

THE ROLE OF TIME PERSPECTIVE IN SELF-
CARE OF TYPE 1 DIABETES IN EMERGING
ADULTS

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Abstract

Type 1 diabetes is a chronic endocrine condition, leading to insufficiency of insulin and an increase in blood glucose levels. Complex daily self-care is required to manage the condition, which can be a burden. For emerging adults (approximately between the ages of 18 to 30 years) with type 1 diabetes, assuming full responsibility for their self-care can be overwhelming and frequently leads to a deterioration in their glycaemic control. Suboptimal glycaemic control is associated with chronic complications of diabetes later in life. It is therefore important to better understand characteristics that influence self-care behaviours in emerging adults, so that individuals can be suitably supported to protect their future health. One characteristic known to influence health behaviour is time perspective. Time perspective is an individual's perception of their past, present and future, and these perceptions of the different temporal zones can influence behaviour to a varying extent. However, the influence of time perspective on self-care of type 1 diabetes in emerging adults, has not been previously investigated.

This thesis presents a sequential explanatory mixed methods study, where an initial quantitative phase was followed with a qualitative phase, to explain the findings. Phase I involved a cross-sectional questionnaire study, where respondents' time perspective, self-care behaviours and the glycaemic control marker HbA1c were reported ($n=75$). Results showed future time perspective was associated with higher self-care scores ($r = .42, p < .001$) and lower HbA1c ($r = -.28, p = .02$). Past negative time perspective was associated with lower self-care ($r = -.33, p < .001$) and higher HbA1c ($r = .47, p < .001$). Hierarchical regression showed that future time perspective uniquely predicted 24% of the variance in self-care ($t = 3.06, p < .01$) and past negative perspective predicted 25% of the variance in HbA1c ($t = 1.98, p = .05$). In Phase II ($n = 18$), thematic analysis of qualitative interviews revealed that self-care was motivated by short-term future goals. Past negative experiences due to diabetes had impacted mental health and produced negative views about the future.

The unique care needs of emerging adults identified in this research are discussed in relation to time perspective theory, and recommendations are made for policy, practice and further research.

Keywords: type 1 diabetes, time perspective, emerging adulthood, self-care, mixed methods

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List of abbreviations

BMI	Body mass index
CFC	Consideration of Future Consequences Scale
CSII	Continuous subcutaneous insulin infusion
DCCT	Diabetes Control and Complications Trial
DKA	Diabetic ketoacidosis
F	Future time perspective
HbA1c	Glycosylated haemoglobin
IFCC	International Federation of Clinical Chemistry
MDI	Multiple daily injections
NICE	National Institute for Health and Care Excellence
PF	Present fatalistic time perspective
PH	Present hedonistic time perspective
PIS	Participant Information Sheet
PN	Past negative time perspective
PP	Past positive time perspective
PTSD	Post-traumatic stress disorder
PTSS	Post-traumatic stress symptoms
SCI	Diabetes Self-Care Inventory
SMBG	Self-monitoring of blood glucose
T1D	Type 1 diabetes
ZTPI	Zimbardo Time Perspective Inventory
ZTPI-TP	Zimbardo Time Perspective Inventory - Temporal Phrasing

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This work is dedicated to all the exhausted NHS frontline staff, who have relentlessly cared for patients since the beginning of the pandemic and will continue to do so, regardless of the circumstances they face.

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Elaine Sharp

21/06/2021

Thesis Introduction

Context for the study: researcher's background

I am currently an academic pharmacist with a background in the NHS, where I spent many years working in a range of different hospital pharmacist roles. One of the posts I held was in a district general hospital, where I was a Paediatric Specialist Pharmacist. Being part of the paediatric ward team exposed me to many different children and young people who lived with chronic conditions and I found myself very interested in them. More specifically, I was interested in the impact chronic conditions and their treatment can have on everyday life for children, young people and their families. With diabetes being one of the more common chronic conditions seen in young people, we often had patients repeatedly admitted to the adolescent ward with acute diabetes complications. Unfortunately, many of these admissions were a consequence of the young person struggling with daily self-care, and I recall the care team's deep concern about the longer-term consequences of suboptimal blood glucose control. They would often express these potential risks to the patients as being a consequence of current behaviours, for example if the young person was avoiding self-care duties. However, it struck me that a warning message about potentially negative health consequences that lie far-off in the future, was perhaps ineffective when it was directed towards someone so young. It led me to question their comprehension of both themselves in the future, and the future chronic complications risks that are associated with diabetes.

These clinical practice experiences therefore led me to carry out the present research.

Overview

Physical time, the sequence of measurable intervals in which events take place, underpins functioning in the natural world at the most fundamental level. The orbits of the earth and moon govern days, months, seasons and the cyclic changes that lie within them. From conception, a living organism is undergoing a constant process of ageing until its death. Time is consistently moving forward, each second that passes is now gone. We exist permanently in the present, but the next moment is always approaching.

However, physical time is only one aspect of the phenomenon. There is also a subjective psychological experience of time that has long been recognised in the literature. In the third century, St Augustine presented the concept of time as a psychological abstraction in his work "Confessions" (1). It is obvious that neither past nor future temporal frames are real in the physical sense. The past no longer exists and the future has not yet existed, but both have a subjective reality within the human conscious. In his discourse, Augustine describes these as a 'present' of things past and a 'present' of things to come, made possible through memory and expectation respectively (1). In the twentieth century, the philosopher Martin Heidegger (1927) similarly described the relationship between the self and the future. Although it is an unreality now in present time, an individual's future will become an actual reality at some point and for this reason, it belongs to the subject in the same way something tangible would (2).

Despite physically existing in the present time, humans have the ability to cognitively project back into the past and also to visualise what might lie ahead in the future. Such past and future cognitions are known to influence behaviour in present time (3). These subjective abstractions have been operationalised as 'time perspective' and this construct forms the theoretical framework for this thesis. Time perspective is an individual characteristic. One person's actions might be strongly influenced by previous past experiences, whereas another might be more influenced by considering the future and possible outcomes arising from their actions (3). It has been recognised that future thinking is a primary motivational force in behaviour (4). There is a plethora of literature showing the motivational influence future time perspective has on behaviour in

different situations, including the area of health behaviour (5). In this arena, future time perspective has frequently been associated with positive behaviours that are protective to health (6).

However, notably lacking from this body of literature, is research in people with existing chronic health conditions and behaviour relating to self-care of such conditions. This is surprising, given the focus on preventing complications in the care of such individuals (7). Chronic conditions often carry a risk of morbidity in the longer-term, which poses a far-off distant threat to the individual's well-being or quality of life. This is the case with diabetes: if blood glucose levels are not kept below a certain threshold over a sustained period, there is an increased risk of irreversible life-threatening and life-limiting complications in the future (8). To mitigate these long-term risks, daily dedication to the manual regulation of blood glucose is required in the present (7). It would therefore seem logical that a future time perspective might have some influence in people with diabetes, as a motivator to carry out self-care.

Diabetes complications tend to develop later in adulthood. However, blood glucose levels above target during adolescence have been associated with complications developing and progressing earlier in adulthood (9). The developmental phase 'Emerging Adulthood' refers to the period between approximately 18-30 years old (10). It has been shown that the cognitive ability to conceptually visualise one's expansive future, develops during late adolescence towards the emerging adulthood period (11, 12). It has also been suggested that adolescents and emerging adults live with a sense of invincibility (13). These factors combined could limit a young person's view of the distant future, or perhaps hinder their comprehension of a far-off threat. Managing diabetes self-care effectively in emerging adulthood, not only serves to reduce the risk of distant future complications, it could also prevent them developing in the proximal years lying just ahead. However, it is unclear what perceptions young people of this age have of either themselves in the future, or the future consequences of their diabetes self-care in present time.

No previous studies have been conducted to investigate the relationship between time perspective and diabetes self-care in emerging adults.

Chapter 1. Diabetes Introduction and Literature Review

Notes on diabetes language

In recent years, there has been growing interest and attention paid to the use of language within the clinical discipline of diabetes (14-16). In routine diabetes services, there are many words, terms and phrases that have become embedded in communication from care teams. However, research conducted among people living with diabetes, has shown the negative impact certain language can have on their ability to manage the condition (17). Managing diabetes is challenging, there are many factors involved and the responsibility lies predominantly with the individual, rather than the healthcare professionals. It is therefore important that a shared language is found, that is positive and empowering to those living with the condition.

There have been several publications highlighting the need for positive diabetes language. Many of these provide guidance on alternative terminology that is more favourable to people with diabetes. For example, not referring to people as 'diabetic' or avoiding the use of terms that apportion blame, such as 'poor control', 'non-compliant' or 'non-adherent' are recommended (14, 15). A summary of some of the more problematic terms, along with recommended alternative language, can be found in Appendix 1.

Recently in the UK, a position statement was published to promote appropriate language within diabetes care (16) and work is underway to incorporate this into national policy (18). Throughout this thesis, the author will endeavour to follow these recommendations for appropriate language.

Diabetes Mellitus

Overview

Diabetes Mellitus is a group of chronic endocrine conditions, where the ability to utilise glucose for energy is impaired or absent. The peptide hormone insulin is secreted from beta cells, located in the Islet of Langerhans in the pancreas. Insulin is required to facilitate uptake of glucose from the blood to cells, where it forms an essential energy source. In diabetes, loss of function of the beta cells leads to a reduction or absence of insulin, which in turn causes hyperglycaemia (8). People with diabetes therefore require manual management of their blood glucose levels. Diabetes is broadly categorised into two primary forms of type 1 and type 2, although there are several other recognised forms (8). In type 1 diabetes, insulin is largely absent and survival is fully reliant on daily injections of exogenous insulin. With type 2, some residual insulin secretory function is retained, meaning blood glucose can be managed by lifestyle or dietary modification, by taking oral medication to reduce blood glucose levels, or by using insulin therapy. This form is associated with modifiable factors such as obesity and lack of physical activity. People with type 2 diabetes form the vast majority of cases, with only around 10% of the diabetes population having type 1 (19). However, for those living with type 1, the daily management of blood glucose is more complex and the burden from self-care can be high (20). These challenging self-care processes may also be required from a very young age, depending on when the condition presents.

The progressive complications of diabetes can significantly increase morbidity and mortality (19). The majority of health outcomes monitored in people with diabetes relate to long-term complications. The Diabetes Control and Complications Trial Research Group (DCCT) conducted landmark longitudinal studies in the 1990s, which demonstrated that the risk of developing chronic complications is strongly associated with suboptimal glycaemic control (7). This series of studies also identified the link between suboptimal glucose control in adolescence and the escalated risk of developing complications earlier in life (9). Therefore, tight management of blood glucose levels through self-care, can significantly reduce the risk of chronic complications in future.

Globally, the estimated number of adults living with diabetes has approximately quadrupled since 1980, currently over 400 million people have the condition and the prevalence of both major types is increasing (21). This has led to diabetes becoming a national and global priority for healthcare providers. In a recent review, the World Health Organization (WHO) have named diabetes as one of four global priority diseases for world leaders, advising that health systems need to respond better to reduce the impact of diabetes, particularly in primary care. Recommendations to address gaps in the current diabetes knowledge base have been advised, with behaviour change being highlighted as a priority target (21).

Self-care behaviours and the related impact of these in emerging adults living with type 1 diabetes, will be the focus of this thesis.

Type 1 diabetes – pathophysiology and management

Type 1 diabetes results from selective, autoimmune destruction of pancreatic beta cells. The beta cell destruction is so extensive, that clinical treatment approaches in people with type 1 assume a position of insulin secretory capacity being lost. This therefore means daily insulin replacement is required. However, it has recently been shown some residual beta cell function likely persists (22, 23). Type 1 diabetes commonly presents in childhood or young adulthood, with a peak onset around age 11-14 years, however it can present at any age (8). Although the true cause of beta cell destruction remains poorly understood, pathogenic environmental triggers including viruses are likely to be involved, alongside genetic susceptibility (8). Unlike type 2 diabetes, type 1 is not modifiable and there are no lifestyle changes individuals can make to reduce the risk or prevent it from occurring.

Glycaemic control and monitoring

Manually controlling blood glucose levels requires a significant amount of self-care by the person with diabetes or their caregivers. In people with type 1, the balance between counting dietary carbohydrate intake, measuring and

interpreting blood glucose levels and adjusting insulin doses accordingly, must be carefully negotiated on a daily basis. Adults are advised to monitor blood glucose levels at least 4 times daily (24), children and young people are advised to do so at least 5 times daily (20), aiming to achieve levels that broadly reflect profiles of those in people without diabetes. The personal impact of living with type 1 diabetes is profound and for children and young people, this impact invariably extends to immediate caregivers and other family members. Maintaining stable glycaemic control and reducing the risk of complications, is therefore highly dependent on these individuals and their ability to manage these activities (25-27). Daily self-care requires a certain level of skill, for example, the ability to interpret data and perform calculations. It also takes discipline to adhere to somewhat restrictive routines. A significant amount of motivation is required to continue with the routine in the longer term, given that from point of diagnosis these daily activities become life-long. Structured education programmes have been shown to improve self-care skills and motivation in adults (28) and are recommended for people with type 1 diabetes. Some studies have also shown they can improve glycaemic control outcomes in adult participants (29). However, these effects have not been consistent across longer periods, suggesting the motivational and educational impact of such programmes are not sustained in the longer-term (29). Moreover, structured education programmes have failed to show improvements in both glycaemic control and psychological outcome measures in adolescent samples (30). In younger people, research focused on identifying characteristics associated with self-care would be of benefit, since focusing on skill and motivation appears to have limited impact.

In addition to frequent daily self-monitoring of blood glucose (SMBG), the National Institute for Health and Care Excellence (NICE) recommends routine monitoring of glycosylated haemoglobin levels (HbA1c). Glucose naturally binds to haemoglobin in the erythrocytes in a concentration-dependent manner. The extent of this, assessed via HbA1c, can provide an indication of blood glucose control over a period of several weeks. Rather than reviewing daily or random glucose levels in isolation, this measure indicates an average level of glycaemic control over the preceding 8-12 weeks (8). HbA1c is reported on two different scales: as a percentage (DCCT scale) or as a mmol/mol value (International

Federation of Clinical Chemistry scale, IFCC). Some equivalent values can be found in Table 1, alongside the mean plasma glucose level that is associated with each one.

Table 1 HbA1c equivalence scales

DCCT (%)	IFCC (mmol/mol)	Mean Plasma Glucose (mmol/L)
6.0	42	7.0
6.5	48	7.8
7.0	53	8.6
7.5	58	9.4
8.0	64	10.1
9.0	75	11.7
10.0	86	13.3
11.0	97	14.9
12.0	108	16.5

The IFCC scale is the recommended scale for use in current practice. However, in the USA and the majority of the international diabetes literature, the percentage scale is still used. In UK clinical practice the IFCC scale has been adopted. For the purpose of this review, values will therefore be quoted using the IFCC mmol/mol scale, but with DCCT % in brackets to align with the literature.

Internationally, annual measurement of HbA1c has become one of the most recognised and widely utilised outcome measures for diabetes health. The UK target value is less than 48 mmol/mol (6.5%) for all people with diabetes (20, 24). However, NICE advises care providers to report data on numbers of people achieving less than 53 mmol/mol (7%). In practice, the very intensive control required to achieve HbA1c of less than 48 mmol/mol (6.5%), is not something many people with diabetes can realistically meet, owing to the high level of self-care required to achieve this. Individualised care therefore advocates the lower the better, with the near-target value under 53 mmol/mol (7%) remaining

desirable (20, 24). These target values are based on evidence showing significant reductions in the incidence of various complications of diabetes (7). Chronic diabetes complications, the use of intensive insulin and the associated HbA1c monitoring, are discussed in more detail in the sections below.

Insulin therapy

For children and young people diagnosed with type 1, the current first line recommendation for insulin therapy is the multiple daily injection (MDI) or basal-bolus regimen (20). This consists of a combination of short, or rapid-acting insulin bolus doses before meals and at least once daily injection of an intermediate or long-acting insulin analogue. This flexible intensive regimen is intended to mimic the physiological insulin secretion of a functioning pancreas. However, therapy should be individualised to achieve glycaemic control, whilst avoiding problematic adverse effects, such as recurrent hypoglycaemia (31). An alternative therapy option, is the continuous subcutaneous insulin infusion (CSII), or insulin pump. In younger children, the CSII is an alternative first line for those whom MDI is considered unsuitable (20). However, for children over 12 years and adults, the CSII is reserved as an alternative option for people experiencing disabling recurrent hypoglycaemia, or where HbA1c remains above 69 mmol/mol (8.5%) on MDI, despite a high level of self-care (24). The pump delivers rapid-acting insulin from a reservoir via an in-dwelling cannula and it can be programmed to deliver a background basal rate, with scope to inject additional higher boluses at meal times (32, 33). Emerging adults with type 1 diabetes, will likely be using one of these two insulin regimens.

