013) and Merleau-Ponty (2014), the focus for Merleau-Ponty is the examination of the perception of events and the interplay between the body, mind and the environment and how these are inseparable elements (Earle, 2010; Merleau-Ponty (2014).

3.5 Introduction to Merleau-Ponty

Merleau-Ponty (1908-1961) continued to evolve the philosophy of phenomenology and is widely believed to have developed the philosophy of ‘embodiment’ despite not explicitly entitling this in his seminal publication ‘‘Phenomenology of Perception’’ (Merleau-Ponty, 2014). Phenomenology of Perception was written in his native French and translated into English by Landes in 2014. Merleau-Ponty (2014) contributed significantly to the development of phenomenology, evolving it further from the earlier work of Husserl and Heidegger and increasing understanding following the publication of the phenomenology of perception. He wrote about this area extensively, which has significant resonance in the study of long-term conditions and the experience of people living with them (Merleau-

Ponty 2014). Perception in this context can be viewed as how we experience something and, importantly for this work, how the world impacts the experience itself (Carman, 2020). The difference between humans versus an object such as a table is that numerous factors affect our interpretation of life events (Merleau-Ponty, 2014; Carmen, 2020, pp.1–2). On a superficial level, perceptions of how we experience something can be affected by something as simple as being too cold, hot or hungry, temporarily impacting perceptions of the event. However, the environmental factors that interplay with our everyday existence have a more permanent effect on our interpretation of the experience. It is thoroughly documented in the management of T1DM that social, psychological and physical elements unsurprisingly impact the ability to self-manage diabetes (Howe and Lewis, 2012; Poulsen and Andersen, 2016; Willers *et al.*, 2018).

Merleau-Ponty (2014) wrote about an experiment designed to explore perception, following an examination of how people who were temporarily made blind for an experiment before being allowed to see again experienced the world. During the experiment, Merleau-Ponty’s (2014) participants wore goggles that inverted their world. For example, the ceiling was, in reality, the floor, and vice versa. He reports that within eight days, the participants have adjusted their interactions with the world, compensating to be able to interact with the world (Merleau-Ponty 2014, p. 255; Allan, Eatough and Ungar, 2015). However, such a transformation was not evident in the adjustment of life with T1DM in the literature presented in chapter two.

Traditionally, in philosophy, the body has been viewed as comprising two distinct parts: the body and the mind as separate entities (Wilde,1999). This cartesian or dualistic thinking has significant limitations in humans living with enduring long-term conditions such as T1DM. Embodiment can be defined in several ways depending on the context that is being examined. Merleau-Ponty (2014) perceived embodiment as being a merging of the body, which is inseparable from the mind. This view diverges from the earlier work of Kant who proposed that the mind and body should be viewed as separate, defining the term dualism (Brooke *et al.*, 2020). Merleau-Ponty (2014) refuted this stance of separation despite continuing to write about them separately in Phenomenology of Perception. Later in his career and very close to his untimely death, in an interview in 1960 with Le Monde (a French newspaper), Merleau-Ponty (2014) describes this as an ‘‘insoluble unity’’, meaning that it is impossible to separate the mind from the body (Moran, 2013).

The separation of the body and mind is a long standing problem in health care, whereby physical and mental health services are primarily delivered by different NHS Trusts. In his essays on perception, Merleau-Ponty (2014) challenges this dualist view and proposes that the body and mind cannot be separated as they are intertwined; one will impact the other. There has been growing interest in this approach within psychology in recent years, whereby authors are drawing on the work of Merleau-Ponty (2014) to explore different ways of treating entrenched illnesses such as psychosis (The Lancet Psychiatry, 2021). Merleau-Ponty's (2014) philosophical branch of phenomenology focuses on the embodiment of a phenomenon to the extent that a situation becomes intertwined with the individual (Peoples, 2020). For example, in T1DM, the condition occurs twenty-four hours a day, three hundred and sixty-five days a year, requiring significant elements of self-care and decisions to be made, such as how much insulin to take; there is no respite or day off when on holiday. It is unsurprising, therefore, that the levels of diabetes distress are high and that this psychological burden can also impact decisions about physical treatment (Joensen, Almdal and Willaing, 2016; Allcock, Stewart and Jackson, 2022). Bury (1982) defined this as ''biological disruption.'' T1DM impacts life by taking the normal physiological glucose regulation, an autonomic regulatory system, to the individual who must take on this role. At the point of diagnosis, this involves a high degree of conscious decision making before being incorporated into the body and the mind, whereby the individual will sense what is required for diabetes management; this is an example of embodiment in T1DM.

In lay terms, embodiment in chronic illness such as T1DM can be defined as the merging of the many elements of the condition to the extent that the individual can make unconscious everyday decisions (Montez and Karner, 2005). Participants describe this as knowing intuitively, for example, their glucose level, whether or not they choose or feel unable to act on this knowledge. It is difficult to know if this is an embodied decision or if other factors may influence the individual to act on or against the embodied experience of high glucose levels. This research will capture this from the context of recurrent DKA.

3.6 Embodiment

The concept of embodiment is fundamental to this research study, which investigated the experience of developing recurrent DKA in T1DM. Zahavi (2019, 2020) described core aspects of phenomenology as a framework to explore human experiences, which included 'selfhood, empathy, temporality, speciality, effectivity, and embodiment.' This section explores further how diabetes is assimilated or embodied in an individual’s life world; Montez and Karner (2005) examined how diabetes impacts the concepts of identity on the body and self.

Embodiment can be viewed as the body and mind's impact on the investigated phenomena. The body and mind interact and are also affected by the surrounding world or environment. Fuchs, (2020) clarifies that embodiment is an incorporation of behaviours by the individual. Behaviours become engrained and autonomous in ways that are affected by the social world of individuals and will differ from person to person (Todres, 2008; Engman, 2019). Fernandez, (2020) suggests that within healthcare, there has been a limited attempt to critically understand the specifics of what it is to live with or experience some aspects of a condition or how it impacts the quality of life. The current study intends to bridge this gap as it concerns what it is like to live with T1DM and the experience of DKA; the findings will be examined phenomenologically. How the body and mind interact within the context of the social and psychological setting of the individual removes this research from the traditional subject area in DKA of causation and positions this study to illuminate the poorly understood experience. To date, morbidity and mortality have been the focus of diabetes research into DKA (Gibb *et al.*, 2016; Dhatariya, 2017; Dhatariya, Skedgel and Fordham, 2017; Shaka *et al.*, 2021).

Merleau-Ponty (2014) is inextricably linked with the concept of embodiment within phenomenology. Despite not making the term explicitly or conceptually in his work by providing a chapter entitled ‘‘embodiment,’’ or writing about the concept directly. His focus within his seminal work, the ‘‘Phenomenology of Perception’’ (2014), is considerably more abstract, focusing on ‘‘sensing.’’ Merleau-Ponty (2014) viewed ‘sensing’ as having an empirical basis, how we can construct knowledge and formulate experience from a combination of the five bodily senses present within individuals (Honderich, 2005, p. 242). Further developing the concept of sensing as an ‘‘external perception and the perception of one’s body vary because they are two sides of a single act,’’ Merleau-Ponty (2014, p. 211).

Although there are separate elements of body, mind and environment, he believes they are inextricably linked, giving rise to a ‘‘fusion of horizons’’ for the individual (Gadamer, 2013). Merleau-Ponty (2014) proposed that ‘‘I must also invert the natural relation between my body and the surroundings, and a human productivity must appear through the thickness of being’’ (Merleau-Ponty, 2014, p.115). Here, Merleau-Ponty suggests that a conscious action being described is relative to the surroundings. The impact, for example, that the situation and environment have on those navigating life with T1DM is well documented in outcome data in T1DM. Those with higher levels of social deprivation more frequently attend Emergency Departments (Akhter, Turnbull and Simmons, 2016; Poulsen and Andersen, 2016; Apperley and Ng, 2017; Hill, Ward and Gleadle, 2019). Merleau-Ponty (2014, p.115) used the term ‘the thickness of being,’ which would appear to relate to the complexity of an individual’s existence and their situation in their social world. Therefore, any decision regarding diabetes management is situated in the context of an individual's lifeworld. Embodiment was central to how individuals perceived their bodily experiences, including during ill health. Merleau-Ponty (2014) wrote extensively about how we can make sense of our place in the world through our embodied actions: “We do not know what we see,’’ leading to being able to act and do things seemingly unthinkingly. In T1DM, this embodiment may relate to calculating an insulin dose or knowing that corrective treatment is required to treat hypoglycaemia without the need to measure a glucose level. HCPs are given credence for expert practice, however little acknowledgement is given to people living and managing their complex health conditions beyond the achievement of biomedical targets; healthcare remains predominantly paternalistic (Dahlberg, 2019).

T1DM, which is classed as a chronic long-term condition, the person is both well and ill in tandem. This is a condition that, once diagnosed, does not manifest with any visible changes to an outsider; there are internal changes (Bury,1992). The resulting actions to alter everyday activities, such as eating and drinking, give the first clue that something different may occur. Externally, this will be the physical actions of administering insulin and checking blood glucose levels. These appear to be intentional acts using the knowledge gained through diabetes education and experience. However, such acts neither define the individual nor make them ill (Dahlberg and Dahlberg, 2020).

Merleau-Ponty (2014) proposed that when we *perceive* something, our reaction is to find context in the world around us. We must experience things to perceive them (Merleau-Ponty, (2014). Situating ourselves and the interpretation of it from our perceptions of the world around us. The individual does not see or experience such events in isolation, as they are also part of the perception.

Suggesting that there are elements of conscious actions that are relational to our surroundings or the environment to enable an action to be instigated. Over time, perceptive experiences will likely impact and influence each other using situational experience to make sense of events. Therefore, it is important to acknowledge that understanding will be linked to an individual's past experiences, ‘*‘I will perhaps understand my past differently and I will accordingly construct it differently.”* (Merleau-Ponty, 2014 p. 362).

Whilst individuals may be able to draw on these experiences to enact a different outcome than before, many individuals living with T1DM continue to be constrained by the social and psychological worlds within which they live. For example, adults with newly diagnosed T1DM do not have past diabetes experiences to refer to when managing their diabetes. Or, in the case of recurrent DKA, it could be assumed or predicted that to construct differently would never lead to recurrent DKA. However, many individuals are constrained by their social and economic worlds, hindered by societal inequalities such as education, economic prosperity, employment and living situations (Overgaard, Christensen and Nexø, 2021). For other individuals who have lost control over their lives and bodies following a diagnosis of T1DM, the development of DKA may be a conscious decision that they feel in control of despite the symptomology and grave consequences.

The phenomenological approach, using the concept of embodiment developed by Merleau-Ponty (2014) will never provide an exact answer about the world under investigation. It is not always possible to explain or provide meaning to phenomena under investigation (Lewis & Staehler pp.162-163). The very nature of phenomenological interviews researching an event means that the participants are now ‘perceiving’ and making sense of the event, placing the experience in phenomenological terms into a sensation (Johnston *et al.*, 2017).

3.7 Time and Temporality

This section will explore the impact of temporality in recurrent DKA. Temporality is a key concept within phenomenology and is one of the four existential elements; the remaining three are ‘‘lived space, lived body and lived human relation’’ (van Manen, 2016, p.101; Jowsey, 2016). Whilst these can all be viewed individually there is invariably overlap within an individual’s experience, just as experience with recurrent DKA is not confined solely to the physical manifestations of the condition itself but is also impacted by the social and psychological environments of the individual. Heidegger (1982, pp. 231-235) said that temporality should not be confused with chronological time; it is far more complex than this. He draws on the Greek definition of time as merging memories and experience. Gadamer (2013) developed these concepts further as he discussed the ‘‘fusion of horizons’’ in the context of experience, the situation of both the participant and the researcher interpreting.

Temporality has several important connotations for research concerned with exploring experience with T1DM participants. If temporality is not addressed as part of the study design, there are significant risks to methodological quality in hermeneutic phenomenological case study research. Diabetes is a condition where, over time, the consequence of blood glucose levels impacting the future life ahead with the presence of acute and chronic complications may come to the fore and the immediacy of everyday living with diabetes, in addition to the lifeworld that came before the diagnosis. Maines (2014) proposed that people with diabetes are intertwined both with themselves and society. So, just as Merleau-Ponty (2014) acknowledged the dualism of mind and body, this adds an additional dimension.

Temporality is defined as lived time, and there is no direct correlation to time itself for phenomenology. While time is linear or cyclical, the certainty of what will happen next is inferred from cultural influences guiding how most people conduct their lives. We get up at a particular time, maybe have breakfast and go to work. All these things may also occur for those with T1DM, but many variables are at play. Their day may not be able to follow such a linear path if they are faced with a clinic appointment or have experienced issues with glucose control that day. Their lived time may get disrupted by having to deal or not with a particular element of diabetes self-management that requires their attention. Societal positioning may also impact how they approach such calls on their time; for example, they may have very scant employer support not to be present at work, thereby forcing individuals to focus on work rather than being able to resolve the immediacy of their current predicament.

Merleau-Ponty (2014) used the analogy of ‘‘time’’ being like a river. Regardless of what individuals desire, time continues to flow past us. Using a metaphor of being on a boat on the river, Merleau-Ponty (2014) stated that we are concurrently ‘‘being in and on it’’ [time]. We cannot alter this passage of time; ‘‘each moment of time sets down an existence after which all other moments are powerless,’’ resulting in previous experiences becoming part of the individual. The events will add to and shape individuals’ perceptions about life with diabetes, particularly their life before and after diagnosis of T1DM, which the literature review noted was problematic for individuals (Balfe, *et al.*, 2013; Visekruna, Edge and Keeping-Burke, 2015; Abdoli, Hardy and Hall, 2017; Willemse, Deacon and Segal, 2018; Carlsund and Söderberg, 2019; Ingersgaard *et al.*, 2021; Fioretti and Mugnaini, 2022;

Holmström Rising and Söderberg, 2022). Previous events will impact interpretation or perception as individuals with T1DM reflect inwardly on their life experiences. These previous experiences shape our perceptions and may affect our interpretation. Merleau-Ponty (2014 p. 482) said ‘‘by taking up a present, I again take hold of my past, and I transform it, but I only do so by committing myself elsewhere.’’ Here, Merleau-Ponty (2014) proposes using past events to make sense of the present. There is a commonality between what has been (life before T1DM) and life post diagnosis. However, it is apparent that this ability to ‘‘transform it’’ does not necessarily result in behaviours and actions that are ideal for a particular outcome, such as avoiding the development of recurrent DKA (Hinder and Greenhalgh, 2012).

3.7.1 **Changes over time**

Green & Hopwood (2015, p.19) agree that there is a variance between what we say we will do (our intention) versus what we actually do, and this may be the narrative that healthcare professionals propose for their patients, i.e., the good intentions of behavioural actions versus the reality of the experience for patients living with T1DM. D'Angelo (2019) writes in his paper about the concept of embodied attention, reporting in detail on the “transcendentalism of embodiment, the bodily subjectivity of attention, and the creativity of embodied attention.’’ Writing from a psychological perspective, how attention can be embodied. D'Angelo (2019) proposed that we do not consciously find the phenomena within us. In contrast to Merleau-Ponty (2014), we may be required to focus deliberately on them to bring them to the forefront of the mind. For instance, if this is a conscious act in T1DM, conscious thought would be required to know when to take a blood glucose level. Whilst this could be conceived as being bodily awareness, descriptions from people living with T1DM would suggest that over time, they can even predict with some accuracy what their glucose level is without needing to do a glucose test (Meltzer *et al.*, 2003; Frankum and Ogden, 2005).

While temporality would indicate an inner sense or awareness of how it feels and what happens to the body as DKA develops, this does not preclude the event from occurring repeatedly. Merleau-Ponty (2014, p. 432) wrote ‘‘we are called upon to forge a conception of the subject and time such as they communicate internally.’’ This inner sense or temporality is integral to how we process and react to events. In T1DM, this is important as many decisions need to be processed; utilising previous experience can help individuals manage their T1DM, harnessing their reflexive self.

3.7.2 **Temporality and T1DM**

Temporality is more complex than first impressions suggest; you would experience a situation once and use this experience to transform experience into altered behaviours. DKA is an unpleasant condition with the person exhibiting symptoms of severe lethargy, extreme unquenchable thirst, and profuse vomiting. At times, there is a dichotomy between what should happen versus the realities of diabetes management. Many patients previously encountered clinically could recite the steps that they could have taken to prevent DKA development, including sickness education from a recent admission with DKA. As a researcher, this is a very frustrating situation, not least because recurrent DKA carries a significant mortality rate (Gibb *et al.*, 2016; Garrett *et al.*, 2019). Merleau-Ponty (2014, p. 482) proposed this assimilation of previous experience and transformation can ‘‘only occur when I commit myself elsewhere.’’ Suggesting there needs to be a degree of conscious thought from the individual. So, although DKA is unpleasant, dangerous and carries the risk of death, for some individuals, this may be an area that they feel they have control over. Making a conscious decision to omit insulin even though they are acutely aware of the implications of such behaviours for both their short and longer-term health.

Merleau-Ponty (2014) described the ‘‘intentional arc,’’ which is the relationship between what the body experiences and the processing of that experience (Dreyfus & Dreyfus 1999, p.103). Over time, it is possible that this assimilation of experience can become embodied, enabling an intuitive knowing of what is required without the need to test blood glucose. Outcomes mirror the autonomic physiological process of glucose regulation that occurs in those who do not have diabetes. Dreyfus & Dreyfus (1999) suggest that once competence has been developed, this can cause individuals to feel an overwhelming sense of responsibility in this phenomenological case study to correctly manage their T1DM. A burdensome situation, and living up to an ethical ideal can add to the development of diabetes distress (Montez and Karner, 2005; Allcock, Stewart and Jackson, 2022).

Merleau-Ponty (2014) suggested that there can be disappointment when another person establishes their ‘‘cogito,’’ an awareness of existence and how this can destroy their version of the awareness of the event. This could be interpreted as the individual losing control of their experience and perceptions of the event of developing DKA when their world collides with the DSN’s version of events, particularly if the DSN does not take the time to understand and listen from the perspective of the person with diabetes in front of them; bringing their clinical views of what should or should not happen, failing to take into account the individual’s life and experiences. This could perpetuate the feelings of failure and diabetes distress, which is thoroughly reported in the literature. So even though a conscious decision may have been made, its validity is questioned; this concept will be explored further during the interviews.

There is no control of the journey, as in the life lived with T1DM. There is no cure currently for T1DM beyond the rarity of transplantation. The only choice individuals have is how extensively to engage with daily diabetes management. Even this decision is impacted by external factors that may be beyond the individual’s control (Zuijdwijk, Cuerden and Mahmud, 2013; Willers *et al.*, 2018). Not only do previous experiences shape interpretation and perception, but the life world or environment plays a key role in shaping how we can process and make sense of events. Where individuals reside within societal structures plays a significant part in the health outcomes attained for those living with T1DM. Social determinants of health, such as income, housing, educational attainment and support from significant others, are well documented to have an impact on diabetes management (Zuijdwijk, Cuerden and Mahmud, 2013; Hill *et al.*, 2015; Willers *et al.*, 2018). Increased levels of education post the age of sixteen reduced the frequency of DKA. Poor support and socioeconomic deprivation increase the incidence of DKA (Apperley and Ng, 2017; O’Reilly *et al.*, 2020).

Much is written in health literature about outcomes, commonalities, and predictors of DKA development and length of hospital stay in the context of individuals with T1DM social world. However, this negates considering the realities of their actual life world (Jack, 2005; Howe and Lewis, 2012; Zuijdwijk, Cuerden and Mahmud, 2013; Apperley and Ng, 2017). Using hermeneutic phenomenology enables the broader perspective or holism to be investigated, examining lived experience. For this research, the participants are invited to participate in a second interview to ascertain how temporal experiences of DKA and life with diabetes have developed. Recruitment was conducted during an unusual period in modern history, whereby the worldwide Covid-19 pandemic commenced in 2020 (WHO, 2021). Gadamer (2013, p. 315) addressed the importance of historical horizons, writing that ‘‘we must already have a horizon to be able to transpose ourselves into a situation.’’ For instance, living with T1DM increased the risks of hospitalisation and death if Covid-19 was caught, coupled with the cessation of routine diabetes care at the start of the pandemic (Gentile, Strollo and Ceriello, 2020; Holman *et al.*, 2020; Mannucci, Nreu and

Monami, 2020). The pandemic created a new horizon for both participants and researchers. How participants navigated their new world in a situation that was thrust upon them; in addition, pre-understanding comes to the fore as experiences were interpreted in the context of the immediacy of the pandemic but also how this may correlate to what is known about diabetes distress and compounding social factors. In a phenomenological study of older adults living with both T1DM and Type 2 diabetes, George and Thomas, (2010) found that participants viewed their diabetes with a sense of inevitability of it not going well, of them suffering harm that was directly caused by diabetes, noting these perceptions were more significant in those that had limited social support.

Merleau-Ponty (2014) discussed the ‘‘structure of temporal experience’’ and how this differs from the ‘‘conception of time’’ (Romdenh-Romluc, 2010, p. 236). It is a vital differentiation when considering human experience, as the focus must remain on the participant's perceptions of the events. What is apparent is how recollections, interpretations or dwelling on experiences such as DKA will be influenced through time by the life events of the participant. So, whilst the commonality between participants is DKA, how it is experienced will differ for individuals. That is not to say that the biochemical disruption will be different, such as alteration of blood chemistry and ketone production, that is the empirical DKA that can be measured. This is not experience; it is a cascade of physiological changes set in place by an absence of circulating insulin, requiring an emergency admission (Thomas, 2005).

Many external influences impact how individuals become embodied within their environments (Johnson, 2017, p. 99). Such factors can comprise economic, political, environmental, and psychological effects that will alter the perception of events or phenomena (Smith 2016). These social determinants of health are thoroughly documented environmental factors that influence and impact those who develop recurrent DKA; how the external environment influences embodiment will be explored during the interviews (Howe and Lewis, 2012; Hill *et al.*, 2015; Poulsen and Andersen, 2016).

The important concept of embodiment is frequently overlooked in traditional nursing education and subsequent clinical practice (Draper, 2014). Yet, it is critical to understand that the focus on how long-term conditions are managed promotes a significant emphasis on self-care strategies, moving the responsibilities from the healthcare system to the individuals living with the condition (Montez and Karner, 2005; Fornasini, Miele and Piras, 2020).

Timing of T1DM diagnosis pre or post-development of the adult self is known to impact self-care strategies and how successful or not an individual is at managing their diabetes. Willemse, Deacon and Segal (2018) reported on the social identities that young adults can construct as they move into adulthood with their changing existence living with diabetes. Participants strived to achieve normality, which was unattainable to many as they lived with an incurable lifelong condition, ‘‘what we have lived exists for us perpetually; the old man remains in contact with his childhood*.”* (Merleau-Ponty, 2014 p. 414). Drawing on some of the findings in the literature on living with T1DM, this concept of contact with our childhood may relate to persistent memories of life before diagnosis and the loss of a normal life now and in the future (Montez and Karner, 2005). If, as Merleau-Ponty (2014) says that we remain in ‘‘contact with our childhood,’’ it would be reasonable to assume that this also applied to our life before diabetes and how those diagnosed later in adolescence or early adulthood may mourn for the life that they have lived and lost before the diagnosis; this is striving for normality which may be an unachievable goal for individuals.

Montez and Karner’s (2005) research examined the ‘‘diabetic body self.’’ What it is to live with diabetes and how this is incorporated into daily life. They proposed that if clinicians understand embodiment, then there is a possibility of being able to influence how an individual can adapt to their life with diabetes. They conclude that this approach fits with the ethos of self-care. Montenz and Karner (2005) also referred to the typology of action problems regarding body relatedness, as Frank (1995) outlined. These four problems were defined as ‘‘Control, body-relatedness, other relatedness and desire’’ referring to how individuals with a chronic illness embody the condition and conform to an ‘‘ethical ideal’’ of how a condition should be managed (Frank,1995). Post-interview, Montez and Karner (2005) concluded that participants related to the four body problems that Frank (1995) discussed and incorporated into their everyday lives with diabetes.

3.8 Lived body (corporeality)

This section will explore the concept of lived body in phenomenology and how T1DM and Diabetic Ketoacidosis (DKA) impact the participant's body from a phenomenological perspective. The individual stories of the participants will be presented and explored in depth during the chapters about the findings. In hermeneutic phenomenology nursing research, the lived body is critical to revealing the participants' experience (Draper, 2014;

Harrison, Kinsella and DeLuca, 2019). Therefore, when the lived body is referred to in this thesis, it should be noted that it includes the physical body and the mind as one.

Merleau-Ponty (2014) is quite clear in the ‘‘Phenomenology of Perception’’ that although the body can be viewed as the “physiological body,’’ this cannot be considered as separate from the lived body, just as the body and mind are viewed by Merleau-Ponty (2014) as a whole (Gallagher,1986; Seamon, 2018). The body in illness has many facets that people with T1DM experience. The beta cells, which produce insulin, catastrophically fail; without intervention by the individual, the body cannot function for long without insulin treatment before DKA develops. The physiological body is broken, but the lived body is now required to make and follow complex decisions about insulin doses according to food intake and blood glucose levels. Gallagher (1986) proposed that the body's physiological state is lived; in T1DM, this is a significant manifestation of everyday life with T1DM.

In the development of T1DM, the body undergoes disruption. Biological disruption was first defined by Bury’s (1982) study of people with Rheumatoid arthritis, which examined the impact of the illness experience. The word diabetes in Greek means to siphon, so even the name of the condition directly relates to a bodily function that becomes impaired at the point of diagnosis, the physiological failure to be able to siphon out the excess glucose and ketones.

Living with a chronic illness such as T1DM, which is invisible to outsiders, but for the person living with T1DM, impacts on life and what were seemingly routine behaviours such as eating and drinking take on a new significance (Engman, 2020).
Engman (2020) suggests that the age of diagnosis will impact the biological disruption as individuals develop with the condition. This premise does not explain adolescents' significant challenges as they transition into adulthood, even when they have had diabetes for several years (Ingersgaard *et al.*, 2021; Commissariat *et al.*, 2023). This disruption can manifest in several social and psychological challenges when navigating their life with diabetes. Whilst Engman's (2020) qualitative study examined transplant recipients' embodied experience, she notes that participants do not necessarily have the language skills to define the embodiment of the condition.
Bury (1982), when defining biological disruption, also stated that there is a need to re-evaluate how individuals can interact with the world around them post-diagnosis. Individuals newly diagnosed with T1DM are known to exhibit feelings of loss and grief for the existence they have had to leave behind as defined in the Kubler-Ross (1969) grief

cycle. Such grief can be enduring and have a detrimental impact on the individual in the long term.

3.9 Chapter summary

Within this chapter, I have presented the underpinning philosophy of this phenomenological case study, which examined the lived experience of developing recurrent DKA. Phenomenology continues to develop over time. This doctoral study drew heavily on the work of Merleau-Ponty (2014) to aid in understanding both the temporal and embodied experience of recurrent DKA and T1DM. Phenomenology provides opportunities for nurses and other HCPs to develop an understanding of the experience of the bodies of the patients they care for.

Chapter 4 Methodology

4.1 Introduction

In this chapter, the justification and rationale for the methodological choices underpinning the chosen study design will be discussed. This chapter builds upon the philosophical orientations of hermeneutic phenomenology (HP) discussed in Chapter Three. Elements of methodology will be discussed throughout, paying close attention to the underpinning philosophy of hermeneutic phenomenology that governed the development of this phenomenological case study. The hermeneutic lens was congruent with the methods used in this case study, which will be discussed in this chapter. (Tuohy *et al.*, 2013; Crowther *et al*., 2017; Dibley *et al*., 2020). Researcher reflectivity remained central throughout each stage of the study.

4.2 Methodological justification

The literature review identified a gap in the research regarding the experience of having experienced diabetic ketoacidosis (DKA). Therefore, choosing the methodology that captured the lived experience of people who had experienced recurrent DKA was a primary concern in the design of this research. Current literature documents the physiological and psychological impact of DKA but not what it is to be in the midst of it. To achieve this, a phenomenological approach was considered optimal to be able to examine the perceptions of participants regarding their experiences of DKA, which will form the phenomenological case (Montez and Karner, 2005; Harrison, Kinsella and DeLuca, 2019; Svenaeus, 2019). Five studies in the literature review examined the experience of T1DM using phenomenology to frame interviews, enabling the participant voice to come to the fore to describe their experiences (Visekruna, Edge and Keeping-Burke, 2015; Fredette *et al.*, 2016; Kruger *et al.*, 2021; Pinar and Turan, 2022; Holmström Rising and Söderberg, 2023). However, Pinar and Turan (2022) did not retain phenomenological congruence for their interview analysis; beyond stating ‘‘phenomenological type,’’ there was no further reference to phenomenology. Nursing research has been criticised for failing to embed phenomenology throughout the research process (Crotty, 1998; Norlyk and Harder, 2010; Paley, 2017). Therefore, this case study is constructed to ensure that phenomenology is embedded.

Other approaches used by studies included in the literature review included grounded theory, narrative analysis and qualitative interview studies, with thematic analysis as the predominant analysis method. However, reflecting upon my ontological and epistemological positioning and the desire to construct new knowledge about the experience of DKA within the body, creating a phenomenological case as the underpinning methodology for this research enabled a glimpse into the worlds of participants. Thus, it provides an opportunity to document the lived experience through the participant’s gaze beyond the clinical metrics of DKA previously reported and discussed in Chapter One. The literature shows that DKA's causation is multi-faceted, with implications for physical and psychological well-being. Phenomenology will enable the multifaceted factors that impact people's lives and potentially influence the physical and psychological well-being of participants in this study.

Nursing practice draws upon taught and experiential learning to develop an understanding of a condition and how the patient may respond during an episode of care (Benner, 1992; Källestedt *et al*., 2023). Yet, whilst nurses' prior experience may augment the care they provide, the literature still does not offer an insider view of the lived experience of DKA to help inform their practice. For instance, in the development of DKA, the body's physiological response to the immediacy of DKA development, defined by rising glucose and ketone levels, is evident when biochemical measurements are taken. What is not reported is what is felt within the body and mind during DKA. Therefore, drawing upon my epistemological positionality using phenomenology will capture the phenomena of DKA to form this case study. Importantly, this research will investigate how the participants feel and perceive their experience, examining the interplay between the body's physical and psychological elements. Phenomenological interpretation will be used to examine embodiment, temporality, and corporeality to maintain phenomenological congruence. It enables the uniqueness and depth of participants' experiences captured during the interviews and the resulting analysis, which will form the case of recurrent DKA (Smythe, 2011; Smythe, 2012; Dibley *et al.*, 2020; Rouse, 2021, pp. 325–328).

4.3 Case study methodology and phenomenology

Case study research has a strong tradition in qualitative research, with many of the original studies originating in the field of education. However, the methodology is not limited to solely investigating large-scale issues such as educational or healthcare delivery across a system (Strake,1995; Simons, 2009; Yin, 2018). There is debate about whether a case study is solely a method or can be utilised as the overarching methodology in research design (Sandelowski, 2011; Thomas, 2011; Hyett, Kenny & Dickinson-Swift, 2014). Simons (2009) discussed that such methodological evolution enables the ability to draw upon the uniqueness of phenomena, a critical element of hermeneutic phenomenology that underpins the interpretation of findings in this research. The overarching construct of a case is that it must be bounded to define the case and subsequently illustrate the uniqueness of the findings (Greenhalgh & de-Graft Aikins, 2024, p.504). Strake's (1995) early definition of the case study as a method to research unique, complex issues fits well with this study, which provided an in-depth investigation of the experience of recurrent DKA, which is known to be a complex and multifaceted consequence of T1DM (Simons, 2009, Bowling, 2023 pp.301-303). There is a precedence in the literature for adopting such an approach to use both case study and phenomenology in the same study (Friberg & Öhlen, 2007; Henry *et al*., 2008; Degand, 2015; Patel, 2015; Timmerman, Baart, Vosman, 2019).

Investigating the experiences of DKA from the perspectives of those who develop it is essential for healthcare delivery of diabetes care if morbidity and mortality outcomes from DKA are to be further improved. However, the fluidity of the numerous approaches available can cause ambiguity when designing and structuring a case study (Yin, 2008, p.3). However, the advantages of flexibility as being suitable to expand the horizon of what is already known about a topic can be advantageous (Yin, 2018, p.49). Therefore, utilising a phenomenological case study to investigate recurrent DKA will enable the creation of new knowledge that can subsequently be applied to changing diabetes nursing practice to challenge the current status of increased morbidity and mortality in this population.

The findings presented in Chapters Five and Six were thematically analysed utilising Braun & Clarke's (2006) six steps of thematic analysis before drawing upon philosophical interpretations underpinned by the philosophy of Merleau-Ponty (2014) presented in Chapter Seven. In this case study, the phenomena are not initially apparent at the outset of designing the research; therefore, as Van Manen (2017) states, it is essential to transparently discuss how such interpretations are made from the study's findings. The case of recurrent DKA in T1DM will be fully explored in the discussion in chapter eight.

4.4 Boundaries in the case of recurrent DKA

The proposed boundaries for this research are formed from the inclusion criteria discussed earlier. In a typology of case study research, Thomas (2011) argued that a case should be created from the participant findings in addition to the analysis and interpretation (Andrews (2024, p.118). Drawing upon this method allows us to consider the participants' experience with recurrent DKA as a unique case (Sandelowski, 2011). The final presentation of the case will be made in Chapter Eight, following recruitment and analysis of the findings.

4.5 Phenomenological interviews

Phenomenology can explain lived experience through many different facets of life, such as the arts, literature and, in this case, healthcare. Each phenomenologist interprets phenomenology differently, so over time, there is a continued evolution of the philosophy (Zahavi, 2020). Indeed, there is no prescriptive way to analyse phenomenological interviews, and there continues to be debate in the literature about how the interview transcripts should be presented and interpreted (Crowther *et al*., 2017; Payley, 2017 p. 9; Zahavi and Martiny, 2019; Crowther and Thomson, 2020). Participants’ experiences from the interview transcripts were also interpreted using a reflexive process drawing on my experience as a nurse researcher. External factors can impact how people interpret events. Individuals' experiences of their social and psychological worlds will impact how such events are perceived (Howe and Lewis, 2012; Hill *et al.*, 2015; Willers *et al.*, 2018). Individuals’ experiences will be analysed to interpret their experiences and reveal the phenomena in their experiences of recurrent DKA (Smythe, 2011; Spence, 2017; Crowther and Thomson, 2020).

4.6 Creation of a hermeneutic interview

A hermeneutic (HP) interview should be reflective and enable the interviewer to take the participant back over the content revealed and bring the interviewer's understanding to guide the direction of the interview (Norlyk and Harder, 2010; Dibley *et al.*, 2020). Challenging the novice researcher to move beyond their interview guide of prompt questions to ensure the interview flows in the direction that enables the participant to share their experiences of recurrent DKA. Epoche can be defined as acknowledging that, as the researcher, I bring pre-understandings of recurrent DKA. These pre-understandings form part of the hermeneutic circle of interpretation (Gadamer, 2013).

HP supports the use of a pilot or pre-understanding interview. This can occur either with the supervisory team or a participant supporting the development of phenomenological interviewing skills. In addition, this pre-interview can enable the development of self-awareness of my pre-held assumptions (Crowther and Thompson, 2017; Crowther *et al.*, 2017; Dibley *et al.*, 2020). Pre-understandings are different from bracketing out all knowledge of the subject under investigation, as Husserl proposed (Dibley *et a*l., 2020). For this research, the supervisory meetings enabled the topic to be discussed ''to and fro'' using hermeneutic phenomenological principles to elicit my pre-assumptions or biases, allowing me to develop the interview questions for the HRA research protocol. Here, I also draw upon my 'fore having.'

The overarching aim of a phenomenological interview is to establish the 'what' or noematic of developing DKA moving beyond what is known physiologically from the metabolic disturbance to the noetic, which is the participants' description of their experience (King, Horrocks and Brooks, 2015 p. 231). Participants had unique stories to tell here, and my role as the interviewer was to guide them to do so, being conscious that, at times, the interview would meander into territory that I was not expecting (Thomas, 2021). In this study, I have used conventional terms such as interview; Smythe *et al*. (2007) argued that to conduct a phenomenological interview is to have a conversation with the participant. However, to gain ethical approval from the HRA, some sample questions were required to be included in an interview guide. Although this approach could potentially limit a phenomenological interview, it did provide a structure and enabled the same questions to be asked of the participants (Creswell and Creswell, 2018).

Hoffding and Martiny's (2015) review paper was written to provide guidance and structure on what should constitute a phenomenological interview. They comment that there is scant coverage on this topic, with most emphasis on how to analyse an interview. A similar theme was also noted by Norlyk and Harder (2020), who reviewed studies that were proposed to be hermeneutic. However, minimal consideration was given to ensuring that studies are methodologically hermeneutic in their design in order to confirm the robustness of the findings.

Phenomenological research aims to uncover the phenomena experienced by the participants, necessitating repeated review and analysis of the interview transcripts (Høffding and Martiny, 2016; Dibley *et al.*, 2020). My experience of DKA is reflexive and based on what others have told me about their time with it. Using my research experience of recurrent DKA, I could adapt the interview questions depending on the participants' responses to explore topics raised in further detail (Smythe *et al*., 2007). Moules and Taylor (2021) drew upon a similar approach in their paper, demonstrating how to conduct a hermeneutic phenomenological interview for a research class. Taylor was a student in the class and had experienced a bereavement. Moules used her ability as an experienced interviewer to be reflexive to Taylor's answers about grief and music (Moules and Taylor, 2021). In these interviews, I could reflect on my previous nursing practice as a researcher.

Merleau-Ponty (2014, p. 370) defines this interview process philosophically:

> “In the experience of dialogue, there is constituted between the other person and myself a common ground; my thought and his are interwoven into a single fabric…We have here a dual being…we are collaborators for each other in consummate reciprocity.*”*

Merleau-Ponty (2014) links the co-creation of data using both the interviewee and interviewer; both are important in revealing the phenomena. This is not dissimilar to what Gadamer (2013) proposed when interpreting transcripts created from interviews it is not the interviewer’s role to directly interpret what is said verbatim. This would be descriptive phenomenology; instead, they should interpret what is said in their context, using both their fore-conception and fore-having. Writing that, ‘‘...considering the real situation of the dialogue, which only he knows since he alone knows both languages being used in the discussion.’’ (Gadamer, 2013, p.319).

During the interviews, I incorporated both perspectives. The common ground is diabetes and DKA, to which participants bring their lived experience, and I bring my clinical diabetes nursing perspective. Interviews are co-created with the participant as they share their experiences. For the first interviews, I used the questions approved by the ethics committee to guide the first interviews. The second interviews were unscripted and were both conversational and relaxed.

4.7 Online interviews

Whilst online interviews may prohibit participation within a population under investigation due to access issues or digital poverty, there are also some advantages to participants (Archibald *et al.*, 2019). Convenience and the option to choose where they were interviewed helped to balance the power away from the interviewer. Edwards and Holland (2015) compared online and in-person interviews and noted that online interviews provided more in-depth data. The ability to record both the interview and review the video as transcribing occurred enabled attention to be paid to participants' expressions and emotions (Irani, 2019; Moules and Taylor, 2021).

This may have had the benefit of increasing access as participants remained at home and may feel more comfortable and confident in their own surroundings. Online interviews can also place participants on a more equal footing with the researcher, redressing the balance of power (Archibald *et al.*, 2019). Online interviews may also widen participation in the research and enable greater disclosure (Irani, 2019; Jenner and Myers, 2019).

Whilst there may be benefits to online interviews for participants, attention must be paid to how an interview is constructed. They may not always be swapped interchangeably with a face to face interview (James and Busher, 2012). A mixed interview using both face to face and Skype was conducted by Krouwel, Jolly and Greenfield (2019) found little difference in the duration of interviews. However, they noted that the range of topics was increased for in-person interviews. This may be due to the interviewer's confidence and ability to be adaptable and reflexive in an in-person interview.

Online interviewing is a multi-step process; using MST as the platform for recording interviews enabled the creation of an initial video recording and word transcript. Once the interview was completed, the transcript was downloaded into a secure OneDrive folder. The original MST recording was then set to expire and deleted to maintain confidentiality. The downloaded interview was listened to again line by line, and a Word document created from the transcript was corrected to reflect what the participants said during the interview verbatim. Interview four occurred during an MST system failure, and this interview was replayed again to hand transcribe it in its entirety. Verifying the accuracy of all the interview transcripts was a time-consuming process due to the depth and length of the recorded interview and the complexity of the information that participants shared. The process of dwelling on the data is congruent hermeneutically, enabling immersion and understanding before commencing the analysis.

For this study, there was a dual approach to reflexivity whereby my previous experience as a DSN underpinned my skills as a researcher. To this end, the assimilation of the stories of people with T1DM whom I had nursed in the past will form a key component of this journaling. Reflecting on these clinical care episodes shaped my clinical practice and the subsequent approach to delivering specialist diabetes nursing care to this group of patients. Reflecting on stories will enable some insight into what it may be to experience such a disruptive event as DKA, but they are not my stories to experience; I can only look in through my lens and imagine how this may be from what I have observed. Involving the researcher as a critical creator of knowledge has become increasingly normalised in phenomenological research (Lowes and Prowse, 2001).

4.8 Patient and Public Involvement

Within healthcare, it is widely accepted that services and research should be designed or co-created with those people who will use the services or are eligible to participate in research (UK Health Departments and Health Research Authority, 2023; Health, 2021; Staley *et al.*, 2021). Less is known about how participants may find being involved in research, especially in hermeneutic phenomenological studies. While post-interview care is built in for participants, those involved in reviewing the proposal and interview questions may also experience distress as they have experienced the events under discussion.

This research protocol was discussed and reviewed by two people who live with T1DM. Both individuals received copies electronically of the Participant Information Sheet, Consent Form and the aims and objectives for the research included in [Appendixes 3, 4 and 5]. Feedback was positive about the study, and no changes were requested for the documents. Some positive comments were also made about the sensitive language used within the ethics application. This was because of my reflexive approach to designing the study following my many interactions as a DSN with people experiencing DKA.

4.9 Sampling in a Phenomenological Case Study

Interviews with participants were designed to provide in-depth, rich data about their experiences from which the uniqueness and phenomena will emerge as the data are analysed. The study recruited participants who had experienced DKA and had T1DM. Dibley *et al*. (2020, pp. 54–55) propose that convenience sampling is an acceptable recruitment strategy for hermeneutic phenomenology. Purposive sampling is an accepted recruitment method for qualitative research and in phenomenological studies whereby the aim is to explore the in-depth experience of the phenomena of interest (Moser and Korstjens, 2018; Peoples, 2021). Campbell *et al*., (2020) suggested that utilising self-selection to identify participation can increase research engagement.

4.10 Recruitment strategy

It is important to note that the development of the qualitative research protocol for the HRA part of the ethics application for NHS participants occurred before the declaration of a worldwide pandemic of Covid-19 by the WHO, (2020), requiring changes to interview venues to maintain both participant and researcher safety. This included requesting and granting additional University ethical approval to recruit via social media, which will be discussed further in this chapter's ethics section.

Following the start of the Covid-19 pandemic significant reductions to routine care were rapidly made in the NHS. Clinical teams were redeployed to provide emergency in-patient care. In addition, people living with diabetes were rapidly noted to be clinically vulnerable, with a 40% hospital mortality rate from Covid-19 (Holman *et al.*, 2020). The nature of the pandemic halted NHS recruitment for the study as it was not deemed a clinical priority. A new ethics application was submitted to the University to seek approval to recruit participants via social media. This was the only change from the original ethics application agreed with HRA and the University (CHLES20210007). All other inclusion criteria remained as described in the original qualitative protocol and ethics applications (Appendixes 1 & 2).

I had initially anticipated that recruitment might be challenging if potential participants did not engage with the DSN's invitation to take part in the study or if patients infrequently attended diabetes appointments, as is well documented with T1DM and recurrent DKA (Govan *et al.*, 2011; Hill *et al*., 2015; Mays *et al.*, 2016). Social media recruitment was advertised on my professional accounts for X (Twitter), Instagram, and LinkedIn to recruit participants who self-selected that they met the inclusion criterion. However, all subsequent recruitment resulted from the post on X. Dixon (2024) reported that in the gender distribution of X users, women only account for 39.1% of users, which may impact participant characteristics recruited for this research. The account had a predominance of HCP followers with the tweet reaching approximately 17000 accounts following a retweet by the NHS lead for T1DM. The suitability for inclusion was also re-confirmed during the consent process before the interview commenced with participants

4.11 Inclusion criteria

The criteria for inclusion in the research are set out below to ensure that participants have had at least two previous episodes of DKA. This criterion was essential to establish as the study collects no demographic or bio-medical information on participants. To avoid inconveniencing participants who may not meet the inclusion criteria, a set of screening questions was checked and clarified via email correspondence if participants were recruited via the social media recruitment arm. The inclusion criteria included being a United Kingdom resident, as people from any country can access social media sites.

- ≥18 years old.
- Type 1 diabetes mellitus (T1DM).
- Admitted to hospital with DKA on two or more occasions (recurrent DKA).
- Willing to be self-recruited via a social media recruitment.
- Ability to give informed consent.
- Ability to complete the interview in English without needing a translator.

This research was not sponsored or funded to be able to complete the translation of interviews, so the decision was made in conjunction with the supervisory team that participants needed to complete the interview by speaking English. Widening access and participation in research is important, but it can be argued further that using a translator where the participant's words and sentences are translated from one language to another language may irrevocably change the account and its meaning as shared by participants (Williamson *et al.*, 2011; Bashiruddin, 2013). Kapborg and Berterö, (2002) encountered several problems using a translator and discussed that language and culture play an important part in both the interview process and interpretation of the interviews. When interviews are translated, they noted that there can be ‘‘ambiguity’ in participants’’ responses. Whilst this may impact the validity of the interviews, this is not the primary aim of hermeneutic interviews but does pose several problems even when the researcher is fluent in both languages; words do not always have a literal meaning from one language to the next, and the meaning can change significantly in translation (Bashiruddin, 2013). For the reasons discussed, only participants who could complete the interviews in English were included.

Four potential participants were excluded after making contact as they were non-UK residents, had only had DKA at diagnosis, or had one episode of DKA post-diagnosis. International participants were excluded because they would have experienced health care differently from that in the United Kingdom. The inclusion criteria provide the boundary of the phenomenological case of recurrent DKA.

4.12 Consent

Once a potential participant expressed interest in participating in the study, an email was sent to acknowledge their interest and confirm that they had experienced DKA on at least two occasions, along with the participant information sheet and consent form, including an explanation of the purpose of the research. Enabling participants to consider their experiences with DKA and how these are valid areas to research and develop a new understanding of this complicated life-threatening condition. The email outlined the interview's purpose and requirements, including the time and location on MST, checking the acceptability of MST with the participants, and supporting them in feeling comfortable about being interviewed and recorded online. One potential male participant declined to participate once he knew the interviews were conducted using MST.

Participants returned the signed consent form via email at least seven days before the interview commenced. At the start of the interview, the consent process was verbally confirmed and recorded as part of the interview process. Participants were advised of their right not to answer questions and that they could withdraw consent during the interview. Before the interview commenced, participants had the opportunity to ask questions at the start of the interview, and the above points were reaffirmed as part of this process. If, after giving consent, the researcher is advised that the participant is incapacitated, unable or unwilling to proceed, they will be withdrawn from the study, and all documents about that individual will be destroyed. No such correspondence was received from any of the participants. If a participant withdrew consent before their interview was fully transcribed, they could opt to have their interview destroyed or continue to be included in the research. None of the participants opted to withdraw their consent to participate.

4.13 The interviews

The interviews were initially anticipated to last approximately sixty minutes or for as long as the participants wished to talk. Each participant was invited to an interview twice, fifteen months apart. Five participants completed the first interview, and four returned for the second interview. Interviews were semi-structured using an interview guide that was not prescriptive. The direction of interviews is dependent on the participants who share their experiences with the interviewer who reflectively directs the interview to develop the co-creation of the data (Ramsook, 2018; Ryen, 2019).

Following the completion of the interviews, the recording was listened to enable notes to be recorded about the intonation of the participant's voice during the interview. This information was reviewed in the field notes and reflective journal context. Interviews were transcribed verbatim, enabling further immersion in the data. Once this process had occurred, the interview transcript was read and reviewed again. Editing included removing the ‘‘ums and ahs’’ from the interview transcripts. Transcripts were re-checked for accuracy, with the recording completed for all the interview transcripts in the first interviews before commencing the analysis process (Peoples, 2021, p. 57). The process was replicated again for the second interview.

Living with T1DM is complicated and time-consuming. It requires frequent, complex daily decisions regarding insulin administration and monitoring blood glucose levels. Therefore, it was necessary that interviews were not burdensome, and I paid attention to the timing of the interviews to avoid interfering with critical aspects of diabetes management, such as mealtimes. The interview schedule helped satisfy both ethics committees that the research was appropriately designed and would be conducted in the participant's best interests.

In total, the five participants completed nine interviews. The purpose of these second interviews was to explore further the content revealed in the participants' first interviews and how their lives had developed over time. This was not for the purpose of member checking for the validity of the first interview, as may be used in some qualitative interviews (Dibley *et al.*, 2020). Creswell & Creswell (2018, p. 200) proposed that the second interview can be used to review the content of the first interview. For this research, the purpose of a second interview is congruent with HP's methodology. It enabled further in depth exploration of the topics raised, which, whilst sharing the commonality of developing DKA, responses will be individual (Cohen, Kahn and Steeves, 2000; Dibley *et al*., 2020). However, this contrasts with what Smythe (2011 pp. 42-43) recommends as she states that a second interview may add little benefit; in fact, participants are asked repeatedly to go over experiences, and this may not only be distressing depending on the topic but may yield little new data to analyse. Temporality means that the event itself does not change over time, but the experience of how we make sense of or interpret it may alter (Boden and Eatough, 2014; Gullick, Monaro and Stewart, 2017; van Manen and van Manen, 2021). Therefore, it is essential to consider the second interview's impact on participants and how they may react emotionally to their previous account.

4.14 Indemnity

Qualitative phenomenological interviews were not anticipated to cause harm to participants. The University's indemnity policy protects participants. Risks to participants' health were mitigated by moving to online interviews at the start of the pandemic (European Centre for Disease Control, 2020; World Health Organisation, 2020). Modifying the interview strategy to ensure that participants could safely complete interviews remotely was a requirement of the social distance rules during recruitment because of Covid-19 (Gentile, Strollo and Ceriello, 2020; Holman *et al.*, 2020). In addition to this, those with diabetes are classed as a higher risk group for the virus, and remote interviewing will ensure they are not exposed unnecessarily to the Covid-19 virus.

4.15 Ethical considerations

This section will demonstrate that several significant processes were developed to protect participants who agreed to participate in the study. The principles of ethics underpin all of my professional practice, regardless of whether this is in the delivery of direct patient care or non-clinical work (Nursing and Midwifery Council, 2018). Beauchamp & Childress (2019, p.12) clearly state that ethical principles should be '(1) respect for autonomy, (2) non-maleficence, (3) beneficence and (4) justice.' These principles underpin my professional practice as a clinician and researcher (Nursing and Midwifery Council, 2018; University, 2018).

Several key policy documents underpin this research. The first is from the Health Research Authority (2023), which provides specific standards in the United Kingdom with a framework for health and social care research. The second is that as a doctoral student at the University, the ethics policy and management of research data policies were utilised in the study design and qualitative research protocol (University, 2016, 2018).

This research was approved by the Health Research Authority (273299) and Care Research Wales. Once granted, the College of Health, Life, and Environmental Sciences at the University also confirmed its ethical approval (CHLES20210007). The ethical approvals are contained within Appendix 1 and 2.

4.16 Participant and researcher wellbeing

Several strategies were used to support the well-being of participants in this case study. Participants' well-being was discussed in supervision sessions, as it is impossible to predict the topics discussed during the interview. To support participants in accessing help, a letter was developed that they could share with their General Practitioner (GP) and submitted as part of the HRA and university ethical review. To support participants at the end of the interview, a general winding down of the conversation enabled them to move away from the subjects they had discussed to mundane everyday topics such as plans for the remainder of the day. This space helped me to ensure that they were not distressed after the interview, and I was also able to remind them about sharing their GP letter. To date, none of the participants appeared distressed after this phase of interview conclusion, and interviews were concluded just as one may end a conversation.

Qualitative research does have the potential to cause some risks to participants. Richards and Schwartz (2002) provided a comprehensive overview of qualitative research challenges for participants, even though it may be deemed less risky than quantitative research. This research has the potential that participation in in-depth interviews could cause distress to participants as they revisited their experiences with DKA. Todres, Galvin and Holloway (2009) propose that a value framework should be used for qualitative research. Participants may be choosing to discuss events that may have occurred sometime in the past, bringing back to the fore their episodes of DKA. This has the potential to cause distress. This was witnessed during one of the first interviews when the participant quietly cried with tears running down their face throughout the interview. Participant wellbeing is paramount, so I offered to pause the interview, but the interviewee declined, opting to continue talking.

As an experienced professional, I believe I have the skills to assess and support participants who may be distressed, both during the immediacy of the interview and subsequently as they refocus on a time that may have been difficult. However, there is a paucity of research to support this view held by both researchers and me, who are also healthcare professionals, that we can offer this support, and it is necessary to maintain the interview as research and not a therapeutic consultation (Richards and Schwartz, 2002). It would be easy to become very involved and feel the need to rectify any concerns that the participant may have. Indeed, as a nurse, I have a professional and moral obligation to cause no harm to participants (UK Health Departments and Health Research Authority, 2023; NMC, 2018; University, 2018). It could be argued that while we bring professional health backgrounds to the research, the primary focus is as a researcher during the interview, and this duality of the role requires careful consideration and reflexivity.

4.17 Data protection and participant confidentiality

Research data governance has been a critical component of the ethics application and protocol. This section will describe how participant confidentiality was maintained and how the investigation is compliant with the requirements of the Data Protection Act (1998), General Data Protection Regulation (2018) and the Information Commissioner's Office (2018.) As a Registered General Nurse, I am governed by the NMC Code (2018). The Chief Investigator acted as the data custodian for the study. This study will comply with the Data Protection Act. (2018) in all aspects of data management, including collecting, storing, processing and disclosing personal information and will uphold the Act’s core principles.

All the interview transcripts were anonymised at the point of the interview. The participants were asked to choose a pseudonym for their interview, and this name was used only on the interview transcripts and subsequent data analysis. The participants' identities were known only to them and me; they were not shared with the supervisory team. The interviews and transcripts were kept securely in a password-protected file that I only knew about in a OneDrive folder (Health Research Authority, 2023). The supervisory team only reviewed the interviews when they were anonymised. All the consent forms have been obtained remotely and received via email; the signed consent form was scanned and stored within my university student OneDrive account. Participants have the right to withdraw their data up to the point of transcription, which was discussed as part of the consent process. In line with the governance for research data and general protection data regulations (GDPR, 2018), transcripts and consent will be stored for ten years, (University, 2019).

Covid-19 altered initial plans to recruit via NHS sites. They required a different strategy to protect participants with T1DM and me as a doctoral researcher (NHS Health Research Authority, 2014; UK Health Departments and Health Research Authority, 2017). Although ethical approvals were in place for interviewing participants from both NHS and via social media sites during the Covid-19 pandemic, paying close attention to advice about contact with others was essential. Therefore, all interviews were completed online. Ultimately, no participants were recruited from the two NHS sites.

4.18 Assessment and management of risk

Participation in research is voluntary; the participant information leaflet contains explicit statements that the information shared with the researcher will not affect subsequent clinical care (Appendix 2). This is extremely important as the participants may raise some sensitive issues during the interview, including reflection on how care was delivered by the clinical teams, as occurred in several interviews. As DKA can be a life-threatening condition, there are arrangements in place to refer to diabetes clinicians if there is any concern for the wellbeing or safeguarding of the participants. The participant's General Practitioner (GP) was notified of participating in the research; participants to date have been asked to email the GP letter to their practice.

4.19 Data analysis

The research was consistently conducted and analysed ethically and transparently, congruent with HP philosophy and in line with the ethical approvals granted by the HRA and the University. The details of ethical approvals are in Appendix 1 and 2.

Heidegger (1932) and Gadamer (2013) developed the overarching philosophy of HP to apply an interpretive approach, known as the hermeneutic circle, to guide analysis. This has been described as ‘‘to-ing and ‘fro-ing’’ with the interview data, going back and forth with the interview transcripts to allow the phenomena to emerge (Crowther *et al*., 2017; Spence, 2017; Crowther and Thomson, 2020; Dibley *et al*., 2020). This is similar to the approach taken by Vagle (2018, p.116), who described this process as ‘‘dwelling in the data.’’

The interview data were analysed in two ways, both congruent with the principles of hermeneutic phenomenology. The nine interviews are a small, rich data set comprising many thousands of words from each participant discussing their unique experiences of DKA. In the first instance, the interview transcripts were repeatedly read to understand the interview data and then to refine the data into categories and, ultimately, themes of participant experiences (Benner, 2012; Dibley *et al.*, 2020, p.115). Creswell and Creswell, (2018, p.192) propose that the researcher first reads interviews and then notes are made on the emerging themes. These are subsequently analysed following the six steps of thematic analysis as advocated by (Braun and Clarke, 2006). Noting that there are limitations and inconsistencies with the methods, producing variability in the quality of the research presented. Miles, Huberman and Saldana (2014 pp. 70-93) provide explicit detail on the coding process, initially dividing this into two cycles of coding and outlining subjects such as emotion and values that a code may fall into. The second cycle details further what arose in the first cycle.

This data set was not expected to be voluminous; the final recruitment phase was aimed at ten participants; therefore, the intention was not to establish commonalities in the participants' experiences. In conjunction with the supervisory team, we opted not to employ what is known as member checking' in qualitative research, whereby the transcript is shared with the participants to verify that the data captured on the transcript is an accurate account (Braun & Clarke, 2013, p. 282; Miles, Huberman and Saldana, 2014, p. 58; McGrath, Palmgren and Liljedahl, 2019). There are several reasons for not following this approach, which is incongruent with phenomenological research. Firstly, the participants may become upset at their stories. Secondly, whilst there is an opportunity to explore and clarify the interview content in the second interview, HP research aims to uncover the lived experience as expressed by participants. Thirdly, if member checking is done, it raises the issue of what to do with any changes, as the experience of the individual first reported has now altered (Bradbury-Jones, Sambrook and Irvine, 2009; McConnell-Henry, Chapman and Francis, 2011; Braun and Clarke, 2013, p. 283).

Once the interview transcript is reviewed and edited, this alters the essence of the experience as told initially. Hermeneutic phenomenology has far more depth than just reporting on the experience (Zahavi, 2019). During the previous chapter, I have discussed in detail the philosophical orientation of this thesis. Underpinning the work is the philosophy of Merleau-Ponty (2014, pp. 361-362), who said, ''My current interpretation is tied to my confidence in psychoanalysis; tomorrow, with more maturity and more insight, I will perhaps understand my past differently, and I will accordingly construct it differently.'' In essence, Merleau-Ponty proposes that the passage of time enables reflection on previous experience. The limitations with validation are consistently reported in the literature; whilst they may have a place in other methodologies, they have minimal value in HP, whose ethos is to interpret conversations to reveal the phenomena (Braun and Clarke, 2013, p. 282; Miles, Huberman and Saldana, 2014, p. 58; McGrath, Palmgren and Liljedahl, 2019).

Analysis and hermeneutic interpretation of the nine in-depth interviews are presented in chapters five, six and seven. The hermeneutic circle requires the interview transcript to be read repeatedly to enable the participant's phenomena to emerge. What is apparent in the literature is that HP is a philosophy and not a method, so there is considerable variability in how to construct research (Austgard, 2012; Tuohy, *et al.*, 2013; Crowther *et al.*, 2017; Vagle, 2019, p. 54). Critical to HP interviews is keeping the underpinning philosophy present throughout the process, reflectively considering the interview and the resulting analysis of interview data in the context of the philosophy of Merleau-Ponty (2014), focusing on the embodiment of the experience of recurrent DKA. Gadamer's (1975) philosophical writings have also been used to structure the interview data interpretation process using the hermeneutic circle.

4.20 Reflexivity

This section will introduce the elements of reflexivity and how they have impacted the development of this research. It will explore the experience of those who have developed recurrent diabetic ketoacidosis (DKA). In tandem with this, I will also illustrate my journey as I developed as a nurse researcher as I wrote this thesis. Within this chapter, I have presented the methodological construction of the research, demonstrating how all elements of the study have been completed. Research should cause no harm or unnecessary inconvenience to the well-being of participants, and this study had full ethical approval from both the HRA and the University of Worcester (Appendix 1). In addition, following a systematic approach through the chapter, I have been able to justify my thoughts and decision making, from the inception of the research idea to its underpinning philosophy of hermeneutic phenomenology guided by the work of both Gadamer (2013) and Merleau-Ponty (2014) to the development of a phenomenological case study following review of the participant's characteristics (Greenhalgh & de-Graft Aikins, 2024, p.504). These overarching principles are present in the design, conduct and analysis of the interviews, which enable an interpretative approach to data analysis, which will be presented in Chapter Five. This research has identified a gap in the literature due to the paucity of research from the perspectives of people living with T1DM who have experienced recurrent DKA. Its completion will enable the perspectives and experiences to be collated to create a unique case about the experience of recurrent DKA in T1DM.

Researcher reflexivity in hermeneutic research forms an integral part of the interpretative cycle. Gadamer (2013) developed this approach further within HP, where researchers' reflexivity is brought to the fore as they to and fro with the interview data (Brown, 2019; Maxwell *et al.*, 2020). During this study, I have kept a reflexive journal and used this and my supervisory notes to help track the progression of the work and the development of my thinking and understanding. At the start of my doctoral journey, I was an experienced DSN and a relatively new academic. My professional orientation felt unstable as I embraced the new direction of becoming a nurse academic. I felt that I was neither as I moved my practice back in some areas to novice as I developed the qualitative protocol for the Health Research Agency (HRA). These feelings became even more unsettling as I grappled with the philosophical readings of Merleau-Ponty (2014) and Gadamer (2013). Even completing the interviews was a very different experience from academic and clinical work, requiring developing a different skill set. Referring to notes in this journal enabled me to see my growth over time and how my feelings and understanding ebbed and flowed during the interviews, ultimately forming part of the analysis process.

Earlier in this chapter, I presented how the interviews were semi-structured and reflexive depending on the areas the participants chose to discuss. Whilst this is the start of a reflexive hermeneutic phenomenology cycle, the process permeates the entire interpretative data analysis process. The first steps of this were to keep a researcher diary that was completed at the end of each interview and again as the interview data were analysed. When the interview transcripts were transcribed and analysed, I brought to the process my understanding from my experience as a DSN. Some of this is shaped by the patients with DKA that I have nursed in the past (Dowling, 2006; Greatrex-White, 2008). Many other influences will affect my pre-understanding of the interview data, and my place and experience in society will invariably influence my interpretations (Maxwell *et al*., 2020; Suddick *et al.*, 2020). Using the diary enabled me to keep track of this and was a valuable adjunct to ensuring I could debrief with my supervisory team.

Etherington (2004, p.15) stated reflexivity involves ‘‘movement.’’ This requires the researcher to be responsive to interviewees during the research while continuing to reflect to develop and refine their skills. As a consequence of this process, the depth of my nursing practice takes on a new dimension. This journey has enabled me to reflect and uncover new knowledge as I met and interviewed participants. The movement here also occurs over time, and I have addressed this with four of the five participants returning for a second interview.

Epistemologically, hermeneutic phenomenology requires the researcher to be part of the process of analysis and interpretation of the findings (Heidegger, 1932; Gadamer, 2013; Vagle, 2018). There is a requirement to be open to the process at all stages of the design whilst also considering the influence and positionality of the researcher. This process should be recorded to provide transparency to the research process (Koch and Harrington, 1998). The intent is not for others to replicate the research or the findings but to be able to view externally the process of the research's conduct. Rigour and the requirements for qualitative researchers to demonstrate it stems from positivist quantitative methods, and as such, its function in qualitative research should be questioned (Koch & Harrington, 1998). Instead, rigour and the process of reflexivity should enable others to see the underpinning methodological and philosophical design through all its incumbent stages (Finlay, 2002). As the researcher is the instrument of analysis in hermeneutic phenomenology, this process is essential both to the researcher and the reader of their work (van Manen and van Manen, 2021). Barak's discursive paper (2022) examines the cultural elements of the hermeneutic researcher and how these are inherent in the research process.

I was aware of the usefulness of being reflexive in the early stages of the doctorate, thinking back and forth about recurrent DKA. I am acutely aware that the idea for this work was borne from my prejudices about the causes of DKA, including the frustration that I experienced as a DSN that the care provided was not enough to be able to prevent DKA occurring repeatedly in a small group of patients with T1DM. Examining my prejudices brought me closer to the topic and has enabled me to develop the research question and aims to investigate the topic hermeneutically (Gadamer, 2013).

Maxwell *et al.* (2020, p 2.) argued the philosophical standpoint for reflexivity but questioned the ambiguity created by Gadamer (2013) when he said, ‘‘hermeneutics must start from the position that a person seeking to understand something has a bond to the subject matter that comes into language through the traditionary text and has, or acquires, a connection with the tradition from which the text speaks.’’ While I agree that there is room for philosophical interpretation, as Gadamer (2013, pp. 318-333) also states, understanding the area under investigation is imperative in hermeneutics. My pre-understandings of both T1DM and DKA have developed over twenty years, but these understandings remain an outsider's view of the reality of living with diabetes. This insider knowledge and reflexive practice enabled me to immerse myself in participants' worlds, actively ‘listening’’ and, most importantly, ‘‘hearing’’ what life involves living with T1DM. This ‘‘attention’’ required in phenomenological studies by the researcher is imperative to ensure that the phenomena can be uncovered during the analysis (Mortari, 2015). Using this approach, I could set aside the clinical frustrations I had experienced as a DSN, instead drawing on the expertise in diabetes nursing that I had developed over this time. Even during the interviews, my approach evolved as the interviews became more conversational and less reliant on the scripted questions I had prepared. This was particularly apparent with the second interview as there were even fewer formal questions, enabling me to act less as a guide and more as a listener as participants explored their experiences living with DKA and T1DM.

4.21 Chapter Summary

Within this chapter, I have presented the methodological construction of the research, demonstrating how all elements of the study have been completed. Research should cause no harm or unnecessary inconvenience to the well-being of participants, and this study had full ethical approval from both the HRA and the University of Worcester (Appendix 19). In addition, following a systematic approach through the chapter, I have been able to justify my thoughts and decision making, from the inception of the research idea to its underpinning philosophy of hermeneutic phenomenology guided by the work of both Gadamer (2013) and Merleau-Ponty (2014) to the development of a phenomenological case study following review of the participant's characteristics (Greenhalgh and de-Graft Aikins, 2024, p.504). These overarching principles are present in the design, conduct and analysis of the interviews, which enable an interpretative approach to data analysis, which will be presented in the three findings, chapters five, six and seven. This research has identified a gap in the literature due to the paucity of research from the perspectives of people living with T1DM who have experienced recurrent DKA. Its completion will enable the perspectives and experiences to be collated to create a unique case about the experience of recurrent DKA in T1DM.

Chapter 5 Findings 1

5.1 Introduction

This chapter contains the first tranche of findings from participants who shared their experiences of recurrent Diabetic Ketoacidosis (DKA). Participants will be introduced through a brief contextual paragraph containing details that they opted to share. The second interview findings from fifteen months later will be presented in Chapter Six. Separating the findings from the first and second interviews enables the temporal elements of the case to be captured. Finally, in Chapter Seven, both sets of interviews will be analysed philosophically.

5.2 Introduction to Participants

Participants were recruited from a ‘‘tweet’’ on the social media platform X, previously known as Twitter. The tweet was shared via the researcher's professional personal account, which had approximately four hundred followers. After the tweet was posted, there were forty-seven likes and fifty-nine re-tweets, including one by the NHSE Type 1 & Technology Lead. The purpose of this research is not to analyse participants' everyday experiences; however, it is helpful to illustrate the length of time they had all already lived with T1DM and their initial experience at the point of diagnosis. All participants presented as female, none were related, and their ages ranged from 20-27 years at the point of consenting to participate in the research. Their age at diagnosis ranged between eight to 18 years old. Residing in the UK, they all discussed attending university and at the point of the first interviews, were either students, working or unemployed. Their living arrangements varied from the parental home, living alone or living with a partner.

Understanding the lifeworld of participants enables the reader to see the person behind the story and glimpse their background to give context to the case. The young women who opted to participate in the case study provided rich, complex accounts regarding their experience of DKA and life with T1DM. These shared characteristics form the case of recurrent DKA in young women who gave the generosity of their time to be interviewed and share their experiences. Introducing the participants' social worlds is an essential step in this phenomenological case study to give them some context. A brief introduction using the pseudonyms they chose follows.

5.3 The participants

Adele*- Diagnosed, aged eight, has lived with T1DM for 15 years. Two years after her diagnosis, her sister was also diagnosed. Adele describes being in and out of the hospital with DKA from about the age of 16. She works as a teaching assistant and has part-time work in a restaurant. Adele continues to live in her parents home.*

Chloe*- Diagnosed on a family holiday in Europe, aged about 14, and has lived with T1DM for around ten years. When she was diagnosed, she described this as being in a 'diabetic coma.' She was admitted to the intensive care unit on the day of her diagnosis. This was in a European country away from her parents. Most of her other experiences with DKA occurred when she was at university. Chloe is living at home with her family and is planning to move out.*

Laura *was diagnosed aged 13 or 14 and has had T1DM for over half her life. Her older sister was diagnosed with T1DM as a toddler. Whilst Laura did not have DKA at the point of her diagnosis, she has experienced it three times. Her sister has never had DKA and was considered well-controlled by her parents and the diabetes team. Laura lives with her boyfriend.*

Mary *was diagnosed at age ten and has lived with T1DM for 14 years. Her symptoms lasted for several months with osmotic Symptoms and weight loss first developing when she was abroad on holiday. However, it was not until the start of the new school year that she was diagnosed and admitted straight into Intensive Care with DKA. She has had another two subsequent episodes of DKA. Mary lives with her boyfriend.*

Phoebe *was diagnosed at eighteen and has lived with T1DM for four years. She was admitted with DKA into the intensive care unit on a family holiday. Her second admission for DKA also occurred when she was away from home; this time, she was admitted with DKA, which resolved before developing DKA again in the hospital. Phoebe has been living in student accommodation.*

All five participants discussed their time away at university, having been diagnosed preceding this. Two of the participants had completed post-graduate education.

5.4 Interviews

All interviews, as previously discussed in Chapter Four, were completed using Microsoft Teams (MST). The duration of both interviews is presented below.

Name	Interview 1 duration	Interview 2 duration	Total duration
Adele	67 minutes	52 minutes	119 minutes
Chloe	77 minutes	56 minutes	133 minutes
Laura	54 minutes	46 minutes	100 minutes
Mary	71 minutes	Did not attend	71 minutes
Phoebe	84 minutes	67 minutes	151 minutes

Table 5

5.5 Themes

Three overarching themes were developed after dwelling on the first interview transcripts for several months. They illustrate the effects on participants but are not presented in order of significance to participants. The themes encapsulate the shared meaning in the interview transcripts and are directly named from the words of participants (Braun & Clarke 2021, pp. 108-115).

The three overarching themes were:

- *Diabetes is constantly on my mind.*
- *The shaming and the blame.*
- *Fighting to stay alive.*

5.6 Theme 1- Diabetes is constantly on my mind

5.6.1 Diagnosis

Receiving the diagnosis of T1DM was particularly impactful and, in some cases, traumatic for the participants in this study, regardless of their age at diagnosis. Unsurprisingly, they reported changes to their bodies in the lead-up to diagnosis, particularly losing weight and tiredness, which are both classic symptoms of T1DM; even though symptoms usually resolve once insulin treatment commences, the legacy of this event stayed with the participants for many years afterwards. The memories remain pertinent even after a long time, which would have impacted how a degree of acceptance and coming to terms with the diagnosis of T1DM is experienced. This area has been discussed in the literature review in Chapter 2 (Cortright, 2021; Kruger *et al.*, 2021; Holmström Rising and

Söderberg, 2022). The point at which diagnosis occurs is pivotal, life changes irrevocably for participants. All five participants were diagnosed with T1DM in childhood between the ages of 8-18 years old. Excerpts from their interview transcripts below illustrate the changed world they now inhabit, with life before and after diabetes clearly demarcated.

> *"I find it hard to accept that I've got it, and then since being in my teen years, maybe from the age of 16-17, umm, I've just been in and out of hospital with DKA."* **(Adele 1.1).**

Although Adele was diagnosed with T1DM approximately five years before becoming a teenager, her diagnosis abruptly disrupts what she expects for her life, which becomes punctuated by hospital admissions with DKA. There is sorrow contained in the previous quote for the effect that diabetes has had on her life and the time it has taken away from being a teenager with the frequency of hospital admissions. Once diagnosed with T1DM, all the participants discussed having to develop as a new person to include a diabetes identity into their existing lives. Participants' lives are differentiated between the life before and after diagnosis.

Chloe was diagnosed fourteen years ago when she was around the age of eight or nine, having now lived more of her life with than without T1DM:

> ''*I still haven't quite accepted it; I do not think*…'' (**Chloe 1.1).**

The lack of acceptance and distress regarding having T1DM can last many years after the diagnosis. For Chloe, in the years after diagnosis, she had frequent DKA admissions. Despite the diagnosis being many years in the past, she remained unsure about acceptance, with doubt expressed about what acceptance would actually mean for her: ''*I do not think.*'' After having lived for so long with T1DM, it is hard to envisage what life might have been like without it. Diabetes is burdensome because it is always there.

Phoebes' acceptance of her diagnosis is also impeded; she was the oldest of the participants when she was diagnosed after her eighteenth birthday but before sitting her A-level examinations. She already had plans in place for her future life, but even for her, it was difficult as being diagnosed with T1DM leads others to question the reality of these plans, such as going away to university:

> *"I think I did not really accept it, and I think there was also a lot of freedom in going like I really struggle with both being here [home] because this is where I was really, really ill and like being close to hospital, I absolutely hate having*

> *my blood test taken, and they were doing that like every month for a while, and I think there's a sense that actually like if I travel 500 miles away [to university], they can't actually get me.''* (**Phoebe 1.1).**

Reflecting on the meaning contained here drew me back many times as I moved from the lens of my DSN practice to a researcher. Phoebe shared that her parents and doctor had suggested delaying university by a year. At first, this appeared to be a practical solution, and it was easy to understand why it was made. If she had delayed attending university, it would have meant staying at the family home for a year because of the diagnosis of T1DM. Phoebe was keen to escape this new life, which now had to include T1DM. The final part of the preceding quote illustrates this. By going away, she holds onto the life she had planned and uses it as a convenient way of avoiding treatment and care that she finds very distressing.

All five participants reported feeling unwell leading up to their diagnosis, but this was not picked up quickly by parents or others outside the family, such as teachers. Phoebe's parents missed her developing symptoms even though there was knowledge of T1DM in the immediate family and in the case of Laura, who had a sibling diagnosed with T1DM approximately fifteen years before she developed symptoms.

> *"My dad just made like an offhand comment about how we should check my sugars because I was thirsty after like weeks of this and then 24.2 [mmol/L]! That number is like burned into my mind, and then I went to the GP the next day. He sent me straight to the hospital, and the hospital said, but we will find a way to manage it at home, and they just sent us off with insulin. I had one practice on an orange, and then that was that."* **(Laura 1.1).**

Laura was shocked that her parents had missed warning signs of her increased thirst, saying it took weeks to be diagnosed with T1DM. Then, when she was finally diagnosed, her parents were perceived to already be experts in managing T1DM because her sister also lived with the condition, so she was not even admitted to the hospital. Subsequently, this caused a longer-term impact on her ability to accept her diagnosis:

> ''*The people who have been treating my sister like they knew my family really well, and I think a lot of them were very familiar to us but not all that familiar to me. Like they knew my sister very well, but I did not feel like they knew me very well, at all.*'' **(Laura 1.2).**

There appears to be assumptive knowledge that the whole family, including Laura, knew about diabetes because of the older sister. They are a family with two daughters, both with diabetes. I think, in Laura’s eyes, this is a failure to see her on her own as an individual and acknowledge how transformative the diagnosis was for her.

Whilst Laura did not require overnight admission to the hospital at diagnosis, this is standard practice in the United Kingdom (UK) for most patients, depending on their clinical condition at diagnosis. The diabetes team will confirm the diagnosis, create a treatment plan including insulin administration and glucose monitoring education, safety netting for low and high glucose levels and review rapidly either as an outpatient or home visit, depending on the individual. How the diagnosis is given and subsequently handled is significant. Laura wanted to be seen for her own sake, separate from her family. Laura felt there seems to be an over-reliance on her family’s perceived ability to manage T1DM because they have already been through this before with their other daughter. Even many years later, the experience of being diagnosed with T1DM remains difficult. They were leading her to perceive that she was invisible to others.

Phoebe was the oldest at diagnosis, and immediately, she was perceived as different from having to sit her ‘A’-level exams in a separate room from her peers. This experience remains at the forefront of her mind, and after being advised to delay going to university where her future dreams rested:

> *“…I was just like, you know what, life's too short to [pause]. I think I thought that waiting another year would make me feel more ill in a way because I'd never planned to take a year out. I was like, well, what am I going to do? I'm going to sit at home counting my rice! You know, like yeah, I do not want to be here, you know, this has never been my plan, and I do not know what I'm going to do. So, I kind of just went for it.’’* **(Phoebe 1.2).**

Developing T1DM was very unwelcome for Phoebe, not only the condition of diabetes but also the timing of it. She sees it as something disruptive to her life. Receiving advice to pause her plans takes away Phoebe’s hopes and dreams for the future she has been working hard to achieve. As a result, this makes her feel different and further impacted by having developed T1DM, but it also causes additional resentment regarding her diagnosis of T1DM.

There are many complex elements to managing diabetes, including food's effect on the body. Mary was diagnosed around the age of eight; what she is about to describe has a long term impact on her and how she is subsequently able to adapt to living with T1DM.

> ‘‘…*and then quite harsh. Back then, they got a black marker and crossed out all the things I'd no longer be able to eat or drink.*’’ **(Mary 1).**

I found this statement very upsetting, and whilst I have not encountered this in my practice, people with T1DM are frequently instructed on what to do, what to eat and when to do so. As recently as the early 1990s, carbohydrates were deemed rations, and a set number of carbohydrates were advised daily. It is a powerful image to think of a black marker pen obliterating what was previously enjoyed in her life pre-diabetes. I found such a statement shocking; it is brutal advice, especially to a child. To remain so vivid to Mary after many years makes me question the damage that ill-phrased comments can cause in individuals’ subsequent life with diabetes. Historically, clinical advice was regimented regarding food intake; even when Mary was diagnosed, dietary advice was no longer as prescriptive and had predominantly moved to an inject insulin dose for what you eat model (DAFNE Study Group, 2002). There appears to be a lack of care and attention regarding how a child would perceive this. It sets the journey with T1DM on a collision course with her mum and the diabetes team to become confrontational. Immediately, Mary adapts her behaviour; this becomes increasingly secretive when she reaches high school and is left more frequently to manage her diabetes independently.

As previously discussed, Laura was not seen as an individual by the diabetes team; she perceives she is just an extension of her sister’s diabetes and part of the family. This resonated with my experience as a DSN whereby I recollect a mother diagnosed many years after her child, yet she felt unseen by the rest of the family and the effects on her wellbeing were not appreciated as she was perceived to know how to manage T1DM.

In the following quote, Laura identified how her body had changed as a child and how these memories of the changed body remain for her:

> *“I mean, I was talking about it and being surprised that we haven't realised weeks before, so it had been like a good few weeks. It was building up. I lost loads of weight as well. I'm really, really skinny, but again, I was fourteen, and your body is really changing, really changing, isn’t it? So, it just seemed like I was taller and a bit thinner and now, looking back, we did not realise quite how thin I was really.’’* **(Laura 1.3).**

There was very significant weight loss around the time of Mary's diagnosis, which still causes an emotive response many years later:

> *"Three stone [her weight] dead on, kind of. That even sounds shocking. I do not think, and I can see pictures… Actually, I have pictures which are just… I used to not be able to look at them because I used to look at them and get angry because I look at my parents and go, how could you not do something? I was bones. I was a skeleton. The photos are disgusting to be quite honest, and I think they feel guilty about it now because now they can see, but there's just no way that you couldn't tell there was something drastically wrong with me…"* **(Mary 1.2).**

Failure to be seen and the visible but unnoticed changes to her body continue to cause anger and disbelief in Mary. Shocked by this depiction of altered body image that was unseen by her parents leading up to diagnosis and the early warning signs provided by such weight loss raise concerns about the parental ability to care for and provide a safe home. This continues to distress Mary over a decade later, referring to the photos very emotionally and describing them as '*disgusting*.'