Complications of diabetes

Acute diabetes complications can be both dangerous and debilitating, for example a severe hypoglycaemia episode could cause serious harm if it were to happen whilst driving. Some people suffer frequent hypoglycaemia episodes, which can significantly affect quality of life and lead to fear and anxiety (34). On the other hand, insulin absence can result in hyperglycaemia. In type 1 particularly, dangerously high blood glucose levels can lead to diabetic ketoacidosis (DKA), a life-threatening metabolic disturbance requiring urgent

treatment with fluid and insulin replacement. Ketoacidosis is a risk in someone who is not using their insulin, or who is using it sporadically. It can also be the result of a situation where physiological insulin requirements have increased. For example, during puberty insulin resistance can occur leading to an increase in dose requirements of as much as 30% (35). In the worst-case scenario, both the acute complications of hypoglycaemia and hyperglycaemia can result in coma and death. Optimal control of blood glucose and education around managing glucose levels, are therefore vital to ensure safety.

Chronic complications of diabetes fall into two main categories. Microvascular complications arise due to atrophy in the small vessels and nerves, this atrophy is strongly associated with hyperglycaemia (8). The microvascular complications of diabetes are retinopathy, nephropathy and neuropathy. The presence of microvascular complications can significantly impact quality of life: retinopathy can result in progressive sight loss, nephropathy can lead to deterioration of kidney function, possibly requiring renal replacement therapy or even transplant. Neuropathy-related problems can cause chronic ulceration and eventual necrosis of the feet or lower limbs, sometimes requiring amputation. People can live with severe, chronic neuropathic pain, which negatively impacts quality of life. Diabetes also carries the risk of macrovascular complications such as myocardial infarction, stroke and peripheral vascular disease. Once present, chronic complications are irreversible, will likely worsen over time and are a leading cause of death in people with diabetes (19).

As part of complications management, NICE recommends a range of regular care and screening processes for children, young people and adults. Broadly these include HbA1c, weight and height, blood pressure, serum creatinine, urine albumin, cholesterol, retinopathy screening and podiatry reviews (36). Keeping up with these key health checks is the responsibility of patients, caregivers and care providers alike and they can help with early identification of chronic complications.

Use of HbA1c as an outcome measure

Despite being such a globally accepted marker for glycaemic control, the extent of how clinically meaningful HbA1c is, has been subject to debate. As a surrogate endpoint, there are potential strengths and limitations associated with this biomarker. Since the present study will include HbA1c as an outcome variable, it is important to further evaluate its usefulness and the reasons why it is prominent in current evidence-based practice.

The US Food and Drug Administration define surrogate endpoints as markers that, although not themselves a direct measure of clinical benefit, are known to predict clinical benefit associated with an intervention (37). They are often favoured in time-limited clinical trials, where a long-term clinical endpoint would prove too costly, such as disease progression or mortality.

In the 1990s, the DCCT study group used HbA1c as the primary surrogate endpoint, to evaluate whether intensive insulin therapy for tight glycaemic control could prevent or delay chronic complications. Since their publication, these longitudinal studies have transformed standard treatment for type 1 diabetes and still form the evidence behind the current international targets for HbA1c (7). The strength of evidence from these studies is certainly compelling. The original sample of 1441 participants were randomly assigned to receive either intensive therapy or conventional insulin in one of two groups: a primary prevention group for those with no retinopathy at baseline and a secondary intervention group for participants with mild to moderate retinopathy.

Participants were followed for a mean of 6.5 years with a completion rate of 99%. The aim was to maintain HbA1c below 42 mmol/mol (6.05%), similar to values in people without diabetes. Significantly positive outcomes were found for all participants receiving intensive therapy, in each of the three types of microvascular complication assessed. For example, after more than five years the primary prevention group had a mean retinopathy risk reduction of 76%, a 34% average risk reduction in microalbuminuria suggestive of nephropathy and a 69% average risk reduction in the appearance of neuropathy. In the secondary intervention group, progression of retinopathy had an average risk reduction of 54%, average microalbuminuria risk was reduced by 43% and

appearance of neuropathy was reduced by an average of 57% (7). In the subgroup of young people aged 13-17 at baseline (n=195), intensive therapy led to a 53% average risk reduction in retinopathy in the primary prevention group, a 70% average reduction in risk of retinopathy progression in the secondary intervention group and a 55% average risk reduction of microalbuminuria in the secondary intervention group (9).

However, fewer than 5% of the total participants in the intensive therapy groups were able to sustain the target HbA1c value of 42 mmol/mol (6.05%) during the study period. The mean HbA1c for those receiving intensive therapy was actually 55 mmol/mol (7.2%), compared with 76 mmol/mol (9.1%) in the conventional therapy group. It is possible that in real life, such low targets cannot be manually achieved and the DCCT findings would support this argument. Nonetheless, the clinical benefit achieved from intensive insulin therapy and a significantly lower HbA1c, is clear.

What is less clear, is how effectively HbA1c functions as a predictor of macrovascular complications. Given the many other clinical variables associated with cardiovascular disease, such as blood pressure and lipid profiles, the correlation with HbA1c has been questioned as an indicator of cardiovascular risk (38). Additionally, although HbA1c is known to be correlated with mean plasma glucose and therefore representative of this (39), it has also been established that notable inter-individual variability exists (40). For example, pooled randomised-controlled trial data including 260 patients with HbA1c between 48 mmol/mol (6.5%) and 58 mmol/mol (7.5%), found that 10% of the sample had a mean plasma glucose less than 6.4mmol/L and a further 10% had mean plasma glucose greater than 9.5mmol/L (40). As can be seen from Table 1 above, corresponding mean plasma glucose values would be expected to sit between 7.8 and 9.4 mmol/L for HbA1c levels in this range.

Given that HbA1c is an average representation, it is unable to indicate if there are contemporaneous variations in plasma glucose. For instance, if a patient was experiencing recurrent hypoglycaemic episodes over a particular three month period, this would likely result in a corresponding reduction in HbA1c.

Where this may appear to be clinically optimal on routine measurement, it is clearly unsafe. Similarly, a clinically acceptable mean value could simply be the result of extreme fluctuations between high and low blood glucose levels, bringing an average that meets desirable levels.

Regardless of the limitations of this biomarker, HbA1c remains the accepted outcome measure for diabetes management, monitoring, and risk stratification in clinical practice. In relation to research, it is approved by the European Medicines Agency as the primary outcome measure for clinical investigations to support claims in relation to glycaemic control (41). It can therefore be considered to hold validity as a surrogate endpoint and will be used to triangulate reported self-care behaviour in the present study.

Emerging Adults with type 1 diabetes

Overview

The typical trajectory of HbA1c, follows a steady rise through adolescence, with a subsequent slow and steady decline through the twenties and the rest of adulthood (42). Large-scale longitudinal data has shown that glycaemic control in type 1, peaks at its least optimal around the age range of 18-20 years, during early emerging adulthood (42, 43). The national median HbA1c for children and young people under 25 years old is around 67 mmol/mol (8.2%) (36). This demonstrates that emerging adults are a particularly high-risk group.

The transition from paediatric to adult diabetes care services, normally around the age of 18, is commonly a difficult journey and has been widely associated with a deterioration in engagement with diabetes care (44). Emerging adults face many new psychosocial challenges (10), for example leaving the parental home and dealing with independent living for the first time. In people of this age who have diabetes, these challenges can negatively impact self-care activities and bring about diabetes-related stress and anxiety (45, 46). It has therefore been acknowledged that emerging adults aged 18-25 years have unique care needs, which sit outside of both paediatric and general adult care settings (47).

However, research in this population is lacking. The age group overlaps paediatric studies, where participants are normally under 20 years, and adult studies, where participants are over 18 years and not normally further defined by age. Further research in this age group specifically, could provide new insight to support the unique care needs of this high-risk population.

Emerging Adults defined

In the year 2000, Arnett proposed a new developmental theory of 'Emerging Adulthood', relevant for industrialised societies (10). Within many western cultures at the time, traditionally adult defining roles such as marriage, home ownership or becoming a parent, were happening some years later than for previous generations. Adolescence is commonly viewed as the time for identity exploration, however the immediate years following the completion of secondary education have been noted as a prolonged time of self-discovery, that is distinct from both adolescence and adulthood.

Arnett posited that emerging adults are young people who don't subjectively identify as 'adult' yet, but are experiencing relative independence, so may feel they are adults in some respects. Turning 18 commonly corresponds with a recognised legal transition to adult status. Additionally, a large proportion of young people in this age group will leave the family home for the first time to attend further and higher education. Those who do remain at home acknowledge an increase in freedom of movement and less parental control (10). These factors make them characteristically distinct from their adolescent counterparts. However, samples interviewed by Arnett reported they did not feel they had transitioned to adulthood yet, citing factors such as being responsible for oneself, making independent decisions and financial independence as benchmarks for this transition (10).

It is worth noting that this construct sits distinctly within certain cultural contexts and may not be universally applicable. The theory has received some criticism in this respect. For example, in some ethnic minority groups, people in this age group often undertake caring responsibilities in the wider family. There are communities where marriage most commonly takes place in the early twenties

(48, 49). Although Arnett acknowledged these issues with heterogeneity of the population, most of the definitive research has been conducted amongst fairly homogenous white university students (10, 50). It has therefore been suggested that Arnett's theory is less a developmental stage, but rather a description of the transitional experiences of predominantly white middle class young people (48). Nonetheless, for young people who would identify with this as a developmental stage, it is likely they will face many new paths to negotiate.

An important characteristic Arnett identified, is an increase in social risk taking among 18-25 year olds, such as binge drinking, substance use, dangerous driving and unprotected sex. Being less restricted by parental control than adolescents, but not yet having some of the constraints of adult responsibility, allows them a natural freedom to explore. For an emerging adult living with type 1 diabetes, this presents several psychosocial and diabetes-related problems. There are some common issues that can impact self-care, which have been well recognised in the literature (44). These issues, that will now be further discussed, are the transition from paediatric to adult care and the mental and emotional health problems that are associated with having diabetes.

Transition to adult care

Transition definition

Transition is the movement from the paediatric care setting to adult care, applicable to all young people who live with chronic conditions (51). The definition used by NICE is:

“a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions, from child-centred to adult-oriented healthcare systems” (52).

Emphasis is placed on transition being a multi-faceted period of change, rather than a one-off handover into adult care. The complex psychosocial needs of the maturing young person must also be supported and given priority, alongside

their medical needs. Despite awareness of the problems young people can encounter when moving from paediatric into adult care services, lived experiences of transition do not appear to be without challenges and are not always reflective of recommended best practice (52-54).

Transition and glycaemic control

A large proportion of research investigating transition of young people with chronic conditions, has been conducted in young people with type 1 diabetes, therefore the associated decline in glycaemic control has been well-documented (55). Longitudinal studies have emphasised the negative impact transition can have on HbA1c values (43, 56, 57). For example, an arm of the SEARCH for Diabetes in Youth Study, a multi-centre cohort study in the USA, investigated factors relating to a successful transition and whether glycaemic control would worsen once in adult care. This involved 185 participants, the mean age for transition to adult care was 20.1 years. Follow-up visits were conducted at 1, 2 and 5 years after baseline. Results showed average HbA1c deteriorated from 58 mmol/mol (7.5%) to 97 mmol/mol (11%) at final follow-up, with odds of suboptimal glycaemic control in those who had moved to adult care being 2.46 (56). Similarly, a UK study involving 108 transitioning emerging adults, who were followed annually over 4 years, showed a significant increase in mean HbA1c, rising from 69.2 mmol/mol (8.5%) at baseline to 74.8 mmol/mol (9%) at final visit (58).

Helgeson et.al (2013) conducted a prospective study to examine transition, self-care and glycaemic control variables. The 118 participants were all at the stage of high school graduation at baseline (approximate age 18), measures included the Diabetes Self-Care Inventory, parent-child relationship characteristics and HbA1c values, which were taken at baseline and again 12 months later (57). At baseline, those still in paediatric care had significantly lower mean HbA1c (66 mmol/mol (8.2%) vs 79.7 mmol/mol (9.44%)) than those already in adult care. Not all HbA1c values were recorded making interpretation difficult, however all participants showed a rise in value over time. Younger age for transition was associated with higher HbA1c. Analysis of variance showed levels of self-care were highest in paediatrics, but during transition self-care deteriorated over

time, after controlling for age, race and social status. These findings are likely reflective of a level of parental involvement still being retained whilst in paediatric care. This study suggests that age of transition is an additional risk factor for deterioration in HbA1c afterwards.

Practical and service-related transition problems

Qualitative data have described some of the experiences of transition and it appears that difficulties with the process are multi-faceted. For example, Sheehan et al. (2015) conducted a systematic review of articles reporting transition experiences, and a set of common themes were identified (53). Within paediatrics, families were reliant on the care team to co-ordinate some of the practical issues within the system, such as referral to allied support, or processing prescriptions and equipment. In adult care, participants reported services were less accessible, appointments were less frequent and the family were not known to the adult care providers. The loss of supportive, personal relationships was sometimes abrupt and young people felt out of place in adult services. Many young people felt unprepared for transition and dissatisfied with the process. It was common for them to struggle to navigate adult care and feel “culture-shocked”. Adult care professionals admitted they did not always know how to meet the needs of young people. Under adult care, there is an assumption that the young person is fully responsible for self-care, however, they were often not ready to take on full responsibility following transition (59). Some parents reported a sense of loss and difficulty handing over full responsibility (53). Young people reported that changes in their lifestyle at this time, such as attending college and balancing employment, also negatively impacted their ability to carry out self-care adequately (53).

A systematic review conducted by Hynes et. al. (2016) aimed to identify barriers and facilitators to clinic attendance in young people aged 15-30 years old with type 1 diabetes (60). Many of the issues identified in this review relate to practical care delivery difficulties. For example, barriers that were highlighted included a lack of collaboration between paediatric and adult care teams and difficulties communicating with adult care providers. Facilitators to clinic attendance included continuity of care from familiar staff and clear procedures

around accessing appointments (60). Paying careful attention to some of the processes around service delivery, could potentially ease the transition burden and encourage continued attendance at diabetes clinics.

Difficulties taking on full self-care

Handing over self-care to adolescents with type 1, has been described as an active and flexible process between the young person and their family, where responsibilities are shared in order to achieve common goals (61). A phenomenological study conducted in Sweden explored self-care handover in a group of 32 teenagers with type 1 diabetes. The teenagers felt parental encouragement was affirming and support from the diabetes team boosted self-esteem, because the young person was made to feel expert in their self-care routines when consulting with care providers. Emotional support and acceptance from peers facilitated practical aspects of daily management. The authors concluded that being allowed to make decisions around self-care and gain knowledge to deal with new situations, would aid transition. Transitioning young people need to be given safe opportunities from families and care teams to practice decision-making, whilst retaining a suitable amount of support in the background. Too much or too little input from parents and care providers, could prove detrimental once in adult care.

However, it has been demonstrated that struggles taking over self-care responsibilities do continue post-transition. Hilliard et. al. (2014) explored some of the concerns and experiences of adolescents and emerging adults with type 1 and their families (54). The study involved adolescents aged 15-17 years (n=20) who were pre-transition and 59 emerging adults aged 18-22 years who were now post-transition. A mixed methods approach was used to gather data, questionnaires and semi-structured interviews were used to research transition expectations and experiences. One identified theme was around building a 'safety net' of social and family support. This was not only important to the younger age group, it was also expressed as important by the emerging adults. They discussed the overwhelming responsibility that comes with taking on all aspects of self-care and the loss of knowing they have the 'back-up' of their family support. Pre-transition parents also reported fears about their child

becoming completely responsible at this later stage and losing their support network.

These concerns were echoed in a different sample. Participants in a small study (n=8) aged 19-25, took part in a series of semi-structured interviews, investigating reasons for non-adherence to self-care. Previous experiences with an overly controlling parent was viewed as problematic, since it led to heightened rebellion against self-care. However, feelings of neglect from family and friends resulting from the loss of support, were also highlighted as barriers to effective self-care (46).

It has been shown that emerging adults in their first year post high school are very likely to take on total diabetes care responsibilities (62), which includes non-daily tasks such as managing clinic appointments or ordering repeat prescriptions. This is particularly likely when first time independent living coincides with leaving school (62). The feelings expressed from the samples described above is, that the switch to becoming totally responsible after transition brings about new challenges that can be overwhelming. There is still a need for ongoing higher levels of support for emerging adults after transition. The impact of losing routine family support, coupled with new autonomous responsibilities, creates a situation where self-care can easily deteriorate. In addition to deeper exploration of some of the themes identified in the above qualitative studies, the present mixed methods study has the advantage of investigating quantitative relationships between individual characteristics and self-care activities in this population, which could strengthen this body of literature.

Mental and emotional health problems

Depression

The prevalence of depression has been reported to be higher in young people with type 1 diabetes compared with their peers (63, 64). However, many previous studies have evaluated adolescents and emerging adults together, making interpretation of data specifically relating to emerging adults difficult.

One longitudinal study involving 117 emerging adults, found the prevalence of symptoms reflecting elevated risk of clinical depression, to be 34%, which was not significantly different from controls (65, 66). Nonetheless, the presence of depressive symptoms in emerging adults with type 1 has been associated with lower levels of self-care (67). In a sample of 175 younger emerging adults (mean age 17.7 years (0.37)), participants with greater symptoms of depression reported lower self-care, had higher HbA1c and were experiencing higher levels of diabetes-related stress (67). This specific type of stress appears to be a particular concern among emerging adults (68).