> *"You know, if you're like, I just look a lot kind of thinner or just like grey. It just kind of like really baggy eyes and that kind of thing, so I probably was not very well."* **(Phoebe 1.3).**

Looking at old photos during the summer after diagnosis, Phoebe can see that she is different; the effect of diabetes is visible externally as her body has altered, although it had not been to her or her parents at the point of diagnosis. Moreover, in Phoebe's case, her first encounter with the hospital team at the point of diagnosis was accusatory, saying that she had not taken her insulin. However, she did not even have a diagnosis of T1DM:

> ''…*I remember being in A&E, and one of the doctors came up to me and was like, why haven't you even taken your insulin? I was like, I never have. I do not understand what you are on about. As you know, I'm so confused and because he thought I knew I was diabetic.*'' **(Phoebe 1.4).**

The doctor in Phoebe's care judges that there must have been intentional insulin omission, utilising clinical reasoning as insulin omission is a common cause of DKA (Cooper, 2016). Still, he fails to acknowledge that Phoebe does not yet have T1DM diagnosed. This negative encounter is one of Phoebe's first experiences with diabetes and health care professionals (HCPs), a passing comment that stays with her in the long term.

The first interviews occurred in the year after Covid-19 developed in 2021. The vaccination programme had just commenced, and those living with T1DM were considered vulnerable; many were on the shielded list, meaning they were advised not to have unnecessary contact with others. So, Laura, for example, who was a teacher, had to continue teaching her class of young primary school children remotely from home. Despite the upheaval in lives, little time was spent in the interviews discussing the impact of Covid-19 on participants.

The consequence of receiving the Covid 19 vaccine earlier than her peers for Phoebe was a blunt reminder that she was different to her peers; she was approaching the end of her first year at university when she received it.

> ‘‘*A lot of stuff leads back to the hospital so, so the last, I mean, the last thing I can think of, that's a good example, was I had my Covid vaccine, and that was very traumatic, not because of anything that happened, but just because like knowing that I needed it. Meant that I was ill.*’’ **(Phoebe 1.5).**

During the first year of covid 19, several UK national lockdowns resulted in being ordered to stay at home and only leave for essential reasons such as buying food, daily exercise or work that could not be conducted remotely. Despite this, the participants did not share much about this time or their experiences. They did it to avoid hospital admissions, so they did not catch Covid-19. However, a sense of isolation was reported when they no longer had access to routine appointments. I had anticipated that they would discuss the risk of dying from Covid-19, but this was not a topic discussed in the interviews.

Living with and managing T1DM requires both time and a concerted effort to perform all of the daily tasks, which are estimated to take around four hours per day (Shubrook *et al.*, 2018). The impact and burden of these demands are presented in the quotes in the next section of this chapter:

> *“I’ve started owning up more now when I have clinics that I'm struggling a little bit, and I haven't injected at lunch for a few days, but I only inject before bed as I've noted if I do not inject in the evenings I struggle to sleep and I wake up at 1:00 am in the morning or something. Then I'll just give myself a big whack of insulin, and by morning, sometimes it hasn't even shifted it [blood glucose level]. It will still be in the 20s even with 30 units of insulin at 01:00 in the*

> *morning because my body is not used to everything; my body is so confused with what's going on.''* **(Adele 1.2).**

In this instance, Adele illustrates the disruption to her life and sleep pattern, but there also appears to be a unity between the effects this has on the body and mind. Reporting she believes that her previous actions and decisions have confused how her body will react to an insulin injection. So, when she injects insulin, she may not get a significant reduction in her anticipated blood glucose levels. She believes this is because her body can no longer respond, ''…*my body is so confused*….,'' is how Adele perceives that her previous high glucose levels have impacted her body.

It was stated with a degree of exasperation that despite injecting insulin, her body had not behaved in the way it was supposed to. Initially, Adele's body let her down when she developed T1DM, and it does so again. The sense of frustration is palpable, and it continues to manifest in the next part of the interview, where she discusses a foot complication. It illustrates how Adele appears to be disconnecting from her body, viewing it as separate from her:

> *"Yeah, disconnect myself from my diabetes a lot. Umm, it is that hurdle. I could go a few days injecting and testing all day, and then I wake up in the morning like, not today; I'm going to have a break today because I can, and I know it is dangerous, but it is wrong to say that until something happens to me, it is not clicking in my mind that I need to change how I am. Like I know people can lose limbs, lose their feet, lose their kidneys, I can lose my eyesight, but I can tell it happens [high glucose levels], which is bad, it is not going to change [her diabetes management].* I disconnect myself from diabetes...'' (**Adele 1.3).**

In this quote, Adele encapsulates the actions of many living with T1DM, with an acute understanding of the consequences of self-management decisions. Still, she is unable to follow the prescribed diabetes treatment. It is not a lack of knowledge, but she articulates a disconnect between her mind and body.

> ''*Like, I'm 23 now, and I could go and completely forget I'm diabetic like I should know, like when I have food, I should test and do my injection and could go a few hours and go, oh my gosh, I completely forgot to inject even though I told myself when I was eating, inject after food, I just switch off it baffles me"* **(Adele 1.4).**

Administering insulin is an essential part of diabetes self-management. In the quote above, Adele can describe the unintentional act of missing injections. She starts with a plan to inject after her meal but quickly moves to bringing to the fore a different voice whereby she is ‘‘*baffled*’’ by the situation. Despite having lived with T1DM for many years, something is preventing her from injecting insulin regularly.

The next quote offers some clues as to why this behaviour is enacted, perhaps a self-preservation strategy despite the consequences.

> ‘‘*So that I want the perfection with the numbers on my blood monitor and the numbers on the scales [for carbohydrate counting]. I scrapped the whole carb counting for years, as this is too complicated for me. To do that and test my blood, so we've just scrapped it to bloods and insulin and see then if I can develop that. I'm returning to carb counting when I'm better, with better control.’’* **(Adele 1.5).**

Daily diabetes self-management creates a significant amount of numerical data, from counting food's carbohydrate value to interpreting blood glucose levels and recording insulin doses. As these are real-time data, when things do not go according to plan, they immediately illuminate this, which can create a sense of inadequacy or failure that is perpetually present, defining how well or not the diabetes is controlled.

Chole divulged how it feels to manage her diabetes, and this next section illustrates the burden and psychological distress that she endures:

> *“It is easier to go, right you, you can feel horrible, choosing to feel horrible. And now you do not have to think about anything because you know you feel horrible because you've chosen to, and that's it. Whereas now if I go, oh, I want to feel better now, it is still constant thinking and injecting and testing and working it out, so I think that's… I remember saying to someone in Uni was talking about it, saying it is a bit of a…; It is a decision between my mental health and physical health***.** *Like when I do not inject myself, it feels like I'm having a break. So, I will. Even though I do not feel very healthy, at least I think normally is what I feel like. If I'm trying to feel physically healthy, I'm constantly thinking about diabetes as well. Man, that is tiring in itself.”* **(Chloe 1.2).**

The burden of T1DM is apparent here, but there are some very interesting factors, particularly the conscious decision to omit insulin because ‘‘*then you feel bad for* a *reason, but it is choosing to feel horrible*.'' It is almost as if this action is a self-punishment or sabotage, the deliberate decision to miss insulin doses gives her some control over her life. Demonstrating the split between the physical need to inject insulin and the mental desire to be free from thinking about her blood glucose levels and having diabetes constantly, to do both is an impossible task for her. Making such a decision enables Chloe to regain control of her body, to feel normal and to forget that she has diabetes, even though such actions cause her to feel ''*horrible*.''

> *"… It is either physically affecting me and mentally or not. Is it down (blood glucose levels), and it is [diabetes] constantly on my mind? I think as well, there's that, so I can't think of the word—sort of self, I do not know, like punishment sort of thing. I do not, I do not like that I'm like this so I will look after it or something... I think there were also with a lot of um things …with my age and everyone else my age. I think there's been a lot recently, umm, about eating disorders with diabetes.''* **(Chloe 1.3).**

Here, Chloe speaks of the constancy of diabetes, the challenges between the physical and psychological burdens, and how you can manage and compartmentalise all the different elements. T1DM impacts perpetually, with significantly negative behaviours developing over time. She is starting to illustrate how the behaviours of managing her diabetes may be a way of control, as may be seen in an eating disorder: the ability to determine what may happen, however dire the resulting actions.

Laura, too, spoke about wanting a break from having diabetes when she went off to university. Yet, although she initially views this as a way of gaining her independence as an adult, she is almost immediately drawn back to requiring her mum's help:

> *"When I went to University, I think I might have, I just felt like I wanted to break from it, and because it'd dominated for years up to going into uni, it made things really tense between me and my mum as well, she wanted me to be paying attention to it and actually doing something about it, so it was quite nice to kind of be away from that tension and yeah just to, to just take a break…you know my first extended stretch of time away from my mum, and I just thought it was a convenient time to completely forget about the fact that I had diabetes at all.''* **(Laura 1.4).**

Laura would like to see her start at university as a new beginning, whereby she chooses to ignore diabetes and create a new version of herself who does not have T1DM. She achieves this for several days before her mum has to come and take her to the hospital as she has developed DKA.

> *"I did not realise that my levels are going up sky high, and I just thought that I felt awful because I was ill."* **(Laura 1.5).**

There is a struggle to perpetually remember that she has T1DM:

> "*I'll just eat a bunch of stuff, and then before I go to bed, I'll go, oh, I've got to inject myself before I go to bed, but I've got no idea what my blood glucose is because, by the time all the foods kicked in, it will be too high for the meter to read. I'll just inject off a feeling."* **(Chloe 1.4).**

Exemplifying the constant battle between the body and mind reported. This demonstrates the embodied knowledge that develops with T1DM over time. "*injecting off a feeling*" is linked to both mind and body. Even though Chloe cannot get an accurate glucose reading, she senses the amount of insulin she should take to reduce her blood glucose levels.

The following interview quote illustrates Adele's perceptions of living with T1DM, whereby she is taking risks with her diabetes management:

> *"From what I remember, my insulin intake has been awful for years, and I played a big game. A perilous game with my diabetes, umm, where I was doing a lot of things I shouldn't have been doing to try and get good, good readings and then with my HbA1c then, it just did not correspond at all with the readings on my blood monitor. Still, all through the years, I managed somehow to bring it through everything. It's actually shocked me how I'm still here, if that makes sense, because I've played a dangerous game. If I saw someone else doing what I did, I would tell them straight away to get a grip and what they're doing is awful, and that's why me and my sister do not discuss each other's diabetes with each other, umm as she's never been admitted to hospital with ketones. Nothing like that, so there's a part of me that's kind of jealous of her, but there is just something; I know exactly what to do, but I just rebel and decide not to do it, and I could like eat lunch, and I won't inject until late at night. I'll give a big whack of insulin before going to bed, knowing I should have just done it a few hours before when I was eating my food, but I just decide not to.*" **(Adele 1.6).**

Mary reports a difference in the symptoms and realities of real-world hyperglycaemia in DKA that she experienced feeling that she is dying, differing from what is documented in textbooks. HCPs understand the consequences of what happens physiologically. They can discuss this as symptoms, but unless they live with T1DM themselves, they do not know how it is to feel a particular sensation in their bodies. Their understanding of hyperglycaemia focuses on the physiological imbalance in disordered glucose regulation gained from theoretical education rather than being able to perceive and understand the inner turmoil that those experiencing DKA feel.

> *"Symptoms were a big thing for me like doctors would play down symptoms like, oh, you, you get shaky when you're too low, and you feel a bit like this, and you know the list of symptoms for high glucose levels, now it feels like you're dying. You literally sit down. You're aware that you're dying. It is not just what you're saying it is."* **(Mary 1.3).**

HCPs can only gain additional knowledge of what it is to experience hyperglycaemia by listening to what those living with diabetes tell them. Whilst time is limited for clinical appointments, what patients experience must be believed and considered to understand the reality of their lived experience.

In the following quote, Phoebe discussed the split between the body, which has let her down, and her mind, which she feels that she can still control, even though the physical body has caused the issue with T1DM, which is also impacting her psychologically.

> "…*putting me on antidepressants, but I just do not really want that like I've heard a lot of people talking about how it makes you feel. Like you feel nothing and or just feel different or yeah, I just I think I felt like I lost so much that I wanted to know that my brain was mine and that sounds, you know, I'm sure they're not that bad, but I just did not want to be put on more medication and actually that kind of every time I put on more medication it stresses me out more because it reminds me that I'm ill and then that reminds me that I was in hospital."* **(Phoebe 1.6).**

Moreover, at the point of the interview, several years after her diagnosis, Phoebe finds any association with her diagnosis, the hospital, and the diabetes team exceedingly challenging to cope with. So, the thought of having medication such as an antidepressant is unpalatable to her as this is yet another external reminder, having to take a tablet, of something being wrong and the consequences of having developed T1DM and DKA.

Whilst T1DM is seen as a hidden condition, its effects sometimes take on unexpected visibility projected by others. In the next section, Adele sees herself in others when watching a documentary with her mum.

> *"Just explained everything, saying when we're going round in circles here like this, there's something that's not getting picked up from the hospital, and we described everything and how I felt and everything, and they said like, well, have you thought about whether Adele has an eating disorder and we looked at a documentary on BBC 3, and it was literally like looking in the mirror they were saying I was doing."* **(Adele 1.7).**

As a result of viewing the documentary enabled Adele to see others who were experiencing the same symptoms as her and made her realise that the challenges that she was facing with managing her diabetes were not unique or solely confined to having T1DM.

For Laura, the external view of her diagnosis is projected back at her by her mum.

> "…*my mum was never confrontational, but I could see the panic, and then I hated that because you have to, you know, kind of brings it home to you, does not it? The fact that she is right, and I should be managing in it, and I'm not very well."* **(Laura 1.6).**

Likewise, Laura's mum's fear regarding her having T1DM may have been unsaid. However, Laura's mum sees the consequences and experiences anxiety about her actions, so Laura is aware of others' concerns and has another view of her reality.

5.7 Theme 2- The Shaming and the Blame

Poorly perceived relationships with the diabetes team and other HCPs were frequently discussed and sometimes caused a considerable burden to participants.

> "*It is just all the shaming and the and the blame, and you just need to do this, and I honest to God, I could not. I just couldn't do it for all those years. I just could not bring myself to do it. I wanted to do it, but I used to explain it is like there was a barrier in me, and I just wanted for love or money; I could not get myself to do those injections and to look after it. I wanted to really, really badly, but I just couldn't."* **(Mary 1.4).**

The experience and feelings evoked in Mary by others’ opinions of her diabetes management are presented in the above quotation. I think that in these couple of sentences, she is articulating many aspects of how it feels to live with T1DM and the guilt that comes when you continually have high glucose and DKA but encounter the inability to change course. This guilt is perpetuated when advice is given about managing diabetes, for example, with extra insulin injections for sickness management. There is an internal barrier to putting into action the steps needed, such as injecting, whereby she describes as wanting to do so but is unable to complete the action. All of this results in distress that is ever-present.

How well someone’s diabetes is or is not being managed is a crucial focus of diabetes appointments and can be seen as a judgement of the individual:

> ‘‘*I've clashed with my team because they've told me that my HbA1c is like normal for like normal person level, and they were like, oh that's too low, and I feel like that really worried me because I was like well, I've spent two years trying to get down to normal level, and now they're telling me that's too low and, Yeah, I do not know. I'm an over corrector (injects insulin to lower glucose levels), so I think that kind of because I struggle with being high again because it reminds me that I'm ill and takes me back to that. Like I'm convinced that every time there's a straight up arrow, I’m going to go back into the hospital.*’’ **(Phoebe 1.7).**

The previous quote from Phobe illustrates how fragile the balancing act of managing diabetes is. For Phoebe, who dreads hospitalisation, her choice of using the term ‘*normal person level*’ when she refers to blood glucose levels suggests that she no longer considers herself normal. These terms for Phoebe only serve to remind her that she is now different and has the lifelong burden of diabetes to contend with, giving others, such as HCPs, a public view of her internal body.

> “*It was almost like double [Insulin dose] that they would expect that I was needing, so I remember them telling me that, and then so I guess I've just kind of equated that to doing badly. I think, and then now they tell me like I'm doing really well, and like I'm normal, and that makes me want to just tighten it more.*” **(Phoebe 1.8).**

The clinical conversation additionally impacts her subsequent behaviour and feeling that glucose levels are never good enough as she strives to return to 'normal', which in

Phoebe’s eyes is a life without T1DM. In the following quote, Phoebe was admitted to a hospital with DKA while on holiday in the UK. She uses an insulin pump, and the cannula fails without her realising whilst away from where she was staying. Once in the hospital, she receives intravenous (IV) insulin and fluids; she is unable to sleep and watches her glucose levels rise as the IV cannula falls out:

> *“OK, this obviously is not good. So, then they came back, and I remember that the medical team just being so angry with me. They were like why did you take the drip off?”* **(Phoebe 1.9).**

Moreover, Phoebe felt that this team was telling her off and blamed her for the DKA despite her regular team acknowledging that her diabetes was very well controlled. The clinical team draws upon their previous experience of DKA due to a lack of insulin and fails to recognise Phoebe’s expertise and approach to her diabetes management. She perceives this as being told off, and the team is ‘‘*angry*’’ in her perception of this clinical conversation.

Phoebe is adept at managing her diabetes, and this expertise is not appreciated:

> ‘‘*I was like, I just thought my pump was working like I do not know. I felt really frustrated because I felt like no one on the MAU (medical assessment unit) knew what a pump was, so I was trying to explain to them the whole night what was going on, and I felt like I was the only one that knew what was actually going on.’’* **(Phoebe 1.10).**

Despite her expertise in her pump management compared to the general ward staff, there seems to be a disconnect between the value of her lived experience and the ward teams, with a failure to utilise Phoebe’s experience of diabetes management, and this is, on reflection, a missed opportunity not only for the immediacy of the hospital admission but also because she will be the one managing her diabetes at home.

> ‘‘*They moved me again [moved wards in the hospital]. The people had no idea what was going on because the second night I was again, I was terrified that I was going to go back into DKA, so this had already been in DKA twice. They put me back on the drip, like brought me down again, and so this was my second night, and I was like, I'm going to go, I'm going to go back into DKA again. So, I was terrified, like absolutely like proper out of it, just so stressed... I just I was just so terrified that I was going to die. And I just felt like no one was taking you seriously. Because I felt like I was the only one that*

> *knew what the issue was and because I kept moving [wards].''* **(Phoebe 1.11).**

During this time, Phoebe cannot build any relationships with the staff as she is moved several times, and it appears that she feels alone and frightened that she may develop DKA again and die.

> ''*There was no doctor on the unit. I was like, please, can I talk to a doctor because I was like the doctor will understand me surely, but there was no doctor. They were like all junior doctors on their own calls elsewhere in the hospital, and I was like, surely there must be a doctor. I just really did not understand what was going on, and eventually, the Ward sister managed to get me some [insulin] pens just to calm me down.''* **(Phoebe 1.12).**

Concerns were expressed that a hospital culture is difficult for patients to navigate. Overnight, for example, there are very few doctors available, and they will be dealing with acutely unwell patients. Phoebe, though, is distressed by her situation, and it is hard to comprehend and accept that she is not an urgent case. Yet the ward sister was different; being there for Phoebe, she took the time to listen and made a judgement that insulin pens were required. I suspect that she used expert nursing skills to make this decision, which, at face value, was not part of the treatment plan, but it does mean that Phoebe feels heard and her needs are acknowledged, alleviating some of her immediate distress.

> ''*The ward sister, she could just see that I was. I think she could understand something else was going on, and I was not going to hurt myself. I was not going to give myself loads of insulin. I just needed it, to like to get some peace of mind, and I think she realised that if you gave it to me, I would also let everyone on the ward sleep because I was just screaming like.''* **(Phoebe 1.13).**

This was the first time during the admission that Phoebe felt secure that she would be okay because she had access to insulin just in case.

> ''*I felt like the diabetes team, as well, because they did not know me, and I did not know them. I just felt like they were really patronising because they kept telling me off for taking myself off the drip. You, like, you need to keep it on like, and they also wouldn't let me check my own blood sugar, and I have a massive thing about again from being in ICU; I like to be in control of, like, what touches me, that sounds really scary.''* **(Phoebe 1.14).**

For example, the loss of control of the body and being touched by others leads to trauma for Phoebe and evokes memories back to when she was first diagnosed. The ward sister noted the therapeutic relationship and interactions with the body, which can be seen beyond the glucose levels. However, for Phoebe, it feels like a breakdown in her clinical relationship with the admitting team; there is an element of blame present through her interactions with the diabetes team.

> ''*I just felt so different and that I was actually unlike the other people. I felt like I knew what was happening to me. So, I'm not going to lie; I want to know what's happening to me. I want to know what you're doing and what you like. I want to know why you're making the decisions you're doing, not because I'm difficult, but because I know what my body needs, and I know that I'm going to go back into DKA.''* **(Phoebe 1.15).**

Participants valued relationships with healthcare professionals. They provided consistency and stability during their disrupted lives with T1DM.

> ''*When I was first diagnosed, there was a nurse called Sarah who was absolutely wonderful. She was an older woman, so almost grandma-type, teaching that kind of thing. Very comforting, and she left shortly after I was diagnosed after, about eight months after me being diagnosed. I think I struggled with that.''* **(Mary 1.5).**

Mary discusses the importance of good relationships with the diabetes nurses, yet when someone leaves, this can be very unsettling for the person with diabetes. This bond may be particularly important for Mary, given the lack of parental attention and support she experienced at home. Yet this relationship can be precarious if the HCPs do not acknowledge the expertise of those that they are caring for:

> ''*I personally feel like nurses and diabetes specialists can be trained all day long on the ins and outs of diabetes, but at the end of that, you have no idea what it feels like. You do not know how it affects you mentally or physically. The feelings it gives you*.'' **(Mary 1.6).**

In this section of the interview, Mary can illuminate the hold that T1DM has on her body, both physically and mentally, but this is her internal challenge, and the HCPs cannot fully understand this. However, well-intended, they cannot emulate the realities of living with T1DM.

Attending the clinic is a routine part of diabetes care and can cause challenges for the participants. They enter the building as experts in their own bodies, and yet they have to hand over this control to others:

> ‘‘*I remember speaking to them and saying to them I did not want to be seen by this certain Doctor, who made me feel awful, and I would only be seen by them. They go, yes, that's fine. And then the doctor would just pull me in because we'd sit in a circle in the circle room, and doctors would just come out and pull you in if they were free, and it used to really upset me. So, I stopped going. I just stopped turning up to clinic because I couldn't trust them, and they wouldn't listen.”* **(Mary 1.7).**

I understand that Mary feels let down, as although the team acknowledged that a certain doctor wouldn’t see her, she is still called in to see them. Hence, they are not trustworthy, resulting in a failed therapeutic relationship, with Mary opting not to attend the clinic again.

The experiences and feelings evoked in Mary by others in these sentences articulate many aspects of living with T1DM. The guilt comes when you perpetually have high glucose, DKA, and the inability to change course. There is an internal barrier to putting into action the steps needed, such as injecting and whereby she describes:

> ‘‘*They also focused on what's in front of them. At that moment, they were so obsessed with my current levels that you had no, never really asked how I got there.’’* **(Mary 1.8).**

In contrast, Laura's diabetes DSN's interpersonal skills are valued; she feels important, which positively affects how she values the consultation.

> ‘‘*He [DSN] always remembers me. I know I’ve also been with him for a few years now, but even like early on my second appointment with him, either he seems to remember, he probably read my file just before I walked in and that the little things like that are really important, I think and there have been lots of times when I've been I've been seeing the same doctor or nurse like the fifth or sixth time and they've got no idea who I am and it immediately annoys you even though I do know that they see hundreds of patients.’’* **(Laura 1.7).**

This perceived familiarity with the DSN created a therapeutic relationship for Laura, as she does not feel ‘‘annoyed’’ by the consultation. It is one less battle to contend with.

5.8 Theme 3- Fighting to Stay Alive

In this next section, the participants describe how they encountered DKA at various points in their lives with T1DM. There were periods of longer-term hyperglycaemia, being on the cusp of DKA, that are described, the first by Laura:

> ‘‘*My levels were completely out of control for my teenage years really; I do not know how I did not end up with DKA a lot more frequently than I did. I think some of it is being young, is not it? Your body is so much more resilient like my body definitely couldn't take that level of abuse now I do not think.’’*
> **(Laura 1.8).**

Here, she described the toll that diabetes and hyperglycaemia cause internally, and Laura equates this to ‘‘abuse.’’ The benefit of the passage of time was to look back and see what was happening to her. I think in this last quote that Laura has been able to articulate the ability to move her life forward away from her past experiences, using them to protect her body from feeling so bad again.

> *“...the time before I had DKA. I really did not feel as much I could have done. I was being so sick, and I kind of knew what I needed to do by then, and I was checking my levels. I could, you know, I would give myself insulin and everything, but I was just so ill I think it already got past the point of me being able to do anything about it myself.’’* **(Laura 1.9).**

There is the sense of inevitability articulated here that DKA occurs regardless of whether she does the right things in self-management and that, on occasion, stopping DKA from developing is impossible.

> *“I find you talk to so many different doctors in there, and the shifts are constantly changing, that by the time anything could have got figured out, you are talking to a completely different team of people so. I do not find they're there to figure out what's going wrong, just there to fix it.’’* **(Chloe 1.5).**

Perceptions of hospital admission are there to only fix the problem there and then and not consider the underlying causes of DKA. It goes against making every contact count the realities for people living with T1DM.

The development of DKA varied amongst participants, yet for all of them, it appeared as an abrupt disruption to whatever they were doing at that point. The following quotes provide some insights into the experience of developing DKA.

> "*I had it two more times when I was in secondary school, yeah? They were somewhat self-inflicted. Though I haven't had good diabetes care whatsoever or control up until the last year, my highest HbA1c was 113, and it was like that for a prolonged period of time. It was not just my highest; I was done fighting for quite a long time, and it is now 46 mmol/mol.*" **(Mary 1.9).**

A shared view was the perception that you do not just live with or manage T1DM, but it is an entity to be beaten, and this is not always feasible for participants:

> "*The third time, they were like, you, you're going to die if you keep doing this, and I was like, I know I just simply did not care. And it was not enough to make me want to do it or look after it because it was such an overwhelming task, and I just did not want to do it*." **(Mary 1.10).**

Mary appears to be numb when the diabetes team tell her she will die because diabetes is "*such an overwhelming task, and I just did not want to do it.*" It appears too much for her, taking over all aspects of her life. The word "*task*" implies things to be done, so here, it appears peripheral to the rest of her life and burdensome. The inner critic is present, and there is awareness of self-destructive behaviour. This correlated with my clinical experience clinically yet is rarely acknowledged so openly at the time of experiencing DKA.

Mary describes this as a fight; managing her diabetes is an internal and external battle. Like any adult navigating a chronic illness, the body is not just yours; other people take an interest and express an opinion on how well it functions.

> "*So, I had it (DKA) three times, like a few years apart. So, um, I had it one time when I was still living at home. I would have been about sixteen. I imagine, and I was really, really ill at that time, and then I had it again straight after moving to university. I went to university and did not even make it to the end of fresher's week. And yeah, my mum had to come and get me and take me straight to the hospital.*" **(Laura 1.10).**

Laura's first opportunity to live independently as an adult ended abruptly as she developed DKA in fresher's week. This immediately inhibited her ability to blend in with her peers and enjoy what is considered a rite of passage.

> "…*whereas I've had it [DKA] three times, and I think a lot of that comes from, you know, that really early stage of diagnosis when there was, yeah, lots of*

> *information that was not given directly to me was the sort of thing that my mum had passed it on, and my mum really tried hard. We're really close now, but you know, those teenagers are difficult, aren't they?”* **(Laura 1.11).**

Whilst the HCP assumptions are that Laura might have mismanaged her diabetes, as has been noted with Phoebe and her experiences, the resulting DKA is actually because Laura did not know how to manage high glucose levels; this information had been given to her mum at diagnosis and not reassessed with Laura as she grew older.

Concerns were expressed about the impact on the body and how the individual feels is not something that is dwelt upon by HCPs who have to focus on the clinical physiological elements of correcting DKA, yet the internal effects linger post-DKA resolving:

> *“It makes me feel so rotten when I have ketones, I’m exhausted and not hungry, not thirsty when I should be eating and drinking to clear the ketones. I just want to sleep, and that's what I do when I have hypers when I've got high blood sugars; I sleep them all off, and hopefully, when I wake up, I’m fine, but I hate it when you’ve got DKA, and you get admitted.”* **(Adele 1.8).**

DKA can start to develop rapidly, so a simple self-management error can have grave consequences, as Mary describes in the next section:

> “*So, I think the first time, I had accidentally forgotten my background insulin and then was very, very sick—the next day. I think I was out. Felt very unwell and was vomiting; it was black vomit. Couldn't even get up, couldn't move, and I remember being in just A&E, and then something happening and being transferred into the resus area.”* **(Mary 1.11).**

My understanding here is the element of risk-taking just to keep going. As Mary says, injections have been a challenge from the outset as she hates them, so there appears to be a conscious decision to take the minimum number of injections, thereby using the long-acting basal insulin to keep her ticking over. However, when she forgets this, it results in the development of DKA, ‘‘*very, very sick*.’’

Mary describes her vomit as ‘‘*black vomit*,’’ and being at the stage again, she couldn’t “*get up or move*.’’ Black vomit would suggest blood clinically, and I am unsure if the term black is used to signify the gravity of the situation for Mary. Depicting the start of DKA development as coming *“on in waves….,*’’ it starts by feeling just like normal high glucose levels.’ My interpretation of this is that using the word ‘‘*wave*’’ is interesting. Waves at the coast keep rolling in, one after another. There is a pattern predictability to this, and initially, it is like high glucose levels, just subtly deteriorating. Mary can describe how these high glucose levels make her feel, impacting how she can function:

> *"I just suddenly couldn't walk or move or breathe properly or anything like that, and it is something that always takes over you."* **(Mary 1.12).**

DKA 'takes over you', that it keeps coming in waves that she earlier, almost that overwhelms the body and mind. Mary continues to say:

> "…*it almost makes you completely dissociate like your body is just fighting to try and stay alive, and there is no thought there."* **(Mary 1.13).**

This is a stark quote with Mary's choice of words to describe her experiences of developing DKA. It appears it has almost taken over or is '*embodied*'; all she can do is "*fight to stay alive."* So, whereby we think that embodiment may usually involve a conscious thought and action, here it comes in, like the waves in the tide. The DKA becomes all-consuming, and it appears that it takes over the mind when Mary says that there is "*no thought there,"* high blood glucose levels disrupt how Mary can function, "*I feel so rotten... I just want to sleep*..." This appears to be dominating the body's equilibrium; with the inability to continue with everyday life due to disruption caused by diabetes. Adele uses this as a strategy to manage her diabetes. However, insulin is required to control glucose levels, and Adele's management response appears to have an element of hope, such as "*when I wake up, it will all be fine*." It is almost as if sleep will reset what she was experiencing yesterday. Therefore, taking a purely physical or psychosocial stance in managing this illness is not sufficient as the condition is embodied, and the body and mind are intertwined.

> "*I just remember; I can remember what I saw and everything, but not like how I felt in myself. I think I just kind of gave up and might let everyone else sort myself out, that sort of thing."* **(Phoebe 1.6).**

Phoebe is very distressed after this portion of the interview. There appears to be some disassociation; there is no control over what is happening to her. In line with ethical practice, there was a pause in the interview, checking Phoebe's wellbeing and eventually, if she wished to continue the interview.

The participants in this study are a young adult cohort, yet they report significant tiredness caused by DKA. This perpetuates after the hospital treatment for DKA has concluded, and they are discharged home. It can last for some time after admission, and the aftereffects of DKA add another element of complexity in managing a chronic disease.

> *"…the constant tiredness, and umm when I've got the DKA, it is like my body just goes strange. I feel sometimes like my legs will feel paralysed, umm, and I'll get the biggest headaches, and I just like my answer to everything is sleep, just sleep. I'll just go for a nap; I'll sleep that off."* **(Adele 1.9).**

There is an element of losing ordinary bodily functions during DKA; the changes that occur physiologically as DKA develops are beyond tiredness, nausea, and vomiting. They overwhelm the person and impact how they can function in everyday life.

> *"I've always been so tired afterwards, and it takes me ages as well. I do not know because I'm sick leading up to it or because of the really bad heartburn I get, but it takes me a very long time to be able to eat."* **(Laura 1.12).**

Concerns about this feeling of indigestion were also experienced by Chloe and, like other participants, she tried to avoid the need to access health care. This decision to avoid the HCPs and hospital admission requires much additional work for those living with T1DM, such as checking glucose levels, injecting additional insulin doses, and checking for ketones. This is a significant effort when feeling very unwell to juggle the treatment and manage her diabetes to avoid DKA. Chloe also articulates the burden of this.

> *"So, a lot of times I will be feeling sick, be feeling a bit acidic. Like I said, I'll just work through it if I can. At the moment, because I've started work, I am a lot more under control, and so I will be constantly thinking about it."* **(Chloe 1.6).**

Notably this quote illustrates the daily impact of hyperglycaemia, feeling unwell or a 'bit acidic' such as nausea and how Chloe experiences these high glucose levels. Even if DKA does not develop, it causes her body to feel different; no matter what her diabetes status is, it is always present.

The approaches described by participants to try and get rid of ketones are varied. Aside from time and being asleep, Adele said:

> *"I have admitted to my mum two or three times that I've got ketones. Umm, even though I know that's not a thing because when I wake up, I know I've got it, and I stumble into the shower and try and wash it off even though I know*

> *that's not a thing I feel like I can do, I go in the shower to feel better, but I feel so rotten it is ridiculous.''* **(Adele 1.10).**

Moreover, in this quote, Adele shares her desire to escape having ketones, and even though she knows ketones are internal chemicals made by the liver, their development is a distressing failure of her body for Adele. She desperately needed to get them out of her system by washing them away even though, in reality, she knows this will not achieve anything. Carel (2016, pp. 92-105) describes this as bodily doubts and limitations; correspondingly, Adele is aware that the ketones disrupt her body and wash them away. However, the action of washing is physiologically impossible to reduce ketones; it offered her hope for some elements of normality.

> *"…it is got to the point now, which is quite bad, but umm, where I'll get them, and I'll test them (ketone levels), and they can be 4.6 or something like that, and I won't well, I won't do the classic inject eat something, if it is my bedtime I'll drink water and just try and get them out that way. But I know when they're 4.6, I'm supposed to go to hospital, but I'm not doing that anymore. I think if I got to the point of throwing up or anything like that, I would definitely go.''* **(Chloe 1.7).**

Fluid replacement is a fundamental part of hospital treatment alongside insulin administration for treating DKA. Still, in Chloe's instant here, she gambles that she will be able to resolve her symptoms by treating herself at home. It appears that this approach developed as she has not been dealt with as ''*urgent*'' during her previous admissions, so she gambles on being able to deal with it using vomiting as her warning to go to the hospital. This resonates with Laura, who speaks of a conversation with her mum:

> ''...*with the second time at university, my mum knew, and I was really, really ill and I was phoning and telling her I was feeling worse and worse, and she kept telling me to check for ketones, and I did not want to because I knew what that meant by then. So, I was just trying to drink as much water as I could, but then, yet again, she ended up having to take me in."* **(Laura 1.13).**

Laura appears to be in denial of what is happening, but I believe it is more complicated than that. Both participants know what being in a hospital with DKA entails, and it is, for them, an unpleasant experience. It appears that Chloe and Laura are trying to regain control of their bodies. So, in this situation, there is an element of bargaining, as if by adapting their actions of diabetes management, they may just be able to let their body get away with it. Chloe is on an insulin pump and says:

> "*Over the past few times in hospital, I've had such a bad experience, but the last time they kind of left me for three hours and then by the time they came to see me, they were like, oh, you do not, you do not need to be treated now. But they'd already put an IV (Intravenous Infusion) in, and I'm pretty scared of IVs."* **(Chloe 1.8).**

Distress was evident in the next section of the interview for Chloe. She reports the lack of urgency by the A& E team to the extent that it prevents her from attending the hospital when she should, increasing the risk of morbidity and mortality from DKA (Sperling, 2016; Dhatariya, 2017; Shaka *et al.*, 2021).

> *"…I'd go into A&E because, because I would be feeling, I'd be feeling sort of dodgy, and I think at that point I was scared because… I know, obviously, it is dangerous, you're constantly told this is a potentially fatal thing, but the more I sort of had it and the longer I've been left waiting with it in hospital, the more I'm like, I think you've got a lot more time than they say. They kind of imply, so, that's probably not the best thing, but I wouldn't, I wouldn't worry about that with other people they probably haven't had it seven times.*" **(Chloe 1.9).**

This causation of DKA by a pump malfunction seems to carry no sense of urgency by the A&E team. During this time, Chloe feels terrible and is also frightened about what is happening to her. However, she becomes less concerned about the urgency of having DKA as the staff do not portray any rush to treat her. She perceives that the lack of urgency or seriousness of DKA to HCPs means it cannot be that dangerous. In that case, there is a possibility this is gambling or taking a chance with the severity of the condition, making me consider if others follow the same route and are unlucky with their outcomes. DKA is serious and can cause death, leading HCPs to look for a self-management cause due to the gravity of the situation, frustrated by the risks seemingly taken by the person with diabetes. Phoebe describes one such encounter:

"*I think they thought I was just trying to be difficult and like I was like an 18-year-old or 19-year-old whatever. Just trying to be, trying to put myself in DKA, like no, thanks. I do not know what they thought I was doing, really, but they were just, I think, as they were there, and they kept telling me how busy they were and how I*

> *was wasting their time. And like I do, that just made me feel awful because I did not. I just really did not want to be there.”* **(Phoebe 1.17).**

HCPs invariably make judgements about patients with DKA, the clinical belief that the person with diabetes must have done something wrong with their diabetes management using their theoretical knowledge of the condition. Reflecting on this would have been a belief that I, as a DSN, may have held, but the difference in my practice would have been to talk and listen to the person, but they are rushed and busy here in the ED department.

Phoebe is away from all of her usual support mechanisms during the early stages of her following admission with DKA:

> “*I think I was just so angry, and I was so traumatised and so upset, and like just I felt so like lonely, and I’ll just like everything that I just whenever anyone said anything to me that just pushed me over the edge.”* **(Phoebe 1.18).**

This is poignant; hospitals are busy places and yet Phoebe feels alone, increasing her sense of vulnerability:

> “*I was like not having it, and obviously, again, they were trying to take loads of blood from me, which I'm not good at that, and they kept at it. I mean, everyone tells me I’m difficult to take blood from normally, let alone when I'm in DKA.”* **(Phoebe 1.19).**

Concerns were expressed about repeating blood tests, which are vital to individualise DKA treatment. However, they can be traumatic for patients. If unable to get blood, this also makes it difficult, especially if the patient anticipates it due to their experience from previous admissions.

Whilst Mary’s experience is different, time and urgency resonate throughout this section of the interview:

> “…*in A&E and I went to the toilet vomiting. I knew what that meant at that point, and so I remember screaming for my friend to get the doctors to tell them they need to do something, and they need to do it quickly and tell them I'm going into DKA and need help. Eventually, they did, and I ended up being in resus. I remember my friend. I remembered lying in resus very in and out of sleep.”* **(Mary 1.14).**

Highlighting finally the perceived urgency to the rapid deterioration, knowing what is impending before the DKA overwhelms Mary, and she becomes semi-conscious, which, in her words, is like ''*sleep*.''

> ''*I had like no veins and had five different doctors trying to get something in me because they just couldn't, and they…. They took my family and my friend out of the room...''* **(Mary 1.15).**

This episode of DKA involved Mary being resuscitated when she went into resus, and there was no certainty that she would survive. Being treated in resus must be incredibly frightening for patients, and it is evident here, as Mary recounts the event, that the memories of a DKA admission last for a very long time, even for years afterwards. This is similar to the experience of Phoebe, who had such an adverse reaction to diagnosis when she was in DKA that she developed Post Traumatic Stress Disorder (PTSD). Clinically, resus is where the sickest patients in the emergency department (ED) get treated. Whilst teams are efficient in their treatment, the environment will sometimes be hectic and may seem chaotic to a patient. Even if they cannot see what is happening to others, they can hear conversations around them and the clinical conversations relating to their care.

Mary's experience of being in the resuscitation unit seems to be a disassociation for her between what is happening and the gravity of the situation, whereby five doctors were trying to get a line in to be able to administer the resuscitation fluids and insulin. Her family were taken away to the relative's room and told that she was being resuscitated. As a researcher with a background in diabetes nursing it made me consider how we should deal with such experiences after acute admission to hospital. Careful consideration must be given to physical, psychological, and social support. The ability to understand what must, in retrospect, be a terrifying experience during an episode of DKA, when survivors can recollect an experience that may have resulted in death. Avoidance of such an experience again may be the reason that participants adopt other home strategies.

There were some suggestions that being in the A&E is frightening, and it was apparent from listening to the participants that they would take steps to avoid attending the ED whenever possible, attendance in the hospital was seen as a last resort.

> *''So, if I have ketones, I've been treating it at home, then try not to go into full DKA; otherwise, I'd have to get admitted in. But I've had a lot of issues with*

> *ketones over the past year, but a lot of it is where I either admit myself in because I struggled to cope with my diabetes and the fact that I had an eating disorder as well, so that hasn't helped when I've had an episode of DKA."*
> **(Adele 1.11).**

Furthermore, developing DKA is not only an unpleasant event but can also occur at the most inopportune moments, further disrupting participants' lives. In the following quote, Phobe discusses one such occasion:

> *'"We got to the top of the hill, and it was like 27 [mmol/L], and I was like, so we could actually make it to the top, which was nice, but by that point, I felt super sick, like I needed to go to the loo, obviously there's no loo's on the top of the hill, so I had I had to go in the bushes, and I was like, ok, this is really bad."*
> **(Phoebe 1.20).**

Only Phoebe reported developing DKA when she was on a walk, and consequently, knowing she was unwell, up a hill away from help, whilst being on the cusp of DKA, caused her to feel panic. There is vulnerability here just by doing something that is considered an everyday activity, such as going for a walk:

''*We [boyfriend] got back in the car, and I was like throwing up in the car, and we got about, I do not know, 10 minutes down, and I was like, you need to call an ambulance because I was like out of it. I do know it is the first time I've ever felt like I was losing consciousness; umm, I do not know how to describe it. I was like, I remember leaning against the window of the car and just like, really not being with it and not knowing what's going on and. My boyfriend called the ambulance.''*
(Phoebe 1.21).

The rapid development of DKA and how this also presents with disassociated symptoms, ''*feeling out of it*'' knowing she needed urgent medical help.

> ''*I remember going into A and E, and I was like, OK, this is not good, and I was just screaming like 'I need insulin'. Someone give me insulin, and I went up to the receptionist, and I was. I mean, luckily, because we called the ambulance, they knew I was coming in. So that was good, and I was like, I just need someone to give me into it like now, and I can understand why they couldn't just give me a pen. I was like, I just need like give it to me, and they're like, 'Oh no, we need to triage you first,' and they took me in. They did my ketones, and they were like, Oh yes, like you are, and I'm like, yes, I know I'm*

> *in DKA, like please just give me insulin, and I just couldn't understand why they wouldn't just prescribe me just insulin, but they just hope they ended up like hooking it back up and I think they were hesitating 'because they were trying to get my pump."* **(Phoebe 1.22).**

Echoing other participants' recollections, Phoebe knows what should happen when she attends the ED, but the HCPs do not appear to have any sense of urgency; again, a differing perception of time is demonstrated. In her perception, there was a delay and a lack of urgency to start treating her.

> *"…there was something nice on the ceiling. So, like, looking at the ceiling, umm, and I remember, like, the hospital chaplain, came in like sat with me because this really freaked out my boyfriend, so he just left, and so I was just in the hospital like, by myself not knowing what was going on.*" **(Phoebe 1.23).**

Quickly the staff realise that Phoebe is scared and in a strange hospital, so they arrange for the Chaplain to sit with her before her mum arrives. Phoebe discussed a loss of control over her treatment and her diabetes management, which she found difficult as she understood what DKA entails. Below, she explains how she felt when in DKA at the point of diagnosis:

> "*I literally just couldn't shift air, and that's what really made my mum worried. I did not really like throwing up or anything. It was more like I, I do get anxious, but I never normally get anxious in that way, and so that was just really weird and like I just couldn't breathe. I just remember the kind of like pressure, almost like I just felt like I couldn't, yeah, shift any air."* **(Phoebe 1.24).**

These interview excerpts reflect the level of distress and panic experienced by participants, leading them to view their diagnosis as a traumatic event. '*Not being able to shift air*' was distressing to listen to as a researcher. For those admitted to the Intensive Therapy Unit (ITU), issues with breathing are a recurring theme; however, participants experienced this before even reaching ITU (Samuelson, 2011). The feeling of not being able to shift air must be terrifying, and it is evident that this, for Phoebe, has a profound impact on her subsequent ability to come to terms with the diagnosis.

> "…*it is kind of a blur from ICU (Intensive Care Unit), to be honest. …like I just do not really remember, I think either I've like consciously blocked it out, or I think I was just so out of it, I just do not really remember how I felt like. I just*

> *remember, I can remember what I saw and everything, but not like how I felt in myself. I think I just kind of gave up and might let everyone else sort myself out, that sort of thing."* **(Phoebe 1.25).**

Phoebe's distress remains palpable throughout this section of the interview. It is as if she is unable to move forward from the initial diagnosis due to the traumatic experiences. Even setting foot into a hospital for routine care becomes problematic, an ordeal to be endured; there is the dread of DKA happening again. During Phoebe's initial admission with DKA, even before she could comprehend what life with diabetes would become, she appeared to disassociate herself from the situation because this was not something she could sort out for herself.

5.9 The initial case of recurrent DKA in young women with T1DM

This section will present the case study findings from the first round of interviews. For all five participants in this phenomenological case study, the diagnosis of T1DM resulted in abrupt changes to their bodies, from the initial weight loss and difficulty breathing at the point of diagnosis to the need to administer insulin doses regularly and intentionally. The requirement to inject and adjust insulin doses is universal for those with T1DM, yet not all of the T1DM population will struggle with insulin administration or develop DKA. For the participants in this case, there was a collective failure to accept their diabetes diagnosis, which subsequently impacted their ongoing decision making regarding managing their T1DM. Three of the participants were diagnosed during or immediately after a family holiday.

In this phenomenological case, the participants were collectively distressed by the shame and burden of their diagnosis of T1DM, and all of them sought ways to regain control over what was happening to them post-diagnosis. Four of the young women used the act of intentional insulin omission to help feel in control. Universally, they knew this would ultimately make them feel worse. Moreover, the judgement of others when they did seek help either for emergency or routine care, especially from HCPs, was a significant finding for this case study. The collective experiences of the participants' interactions with HCPs predominantly illustrated a negative experience. They felt judged about having diabetes, and diabetes specialist clinicians were just as likely to perpetuate this distress as non-specialists. The result of this judgement was to delay accessing emergency care even though it was reported that they were aware that they might die during an episode of

DKA. In this first round of interviews some key findings for the case of recurrent DKA have been reported utilising case study methodology to establish the phenomena of recurrent DKA.

5.10 Chapter summary

I have presented the experiences from the first round of interviews with participants who agreed to participate in this research to understand their experience of developing recurrent DKA and utilising the work of Merleau-Ponty (2014) to help conceptualise the analysis from the lenses of temporality and corporeality and examining how these can be related to the lived experience of the participants and episodes of DKA that they shared as an element of commonality by having a diagnosis of T1DM and having experienced DKA.

Temporality was featured across all the interviews. It started from the day of diagnosis of T1DM, which can be seen as a defining moment in participants' lives, like a watershed moment. Life becomes defined before and after diagnosis. It is never quite the same again for Adele, Chloe, Laura, Mary, and Phoebe. After that, the management of T1DM infiltrates all aspects of life, including starting university and how the necessity of taking on insulin injections, glucose monitoring and interactions with the diabetes team all take time. These elements of self-management are externally visible signs of self-management tasks, but they take time away from other activities.

What emerged from the first findings was that the experience of DKA encompassed both temporality and corporeality. There were occasions when the urgency of the DKA was not recognised and acknowledged by HCPs, leading participants to take significant risks with home management strategies to avoid attending the hospital. Yet even when they did go to the hospital, judgements were made regarding diabetes management, and they were not always seen to be a priority. Episodes of DKA resulted in participants facing their mortality and potentially a premature end to their lives.

The experience of living with T1DM and developing DKA has a profound effect on participants' corporeality and how they experience their bodies. Their bodies change from the early days of weight loss, thirst, and difficulties in breathing in the time leading up to diagnosis. After that, they have to think for the body to maintain its equilibrium of glucose levels. Their bodies also become necessary to others as they navigate the healthcare system and have to provide accounts for how they have managed diabetes. During DKA, there can be a disassociation as they hand their body over to the HCPs to treat them and keep them alive. They know what is happening to them but can no longer look after themselves. This can be a traumatic event both at the time and when they look back at the event.

The thematic analysis of the first interviews of this case study has shown how DKA is waiting in the background to reappear if there is a miscalculation or hiatus in managing T1DM. It is omnipresent for the participants as they make sense of their changed worlds and contend with the effects that T1DM has on their lives, waiting to re-emerge at any moment and adding to the burden that recurrent DKA has on the lives of people living with T1DM.

The findings of the second interviews will be presented in chapter six. These took place fifteen months after the first interviews and start to illustrate the changes in the participants lives with T1DM.

Chapter 6 Findings 2

6.1 Introduction

This chapter illustrates the phenomenological journey of participants and presents case study findings from the second round of interviews, conducted 15-16 months after the first interviews. The same participants were invited back to share their experiences. Temporality remains a crucial focus for this research and the experience of recurrent diabetic ketoacidosis over both chronological time and the subjective time of lived experience. In this chapter, I focus on participants' experiences during the previous year, exploring the complexities of living with a diagnosis of T1DM. Participants' lives will perpetually evolve, so the second interview explored their experiences of recurrent DKA in the context of their life with T1DM.

Maurice Merleau-Ponty (2014) discusses the relationship of the ‘‘mind’’ with the external world. The changes in individuals over time will be unique, and the expectation is that this chapter does not intend to draw on experiences as a continuum:

> ‘‘…*one could conceive neither of the encroachment of the one upon the other, nor of confusion of one with the other, nor of passage from one to the other, nor even of contact between them.*”

The world and lived experiences remain linked to that moment in time, and this chapter should be seen as a new opportunity to glimpse into the lifeworld of the participants, a further unveiling of the experiences of living with T1DM.

The five participants were invited back for a second interview at a time and date to suit them. Four of the participants responded and agreed to participate. One participant did not respond to the email invite. Two months later, a further email enquired whether she wished to participate again and, if not, thanking her for her time and contributions to the first interview. Although Mary did not respond to this request, her experiences of recurrent DKA are captured in the first findings chapter.

Before commencing the second interview, I re-read the transcripts of the first interview. As before, consent was confirmed at the outset of the interviews conducted on Microsoft Teams (MST), with both audio and video recordings captured. As with the first round of interviews, the interview transcript was downloaded and checked for accuracy by replaying the digital recordings. Immersing myself back into the transcripts allowed me to get to know the participants from a perspective different from the actual interview. First, I found the immersion to be intense, being in the moment with the participants, and at times, these were very emotional as participants discussed their experiences. I also reflected, hoping that everything was all right with Mary. The sense of the unknown resonated with me as a nurse researcher to the times that patients stopped attending clinic appointments, and the reasons were unknown.

The focus of these second interviews was primarily on participants' lives with T1DM over time and with specific exploration around any episodes of DKA experienced by the participants. Whereas the first interview had a list of semi-structured questions to provide guidance, the second interview did not; these interviews were more conversational. Nor was the intent to delve back into the data contained within the first interviews; that moment in time had passed. Van Manen (p. 21, 2014) described this process as involving the ‘‘pathic phenomenality of phenomena, and the vocative expressivity of writing not only our head and our hand, but our whole sensual and sentiment embodied meaning.’’ Thereby, the process of interpretation has already occurred for the first interviews from that moment in time and, therefore, will not be influenced by the second interviews' content, which is not the purpose of this phenomenological case study research. The first interviews and their analysis have already been created first by the participants and then by me as the researcher (Gadamer, 2013, p. 307).

Having the opportunity to meet and interview the participants for a second time enabled additional consideration of how time passes and the experiences of life with T1DM during this period have been perceived. T1DM is classed as a chronic illness; aside from transplantation, there is no cure, no quick resolution, and so the body has to endure diabetes day after day continually; there is no respite, no day off (Balfe, Doyle, *et al.*, 2013; Litterbach *et al.*, 2020; Holmström Rising and Söderberg, 2022). Martino and Freda, 2016, pp. 625-626) interpretative thematic analysis with breast cancer patients explored the meaning-making of the condition from a temporal perspective. The phrase ‘‘the time of the illness and the illness of time’’ articulated what it is for those experiencing enduring conditions; whilst this is not specific to T1DM, it summarises living with a condition over time. Whilst the participants in this research have shared the experience of recurrent DKA and T1DM, how this is perceived and anticipated will be very individual (Watts, O'Hara and Trigg, 2010b; Willemse, Deacon and Segal, 2018; Fioretti and Mugnaini, 2022).

This passage of time may sound mundane and unimportant, but it is fundamental in chronic illness. Toombs, (1990) makes an important point that temporality is very different for both clinician and patient. Such differences can manifest in poorly phrased clinical conversations about, for example, glucose control over time, whereas for the person with diabetes, the complexities of living with T1DM are entangled across all their lives; it is not a neat linear element that only requires attention occasionally. As Hansen *et al.*, (2018) reported in a scoping study investigating work and temporality with T1DM, not only was having diabetes 'omnipresent', but the pull of diabetes management required a delicate balancing act, requiring times to be absent because of attending to diabetes in addition to 'presenteeism' requiring presence at work even when unwell adding another challenging dimension to lives. Several of the participants discussed this in these interviews.

The Interview transcripts were listened to and re-read many times to ensure complete immersion and to focus on the participants' stories individually. Individually each interview transcript was analysed and interpreted in its entirety for each participant before moving on to the following interview. As the researcher, I went back and forth with the scripts, noting that ideas and thoughts sprung into my mind more freely than in the first round of interviews. However, acknowledging development as a researcher in this process; with increased understanding of phenomenology. During the intervening months a more complex understanding of recurrent DKA and life with T1DM had evolved. Following a review of the reflexive diary and the notes from doctoral supervision sessions, it is apparent that I, too, have changed over time. While I remained, an outsider looking into participants' lives, this time, their voices resonated with me as I read the text. Even without the benefit of the audio recording, the participants were with me; I could hear their voices in my head – I had got to know them now. This time, it felt like a more profound, more complex experience; I became more comfortable with the process and increasingly confident in my ability as a doctoral researcher. I would describe this reflectively as being more receptive to the phenomena present.

6.2 Participant update

Below is a brief update for Adele, Chloe, Laura, and Phoebe as there are some changes to their lives since we met them last:

Adele- Continues to live at home, has reduced the number of jobs she has to one, and has had three hospital admissions since we last met, one of which was for DKA. In addition to these admissions, she has required emergency laser treatment for retinopathy with sudden sight loss and has experienced polyneuropathy (nerve pain in several locations). She continues administering insulin via pen injections and occasionally uses a glucose sensor. Adele still requires the support of her parents and lives at home.

Chloe- Has now left home and is living with her boyfriend. She has a new job and has not had any DKA admissions but has had a hospital admission. She finally has access to an insulin pump and occasionally uses glucose sensors. She is in regular contact with the diabetes team.

Laura- She has just had a baby who had to be delivered early at 32 weeks, which was a big shock to her, but she has felt very well supported throughout her pregnancy. However, her time in the hospital to deliver the baby was a challenging experience as she was not allowed to self-manage her diabetes. She is using both an insulin pump and a glucose sensor.

Phoebe—She has completed her BSc and MSc and is about to start a new job as a teacher. Since we last met, she has moved several times to a new town. She is also using an insulin pump and a continuous glucose sensor. Phoebe has also completed the remote Dose Adjustment for Normal Eating (DAFNE) course.

6.3 Themes

The analysis of the interviews this time was completed by hand, coding and making sense of the meaning contained in the participants' stories. Interview scripts were analysed again using the underpinning philosophy of Merleau-Ponty (2014)**.** Once this iterative process concluded, the codes were aggregated initially into ten themes, which were reviewed and analysed into the final four themes using Braun and Clarke's (2006) six-stage thematic analysis:

- *Watching it constantly.*
- *Bringing me down.*
- *Importance of others.*
- *I feel really broken.*

Pertinent findings and the resulting interpretations are presented in the remainder of this chapter. As this is a new dataset, the resultant themes are unique to this round of interviews, and it is essential to note that there is no reference to the first interviews or their findings in this chapter.

6.4 Watching it constantly

Managing T1DM continues to be burdensome and requires a lot of effort for the participants; at times, it results in an emergency hospital admission for causes other than diabetic ketoacidosis (DKA). Adele, for example, has started to develop the chronic complications of T1DM. Even when under the care of the hospital team, what is happening to the participants' bodies is not always immediately apparent; there is uncertainty for the clinicians as to what may be wrong. Such admissions to the hospital steal the time that may be devoted to other aspects of life away from diabetes management; for Adele, managing work became challenging as she was in the hospital or recovering from complications:

> *"I was in and out of hospital for about three weeks, and then they weren't quite sure what it was. They said it was an abscess. Then they said it was a cyst that needed draining. Then they said it was an inflammation. So, to this day, I still do not fully know what was wrong.''* **(Adele 2.1).**

Here, she describes both the passage of time and the uncertainty that the body experiences during acute illness. There is also the loss of control to others in the hospital team. Adele must hand over control of her body to others and loses control of her time because of the co-existing unknown conditions. There seems to be an element of acceptance that this is how it is; even the medical team is unsure about what may be wrong, and there is no immediate diagnosis from the doctors. This episode marks the start of a series of diabetes complications that start to occur for Adele, all at the point in her life that she is beginning to pay greater attention to self-managing diabetes and enlisting professional support such as mental health practitioners to help her to do this:

> *"I had the appointment back at the beginning of the year, and they were like, oh my gosh, you need to come back as an emergency. You've had a bleed in the back of your eye…''* **(Adele 2.2).**

This quote shows a sense of urgency to treat the bleed (retinopathy) to try and preserve her sight. Although Adele had experienced a sudden bleed in the eye, resulting in abrupt loss of vision, the physiological changes will have developed over a much longer duration. Suddenly, time sped up for her with a new sense of urgency for treatment of her sudden sight loss; previously, the development of diabetes complications over the years that she has lived with T1DM was an abstract concept. This is significant for Adele now that diabetes is having an impact on her time and is disrupting other aspects of her life, but there is a sense of lack of control over these events, as expressed in the following quote:

> "*Back after my kidney infection, umm, things have just gone downhill, umm, because I just felt like I was missing out on everything. I had to constantly take time off work, and I haven't done the full month since June (2021) because I've had to be off constantly and because I had an episode of DKA.*" **(Adele 2.3).**

The impact of having T1DM and living everyday life. There is a constant interruption to activities such as work and the time required to attend hospital appointments and admissions. The long-term effects of T1DM are now spiralling into complications for Adele. Her world has become further constrained by diabetes, which takes away choices. She is starting to be limited in life by these complications.

Of interest are the situations where participants must hand over elements of their bodily function to others are a regular occurrence in life with T1DM. The expectation is that treatment is advised, and health professionals will measure glucose levels to assess how well the diabetes is controlled. This can cause burden and distress. In the next section, Phoebe describes how it feels to complete the structured education course DAFNE, which she reported as a requirement for gaining access to insulin pump funding. Yet what is supposed to support can cause unexpected reactions:

> *"And then because I when you start thinking, like, overthinking about stuff, everything went haywire and they were like, oh, you should adjust your levels there. You should adjust your levels here. And it was like constantly testing, constantly changing the levels."* **(Phoebe 2.1).**

This illustrates that, for Phoebe, there is an overwhelming burden of managing her diabetes. This is made worse when she attends the DAFNE course. The educators also offer their clinical views of what is required for this daily management in line with the DAFNE curriculum. However, Phoebe knows her own body, and when the diabetes team starts to make changes, she feels that there is not always the consideration that they consider her expertise. So, she goes along with it but does not draw attention to the fact that she quickly reverted back to managing her diabetes in a way that she knew worked for her.

Three participants now use an insulin pump, with only Adele continuing sub-cutaneous injections. This technology provides a positive experience, but there are also some challenges encountered:

> *"I think because I've come onto the pump, I think things have calmed down a lot, and I do not know if I mentioned before that I can smell when I have ketones, and my boyfriend can as well; he'll say, smells like you got ketones.''* **(Chloe 2.1).**

There are external signs of diabetes, with the smell of ketones (like pear drops/acetone) being visible to others as an external manifestation of high blood glucose levels. Chloe reported that her boyfriend has given her a lot of support in helping her manage her diabetes. Laura's perception and signs of high glucose levels have changed over time. Now, they occur at much lower levels as her blood glucose levels have improved:

> ''…*if I'm even running at like 10 or 12 for an hour or so, I can feel it. I find that mind-blowing because, you know, when I was younger, I'd be running at like 20 all the time.''* **(Laura 2.1).**

For the first time in these interviews, the risk of hypoglycaemia starts to become a concern:

> *"I'm really anxious about having hypos like while I'm on maternity leave and while I've got her [baby] on my own, and so yeah, that's the worry. It is really rare that I have, you know, severe hypos when I'm awake, but if I'm asleep and then I go low and when I wake up, like sometimes. I'm really not like very competent.''* **(Laura 2.2).**

Interestingly, Laura's continuous worry about glucose levels has changed; now that she is a mother, it is not just herself that needs to be considered. There is the additional responsibility of caring for her baby safely, as well as the daily care she requires to manage her diabetes. In addition, she had to contend with caring safely for her daughter. This puts an additional burden on her, which is forever present. The time of maternity leave is complicated not just with caring for a newborn baby as a mother but, in this case, by worrying about the risk of hypoglycaemia. Currently, Laura has very tightly controlled diabetes; now, her diabetes is affecting her differently.

> ‘*‘Maybe yeah, maybe it is my brain causing the symptoms. I do not know because the other thing is I'm aware pretty much all the time because of my phone. Obviously, on my phone now, it always says at my level that are, so I know if I'm 10, and then I know an hour later if I'm still 10. So maybe I just that I have all those symptoms because I'm aware that I'm running high anyway; I do not know.”* **(Laura 2.3).**

Of interest is the experience for Laura who is also using a glucose sensor, and this technology results in a glucose reading always being visible. Its direction of going up or down is denoted with an arrow. Whilst such technology is transforming the ease of gaining a glucose reading, such visibility also means that it is difficult to ascertain if the symptoms of changing glucose levels are caused by the brain or were present anyway as physical symptoms of increasing glucose levels.

> “*I was barely going high at all, but that is because I was watching it constantly, but I've never looked at my phone more than I did when I was pregnant because you always wanted to see what my levels were…”* **(Laura 2.4).**

Laura's focus on managing diabetes has taken on different priorities during her pregnancy. Still, whilst she is now able to successfully self-manage at home, this becomes far more difficult during hospital admissions, whereby she is not permitted to monitor her glucose levels or remain on her subcutaneous insulin pump:

> “…*the other big frustration that I had in the hospital was that I couldn't get any information about the carbs in all of the hospital food. It is just that it is just bananas*.” **(Laura 2.5).**

However, this makes it very challenging to calculate insulin doses accurately and adds a complication that Laura is unable to resolve, causing unnecessary worry at a very complicated time when she is about to have her baby eight weeks before term:

> *“I did not know if my levels were going really high because I'd given myself the wrong amount and for the meal or if it was just some sort of hormonal surge happening. So yeah, that definitely was a frustration in those first few days.*” **(Laura 2.6).**

The external devices continually displaying glucose levels, which Chloe continued with, mean that there are continuous judgements to be made about insulin adjustments; the accuracy of the data is deemed sufficient for home use but not for an inpatient, which is frustrating for Laura. However, the visibility of the current glucose and its trend of travel has the potential to be both burdensome and very positive for the participants. For Chloe, other benefits were unexpected, as the insulin pump and glucose sensor removed the need for her to be constantly involved with diabetes management; in effect, she handed control over to the machines.

> *"I went on the 780 G, which is the one with the smart guard. So, automatic basal programming. Which I found amazing. So, I went up straight from, I was something ridiculous like 14% in range, and I went straight up to 69% within a couple of weeks.''* **(Chloe 2.2).**

This provides some insight into Chloe's potential freedom. Finally, the treatment was effective for her, and she started to see rapid improvements and increased consistency in blood glucose measurements. She had wanted to have an insulin pump for a while, so the experience was somewhat bittersweet as it took a long time for her to gain access to it. However, it is not always straightforward, and there are occasions when the technology also fails abruptly, as the pancreas does at the outset of developing T1DM.

> *"…the Dexcom's being really helpful. Uh, because it alerts me, so it is taking off a lot more of that, like anxiety because I can set it, and it like wakes me up and things like that. So, both on the high end and the low end because they said I'm quite unusual because a lot of people get really anxious about lows, but I'm way more anxious about highs because I've been in DKA twice*.''
> **(Phoebe 2.3).**

Continued anxiety regarding developing DKA again is the greatest fear for Phoebe, partly due to the need to go to the hospital if she were to develop it. She now associates hospitals with developing DKA and T1DM, and they bring back traumatic memories of her initial diagnosis when she was in DKA. After these early events, Phoebe's reaction was so extreme that she was subsequently diagnosed with Post Traumatic Stress Disorder (PTSD). Furthermore, technology such as insulin pumps and glucose sensors is not infallible, and when participants begin to trust and rely on it, any disruption is keenly felt.

> *"There was a sort of a lot going on, and I think everything that could fail with my pump managed to fail as the infusion set failed. The sensor failed.*

> *Everything failed at the same time, and then my blood just took a bit of a… I wanna say like it just it just skyrocketed sort of thing and took me a few hours to get back under control.”* **(Chloe 2.3).**

In this portion of the interview, there is significant frustration that glucose levels deteriorate rapidly when the diabetes technology fails. Being reliant on pumps and sensors does not mean that it is infallible. There are also challenges when such equipment must be changed, disrupting the ease of viewing glucose levels.

> *“Every week, the sensor expires. I have to take the sensor off, take the transmitter out, and charge the transmitter for about an hour. And maybe like an hour and a half. And then I have to put a new sensor on, put the transmitter on, and set it up for two hours so it [sensor] can be down for three hours, maybe even four hours, before it’s back up and running. And in those four hours, my blood is going up to like 23.*” **(Chloe 2.4).**

Some new challenges are emerging for the participants. Technology supports the participants, but during glucose sensor changes, the pump cannot autocorrect blood glucose, resulting in periods of hyperglycaemia for Chloe. Hence, the ease of improved glucose control becomes disrupted. Once access to insulin and glucose monitoring technology is gained, it can also mean that there is real-time exposure to the current glucose levels, so when Laura was pregnant, she said.

> “*…but I’ve never looked at my phone more than I did when I was pregnant because you always wanted to see what my levels were…”* **(Laura 2.7).**

Here, watching it constantly does not refer only to glucose levels but other aspects of life that T1DM affects, such as dietary intake and the body and mind’s response to this, as several of the participants battle disordered eating. In this instance, it is not just glucose levels being watched but also the changing body, which can be problematic for some participants.

> “*I'm gaining weight. Slowly. I'm still coming to terms with that, and because I still get the days where I'm just like, I need to be, I need to lose weight….because, after the eating disorder, my body just feels exhausted all the time. And I do stuff around what I think my body can do instead of trying it and then seeing.”* **(Adele 2.4).**

Adele reported that she is recovering from an eating disorder, and not only has this taken its toll on her body and her mental health, but she is also acutely aware of how easily she could slip back into the grips of it. She has open access to the eating disorders team but is no longer being seen by them regularly. In contrast, Phoebe does not have a diagnosed eating disorder, but she is acutely aware of how easily she could develop controlled eating behaviour:

> *"I suddenly started being like, oh I can't have that, cause that's more than 30 grams of fat, and then I have to count it, or I can't have that because you know, and I started, like, stopping myself eating things which I'd never done before… I then started getting really stressed about counting not only carbs but protein and fat. And like that's just from a sort of mental health perspective and like an eating disordered eating type perspective.*'' **(Phoebe 2.4).**

One concern was reported by Phoebe, who was aware that she has the potential to become restrictive about food and develop disordered eating, a trait in her first interview that her mum had identified. There is an intense focus on food for DAFNE participants:

> *"I just kind of did the course, but not going to say, I went back to doing what I was doing before, but what I was doing before worked.*'' **(Phoebe 2.5).**

There is an overwhelming burden of managing T1DM due to the volume of daily decisions to be made (Ersig *et al.*, 2016). This difficult time for Phoebe lasted for several months, a protracted time. Before undertaking the DAFNE course, Phoebe had reported excellent glycaemic control, and the requirement to undertake DAFNE appears to be to fulfil a funding requirement for an insulin pump. Phoebe is keenly aware of her body, and when the diabetes team gets involved and suggests changing doses, she reported that it causes her glucose levels to go ''*haywire*.'' Suddenly, the strategies for managing T1DM are being questioned by the diabetes educators:

> ''*I just thought it was very impractical for everyday life because it made*
>
> *me a lot more anxious about counting everything."* **(Phoebe 2.6).**

The impact of diabetes distress in this situation affected both her psychological and physical wellbeing, impeding her ability to follow the advice given by the DAFNE educators.

> *"I often do during the week, like I try and have carb free lunches or something because it just means I do not have to bolus, I do not have to think about it.*

> *They're like, well, actually, you should have given bolus for that, because although there are no carbs, there's loads of protein and fat, and I would just like this is never going to escape me and I think. Sometimes it was nice just to have those meals that I did not feel like I had to think about it."* **(Phoebe 2.7).**

As Phoebe identified, structured education courses intensely focus on daily self-management decisions. During DAFNE, Phoebe has to draw her attention to other food groups besides carbohydrates, including protein and fats. She was observing the impact of these on her blood glucose levels. In the past, she did not focus on these food groups, but now, with this new knowledge from the DAFNE course, she must consider everything she eats and how it interacts with her glucose levels. It was not the complexity of doing this but that having T1DM had taken away yet another part of her previous life without diabetes.

> *"So, I feel like it was just too much. And with all the basal testing, that's really draining because it is. You have to test it, and then if it goes wrong, you change something. Then you have to test it again, and you know… And so, it was like I would sometimes just not eat for two days because I was basal testing. But then I'm not eating. And then I was grumpy and like not focusing on my work."* **(Phoebe 2.8).**

The effects and impact on her life go beyond the time of the actual course. The effects on basic needs such as food are significant and beyond what is anticipated by completing the DAFNE course. Now, all food has to be considered for its effect on blood glucose levels and requirements for insulin. Adele's response is similar, although she has not yet completed the DAFNE course. Following the principles of DAFNE is an intense experience, as Phobe illustrates. However, for Adele, even counting carbohydrates to calculate an insulin dose was too burdensome, so she reverted back to fixed insulin doses per meal calculated by her DSN:

> *"I started carb counting, and it got too much. I've got like more things going on. Yeah, I get distracted, and I do not do it. So, I am back to basics at the moment. I take four units for breakfast, six units for lunch and eight units for supper, and I just stick to that for now. Just so I am on the safe level."* **(Adele 2.5).**

Carbohydrate counting is not an easy element of treatment for Adele. It adds another dimension to every day and becomes burdensome to the extent Adele uses the phrase “*safe level*.” Her ability to remember to inject insulin regularly is described in the following quote:

> “*It is either going to be done straight away, or it won't be done until I'm home and going to bed. So, it is that thing that I need to just figure out why. I'm not giving it straight away. Because then it peaks, and then it'll like to stay high for a bit, and then it'll come down, and then I'll be like, oh, I'll do it in giving insulin now and then. It'll just mess up my whole readings. Yeah, that's the thing. I just delay and delay.”* **(Adele 2.6).**

The impact of such a management strategy is perplexing for Adele and is not a deliberate act; not only does it mean her glucose levels will stay high with the resulting feelings that this brings, but she is aware of the longer-term implications that adversely affect her and how she feels. This makes her feel guilty and worried; she also knows others, such as the diabetes team, will pass some form of judgment regarding how her diabetes is managed.

Concern about the intense focus on food becomes increasingly apparent at external events such as at a BBQ where food is abundant. Adele must navigate this without drawing attention to herself as she does not want to make this aspect of diabetes and eating disorder visible to friends as she is worried it may spoil the occasion for others:

> “*Usually, when he's in charge of the food, he does a feast, and there's so much food there that it is actually a bit overwhelming. So, I think it'll be more of a nibble here and there, more than a sit down and eat everything straight away*.” **(Adele 2.7).**

Having to consider the impact on the body and mind when faced with a significant quantity of food is challenging for Adele as she recovers from an eating disorder. The situation is also complicated by the burden of having to inject insulin in the presence of others. Injecting continues to be problematic for her.

> “*I am still today struggling to inject straight away. I will usually sometimes delay an insulin injection, but I'll end up giving it eventually because I'm still struggling or, as hard as it is to believe, I forget because my mind just floats away straight away, and I can't concentrate on things. And unless I do it straight away. I haven’t done it, and then I'll remember a few hours later, I was like, oh my gosh, have I done my insulin, or was that yesterday? So, then I'm just like, I won't do it just in case, and then I get low bloods*.” **(Adele 2.8).**

Here, Adele articulates the physical impact of high glucose levels on her cognitive function and ability to remember. There is, for all those living with T1DM, the perpetual burden of having to remember to administer insulin, a life sustaining treatment. The challenges for Adele when she forgets to take her insulin are not an intentional act, ''*It just floats away*…'' She has the best intentions, even going as far as holding her insulin pens, yet something is hindering her from completing this deliberate act of insulin administration.

For Laura, the constancy in watching her glucose levels takes on a different meaning. Her views of having T1DM are poignant; there is an element of resignation to her approach, which seems to stem from a sense of responsibility and the necessity of doing so, having become a mum.

> ''*I think, like from having to watch it so closely through pregnancy, it really has become second nature now in a way that it was not for me before. And so yeah, I did not like it in a way. It just does not feel, does not feel as annoying now.''* **(Laura 2.8).**

I do not know if this is acceptance or resignation about having diabetes, but for Laura, the very nature of having it is less 'annoying.'

> ''…*you know, took me 15 years and one pregnancy to get my head around that. And I do not think there's really a quicker way to do it. I think you know you just need to take that time to really monitor how your body feels*.'' **(Laura 2.9).**

It is almost as if accepting T1DM is a process that cannot be rushed; this new existence requires getting used to the changed/lived body that occurs after diagnosis. Drawing on reading the philosophy of Gadamer (2013), Heidegger (1932) and Merleau-Ponty (2014) offers the opportunity to view the body differently in this research. However, such texts can be challenging to interpret, although they offer a different way to understand the experience (Smythe and Spence, 2020). Johansson, Ekebergh, and Dahlberg's (2009) phenomenological study examined the experience of falling ill with T1DM. It proposed that such a situation as 'a false reconciliation' occurs because there is little alternative if they are not defined by having diabetes.

6.5 Bringing Me Down

The participants frequently discussed their daily battles with managing their diabetes. This section illuminates the internal aspects of diabetes management and how they intertwine the body and mind. These actions are not necessarily planned and add to the distress of managing T1DM.

> ‘‘*I'm hoping that she can help me figure out what's blocking me and stopping me from doing the injections because I know what I'm doing is wrong. But I can't stop myself from doing it. So, it is really difficult because it is bringing me down so much.’’* **(Adele 2.9).**

This quote from Adele resonated with me. She articulated what I had found previously in patients with recurrent DKA that I had nursed, describing the merging of the psychological barriers with the physical actions of insulin administration. There are internal barriers to acting on what she knows is needed to make her feel well, the constancy of this battle impacted Adele.

> *“I was completely empty, but everything was going around in my head if that makes sense*.’’ **(Adele 2.10).**

Consequently, Adele is beyond feeling emotion in this instance, yet the thoughts surrounding living with T1DM are all-encompassing. There appears to be nothing left to give to managing her diabetes, but the thought of doing so swirls around, taking over so she cannot escape the hold that having T1DM has over her. There is no respite. Adele, however, is not alone in these depictions of the burden of diabetes. Chloe also faced significant struggles:

> ‘‘*I think it was last night. I got home, and I couldn't do anything. I couldn't make myself do anything, but I was just upset. I was like, I just feel horrible*.’’ **(Chloe 2.5).**

Furthermore, the enormity of managing diabetes is just too much at times, and although they chose different words to describe how they feel, there is shared meaning in what they have experienced:

> *“I can feel it without actually feeling. I can sort of guess because somewhere within my brain, it can feel things*.’’ **(Chloe 2.6).**

Additionally, this description appears to illuminate the sensations that the body experiences sub-consciously for Chloe, so even where there is no active thought about the diabetes, there is a presence, an existence; there is no escaping from having T1DM.

Likewise for Phoebe, knowing that she has T1DM has changed how she regards her body, who should have access to it, and the expectations of others as they help her manage the diabetes.

> ‘‘I *can't like my physical body. It triggers this kind of dislocation of ‘like.’ I think that's almost why I sometimes get upset if people touch me or, like, because it reminds me of that, that, like, my physical body is this different thing that I do not have sole control of anymore... And blood gets taken out of me, and I do not have any control of that anymore because it is like I know it has to be done, but in my head, I'm like, this shouldn't be happening.*’’ **(Phoebe 2.9).**

When she describes how she can deal with the situation now that she has diabetes, there remains a yearning for her previous world without the condition. Phoebe perceives that she is no longer in control of her body since developing T1DM. Initially, her experience with T1DM involved being resuscitated and being in the intensive care unit, whereby the HCPs had to complete invasive treatments. Phoebe dislikes HCPs touching her body to take blood or perform an examination, but she adopts strategies to prevent this from happening.

> ‘‘*Before and after, and I think that's a lot to do with like. So, the thing happened to my actual body versus how I was shutting it off in my head and, like…When I can feel like I have control of my body, is then I'm great. I'm like the whole person. And then when things happen to me that I am not in control of, that's where I'm like, oh this is this is two different things and, I do not know, I do not know, but it is that kind of feeling. Like how I feel and how I look, but not how I look physically. You know what I mean? Like how I know my body works and how I work in my head are different.*’’ **(Phoebe 2.10).**

Although Phoebe’s perceptions change depending on the situation encountered. So, being comfortable with her body is equated to being in control of daily life. Still, when others are involved, the separation between mind and body develops, as she illustrates in the following quote:

> *‘If I'm not in an environment where I'm being challenged to recognise my diabetes, I won't. Like I look after myself very well, but it is kind of second*

> *nature, and like I try not to think about it. It is almost just part of routine. But then what? I'm really challenged to think about it and really look and be like the whole person is there's this massive part of you that you do not really talk about. That's really challenging because it is, I do not talk about it because it is like I just try and suppress it so that I do not have to think about it."* **(Phoebe 2.11).**

However, for Phoebe, treating diabetes as separate from her is a coping strategy, yet others, such as HCPs, draw her attention directly back to her life with T1DM through their acts of delivering care.

> *"It is those kinds of emotional comments that I really struggle with because I do not think about it emotionally because when I do, it makes me really upset."* **(Phoebe 2.12).**

Again, there is this separation for Phoebe of life with and without diabetes, where she tries not to let it occupy her thoughts, seemingly to protect herself from having to accept having T1DM and this new life it has caused.

In contrast, by the second interview, Adele felt more in control of her diabetes, and there was a sense of optimism that her life may change. Conversely, she experienced an abrupt change in her health. Despite managing to inject more frequently with improved glucose levels, she is starting to be impacted by chronic complications. These are different from the DKA she had previously encountered, subsequently finding that admission to the hospital cannot easily or entirely resolve them.

> "... *Umm, because of my independence and everything's just going… I was literally driving on Friday, and by Saturday morning, my eyes had gone. And then by today, they're back."* **(Adele 2.11).**

This illustrates the anguish for Adele in relation to what her future life might be, and the new challenges she faces as a direct consequence of T1DM. The loss of her independence with being unable to drive at times or make plans is significant for someone who is struggling to gain independence and leave the family home. Adele understands that having lived with high glucose levels is detrimental to her body now, with the sudden loss of her eyesight. Still, she cannot change her approach to diabetes management.

6.6 Importance of others

For the participants in this study, little time is spent discussing significant others. However, the importance of the relationship with the diabetes team continues to be necessary for participants. The impact on participants' feelings following interactions with healthcare professionals was frequently discussed during the interview. Phoebe continues to strongly associate her interactions with HCPs as traumatic, as they remind her of when she was first diagnosed.