Diabetes Distress

Diabetes distress is characterised by a set of negative, often hidden emotions, arising from the burden of living with diabetes and the complex management it requires (69). Diabetes distress is distinct from general anxiety and may be more common than other clinical affective disorders (68). Causes of diabetes distress are varied and can include the practical challenges of managing glycaemic control, distress can also arise from feelings of isolation and powerlessness (69). If severe, it can lead to a state of complete burnout and avoidance of self-care (45). Studies that have measured diabetes distress specifically, as opposed to general stress, have found the incidence of this phenomenon to be high in emerging adults (70). For example, in a sample of 283 emerging adults, diabetes distress classified as clinically significant, was found in 27.9% of participants (68). In another sample of 185 emerging adults (aged 18-30 years) with type 1, 60.1% were classified as having diabetes distress, this was significantly higher than 50.8%, which was found in adults over 30 years old ($p = .004$) (70).

As with depression, the presence of diabetes distress can negatively impact self-care and glycaemic control. Baucom et. al. (2015) investigated the impact of both diabetes-related stress and general stress on daily self-care. The investigators found more severe diabetes distress was associated with less self-care activity, however general stress was not significantly associated with self-care (67). This highlights the value of research using specific measures of stress and anxiety that is uniquely caused by having diabetes. Sources of

diabetes distress identified from previous research include powerlessness, negative social perceptions, physician-related distress, family and friend-related distress, hypoglycaemia distress, management distress and eating distress (71). It has been shown that trouble with diabetes management is most strongly associated with higher HbA1c, whereas powerlessness, reflecting a sense of diabetes being out of one's control, is associated with the highest mean level of distress (71). Qualitative research in emerging adults has revealed there are other sources of distress uniquely pertinent to this population. For example, participants in a study by Balfe et. al. (2013) reported fear of long-term complications, more specifically the future risk of amputation, as a specific source of distress in this age group (n=35, age range 23-30 years). Participants in this study also reported living with diabetes restricts them from 'normal' activities with friends and that they feel stigmatised by the condition (45).

Diabetes stigma

It has been reported that the general public are largely unaware of diabetes being a stigmatised condition, yet many people with diabetes have directly experienced social stigma (72). The rate of stigma-related experiences appears to be substantial. From a survey conducted among over 5400 participants in the USA, 76% of respondents with type 1 reported experiencing stigma, which was significantly higher than in those with type 2 (52%) (73). This study also reported that stigma association was significantly higher in people with type 2 who used insulin, suggesting insulin use is a salient factor in stigma experiences. Respondents cited various forms of stigma arising from misunderstandings, such as beliefs that diabetes is contagious, that it is a result of personal failure of responsibility, and that all forms of diabetes are the same.

Emerging adults with type 1 have voiced that stigma due to public misunderstanding of the differences between type 1 and type 2, is particularly troubling for them (45, 74). They have expressed frustration and anger about experiencing judgement through negative stereotypes, for example that their diabetes must have been self-induced, or they are 'unhealthy', 'fat' or 'lazy' (74). Since type 2 diabetes most commonly features in the media, emerging adults often felt judged if they were public about their condition, as people assumed

their diabetes was preventable (45). They believed that type 1 was often neglected by the media and policy makers, which contributes to this misunderstanding (45).

Stigmatisation not only has an emotional impact, it can also adversely affect self-care. Non-disclosure of diabetes would appear to be a common consequence for emerging adults with type 1 (45, 73). Other problems arise from having to perform self-care in public or in social settings. Emerging adults have reported feeling self-conscious about public insulin injection, finger-prick testing or wearing a pump device and expressed that this is a barrier to self-care (45, 46). The age range 18-22 years has been highlighted as a time when this was most significant, most likely arising from an enhanced desire at this age to be socially accepted by peers.

Conclusions

It is evident that the late teens and early twenties bring additional unique problems for those with type 1 diabetes. Glycaemic control is commonly suboptimal in this age group. There are challenges arising from the transition to adult care settings and independent living, that can have a detrimental impact on diabetes self-care. Moreover, evidence suggests psychosocial problems including mental and emotional health disorders, are prevalent in this population and are a barrier to effective diabetes management.

From this review of the literature, it can be concluded that this is a high-risk population, who present a complex clinical problem for diabetes care providers. A deterioration in their self-care or glycaemic control at this stage in life, has potential to impact their health and well-being in the future. It is therefore necessary to understand more about what controls their self-care behaviours and to identify new ways to support the unique care needs of this population.

Chapter 2 will now discuss health behaviour in more detail.

Chapter 2: Health Behaviour

A health behaviour is defined as an action that aims to prevent disease or ill-health, or to promote good health. In other words, it is behaviour that seeks to sustain a state of health (75). It can involve either a proactive preventative action, for example taking regular physical exercise, or it could be the avoidance of a potentially risky behaviour, such as not smoking. Most human behaviours are partly under volitional control, in response to internal and external stimuli. Other factors that play a role include attitudes, beliefs, personality traits and expected social norms (76). Behavioural actions, including those relating to health, can therefore be conditioned through processes of self-evaluation and modelling (76).

Health behaviour became subject to extensive study in the latter part of the twentieth century and as a result, psychological models have been posited that seek to predict health behaviours. The models draw on social cognitive factors as a means of explaining behavioural choices and actions (77-80). In clinical practice, having a successful model that predicts health behaviour offers clinicians a theory-based means for intervention and support towards positive behavioural changes. As previously discussed in Chapter 1, for people living with type 1 diabetes, individual health behaviour is a crucial determinant of both daily blood glucose management and longer-term health outcomes. For this population and in particular, the high-risk emerging adult group, it would be of benefit to have reliable models that can predict health behaviour.

This chapter will initially describe some of the major social cognitive health behaviour models. A discussion will then be offered regarding their application to emerging adults and young people with type 1 diabetes. Following this, some of the limitations will be highlighted from evaluation of the wider literature. Finally, a rationale will be provided as to why the social cognitive models have not been chosen for application in the present study.

Social Cognitive Theory

Albert Bandura's Social Cognitive Theory explains that intentional behaviour is executed by means of self-regulatory systems (78). Humans self-monitor their own past behaviour, thoughts and feelings in different circumstances. They will appraise successes and failures, set future goals and use progress monitoring to help achieve them. These systems require self-efficacy, that is, a belief that one is capable of carrying out the desired action to succeed. External references may also be used for comparisons, such as the success of other people and one's own behaviour is judged accordingly. In order to form healthier habits or successfully make a healthy behavioural change, Bandura argues that self-efficacy beliefs and outcome expectancies operate as key determinants within the self-regulatory system (81). These principles are foundational to the other health behaviour models described below.

The Theory of Planned Behaviour

A model that has frequently been used to predict health behaviour is the Theory of Planned Behaviour (80). According to Ajzen, a reasoned assessment is made on whether to follow a course of action or not. A combination of motivational goals, perceived potential consequences and the individual's attitude towards the behaviour, contribute to the assessment. The theory contains three main constructs: attitudes towards the planned behaviour, perceived subjective norms and social pressures, and perceived level of behavioural control. All three constructs lead to the formation of behavioural intentions, which act as a mediator and ultimately lead to the course of action (82).

The Health Belief Model

The Health Belief Model was developed following research into why people do not always respond to public health programmes, or use health services (77). According to this model, the motivation to adopt a preventative health behaviour is the result of what essentially becomes an analysis of perceived risks against perceived benefits. Individual perceptions of risks and benefits are moderated

by variables such as socio-economic demographics, knowledge of the disease and media influences.

The model contains construct variables relating to what Rosenstock et al. (1966) describe as a state of 'readiness to act'. Perceived susceptibility is a subjective belief about the likelihood of contracting or suffering from an illness, whereas perceived severity is belief about the consequences, for example physical pain or emotional distress. When assessing whether to follow a particular course of action, an individual will weigh potential benefits of the action against likely barriers. For example, if an overweight person believes they are at high risk of suffering from hypertension (high perceived susceptibility) and that hypertension is dangerous (high perceived severity), they might review the benefits and barriers associated with following a weight loss programme. Benefits could include less chance of hypertension, looking slimmer and increased self-esteem, however, barriers might be financial costs of a gym membership, time pressure or possible injury caused by increased exercising.

The model has been refined over the years, and another construct that has been added was the influence of 'cues to action' (83). Cues to action are triggers that can catalyse readiness to act, these are most likely to be external variables such as public health campaigns or previous experience of the illness. However, they can also be more personal or internally driven, for example noticing an increase in body fat or experiencing warning signs such as a smoker's cough. Further extension of the model included the constructs of locus of control and self-efficacy (84), however, many studies conducted have used the original four constructs of susceptibility, severity, barriers and benefits.

Common Sense Model of Illness Representations

Leventhal et al.'s (2003) Common-Sense Model is a self-regulatory model centred on the individual's beliefs about the illness (85, 86). From these beliefs, coping behaviours can be predicted through the model. A contemporary of Rosenstock, Leventhal's early work investigated responses to fear appeal messages. It was found that the effects of fear motivation were both transient

and of limited impact, particularly if the message is presented without any action strategies to reduce danger from the threat (85). At the core of the Common-Sense Model is the subjective representation of the illness, which incorporates five factors: the identity (usually via symptoms), a perceived timeline (e.g. illness duration or time a treatment will take to work), consequences or expected outcomes, cause of the illness and finally controllability of the illness. Responses to the illness are presented under the parallel categories of fear control (from initial emotional response to the stimuli) and danger control (cognitions arising from assessing and managing the threat). Coping strategies are then formed and an action is carried out accordingly. This is followed by an appraisal and subsequent re-adjustment as necessary, as part of a feedback loop.

Application of the models in young people with type 1 diabetes

The social cognitive models described above have been applied in a diverse range of health behaviour studies, as such there is an extensive body of literature evaluating their use. In the main, the models have shown utility in predicting health behaviours in adults, for example in the uptake of cancer screening (87) or the adoption of healthy eating behaviours (88). Previous application of the models has also included investigation of health behaviours in young people with type 1 diabetes. It would seem appropriate to expect the social cognitive model constructs to predict self-care behaviour for management of type 1 diabetes. For example, high levels of self-efficacy would be required to develop competence in self-care activities. Cues to action may include results from checking blood glucose levels or feeling symptoms of hypoglycaemia. An assessment of the likelihood of chronic complications, would likely involve the four Health Belief Model constructs of severity, susceptibility, barriers and benefits and any of these could contribute to a subsequent self-care behaviour. However, previous studies conducted in young people with type 1 diabetes have produced conflicting data for both glycaemic control and psychological outcomes, with many studies failing to show significant utility of the models (89-91). Some examples are discussed below.

In a study involving 87 adolescent females with type 1 (age range 16.1 - 21.4 years), researchers compared the Health Belief Model, self-efficacy and some constructs of the Theory of Planned Behaviour, to investigate which model predicted intentions around safe sexual health practice (92). This study found that a composite combination of some of the measured constructs, rather than one particular model, produced the best fit from the data. High self-efficacy, cues to action and low perceived barriers, were the strongest predictors, explaining 26% of the variance in intentions towards safer sexual health behaviours (92). These findings suggest that, although some of the measured constructs are important in predicting intentional behaviour in adolescents, the existing models themselves do not have the same utility in predicting behavioural choices when compared with adult samples. It should be noted that measurement of intentions may not correlate with actual behaviours. Additionally, this study was not investigating diabetes outcomes, limiting both the strength and usefulness of these findings.

In another example, the Health Belief Model was analysed for its ability to predict self-care behaviours in a sample of emerging adults aged 16-25 years (n = 118) (89). In this study, an extended version of the model was used, which included measures of self-efficacy, locus of control, health value and social support (93). Overall, the model explained 12% of the variance in self-care, however the only significant predictors were found to be family support, internal locus of control and self-efficacy. Again, some constructs have been shown to predict behaviours in this sample, however, none of the four original constructs of the Health Belief Model predicted self-care. In adolescents and emerging adults, it is possible that other variables have an influence on health behaviour, for example personality traits. It would appear that social cognitive theory can only partially predict behaviour in younger people with type 1 diabetes.

Other studies have incorporated social cognitive theory, to design clinical interventions aimed at improving self-care in young people with type 1 diabetes (91, 94, 95). These studies have also produced limited evidence of efficacy. For example, in a randomised-controlled trial involving motivational text message support for children and adolescents (n = 92, age range 8 – 18 years), a significant reduction in HbA1c, alongside improved self-efficacy and child self-

reported adherence was found (94). However, a study using a coping skills training intervention to enhance self-care among younger adolescents aged 11 – 14 years (n = 320), did not show significant improvements in glycaemic control or coping measures at 3 and 6 months, when compared with controls (91). The training intervention had been based on social cognitive theory principles and aimed to enhance self-efficacy and skills development, however, it was not made clear how.

Lack of clarity about how interventions are based on social cognitive models, is an issue that has been highlighted in a recent systematic review about theory-based interventions to improve self-management of chronic conditions (96). In this review, which included studies involving adolescents with type 1 diabetes, the authors concluded that variation in effectiveness of the interventions, could be down to a lack of explicit application of the theory to design of the interventions (96). However, another reason for the conflicting evidence described in the sections above, could be the varied age ranges of participants included, from children through to emerging adults. The likely influence of the developmental capacity of participants and amount of parental involvement in self-care responsibility, cannot be underestimated.

It is challenging to interpret these data and relate findings to the target sample for the present research. It would appear that some constructs within the social cognitive models can predict self-care behaviour to an extent, including self-efficacy, cues to action, low perceived barriers, locus of control, health value and social support. However, there is a lack of evidence supporting utility of the other constructs. Additionally, evidence supporting use of the models in emerging adults specifically is lacking, since the studies have mostly involved younger adolescents or a mix of some adolescent and emerging adult age groups. This could influence findings, due to developmental differences between participants and the likely involvement of parents in self-care responsibility.

General limitations and criticisms of the models

Many studies involving health behaviour models have measured intentions as a dependent variable, rather than actual behaviours, because it has been recognised that intentions are a strong mediator of behavioural outcomes (97). However, this raises the question as to whether intending to carry out a particular behaviour always precedes the action itself. A meta-analysis of meta-analyses using the Theory of Planned Behaviour (total sample size $n=82,107$), investigated intention-behaviour correlations in health behaviour areas such as weight loss, exercise participation, cancer screening and condom use. The investigators found a sample-weighted average correlation of $r=0.53$, with $R^2=0.28$, which would support the argument that intentions are a 'moderate' predictor of behaviour (98). However, in real life, actions don't always correlate with intentions (99). People can form positive intentions but not act. Conversely, someone might carry out an action they had not previously intended, highlighting that there can exist a notable intention-behaviour gap. It has been shown in various samples that the most common type of intention-behaviour gap is when positive intentions do not result in the intended behaviour (98). The predictive utility of the Theory of Planned Behaviour model is therefore limited by the lack of correlation between intentions and actual behaviour.

As highlighted in the previous section, criticism has been levelled regarding the predictability of some of the constructs within the social cognitive models. For example, the perceived social norms construct of the Theory of Planned Behaviour has failed to show correlation with intentions in several studies (100, 101). The Health Belief Model has also shown limited predictability of its four original constructs in adults. A meta-analysis published in 2010 analysed data from 18 longitudinal studies ($n=2702$) (102). Correlation results of the effects of the four variables were as follows: severity $r=0.15$, susceptibility $r=0.05$, benefits $r=0.27$, barriers $r=0.30$. As can be seen, the predictability value of the susceptibility construct in this sample is virtually negligible. Perceived severity resulted in a small correlation and benefits/barriers slightly larger correlations. Findings also showed the amount of time between measuring the constructs and measuring the outcome behaviour, moderates the relationship, where the impact fades with time (102). This was the case for perceived severity,

susceptibility and benefits: the predictability of these constructs diminished if the behavioural measure was taken a long time after the Health Belief Model measures. In other words, the model is more effective at predicting health behaviour in the shorter term.

Another notable consideration involving time scales is that beliefs could subsequently change as a consequence of a new behavioural response (103). For example, if someone chooses to follow a treatment programme, over time they may start to feel new benefits such as symptom alleviation. This would likely change their perception of illness severity, benefits and barriers. Alternatively, they might come across problems and constraints they hadn't anticipated, for example experiencing adverse effects with a new medication. This type of re-assessment of all four Health Belief Model constructs, limits the model's ability to predict sustained or longer-term behaviour. The model was originally designed to predict the uptake of preventative behaviours, as opposed to treatment or self-care behaviours for an existing condition (83). This therefore limits the usefulness when assessing the daily self-care required to manage chronic conditions such as type 1 diabetes.

The Common-Sense Model has been applied to people with chronic health conditions, as a means of predicting coping and self-management behaviours. The effectiveness of the model was extensively reviewed by Hagger & Orbell in 2003. Their meta-analysis of 45 studies revealed consistently significant relationships between illness representations, coping and illness outcomes. High controllability was associated with adaptive coping measures, such as social functioning, low psychological distress and increased well-being. However, a strong illness identity (meaning higher perceived symptoms), a chronic timeline and perceived serious consequences, were all associated with maladaptive coping and outcomes (104).