> "*I've had a lot of experience of not being near the team because since I was diagnosed, I went to university, and I quite like it because it makes me sound really bad, but it means I do not have to go in. I've got the excuse that I do not have to go into the hospital, so I always have video appointments. Which I quite like.*" **(Phoebe 2.13).**

Distance and time, in this quote example for Phoebe, means that by living away from her diabetes team, she negates the need to go into the hospital at all. The place of hospitals causes reoccurrence of Post-Traumatic Stress Disorder Symptoms (PTSD). However, the hospital where her diabetes team are based is not where she was admitted at the point of diagnosis with T1DM when she also had DKA. Some four years later, this memory remains profoundly upsetting for Phoebe. It seems to be associated with the shared function of a hospital building and the diabetes team rather than merely the physical space. She agreed to complete an online structured education course, DAFNE, which, due to Covid-19, accelerated the availability of an online option:

> *"One thing over a month [discussing DAFNE], rather than testing everything in five weeks and being told about all the complications and being told about how likely you are to die and like, it is just so much information. I'm doing it alone on a screen as well. I just come away from it like, what's the point? Like, why am I even trying?"* **(Phoebe 2.14).**

In the previous quote, Phoebe discusses some of her experiences attending a remote DAFNE course. Initially, the fact that she did not need to attend a hospital to receive the education, yet the remoteness of the course became problematic, bringing to the fore different feelings for her; there is the absence of connection with others in the physical world. The diabetes educator focuses on potential complications, but this evokes feelings of despair and a sense of inevitability for their development in her life ahead with T1DM. This is yet another area where Phoebe feels that she has lost control over her own body when she is assessed for the development of diabetes complications, although she has yet to develop these. It is all too much to take in, and regardless of her own decisions, she feels she is at the mercy of internal factors in her body just because she has T1DM. The course is online, meaning the usual peer support is not as readily available, and the feeling of being alone with diabetes persists. There is also intense scrutiny of her daily diabetes management, which evokes some unsettling feelings for Phoebe:

> *"I'm normally quite good about it. About trying not to let it become too much of a thing, but when you're told that you have to keep a diary of everything you eat. And then I started feeling guilty if I did not tell... I tried to sneak food and not put it in the diary. And there was like, why am I doing this? Like, it does not matter, but it is really hard when you feel like someone's judging your food diary as well."* **(Phoebe 2.15).**

The effect of following the rules and being judged as part of the DAFNE course caused distress. Doing this over five weeks, though, caused Phoebe to focus on the food she eats to the degree that she is starting to enact secretive behaviours. She is also worried about the anniversary of her diagnosis of T1DM and how this could spiral into restrictive behaviours.

> *"The more they come into contact and the more like I realised that I can't just separate them, it is really a tough spot. And when it comes up too, I'm really nervous about April because it is like. It is five years [since diagnosis], and that's like a bit of a reality check in a way because… It just felt like a long time, and it is like, wow, that is a long time."* **(Phoebe 2.16).**

Phoebe discussed her old and new versions of herself. Her body has changed over time, yet because time is rapidly passing by, there is starting to be a merging of herself 'as they come into contact with life before and after diabetes.' Yet the time before is receding rapidly into the past:

> "*… always been like just get through the next day, like next month next year, and then I think the longer it goes on for, the longer you're like, uh, right? This is actually a lifetime thing. It is almost like you do not really believe it until I think that's why I five years feels like such a long time because it is suddenly like, oh, five years, and then you're like, well, another five years, another five years. And I think it feels like a bigger. Not an achievement, but like a milestone, I guess."* **(Phoebe 2.17).**

These findings are suggestive of changing perceptions of diabetes over time, but this time is passing rapidly, and there is nothing to stop this life with diabetes. For Phoebe, her life before and after diagnosis feels clearly demarcated. Adele's experience is not focused on the years as Phoebe's is, but on days and months, and then she encounters an abrupt resistance to having diabetes.

> "… *because I have good days and bad days, and then I have a good few months and then something just tells me to just stop. So, I need to figure that out*." **(Adele 2.12).**

Adele reported the importance of support over time from the diabetes team, resulting in being referred to a psychologist, an important point in her time with diabetes for Adele and her future life. She spoke about the positivity that she felt about such a referral and how she thought she would be able to get on '*just fine*.' HCPs continued to play a significant role in the participants' lives, to the extent that little was discussed about relationships with partners, family, or friends. However, all the participants in these second interviews discussed their interactions with the diabetes team. Their perceptions varied about how health professionals perceived them, but the importance of someone who would advocate for them was paramount.

> *"He [G.P.] is amazing, and yeah, I think he wrote me referral letters to them, probably about 8-9 or ten times. And then eventually, they [the diabetes team] started listening. I do not know what I think; they sort of gathered he was not going to leave her alone."* **(Chloe 2.7).**

Having her GP advocate for her clinically is paramount for Chloe. Getting the treatment that Chloe requires does not just happen naturally with time. She fought the system and had little resilience left to navigate to get access to diabetes care and diabetes technology that will take some of the daily burden away from managing diabetes:

> "*It's all taken a very long time. It is… It is a bit annoying that. I do not know if everyone, sort of, is treated differently. Depending on it, it will be things like how much they like you, how much they get on with you, and how upset you are.*" **(Chloe 2.8).**

Across the participants' second interviews, the importance of value and relationships with the diabetes team reoccurs. The sense of being important and liked and the need for her distress to be visible to access care is difficult to hear. Chloe's GP is very supportive and continually advocates for her, eventually enabling a route back for Chloe to be able to see the diabetes team. Yet even when the diabetes team sees her for an appointment, she perceives this to be as much about the expensive equipment that is attached to her rather than her as a person with diabetes, as if the insulin pump and glucose sensor somehow increase her visibility. However, Chloe feels this change in the diabetes team's approach is due to technology.

> *"I did end up getting a bit upset with them, and I said, I do feel like I'm getting more support now, but I feel like I'm only getting that support because I've got about seven grand of money attached to me constantly. I said I do not, I do not particularly care as long as I'm getting support. I do not care for the reason, but it was an obvious change as soon as I went on a pump. That is when they started talking to me.*'' **(Chloe 2.9).**

While Chloe is pleased about this change in her relationship with HCPs, perceiving that she is now valued, she feels cynical about it and its reasons for it having occurred after asking for help for such a long time. She believes they are currently caring for the technology attached to her body. From her viewpoint, that makes her visible again, not that she required help managing T1DM. That is her perception of this change in relationship with the HCPs and access to different treatments.

> *"I asked for it [help] over and over, and they do not see how important it is. I'm there, yeah, so at a point where they're probably worried that I'm going to, you know? Go home and, you know, crash my car on the way home as I'm so upset. So, which I guess is good that you know that they do care at that point, but I feel like they should care before that point as well."* **(Chloe 2.10).**

In this section of the interview, Chloe is upset about her interactions with the diabetes team and how she has had to get into such difficulties before she received the care she was expecting. In her mind, her distress was the trigger that made her seem an outward sign of how hard she was finding it living with diabetes.

The value of this contact and support is significant for Chloe even when it disrupts other aspects of her life due to the time required, and it makes her diabetes visible to others, such as her employer.

> ''*Whenever they give me the option to have a face to face appointment or a phone one, I'll always choose the face to face one even though in my previous job, it is putting my job sort of in a bad place because they weren't happy with me having all the appointments.''* **(Chloe 2.11).**

The previous quote illustrated the time that participants regularly have to devote to managing their diabetes. Although there is the expectation that this time will be given along with daily self-management activities, when the participants move from their home environment to the hospital, this time and expertise are not always valued:

> ‘‘…*they put me on a sliding scale because they knew that my levels were going to go really high after the steroids [given to develop foetal lung maturity], and I was quite frustrated about that because essentially my pump is a sliding scale. I could have used my pump and increased the dose as much as we needed, and we did argue that, and I was just firmly told I had to have a sliding scale*.’’ **(Laura 2.10).**

While technology is acceptable for home use, the reality for Laura as an in-patient is that the hospital team will manage her diabetes using an intravenous insulin infusion, resulting in her having to rely on others who know much less than she does about her diabetes. Her experience of this is that the HCPs play catch up continuously to control her blood glucose levels. The maternity team treat her paternalistically, ‘‘*I was firmly told*,’’ yet she is an expert in her daily diabetes management, evidenced by her HbA1c, yet the team does not acknowledge this.

6.7 I Feel Really Broken

Having T1DM results in changes to the body; there is the external visibility of insulin administration, blood glucose monitoring and the internal changes due to diabetes as complications start to emerge. The body's ability to sense or experience fluctuating glucose levels and internal feelings has changed significantly over time. In the following quote, Chloe describes how she has reflected on an episode of DKA:

> ‘‘…*but in time when I look back, I'm like, oh no, no, I understand. I understand now, but it is, yeah, it is one of the things where you are making full sense, and you are all there, and you have all your logic and your common sense, but when you look back, and you're like, oh, none of that was there*.’’ **(Chloe 2.12).**

For example, Chloe’s perception of what she was doing made sense; even though her glucose levels were very high at the time, it all felt logical to her. Yet, in just a short passage of time in her life with T1DM, she can dwell on the past and realise that this perception was an illusion even to her. Her version of life is now different, and she cannot wholly relate to the old version of her life with T1DM. Without realising what she has experienced, she is interpreting her lived experience.

Analysis of these interviews has shown that lives and bodies are impacted by having T1DM, which rises to the fore at unexpected times. For example, travelling through an airport can be a stressful experience for anyone, but for those with T1DM, there is the necessity to make others aware of diabetes when, for example, going through security; this is generally in a very public environment:

> *"When I was travelling as well, like going through security and things because when I when the pump gets taken away from me, it is almost like a baby with like their best toy. I'm like, I can't live without this thing, and I really get stressed if I can't see it or if someone threatens to take it away."* **(Phoebe 2.18).**

This suggests the insulin pump has become an extension of Phoebe. So much so that she is bereft when it is away from her. It has become an essential part of her life and is, perhaps, more than just a device to deliver insulin. Handing the pump over to the security staff exposes her vulnerability and reliance on this external source of insulin; it also draws attention to the differences that she now experiences from others without diabetes.

> "*I got really anxious and like teary and upset, and people do not understand like they think. A lot of people think I have a fear of needles, or I just feel like people won't understand because it is not anything tangible like that...*"
> **(Phoebe 2.19).**

The real but invisible fear that Phoebe perceives is highlighted in the previous quote, where the connection between her mind and body, cannot be seen by others. However, the external items of diabetes management are a visual cue for others who draw their own conclusions about Phoebe's reactions. The anxiety of living with diabetes is reported as ever present, but this seems to stem from the thought of requiring hospital treatment for any reason, the risks of which Phoebe has reduced significantly with her textbook levels of glycaemic control, and to the extent that she subsequently advised that her glucose levels are "*too well controlled*."

"*I have the same thing at airport security because I really do not like people sort of touching me, but it is not touching me. It is like. I do not know. Again, it is, it is almost like seeing things come into my peripheral vision or like it is like me not having control over my body because that's how I felt when I was in hospital.*" **(Phoebe 2.20).**

In this extract, Phoebe refers to the hospital admission at the point of diagnosis. Her body and mind remember where she had little control in the ITU, and these feelings are overwhelming, so much so a visual image can set the fear into motion. T1DM has required others to access her body, such as for a blood test or foot examination. Although she understands the rationale underpinning these events and the necessity for them, the reality of such actions continues to highlight that she has a chronic illness.

"…it is just like I do not know; I don't like drawing attention to it. And again, it is like a hypocritical thing. I almost just want everyone to know without me having to say anything, but I know the world does not work that way." **(Phoebe 2.21).**

The previous quote illuminated how Phoebe struggles between the invisibility of T1DM and wanting others to be aware of it without having to draw attention to it. I think this has to do with acceptance and being seen as Phoebe, who happens to live with T1DM, yet life is not simple like that. Using a sunflower lanyard helps her show without saying that there are some things she finds challenging since Covid-19, the symbolism of the sunflower lanyard has become increasingly recognised by the public to alert to hidden disabilities:

> *"…but when I'm in that situation or I'm like triggered by something. It is really hard to rationalise it and be like... This is because of this. It is just it is more the immediate and like feeling like my and my body's being, like, violated by someone, and they're not. They're just like, I know rationally they're doing like a security check or whatever."* **Phoebe 2.22).**

Emerging from interviews was the lack of acceptance of the diagnosis of diabetes, which continued to resonate across the participant's lives to varying degrees. This is not a static situation, though, and the levels of burden vary depending on how well the diabetes is perceived to be controlled. Chloe illustrates this by describing extreme opposite perceptions of living with T1DM:

> ''*I think it is one of those things that... When it is going well, I sort of accept it, and I'll say yeah, whatever. But then when it is not, it does just feel like the end of the world, like why do I have it?' … I think I sort of got to a point of accepting it, and now I've gone back and because, I do not know if I get it in my head that things would be better without it. Which, well, they would be."*
> **(Chloe 2.13).**

In addition, there is also an internal battle with having T1DM and trying to convince herself that things would be better without diabetes; again, acceptance fluctuates, although it changes over time. Such time is linked to diabetes control, not chronological time, whereby, as the months and years pass, there is far more acceptance. This is not universal, and for Phoebe, there is a clear separation of life after diagnosis:

> *"I think it is hard because I do not feel like... Because I've done with these things, my life, diabetes, or attitude to diabetes has been like stagnant. Because I kind of felt like there's the diabetes me and then there's like me before, and because I'd applied to university and pretty much done [pause], I had not done my 'A' levels by then, like I got up to the Easter of my 'A' level year pre-diabetes like it is almost like that's the last bit of me left and then…"* **(Phoebe 2.23).**

Phoebe has a clear distinction of her identity pre and post diagnosis. A sense of loss is expressed here: "*It is almost like that's the last bit of me.*" After diagnosis, she is no longer the Phoebe she knew and expected to be diabetes was not part of her plans. Phoebe had already envisaged her future life, and although she has managed to fulfil her aspirations, they have now had to incorporate having diabetes:

> "*The old me would have done all these things, so that's the bit of me that's left like the normal mean everyday life doing the things that normal 18- to 22-year-olds would have done. And then underneath there's this other me that happened in 2018, and she just kind of sitting there, and sometimes the two bits connect. That as much as possible, I try to not let them because I do not really want to lose that sense of the me and the normal world or like how I felt like I was before.*" **(Phoebe 2.24).**

Additionally, now that she has diabetes, Phoebe also has to contend with others viewing her achievements as extra special because she has been diagnosed with T1DM, compared to what she had envisaged for herself as a young woman. There is a disconnect about Phoebe's perception of self here. She says:

> "*Like, I really do not know how to describe it, but it is like. I do not want those two realities to touch sometimes and then I think I get most upset when they do, you and when they're kind of come like crashing back to reality and like the person like, I can't dissociate from this second person anymore... I think it was almost at that point it was like I could not control my physical body, but in*

> *my head, I still felt like a different person, and I do not know whether that was the point that these two, it was kind of like. I feel really broken as a physical person. And that does not fit with where my head is at because my head still feels like it is working at the same place."* **(Phoebe 2.25).**

Here, Pheobe construes the body as 'sick' as she has been in hospital and diagnosed with T1DM, but mentally, to all extent and purposes, she is unchanged. The changing identity and sense of self persists for Phoebe, who is trying to deal with the situation as two separate versions of herself, and this seems to start from the very outset of diagnosis but remains problematic several years later:

> "…*almost like I remember vividly, like being admitted to hospital the first time. And feeling because I couldn't move my body and I was like so many wires and stuff, that was the point. That was like, ok, my physical body is doing one thing, but in my head, I was like, I need to revise for my 'A' levels.*" **(Phoebe 2.26).**

There is an internal battle between Phoebe's body, which is now constrained by being attached to medical equipment, and her mind during a serious illness she has yet to develop an understanding of. Dwelling back to the diagnosis four years ago, there is a separation of identity that persists: *"I do not want the two realities to touch."* Having diabetes is not yet assimilated for her. Despite this, she can manage her diabetes very effectively from the perspective of HCPs achieving the advised targets, yet having T1DM is an ever-present burden.

However, the situation differs for Adele, who endeavours to normalise her glucose levels many years after her diagnosis. Her body does not respond as expected and is starting to display painful symptoms that have been damaged some time in her past life by diabetes. In the following quote, she describes the torrid experience of nerve pain in graphic terms:

> '*'I had to take a month off work because my body was in so much pain, and we weren't sure if it was neurological, neuropathy and stuff with the diabetes, and so I was having pain from my fingertips down all the way to my toes and I was having panic attacks and everything like that, and I was just; I just couldn't work or anything. I physically couldn't walk some days, and my body was literally fine one minute, and the next minute, I was screaming in pain"* **(Adele 2.13).**

These symptoms appear as an extreme reaction in both the body and mind, with the interplay between the physical and psychological, as Adele experiences panic attacks in addition to the physical symptoms of what appears to be neuropathy. Here, the damage the body displays from previous high glucose levels seems to have disrupted the equilibrium between the physical and the mind. Consequently, Adele is being overwhelmed with all the daily activities of managing diabetes. It has got to the point where there is nothing left of her to give for Adele to give, and even the very actions of eating and injecting are now all too much. In the next section, she reaches a crisis point when at work, her mum has to be called to take her home:

> *"I had an episode of umm DKA about seven weeks ago, and I was admitted to hospital. Ummm, lack of eating, lack of injections, everything. I just had enough, and one day, I drove to school and just arrived. And I do not know how I got there because I was just a mess. And I spoke to the secretary, and I just broke down, and I was just like, I can't do this anymore…I do not want to be here. I need to go home, but I can't go home on my own. I said I'm not safe to drive because I do not know where I'll end up…*" **(Adele 2.14).**

Adele became distraught in this section of the interview, but there is also a sense of resignation that there may not be a future for her. The not knowing ''*where I will end up*'' whilst not appearing to be direct suicidal ideation, I think she was very aware that she could come to serious harm by being in the car; she was past caring about the outcome of the journey and what would happen to her. Ultimately, she was admitted to the hospital due to this episode. Initially, HCPs perceived this was directly related to issues with her diabetes self-management as she could not administer her insulin. However, it transpired other events are happening to her body:

> *"… eventually agreed to go to the hospital because I knew then in my head that I needed that help, and I was not going to do it myself. So, at least that kind of was in a safe place…then they were like, right, the mental health team won't see you until you're in a fit state, and I was like, I'm not doing it. I refused everything they did, blood tests and everything, and I had a pain. I was complaining with pain in my stomach and in my back, and I thought my kidney infections coming back…''* **(Adele 2.15).**

Although Adele perceives the hospital as a safe place, she refuses to participate in diabetes self-management. Adele knows her own body and recognises although she cannot do anything to help herself, the HCP's role and perspectives will be different as they must follow guidelines to treat the DKA. Taking over her diabetes management, if necessary, to commence intravenous insulin and fluids, meaning Adele can hand over her responsibilities to HCPs. Adele discussed that during this admission, the mental health team wouldn't review her until the diabetes was stabilised. Conversely, this is despite her physical and psychological elements of diabetes care being linked, with both parts requiring expert care. This is a classic example of the separation of physical and mental health, which are being viewed as two separate entities by HCPs. There is an apparent intertwining of the two elements in Adele's presentation of both physical and psychological distress, and both require resolution with a joint plan of care.

These dreadful feelings experienced by Adele are caused by a severe infection that ultimately required surgery. Still, the assumptions are made that her current presentation is due to her poor self-care:

> *"So, a few hours later, they took me to surgery. I had a keyhole surgery and, umm, whilst they would go in towards the appendix, they found out that I'd had a burst cyst on my ovaries and everything, so they cleaned that up and took my appendix out.''* **(Adele 2.16).**

There appear to be significant, protracted conditions for Adele that eventually result in emergency surgery after the body could no longer cope with the internal turmoil of appendicitis and ruptured ovarian cysts. Somehow, Adele recognised this but expressed her anguish by refusing to be able to continue with diabetes self-care activities; here, both the mind and body are in a distressed state.

The experience for Phoebe is different; after the physical disruption and development of DKA, which required admission to an intensive care unit, her longer-term ambition with diabetes management is not to have to see the hospital or the staff as they are a perpetual reminder that she has T1DM and take her back to the point of diagnosis.

> *"I think so much of my idea as well of being diabetic is indistinguishable from DKA, I think. To like to sum it up into one thing, I think that's what I really struggle with because the point that I knew I was diabetic was when I was in DKA.''* **(Phoebe 2.27).**

At the start of her diagnosis with T1DM, Phoebe was in DKA, which remains omnipresent. She feels that she cannot escape from the DKA at the point of diagnosis. The memories of being diagnosed result in Phoebe avoiding all but essential contact with the diabetes team, and Covid-19 justifies avoiding in-person appointments. Perspectives of the hospital are varied for participants, but consistently, it is a place that they would rather avoid attending.

Similarly, for Chloe, the hospital is a place of last resort; she feels that following self-management strategies may be just as successful as a hospital admission:

> *"I mean, if that happens, I'm probably not sure whether to go to the hospital… or wait until I can't get it down or until I start feeling horrible, and because it is not as I said, but not much fun experience*." **(Chloe 2.14).**

Avoiding going to the hospital is much more significant and prevalent than anticipated. Participants saw hospital admission as a last resort and typically tried several self-management strategies to prevent DKA from developing and avoid admission. The experiences of being in the hospital can be upsetting when dwelling on the event and the interactions with HCPs.

> "*I looked back on like certain like hospital experiences, and I can like remember like there's a nurse getting annoyed with me and me being like. Why? Why are they being like that? What's wrong with them when it is me being annoying and me being frustrating, and I do, I do think that they still shouldn't have got annoyed with me.*" **(Chloe 2.15).**

Chloe is sharing her sense of frustration that she feels that staff are not empathetic to her situation. Reflecting on my own previous practice as a DSN, this may be because the teams 'do care' for the patients, and the anxiety about patients dying comes to the fore for the diabetes team. However, this creates a different viewpoint for Chloe, who feels that HCPs do not care about her. She described using an insulin pump as she was allergic to long acting insulin. One such allergic reaction required steroids to dampen down the immune response, which in tandem caused her blood glucose to go very high.

> *"I wanted the allergic reaction on my arm to sort of calm it down because it was getting really bad, and I ended up going into hospital because obviously, steroids throw you right off. And so, I went into the hospital, and my ketones were like 3.4 [mmol/L], and when I got there, they had calmed down. I think probably because of Covid-19, it took so long for ', that sort of thing just sorted itself out. Which is one thing to be grateful for because I do not really enjoy the hospital experience."* **(Chloe 2.16).**

Chloe appears to be on the cusp of DKA in the preceding quote, but because it took time to be reviewed by the team once she arrived at the hospital, it gave her time to avoid DKA; she could take control and control her body. However, as she does not like being in the hospital, this extra time to receive treatment enabled Chloe to prevent a full admission; she saw the delay in being treated as a benefit of the changes to practice, which developed from reducing the risk of Covid-19 transmission.

> *"I would go into hospital and would be like 14, but I still have tons [ketones] and enough to stay in the hospital for three nights and stuff like that when my blood was not. Was not even above 20. So, I think that was definitely more to it…I said I could be fine when my bloods between 30 and 40, but I think... it stopped measuring, do not know. Yeah, I do not know when it really kicks in, but I know I can tell from, like when you know when your graphs going up, and you do not do anything about it, so it is sort of just continuing the same sort of way [up]. I'll probably be fine, still functioning normally at 35!''* **(Chloe 2.17).**

Chloe's perception is that her body can compensate and continue to function despite the glucose levels being too high for the sensor to record; however unpleasant feelings are reported:

> *"I think physically, I think I'd have to be up a few hours. I just, I do not know, I can sort of tell when, like because I got a bit of a funny taste in my mouth and. And eventually, I start screaming death. Yeah, like I, I do not know, I feel like, especially if I'm walking upstairs. I feel like my knees are swollen or something like they do not want to move, and that's me. And but yeah, I get out of breath a bit quicker and stuff, but that's only if I'm high for like a few hours.*'' **(Chloe 2.18).**

In this instance, Chloe is describing the most terrible feelings, '*screaming death*', which, alongside other physical changes such as breathlessness and unexpected symptoms, must be an extremely difficult experience for a young adult.

> ''*I get like a specific type of headache, and it just feels different to other headaches, and I just start to feel like exhausted really, really, quickly. And even now, even now that I'm postpartum and being woken up every two or three hours like it is just a different feel and a different headache, different tiredness, and I definitely get like muscle aches as well.*" **(Laura 2.11).**

Over time Laura describes the emergence of different internal changes to her body's sensation of a glucose of 11-12 mmol/L. So, without knowing the actual glucose, there are internal warning cues of headache, tiredness, and the feeling within the muscles as her glucose rises. The participants use a range of evocative descriptions to describe the internal battle with increasing glucose levels, and if they are unable to halt this, the development of DKA occurs. This battle becomes external and visible to others, such as HCPs, when participants must attend the hospital. Regular self-care decisions such as glucose monitoring and insulin administration then become the remit of the HCPs as participants' bodies become something to be treated; within these interactions, there continues to be a significant disconnect between the physical and psychological experiences of the participants.

6.8 Development of the case of recurrent DKA in young women

Following the completion of the analysis from the second round of interviews, it was evident that despite the passage of time, the returning four young women continued to endure significant challenges with acceptance of their diagnosis of T1DM. However, this experience was reported as being detrimental to their well-being, with levels of distress remaining high. The participants in this phenomenological case study reported that having T1DM altered their perceptions of who they were, and at times, they felt that their diagnosis continued to define them. Using an insulin pump and glucose sensor also exposed vulnerability due to the perceived reliance on external devices to remain well. Further emphasising the changes that have occurred to them since their diagnosis which they were still struggling to accept. Despite having been diagnosed with T1DM in the past, the subsequent impact that managing T1DM had on their available free time resonated with the participants in this case study. Examples of this were planning activities and employment around managing their diabetes; in essence, T1DM constrained when and what they could do.

A key finding in this case study was that by the time of the second interview, DKA had less dominance over participant's lives, with only one reported further episode of DKA since the first interviews. However, despite the reduction in DKA development, the young women in this case study continued to experience distress from having T1DM and had not yet been fully able to accept their diagnosis.

6.9 Chapter Summary

In this chapter, I have presented the continued temporal journey of Adele, Chloe, Laura, and Phoebe. During the intervening time since the first interviews, another year of living with T1DM has ebbed by. Participants reported key life events such as graduation, new jobs, moving and having a baby. These were significant life events, markers in time; the time living with T1DM continued to stretch ahead for the participants, and for most, it had already exceeded their time living without T1DM. Despite this, the very nature of having T1DM is not yet fully incorporated into the participants' realities; it remains burdensome, an entity to be remembered.

There were four themes identified from the data itself within the interviews:

- *Watching it constantly.*
- *Bringing me down*
- *Importance of others.*
- *I feel really broken.*

The language chosen by participants encapsulating these themes summarises the enormous effort of living with T1DM for this group of young adults. Some positive events were shared, and now DKA plays a less intrusive part in their lives. With only Adele having recent experience with it, the participants spend time discussing the impact of high glucose and their experiences of how they feel have changed. For Laura, after running blood glucose levels very tightly during her pregnancy, she experiences feelings of altered equilibrium as her blood glucose levels rise, these feelings now occur at much lower levels than she had previously experienced. The sensations of high glucose levels, even when not having developed DKA, are significant in altering the body's functions, with pain and breathlessness present for Chloe. For Adele, the toll of prolonged high glucose levels has started to cause prolonged symptoms as the chronic complications or retinopathy and neuropathy have emerged to disrupt life again at the point when she feels better placed to deal with living T1DM.

The tone of these second interviews highlighted the daily battles of living or co-existing with T1DM. Having T1DM was separated from the rest of their lives and is not assimilated into their identities despite the longevity of their T1DM diagnosis. There is a perpetual battle with blood glucose levels and the resultant daily tasks that are necessary just to feel well. The struggle to manage T1DM continues and participants' physical and mental wellbeing remains in a constant state of flux.

The final findings chapter is presented in chapter seven. Analysis in this chapter focuses on the philosophical interpretation of both rounds of interviews, reporting on experiences from embodiment, temporal, and corporeal perspectives to provide a novel analysis of recurrent DKA and T1DM.

Chapter 7 Findings 3 Through the Lens of Merleau-Ponty

7.1 Introduction

Chapters five and six presented a thematic analysis of the findings from the participant interviews. Chapter Seven will provide an interpretation of findings from both sets of interviews, drawing on the work of Merleau-Ponty (2014) to inform the analysis. Focusing on three areas: embodiment, temporality, and corporeality. Presenting and interpreting findings drawing on the philosophy of Merleau-Ponty provides another previously unreported analysis of the experiences of participants with T1DM and DKA. Both are complex conditions; how the participants experience and make sense of their altered worlds can be further understood by drawing upon philosophical interpretation. However, there will be differences between the interpretations made from the interview transcripts as participants' perceptions of their experiences are analysed. The words of Merlau-Ponty (2014, p. 211) are essential to consider at the start of this chapter, “external perception and the perception of one’s own body vary together because they are two sides of a single act.’’

7.2 Embodiment

This section will explore how the findings represent the embodied worlds of participants, including examples of their descriptions of the experience of developing DKA and living with T1DM. Drawing upon the phenomenology of Merleau-Ponty, embodiment is an intertwining between the physical and psychological in the body. Although Merleau-Ponty does not provide a chapter on embodiment in The Phenomenology of Perception (2014), he does write about ‘‘sensing.’’ Living with T1DM requires assimilation of the condition to become part of them, incorporated into their body; even if not consciously thinking about T1DM, their body feels or senses the effects of fluctuating glucose levels. Merleau-Ponty (2014, p. 215) said ‘‘all knowledge is established within the horizons opened up by perception.’’ Therefore, the experiences in T1DM are incorporated and can be used to understand future experiences of the same phenomena.

There is simply no getting away from having T1DM despite participants desiring the ability to take a break from diabetes. The physical disruption of high glucose levels quickly leads to DKA, the sensations of which are felt both in the mind and the body. For Phoebe, this started on the day of her diagnosis with T1DM when, after not feeling quite right, she developed DKA and was admitted to the ITU. Subsequently, she struggled to let go of the memories of that first admission and accept her diagnosis.

> *"I think so much of my idea as well of being diabetic is indistinguishable from DKA, I think. To sum it up into one thing, I think that's what I really struggle with because the point that I knew I was diabetic was when I was in DKA."* **(Phoebe 3.1 (2.27)**.

The events of being diagnosed were traumatic, adversely affecting both her long term perceptions of having T1DM and also demarcating her identity before and after diagnosis. Phoebe continues to keep her diagnosis very separate from her identity as this still offers her the links back to her previous life before diabetes. There is an element of control of the situation by consciously choosing not to accept the diagnosis, which would alter her beliefs about who she is. In the following quote, Chloe discussed the challenges she faced with living with T1DM:

> *"I think it is one of those things that... When it is going well, I sort of accept it, and I'll say yeah, whatever. But then, when it is not, it does just feel like the end of the world, like why do I have it? … I think I sort of got to a point of accepting it, and now I've gone back because I do not know if I get it in my head that things would be better without it. Which, well, they would be.''* **(Chloe 3.1 (2.13)**.

The overwhelming burden of living with T1DM cannot be underestimated. Adele, Chloe, Laura, Mary, and Phoebe all spoke at length about the distress that living with T1DM has on their lives, even many years after diagnosis. There is sorrow in their accounts. A lack of acceptance of their diagnosis resonated across the young women interviews; the following two quotes illustrate how enduring the lack of acceptance is:

> ''*I still haven't quite accepted it; I do not think*…'' (**Chloe 3.2 (1.1)**.

The inability to be able to come to terms with a diagnosis is not only distressing but life-threatening as well.

> ''*Throughout my childhood, I struggled with my diabetes. I find it hard to accept that I've got it, and then since being in my teen years, maybe from the*

> *age of 16-17, umm, I've just been in and out of hospital with DKA.”* (**Adele 3.2 (1.1).**

The following quote from Chloe illustrates the sensing of the body; even at the point that the technology of a glucose meter fails to produce a glucose value beyond a high reading, she used embodied knowledge to calculate her insulin dose and inject, the consequence of which could be severe hypoglycaemia if this is incorrect:

> “*I'll just eat a bunch of stuff, and then before I go to bed, I’ll go, oh, I’ve got to inject myself, but I’ve got no idea what my blood glucose is because, by the time all the foods kicked in, it will be too high for the meter to read. I’ll just inject off a feeling.’’* (**Chloe 3.3 (1. 4).**

Chloe describes an inherent sense of knowing that cannot easily be explained. The sensations of glucose levels are not merely confined to hyperglycaemia. In the following quote, Laura illuminates how she, too, can feel her glucose levels, but this has changed over time:

> ‘‘…*if I'm even running at like 10 or 12 for an hour or so, I can feel it. I find that mind-blowing because, you know, when I was younger, I'd be running at like 20 all the time.’’* **(Laura 3.1 (2.1)**.

These ‘‘feelings’’ are embodied, and it appears that the mind can interpret the physical disruption in the body caused by fluctuating glucose levels:

> *“I can feel it without actually feeling. I can sort of guess because somewhere within my brain, it can feel things*.’’ **(Chloe 3.4 (2.6)**.

In the previous quote, Chloe describes how she knows her glucose levels because she has developed embodied knowledge. Merleau-Ponty (2014) describes this as ‘‘ …*the perceptual synthesis is temporal. Subjectivity, at the level of perception, is nothing other than temporality*…’’ (Merleau-Ponty, 2014. p. 248). Therefore, for participants, the actions of injecting insulin and monitoring their glucose levels are two visible aspects of diabetes management. They are an observable reminder of the differences in their bodies, drawing on embodied knowledge for themselves and others. It is a visible representation of their diabetes diagnosis. Frequently, glucose monitoring and injecting insulin can be a struggle to endure, with factors such as carbohydrate intake and activity levels impacting the body’s response to the injected insulin.

> ‘‘*Like, I’m 23 now, and I could go and completely forget I'm diabetic like I should know, like when I have food, I should test and do my injection and could go a few hours and go oh my gosh, I completely forgot to inject even though I told myself when I was eating, inject after food, I just switch off - it baffles me*’’ **(Adele 3.3 (1.4).**

Frequently, intentional insulin omission is reported in recurrent DKA development, yet in this quote, Adele describes the unintentional act of missing injections. She starts with a plan to inject after her meal but quickly moves to bring to the fore a different voice, whereby she is ‘baffled’ by the situation. Despite having lived with T1DM for many years, there is just something hindering her.

This risky behaviour of ignoring diabetes for a time gives respite from having T1DM. Laura, for example, consciously decided at the start of her first term at university to take a break from having diabetes:

> *“…so, it was quite nice to kind of be away from that tension and yeah just to, to just take a break…you know, my first extended stretch of time away from my mom and I just thought it was a convenient time to completely forget about the fact that I had diabetes at all.”* **Laura (3.2 (1.4).**

This and the quote below illustrate the playoff between the conscious decision and the resulting sensations of such an action.

> *“Like when I do not inject myself, it feels like I'm having a break.”* **Chloe 3.5 (1.2)**.

In the quote above, Chloe draws attention to her conscious decision to stop injecting to give her a break and to feel normal. Before their diabetes diagnosis, the participants desired to reclaim their lives and bodies, which resonated with them. While they could rationalise these thoughts, they knew the results, such as ‘‘…*choosing to feel horrible…”* **(Chloe 3.6 (1.2).**

Conscious thought was not always sufficient to stop participants from missing insulin injections, so although they could explain that omitting insulin doses would be dangerous, this was not sufficient to change course. Indeed, the resulting inertia caused predictable sensations in the body from high glucose, feeling tired, thirsty, and nauseous. Although, at first, it would seem that there is a conscious separation of mind and body with such a decision, they are intrinsically intertwined for these participants.

> '*'I did not realise that my levels are going up sky high, and I just thought that I felt awful because I was ill.''* **(Laura 3.3 (1.5).**

This is the resultant sensation experienced during insulin omission. Although such an action avoids the conscious thought process of enacting an injection, the body quickly senses this change without using external measurements to validate it, such as a glucose reading. In addition to the body sensing change, individuals can articulate what happens with high glucose levels; they know what is ahead as they develop DKA but are powerless to stop it even though they understand the risks.

No area escapes the clutches of T1DM. Even the ordinary parts of life have T1DM waiting in the wings to make its presence felt, such as DKA, chronic complications or times such as pregnancy, which is complicated by having diabetes. All five participants spoke about elements of this disruption to their lives; as Merleau-Ponty (2014) says in this quote, there is an element of inevitability *"The present is the outcome of the past, and the future is the outcome of the present…'* Merleau-Ponty (2014, p. 433). The previous quote does not refer to specific conditions, such as T1DM, but situates the body's place in the world. The meaning of it resonates and can be used to understand the phenomena contained within participant's experiences. Where there is a constant battle with glucose levels, the body and mind endeavour to continue. What occurs today regarding glucose levels can generate an outcome for tomorrow; in the context of T1DM, the emergence of chronic complications, which in Adele's story, start to appear when her glucose levels have improved significantly. Still, the legacy effects of yesterday's high glucose mean the situation is more complex. In the following quote, Adele discussed the impact of an abrupt loss of vision caused by retinopathy (a bleed in the back of the eye commonly occurring with prolonged high glucose levels and duration of diabetes).

> ''*... my independence and everything's just going… I was literally driving on Friday, and by Saturday morning, my eyes have gone. And then by today, they're back.''* (**Adele 3.4 (2.11).**

Adele did not know whether the abrupt loss of her vision would be permanent or happen again in the future. She was fearful of this event, which had the potential to dramatically alter her life even further and increase her reliance on others. The findings of this study and the literature review demonstrated that those who experience DKA spent surprisingly little time dwelling on either DKA or the chronic complications of T1DM. When complications were discussed, it was primarily in the context of the impact on everyday life, perhaps explaining why there is little regarding DKA previously captured in the literature.

The participants in this research had done their best to adapt to and live with T1DM. This process of embodiment for the participants changed over the time between the interviews and was not a static state. Drawing upon their previous experiences and incorporating knowledge about living with diabetes. However, this was not always straightforward, sometimes directly related to the glucose levels, whether they and others perceived it was going well. Although participants were frequently able to interpret and sense their diabetes presence, they consciously did not want to do so. There is a battle to retain elements of control over their bodies, even when this causes them to develop DKA.

7.3 Temporality

Temporality is defined as lived time; for the participants in this study, it is focused on how they live with and experience T1DM and the episodes of DKA. The young women in this study have had to adapt to living with T1DM over many years, yet they still yearn for their life prediabetes. The interviews were spaced fifteen months apart, enabling exploration of how experiences will have changed over time. Merleau-Ponty (2014) referred to this: "*By taking up a present, I again take hold of my past, and I transition it. But I only do so by committing myself elsewhere*," (Merleau-Ponty (2014, p. 482). Here, Merleau-Ponty suggests we use past events to make sense of the present. The interviews have shown how participants' temporal experiences of living with T1DM and experiencing DKA have adversely impacted them across all areas of their lives. The participants in this study were all young women who were anticipating and looking forward to their adult lives. Their lives are complicated by having diabetes. For Adele, life is becoming increasingly defined by T1DM to the detriment of work and social activities. The period that she refers to in this excerpt is a year:

> "*Back after my kidney infection, umm, things have just gone downhill, umm, because I just felt like I was missing out on everything. I had to constantly take time off work, and I haven't done the full month since June (2021) because I've had to be off constantly and because, uh, I had an episode of DKA.*" (**Adele 3.5 (2.3).**

Adele's quote exemplifies how much more involved managing T1DM is than glucose readings and insulin injections. T1DM for Adele means she is missing out on life; she is suddenly burdened by other complications that cause prolonged ill health. Similar findings were reported in findings by Balfe *et al.*, (2013) and Carlsund and Söderberg, (2019).

Having a diagnosis of diabetes alters Phoebe's expectations and life experience:

> *"I think it is hard because I do not feel like... Because I've done with these things, my life, diabetes, or attitude to diabetes has been like stagnant. Because I kind of felt like there's the diabetes me and then there's like me before, and because I'd applied to university and pretty much done [pause], I had not done my 'A' levels by then, like I got up to the Easter of my 'A' level year prediabetes, like it is almost like that's the last bit of me left and then…"* **(Phoebe 3.2 (2.23).**

Here, Phoebe splits the pre and post diabetes versions of herself. Her identity gets stuck at the point of diagnosis, and she is no longer sure of herself in the new world with T1DM. Participants reported that developing T1DM was a clearly demarcated event; life after diagnosis was unfamiliar and full of complicated decisions. There is a loss of their uncomplicated self, present until diagnosis. '*That's the last bit of me left then,*' said Phoebe as if once she had T1DM, she was no longer just Phoebe. Her future changes course overnight with the development of T1DM; she no longer feels in control of her future life, and there is sadness about the life she has had to leave behind; having T1DM is an unwanted change to their bodies.

Yet Merleau-Ponty (2014, p. 399) wrote that the changes were perpetual: *"*Thus, we do not possess our entire reality at each moment, and one has the right to speak of an inner perception, an inner sense, an 'analyser' between us and ourselves, that at each moment more or less the distance towards knowledge of our life and being.*"* Participants discussed their knowledge of diabetes management and, at times, how doing what was expected became impossible. This was much more complex than a lack of knowledge regarding avoiding DKA.

> "*The third time, they were like, you, you're going to die if you keep doing this, and I was like, I know I just simply did not care. And it was not enough to make me want to do it or look after it because it was such an overwhelming task, and I just did not want to do it*." **(Mary 3.1 (1.10).**

This quote is one of many poignant quotes from the participant's interviews. It appears that this is a very outward sign of the diabetes distress that Mary was facing. Yet the answer by the HCPs is to tell her, "*You are going to die,"* illustrating that whilst guidelines may state the requirement ‘to educate’ about sickness management to prevent future episodes of DKA, in cases of recurrent DKA, this may be a futile approach (NICE, 2022; JBDS, 2023). This leads to increased feelings of burden and blame on individuals and may explain why this cohort was repeatedly admitted.

> *“…it is got to the point now, which is quite bad, but umm, where I'll get them, and I'll test them (ketone levels), and they can be 4.6 or something like that, and I won't well, I won’t do the classic inject eat something, if it is my bedtime I’ll drink water and just try and get them out that way. But I know when they’re 4.6, I'm supposed to go to hospital, but I'm not doing that anymore. I think if I got to the point of throwing up or anything like that, I would definitely go.’’* (**Chloe 3.7 (1.7).**

Chloe takes a chance on her health, a calculated risk of what may happen, drawing on her previous experiences in the hospital where she felt it took a long time to be assessed and treated.

> *“…I'd go into A&E because, because I would be feeling, I'd be feeling sort of dodgy, and I think at that point I was scared because… I know, obviously, it is dangerous, you're constantly told this is a potentially fatal thing, but the more I sort of had it and the longer I've been left waiting with it in hospital, the more I'm like, I think you've got a lot more time than they say.*’’ **(Chloe 3.8 (1.9).**

Merlau-Ponty (2014) wrote: ‘‘Each moment sets down an existence after which all other moments are powerless.’’ (Merlau-Ponty, 2014, p. 413). So, for Chloe, the experience remains part of her and shapes her future experience of DKA, impacting her perception and interpretation of how HCPs respond to DKA.

Phoebe describes one such encounter when she was admitted to hospital with a cannula failure from her insulin pump:

> *"I think they thought I was just trying to be difficult and like I was like an 18-year-old or 19-year-old whatever. Just trying to be, trying to put myself in DKA, like, no thanks. I do not know what they thought I was doing, really, but they were just, I think, as they were there, and they kept telling me how busy they were and how I was wasting their time. And, like I do, that just made me feel awful because I did not. I just really did not want to be there.’’* **(Phoebe 3.3 (1.17).**

In her interviews, Phoebe spoke about her distress of not only being in a hospital but her interactions with the HCPs. This admission was caused by a cannula failure when she was away on holiday, disrupting what she was able to do; having diabetes again alters her plans.

In the following quote, Mary discusses how rapidly DKA developed, and she was acutely aware of what was happening in her body:

> "…*in A&E and I went to the toilet vomiting. I knew what that meant at that point, and so I remember screaming for my friend to get the doctors to tell them they need to do something, and they need to do it quickly and tell them I'm going into DKA and needed help. Eventually, they did, and I ended up being in resus. I remember my friend. I remembered lying in resus very in and out of sleep."* **(Mary 3.2 (1.14).**

Time speeds up as Mary succumbs to having DKA rapidly, catching the HCPs unaware. She could sense it, but within a short time, she required resuscitation on the cusp of being unconscious *"in and out of sleep."*

The hospital was not a place these participants wanted to attend. They frequently employ risky strategies to stay at home, keeping themselves invisible and out of reach from negative comments for as long as possible.

> *"So, if I have ketones, I've been treating it at home, then try not to go into full DKA; otherwise, I'd have to get admitted in. But I've had a lot of issues with ketones over the past year, but a lot of it is where I either admit myself in because I struggled to cope with my diabetes and the fact that I had an eating disorder as well, so that hasn't helped when I've had an episode of DKA*." (**Adele 3.6 (1.11).**

The temporal experience of the participants varied and was closely linked with how the young women experienced their bodies in this case study. These experiences were never static; having T1DM was always there for them, regardless of how much they did not want it to be visible. There is a commonality between what has been and what is happening now. However, it is apparent that the ability to '*transform it'* does not necessarily result in behaviours or actions ideal for wellbeing, such as avoiding DKA. While temporality would indicate that there is an inner sense, an awareness of how it feels to develop DKA from their previous episodes, this does not preclude it from happening again. There is a dichotomy between what should happen versus what does happen. The transformation ''*can only occur when I commit myself elsewhere''* (Merleau-Ponty 2014, p. 482), illustrating the need for conscious thought in diabetes self-management.

7.4 Corporeality

This section will focus on the lived experience of the body in T1DM for the participants, including how the experience changes when DKA develops. However, as previously discussed, viewing DKA as a separate entity from the rest of their lives with T1DM is impossible. The risk of its re-emergence is always close by. In addition, how the body is viewed, including the public visibility of diabetes, will be explored. Within the literature, the stigma of having to expose a condition to others externally was reported frequently in the studies in Chapter Three. This for Adele, Chloe, Laura, Mary, and Phoebe was not just confined to the lay population; they also had to contend with judgements made by HCPs regarding their diabetes management during clinic appointments and emergency hospital admissions.

There is the desire for support, but how this is gained is not always what is required:

> ''*They also focused on what's in front of them. At that moment, they were so obsessed with my current levels that you had no, never really asked how I got there.''* **(Mary 3.3 (1.8).**

In this instance, Mary was discussing an admission with DKA, and this quote illustrates a Cartesian approach to care, split between the physical and the psychological, where Mary is a body to be fixed. Whilst this is an essential component of DKA management, there is the need for the whole body, physical and psychological, to be seen and treated. Authenticity is essential, and attention should be given to acknowledging the real life experiences of those in our care; participants commented on the lack of understanding by others, as illustrated in the following quote by Mary:

> ''*I personally feel like nurses and diabetes specialists can be trained all day long on the ins and outs of diabetes, but at the end of that, you have no idea what it feels like. You do not know how it affects you, mentally or physically. The feelings it gives you*.'' **(Mary 3.4 (1.6).**

Participants valued others' understanding of the impact of diabetes on the lived experience of having diabetes. For Mary, though, the realities of living with T1DM were unlikely to be fully understood as others could not experience what her body and mind do. There is hope here that someone else can change her course of direction beyond being re-educated on sickness management, which does not resolve this great challenge of inconsistent insulin administration.

In the quote below by Mary, she was adversely impacted by her interactions with HCPs who were just following clinical guidance:

> *"It is just all the shaming and the and the blame, and you just need to do this, and I honest to God, I could not. I just couldn't do it for all those years. I just could not bring myself to do it. I wanted to do it, but I used to explain it is like there was a barrier in me, and I just wanted for love or money; I could not get myself to do those injections and to look after it. I wanted too really, really badly, but I just couldn't."*
>
> **(Mary 3.5 (1.4).**

Frequently, participants battled to manage their diabetes; for example, Adele is acutely aware of what she is not managing to do with the resultant intense feelings for her.

> ''*I'm hoping that she can help me figure out what's blocking me and stopping me from doing the injections because I know what I'm doing is wrong. But I can't stop myself from doing it. So, it is really difficult because it is bringing me down so much.''* **(Adele 3.7 (2.9).**

The last two quotes from Adele and Mary resonated with my DSN experience of nursing those with DKA. There is a split here between knowing, wanting, and needing to do something that was very apparent when it came to insulin omission. There is an internal barrier that seemingly prevents action. There is uncertainty in this behaviour between the conscious and the unconscious, where these decisions enable some control over T1DM.

Chloe recounted the difficulties she experienced after clinic appointments, which added to her distress; she is aware of the visibility of this distress to the diabetes team and relied on her General Practitioner to advocate for her, on her behalf. Such visibility of distress illustrates the corporeality of living with T1DM to the clinical team; it brings to the fore the visibility of diabetes on her to others.

> *"I asked for it [help] over and over, and they do not see how important it is. I'm there, yeah, so at a point where they're probably worried that I'm going to, you*

> *know? Go home and you know crash my car, on the way home as I'm so upset…"* **(Chloe 3.9 (2.10).**

The importance of developing a good relationship with the diabetes teams was significant for these young women, yet regularly, they felt they had little control over their bodies. Mary said in the next quote that this adversely impacted how she subsequently interacted with the diabetes teams.

> *"I remember speaking to them and saying to them I did not want to be seen by this certain Doctor, who made me feel awful, and I would only be seen by them…So, I stopped going. I just stopped turning up to the clinic because I couldn't trust them, and they wouldn't listen."* **(Mary 3.6 (1.7).**

However, diabetes clinic appointments are not intended to make people living with T1DM feel awful. Still, when such feelings arose, this too had a detrimental impact both on ongoing management and the increasing diabetes distress. The language used in such consultations was remembered for a long time afterwards.

> '*'I've clashed with my team because they've told me that my HbA1c is like normal for like normal person level, and they were like, oh that's too low, and I feel like that worried me because I was like well, I've spent two years trying to get down to normal level…*" **(Phoebe 3.4 (1.7).**

Phoebe's fear of DKA and hospital admission was frequently discussed in her interviews. However, even when she achieves physiologically normoglycaemia, her team is still dissatisfied. This continues to draw attention to the fact that she has a long-term condition and, in her eyes, not at a 'normal level,' causes distress. Demonstrating that the impact that the words used in clinical conversations with patients with T1DM can have long-lasting effects.

Having DKA causes terrible feelings and sensations in the body. It takes over, and several participants discussed the stark reality of being faced with death during an episode of DKA. There appears to be a disassociation between the mind and body. It is almost a quiet resignation that there is nothing more that they can do for themselves, and they are all consumed by living through the episode of DKA that makes them feel that they are dying. Comments such as ''black vomit'' and ''struggling to breathe'' express some of their perceptions of the experience; the body is fighting to stay alive, but the mind cannot take it anymore. Participants are acutely aware that they may die, but by the time they are being resuscitated, they are just occupying their body and are unable to respond.

Yet the body also has the sensations of being in DKA, the excess thirst, urination, tiredness, and vomiting, all of which are interpreted as signs of impending DKA. This is illustrated in the following quote from Adele:

> *"It makes me feel so rotten when I have ketones; I'm exhausted and not hungry, not thirsty when I should be eating and drinking to clear the ketones. I just want to sleep, and that's what I do when I have hypers when I've got high blood sugars, I sleep them all off, and hopefully, when I wake up, I'm fine, but I hate it when you've got DKA, and you get admitted."* **(Adele 3.8 (1.8).**

These feelings in the body impact everything, overwhelming her body:

> *"I just suddenly couldn't walk or move or breathe properly or anything like that, and it is something that always takes over you."* **(Mary 3.7 (1.12).**

Participants used different strategies to feel well again; here Adele describes trying to get rid of ketones:

> *"…even though I know that's not a thing because when I wake up, I know I've got it, and I stumble into the shower and try and wash it off even though I know that's not a thing, I feel like I can do, I go in the shower to feel better, but I feel so rotten it is ridiculous." (***Adele 3.9 1.10).**

When DKA is fully developed, every breath is a battle to stay alive as glucose and ketone levels rise and the body's equilibrium is impaired (the blood becomes acidic as acidosis develops). The fight is at the cellular level and takes over the essence of the individual; it becomes all consuming. Participants shared how sick they felt, using words such as '*'disassociated*'' and '*'no thought there*'' to describe how they felt in DKA. Whereas T1DM is a daily battle they have some control over, even when consciously opting not to administer insulin, by the time they have developed DKA, they have lost their bodies to the process. They are acutely unwell and rely on HCPs to manage their bodies and take control of the situation. Often, this required resuscitation.

7.5 Phenomenological case of recurrent DKA

The findings in this chapter form the phenomenological case of recurrent DKA, combining the phenomenological principles of embodiment, temporality, and corporeality to illustrate how the young women in this case perceive DKA and are affected by living with T1DM. Interpreting the experiences utilising hermeneutic phenomenology enabled previously undocumented insights to be reported regarding the unpleasant experience of developing DKA. During an episode of DKA as it developed, there were a number of bodily sensations experienced; these, however, were not just constrained to symptoms felt solely in the body such as thirst and lethargy, which are both early symptoms of hyperglycaemia; for example, the effects of high glucose could also be felt in the mind before a glucose measurement was recorded demonstrating embodied knowledge.

The young women discussed the occasions when they were acutely unwell with DKA; being aware of what was being done to them by HCPs but unable to actively participate in their own care. For this case, of particular importance was the sensations of DKA as it developed, describing being ''*taken over*'' as DKA developed, ultimately leading to feelings of disassociation being reported. No longer were participants able to respond to correcting raised glucose and ketone levels despite the internal effects that raised levels caused. Drawing together the individual's perceptions over two interviews also demonstrated differences in experiences over time (Yinn,1999; Patel, 2015). During the intervening fifteen months between interviews, the dominance of DKA in participants' lives had waned. Yet, a lack of acceptance regarding their diagnosis, and challenging interactions with HCPs continued to be impactful. In this case, there was a continued tension between the risk of developing DKA and living with T1DM.

7.6 Chapter Summary

Using Merleau-Ponty's (2014) philosophy has enabled additional understanding of the experience of DKA whilst also living with T1DM to inform the creation of this phenomenological case study. It is evident that the participant's relationship with their body changes at the point of diagnosis. At regular intervals, HCPs scrutinise the impact of self-care decisions on the participants. Such interactions can be distressing, and there continues to be the desire to retain some control over the body, even to the detriment of feeling very unwell. For these young women, the impact having T1DM has on their experiences and lived time cannot be underestimated. Although diabetes does become embodied with the ability to sense the changes in their bodies and mind caused by fluctuating glucose levels, it was evident that having T1DM was distressing and that this burden was always there. The impact of diagnosis did not diminish with time, yet it altered the participant's experience of the future time as they forged their adult lives.

Chapter 8 Discussion of the Phenomenological Case Study

8.1 Introduction

The discussion chapter presents a synthesis of the phenomenological case study findings exploring the experience of having recurrent Diabetic Ketoacidosis whilst living with Type 1 Diabetes Mellitus (T1DM) and defines the original contribution to knowledge.

The participants for this research shared characteristics beyond recurrent DKA and T1DM, and their experiences are presented in chapters five, six and seven. All actively self-selected to participate, had been diagnosed with T1DM before they were eighteen years old whilst living at home with family. At the point of recruitment, they were all users of the social media platform X, although they infrequently referred to social media in the interviews. Finally, they were all young women whose ages ranged between 23-29 who had previously attended university, and by the final interview, all were in employment. The homogeneous features shared by Adele, Chloe, Laura, Mary and Phoebe will be drawn on to form this phenomenological case. This approach will enable the presentation of their lived experiences of recurrent DKA to be portrayed collectively and as a coherent ‘‘case’’. To ensure a comprehensive discussion in this chapter, I will refer to participants' experiences throughout whilst also utilising previously cited literature, methodological principles, and, where necessary, new literature. The chapter will be structured to consider the original findings before examining the broader implications of the research aims.

In addition to the main aim of understanding the lived experience of developing recurrent DKA from the perspective of those with T1DM, I set out to answer additional sub-aims presented below, which I will discuss within this chapter:

- What do adults with T1DM perceive as the cause for developing DKA?
- What factors influence and impact self-care decision-making in adults with TD1 who have recently experienced DKA?
- How do people with diabetes who have experienced DKA use the information provided in diabetes education?

- How useful are current diabetes educational strategies in addressing the issues or factors identified?

The development of insight and learning from the perspective of insiders' lived experience is essential as each episode of recurrent DKA increases the risk of mortality for young adults with T1DM (Kent, Williams and Gill,1994; Gibb *et al.*, 2016; Hamblin *et al.*, 2022). Recurrent DKA continues to reoccur in some young adults with T1DM despite diabetes clinical care and DSME (Gibb *et al.*, 2016). Previous literature has failed to establish a cause for these recurrent episodes, warranting further research to develop understanding through lived experience of participants with recurrent DKA. The creation of a phenomenological case study enabled the creation of a rich body of experience from young women with DKA. Ultimately the case could be used to inform clinical care and the identification of additional care requirements in this population. The complexities of managing T1DM and developing DKA are multi-factorial, as the five young women participants in this study have illustrated during their interviews. The findings of this case study illuminate the pervasiveness of DKA's deleterious symptoms and the physical, psychological, and emotional impact of recurrent DKA.

8.2 The phenomenological case of recurrent DKA

Once the purposive recruitment process concluded for this study, it was evident that the participants shared common characteristics that went beyond their diagnosis of T1DM and recurrent DKA. All were young women who had been diagnosed with T1DM in childhood or late adolescence, had experienced recurrent DKA, and as described above their shared features provided a boundary that forms the case for this research (Simons, 2009; Yin, 2018, p.49; Negrin *et al.*, 2022).

The prevalence of DKA is higher in women than men (Barski *et al.*, 2011; Cooper *et al.*, 2016; O'Reilly *et al.*, 2021). In addition to the usual causes of DKA, young women also have to navigate the challenges of hormonal disturbances during their menstrual cycle, which can lead to insulin resistance and hyperglycaemia (Barata *et al.*, 2013; Visekruna, Edge and Keeping-Burke, 2015). Therefore, as DKA occurs more frequently in females it may explain why the eventual sample was comprised entirely of female participants. Participant's experiences and perceptions reported in this study provide a new and unique contribution to the existing evidence and will be discussed thematically and philosophically in this chapter. Drawing upon the participant's narratives will illustrate the phenomenological case comprised of rich data.

The participants had a problematic relationship with both acceptance of the condition and its impact on their sense of identity. The findings have shown the level of distress that the participants endured every day and the ability to switch off from administering their insulin gave them a brief respite to be able to revert to their lives as if they were unencumbered by diabetes.

8.3 Summary of the Key Phenomenological Case Study Findings

Thematic analysis of data from the interviews at two time intervals using Braun & Clark's (2006) process of analysis resulted in seven themes. The themes presented in chapters five and six are presented below for clarity:

Themes: Findings 1

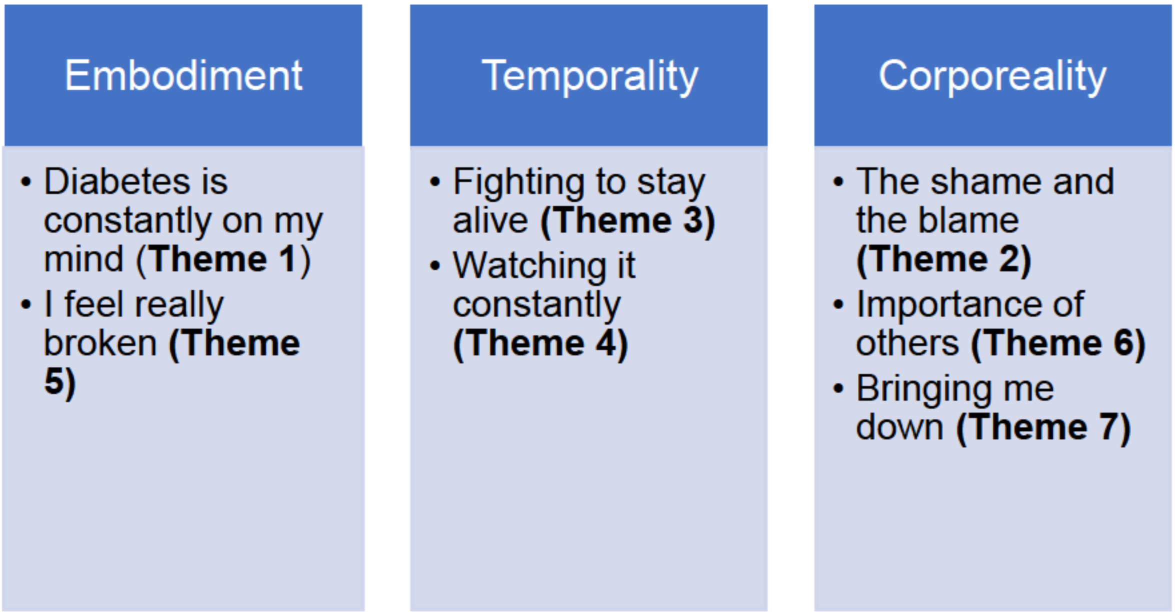
- *Diabetes is constantly on my mind*
- *The shaming and the blame*
- *Fighting to stay alive*

Themes: Findings 2

- *Watching it constantly*
- *I feel really broken*
- *Importance of others*
- *Bringing me down*

Figure 2- Themes from findings in Chapters Five and Six

In this discussion chapter I will also draw upon the philosophical analysis presented in chapter seven, which focused on the phenomenological concepts of embodiment, temporality, and corporeality, to understand the physical and psychological experience of DKA. The phenomenological analysis offers an additional novel contribution to knowledge and explores how the participants perceived the experience of DKA internally. Importantly, it draws the thematic and philosophical analysis together, ensuring philosophy remains embedded throughout the thesis to create the phenomenological case study.



Embodiment	Temporality	Corporeality
• Diabetes is constantly on my mind (**Theme 1**) • I feel really broken **(Theme 5)**	• Fighting to stay alive **(Theme 3)** • Watching it constantly **(Theme 4)**	• The shame and the blame **(Theme 2)** • Importance of others **(Theme 6)** • Bringing me down **(Theme 7)**

Figure 3 Philosophical Presentation of the Themes

8.4 Theme 1 - Diabetes is constantly on my mind

In this first theme, the burden of living with T1DM had a profound effect on participants, starting at the point of diagnosis, whereby their lives were suddenly irrevocably changed. The impact of being diagnosed with T1DM was long lasting, with a failure to be able to accept the reality of their new world, living with a chronic long-term condition (Due-Christensen *et al.*, 2018). Although lack of acceptance has been reported in the literature, there is a gap in the evidence regarding the acceptance of T1DM and recurrent DKA. The findings of this case study highlight the relationship between a lack of acceptance, which was shared by participants and their subsequent decision making, therefore increasing the risks of recurrent DKA development, suggesting that recurrent DKA may be linked to a lack of acceptance of the T1DM diagnosis. This study's findings are somewhat supported by Schmitt *et al*. (2018), whereby lower acceptance levels correlated with both increased HbA1c levels and distress. The findings in this case study of young women experiencing recurrent DKA correlate with the literature on distress and burden within the T1DM population, as presented in Chapter Two. Being diagnosed with T1DM in childhood and adolescence, meant that participants had memories of their lives before memories of diabetes, and had already begun to construct their social worlds and identities pre-diagnosis, correlating with the findings reported by Abdoli, Hardy and Hall, 2017; Willemse, Deacon and Segal, 2018; Cortright, 2021; Fioretti and Mugnaini, 2022). While previous studies have identified the impact of reduced social support on adaption to diagnosis, most participants in this study received family support, suggesting that acceptance may be impacted by other factors (Chilton & Pires-Yfantouda, 2014; Harazneh, Malak & Ahmad (2024).

Participants in this phenomenological case study continued to be allured to the memories of life without diabetes, drawn back to a simpler existence where they could just be themselves without the burden of continually thinking about diabetes management, even when diagnosed before adolescence. Their desire to have a day off from diabetes did not relent, and whilst the participants were knowledgeable about their diabetes management, they longed to feel ‘’normal’’ again. Being diagnosed with T1DM impacted identity development and this case correlates with the literature (Holmström and Söderberg, 2022). This was particularly apparent for Phoebe, the oldest participant, to be diagnosed with her identity being further developed as she was a young adult. For her, there were two Phoebes, pre and post-T1DM. Participants ability to live with diabetes in a more managed way differed from that reported by Habenicht *et al.* (2021); Kruger *et al*. (2021); Holmström Rising and Söderberg (2022). In these studies, there was an element of having to get on with it, and whilst participants could not go back to life pre-diabetes, they could more successfully accommodate T1DM into their lives, recognising that this was a necessary step in adaptation to life with diabetes (Abdoli, Hardy and Hall, 2017). However, this was not the case for Adele, Chloe, Laura, Mary, or Phoebe, who did not discuss any advantages of being diagnosed with T1DM. Conversely, adaptation does not occur immediately in adolescence and can be seen as a gradual process (Chilton and Pires-Yfantouda, 2014). Failure to adapt and accept the diagnosis of T1DM can lead to subsequent maladaptive behaviours and intentional omission of insulin is such an example (Whittemore, 2010; Jaser *et al.*, 2012; Rewers *et al*., 2014).

Adaptation to the diagnosis of T1DM correlates with an increased likelihood of achievement of target glycaemic control (DCCT, 2003; Whittemore *et al*., 2010). Participants infrequently referred to HbA1c throughout both sets of interviews, despite the clinical focus of this measurement. It is, however, worth noting that this research did not investigate the HbA1c level of participants unless they specifically discussed it. However, HbA1c was an in-frequent element of the interview conversations, possibly less important to the participants than health care professionals (HCPs).

In their updated conceptual model, Whittemore *et al*. (2010) also acknowledge the importance of both physical and psychological elements for successful acceptance and where this is not in place, there is an increased risk of maladaptive self-management, including an increased tendency to psychological disorders, including disordered eating and increased risk of DKA development. Garrett *et al.* (2020) have described recurrent DKA as having a psychological component to its origins. Despite this being recognised for many years in the diabetes research literature, the delivery of post-recurrent DKA care has not been significantly adapted in the intervening years (Polonsky *et al.*, 1994; Randall *et al.*, 2011; Fisher *et al.*, 2018; Hamblin *et al.*, 2022; JBDS-IP, 2022).

Examining psychological flexibility as a predictor of reduced morbidity in T1DM, Kamody *et al.* (2018) concluded that the ability to adhere to treatment predicted reduced morbidity. Self-management issues are a previously well-documented cause of DKA and were frequently discussed in these interviews (Dhatariya, Skedgel and Fordham, 2017; Yan *et al.*, 2017). While consistency in injecting sufficient insulin means it is unsurprising that there was a reduction in adverse events, it differs from the participants in this research, who were often very self-aware of the requirements to adhere to but unable to enact the intentional act of injecting insulin. The inability to do so has its foundations in the embodied, temporal, and corporal elements of living with T1DM. The omission of insulin profoundly alters homeostasis, rapidly overwhelming the body as glucose and ketone levels rise (DeFronzo, Ferrannini & Zimmet, 2015; Farsani *et al*., 2017, pp 789-803). This experience will be discussed thoroughly in Theme Three- Fighting to Stay Alive*.*

This research did not aim to explore eating disorders. However, the omission of insulin can also have its roots here; deliberate omission of insulin in T1DM has been informally classified as the eating disorder diabulimia, which does correlate with recurrent DKA (Staite *et al*. 2018). There are differences in the population with an eating disorder and T1DM, with a different identity reported by Goddard & Oxlad, (2023) in a meta-analysis. Insulin omission was noted to be a form of self-destruction similar to the accounts of Chloe and Adele, the option to withhold insulin even though they knew they would quickly feel unwell.

The omission of insulin also gave Adele and Chloe some semblance of control. Routine discussions about food, weight, and height measurement occur regularly at a diabetes outpatient appointment. In this group of young adult women, it lays open the potential to develop disordered eating behaviours. Still, the focus of this appears to be the destructive relationship that they had with their diagnosis of T1DM rather than solely on weight loss. Such behaviours echo the findings of studies that reviewed omission and the development of hyperglycaemia or DKA. In a systematic review, Robinson *et al*., (2021) reported their findings that diabetes distress is due to the enduring impact diabetes has on individuals, correlating with the experiences reported in the findings of this research, where the effort of injecting was just too much. Consistent with previously reported findings, adding an additional dimension regarding the narrative behind insulin omission highlights the complexity of such decisions. Whilst only Adele had a diagnosed eating disorder, it was apparent that disordered eating was a feature of participants' lives. The focus on food started on the day of diagnosis: '*'They drew a black line through it,"* denoting the food that was no longer permissible to eat for Mary. Food became one element of T1DM management that they could control even when it was detrimental to both their diabetes management and how they were feeling.

Food and irregular insulin administration were featured in different ways for these participants. Still, overall, however disordered the decisions may have been to omit insulin, it appeared to not be solely about causing weight loss but the ability to retain some control over their bodies, even if paradoxically, this caused the terrible feelings of hyperglycaemia to be experienced when insulin was omitted. The act of insulin administration was frequently impossible for the participants in this research.

8.5 Theme 2 - The shaming and the blame

Shame and blame were reported frequently by the young women in this case study. These feelings started from the point of diagnosis, eventually impacting decision making including when to access emergency care or diabetes outpatient appointments. Similar findings have been reported in diabetes and diabulimia literature; there is a lack of authentic awareness from HCPs who may not have diabetes or fully understand the impact of T1DM on the body or psychologically, which can perpetuate feelings of blame and stigma (Browne *et al.*, 2014; Coleman and Caswell, 2020; Habenicht *et al.*, 2021; Goddard and Oxlad, 2023). Adele recognises that she is unlikely to be able to resolve her precarious diabetes management without the help of a psychologist. Diabetes clinics have high rates of missed appointments, and whilst this research did not focus on such metrics, encounters with HCPs may influence subsequent attendance at appointments; this was undoubtedly the experience for Chloe, Mary, and Phoebe (Lawson *et al.*, 2005; Cooper *et al.*, 2016). Similar experiences were reported by both Scholes *et al.* (2013) and Visekruna, Edge and Keeping-Burke (2015), whereby participants felt judged by others for their glucose readings, which were used to define how 'good' their diabetes was and how well it was being managed. Ndjaboue *et al.'s* (2020) study examined patients' perspectives on improving diabetes care, reporting the blame and shame that an

HCP can subsequently cause, highlighting the importance of respectful communication during episodes of diabetes care.

Adele and Chloe placed significant value on their encounters with HCPs during the interviews. If outpatient appointments were not perceived as positive, it could damage their subsequent diabetes management, missing future appointments and adding to the burden of their distress. Chloe discussed leaving appointments in a distressed state and opted to miss insulin injections afterwards as a method of feeling better about the encounter and regaining control. The importance of the relationship with HCPs valued by these participants correlates with Brewster *et al*.'s (2020) multi-national systematic review whereby attendance increased if the staff had good interpersonal skills and with continuity of HCP to develop a therapeutic relationship. Laura spoke of the minute or two at the start of the consultation whereby the DSN asked about things not specifically related to diabetes, such as running; the act of being remembered from one appointment to another was valued.

The level of adverse impact and distress was measured by Berkovic *et al.*, (2022), who found that 23% failed to attend subsequent follow-up appointments, highlighting that it is essential to consider the multifactorial nature of the failure to attend follow-up post DKA admissions and outpatient appointments. These clinical interactions with patients can have adverse effects; it is hard to imagine as an adult attending an appointment and being judged by the numbers on a blood test, seemingly defining their ability to look after their diabetes. Yet, this was frequently the experience of participants in this case study, who felt a negative response and limited acknowledgement of their psychological wellbeing during consultations; similar experiences were reported by Scholes *et al*., (2013). Surprisingly, the level of distress was just as likely to be caused by a diabetes HCP versus a non-specialist HCP for the participants of this case study.

The distress of living with T1DM received increased international attention in 2024, with the publication of an international consensus regarding ending diabetes stigma published by Speight *et al.* (2024) and correlating with the experiences described by the participants in this research. A key element was the interaction with the health care professionals having a significant impact on increasing distress and subsequent self-care behaviours, which may be detrimental to the participant (Kibbey *et al.*, 2013; Hill, Ward and Gleadle, 2019; Skinner, Joensen and Parkin, 2020). When being assessed, the snippets of conversations and questions stayed with the participants long after the event. The extreme sensations reported by Chloe after a problematic consultation meant she would consciously omit insulin doses, an aspect that she had control over. Insulin omission is more frequently reported in young women and can be linked to disordered eating (Polonsky *et al.*, 1994; Kichler, Moss and Kaugars, 2012; Hirsch and Gaudiani, 2020; Hall *et al.*, 2021). Yet only 0.8% of participants in Akhtar, Dockray, and Simmons's (2008) questionnaire on the causes of missed appointments reported a struggle to manage diabetes. Several of these research participants felt their HCP who made them feel well supported, especially where they had their own lived experience of T1DM. Yet for the others, there were surprisingly significant negative connotations from attending the diabetes clinic and admission.

Whilst the participants in this case study are now young women, they continued on occasion to seek support from family members. Whilst this did at times impact the development of adult autonomy, it was seen as a necessity (Willemse, Deacon and Segal, 2018; Ingersgaard *et al.*, 2021; Orben *et al.*, 2022). Interestingly Adele recognised that because of the complexity of her diabetes, she would not be safe currently living away from home. Even though her parents played little part in her daily diabetes management, knowing they were close by was essential to her. Social support of a significant person was noted to reduce the risk of subsequent DKA by Forbes *et al.* (2020). As Moffett (2013) reported, this type of support was also crucial during an episode of DKA.

The second unexpected finding related to participant experiences when they were admitted to the hospital for assessment and treatment for DKA. At this point, their interactions with HCPs were commonly perceived to be negative. Two elements were shocking, given what has been previously reported in the literature. Firstly, the encounters with health care professionals (HCP) were not always therapeutic in the participant's experience. DKA is a medical emergency, yet frequently, when attending the ED, they did not feel they were viewed as urgent, correlating with Moffett *et al.'s* (2013) findings. Toombs (1990) suggests this is because of the differences in how a patient and an HCP perceive a clinical condition and time. Therefore, it would be expected that HCPs draw upon their professional knowledge in managing DKA, which stipulates the urgent nature of DKA treatment (JDBS, 2023; NICE, 2023). This would, however, contradict the experience of both the participants in this research and Moffett *et al*. (2013). The temporal experience of DKA varied for these participants, but why there was such a difference between the urgency of treatment and what was perceived to occur is not easy to explain and warrants further investigation. Adele, Chloe, and Mary all discussed how a lack of urgency by HCPs enabled them to stay at home for longer in the early stages of DKA, as, during previous admissions, they did not perceive that the HCPs prioritised their treatment as urgent.

Participants experiences ranged from feeling blamed about the occurrence of DKA and reflecting on the clinical training and knowledge of HCPs; however, to participants, it feels accusatory whereby their lived experience was not acknowledged nor utilised to plan their future care despite their understanding of diabetes (Scholes *et al.*, 2013; Habenicht *et al.*, 2021). Chloe, for instance, said ''*no one ever asked how I got here*.'' Highlighting that care in this population remains to be sufficiently individualised once the DKA has been resolved. Yet standard care recommended by NICE (2022) is still to provide DKA prevention education. It is evident from the participant's stories and the literature that recurrent DKA is multi-factorial, and the context of psychosocial worlds should be explored in this population (Butalia *et al.*, 2013; Del Degan *et al.*, 2019; Forbes *et al.*, 2020; Garrett *et al.*, 2021) . The risk factors for the reoccurrence of DKA have been reported to increase with reduced age, distress and depression, substance misuse and increased deprivation across a range of studies (Cooper *et al*., 2016; Bradford *et al*., 2017; Brandstaetter, 2019). The reception received on arrival at hospital emergency departments (ED) may explain why attending is seen as a last resort, managing for as long as possible at home despite the inherent risks of this approach. Such a strategy delays corrective treatment and may be part of the reason why those with recurrent DKA have a higher rate of mortality from DKA, both at the time of admission and in the subsequent years afterwards (Misra, 2015; Gibb *et al.*, 2016).

Analysis of the findings has illustrated the corporeal experience of having T1DM and recurrent DKA. After the diagnosis, participants had to accommodate diabetes and make sense of their changed bodies. Diabetes is ever present with very limited respite from thinking about the impact it will have on them. In addition, for these young women, their bodies were now scrutinised by HCPs at regular intervals, providing judgement on how they had chosen to manage diabetes; in reality, this felt like a judgement of their lives as although unwanted, diabetes was an integral part of them. Drawing on philosophy here adds another dimension to understanding the meaning of experiences and demonstrates how the case of recurrent DKA is partly informed by the negative interactions with HCPs and omitting insulin thereafter offered participants some perceived control over their situation (Carel, 2016; Suddick *et al.,* 2020).

8.6 Theme 3 - Fighting to Stay Alive

Perhaps the most evocative of the findings was the theme '*'fighting to stay alive,"* which was the battle that participants had to fight continuously to feel well and function in their social worlds. The feelings discussed in this case have not previously been captured in the DKA literature. The language used by participants to describe the effects of living with T1DM and subsequent development of DKA was emotive. This finding provides new insights into the experience of DKA, illuminating the human reality of experiencing such an event and giving it increased meaning beyond the scientific language of healthcare professionals. Participants gave new insights into how dreadful the recurrent DKA experience was. Yet even though they knew that DKA could result if they could not inject their insulin doses, this understanding was insufficient to alter their self-management, leading to the trajectory of DKA development. Poor concordance with insulin administration is widely reported to be the most significant cause of DKA development (Yan *et al*., 2017; Del Degan *et al*., 2019; Flores *et al*., 2020). Although Dhatariya, Skedgel and Fordham (2017) reported in a national survey for DKA management that acute illness was attributable to approximately half of all cases of DKA, whereby increased secretion of counter regulatory hormones increases insulin resistance (Kitabchi, Umiierrez and Murphy, 2015).

Moreover, such variance, in contrast to other studies, may be due to the number of clinicians submitting data on behalf of their units. However, if an acute inter-current illness such as infection plays a more significant part in real-world admissions for DKA, the blame and stigma should ultimately be reduced. However, this did not match the participants' current experiences of being treated during an episode of DKA.

Adolescence is frequently a time of risk taking and the context of this developmental stage should be considered for the participants in this case. DKA occurred most frequently in adolescence for the participants in this research. Scaramuzza *et al.* (2010) reported experimenting with alcohol and recreational drugs at a higher level in adolescents with T1DM than controls without diabetes. Yet these factors were not frequently spoken about in the interviews, with only Laura alluding to the time that she developed DKA in 'freshers' week', but this was seen as the overarching desire to keep diabetes invisible from her new peers at university rather than drinking excess alcohol.

The resultant feelings reported by participants of being taken over with "*black vomit"* and the struggle to walk and breathe as DKA developed to the point of "*no thought there"* hints at the disassociation experienced when DKA becomes developed, poignantly illustrating the corporeal effects of DKA. These findings help us understand the psychological distress experienced by participants, offering a different lens through which to view recurrent DKA. Whilst the distress from DKA is thoroughly documented, in the causation of recurrent DKA, the narratives used by these participants may help explain why those with recurrent DKA experience such distress (Moffett *et al*., 2013; Fobes *et al*., 2020; Garrett *et al*., 2020).

Contrary to other studies which report poor knowledge as a reason for DKA development (Moffett *et al.*, 2013; Forbes *et al.*, 2020, NICE, 2023), for these young women, once sickness management education had been received, lack of knowledge was not the reason for their subsequent development of DKA. Correlating with my previous experience as a DSN, providing what felt like increasingly futile DKA prevention education failed to prevent future admissions and increased the burden of stigma felt by the patient. In the hours leading up to the development of DKA, participants had to make several complex decisions, not least the conscious decision to maintain some control over their body by omitting insulin, driven by the desire to take a break from having T1DM. Intentional omission of insulin was reported to offer a semblance of control over the situation by the participants and can be a strategy for controlling distress (Goddard and Oxlad, 2022). In addition, participants believed they had time available to stay at home. Such experience is both embodied, temporal, and corporeal for participants. Merleau-Ponty (2014) did not explicitly write about diabetes; his quote below however, can be used to explain how the result of actions set in motion for future events: *"*The present is the outcome of the past, and the future is the outcome of the present…'' Merleau-Ponty (2014, p. 433). In the context of this research, this quote brings together how previous experiences can shape current decisions, such as insulin omission resulting in DKA, perpetuating the cycle of recurrent DKA that participants in this research experienced.