Data on the effectiveness of the Common-Sense Model to predict health behaviours, are limited by a lack of consistent means of measuring coping behaviours. Many studies have used generic problem-solving measures rather than disease-specific tools, which are more likely to measure uniquely associated management behaviours. Another limitation of these studies, is that

most have been cross-sectional, and therefore unable to show causality between the illness representations and coping behaviours. Moreover, without longitudinal outcomes, it is not possible to know whether the passage of time would change either the illness perceptions or the coping behaviours. Carrying out a coping action, regardless of whether adaptive or maladaptive, would be expected to lead to changes in perception of illness identity, timeline, consequences or controllability. As time passes, we simply cannot know whether the associations would remain.

For the social cognitive models, a change in perceptions over time would clearly impact the effectiveness of the model. Temporality is an important factor that should be considered in relation to health behaviour over the longer-term, such as daily self-care of type 1 diabetes. Moreover, past or habitual behaviour should be considered as part of any timeline (105). Past health behaviour is known to be a significant predictor of present behaviour. For example, past physical exercise behaviour has been shown to directly and indirectly predict intentions to exercise, via self-efficacy and attitudes respectively (105).

Rationale to reject the models for the present research

The social cognitive models have not been chosen for use in the present study for various reasons. As discussed in the previous section, evidence in support of the models for predicting behaviour in emerging adults is lacking. The models give little account for dynamic changes over time, which requires consideration when exploring self-care for chronic conditions. Additionally, there is a lack of consideration given to emotional responses that can contribute to behavioural outcomes, with emphasis being on volitional responses (106).

However, a more compelling reason, concerns the underlying assumptions these models make about the way individuals make their choices. The ability of the models to predict health behaviour is dependent upon rational choices being made, in response to weighing risks against possible beneficial outcomes. It can be argued that emerging adults may not weigh their decisions in the same way a mature adult would, therefore attempting to fit them into a 'rational patient' model is problematic.

According to traditional theories about rational choice, behavioural actions arise from choices that will maximise utility from the available resources (107). Rational actors will seek out and evaluate the best information available to them, particularly for major decisions, such as those concerning health (107). As previously discussed in Chapter 1, emerging adults are more likely to take risks in relation to their health, when compared with older adults (10, 108). One possible explanation for this, is that health-related decisions are made more impulsively, because emerging adults have higher levels of uncertainty about the future when compared with adults (108). A lack of knowledge and experience may lead them to decisions that would appear irrational to a more experienced adult, but they are simply a reflection of limited understanding of all the possible consequences (12). Moreover, where there is uncertainty about the future, an expected utility assessment may not be driven by future benefits, but influenced by other factors, such as responding to peer pressures or perceived immediate gains (12). It is likely that individuals in the emerging adult age group would still hold uncertainties about distant future outcomes (11). For these reasons, it cannot be assumed that processes underlying emerging adults' health behaviour would align with the principles of the social cognitive models. Moreover, the original empiric evidence showing the effectiveness of the social cognitive models involved adult samples (77, 79, 80). Given the developmental considerations discussed above, using these models in emerging adults that were designed for and tested in adults, is not supported by evidence.

In summary, social cognitive models have shown ability to predict health behaviour in some circumstances and some populations. However, health behaviour is complex and there are factors that social cognitive theory doesn't necessarily account for. The models depend upon a rational assessment of risk against potential benefits based on evidence from adult samples, which may not be applicable universally across populations such as emerging adults. For these groups, it would be of interest to evaluate individual characteristics that have been associated with health behaviour instead. The present study will focus on associations with time perspective (109, 110), which will be detailed in the next chapter.

Chapter 3. Time Perspective

In the previous chapter, health behaviour and social cognitive models to predict health behaviour were examined. However, it was noted that evidence is lacking about the effectiveness of such models in predicting self-care behaviour in emerging adults with type 1 diabetes. Additionally, it was proposed that emerging adults may not make decisions in the rational manner these models require, meaning examination of other individual characteristics known to influence health behaviour would be of benefit. Given its relevance for conceptualising future health complications and promoting self-care, for the present research, associations between time perspective and health behaviours will be investigated.

This chapter will provide an overview of time perspective, including notable differences in time perspective across the life-span and characteristics that have been associated with time perspective. However, the main focus will be to review the existing literature showing the associations between time perspective and health behaviour.

Background

The influence of time perspective on behaviour was made prominent by the psychologist Kurt Lewin (111). He defined time perspective as coming from the totality of a person's view of their past and future, at any given present time (111). Lewin explained that views of the past or future, even if incorrect or unreal, constitute a reality for the individual and form simultaneous parts of their time perspective. The interaction between these parts influences behaviour and since the context relates to a specific time in the present, these factors are dynamic and their influence may change accordingly.

Over the years, scholars have debated how to define and assess time perspective. For example, philosophical questions have been raised about duration and succession, since what is considered to be 'present' is subjective abstraction, in the same way that past and future are abstractions (112). The

literature shows early attempts to measure time perspective, for example by use of timelines, where participants identified and arranged important life events, or by means of story-telling, to identify future expansiveness (113, 114). However, in the late 1990s, Zimbardo and Boyd's conceptual framework of time perspective provided both refinement to the definition and an inventory to measure time perspective (3). This model has been widely cited in the literature since its publication and the validated scale has been used repeatedly across many studies and populations. It will therefore be applied in the present study.

According to their original model, the three temporal frames of past, present and future are further subdivided into five perspectives of past positive, past negative, present hedonistic, present fatalistic and future. Past positive reflects a favourable attitude of warmth and nostalgia towards the past, whereas past negative reflects a pessimistic and unfavourable view of the past. In both cases, this attitude can come from actual past experiences, or from the individual's reconstruction and beliefs about their past, in either a positive or negative way. Present hedonistic perspective reflects a pleasure-seeking attitude with little regard for consequences of actions. Present fatalism is demonstrated by an attitude of hopelessness towards the future and a sense that outcomes are beyond the individual's control, likely down to fate. Future time perspective is characterised by a focus on achieving goals and being motivated by reward. The authors argue there are individual characteristic differences across these five perspectives, measurable using the Zimbardo Time Perspective Inventory (ZTPI) (full details of the inventory can be found in Chapter 4).

Time perspective across age groups

Studies have shown that there are characteristic differences in time perspective, according to age (115-117). For example, a study conducted by Chen et. al. (2016), mapped differences across five groups, including children (aged 9-11 yrs), teenagers (12-18 yrs), young adults (19-40 yrs), middle-aged adults (41-64 yrs) and older adults (>65 yrs)(115). The results from 1,901 participants were plotted as a time perspective trajectory across the age groups. Future time perspective scores showed a rise from teens through adulthood, then a decrease in older adulthood. Both present hedonistic and past negative

perspectives peaked in the teenage group then generally declined. The present fatalistic scores were lowest in childhood and steadily increased with age. Participants showed a general decline in past positive across the age groups (115).

Differences have also been noted depending on whether individuals have a time expansive or time limited view (117). It has been shown that motivation for goals becomes more emotionally driven in older adults who have a more time limited outlook, compared to younger adults (117). More recently, Laureiro-Martinez and colleagues conducted a meta-analysis to investigate age-related differences in time perspective scores (116). A total of 72 studies representing 29,819 participants were included for analysis. Meta-regression was applied to compare mean ZTPI scores against mean age. Results showed a negative relationship between aging and both past negative and present hedonism, similar to the findings from Chen et al.

These studies suggest that time perspective changes at different stages across a lifespan. However, it should be noted that most of the data above are extrapolated from cross-sectional rather than longitudinal studies. Although they provide a picture within age groups, they cannot show individual changes in perspective over time. These data would suggest that for a sample of emerging adults, characteristic dominance in past negative and present hedonistic perspectives could be expected, possibly with lower future time perspective. It would be of interest to know whether a difference in time perspective profile would change the associations between time perspective and health behaviour in emerging adults, when compared to other adult samples.

Time perspective associated characteristics

Zimbardo & Boyd's (1999) original research identified associations between the five time perspectives and emotional and behavioural characteristics (3). Past negative is associated with higher levels of anxiety, depression and aggression and with lower emotional stability, impulse control and self-esteem (3). Past positive is associated with higher self-esteem, happiness and friendliness, and with low levels of anxiety or aggression (3). High scores on the present

hedonistic scale are positively correlated with sensation seeking, aggression and ego control, but negatively correlated with considering future consequences, conscientiousness or a preference for consistency (3). The present fatalistic scale shows associations with depression, anxiety and novelty seeking, however negative associations have been found with self-esteem, conscientiousness and considering future consequences (3). Finally, future time perspective is positively associated with conscientiousness, considering future consequences, a preference for consistency and reward (3). It is negatively associated with novelty or sensation seeking, with aggression and ego control (3).

The ideal for well-being is presented as a balanced time perspective, reflected by a higher score in past positive, moderate to high scores in future and present hedonism, and lower scores in past negative and present fatalism (118). It has been suggested those with a balanced time perspective can switch the dominant influence depending on the situation. This would prevent too much influence of one of the higher scoring perspectives leading to adverse behaviours (118). For example, too much future time perspective and emphasis on goals could bring about anxiety, whereas excessive present hedonism could result in impulsive risk taking. Being able to balance the influence of these perspectives, would allow a person to take pleasure in living in the moment, but with sufficient consideration still being given to the consequences of their actions. However, at present, there appears to be a lack of empirical evidence regarding balanced time perspective. There is a lack of consistency in how balanced time perspective is numerically defined which limits interpretation (119). Zimbardo's theory does not apply threshold metrics to determine 'high', 'moderate' and 'low' scores on the scales, however an ideal score profile across the five perspectives is proposed (120). These optimal scores have been determined from an extensive cross-cultural database and equate to 4.60 on past positive, 4.00 on future, 3.90 on present hedonism, 1.95 on past negative and 1.50 on present fatalism (121). These figures appear to have been estimated from normal distributions, however, it has not been made clear whether the optimal balanced time perspective profile has been generated from data, theory, or both. The present study will focus on the original five time

perspectives and evaluate variables against these, rather than on the balanced time perspective profile.

Summary

There are evidently natural changes in time perspective across different age groups. In younger people specifically, there is increased likelihood they will hold a negative view of the past, have a present hedonistic outlook and be less future focused. The various time perspectives are known to be associated with a range of characteristics. These would suggest that the typical time perspective profiles of younger people could result in negative behaviours, perhaps from associated anxiety and depression, or through lack of consideration for the consequences of their actions. In light of these associated characteristics and the permutable nature of time perspective, there has been interest in its application in a wide range of social and motivational research disciplines. Examples include cultural (122), occupational (123), consumer behaviour (124), academic achievement (125) and health behaviour (126). The latter of these, health behaviour, will be the focus of the rest of this chapter.

Time Perspective in health behaviour research

Studies investigating the role of time perspective in health behaviour have covered many topics, for example the uptake of health screening (127), the use of substances (128, 129), healthy eating (130), weight loss (130) and physical activity (131). The association between future time perspective and the adoption of health protective behaviours, or the avoidance of health risks, has been demonstrated through meta-analysis of many of these studies (5, 6). The following sections discuss some of the associations between time perspective and specific health behaviours. Additionally, some evidence showing use of time perspective interventions to improve health behaviours is highlighted.

Substance use

Studies have demonstrated the influence of time perspective on health behaviours relating to substance use, particularly among emerging adult

student populations (128, 129, 132). Future time perspective has been negatively associated with substance use, whereas both the present perspectives have been associated with higher substance use (129). For example, Keough et al. demonstrated that future perspective was negatively associated with alcohol, tobacco and recreational drug use (128), such that, those scoring higher in future time perspective reported less frequent substance use. This study included a large (n=2627) and diverse participant group in the USA, recruiting youth and adults from high schools, community colleges and various universities. The strongest associations were found between higher substance use and the two present time perspectives.

Similarly, a large scale study conducted in 1620 high school students aged 12-16 in Northern Ireland, showed higher alcohol consumption scores were significantly associated with both the present perspectives, and were negatively associated with future time perspective (129). Drinking scores were also found to be positively associated with past negative, but negatively associated with past positive scores, suggesting that past time perspective may also have an influence in health behaviour.

Sexual health

An association between future time perspective and reduced risk taking in sexual practice has previously been demonstrated in a 1996 study (133). In a sample of 188 heterosexual US college students, future perspective was associated with less sexual experience, fewer partners and more protective measures against HIV infection.

More recently, future time perspective was shown to be associated with less risky sexual behaviour in a sample of emerging adults aged 18-26 (134). Participants were recruited in central South Africa to take part in a cross-sectional study. It was hypothesised the relationship between risky sexual behaviour (measured by the Perceptions of HIV/AIDS Risk Survey) and self-efficacy would be moderated by time perspective. Results did not show a moderating effect of future time perspective on self-efficacy, but findings did show a negative correlation between risk behaviours and both future

perspective and self-efficacy, such that higher future time perspective and self-efficacy, were associated with less risky sexual behaviour.

Diet, exercise and mixed health behaviour studies

Some studies have assessed the role of time perspective in a collective range of general health measures, such as smoking, body mass index (BMI) and levels of physical activity. Results have been conflicting, but many of the data have shown future time perspective to be associated with healthier behaviours (131, 135). For instance, Hall et al. showed future perspective was associated with enhanced uptake of weight management plans, in adults newly diagnosed with type 2 diabetes (n=204) (130). The researchers hypothesised future-oriented participants would demonstrate better uptake of weight management behaviours. Results showed that participants with higher future time perspective reported less fatty food choices and increased levels of physical activity, over a 6 month follow-up period (130).

In a community sample of people with lower than average socioeconomic status in the USA, participants who exercised 3 or more times weekly scored higher in future time perspective, but there were no differences in any other time perspectives according to exercise frequency (136). None of the ZTPI scores differed according to BMI. These findings were in contrast to an earlier study conducted in an English community sample of adults, which found that future orientation, as measured by the Consideration of Future Consequences scale, was associated with a lower BMI (137). This perhaps suggests socioeconomic status confounds the relationship between time perspective and dietary or exercise behaviours.

In a sample of Greek adults, an association between future time perspective and higher levels of physical exercise was demonstrated (138). This study additionally found higher BMI to be associated with past negative and present fatalism. Present hedonism was associated with higher levels of physical exercise and the authors proposed this could be due to exercising being perceived as a pleasurable activity, bringing immediate reward. It could also be a consequence of striving for a better body image.

Since regular physical exercise is a recommended component of self-care for type 1 diabetes, these findings are of interest for the present research. The present study will assess whether similar associations exist in an emerging adult sample, who are required to regularly exercise as part of routine management of an existing condition.

Screening uptake

Some studies have demonstrated a positive relationship between future time perspective and the uptake of preventative health screening, or favourable attitudes towards screening (127, 139). In one study, data from a sample of 709 adults in the UK were analysed to identify associations between socio-economic status, future time perspective as measured by the Consideration of Future Consequences (CFC) scale (140) and attendance at flexible sigmoidoscopy screening for bowel cancer (127). The researchers found higher socio-economic status correlated with screening uptake, and this relationship was mediated by consideration of future consequences. These findings suggest higher socio-economic status better enables the individual to consider future consequences, and perhaps comprehend the benefits of screening.

An earlier UK study assessed differences in intentions towards type 2 diabetes screening programmes between high CFC and low CFC scoring participants (139). Of 210 participants, those with high CFC were found to hold more positive attitudes towards screening, had higher perceived behavioural control and higher intentions to participate in type 2 diabetes screening. Although this study was conducted in adults and related to diabetes prevention, it is possible that emerging adults who consider future consequences would hold more positive attitudes towards screening for long-term complications, in a similar manner.

Time perspective and subjective well-being

Studies investigating correlations between time perspective and subjective well-being, life satisfaction or mood, have commonly found past negative

perspective to be a significant negative predictor of these measures, whereas future time perspective was not consistently associated (141-143). For example, in a Polish sample of 260 students, past negative was the strongest and most consistent predictor of the three measured mood dimensions of energetic arousal, tense arousal and hedonic tone (143). In this study, future time perspective was not significantly related to mood.

Similarly, in a sample of 260 students in Scotland, past negative was found to be a strongly negative predictor of subjective happiness, but future was not correlated (142). A larger study conducted by Boniwell et.al. (2010) across UK and Russian samples, found that participants displaying a balanced time perspective were significantly higher in subjective well-being and life satisfaction (total n=468) (141). This was consistent across the two nationalities. However, in both these investigations, numbers of participants representing a balanced time perspective have been low. Of the sample in Scotland, the balanced group contained 13 participants, compared with 247 in the non-balanced group. In the studies by Boniwell et.al. (2010), 41 out of 179 (UK) and 29 out of 289 (Russia) were classified as demonstrating balanced time perspective. This is suggestive that a balanced time perspective trait is uncommon, at least in these samples.

Nonetheless, interest has recently grown in the potential usefulness of balanced time perspective. For example, a psychotherapy technique of time perspective coaching has been described in the literature (144). The client's ZTPI profile is compared against the ideal balanced profile, then strategies are devised to diminish influence from the negative perspectives and enhance the influence of positive ones. This has been investigated in people suffering from post-traumatic stress disorders (PTSD) (145). The therapy aims to enhance past positive and compensate for past negative, to enhance present hedonistic over fatalistic and to promote a positive outlook for the future. This is done by encouraging more social interactions that take focus off the individual (e.g. helping others in the community) and by identifying coping strategies to move seamlessly into positive perspectives from negative ones. The authors suggest time perspective therapy could be applied to clinical situations other than just PTSD. It is unclear at present whether this is an efficacious therapy to enhance well-being, it does not appear to have been subjected to any clinical trials.

Adherence to treatment recommendations

To date, very few studies have investigated the role of time perspective in self-management of chronic conditions. However, one study has demonstrated a relationship between future time perspective and medication adherence, where proportional increases in future time perspective scores correlated with an increase in self-reported adherence (146).

Participants were recruited from US multi-cultural community samples (n=178) and were adults taking prescribed medication for either hypertension or diabetes. Present and future subscales of the ZTPI were measured alongside the Morisky Medication Adherence Scale. Results additionally demonstrated a positive association between adherence to medication and increasing age. This study had some limitations. Firstly, the past time perspectives were not measured, despite prior research suggesting an association between past time perspective and health behaviour (129, 138, 147). Diabetes and hypertension were taken collectively as a generic example of adherence to treatment for chronic disease, data were not analysed separately for the two conditions. The authors justified this as having been done in previous studies. However, hypertension requires little self-care and monitoring in comparison to diabetes. In diabetes, patients have other dietary and lifestyle recommendations in addition to medication. Nonetheless, this investigation provides evidence to suggest future time perspective is associated with increased adherence to medication for chronic conditions. The present research will expand on this evidence by examining whether future time perspective is associated with a range of self-care behaviours for type 1 diabetes specifically.

More recently, a study involving 129 adults (age range 18-88 years) with type 1 diabetes was conducted to investigate whether a balanced time perspective was associated with frequency of blood glucose monitoring (148). Results showed that having a balanced time perspective was a significant independent predictor of more frequent self-monitoring of blood glucose (148). Since the purpose of this study was to investigate associations with a balanced time perspective, the authors did not report correlational data from the original ZTPI

constructs. It would be of interest to know if any of the five underlying perspectives was having more or less influence on self-monitoring. The present study will therefore investigate all of the time perspective constructs and their associations with self-care.

Although data are limited, these studies are encouraging, because they have shown significant associations between time perspective and the self-management of chronic conditions, including diabetes. There is evidently a lack of research on the role of time perspective in self-care of chronic conditions, which is a gap this thesis aims to address.

Interventions to encourage future time perspective

Given the body of evidence showing an association between future time perspective and healthy behaviours, it is unsurprising that attempts have been made to experimentally induce future time perspective. A few small studies have shown that interventions designed to foster longer-term thinking, could increase positive health choices (149, 150).

For instance, Hall and Fong (2007) showed that a short time perspective intervention led to a non-significant increase in number of hours engaging in exercise, and a significant increase in higher intensity exercise, in a sample of 81 university students (149). The intervention was based on a standard goal-setting physical fitness programme, but designed to make participants more cognisant of long-term implications of present behaviour. Materials were designed to show that the benefits of long-term gains outweigh short-term costs. For example, one activity required participants to visualise costs and benefits of exercising in a time-focused set of weighing scales, leading them to conclude that almost all costs are short-term and the majority of gains are long-term. Participants were randomly allocated to intervention, a standard goal-setting fitness programme or no treatment conditions. This study was limited by participants being self-selected volunteers, who had already registered for an aerobics class for a whole term. Since these were people already motivated towards intense exercise, the results of the intervention may not be generalisable to less motivated populations, or to people with existing health

problems. Additionally, the sample size was small and the lack of validated interventions available may explain why the increase in number of hours of exercise participation was not significant.

An intervention designed to promote sun protection behaviours in teenagers showed that more expansive future thinking can be promoted (150). Adolescents aged 13-19 years (n=253) were allocated to an intervention based on a range of sun protection predictors, or to a matched control on a different health protective topic (dental hygiene). The time perspective element of the intervention involved taking UV photographs of participants which highlighted areas of sun damage. Feedback was given on level of sun damage, likelihood of wrinkles, sun spots and potential cancer risks. Measures were taken by a questionnaire which included time perspective statements to assess long-term health perspective, for example 'Long term health is more important to me than having as much fun as possible'. Participants completed questionnaires at baseline, then again at 5-8 weeks following the intervention. Longer time perspective was reported post-intervention, along with lower appearance motives for tanning. However, no measures were taken on sun protection behaviours, therefore cautious interpretation is advisable. It is not possible to assess whether the increase in future time perspective would correlate with the intended protective behaviours.

Although these examples show some promise on changing perspective, an influence on behaviour cannot be assumed. Consideration should also be given to the influence of other time perspectives. It is not clear whether enhancing future time perspective alone would be associated with healthier choices across different situations. As has been outlined in the discussion above, there is some empirical evidence showing the influence of past negative and present time perspectives in health research. Perhaps the role of the other time perspectives would merit further investigation, altering the influence of these perspectives, might provide an additional target for behavioural intervention. Focusing on future time perspective alone could potentially limit the therapeutic possibilities.

Conclusions

The influence of time perspective on health behaviour is evidently far reaching. Consistent associations have been replicated in a wide range of populations and health behaviour contexts. It is clear that future time perspective is associated with more positive health behaviours, however, the other time perspectives appear to have influence too. What is lacking from this literature, is exploration of the role of time perspective in relation to chronic disease self-management behaviours. Chronic conditions often require complex daily self-care routines in order to retain a state of good health. However, they are typically associated with morbidity in the longer term, or even shortened life expectancy. In the case of diabetes, present time self-care activities can potentially have a positive impact on future health outcomes. Since most future time perspective and health behaviour associations have been identified in healthy volunteer samples, it would be beneficial to investigate the relationship further in diabetes self-care.

The present research

The present research aimed to identify the relationships between time perspective and diabetes self-care in emerging adults. Perceptions about future complications of diabetes held by this population were also explored. The main research questions for this study were:

1. Is future time perspective associated with higher levels of self-care activity? It is hypothesised that scores in future time perspective will be positively associated with self-care and negatively associated with HbA1c levels.
2. Are any other time perspectives associated with self-care or HbA1c and in what ways?
3. What experiences of living with type 1 diabetes are connected to time perspective?
4. What are the perceptions of future complications among emerging adults and how does this affect self-care in present time?

The following chapter will provide a detailed discussion of the methodology that was chosen to address these research questions.

Chapter 4. General Methodology

To appropriately address the main research questions that were proposed at the end of Chapter 3, a mixed methods approach has been taken. This chapter will firstly provide a description of mixed methods, including its historic origins, some recognised techniques and its application in research. A critical discussion is offered on some of the limitations of mixed methods. Moreover, a justification will be provided to support use of this methodology in the present research. The subsequent sections will then provide detailed explanations for the methodological approaches that were adopted in both the quantitative and qualitative phases of this study.

Mixed methods research overview

The use of mixed methods in research is a relatively new phenomenon. The methodology was in its infancy in the early 1990s, and started to gain more recognition post millennium, becoming increasingly utilised within the social and human sciences (151). Mixed methods can be broadly defined as the integrated use of quantitative and qualitative research methods within the same study (152). However, quantitative and qualitative methods are fundamentally distinct from one another and relate to the philosophical position of the research questions they are designed to answer. Quantitative research is underpinned by the positivist paradigm, that is, a view of factual knowledge being revealed solely by observable quantifiable elements (153). Positivists believe there is a single true reality that is separate and unknown to the researcher. This view is typically held within physical science disciplines, where measurable numeric data are used to test hypotheses. Qualitative research however, is underpinned by the constructivist (or interpretivist) paradigm, a stance generally adopted within the social sciences. From this perspective there is not a single observable factual reality, but multiple constructed realities. Context-specific meaning of these realities is interpreted by researchers, through use of narrative and hermeneutics (152).

These distinctions caused impassioned debate during the early years of mixed methods research, with purists on either side arguing that the two techniques cannot, and should not, be mixed (154). In recent years, however, mixed methods approaches have become more widely accepted within the research community (155). So much so, the technique has been presented within its own new paradigm of pragmatism.

The Paradigm Wars

The philosophical differences between the positivist and constructivist views, have certainly raised difficult questions regarding mixed methods research. How can one approach, that has belief in a singular objective reality at the heart of it, be integrated with another approach, where any number of realities are both possible and constructed?

The debate that has become known as the 'Paradigm Wars' in the literature, ensued from this question and was battled through the 1980s. More notable participants included Guba & Lincoln, constructivists who argued that questions of research methods should fall secondary to questions of paradigm (154). Guba & Lincoln provided a critique of fundamental distinctions between the two paradigms, suggesting these differences prohibited integration of quantitative and qualitative methods (153). The authors posited five opposing axioms of the paradigms, a sixth has been proposed by subsequent authors (156). The axiom differences are shown below in Table 2.

For most part, this debate was focused on education and teaching research. Historically within this discipline, quantitative methods had formed the mainstay of research outputs, but it was recognised by critics that a scientific basis was failing to identify means to improve teaching (157). In his review of the wars at the close of the decade, Gage (1989) highlighted the shift this caused. Interpretive qualitative research started to prevail, as researchers sought to understand perspectives within the classroom. Process and product driven studies focused on achievement outcomes, gave way to studies investigating how teachers understood, explained and presented material.

Table 2 Six axioms within the two paradigms, showing the opposing nature

Axiom	POSITIVIST	CONSTRUCTIVIST
1 Ontology (the nature of reality)	There is a single reality	There are multiple constructed realities
2 Epistemology (the nature of knowledge)	The knower and the known are independent of each other	The knower and the known are inseparable
3 Axiology (the role of values)	Inquiry is value-free	Inquiry is value-laden
4 Generalisations	Time and context-free generalisations are possible	Time and context-free generalisations are not possible
5 Causal linkages	There are real causes, that are temporally precedent to effects	It is impossible to distinguish causes from effects
6 Deductive logic	Emphasis on <i>a priori</i> hypotheses, arguing from the general to the particular	Emphasis on arguing from the particular to the general e.g. grounded theory

Content adapted from: (153, 156)

Schrag (1992) argued however, that it was not possible to avoid educational research methods that were aligned with the positivist paradigm (158). He questioned the usefulness of the interpretivist approach on a wider scale. Although it identifies relational meaning within the school or classroom environment, quantitative approaches will always be necessary to translate these findings to policy level. As an example, he cites qualitative research that showed a cultural mismatch affecting native Hawaiian children and their verbal interactions in the classroom. In Hawaiian culture, speakers overlap in a social setting, rather than waiting for a pause. However, in the classroom, teachers expect children to listen and wait for a pause before speaking. Schrag points out that the wider benefit of this finding was only possible through a controlled

trial. Higher reading achievement was shown amongst children in an intervention group, where speaking was permitted to overlap, versus a control (158). The quantitative data therefore served to complement the qualitative data.

The 'wars' culminated in the 1990s with what has been referred to as the compatibility thesis (159). The prospect of the two paradigms sitting side-by-side was promoted by Datta, who proposed co-existence was possible since both paradigms were widely recognised, both were supported by research communities and both had brought much learning and influence (160). Gage similarly concludes his review of the debate, stating the two types of research are not mutually exclusive. In fact, more insight within the discipline of education research has arisen when studies incorporated both methods (157). Guba & Lincoln however, argued that such is the centrality of paradigms in any type of inquiry, resolution of the debate could only come from emergence of a new paradigm (154).

Pragmatism

In 1988 an alternative argument was presented by Howe, that it was untenable for research methods to continue to be determined by paradigms. As such, he proposed that in the case of the quantitative-qualitative debate, research methods can inform the paradigm in a two-way relationship (159).

Pragmatism as an epistemological paradigm, equally recognises existence and relevance of both the physical and social worlds (161). This reflects the notion that knowledge is both constructed and based on the tangible physical environment. Pragmatism therefore enabled the integration of mixed methodologies and finally presented a resolution for the quantitative-qualitative debate (162). In behavioural and social science research, it provides a philosophical view, whilst additionally allowing the researcher to choose methods that are appropriate to the questions of interest to them (153).

Mixed methods designs

A clear benefit of mixing methods is the capacity for triangulation of data. When exploring complex phenomena such as human behaviour, incorporating quantitative and qualitative methods in an integrated way, allows for each to provide unique insight the other cannot (151). By triangulating both sets of data, a more comprehensive understanding of the problem can be obtained. There are recognised mixed methods designs that provide a means for data triangulation, which are outlined in many research methods texts (151, 152, 163, 164).

The quantitative and qualitative phases can be conducted in parallel or in a sequential format. It is common, although not essential, for researchers to identify dominance of one method, depending on the type of problem they are investigating. Parallel design studies involve collection and analysis of the two types of data from separate studies running alongside one another. Results will then be compared and interpreted, providing a complement to one another. In sequential studies, phases are conducted in a stepwise format, where one phase informs the next. The two common designs for sequential mixed methods are explanatory and exploratory. It is typical for explanatory studies to have a dominant quantitative phase, followed by a qualitative phase, which is used to explain and provide meaning for the quantitative results. Exploratory studies generally have a dominant qualitative phase, which then feeds into the quantitative phase. In both cases, the overall interpretation will involve an integrated discussion on both sets of findings. Further details of the more common designs are outlined below in Table 3, along with some examples of the type of problem each would be appropriate for (151).

Table 3 Common mixed methods typologies

Design	Timeline with dominance	Data analysis and integration	Examples when used
Convergent, parallel	Conducted at the same time in parallel. QUAL + QUAN <i>or</i> QUAL + quan <i>or</i> qual + QUAN	Data sets are collected and analysed separately, findings are then interpreted in a side-by-side comparison discussion.	Understanding complex problems e.g. psychological, to help confirm/ disconfirm. Where combined data on views adds to scale data e.g. consumer behaviour
Sequential, explanatory	Conducted in sequence, quantitative first. QUAN → qual	Quan data are collected, analysed then used to inform questions for qual phase. Uses same sample from quan phase. Findings are interpreted in an integrated discussion on how the qual data have explained the quan data.	In deductive investigation, where theory exists. To identify patterns/relationships and explain mechanisms e.g. in health behaviour. To help explain unusual findings or outliers
Sequential, exploratory	Conducted in sequence, qualitative first. QUAL → quan	Qual data are collected, analysed then used to inform design of the quan phase. Uses different sample from qual phase. The two databases are not compared, discussion on how qual informed quan, and if quan showed generalisability	In inductive investigation, where theory is to be generated and tested e.g. development of a psychometric test

Capitalisation in column 2 represents dominant method. Quan = quantitative, qual = qualitative (151, 153, 163).

Limitations of mixed methods

There is little doubt that many complex problems would benefit from the comprehensive triangulation of data mixing methods permits (163). However, there are limitations that should be noted.

Many scholars still retain purist views and hold firm to the traditional positivist or constructivist paradigms. Such views held amongst the research community can limit the usefulness of data if it is not considered to be valid. Another consequence is that research methodology training may be limited to the historical view of the discipline in question (165). Mixing methods is a lengthy and difficult process, it requires sufficient training and skill in both quantitative and qualitative techniques. There is therefore a risk of researchers lacking skill in one or both techniques, limiting the robustness of the study methods.

General concerns can also be raised around validity (151). Validity of quantitative measures should be established, but there may be a risk of small sample sizes, particularly in longer sequential design projects. Sampling needs to be appropriate for the typology. For example, in sequential exploratory design projects, use of the sample who informed instrument design to quantitatively test the instrument, could invalidate the results by showing the same themes. It would therefore be difficult to establish the generalisability of the results.

Innovation is required to be able to make meaningful associations between the two sets of data. There is also the risk that researchers miss the full possibilities of triangulation, for example by not asking the right questions therefore missing important themes, or not fully seeing the links between the sets of data. It is challenging to genuinely integrate the data and interpret accordingly. Aside from the recognised mixed methods designs outlined in Table 3, there are many other means to integrate the data in a mixed methods study. Indeed the convergence can take place at any point, including sampling, analysis or interpretation (152). This presents multiple potential opportunities for researchers to miss something meaningful from the data.

Use in health research

In the early days of mixed methods, examples of where the methodology can be of benefit in health research were highlighted (163, 166). The complexity of applied research in healthcare, merits the potential depth offered by triangulation of data. For example, a study using a sequential exploratory design among gay and bisexual men aimed to develop the content for a survey on HIV and AIDS related issues (166). The focus groups in the initial phase, enabled access to the community and allowed generation of important questions to be included in the quantitative survey.

The use of mixed methods in health sciences has gained significant recognition following a steady increase in its use over a few decades. A review published in 2007 showed mixed methods use in funded health research in England, increased from 17% in the mid 1990s to 30% by 2004 (167). Similarly in the USA, the number of federal funded health projects claiming to use mixed methods rose to 535 in the years 2009-2014 (168). This was an increase from a total of 226 between the years 1997-2008.

Health sciences historically have come from a positivist tradition, using empirical methods such as controlled clinical trials. However, it has been acknowledged that a growing interest in the addition of qualitative methods, helps health providers better understand their patients (169). In the UK, the Medical Research Council advocates use of qualitative methods alongside quantitative, when designing complex interventions for use in patients (170). Best practice guidelines for mixed methods health research have been produced by the US National Institutes of Health (155). These guidelines are reflective of just how prominent mixed methods has become in the discipline of applied health research.