Nevertheless, the mainstay of post DKA diabetes care is to provide repeat education on managing subsequent illness and high glucose levels (NICE, 2022; JDBS, 2023). The immediate priority, because of the structure of clinical teams, is to focus on the physical elements of the body with a failure to support the psychological aspects of recurrent DKA. The participants in this study clearly showed that knowledge was not a factor in DKA development. Whilst education is essential at the point of recurrent DKA, alternative strategies should also be considered, including exploration of what the individual perceives to be their challenges in living with T1DM; as Chloe poignantly said, '*'no one ever asked how I got there*.*"* In addition to considering the social aspects documented to increase the risks of DKA reoccurrence (Cooper *et al*., 2016; Bradford *et al*., 2017; Brandstaetter, 2019).

8.7 Theme 4 - Watching it constantly

The time taken away by having T1DM is encapsulated in this theme. The participants in this case study were all trying to forge ahead with their lives, holding down jobs, but they spoke at length about how having T1DM interfered with these activities. The time that could have been devoted to other activities (Shubrook *et al.*, 2018). Instead, thought is required to anticipate how the body will react to a particular situation. Participants spent time planning and anticipating the impact that their diabetes management would have on their home and work lives, social activities, and attendance at diabetes appointments. This finding echoes previous research (Willemse, Deacon and Segal, 2018; Holmström Rising and Söderberg, 2022).

Participants in this research were all young women who had to contend with the additional impact of hormones during puberty, which also impacts the menstrual cycle and pregnancy (Iina *et al*., 2020). Hormonal changes can cause insulin resistance and hyperglycaemia, which, if uncorrected, can lead to the development of DKA. Such effects also vary across the duration of the menstrual cycle, which adds another complexity of unpredictability for young women with T1DM (Barata, 2013; Dey, Dasgupta & Roy, 2019). There is limited acknowledgement of these additional tasks of managing T1DM in young women. Monitoring glucose levels, administering insulin and pre-empting the glucose response from food or activity are invariably time consuming and appear in this group of participants to add further to their diabetes distress. For the participants, there was little respite from the constancy of T1DM, echoing the work of Scholes *et al*. (2013) and Markowitz *et al*., (2019). Frequently, participants discussed how they planned their social and work lives around their T1DM, which directly impacted what they felt they could do, often curtailing activities because they did not feel well enough. Adele frequently planned activities around her need to sleep during the day because she was excessively tired from prolonged hyperglycaemia.

Within theme four, the first references to the longer-term implications of T1DM arise; Adele had developed damage to the blood vessels in her eye caused by high glucose levels and the duration of diabetes (Polonsky *et al.*, 1994; Sritharan *et al.*, 2021). Just as in the studies included in the literature review where the discussion of complications was brief and where it was made in this study, it was relational to their effects on everyday life.

Managing pregnancy and post-partum, for example, changed Laura's gaze from her own needs to that of her baby. With the development of retinopathy, Adele was most concerned with the practical aspects of such a condition and the inability to continue driving, she also had to take long periods of time off work and had to give up her second job. Goddard and Oxlad, (2022) reported that intentional insulin omission increased the risk of retinopathy, so there are serious consequences to the complications of diabetes. This was recognised by participants in this case study, who illustrated their attempts to manage an increasingly complicated condition; with increased perceptions of burden, and an ongoing negative impact on their current life and future aspirations (Holt *et al.*, 2022).

8.8 Theme 5 - Bringing Me Down

In the second interview, the psychological impact of recurrent DKA and T1DM offers additional perspectives from participants. The burden and constancy of diabetes were discussed in theme one, and in theme five, the longer-term implications will be considered. In this chapter, I have already discussed in the literature review the close affinity between distress, depression, and the incidence of developing recurrent DKA (Cooper *et al*., 2016; Gibb *et al*., 2016; Bradford *et al*., 2017; Hessler *et al*., 2017; Schmitt *et al*., 2018; Brandstaetter; 2019; Flores, 2020). The impact of these on the development of DKA is more difficult to establish and requires further research to examine the burden and distress and how this may persist after an episode of DKA.

Central to the development of DKA was the administration of insulin, particularly when participants were struggling to inject, knowing that quickly they would feel even worse. Self-management errors are responsible for many DKA admissions (Dhatariya, Skedgel and Fordham, 2017; Yan *et al.*, 2017). However, participants were acutely aware of this fact and knowing that they were unable to inject added to the burden of guilt and psychological distress that they experienced. The constancy of distress should not be underestimated and can lead to the development of a subsequent depressive illness (Fisher *et al.*, 2012; Balfe, Doyle *et al.*, 2013). Although participants did not directly report diagnosed depression, daily management was reported as brutal, similar to the findings of Balfe *et al*. (2013) study of young adult perspectives of living with T1DM.

To date, the impact of this daily burden from the perspectives of those with lived experience of recurrent DKA has been underreported. As the feelings of burden are ever present, so is the chance of DKA development; it is almost like the villain waiting in the wings to take over, and at times, there is little that the individual can do to prevent it. Additional research is required to explore this fully.

8.9 Theme 6 - Importance of others

The importance of others, such as family, friends, and HCPs, was a central theme in the studies included in the literature review. It is noteworthy that this did, at times, impact the development of adult autonomy, where participants felt they had to rely on others compared to those without diabetes. It was, however, seen as a necessity to help them cope with T1DM (Willemse, Deacon and Segal, 2018; Ingersgaard *et al.*, 2021; Orben *et al.*, 2022). For the young adults in this case study, there was not the same reliance on family and significant others, although this was reported to be beneficial in preventing DKA from developing (Semenkovich *et al.* (2019) Forbes *et al.*, 2020). Rarely did they discuss family and significant others as part of their experience of DKA or life with diabetes, instead focusing on the interactions with HCPs who helped them manage their diabetes routinely and during the emergency admissions with DKA; frequently, these interactions were not viewed as positive.

Social support of a significant person was noted to reduce the risk of subsequent DKA episodes by Forbes *et al.* (2020). Only Adele referred to this, relying on parental support when she was struggling with managing diabetes; however, the other participants placed increased value on their interactions with HCPs. Yet if clinic appointments or DSME, were not perceived as positive, it could damage subsequent diabetes management, adding further to the burden of distress. The findings from Brewsters *et al*., (2020) systematic multi-national review examined reasons for missed appointments correlated both higher HbA1c levels and the importance of a good relationship with the health care professional. The importance of this was frequently discussed in the interviews in this case study.

The recurrent DKA population with higher levels of psycho-social burden are a population that is easy to get lost to follow up in the health care system, risking being discharged from diabetes clinics for non-attendance. Further increasing the risks of subsequent DKA admissions has been reported by Gupta *et al.*, (2019). Participants stressed the importance of interactions with diabetes professionals, which could have adverse effects, to improve their experience of receiving diabetes care. The level of adverse impact and distress was also measured by Berkovic *et al.*, (2022), who found that 23% failed to attend subsequent follow-up appointments, highlighting that it is essential to consider the multifactorial nature of the failure to attend follow-up post-DKA admissions and outpatient appointments. Adele, Chloe, Laura, Mary, and Phoebe all felt a negative response and limited acknowledgement of their psychological well-being or acknowledgement of how hard living with diabetes was.

8.10 Theme 7 - I feel really broken

Participants in this case study discussed changes to their bodies and mindset in this final theme. There are initial changes to the body of weight loss and thirst, for example, the visible differences of insufficient insulin circulating. Yet essentially, T1DM is an invisible disease, but its treatments are not, becoming more visible in recent years with the advent of continuous glucose sensors and insulin pumps (NICE, 2023). This technology is a positive addition to achieving glycaemic targets proposed by DCCT (1993) and NICE, 2023). However, the technology is not without limitations, especially how it is perceived, with the device's visibility being a limitation for some pump users reported over several decades (Barnard & Skinner, 2007; Hayes *et al.*, 2011; Reidy *et al.*, 2018). The insulin pump can be a visual reminder of the changed body and can be associated with altered body image. External visibility also signals this difference to others, making the condition visible; sometimes the participants would rather keep it hidden to maintain control over sharing their diagnosis. Hess (2018) questioned whether the insulin pump has to be seen as an extension of the body. Noting the complexity of the relationship with the external technology of insulin pumps.

Although the participants acknowledged the benefits of insulin pump therapy and continuous glucose monitoring, the reliance on external technology was difficult at times to reconcile and not a complete panacea to having T1DM, echoing the findings of Reidy *et al.'s* (2018) review. On occasion, there was increased stress, for example, when travelling or if the insulin pump abruptly failed, leading to DKA, further exposing the body's vulnerability (Grose *et al.,* 2018). Phoebe discussed the bittersweet relationship she had with the insulin pump and the anxiety it caused if taken away from her during a DKA admission and when travelling through security at an airport.

When DKA developed, this was another reminder of the broken body with the necessity of receiving treatment in the hospital from a variety of health professionals. Several of the participants spoke about the times they were resuscitated. In the recurrent DKA population, this is a frequent occurrence but not discussed in the literature in the context of DKA. On occasions, this necessitates admission to the Intensive Therapy Unit (ITU), but the longer-term vulnerabilities of the individual are not routinely addressed in post-

DKA care if this occurs. Both Mary and Phoebe shared distressing accounts of these times, and Mary, in particular, was faced with the knowledge that she may die from DKA. The broken body encapsulates how the participants perceived living with T1DM to be; their existence was precarious and reliant on insulin injections.

8.11 Implications for Clinical Practice

In the previous sections, a synthesis of the key findings generated in this research was presented in conjunction with their situation within the literature. The embodied, temporal, and corporeal experiences were also discussed and these are drawn together to form the phenomenological case of recurrent DKA. Distress, the burden of recurrent DKA and T1DM, and the interactions with HCPs were critical findings in this case study, with recurrent DKA correlating with previously reported findings in the literature.

At the outset of undertaking this phenomenological case study, it was difficult to identify what may have been important to participants who had recurrent DKA. All of the participants live with T1DM; therefore, the experience of doing so was evaluated in the literature review. Many unique and original findings were reported by participants in chapters five, six, and seven, which have not been discussed in the literature previously. Despite the known consequences of intentional insulin omission, the element of self-sabotage to retain control over the body was an unexpected finding as it was not linked to the desire to lose weight. In addition, there are graphic descriptions of how DKA developed and the disassociation between mind and body during the development of DKA and at the point of being resuscitated.

As outlined at the beginning of this discussion chapter key aims were developed to increase understanding regarding the subject of recurrent DKA. There are two areas of focus: understanding recurrent DKA to improve clinical outcomes and developing an understanding of the experience through the lens of participants and the impact that DKA has on the body and mind. The participants discussed the experiences that were important to them regarding experiencing DKA and living with T1DM, and it is with this perspective that the next section is presented.

8.12 Diabetes Educational Strategies and DKA

Diabetes education programs such as DAFNE and Bertie effectively educate the majority with T1DM with clinically significant reductions in HbA1c levels and DKA admissions reported consistently (DAFNE Study Group, 2002; Humayun *et al.*, 2018). Reflecting on what is contained in the literature and my clinical understanding, I observed an online DAFNE course as a doctoral candidate. The peer support gained cannot be underestimated; the importance of peer support has also been reported in a review by Heller *et al.,* (2020). There are some differences, however, for the participants in this case study as they rarely spoke of education, significant others, or peer support in managing their diabetes. Still, they frequently discussed the support from HCPs but frequently referred to the negativity of this support. Following a negative appointment, the resultant feelings stayed with the participants for a long time and, on occasion, to the detriment of subsequent attendance. Failure to attend appointments should, therefore, be viewed as a warning sign in the recurrent DKA population, with additional strategies developed to support re-attendance at diabetes clinics.

It is evident that for a minority group with recurrent DKA, repeated education at the point of admission is futile; additional strategies are required, including an in-depth psychological assessment (Garrett *et al.*, 2020). HCPs are governed by their professional training, which is Cartesian in its design, separating the mind and body into very different specialities, such as physical and mental health. When considering chronic diseases such as T1DM, as this research has illuminated, there should be greater emphasis on the person's lifeworld, requiring a different, more holistic approach to care and education. Despite the improvements in insulin delivery methods and glucose monitoring, morbidity and mortality rates have changed surprisingly little over the decades. In addition, socio-economic issues and health literacy should also be considered and assessed, which may preclude appointment attendance.

8.13 Implications for diabetes nursing

This phenomenological case study fits well with the underpinning elements of being a nurse researcher, which is the desire to understand the context of the patient in front of them. Yet despite the advantages of this, nursing is frequently moving away from the more abstract elements of 'nursing care' to a technological world, where the patients within are 'there to be fixed' a series of tasks in complex healthcare systems.

Nursing curricula focus on the biomedical model, risking losing the essence of nursing. What it is to be a nurse is difficult for many in the profession to articulate, but it is clear that nursing is complicated and cannot be explained by the myriad of tasks that a person in their care may require. Experienced nursing practice has an element of embodied knowing or intuition that can only be gained from reflecting on the experiences of nursing others (Benner, 2000). This is the experience that I draw from, remembering and reflecting upon those I cared for with DKA. This is very different from the participants' experience in this research; however, they valued the interest in their experience and the time offered to talk about their experiences with DKA as they had not previously been afforded that opportunity.

The totality of the body during an episode of DKA has been explored in depth in this thesis. The temporality of DKA exposes the individual’s vulnerability to others, such as the HCPs. Merleau-Ponty's (2014) philosophy enables understanding of the body's and mind's intrinsic unity (Benner, 2000). The very essence of having DKA and being in a hospital resulted in the necessity of handing over their bodies to the doctors and nurses. Temporality was hyper resonated, but despite this, the mind and body became separated; there was a powerless separation of being unable to change the course of events occurring in their bodies, but this was not because of a lack of knowledge about sickness management. The participants had this knowledge, sharing this commonality with the patients I had cared for with DKA in my clinical practice as a DSN.

Whilst nurses need to understand the pathophysiology of a disease such as T1DM, I would argue it is even more critical to understand the lifeworld of their patients, especially when faced with a chronic disease such as T1DM (Keller, 2020). As a DSN, recurrent DKA is both frustrating and intriguing. It is frustrating as you want the best outcomes for the individual with DKA and because it is evident that another episode of sickness management is unlikely to achieve anything tangible and will amplify the feelings of distress and blame so frequently reported in this study and the literature review.

Guidelines and treatment protocols such as the JBDS (2023) guidance for the management of DKA are beneficial for the majority of patients in the population, but for the small number who develop recurrent DKA, thinking needs to be different, and care individualised, so that is appropriate. At no point in this research was there intent on finding commonality amongst the participants aside from the shared diagnosis of recurrent DKA, but what was evident from the analysis was the degree of psychological distress that was ever present many years post-diagnosis of T1DM and on many occasions DKA. Often, interactions with the diabetes team exacerbated this. This may be partly due to the formulaic guidelines, which we expect all living with T1DM to fit within for care once DKA has resolved.

Nursing practice sees and cares for those most vulnerable in the resuscitation, intensive care units and hospital wards. Nurses provide intimate care to another's body to keep them alive. Whilst at these moments, the participants were no longer in charge of their bodies, or what happened to them as they were too sick, they retain vivid memories of these times, snatched conversations about them and are well aware that they may die. These young adult women are not expecting to face death so regularly or at such a young age. Beyond the immediate emergency treatment by nurses in the hospital, the role of the DSN should be considered, and objective evaluation should be given to the efficacy of repeat DKA prevention education in this population. DSNs could focus on listening to the back story behind the individual: What does having diabetes mean to them? '*'No one ever really asked how I got there,"* such a simple question, but this is not the focus of acute DKA management.

If DSNs can identify with the core values of nursing, there is the potential to provide meaningful care that helps those with re-current DKA deal with the complexities in people with diabetes's psycho-social worlds. T1DM is in an exciting era, with access to hybrid closed-loop systems to deliver insulin and maintain glucose levels to normal physiological levels (NICE, 2023). This means that diabetes nursing is becoming increasingly technical. For many patients, such systems remove the constant decision-making and burden regarding calculating insulin doses and administration, which is transformative. However, this does not cure diabetes, and there are perpetual reminders of the differences in their bodies; being attached to a sensor and insulin pump is an external visual reminder of T1DM. Todres, Keen and Kerr, (2010) interviewed insulin pump users who felt more equal in their interactions with HCPs, similarly echoing the experience of an anthropological account by Berk, (2018). Technology can make the role of a DSN rewarding, but they should also ensure that their other nursing skills are maintained and continuously developed, focusing on the person and not just the technology attached to them (Zyblock, 2010). This will be particularly key for future DSNs, who ultimately view closed-loop technology as the mainstream of T1DM management. As discussed, nursing is much more than completing a series of technical tasks, but this still has the potential to define nursing practice.

The participants in this study wanted the DSNs to support and care for them while acknowledging the complexity of managing diabetes. They sometimes felt they were the silent partners in their diabetes management, especially during inpatient admissions where they were no longer involved in their diabetes management. When things had not gone to plan, participants often felt '*'the blame and the shame*'' from HCPs, including the nurses, experiencing stigma regarding their diabetes management. It was evident that the participants in this research also internalised the anguish of having T1DM and, at times, made decisions about diabetes management that made them feel awful after a consultation that they felt had not gone well. They required someone who could listen and understand their perspectives of their life worlds, acknowledging the complexity of managing diabetes and other aspects of their life.

8.14 How can philosophy be used to deliver nursing care?

The findings from this case study offer a rich insight into the experiences of DKA and living with T1DM that are not fully captured elsewhere in the literature. It also highlights the importance of understanding the experience of DKA in the body and mind. Current healthcare settings frequently understand and evaluate 'patient experience' to measure how quickly and efficiently a service has been provided. Patient experience is much more than that, particularly for people with T1DM and recurrent DKA. Scant attention was paid to the feelings and experiences of these participants' bodies, and frequently, this attention is reduced to evaluating and interpreting the values of glucose levels to optimise glucose control. In the three findings chapters, I have presented the experiences of being in DKA in the case study of young adult females with T1DM. The findings from this case have shown that it is frequently as much about what is unsaid about participants' lives rather than the blood glucose and ketone values that the clinical team see during an episode of DKA. The omission of insulin occurred as it was an overwhelming task, but the act, when intentional, can give control back; even though this was understood and rationalised as a dangerous situation, it is insufficient to change course for these participants. Utilising phenomenology to help understand the role of the lived body in DKA enables nurses and the broader HCPs team to focus their gaze on the realities of participants' lives and what is important to them. Mary discussed the HCP's focus on glucose readings and the failure to inquire about what was happening outside of the hospital that could lead to DKA. The development of DKA is multifactorial and much more than the superficial questions regarding insulin administration or checking a glucose reading. Participants in this research explained how they became overwhelmed during DKA, with grave sensations in both the body and mind reported. Echoing other findings, participants in this study and Habenicht *et al*., (2021) reported a lack of authenticity and understanding about T1DM if others did not have the condition. It would appear that they were articulating their experiences of corporeality. Therefore, HCPs should draw upon this lived experience of the body in T1DM to inform the delivery of diabetes care. In addition, the findings reported in the case of recurrent DKA illustrated that insulin omission, when intentional, should be viewed as a marker of diabetes distress. This should trigger professionals to conduct an additional exploration of underlying factors and triggers for recurrent DKA, in addition to the usual post DKA care.

8.15 Limitations of Phenomenological Case Study Methods

In this chapter, the case study's findings were interpreted using the work of Merleau-Ponty (2014) and the underpinning literature from Chapter Two. Phenomenology allows for an in-depth analysis of the participants' lives with T1DM to develop an understanding of the participants' experiences of recurrent DKA. Adapting the original recruitment strategy due to COVID-19 ultimately resulted in a self-selecting participant group. The change to include recruitment from social media resulted in a participant group who were all active users of social media. There are disadvantages and benefits to this approach. The group comprised five young adult female Caucasians who received care in different parts of the United Kingdom. Whilst DKA predominates in young women, it does not capture experience across the breadth of the United Kingdom's DKA population and notably failed to recruit males or participants who were not Caucasian. Participants self-selected inclusion of their own volition; there was no encouragement from an HCP inviting them to participate. Conversely, self-selection and conducting interviews on Microsoft Teams enabled the power balance to shift to a more equal footing between the researcher and the participants. They knew they were discussing these experiences of DKA with a doctoral candidate who had also been a DSN and was not involved in their care nor had any judgment to make regarding their diabetes management. This opened up the conversation quickly for them to be able to discuss their experiences of DKA.

8.16 Researcher reflexive transformation

During the completion of this doctoral study, notes were recorded in a reflexive journal. Reflection is a critical element of hermeneutic phenomenology and qualitative research

(Koch & Harrington (1998); Etherington, (2004); Maxwell *et al*., (2020). Drawing upon journal and supervisory notes to help track the work's progression and development of thinking and understanding. At the start of this research, I was an experienced DSN and a new academic. My professional position felt precarious as I embraced the new direction of becoming a nurse academic, moving my practice back in some areas to novice as I developed the qualitative protocol for the Health Research Agency (HRA). These feelings became even more unsettling as I grappled with philosophical readings of Merleau-Ponty (2014). Referring back to the journal enabled me to see my development over time and how my feelings and understandings ebbed and flowed during the interviews, ultimately forming part of the analysis process.

Completing the interviews as a researcher meant that I could develop different skills during the interview, which were responsive to the participants at the moment. There were times, for example, when Chloe and Phoebe became very upset during the online interview, requiring me to draw back and develop my nursing skills of effective, empathetic communication to ensure that they were no longer tearful by the end of the interview. There was a sense of frustration for me as I wanted to comfort the participants, for example, through the gesture of touch or offering tissues and a drink, which were simply impossible in an online interview. Afterwards, reviewing the recording put me back in the moment I had had with the participants, the tone of voice, facial expressions, and, of course, the tears and the emotions expressed by participants. This immersion - going back and forth with the data is the aim of hermeneutic phenomenology (HP) but is not always acknowledged (Dibley *et al.*, 2020).

Embarking on this research journey has changed me as a person, a nurse, and an emerging researcher. My perspectives, views, and understanding of T1DM have also matured. The information shared in the interviews and the raw realities of life with T1DM were sometimes complex to process. The content of the interviews gave me a very privileged view, which required careful interpretation to do justice to the participants' stories. Many of my supervision sessions discussed this change in me as a PhD candidate, including how I could incorporate the philosophy of Merleau-Ponty (2014), particularly temporality and embodiment. The time and changes that occurred for participants were also intrinsically part of my journey. Time has shaped my knowledge and experiences, widening my horizons (Dibley *et al.*, 2020; Maxwell *et al.*, 2020; Suddick *et al.*, 2020). Consequently, for hermeneutic phenomenological researchers, there is an ethical responsibility to use reflexive practices appropriately to ensure that the interpretation of the data, in this case, interview transcripts, is consistent with the philosophical works (Merleau-Ponty, 2014). Throughout this research, I have drawn on the ‘Phenomenology of Perception’ to help me understand the participants with a new researcher's perspective. Using this developed knowledge has made me want to provide clinical nursing care again, and whilst I remain in academia, I use this to develop my teaching for undergraduate nurses.

The reflexive approach taken to conduct this phenomenological case study has been discussed in this section. This illustration of reflexivity provides a transparent account of the method I have used. Importantly, how this is congruent with the underpinning philosophy of hermeneutic phenomenology, the introspection that occurs during supervision or when taking five minutes to think has enabled me to thoughtfully consider how I have developed as a researcher as I develop the research and this thesis.

Completing the case study investigating the lived experience of developing recurrent DKA has enabled new insights to be gained that have not been captured before. Recurrent DKA comes with a risk of premature mortality and morbidity, leading to an element of certainty to its reoccurrence. This case study illustrated that this is an overly simplistic view of life with recurrent DKA and T1DM. The participants have discussed the profound effect that developing DKA had on them and how it takes over their bodies and causes them to feel that they are about to die. The relationship between the mind and the body in T1DM and recurrent DKA is also adversely impacted. Having DKA was experienced as a whole, taking over both the mind and body and as such, the physical and psychological must be considered in tandem when providing care.

Participants could discuss their desire not to develop DKA again but, at times, reached the state where they could not enact any *“conscious thought*.’’ The development of DKA was not for these participants due to a lack of understanding about preventing high glucose levels and ketones; I would argue that the manifestation of DKA provides an external view of the participants' distress and the desire to be free from their life with T1DM. Therefore, differing care strategies should be considered for those readmitted with DKA, including routine psychological support and post-resolution of the DKA. Offering the usual DKA preventative education only strengthened the feelings of distress and blame felt by the participants in this study.

8.17 Chapter Summary

In the discussion chapter, I have synthesised the essential findings and considered how they relate to the current literature regarding recurrent Diabetic Ketoacidosis (DKA) and living with T1DM. In addition, elements of nursing practice have been examined in light of the findings to develop additional understanding of the participants' perspectives on DKA.

The development of DKA has been shown by the experiences of the five participants to be wholly unpleasant, taking over the body and mind, caused not by a lack of knowledge but the distress of perpetually having to inject insulin and live with T1DM. At times, this experience was made worse because of the interactions of health care professionals (HCPs), causing participants to feel blamed, further amplifying the feelings of distress. Although the lived experience of DKA has not been previously reported, there are similarities with the experiences of living with T1DM with a high degree of distress that did not subsequently fade after their diagnosis. During an episode of DKA, the feelings reported in the body and mind were terrible and quickly overwhelming, highlighting the disassociated symptoms experienced when faced with resuscitation. One notable finding from this case study was the participant's belief that they had more time in the developing stages of DKA. These views were formed following experiences from attendance in ED departments, both from the delay in receiving treatment and the blame that they perceived from having developed DKA. Such experiences then subsequently impacted decision making about when they should access emergency care.

Several recommendations for developing nursing, particularly specialist nursing practice, are discussed in the conclusion chapter. It is essential to consider the interactions with the individual living with T1DM to reduce the risks of causing additional distress. Developing an understanding of philosophy for nursing practice of the embodied, temporal, and corporeal experience of DKA and T1DM is crucial as diabetes nursing moves into a technical era and moves its gaze away from the person to the technical readings from glucose sensors and insulin pumps. Utilising case study methodology has enabled the thematic and phenomenological findings to inform the case of recurrent DKA in young women with T1DM.

The final chapter of this thesis is the conclusion presented in Chapter nine. In this chapter, I will summarise the thesis and make additional recommendations for future research.

Chapter 9 Conclusion to the thesis

9.1 Introduction

In this concluding chapter, I will present a synopsis of the thesis and clarify the original contribution to knowledge regarding the lived experience of developing recurrent DKA presented as a phenomenological case study. In addition, the findings have implications for diabetes nursing care and recommendations for future research on recurrent DKA. Historically, people with T1DM experiencing recurrent DKA have poorer outcomes, increased mortality, and may miss diabetes clinic appointments.

This research investigated the lived experience of developing recurrent diabetic ketoacidosis, utilising a phenomenological case study approach in both the design of semi-structured interviews and subsequent analysis and interpretation of the findings. Nine interviews were completed with the cohort of five young women, who generously shared their experiences of having lived through episodes of recurrent DKA. The strengths and limitations of the methodological approach will be discussed.

Conducting this phenomenological case study exploring the lived experience of developing DKA offered a unique insight into the participants' world. The literature review presented in Chapter Two failed to locate research previously conducted in this area. Many of these studies provided significant evidence about the complexities of living with T1DM, which bore striking similarities to the experiences of living with T1DM for Adele, Chloe, Laura, Mary, and Phoebe. In addition, this research investigated the experience of living through an episode of DKA to create the case of recurrent DKA. Such occurrences of DKA were all-consuming, and this research captured the terrible feelings present in both the body and the mind. Participants discussed the struggle to continue to breathe and the feeling of nausea, all whilst being aware that they may die during DKA. The feelings of shame and blame from health care professionals were also at the forefront of their minds, attendance at the hospital caused feelings of shame during their interactions with Health Care Professionals (HCPs).

Mortality rates for recurrent DKA remain stubbornly entrenched across the developed world's healthcare settings, with a risk of death between 1-5 % reported in the United Kingdom up to five years after DKA admission (Misra & Oliver, 2015; Gibb, Teoh, Graham and Lockhart, 2017). The death rate shows no signs of improvement despite the advancement of diabetes technology (O’Reilly *et al.*, 2021). DKA deaths predominantly occur in young adults, and in particular young women, correlating with the age and gender of participants in this case study (Gibb *et al.*, 2016; O’Reilly *et al.*, 2020; O’reilly *et al.*, 2021). Despite access to free health care, insulin and DSME in the UK, DKA continues to occur (JBDS (2022); NICE, 2022). Echoing previous experience as a DSN, some individuals frequently attended the hospital having developed DKA despite understanding preventative DKA strategies very well. With its rich dataset, this phenomenological case study offered a first glimpse into capturing the realities of DKA through the participants' lens. It also provides additional context to the complexities of living with T1DM, which cannot always be fully explored and understood during diabetes clinical appointments.

9.2 Original Contribution to knowledge the Case of recurrent DKA

The original contributions identified from conducting this research are:

- T1DM and the development of recurrent DKA is a temporal condition, always on the periphery of the participants’ lives. The potential for it to develop is present every day, just a few hours away from an insufficient insulin dose being administered.
- Insulin omission offered a brief opportunity to be free from having and living with T1DM. Whilst the young women in this case understood the futility of such an approach, it was insufficient to overcome the lure of life without T1DM. Intentional omission of insulin enabled participants to have some control.
- There is a dissociation between the mind and the body during DKA.
- The participants shared the commonality of being young women and not having accepted their diagnosis of T1DM despite many years passing since they were diagnosed.
- Interaction with the diabetes and hospital teams can adversely impact subsequent self-management of diabetes. Ranging from missing appointments to delaying attending the Emergency Department (ED) for care because they want to avoid the reactions of the HCPs.
- DKA did not occur due to a lack of knowledge about how to manage sickness or hyperglycaemia. Conversely, delivering additional education on sickness management in the recurrent DKA population is unlikely to prevent another episode from re-occurring.

- Participants' perceptions of the urgency of DKA formed from previous admissions led them to view DKA as less urgent than HCPs wanted them to believe, resulting in risky delays in accessing treatment.

This research builds upon other studies that have explored the experiences of living with T1DM. It provides a different perspective regarding the experience of developing DKA in young women that is been absent from the literature. Participants spoke at length about their lives; their knowledge of developing DKA was captured within these accounts. Previous studies have not grasped what it is to live through such an episode of DKA. The development of DKA for these young women started long before the blood glucose and ketone levels began to rise. DKA is always just a few hours away from a missed or reduced insulin dose, so every day, there is the potential for it to develop again. Just as the participants face the daily onslaught of decisions regarding their diabetes management, when they take a moment to deliberately forget the need to inject insulin, just for a moment, they can reach back to their life before diabetes. However, even this escape is transient as DKA quickly takes hold. There is, however, a fleeting moment when they are free from the burden of T1DM, but this is always a short-lived experience.

Developing DKA was reported to be dreadful for Adele, Chloe, Laura, Mary, and Phoebe. During such episodes, they drew on various solutions to try to stop DKA from fully developing. Eventually, these were futile, and they were resuscitated in the hospital. During these occasions, there was a disassociation between their mind and their body, so even when they were faced with death, they seemed to be able to dwell for a time in a different place, allowing the HCPs to treat them.

The young women in this case study shared their experiences of developing DKA, reporting that they felt like death; it was apparent that there was a clear disassociation between their body and mind during DKA. They could discuss what they should do (insulin administration) but had reached the stage where it was impossible, even though they were acutely aware of how ill they would subsequently feel. They were knowledgeable too, that they may not survive, yet even this was insufficient to alter the trajectory of DKA. Chloe used the words ''*choosing to feel horrible'' in* one part of her interview. There seems to be some correlation with Staite *et al*.'s (2018) study, which reported that insulin omission gave participants some control. Having T1DM impacted all areas of the participant's lives; it is like a squatter in their bodies, and being able to dictate insulin administration or omission enabled an element of control, a tantalising moment of freedom where they no longer had to think about having T1DM however adverse the outcome for them as an individual.

When DKA developed, they became so overwhelmed that although they were aware of the clinical conversations around them, they could do nothing for themselves at this stage. This separation of the mind and body, '*'no conscious thought there"* (Mary 1), was perhaps the body's way of surviving such an episode. In their previous experiences of being resuscitated with DKA, this was the case. It is an essential element to consider as current guidance stipulates education about sickness management before being discharged home, and correlating with my own clinical experience, it is not a lack of knowledge that is the root cause of DKA. The reasons are far more complex, and repeatedly going over sickness management could reinforce feelings of guilt and blame in the person with diabetes. This should not be the approach to post DKA care and education. It was evident from the participants in this study that they hated being in DKA, the feelings that it caused in their body and mind and how they were received at the point of admission when in DKA by HCPs. They already felt dreadful from the effects of DKA, and the response of the HCPs, where they felt blamed for omitting insulin, only made them feel worse.

The feelings of DKA in the body did not end at the point of discharge from the hospital either, yet frequently, they were discharged home and expected to pick up where they had left off. Feelings of tiredness and nausea, whilst documented in the development of DKA, persisted for days after the DKA had resolved for the participants in this case study. The mind also continued with the feelings of distress after DKA; the reaction of others is burdensome after they have been admitted to the hospital.

The dislike of hospitals and HCPs was frequently discussed during the interviews. Firstly, it is linked to the point of diagnosis whereby they suddenly become different to others. There is a loss for their old worlds pre-T1DM. The physical buildings remind them that attending appointments takes time from their lives and remind them that they are different. Secondly, the interactions within the hospital by both regular HCPs and the specialist diabetes teams were frequently reported as distressing. During such attendances, their bodies are continuously assessed, and they feel judged, even just for a routine diabetes appointment. There can be the expectation that it will not be straightforward. The words they hear from HCPs also seem to impact them significantly. Mary vividly remembered the black marker pen crossing out her favourite foods and being told that she could no longer eat them. Chloe was so distressed by her appointment that she could not return to her next appointment. There is also the judgment for missing appointments, which perpetuates these feelings of distress.

Living with T1DM is a temporal experience. Diabetes disrupts participants' perceived place in the world; it is unwanted, and time must be given to help people craft this new identity. Yet, at the point of diagnosis, the focus is on the necessity of insulin administration and other practical aspects of managing T1DM. The fact that the participants in this research had not accepted their diagnosis of T1DM suggests that additional attention should be paid to the psychological elements of T1DM.

For these individuals, having diabetes had not been accepted or effortlessly assimilated; there was a significant urge to return to life before diabetes. So even when the participants knew that missing insulin doses would make them feel awful, the lure of going back to the time pre-diabetes was overwhelming; they could control their bodies in the short term and forget about having diabetes.

Analysing and presenting the findings of a phenomenological case of young women who had experienced recurrent DKA enabled a different perspective to be drawn from the findings as a collective rather than an individual experience. This is an important consideration if the findings are to be applied to informing clinical care in the recurrent DKA population.

9.3 Embodiment of diabetes

The findings from this research have illustrated that living with diabetes is embodied, but for participants, it is unwanted and unaccepted. There can be a few chronic conditions that require such daily adaptations and adjustments to feel well and function physiologically, such as T1DM. The very nature of having T1DM was an intrusive element in the participant's lives. When they make conscious decisions to take a break, such as in times of insulin omission, the sensations of high glucose levels and ketones quickly make their presence known. Now, the body moves to battle these terrible feelings as DKA develops, serving as another stark reminder that their bodies have changed because they have T1DM.

There appears to be a conscious desire to be rid of T1DM occasionally; the mind and body are inextricably linked in these situations. While the mind can rationalise, that insulin should be injected, this conscious thought cannot always be directed towards completing the insulin injection. The participants have said they are overwhelmed by DKA, which may partly explain the disassociation they reported when they were reluctantly admitted to the hospital in DKA.

For the participants in this phenomenological case study, DKA rarely developed because of a lack of understanding about sickness management aside from Laura's initial DKA episodes because there were assumptions that her parents would educate her. These findings share similarities with my clinical experience of nursing people with DKA; patients could tell me about their plans for correcting hyperglycaemia, but something stopped them from enacting these. For the participants in this research, the distress of living with T1DM and wanting a break from the burden of self-care were critical factors in developing DKA.

9.4 Temporality of diabetes

The participants' experiences in this research have illuminated the temporal nature of living with recurrent DKA and T1DM. Being diagnosed with T1DM irrevocably alters the sense of identity, and there is a clear division in views pre- and post-diagnosis. Whilst this research was not explicitly investigating the experiences of living with T1DM, the impact was profound, permeating all areas of their social world, meaning they were yet to conclude any positivity from their changed circumstances, as Pinar (2022) had also reported.

The point of diagnosis changed the future dreams and aspirations of the participants, and the impact of their diagnosis was perpetuated in this group with recurrent DKA. Managing such a complex condition as T1DM encroached on every aspect of daily life and required a great deal of thought which was also time consuming, taking up time that could have been diverted to other activities other than health. This resulted in a lack of spontaneity, as was the requirement to factor in having T1DM into all decisions; they had to consider the impact an action or event could have on their diabetes, even if they felt well enough to do it. This could be disruptive and sometimes limited to what they wanted to do, from social activities, living independently away from the family home or attending university. There is a lack of control from living with T1DM, which was extenuated during episodes of DKA whereby it was all consuming on the body. During these occasions, they experience DKA as something that is controlling them, losing the ability to complete everyday activities. The disruption to the participants' worlds lasted for some time after the DKA was medically resolved, but they were conscious that its presence could quickly re-emerge. Illustrating the different ways the participants felt they lost control over what might happen in the future.

In this phenomenological case study, there were altered perceptions about participants' identities, which were hard to reconcile. This was, however, less about others' views, so they did not report the stigma of living with T1DM aside from their contacts with HCPs, where they felt shame and blame for having developed DKA, leading them to try and self-manage for as long as possible at home. The impact and burden reported were very much internalised, hidden from view even from significant others; this may be why they found having T1DM so burdensome. Drawing on Merleau-Ponty's work in the Phenomenology of Perception (2014, p. 215), he wrote about the individual perceiving what was happening to them. If this is applied to the life world of these participants and others reported in the literature review in Chapter Two, it becomes easier to understand the disruption in their life, which was also discussed by Balfe *et al.*, (2013); Fredette *et al.*, (2016); Abdoli, Hardy and Hall, (2017); Mullan *et al.*, (2020); Holmström Rising and Söderberg, (2022) and Pinar and Turan, (2022).

9.5 The corporeality of diabetes

T1DM causes abrupt physiological disruption to the body not only at the point of diagnosis but these changes continued thereafter. Utilising the phenomenology of Merleau-Ponty (2014) to help understand and interpret the meaning of the participants' interviews. I have explored the effects of recurrent DKA on the body and the mind, linking them inextricably. Participants did not view them as separate elements and were acutely aware of the toll that having DKA and T1DM has on them.

Conversely, current diabetes care is focused on either treating the physical effects of diabetes on the body, supporting people to achieve tight glycaemic control, or time in range to prevent the long-term complications of diabetes, and yet rarely is there any emphasis placed on the complexity and burden of living with the condition (NICE, 2022). Long-term complications of diabetes were not the participants' current concerns, despite the links between DKA and elevated HbA1c levels increasing the risks of these complications occurring. The impact on daily life for the participants and how they may feel on any given day was given precedence in their interviews. They were caught up in the here and now, not what may be a distant event in the future; living through today was difficult enough. On the one occasion when they were discussed, the focus was on how they would impact the ability to live independently and the uncertainty this caused rather than the actual impact on the body and any long-term poor outcomes. This differs from the focus of diabetes appointments, which focus on glucose control and prevention of complications.

Participants reported that during an episode of DKA, they experienced varying feelings and could sense them both in their bodies and minds, enabling them to interpret what they were experiencing. Both body and mind appeared to be working together in unison. Once the glucose readings began to rise, these sensations came in waves, building up to the crescendo of DKA. They made the participants feel tired, thirsty, and very sick, the osmotic symptoms of hyperglycaemia. Once the beginning of DKA started its grip on their body, it was hard to stop it from getting worse; even though they knew extra insulin was required, this was either impossible to administer or too late to make a significant difference to the outcome of developing DKA. The actions of insulin omission appear to be a perverse decision. Still, on occasion, episodes of DKA enabled participants to walk away just briefly from having T1DM, where they took a deliberate break from insulin administration by intentionally omitting doses.

It is challenging to split the temporality and corporeality of T1DM and recurrent DKA as this research has shown they are inextricably linked or, as Merleau-Ponty (2014) says, ‘‘intertwined.’’ Just as the physical and psychological aspects of having diabetes are as one for this group of participants, their diabetes care is structured predominantly to meet either their physical or psychological needs; Adele's last admission was an excellent example of this where she had to wait until the DKA resolved before being allowed to see the mental health team. This case study was designed with phenomenology at the heart of the methodology. Conducting the case study phenomenologically enabled a deep understanding to be developed among the five young women who had all experienced recurrent DKA to capture their perspectives of lived experience. The phenomenology of Merleau-Ponty (2014) was used to support the analysis and interpretation of the experience of recurrent DKA. This study found that DKA holds its grip on both the minds and bodies of the participants during the actual episode of DKA. Still, after that, it remained waiting in the wings to make another unwanted appearance for the participants.