The appeal of mixed methods to health science researchers is understandable. The desire for robust and generalisable quantitative results, can be complemented and made more meaningful, via the richness of lived experience.

Together, a better understanding of multi-faceted problems can be gained, providing a valuable means to shape policy and practice.

Justification for use in the present study

The present study began with a complex health behavioural problem and as such, the proposed research questions could not be addressed by a single research method. The theoretical framework presented in Chapter 3 merited a quantitative approach, that would enable hypothesis testing on whether self-care behaviour was associated with time perspective. However, these quantitative methods alone would not provide meaning behind the behaviour or any relationships detected (154). Additionally, inquiry into emerging adults' perceptions of future diabetes complications was something that required investigation by qualitative means, to allow full discursive freedom.

The epistemological paradigm underpinning this thesis was therefore pragmatic. In taking this view the research methods were chosen according to the nature of the questions being asked. Since the problem was set within an existing theoretical framework, a sequential explanatory model was chosen (see Table 3). The dominant quantitative phase was used to test the nature of relationships between time perspective and diabetes self-care behaviours in the sample. Results from the quantitative phase could then inform the topics for data collection in the qualitative phase. By providing a comprehensive understanding of the nature and meaning of the relationship between time perspective and self-care, there was potential for new insight to inform clinical care and practice for this high-risk group.

Phase I: Quantitative study

Research questions addressed:

1. Is future time perspective associated with higher levels of self-care activity? It is hypothesised that scores in future time perspective will be positively associated with self-care and negatively associated with HbA1c level

2. Are other time perspectives associated with self-care or HbA1c and in what ways?

Cross-sectional questionnaire design

The quantitative phase aimed to address research questions 1 and 2 outlined above. Measurement of both self-care and time perspective would need to be conducted using validated metric scales to allow for comparison with previous studies, therefore a self-reported questionnaire design was appropriate for this study. There are many advantages to questionnaire research, such as the low costs involved, ease of production and administration to participants and the ability to measure multiple outcomes from a single data collection process (171). Use of questionnaires to conduct cross-sectional data collection, that is, taking a population snapshot at a single point in time, is cited as a useful means of identifying prevalence or associations between variables in applied health research (171, 172). However, cross-sectional studies have known limitations, for example, associations identified do not translate into explanations of causality (171). For this, temporal order is required, which is clearly absent from data collected at a single point in time. Nonetheless, cross-sectional data collection provides a good starting point for the identification of correlations between variables, that can then be further explored. Since this was the overall intention of this mixed methods study, cross-sectional use of a questionnaire was considered most suitable.

Time Perspective measurement

The Zimbardo Time Perspective Inventory (ZTPI) was chosen to measure the construct of time perspective. The inventory contains scales for the five perspectives of past negative, past positive, present hedonistic, present fatalistic and future. Items included in the inventory were theory-driven and refined following years of in-depth research, including repeated factor analyses.

The original inventory contains 56 items in total, responses are rated against a 5-point Likert scale ranging from 'very untrue of me' to 'very true of me'. Items

for past negative include statements such as 'I think about the bad things that have happened to me in the past' and 'I've made mistakes in the past that I wish I could undo'. In the past positive domain, respondents rate against statements including 'on balance, there is much more good to recall than bad in my past'. The present hedonistic scale, reflecting a tendency to enjoy living in the moment, includes statements such as 'ideally, I would live each day as if it were my last'. Examples of present fatalistic items are 'it doesn't make sense to worry about the future, since there is nothing I can do about it anyway' and 'spending what I earn on pleasures today is better than saving for tomorrow's security'. Items such as "I believe that a person's day should be planned ahead each morning' and 'I meet my obligations to friends and authorities on time' measure future time perspective.

A copy of the full ZTPI can be found in Appendix 10. Since its launch, the ZTPI has undoubtedly become the most recognised means of measuring time perspective. It has been tested across cultures and translated into numerous languages. To list just a few of the examples; Italian (173), French (174), Spanish (175), German (176), Czech (177), Lithuanian (178), Greek (179), Russian (180) and Japanese (181).

However, the original 56-item inventory is long and several adaptations have been made to create shortened versions. The phenomenon of 'survey fatigue' has been well documented, where respondents are less likely to take part or complete a questionnaire if they perceive it to be long (182). In this type of research, keeping questionnaires as short as possible is therefore recommended (183). For the present study, the decision was made to use one of the shorter versions, because the questionnaire would also include demographic and reported self-care data.

Several shortened versions of the ZTPI have been developed, with the number of included items ranging between 15 and 36 (173, 184-187). For most of these shortened scales, the decisions on which items to include have been based on exploratory factor analyses. However, a limitation to this type of data driven approach, is the fit of the scale is sample specific and may not be replicated in different samples.

Worrel et. al. took a different approach to developing a shorter form of the ZTPI (188). Adopting a theoretical rather than data driven approach, the authors identified items with 'temporal phrasing' from each of the five perspectives, and included only these. A 25-item scale was produced (ZTPI-TP), with each item containing words or phrases that were specifically related to time, for example 'the past' or 'on time'. Using data from five different samples (total n=3261), exploratory structural equation modelling showed moderate to good fit indices. Due to the theoretical approach to its development, the ZTPI-TP has been chosen as the shortened inventory for use in the present study.

Diabetes self-care measurement

Many instruments have been developed to assess self-care related behaviours in diabetes (189-195). However, some do not ask respondents to report actual self-care behaviours and are measuring constructs related to self-care. For example, the Problem Areas in Diabetes scales for adults and young people (PAID and PAID-T respectively), have been designed to measure levels of diabetes distress (194, 195). The Perceived Diabetes Self-Management Scale (PDSMS) measures exactly that, how the participant perceives the effectiveness of their self-management, it does not ask them to report on activities (191).

Other measures are aimed more generally at diabetes and do not account for type 1 or type 2, for example the Diabetes Self-Management Questionnaire (DSMQ)(196) or the Summary of Diabetes Self-Care Activities (DSCA)(190). For the purposes of this study, an instrument more specific to type 1 diabetes was desired.

Additionally, if possible, an instrument more specific to emerging adults was favourable. Some of the instruments aimed at young people were considered inappropriate, since they target younger adolescents who are still receiving parental care. For example, the Self-Management of Type 1 Diabetes for Adolescents (SMOD-A) contains a subscale on 'collaboration with parents' (193).

The Diabetes Self-Care Inventory (SCI) has been validated for use in type 1 diabetes in children and adults, and has the benefit of being a short (14-item) questionnaire (67, 192, 197, 198). Respondents rate items on a 5-point Likert scale from 'never' to 'always, every time without fail' in response to various self-care activities. Each item begins with the statement: 'in the past month, how frequently have you followed recommendations for...'. A copy of the original SCI can be found in Appendix 9.

The instrument was adapted in 2007 by Helgeson et. al., who added a further eight items of behaviours that are uniquely recognised in young people (199, 200), such as deliberate falsification of blood glucose data. It is this adapted version that has been chosen as most appropriate for this study, since it incorporates the most likely self-care activities and behaviours relevant for emerging adults with type 1.

A copy of the full questionnaire, Participant Information Sheet and consent form can be found in Appendices 2-5.

Phase II: Qualitative Study

Research questions addressed:

3. What experiences of living with type 1 diabetes are connected to time perspective?
4. What are the perceptions of future complications among emerging adults and how does this affect self-care in present time?

The qualitative phase aimed to address research questions 3 and 4 and follow up on findings from the quantitative phase. It is important to examine some of the reasoning that informed the qualitative methodological choices, in order to provide a suitable justification and demonstrate transparency. This will be discussed in the following sections.

Interviews

Data collection for qualitative inquiry can take many forms. Some of the more common approaches include field-based observational data collection, questioning through focus group or individual interviews and examination of documentation. The present sample needed suitable space to reflect on their lived experiences. They would also require sensitivity, given that some of them would likely be experiencing significant challenges with their self-care and may feel reluctant to speak openly in a group situation, for example. It was therefore considered most appropriate to conduct individual interviews.

Qualitative interviews have the intention of gaining insight into the perspectives of another individual and they are based on the assumption that the other person's perspective holds meaningful knowledge and value (201). The interview provides a means of gathering rich data on experiences, views and feelings, to a depth that other methods of data collection cannot, such as questionnaires or observation. Interviews can range from entirely informal conversations to highly structured and standardised questioning. Due to the explanatory nature of the present study, an informal unstructured typology was not considered appropriate. Since the interviews needed to address specific questions derived from novel findings in Phase I, this would require at least some directed questioning. Conversely, if the interviews involved lines of questioning that were too structured and proscriptive, there was risk that the resultant data would not provide deeper meaning, but would merely produce more evidence in support of the Phase I findings. For these reasons, the decision was made to follow a semi-structured format. This method of data collection is well recognised within investigations about individual people's experiences and perceptions around health and healthcare delivery (202).

Semi-structured interviews typically include an interview topic guide that has been designed according to the study purpose and research questions (201). Interview guides will normally contain open-ended questions to allow exploration, however guides may also contain some initial neutral questions to help build rapport (203). A clear benefit of this guided approach is that the researcher can elicit the desired specific information from each participant,

within the given time constraints of the interview (201). It can also assist less experienced interviewers, particularly with the first few interviews in a sample, by providing a directional framework and sense of security (201).

Historically, interviews conducted for qualitative research have been carried out in person or over the telephone. More recently, developments in digital technology have resulted in video chat platforms becoming an alternative means of synchronous interviewing (204, 205). Interest in this format was greatly accelerated in the early part of 2020, due to the COVID-19 pandemic leaving researchers with very limited in-person options (206). During the design stages of the present study, young adult representatives strongly recommended offering video chat interviews as an alternative to in-person interviews, they believed this would increase interest and potential recruitment from the targeted population.

Previously, there has been criticism and caution advised around use of digital interviewing. The loss of relationship and immediacy that can only be gained through in-person interactions, has caused concern among qualitative researchers (207). These concerns have possibly contributed to under-use of the telephone in particular, as a viable medium for qualitative interviewing (207, 208). However, much of this literature pre-dates the use of video chat platforms.

Because of COVID-19 social distancing requirements, video chatting has recently revolutionised communication, it rapidly became accepted and is now practised daily in most societies. Moreover, some of the early arguments against digital forms of interviewing, related to the centrality of non-verbal communication and personal cues (207). Whilst these are appropriate criticisms for asynchronous digital media communication, such characteristics are largely retained in a video chat social space. According to Daft & Lengel's Media Richness Theory, the communication 'richness' of a medium depends on whether (i) immediate feedback can be given or received, (ii) multiple cues can be interpreted, for example non-verbal body language, (iii) sufficient variation in language is possible to enhance understanding and (iv) the message can be personally focused (209-211). An in-person interview therefore provides a richness that is unlikely to be equalled by any other means. The immediacy and

ambience of a face-to-face interaction cannot be engineered through digital alternatives and for this reason, in-person interviews are considered gold standard. However, when evaluated against the four criteria above, synchronous video chat interviewing has good capacity to facilitate an effective exchange and provide a relatively rich alternative medium to in-person interviews.

There are of course, several challenges. Video chat platforms are a barrier to those unfamiliar with this type of technology, or to those who do not have access to the devices required, which could exclude potential participants. Technical problems such as time lags or poor connectivity, can lead to gaps in the data. It has been suggested that researchers account for these possibilities and incorporate procedures within the study design to mitigate or cope with this (210, 212). Suggestions include running practice interviews in advance and ensuring access to alternative platforms as a back-up. Personal security may also be a concern to researchers and participants alike, therefore the avoidance of use of personal accounts by researchers is recommended (210).

Despite this, in a population where video chat interviewing is deemed to be a desirable means of contact, there are certainly notable benefits. Participants do not need to travel to a venue for the interview, which saves time and costs for the study. It considerably widens the geographic pool of potential participants and may lead to the inclusion of people who would be less likely to volunteer for an interview in-person. A recent study among young people aged 15-25, showed that video chat interviewing increased participation from harder to reach individuals, who reported they would not have felt comfortable discussing personal details with the researcher in-person (206). When taking part in the interview itself, participants can choose both when and where to be interviewed and may feel more secure in their own private space. The young participants in the Upadhyay (2020) study cited above, were asked about the video chat interview experience afterwards. They reported feeling more reassured about confidentiality since they were in their own home. They also fed back that video chatting from home gave them a sense of control over the interview and made the experience more comfortable (206).

Aside from practical benefits, the question remains as to whether video chat interviewing would be as effective as in-person interviewing, given the loss of a truly shared social space between researcher and participant. Researchers compared data from two qualitative studies, where data had been collected using both in-person and Skype™ interviews (213). In both these studies, adult participants (n=51 and n= 39) were given the choice of media for their interview, approximately 40% opted for Skype™ interviews. The researchers found that Skype™ interviewing neither resulted in shorter interviews as had previously been suspected, nor did it result in greater scheduling disruption or cancellation. On analysis, both sets of data showed no differences structurally or thematically, between in-person and Skype™ interviews. However, the authors did find that interviews conducted in a public space produced only limited disclosure, regardless of whether they were in-person or via Skype™. This led to the conclusion that privacy, rather than the medium, was a key determinant of interview richness (213).

On balance, for the present study there were potentially many gains to be had from interviewing the emerging adults using video chat platforms. Widening the geographic pool through remote accessibility increased the chances of reaching participants from Phase I, where recruitment and participation had largely been conducted online. Additionally, the sense of privacy, security and control that has been favourably reported by emerging adults in a previous sample, would hopefully increase the recruitment potential and level of disclosure from the target sample, if this form of media was available as an option.

Sampling and Data Saturation

Qualitative research is not normally concerned with generalisability, therefore samples for qualitative studies are identified using non-probabilistic means. A common approach to this is 'purposeful' sampling (201). In this method, participants are targeted as being those cases from which most can be learnt about the phenomenon of interest, they are essentially selected according to a pre-determined set of criteria that are most likely to answer the research questions (203).

The qualitative methodological literature shows that many variations and different subtypes of purposeful sampling exist (151, 201, 214). For example, 'typical' or 'unique' purposeful sampling techniques can be adopted, depending on whether the researcher is interested in obtaining an average representation of certain characteristics of the phenomenon (typical), or more unusual or atypical attributes of the phenomenon (unique) (203). Another variation is where samples are identified simply by convenience, that is, according to the available time, opportunities and resources for data collection (203). It could be argued that an element of convenience sampling will be applicable to all research studies. However, there is risk that mere convenience sampling alone could attenuate the possibility of achieving a desirable data-rich sample. Perhaps a more widely used technique is the 'snowballing' or 'chain' type of purposeful sampling. This is where some early participants in the sample are asked to identify other cases within their networks, which can be a useful way to gain access to a data-rich group. However, it can also lead to inclusion of participants who are more likely to share similar perspectives or experiences of the phenomenon (201).

For sequential explanatory designs, the desired sample will normally be those that can best reflect findings from the quantitative data. However, cases considered outliers from the quantitative analysis are also desirable. The reasons for this relate to the underpinning interpretivist nature of qualitative research: often cases at the outward edges of the spectrum are best placed to shed light on the rest of the data (215). For the present study, a typical sample from Phase I was required for two reasons. Firstly, if any anticipated relationships between time perspective and diabetes self-care were identified in Phase I, a typical sample would be required to provide explanation behind these relationships. Secondly, a typical sample would be able to offer insight around life experiences with diabetes and the general perceptions about future complications held by this population.

Although qualitative studies are not concerned with statistical power, the issue of qualitative sample sizes has been subject to extensive debate. Data saturation, or the point at which no new information is obtained, has been cited as a quality criterion within qualitative methods (216). Many researchers will

commit to data collecting until the point of saturation is reached, however, argument has been made that this coveted saturation point can be whenever the researcher declares it so (215). Methodological studies have been conducted to try and operationalise the concept of saturation, using mathematical models. In one frequently cited study from 2006, the authors concluded that code frequency and stability (meaning codes no longer required revisions of definition) was largely achieved from the first twelve interviews (217). In this study a total of sixty semi-structured interviews were coded and chronologically analysed in sets of six across ten time points. After twelve interviews, 88% of the total number of codes had been developed and 58% of the code definition revisions had been made (217).

The application of quantitative metrics to determine the optimal sample size for a qualitative study, seems somewhat contradictory. Focus is on the particular in qualitative research, therefore concerns over sample size should be remote. Additionally, the subjectivity of saturation means that it is not uniform, for example, a highly homogenous sample is likely to produce data saturation far sooner than a highly heterogenous sample, which might never produce truly saturated data (215). It is arguably of more value to identify the right sample, that is, the one that is most likely to meet the purpose of the inquiry. With regards to the size, in practice, a small number of the right type of participants can provide a far deeper understanding of the phenomenon (201). Target sample sizes for qualitative samples are therefore more likely to be the result of a balanced judgement, where researchers have weighed the intentions of the research against the available time, resources and recruitment possibilities. For the present study, a target sample of 15-20 was deemed appropriate. According to Guest (2006), this number would likely achieve saturation and provide rich insight, whilst at the same time mitigate the risk of the available time and resources becoming exhausted.

Reflexivity

Since interviews involve a human researcher and human participant, both these parties will bring their own perspectives, experiences and assumptions to the process. The act of interviewing is an intrusion into the world of the participant,

where the researcher is not situated separately from the participant (218). Reflexivity is therefore a responsibility that qualitative researchers carry, it requires them to look critically at themselves and to reflect on how their own subjective position might have influenced the collection and analysis of the data (214). Without reflexivity, there is a risk that a researcher's interpretation of the data is exactly that, something that is unique to them and understandable through their eyes only (219). Acknowledgement of how the researcher's own position may have influenced how they approached and understood the data, can contribute to a more meaningful understanding of the findings within the wider research community.

It should be noted that the interview is a socially constructed situation. It is booked and organised to take place at a certain time, in a certain location and both interviewer and participant have differing social roles that they play throughout the process (202). In the case of applied clinical research, dynamics which must be acknowledged include prior knowledge and experience of the phenomenon held by the researcher. Clinical researchers typically come from a historically positivist stance, where practice is routinely guided by evidence-based medicine. The clinical researcher is therefore at risk of seeking objectivity, rather than seeking to understand multiple perspectives (220). Another risk comes from the pre-conceived view of physical disease states as being separate from the mind, this view is characteristic of the clinical world (220). The researcher requires sufficient self-awareness of underpinning beliefs such as these. If their presence was to influence interpretation, there is serious risk of the experiences or perspectives of participants being invalidated.

Since the present researcher has a clinical background and limited qualitative research experience, some steps were incorporated into the procedures to place prominence on reflexivity. These included a pre-interview meditation to increase self-awareness and the keeping of a reflective diary during the data collection phase. These are described in more detail in the methods section in Chapter 6.

Data analysis

The approach to data analysis should be chosen according to the purpose of the research and there is a range of recognised analysis methods within the qualitative field.

One of the more common theory-based types of analysis is phenomenology, which aims to capture the meaning and essence of people's lived experiences of the phenomenon under investigation (201). Phenomenological analysts will approach a dataset inductively and identify the nature of the phenomenon, as expressed from the point of view of the subject. Another commonly cited form of qualitative analysis is Grounded Theory, which places emphasis on the process of generating theory. Grounded theorists take an inductive approach to the data, they identify categories, properties and conceptual links across the dataset to generate substantive theory (216). For the present study, although experiences of living with type 1 diabetes would form a central component of interview discussions, the purpose was not to establish the full structure of this phenomenon, but to relate these experiences to the existing time perspective framework. Additionally, some of the data collected would not be based on lived experiences per se, but would come from abstraction, for example, about what might happen in the future. A phenomenological analysis was therefore not appropriate. Generation of working theory was not the core aim of this research either, meaning Grounded Theory was also unsuitable.

The main purposes of this research were to understand how living with type 1 diabetes is connected to time perspective and to find explanation for the relationships established in Phase I. For this reason, a deductive approach to the data would need to be adopted. It was therefore decided that a more general method of thematic data analysis was required, ideally following a recognised process. The widely cited methods for thematic analysis described by Braun & Clarke (2006) were chosen as being suitable (221). This format incorporates a series of analysis decisions being made in advance, which enhances transparency behind the process of identifying themes. Moreover, this gives the analyst scope to choose the best approach according to the research questions and purpose, for example whether inductive or deductive, or

whether semantic themes are appropriate as opposed to deeper, latent themes. The flexibility of this strategy for thematic analysis enabled the twofold purpose of the present study to be fulfilled. Details of decisions made in relation to the thematic analysis for the Phase II study, are outlined below in Table 4.

Table 4 Key decisions made in advance regarding elements of the analysis, as stipulated by Braun & Clarke (221)

Element	Decision	Rationale
Underpinning epistemology; realist/essentialist or constructionist	Realist/essentialist paradigm	This paradigm assumes motivation and meaning relate directly to personal experience. A constructionist stance does not focus on individuals, but seeks to theorise meaning from a sociocultural context. This perspective does not fit the research purpose. The realist/essentialist perspective aligns with the pragmatic stance taken for this mixed methods project
Considered as a theme	Prevalence and/or salience	Codes will be assigned according to the research questions (any data relating to the five time perspectives or future complications). Themes will be identified according to characteristics of these data and any prevalent or notably salient characteristics will be tested as a theme
Use of the dataset	Aspects of the data, not the full set	To appropriately address the research questions, aspects of the data will be extracted for analysis. It is not the purpose of this study to fully analyse whole participant narratives. Taking aspects of the data will enable a more nuanced examination of time perspective connections and the relationships identified in Phase I
Inductive or deductive analysis	Deductive	The thematic analysis will be conducted using the time perspective framework and the novel Phase I findings. The analysis approach is therefore deductive
Semantic or latent themes	Semantic themes	For this study, interpretation of explicit level themes is appropriate. Latent thematic analysis seeks to theorise underlying concepts and ideologies, which is more appropriately aligned with a constructionist epistemology

Reliability of coding

It has been suggested within the qualitative research field, that inclusion of procedures to independently assess the reliability of data coding can provide better assurance of quality and enhance rigour (222). The use of independent coders, enables an assessment of the extent of agreement on interpretation and also provides a means of evaluating and refining codes, through iterative discussion (223). The use of Cohen's kappa has been recommended with smaller sample sizes, beyond use of a simple percentage calculation, since the statistical test can correct for chance (222). However, many objections have been raised that the use of numeric testing of reliability in this way, is contrary to the interpretivist nature of qualitative research and therefore not relevant (223). For the present study, a simple process of inter-coder reliability will be adopted. Details of the full procedures that were followed for the qualitative study can be found under the methods section in Chapter 6.

Conclusion

This chapter has provided a rationale in support of a mixed methods approach, in order to sufficiently explore the complexity of diabetes self-care in emerging adults with type 1 and the influence of time perspective within this phenomenon. The present research will take place in a two-step sequential explanatory format, with a quantitative cross-sectional questionnaire study being followed by qualitative semi-structured interviews. The subsequent chapters of this thesis will report on the quantitative (Chapter 5) and qualitative studies (Chapter 6) that were conducted, with the concluding Chapter 7 providing an integrated discussion on both sets of data.

Chapter 5. Phase I: Quantitative Study

This chapter contains the full report on the Phase I quantitative study that was conducted. The following sections provide an overview of the background and aims of the study, along with a description of the methods that were used. Results are then presented and discussed, highlighting findings that were followed-up in the Phase II qualitative study.

Introduction

As reported in Chapter 1, emerging adulthood is recognised as a prolonged developmental period following adolescence and occurring approximately between the ages of 18 and 30 years old (10). For emerging adults with type 1 diabetes, it is typical to assume full self-care responsibility from parents and this can bring about new practical challenges (62). For example, non-daily responsibilities such as ordering prescriptions and managing appointments, have been shown to significantly increase due to independent living (62).

Taking on full responsibility for self-care can feel overwhelming for emerging adults and can hinder glycaemic control (54). For those who were diagnosed in childhood, numerous studies have shown a deterioration in glycaemic control following the transition from paediatric to adult care settings (58). For example, one study following a sample of emerging adults across 4 years after moving to adult care, demonstrated an average deterioration in HbA1c from 69.2 mmol/mol (8.5%) to 74.8 mmol/mol (9.0%) (58).

Emerging adults are also less likely to remain engaged with diabetes care services after leaving paediatrics. Established reasons for this include communication barriers and a sense of loss of their known supportive care providers (60). Qualitative research suggests anxiety and emotional distress about glycaemic control are a barrier to self-care among people of this age, with fears about future diabetes complications being voiced as a pertinent source of distress (45). Previous research has shown that having a sense of hopelessness about the future is associated with health-compromising

behaviour in adolescents and emerging adults (129). However, having a focus on future goals has been widely associated with healthy behaviours (6).

There is a plethora of literature showing the association between future time perspective and motivational behaviour (110). In health research, future time perspective has been positively associated with physical activity (138) and engagement with health screening (127), whereas it has been negatively associated with smoking (224). Research among emerging adults and adolescents has shown these groups are likely to engage in high risk social behaviours (10, 225). Among these younger people, future time perspective has again been associated with healthy behaviour, such as less hazardous alcohol use (128) and less risky sexual behaviours, including having fewer partners and using condoms (133). Past negative and present time perspectives, however, have been associated with increased alcohol use among emerging adults (129).

Research investigating the influence of time perspective in self-care of chronic conditions is lacking, since most studies have been conducted in general population samples. However, that which does exist shows similar findings. In middle-aged and older adults, future time perspective has been associated with better weight management in those newly diagnosed with type 2 diabetes (130) and with adherence to medication taking for hypertension or type 2 diabetes (146). A recent study in adults with type 1 diabetes demonstrated an association between having a balanced time perspective (higher in past positive and future, moderate in present hedonistic and lower in past negative and present fatalistic) and more frequent blood glucose monitoring (148). To our knowledge, no research has been conducted to investigate relationships between diabetes self-care and time perspective in emerging adults.

The present study will address the following research questions:

1. Is future time perspective associated with higher levels of self-care activity? It is hypothesised that future time perspective will be positively associated with self-care and negatively associated with HbA1c levels
2. Are any other time perspectives associated with self-care or HbA1c and in what ways?

Methods

Recruitment and participants

Recruitment took place over two time periods, between September 2017 and May 2018 and between October 2019 and May 2020. Eligible participants were adults aged 18-25 years, who had been diagnosed with type 1 diabetes for at least 12 months. Ethical approval from the University of Brighton PABS Research Ethics Committee was granted in August 2017. Ethical and Health Research Authority (HRA) approvals to recruit within the local young adult NHS diabetes clinics, were granted in late November 2017 (see Appendices 6-8 for all ethical approvals). Advertisements were placed on Diabetes UK's Research web pages, magazines and associated social media platforms, to target emerging adults. Recruitment support was provided by Sussex Community NHS Foundation Trust, by promoting the study in dedicated young adults' clinics.

Several pragmatic decisions were made as a means to try and enhance rates of participation. Firstly, data were gathered anonymously. It has been shown that responses to questions in relation to sensitive information are more likely to be answered if data are gathered anonymously and participants are assured of their anonymity (226, 227). Although not deeply sensitive in nature, it would be a reasonable assumption that diabetes self-management behaviours are personal and carry a level of sensitivity, particularly for someone who is less engaged and is perceived to have suboptimal glycaemic control.

Secondly, local and national recruitment methods were employed in an attempt to pull from a wider population, since type 1 diabetes has relatively low prevalence and the inclusion age range narrowed eligibility considerably. It was deemed acceptable for participants to self-report their most recent HbA1c level, to allow for anonymous participation at a national level, which limits reliability of these values. However, the Participant Information Sheet (PIS) encouraged participants to confirm their recent result with their diabetes care providers, before completing the questionnaire. Where possible, HbA1c for those recruited

from the local clinic was provided from clinic records, as described below in the procedures section.

Thirdly, the questionnaire was made available both electronically and on paper. The electronic version was securely stored on a dedicated website. Quick access to the website was provided on posters and flyers in the form of a QR code.

Measures

During the design stages, collaboration was made with a local primary care diabetes clinic for young adults. Nursing and medical representatives contributed to the development of the questionnaire and related materials, along with a young adult patient representative. Demographic variables on the questionnaire included some factors that are known to influence self-care, such as gender, education level, duration of diabetes and insulin delivery method (228). Participants were asked to report on the presence and nature of any diabetes complications and also to provide their recent HbA1c, to enable triangulation between self-reported data and current glycaemic control. The questionnaire was constructed using onlinesurveys.ac.uk. A copy of the full study questionnaire can be found in Appendix 2.

Self-Care

Participants were required to rank their behaviour on a 5-point Likert scale in accordance with statements about various self-care activities, such as checking blood glucose or adjusting insulin doses (see Appendix 9). There were slight amendments made to some of the language for a UK audience, for example the term 'reactions' in the UK is known as 'hypos' or 'hypoglycaemia'. Items 13 and 14, relating to exercise and vigorous exercise respectively, were merged to 'exercising regularly' for simplification, as has been done in previous research (229). Calculation of the overall self-care score includes items 1,2,5,6,7,8 and 13 (192). The additional 8 items known to reflect behaviours seen in young people (199, 200) were all used in calculation of overall adherence to self-care, with negative behaviours being reverse scored. Cronbach's alpha suggested

good internal reliability of the SCI scale for reported diabetes self-care behaviours ($\alpha = .80$).

Time Perspective

The Temporal Phrasing short form of the Zimbardo Time Perspective Inventory (188) includes 25 items from the original (see Appendices 2 & 10). Participants rank their agreement from 'very untrue of me' to 'very true of me' on a 5-point Likert scale. There are five items for each of the past positive, past negative and present hedonistic time perspectives. Four items relate to the present fatalistic perspective and there are six items for future time perspective. All items are included in calculation of the mean for each time perspective, with negative items being reversed scored according to the original author instructions (121). Reliability assessment of the time perspective subscales revealed good internal reliability for the past positive ($\alpha = .69$), past negative ($\alpha = .81$) and future ($\alpha = .69$) subscales, however internal reliability for both present hedonistic and present fatalistic subscales was low (Cronbach's $\alpha = .42$ and $\alpha = .38$ respectively). These findings are comparable with those found in previous assessment of the scale (188).

Procedures

The questionnaire and full participant information were made available electronically via a dedicated secure website designed by the researcher (<https://blogs.brighton.ac.uk/youngt1peeps>), paper copies were also available upon request. Eligible participants who already knew their recent HbA1c result were invited to complete the questionnaire. Agreement to consent was obtained as a step prior to completion of the questionnaire.

In local clinics, the researcher and Young Adults Specialist Nurse promoted the study to clinic attendees, using the posters and flyers. Anyone wishing to take part who did not know their HbA1c, was allocated a unique identification number and written consent taken, allowing permission for anonymised HbA1c results to be shared with the researcher. The clinic provided the researcher with an anonymised list of HbA1c results matched to unique numbers, at the end of the recruitment period. As thanks for their time, participants were offered the

option to enter a prize draw for a £20 shopping voucher. For this, a valid email address was requested, all of which were deleted from records once the prize draw had taken place.

Data analysis strategy

Statistical analyses of the data were conducted using IBM SPSS version 26.0. To determine whether significant relationships existed between demographic variables and the outcomes of self-care or HbA1c, independent t-tests or ANOVAs were conducted as appropriate. Pearson's correlations were conducted to investigate relationships between continuous variables, which included age, time perspective and the dependent variables of self-care and HbA1c. Where data did not follow a normal distribution, suitable transformations were made. To investigate the unique predictability of time perspective on the dependent variables and to control for any demographic variables, hierarchical regressions were conducted. A sample size calculation was performed using G-Power (230). In order to detect a medium effect size ($f^2 = 0.15$) with 80% power and alpha at 0.05, a total sample size of 77 was required.

Preliminary Analyses

A total of 81 individuals completed the questionnaire. Three were excluded on the grounds of being outside the eligible age range (>25 years), leaving 78. Observation of frequency data revealed some likely outliers due to very high HbA1c values. Casewise diagnostics were performed to investigate if these cases were outliers due to distance. Cook's Distance and Centred Leverage Values were also calculated to assess whether they were outliers by influence. Only one single respondent (case 61) was found to have a large residual value in Casewise diagnostics; their actual HbA1c was 196mmol/mol (20%) but the predicted value was 53.7mmol/mol (7.1%). This same case had a Cook's value > 1 (1.42), suggesting they were an outlier influence. The mean Centred Leverage value was .014, cases with Centred Leverage greater than 3 times the mean should be of concern. Case 61 had a value of .046 and was therefore confirmed as an outlier from each of these tests. A further 2 cases (cases 76 and 77) were noted to have high Centred Leverage values compared to the rest

of the sample, with .117 and .146 respectively. These respondents both had HbA1c levels of 130mmol/mol (14%). Although Cook's values for these two cases were not close to 1, their values were higher than anyone else in the sample by a factor of 10, after excluding case 61. All 3 of these cases were therefore considered outliers and removed from further analysis, leaving a final sample of 75.

To determine whether the intended parametric statistical tests were appropriate, underlying assumptions of normal distribution were assessed. This was done both observationally and by use of Kolmogorov-Smirnov and Shapiro-Wilk tests. Three variables had statistically significant results, suggesting a non-normal distribution of these variables. These were HbA1c ($W(66) = .927, p = .001$), age ($W(66) = .940, p = .003$) and past positive time perspective ($W(66) = .926, p = .001$). From observation of the histogram and normal QQ plots, the distribution of age and past positive perspective were deemed to be close to normal, with a negative skew observed on the past positive perspective variable. Data for the dependent variable HbA1c were noted to be positively skewed and were log transformed, resulting in a normal distribution identified by Shapiro-Wilk test ($W(66) = .980, p = .37$). All other variables showed non-significant results representative of normal distributions. Underlying assumptions of normality were pragmatically considered to be upheld. However, due to the negative skew on the single variable past positive perspective, additional correlational analyses using non-parametric Spearman's rho were conducted, as a back-up to the parametric regression analyses.