Phenomenology has enabled different perspectives of this complicated condition to help understand the experiences and worlds these participants inhabit. Developing recurrent DKA is far more complex in this group than the intentional act of insulin omission.

9.6 Limitations of the Phenomenological Case Study

This section will present and discuss the limitations of this work using a reflexive approach, which I have drawn upon throughout this doctoral study. The context of this will be to consider the limitations of the research during a global pandemic, as well as the methodology, philosophy, and analysis of this study.

The research design for this thesis was initially designed before the world entered an unprecedented global pandemic for the Covid-19 virus (European Centre for Disease Control, 2020; World Health Organisation, 2021). Necessitating a change in the recruitment strategy and an amendment to the university's ethics application to be able to conduct interviews online instead of the original plans for in person interviews recruited from two National Health Service Trusts (NHS) (Appendix 2).

Interviews were, therefore, conducted online, and whilst this worked well given the situation, phenomenological interviews are more frequently performed face to face. As the participants were recruited via an X (Twitter) tweet, I was meeting them solely online; apart from being a resident in the UK, I was unaware of where they lived or who provided their diabetes care, aside from receiving it within the NHS. Since I was not connected to their clinical teams, this may have given participants increased confidence to share their experiences candidly.

Five young women were recruited to the case study via social media, but only four opted to be interviewed a second time, completing nine interviews in total. It is unknown why Mary did not return. The increased length of time between interviews may have played a part, but there is always the uncertainty that she may have died from another episode of DKA.

At the start of the pandemic, society had rapidly moved to conduct work remotely wherever possible, such as via online platforms such as Microsoft Teams, resulting in a particular element of familiarity with this as an interview medium for the participants. There are disadvantages, though; when participants became emotional, I could not draw on nursing skills such as therapeutic touch to provide comfort or reassurance. As the interviews were online, I had to be responsive to the more subtle signs of emotion, ensuring the participants did not feel any adverse effects or harm from participating in the research.

From the outset of the pandemic, the risks to people living with T1DM from Covid-19 placed them at a higher risk of mortality if they had diabetes (Fedeli *et al.*, 2022; Lv *et al.*, 2022). During the early stages of the pandemic, unnecessary contact with others was advised against. The original time frame of repeat interviews at three to six months slipped. This was frustrating for the speed of progression and may have meant that Mary did not return because a more extended time had subsequently passed or something else had happened to her.

In phenomenological case study research, the sample size has no prescribed number of participants, and it was not the intention to reach data saturation for the themes generated or to determine generalisability from the case study. Nevertheless, recruitment was set to recruit ten participants who had experienced DKA on at least two occasions (recurrent) for the research protocol and ethics application for the HRA and the University. Subsequently, five participants were recruited, all young women under the age of thirty that form this case study. Recurrent DKA is more prevalent in young women, but it is not exclusive to them; therefore, without including men’s experiences, it is impossible to know if male perspectives echo what this cohort reported and if male bodies experience DKA in the same ways as young women. This will be important to investigate and capture for other researchers to establish in the future to aid a deeper understanding of the recurrent DKA population.

9.7 Strengths

This section will present the strengths of the phenomenological case study. All five participants completed the first interview, and four returned fifteen months later for the second interview. Mary did not respond to subsequent invites or the email thanking her for participating. The unknown fate of Mary was worrying, with the possibility that she could have died remaining at the forefront of my mind. Whilst this research did not recruit the original sample size of ten participants, the interviews of the five participants were both long and in-depth, containing very rich data, remaining congruent to a phenomenological interview (Moules and Taylor, 2021). Having a smaller group enabled a richer phenomenological interpretation to be developed for the case study, which may not have been possible with the initially anticipated sample size, given the thesis word count. In addition, DKA has a higher prevalence in young women, who are representative of the participants in this case (Weinstock *et al*., 2013).

Initially planned three to six months apart, the second interviews were not completed until fifteen months later. This unforeseen delay enabled the participant's temporal journey with T1DM and DKA to be further developed, allowing the additional experiences to be captured and analysed. Interestingly, during this initial period of lockdowns during Covid-19, which were reported as socially isolating, the participants avoided developing DKA. The temporal nature of recurrent DKA and T1DM was further developed in the case during this intervening time.

Completing a phenomenological case study to define the phenomenon of recurrent DKA has enabled the interpretation of the young women's individual experiences to fully develop the case of recurrent DKA. Moreover, utilising case study methodology has the advantage of enabling the collective phenomenon to be identified over a period of time, congruent with the underpinning phenomenology and case study methodology. The rich phenomenological findings were interpreted thematically and hermeneutically to inform the case development. Enabling the phenomena to be used to inform the generation of theory to inform new research to ultimately inform diabetes care.

9.8 Research impact

This research was borne out of clinical curiosity and frustration that adults with recurrent DKA sometimes die. Clinically avoidable and tragic deaths of young adults are also a profound loss to their significant others, friends and the diabetes teams involved in their care. Premature death in this population also has a broader societal impact, with the immediacy of the cost of hospital admission and the loss of contribution to society for the loss of the individual due to their premature death. Whilst policy attests to these costs, the HCPs also feel the burden of the loss of the individual. Even when only having briefly met them, the death of a young person is very upsetting, and as a DSN, I vividly remember many years later the two patients whom I knew who died in DKA.

Narratives from participants illuminated the psychological and cognitive processes and internal mechanisms that resulted in DKA. This research provides first person accounts of what it is like to live through an episode of DKA and its impact on the mind and the body. Other researchers have explored the psychological elements of DKA to provide an understanding of what individuals are enduring, exploring the psychology behind DKA, such as Garrett *et al*. (2021), whose work can inform new solutions to delivering diabetes care. Garrett *et al*. (2021) developed a psychological intervention for those who develop DKA. However, where his work offers potential developments in post-DKA care, it does not focus on the experience of DKA on the individual as this research has done.

The participants in this case study frequently experienced DKA, which was a very unpleasant experience. Inclusion criteria deliberately excluded those with only one episode of DKA, which may have occurred at the point of diagnosis. What was evident between Adele, Chloe, Laura, Mary and Phoebe was a disconnect between knowing what to do and being able to complete the actions of diabetes self-management that would prevent DKA from occurring. This study did not intend to investigate living with T1DM, which is known to be exceedingly burdensome, and this was evident across the case; the unrelenting requirement to inject insulin according to dietary intake and blood glucose levels that must be completed to feel well. However, the presence of DKA remained with the participants; it was embedded in their lives.

There was also frustration expressed by the lack of understanding from others, especially by the HCPs, including the diabetes teams. Scholes (2013) reported a lack of understanding, echoing the experiences of these participants who felt blame and judgement from the HCPs. This was anticipated following experience from previous admissions, whereby they felt judged that they had caused DKA by failing to inject insulin; the effort of doing so was just too much, bringing them into direct conflict with the HCPs at the point of admission. This creates a dichotomy as HCPs draw on their professional education and understanding of the causation of DKA. However, such education fails to address fully the realities of their life for those with recurrent DKA.

The lived experience of HCPs was seen as a desirable characteristic to the participants; although they appreciated that not all of the clinical team would have diabetes, it was admired and respected when they did. Taking the time to ‘know’ them was also valued, emphasising the importance of good communication skills by the DSN team; this appears to be seeing them for who they are, the individual who has diabetes, as opposed to being a body with T1DM or the ‘Type 1 Diabetic.’ The value of lived experience and empathy to participants in this study highlights that changes to professional education are warranted. Incorporating lived experience into both textbooks and in class teaching with service users to develop an understanding that starts at the point of diagnosis through to the complications such as DKA would enable understanding of differing perspectives beyond the traditional bio-medical model.

The participants in this case study did not relish going into the hospital with an episode of DKA and frequently even for routine clinic appointments. During such events as DKA, they encountered feelings of blame from the HCP's comments. To avoid these, they chose to adopt delaying access to emergency care, often with the misguided belief that they had plenty of time to do so, as during earlier admissions, they perceived that the HCPs did not rush to treat them, often because they felt blamed for developing DKA. These opinions were formed from earlier experiences of attending a hospital in DKA. It is also worth noting that during the Covid 19 pandemic, participants opted to stay away from the hospital, self-managing at home with additional insulin because of the risks of catching Covid 19 once admitted.

Review by a member of the diabetes team should also explore how the person with T1DM is feeling about the complexities of managing the condition and what they perceived is happening to them. Future development of diabetes care post DKA must follow a different strategy, including routine referral for psychological support. Incorporating such a professional into routine in-patient care opens up the possibility of routine appointments with a mental health nurse or psychologist embedded into diabetes specialist teams.

The five participants in this case study all chose to discuss the time around their diagnosis. What surprised me was how these experiences remained so vivid many years later. Not only was this time still very upsetting, but they were still mourning the loss of their life without diabetes when they could have just been Adele, Chloe, Laura, Mary or Phobe. The legacy of being diagnosed with T1DM persisted into adulthood. The participants in this study were predominantly diagnosed before paediatric diabetes teams had a psychologist in the team, as are the majority of the adult T1DM population. Attention should, therefore, be paid to the legacy effects of being diagnosed with T1DM; in this sample, being diagnosed with T1DM remained traumatic many years after diagnosis.

They now carried the burden of having T1DM. They had to continually adapt life to managing T1DM, from having to spend additional time isolating during the covid 19 pandemic and earlier vaccination than their age-related peers to the time spent managing diabetes. Even having a baby was probably adversely impacted by her T1DM diagnosis for Laura, being delivered at thirty-two weeks because of declining insulin requirements, increasing the frequency of hypoglycaemia.

9.9 Significance to diabetes nursing and people with T1DM

In this section, I will present recommendations for nursing, specifically diabetes specialist nursing. Whilst writing this thesis, I have drawn heavily on the phenomenology of Merleau-Ponty (2014) in the Phenomenology of Perception to aid understanding and interpretation of the interviews. Enabling a different view of DKA and living with T1DM to be developed. Until embarking upon this doctoral study, I had very little understanding of the discipline of philosophy and how it may help me interpret my nursing practice. It had not been introduced in mainstream nursing education. Consequently, this research has shown how using phenomenology as the underpinning philosophy can be applied to develop an understanding of what those living with T1DM experience daily and during episodes of DKA.

Hence, there are also recommendations for diabetes nursing to consider as it moves towards an increasingly technical speciality, supporting individuals in managing both insulin pumps and continuous glucose sensors. It will be necessary for diabetes nurses to continue to maintain nursing expertise that focuses on more than just the technology but how diabetes affects the body as a whole and the intertwining of the body and the mind. The findings from this work illustrate the immense daily challenges those living with recurrent DKA and T1DM face. When clinic appointments are attended, and the clinician has to focus on the downloaded pump and glucose sensor data, it might appear to the person with T1DM that the focus is just on the expensive technology attached to them rather than them as a person. Living with T1DM invariably defined the participants in this study, and there is a danger without careful attention and planning of consultations, they could be ‘seen’ even less than previously.

Being visible for who they were and not just a person with T1DM was essential to these young women; they did not want to be defined by having T1DM as they had yet to come to terms with their diagnosis of T1DM. DSNs are privileged in the diabetes team; the same DSN will often care for the same person for many years, supporting them through many life changes. A DSN must continue to draw upon their nursing expertise to identify where an individual does not appear to be responding as expected to the delivery of diabetes care and look for alternative solutions in tandem with their patients. Participants in this research reported that no one had ever asked what else was happening when they were admitted with DKA or subsequent follow-up appointments. Applying phenomenology enables an increasingly holistic approach to delivering diabetes care, providing the opportunity to explore the impact of DKA on the body and mind.

9.10 Recommendations for care

This phenomenological case study has presented a rich insight into the experiences of recurrent DKA and life for the five participants. It is the first time that such experiences have been captured and interpreted using a phenomenological approach drawing on the philosophy of Merlau-Ponty (2014). HCPs should ask all their patients with DKA what they believe may be happening to them in an open, non-judgmental way. This may offer the opportunity to tailor care that is most appropriate for the individual before them rather than making assumptions based on their previous experience and professional education regarding diabetes and DKA management.

Future work should capture the experience of men with recurrent DKA to establish their perspective and participants who are not Caucasian. Without such information being available, not only will this be a missed opportunity to develop a new understanding of DKA, but it will also be essential to inform any care strategies that meet the recurrent DKA population's needs.

Language and avoiding the '*"blame and the shame"* reported by this cohort was a disappointing finding. As previously discussed in Chapter 9, there may be many reasons why participants reported this to be their perception of diabetes care. Already, there is national guidance with the publication of documents such as Language Matters (NHS England, 2018). Yet, it was apparent that this was still problematic for the participants as recently as 2022. Therefore, focus should remain on the delivery of undergraduate and post-graduate health education to ensure that the stigma experienced by those living with T1DM is eliminated. Such behaviours and language, even when unintentional, should be challenged either by other HCPs or the person with T1DM. The culture of clinical environments can also mean that HCPs change their approach from individualised patient centred care in line with the values of others around them in the clinical team. Diabetes and emergency teams should be evaluated from a service user's perspective regularly as part of the in-patient and national diabetes audit. In addition to feedback that is condition specific, the development of the friends and family test would be one method to do this.

For those living with T1DM, in addition to the clinical skills they are educated to master, attention should be paid to instilling confidence to challenge and become an equal partner in the clinical conversations regarding their diabetes management. Diabetes structured education can help with this process. Still, it should not be relied upon as access is at least six months post diagnosis and frequently longer due to availability. Building in additional time to appointments to establish the impact of diagnosis to acknowledge that diagnosis is life changing as for the young women in this case study this is a point in time that they got stuck at.

Patient public involvement in the research and design of NHS services is firmly advocated but remains poorly executed by both clinicians and researchers alike (NIHR, 2023; NHS, 2019). Part of the recommendations involves recruiting new diabetes clinicians with a service user on the interview panel. This will help assess staff communication skills and ensure that the staff's values match the patient's and organisation's requirements. This already occurs for many undergraduate nursing courses, but professional cultural values must continue to be assessed post-registration. This, alongside national issues such as ''Language Matters'' (NHS, 2018), will ensure that there are continued challenges to the inadvertent stigma experienced by people living with T1DM.

A key recommendation of this research is that there should be increased screening and treatment for the psychological distress of having T1DM, especially in those who repeatedly present with DKA. This starts at the point of diagnosis. The pain of living with T1DM was presented in Chapters Two and Three of this thesis (Polonsky *et al*., 2005; Joensen, Almdal and Willaing, 2016; Jones *et al.*, 2016; Dennick, Sturt and Speight, 2017; Hessler *et al.*, 2017). The participants in this research remained distressed following their diagnosis of T1DM, resulting in frequent admissions with DKA. During such admissions, guidelines stipulate repeated education in managing illness and avoiding DKA; yet unless the psychological distress is addressed, it would appear in this group to be a futile endeavour, echoing what drew me to investigate this topic. Inadvertently, it further strengthens the feelings of blame and shame experienced regarding another admission with DKA; lack of knowledge was not the causation of DKA, but the challenges of injecting and desire to forget they have T1DM was.

Guidelines such as the NICE (2022) Management of T1DM are there to guide but may not always fit the needs of all those living with T1DM. The findings from this research lead me to suggest clinicians should now consider alternative strategies in the recurrent DKA group, which may reduce recurrent admissions to reduce the mortality rate for DKA. Instead of more education, in collaboration with the person with T1DM, time should be taken to explore what else is happening that may lead to DKA developing again. This should occur in conjunction with a routine referral to organise psychological support. Specialist diabetes teams should consider employing a mental health registered nurse to be embedded into specialist diabetes teams. This would be a first step to acknowledging the challenges faced when living with T1DM; as advanced practice roles rapidly expand, this person could also provide other aspects of diabetes nursing care, such as prescribing.

9.11 Recommendations for future research

Following the completion of this research, which captured the experience of developing recurrent DKA, a number of recommendations for future studies investigating this underrepresented group are outlined below.

- The experiences of men who develop DKA should be sought to ascertain if they, too, experience DKA in the same way as the young women in this case study.
- The sample was under the age of thirty, which correlates with the predominant age range of DKA; however, the experience of older adults is not yet known.
- In this research, as per the ethical approvals, the experience of recurrent DKA is captured in a UK population with access to free health care. Perceptions may have been different if they had to access an insurance-based system.
- A broader cross-section of the DKA population to include participants from other ethnicities.
- Co-design post recurrent DKA care with those who have lived experience.
- Exploration of HCPs beliefs about DKA and living with T1DM.
- Development of undergraduate and postgraduate education to consider both physical and psychological care in T1DM and DKA.
- Explore how DSNs can continue to ‘nurse’ the person with T1DM and not the technology in an increasingly technical era of diabetes treatment.

9.12 Chapter Summary

The research and findings in this phenomenological case study offer a unique glimpse into life with recurrent DKA in those with T1DM using the philosophy of Merleau-Ponty (2014) to aid interpretation. Previously, the lived experience of developing recurrent DKA had not been investigated from the perspectives of those who endured it. During such episodes, the HCP's role was to resuscitate, treat, and cure that episode of DKA, with limited opportunity to see the individual beyond this. As mortality remains high in recurrent DKA, the findings of this study provide an alternative understanding captured from the perspectives of those who have experienced recurrent DKA firsthand. This was phenomenologically interpreted to build an account of the experiences of the body and mind, which were intertwined; one would impact the other. This phenomenological interpretation enabled the analysis to consider both the temporal and corporeal nature of living with both T1DM and during the episodes of DKA.

The effect of developing DKA cannot be neatly divided between the body and the mind. For the participants in this study, it is inextricably linked to their perceptions of their experiences both of DKA and T1DM. The body and the mind are profoundly affected during the development of DKA, which was always close by the participants, waiting again to remerge. This added to the burden of living with T1DM. In this phenomenological case of young women with T1DM, DKA was both a temporal and corporeal experience and whilst having diabetes and DKA were embodied, the participants wanted to deal with neither, yearning for life without diabetes.

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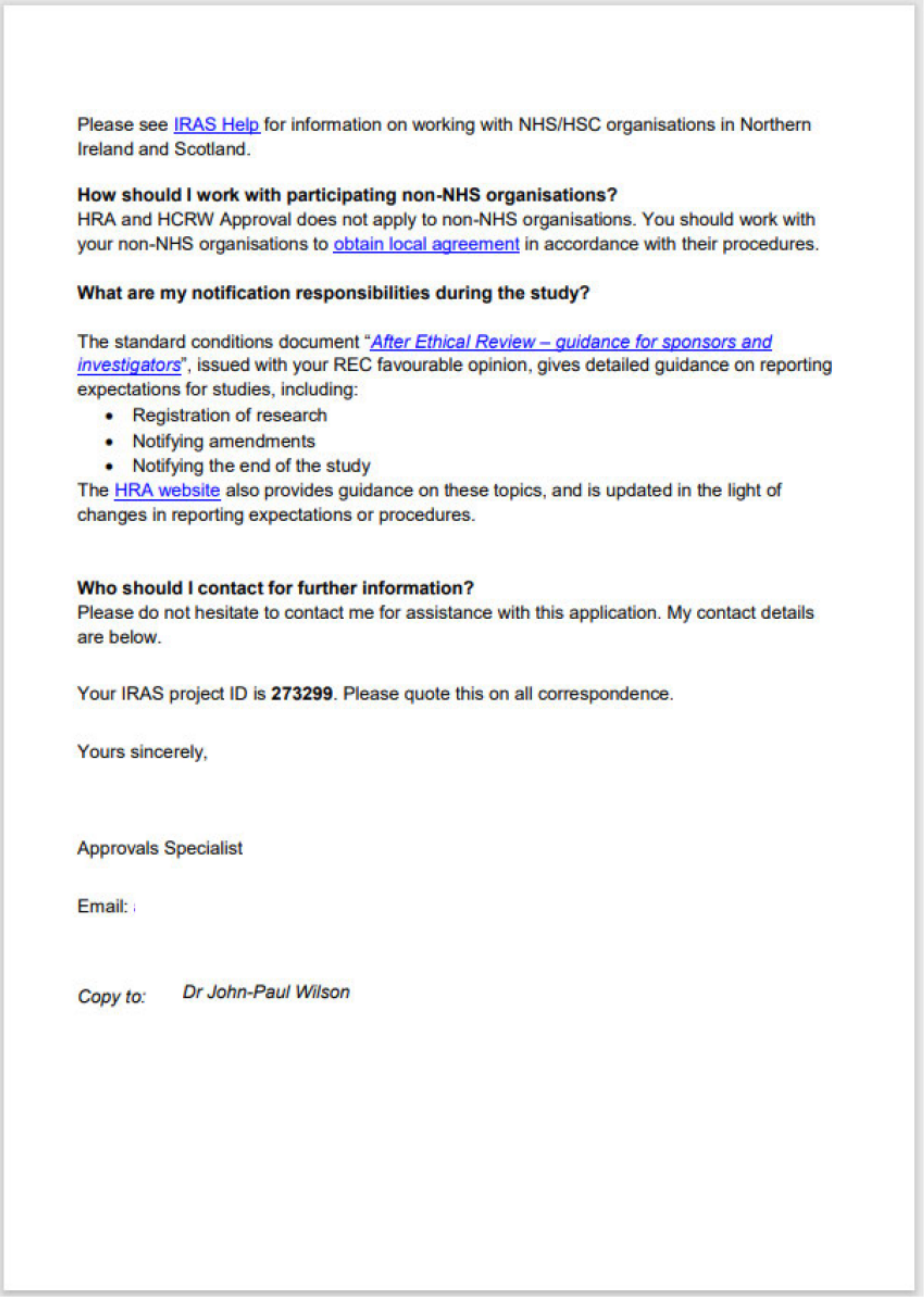
Appendix 1 Health Research Authority ethical approval



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

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

What are my notification responsibilities during the study?

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

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

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

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

Your IRAS project ID is **273299**. Please quote this on all correspondence.

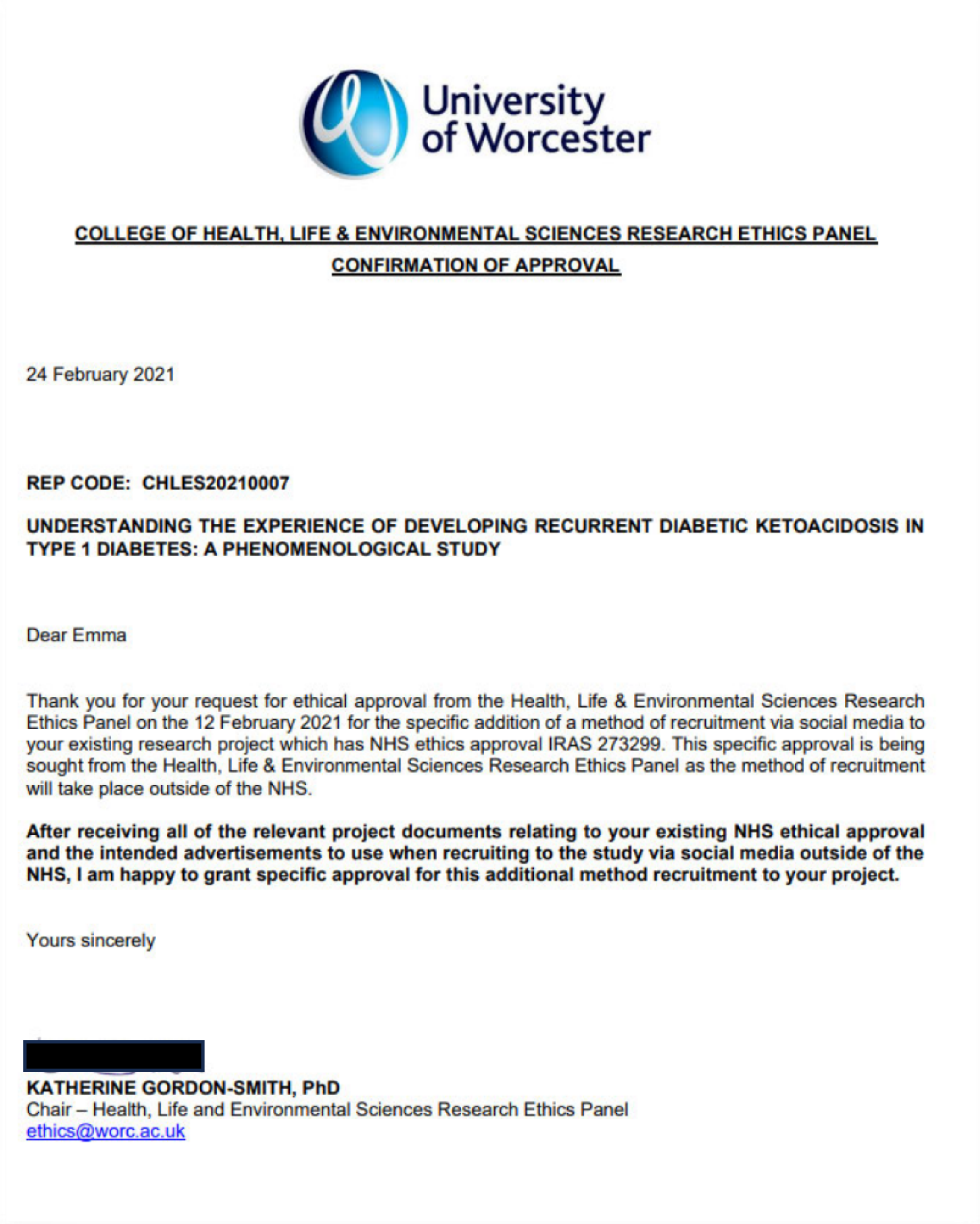
Yours sincerely,

Approvals Specialist

Email:

Copy to: *Dr John-Paul Wilson*

Appendix 1 University ethical approval



University of Worcester

COLLEGE OF HEALTH, LIFE & ENVIRONMENTAL SCIENCES RESEARCH ETHICS PANEL

CONFIRMATION OF APPROVAL

24 February 2021

REP CODE: CHLES20210007

UNDERSTANDING THE EXPERIENCE OF DEVELOPING RECURRENT DIABETIC KETOACIDOSIS IN TYPE 1 DIABETES: A PHENOMENOLOGICAL STUDY

Dear Emma

Thank you for your request for ethical approval from the Health, Life & Environmental Sciences Research Ethics Panel on the 12 February 2021 for the specific addition of a method of recruitment via social media to your existing research project which has NHS ethics approval IRAS 273299. This specific approval is being sought from the Health, Life & Environmental Sciences Research Ethics Panel as the method of recruitment will take place outside of the NHS.

After receiving all of the relevant project documents relating to your existing NHS ethical approval and the intended advertisements to use when recruiting to the study via social media outside of the NHS, I am happy to grant specific approval for this additional method recruitment to your project.

Yours sincerely

[redacted]

KATHERINE GORDON-SMITH, PhD
Chair – Health, Life and Environmental Sciences Research Ethics Panel
ethics@worc.ac.uk

Appendix 2 Participant Information Sheet

PARTICIPANT INFORMATION SHEET AND PRIVACY NOTICE
IRAS 273299

TITLE OF PROJECT: Understanding the experience of developing recurrent Diabetic Ketoacidosis in Type 1 Diabetes: a phenomenological study.

Invitation

The University of Worcester engages in a wide range of research which seeks to provide greater understanding of the world around us, to contribute to improved human health and well-being and to provide answers to social, economic and environmental problems.

We would like to invite you to take part in one of our research projects. Before you decide whether to take part, it is important that you understand why the research is being done, what it will involve for you, what information we will ask from you, and what we will do with that information.

We will in the course of this project be collecting personal information. Under General Data Protection Regulation 2016, we are required to provide a justification (what is called a “legal basis”) in order to collect such information. The legal basis for this project is “**task carried out in the public interest**”.

You can find out more about our approach to dealing with your personal information at https://www.worcester.ac.uk/informationassurance/visitor-privacy-notice.html.

Please take time to read this document carefully. Discuss it with friends and relatives if you wish. Feel free to ask the researcher any questions you may have and to talk to others about it if you wish. You will have at least seven days to decide if you want to take part.

What is the purpose of the research?

This study aims to investigate the experiences of people with Type 1 Diabetes who have experienced Diabetic Ketoacidosis (DKA) on more than one occasion. These experiences haven't been formally captured before by researchers. This new knowledge will be analysed and grouped by themes which may be used to inform the delivery of diabetes care in the future.

Who is undertaking the research?

Emma Innes
Chief investigator
Inne1_18@uni.worc.ac.uk

Who is funding the research?

There is no funding for this research. It is being undertaken as part of a PhD award.

Who has oversight of the research?

The research has been approved by both the Health Research Authority [IRAS 273299] and the Research Ethics Panel for the College of College of Health, Life and Environmental Sciences in line with the University's Research Ethics Policy. The University of Worcester acts as the "Data Controller" for personal data collected through its research projects & is subject to the General Data Protection Regulation 2016. We are registered with the Information Commissioner's Office and our Data Protection Officer is Helen Johnstone (infoassurance@worc.ac.uk).
For more on our approach to Information Assurance and Security visit: https://www.worcester.ac.uk/informationassurance/index.html.

Why have I been invited to take part?

You have received this invitation because you have Type 1 Diabetes and have had more than one episode of Diabetic Ketoacidosis. We are hoping to recruit 10 participants to this study.

Do I have to take part?

No. It is up to you to decide whether or not you want to take part in this study. Please take your time to decide; we will wait for at least seven days before asking for your decision. You can decide not to take part or to withdraw from the study up to the point of transcription of your interview. If you wish to have your data withdrawn please contact the researcher with your participant number and your data will then not be used. If you do decide to take part, you will be asked to sign a consent form.

What will happen if I agree to take part?

If you agree to take part, you will;

- be contacted to arrange an interview with Emma Innes who is the Chief Investigator
- the interview will be arranged for a mutually convenient time at either Worcester Royal Hospital/ Hereford County Hospital, the University of Worcester, Microsoft Teams or via telephone.
- interviews are expected to last as long as you wish but are anticipated to last around 60 minutes
- the researcher will ask some questions about you, how long you have had diabetes and what your experience of having DKA is like
- the interview will be audio-recorded and if on Microsoft Teams there is also the option to audio & video record

- following the first interview, you will be invited to complete a second interview in 3-6 months by the Chief Investigator Emma Innes.
- If you agree to the 2nd interview the chief investigator will contact you on the original contact details that you supplied and a mutually convenient date and time can be agreed.

- the recording from the interview/s will be transcribed by the chief investigator and anonymised at the point of transcription.
- you have the option to withdraw from the study at any point until the transcription of your interview/s.
- the anonymised transcription will be retained securely on Emma Innes' University OneDrive for 10 years in line with the University of Worcester Policy for Effective Management of Research Data (2016).
- The transcripts will be destroyed after 10 years and deleted from Emma Innes' University of Worcester OneDrive account.

What are the benefits for me in taking part?

This research will add to the contribution of knowledge about the experiences of people with Type 1 diabetes who have also developed recurrent DKA. Little is known about this from the perspective of someone living with type 1 diabetes as research has focused on the initial treatment and education on sickness management. This research will enable a better understanding of how it is to experience DKA and this knowledge will be analysed with other participants experiences to find common themes to make recommendations about developing diabetes care.

Are there any risks for me if I take part?

The research;

- it is not anticipated that this research will cause any risks to you
- if the research causes you to feel upset then you are advised to contact your Diabetes Specialist Nurse or General Practitioner
- this research is covered by the University of Worcester Public Liability & Indemnity Insurance policy https://www2.worc.ac.uk/finance/documents/TWIMC_Letter_2020-21.pdf

What will you do with my information?

Your personal data / information will be treated confidentially at all times; that is it will not be shared with anyone outside the research team or any third parties specified in the consent form unless it has been fully anonymised. The exception to this is where you tell us something that indicates that you or someone else is at risk of harm. In this instance, we may need to share this information with a relevant authority; however, we would inform you of this before doing so.

During the project, all data/information will be kept securely in line with the University's Policy for the Effective Management of Research Data and its Information Security Policy.

We will process your personal information for a range of purposes associated with the research:

- To use your information along with information gathered from other participants in the research to seek new knowledge and understanding that can be derived from the information we have gathered.
- To summarise this information in written form for the purposes of dissemination (through research reports, a thesis, conference papers, journal articles or other publications). Any information disseminated/ published will be at a summary level and will be fully anonymised and there will be no way of identifying your individual personal information within the published results.
- To use the summary and conclusions arising from the research for teaching and further research purposes. Any information used in this way will be at a summary level and will be fully anonymised. There will be no way of identifying your individual personal information from the summary information used in this way.

If you wish to receive a summary of the research findings or to be given access to any of the publications arising from the research, please contact the Chief Investigator via Inne1_18@uni.worc.ac.uk

How long will you keep my data for?

Your personal data will be retained for 10 years as required by law or a specified regulatory body.

At the completion of the project, we will retain your data only in anonymised form. This anonymised data will be archived and shared in line with our Policy for the Effective Management of Research Data. *or* we destroy all data relating to the project.]

How can I find out what information you hold about me?

You have certain rights in respect of the personal information the University holds about you. For more information about Individual Rights under GDPR and how you exercise them please visit: https://www.worcester.ac.uk/informationassurance/requests-for-personal-data.html.

What happens next?

Please keep this information sheet. If you do decide to take part, please either contact the researcher using the details below.

Thank you for taking the time to read this information.

If you decide you want to take part in our project, and we hope you do, or if you have any further questions then please contact: Emma Innes Inne1_18@uni.worc.ac.uk or 01905 542045

If you have any concerns about the project at this point or at any later date you may contact the researcher (contact as above) or you may contact the Supervisor / Principal Investigator / Project Lead: Dr Yvonne Thomas- Director of Studies y.thomas@worc.ac.uk or 01905542610

If you would like to speak to an independent person who is not a member of the research team, please contact Michelle Jellis at the University of Worcester, using the following details:

Michelle Jellis

Secretary to Research Ethics Panel for College of Health, Life and Environmental Sciences
University of Worcester
Henwick Grove
Worcester WR2 6AJ
ethics@worc.ac.uk

Appendix 3 General Practitioner Letter

University
of Worcester

Date

Dear Dr…………………………………..

[insert name and date of birth: this section is completed by the participant] has voluntarily consented to take part in a research study IRAS 273299 Understanding the experience of developing recurrent Diabetic Ketoacidosis in Type 1 Diabetes: a phenomenological study.

Your patient [Mr/MRS/MS insert name] agreed to participate in a digitally recorded interview earlier this week. The interview lasted [ ] minutes and was focused on his/her experiences of Diabetic Ketoacidosis (DKA). It is not expected that this study will cause any harm to participants.

This research will add to the contribution of knowledge about the experiences of people with Type 1 diabetes who have also developed recurrent DKA. Little is known about this from the perspective of someone living with type 1 diabetes as research has focused on the initial treatment and education on sickness management. This research will enable a better understanding of how it is to experience DKA and this knowledge will be analysed with other participants experiences to find common themes to make recommendations about developing diabetes care.
If you have any further questions or concerns then please contact the Principle Investigator: Emma Innes Inne1_18@uni.worc.ac.uk or 01905 542045

If you have any concerns about the project at this point or at any later date you may also contact the Supervisor: Dr Yvonne Thomas- Director of Studies y.thomas@worc.ac.uk or 01905542610

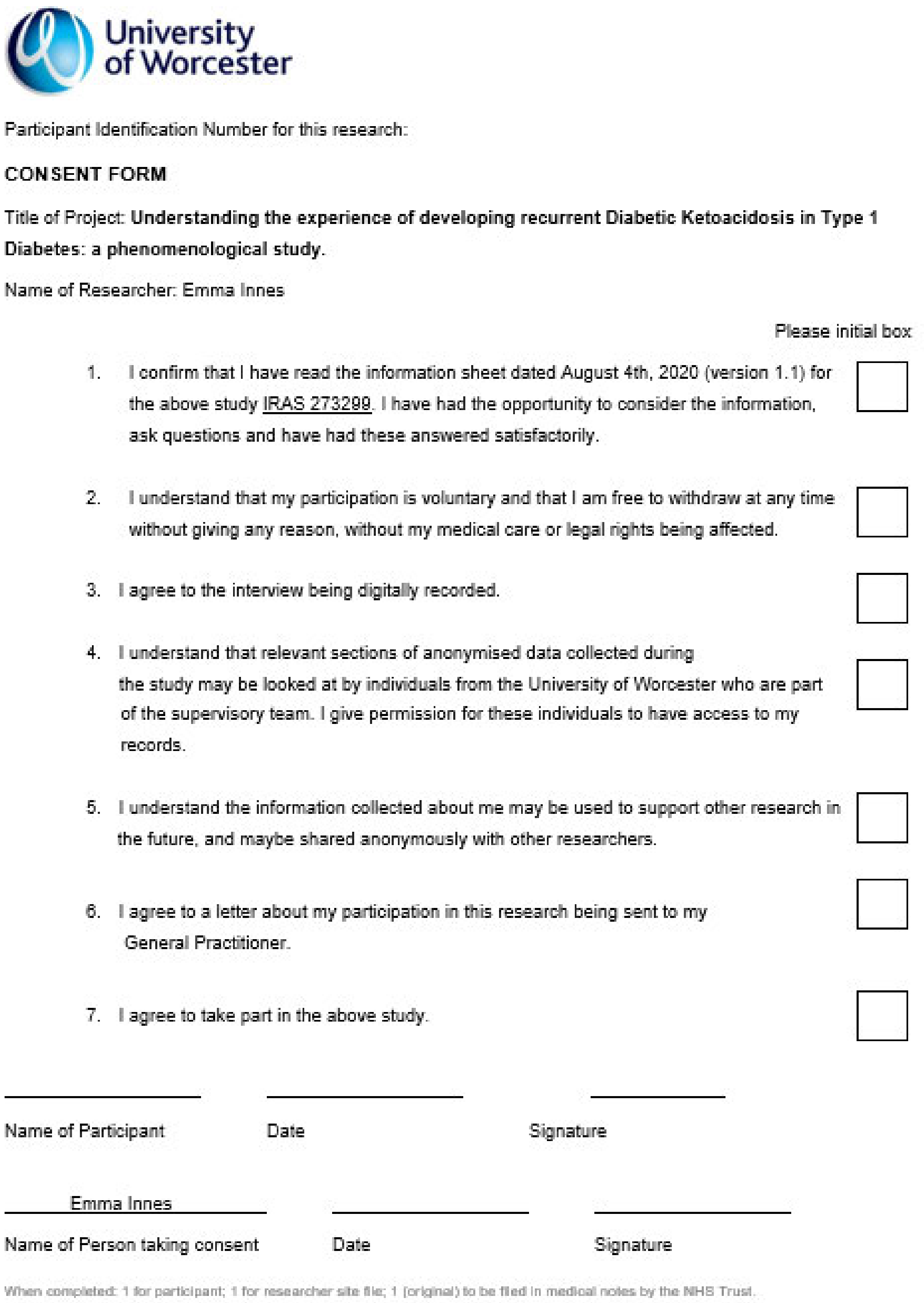
If you would like to speak to an independent person who is not a member of the research team, please contact Michelle Jellis at the University of Worcester, using the following details:

Michelle Jellis
Secretary to Research Ethics Panel for College of Health, Life and Environmental Sciences
University of Worcester
Henwick Grove
Worcester WR2 6AJ
ethics@worc.ac.uk

Yours Sincerely

Emma Innes- PhD student

Appendix 5 Consent form



Participant Identification Number for this research:

CONSENT FORM

Title of Project: **Understanding the experience of developing recurrent Diabetic Ketoacidosis in Type 1 Diabetes: a phenomenological study.**

Name of Researcher: Emma Innes

Please initial box

1. I confirm that I have read the information sheet dated August 4th, 2020 (version 1.1) for the above study IRAS 273299. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to the interview being digitally recorded. ☐
4. I understand that relevant sections of anonymised data collected during the study may be looked at by individuals from the University of Worcester who are part of the supervisory team. I give permission for these individuals to have access to my records. ☐
5. I understand the information collected about me may be used to support other research in the future, and maybe shared anonymously with other researchers. ☐
6. I agree to a letter about my participation in this research being sent to my General Practitioner. ☐
7. I agree to take part in the above study. ☐

Name of Participant ____________ Date ____________ Signature ____________

Emma Innes

Name of Person taking consent ____________ Date ____________ Signature ____________

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be filed in medical notes by the NHS Trust.