Results

Respondents were all aged between 18 and 25 years ($M = 21.79, SD = 1.97$), were educated to a high level (87% reported having A-level, equivalent or higher qualifications) and predominantly female (77%). More of the sample reported longer duration of diabetes, with 59% having been diagnosed more than 10 years prior. There were 51% of respondents using a multiple daily insulin injection regimen, the remaining 49% were using a continuous insulin infusion pump. Approximately 20% reported having complications of diabetes. Not all respondents reported a recent HbA1c value ($n=67$) and the mean HbA1c

for the sample was 63.3 mmol/mol (10.1%, $SD = 13.71$). Detailed sample characteristics can be found in Table 5.

Table 5 Main characteristics and sample means with SD

Characteristic	N	Mean (SD) / prevalence %
Age	75	21.79 (1.97)
Gender		
Male	16	21.3
Female	58	77.3
Transgender	1	1.3
Education level		
Up to 5 GCSE	7	9.3
Apprenticeship	3	4.0
A level or above	65	86.7
Duration of diabetes		
1-10 years	31	41.3
>10 years	44	58.7
Insulin regimen		
Multiple daily injections (MDI)	38	50.7
Continuous insulin infusion (pump)	37	49.3
Complications present (yes response)	15	20
Past positive	75	3.57 (0.74)
Past negative	75	3.42 (0.83)
Present hedonistic	75	3.40 (0.55)
Present fatalistic	75	3.07 (0.64)
Future	75	3.29 (0.67)
Self-care	74	3.77 (0.50)
HbA1c (mmol/mol)	67	63.33 (13.71)

Demographic factors and self-care or HbA1c

Independent *t* tests showed there were no significant differences between reported self-care or HbA1c, according to the duration of diabetes (self-care: $t(72) = -1.05, p = .30$, HbA1c: $t(65) = -.32, p = .75$), or the type of insulin device used (self-care: $t(72) = -.52, p = .60$, HbA1c: $t(65) = .26, p = .79$). A significant difference in self-care was found between those with or without complications ($t(71) = -1.98, p = .05$), where those with existing complications reported lower self-care ($M = 3.54, SD = 0.54$) than those without ($M = 3.83, SD = 0.49$). One-way ANOVAs to investigate differences between levels of education on the two outcomes of self-care and HbA1c, revealed no significant differences by demographic groups (self-care: $F(4,69) = 1.66, p = .17$, HbA1c: $F(4,62) = 1.32, p = .27$). A significant difference was found between reported self-care, ($t(71) = 2.37, p = .021$) where males reported higher self-care activity ($M = 4.04, SD = 0.43$), than females ($M = 3.71, SD = .49$). No differences were found in mean HbA1c between the male and female groups ($t(64) = -1.09, p = .28$)¹.

Time perspective correlations

As can be seen in the main correlation matrix in Table 6, several significant relationships between the time perspective scales were identified. Past negative perspective was inversely associated with past positive ($r = -.31, p = .006$). Past negative was also inversely associated with future time perspective ($r = -.33, p = .004$), but positively associated with present fatalistic ($r = .23, p = .047$). A positive correlation was found between the two present time perspective subscales ($r = .40, p < .001$). Additionally, present hedonistic and present fatalistic perspectives were both inversely associated with future time perspective ($r = -.27, p = .02$ and $r = -.35, p = .002$ respectively).

¹ In the gender category the single transgender respondent was excluded from analyses, leaving male and female groups. Variation in degrees of freedom are reflective of missing data.

Self-care correlations

A significant negative association was found between the two dependent variables of self-care and HbA1c ($r = -.50, p < .001$). A positive correlation was found between future time perspective and reported self-care ($r = .42, p < .001$). Inverse associations were found between past negative perspective ($r = -.33, p = .004$) and present fatalistic perspective ($r = -.32, p = .006$), with the dependent variable self-care.

HbA1c correlations

An inverse association was shown between future time perspective and HbA1c ($r = -.28, p = .02$). A positive association was found between past negative perspective and HbA1c ($r = .47, p < .001$). This dependent variable was also found to be positively associated with present fatalistic perspective ($r = .32, p = .008$) and negatively associated with future time perspective ($r = -.28, p = .02$).

Table 6 Bivariate correlations between age, time perspective and outcome variables (Pearson's where data followed normal distribution, Spearman's rho otherwise)

Variable	2.	3.	4.	5.	6.	7.	8.
1. Self-care	-.50**	.09	-.05	-.33**	-.15	-.32**	.42**
<i>N</i>	66	74	74	74	74	74	74
2. HbA1c	---	-.15	-.09	.47**	.12	.32*	-.28*
<i>N</i>		67	67	67	67	67	67
3. Age	---	---	.05	.09	-.18	-.06	.07
<i>N</i>			75	75	75	75	75
4. Past pos	---	---	---	-.31**	.14	-.10	.10
<i>N</i>				75	75	75	75
5. Past neg	---	---	---	---	.17	.23*	-.33**
<i>N</i>					75	75	75
6. Pres hed	---	---	---	---	---	.40**	-.27*
<i>N</i>						75	75
7. Pres fat	---	---	---	---	---	---	-.35**
<i>N</i>							75
8. Future	---	---	---	---	---	---	---
<i>N</i>							75

Past pos = past positive, past neg = past negative, pres hed = present hedonistic, pres fat = present fatalistic.

**p < .05, **p < .01*

Self-care hierarchical regressions

Hierarchical multiple regression analyses were conducted to investigate the independent predictive power of time perspective on self-care. To control for gender, this was entered in the first step, along with other demographic variables of age, duration of diabetes, qualification level, insulin device used and whether complications were present. Time perspectives were then entered in the second step. As can be seen in Table 7 on the following page, model 1 was significant ($F(6,66) = 2.22, p = .05$). Gender was the only significant predictor of self-care, as identified above ($t = -2.33, p = .02$), explaining approximately 17% of the variance. Model 2 was also significant ($F(5,61) = 4.90, p = .001$) and after controlling for gender, future time perspective remained a significant predictor of self-care ($t = 3.06, p = .003$), explaining a further 24% of the variance in reported self-care.

Table 7 Multiple hierarchical regression with self-care

IV	Beta	t	p
<u>Model 1:</u>			
Age	.040	.305	.76
Gender	-.271	-2.33	.02
Duration	.160	1.34	.19
Qualification	.024	.193	.85
Insulin reg.	.058	.515	.61
Complications	.183	1.53	.13
$R^2 = .168, F(6,66) = 2.22, p = .05$			
<u>Model 2:</u>			
Age	.035	.295	.77
Gender	-.293	-2.72	.008
Duration	.162	1.51	.14
Qualification	-.021	-.173	.86
Insulin reg.	.040	.383	.70
Complications	.067	.605	.55
Past Negative	-.210	-1.73	.09
Past Positive	-.128	-1.01	.32
Present Hed.	.117	.940	.35
Present Fat.	-.190	-1.61	.11
Future	.350	3.06	.003
$R^2 \text{ change} = .238, F(5,61) = 4.90, p = .001$			

HbA1c hierarchical regressions

A similar procedure was followed to determine the predictability of time perspective on HbA1c. Demographic variables were entered in step 1, with time perspective variables entered as a second step. Model 1 was not significant ($F(6,60) = 1.37, p = .24$), however model 2 was significant ($F(5,55) = 4.40, p = .002$). Past negative time perspective was the only significant predictor of variance in HbA1c ($t = 1.98, p = .05$), explaining approximately 25% of the variance. Results are shown below in Table 8.

Table 8 Multiple hierarchical regression with HbA1c

IV	Beta	t	p
<u>Model 1:</u>			
Age	-.235	-1.61	.11
Gender	.205	1.64	.11
Duration	.004	.034	.97
Qualification	.090	.637	.52
Insulin reg.	-.057	-.464	.64
Complications	-.197	-1.53	.13
$R^2 = .120, F(6,60) = 1.37, p = .24$			
<u>Model 2:</u>			
Age	-.225	-1.70	.10
Gender	.198	1.70	.10
Duration	-.080	-.682	.50
Qualification	.208	1.56	.12
Insulin reg.	-.045	-.399	.69
Complications	-.078	-.633	.53
Past Negative	.286	1.98	.05
Past Positive	-.193	-1.35	.18
Present Hed.	-.028	-.199	.84
Present Fat.	.189	1.51	.14
Future	-.123	-1.01	.32
$R^2 \text{ change} = .251, F(5,55) = 4.40, p = .002$			

In summary, significant findings from the hierarchical regression analyses were that both male gender and future time perspective were unique predictors of higher self-care scores and past negative perspective was a unique predictor of higher HbA1c level.

Discussion

This study has produced novel findings about relationships between time perspective, diabetes self-care and HbA1c in a sample of emerging adults living with type 1. Demographic variables of age, duration of diabetes, level of qualification, or type of insulin regimen used were not found to be associated with self-care. However, female respondents and those with existing complications of diabetes scored significantly lower on reported self-care. None of the demographic variables were associated with HbA1c. As hypothesised, future time perspective was positively associated with self-care and negatively associated with HbA1c. Past negative time perspective was associated with self-care and HbA1c in the opposite way, where past negative perspective was inversely associated with reported self-care scores and positively associated with HbA1c. Other significant associations between time perspective and the outcome variables were that present fatalistic time perspective was also inversely associated with self-care and positively associated with HbA1c. None of the relationships between present fatalistic perspective and the outcome variables showed significance on hierarchical regression analyses.

Future time perspective findings

These findings add to the body of literature associating a future time perspective with positive health behaviours. They also support two previous general adult studies, where future time perspective was associated with self-management behaviours for diabetes (130, 146), suggesting future time perspective is motivational towards diabetes self-care. However, the present research provides novel data regarding future time perspective and such behaviour in an emerging adult population.

It is comparable with previous age-matched samples that the mean future time perspective score was low in this sample (128). The future score for the sample was the second lowest of the five perspectives, with only present fatalism scoring lower. As hypothesised, future time perspective was associated with higher self-care and lower HbA1c. However, the lower sample mean in future time perspective merits further investigation of this relationship. Whilst it is possible a future time perspective is motivational towards diabetes self-care, the influence may be limited in this population who have a lower future dominance. Being lower in future time perspective could also mean that the emerging adults in this sample would not give much consideration to potential complications of diabetes and perhaps that their outlook is less expansive. The qualitative study in Phase II will examine perceptions about the longer-term future and chronic complications in more depth.

Self-care and glycaemic control outcomes

The sample mean HbA1c of 63.3 mmol/mol (7.9%) was higher than national target recommendations, but is comparable with diabetes monitoring data for this age group (231). Self-care activity was found to correlate with HbA1c, which would suggest the reported behaviours represented a reasonably accurate assessment of self-care. However, the SCI scores themselves are harder to interpret.

The results showed comparable values with age-matched samples; SCI scores in adolescents and emerging adults have been reported to range between approximately 3.5 to 3.77 in previous studies, the latter of these was the mean score in the present sample (57, 232). However, there appears to be no consensus in the literature with regards to threshold values, depicting what corresponds with low, moderate or high levels of self-care activity for example. It is not possible to know which values would translate to desirable glycaemic control in clinical terms.

In the present sample, those with existing diabetes complications scored significantly lower in self-care, suggesting consensus on SCI thresholds may be clinically beneficial. Additionally, in this type of study where data were self-

reported, the influence of social desirability bias can lead respondents to inflate data (233). People who self-select to take part in medical research tend to have a motivation towards the condition of interest. From this, it can be hypothesised that the emerging adults in the present study would take an interest in their diabetes and perhaps represent those who are more motivated with their management. It is therefore possible that the true level of self-care in the sample and wider emerging adult population, is lower than was reported here.

Male respondents were found to have significantly higher scores in reported self-care than female respondents. Previous studies investigating gender differences in adherence to type 1 diabetes self-care among adolescents, have shown conflicting results, with some finding adherence to be higher in males (234) and others finding the opposite (235). In a study involving 175 emerging adults with type 1, no differences were found in levels of self-care adherence between male and female participants (67). The difference observed in the present sample would therefore merit further exploration, however, these results should be interpreted with caution, given the lack of balance between gender groups.

Other time perspective findings

Data from the other time perspective profiles seemed largely consistent with previous literature, demonstrating characteristics typical of young people. The sample scored highest in past positive with approximately equal scores on the past negative and present hedonistic scales as next highest results. As previously described in Chapter 3, it has been shown that younger people are more likely to be past and present focused than older adults, commonly scoring higher in past negative and present hedonistic perspectives (115, 116). The significant associations between past negative perspective and the main outcome variables were concerning. A small, but significant negative association was found between past negative and self-care. Past negative time perspective also correlated with HbA1c level and this was a stronger relationship. In summary, high past negative perspective was associated with lower reported self-care and higher HbA1c.

The influence of past negative perspective on health-related behaviours has been less frequently investigated in studies, when compared with future time perspective. However, some consistent findings associating past negative with adverse behaviours are apparent from the literature. For example, Zimbardo & Boyd (1999) highlighted the influence of past negative perspective in subjective well-being after experiencing a traumatic event (3). Longitudinal research showed past negative was associated with elevated distress, less coping and less emotional growth in the aftermath of the event. Past negative perspective has also been associated with higher body mass index, higher perceived poor health and increased problematic alcohol use among adolescents (129, 138). Past negative perspective has been shown to be a significant negative predictor in subjective well-being and satisfaction with life (141, 142). In view of the significant findings between past negative and the primary outcome measures in the present sample, it can be surmised that some respondents in this sample are experiencing a significant amount of psychological distress. Since depression and diabetes distress have been linked with lower self-care in young people, these phenomena may provide an explanation for the links between past negative and glycaemic control in this sample (63, 70, 236-238).

Moreover, it is possible that the higher past negative perspective in this sample is connected to having diabetes. It is well recognised that post-traumatic stress disorder (PTSD) or post-traumatic stress symptoms (PTSS), can arise as a consequence of diagnosis of a life-threatening condition such as cancer (239).

Martz & Livneh (2007) have previously investigated the connection between post-traumatic reactions and time perspective in people diagnosed with type 1 diabetes (240). A significant negative relationship was found between denial and future time perspective, leading the researchers to conclude that denial, as a symptom of PTSD, truncates future time perspective (240). However, the incidence of PTSS reactions following type 1 diabetes diagnosis is unclear. The incidence among children has been estimated to be around 5% (241), but most diabetes studies have investigated PTSD in parents following child diagnosis (241). It is unknown whether PTSS reactions might be present in a sample of emerging adults and if such symptoms would be connected to a past negative view. Additionally, traumatic incidences relating to living with diabetes can occur

over the years following diagnosis, for example severe hypoglycaemia episodes or diabetes ketoacidosis. Perhaps events such as these could be related to a past negative perspective, or could indeed cause post-traumatic stress reactions themselves.

Interestingly, post-traumatic reactions to other chronic and potentially life-changing conditions, have been found to relate more to the future than to the past. In a study from 2004 involving 58 adults diagnosed with multiple sclerosis, a large proportion of the sample had experienced post-traumatic stress symptoms, with nine meeting criteria for PTSD diagnosis (242). The researchers categorised intrusive re-experiencing thoughts as being either future or past oriented. It was found that future oriented stressors, for example worries about becoming confined to a wheelchair, were more strongly predictive of PTSD. The authors concluded the sense of a foreshortened future is more likely to contribute to PTSD, than reconstructions of the past diagnosis event.

These studies suggest that time perspective is influenced and potentially altered, following diagnosis and subsequent adjustment to living with a chronic condition. Even though the mean time perspective profiles of the present sample appeared consistent with age-matched samples, it would be of interest to explore meaning behind their past, present and future perspectives. Understanding ways in which their time perspectives are connected to living with diabetes, could explain why the significant associations were found in the present study. This will be investigated further in Phase II.

Limitations

This study was limited in several ways. The sample of 75 was small and slightly under-powered. Respondents were self-selected and therefore may not be fully representative of the wider population of emerging adults with type 1 diabetes. Additionally, those with lower levels of education and males were under-represented. The incidence of type 1 diabetes is broadly equal in birth assigned males and females (243), however, previous research has demonstrated females are more likely to respond to questionnaires than males, which may explain the distribution in this sample (244). Nonetheless, given the uneven

distribution across these two groups, interpretation of the difference found between males and females on self-care score requires some caution. The questionnaire asked for an estimate of diabetes self-care which may not be truly reflective of reality. However, a validated metric was used and has shown internal consistency in this sample and in previous literature, with Cronbach's $\alpha = .80$ (198). Not all respondents had recent HbA1c values and for the majority, HbA1c was self-reported and not confirmed from clinic records. The reliability of the ZTPI-TP was low for the two present subscales, making interpretation of associations from these subscales inconclusive. This adapted version of the scale would require further testing in larger samples to assess its reliability. Perhaps with the original ZTPI instrument, clearer relationships with the present time perspectives may have been identified.

Conclusions

This study has shown a significant association between future time perspective and reported self-care behaviours for glycaemic control among emerging adults with type 1 diabetes. Additionally, higher future time perspective was shown to be associated with lower HbA1c. An inverse relationship has been shown with self-care and past negative perspective, which triangulated with HbA1c. These novel findings add to the existing literature on time perspective and health behaviour. It can be surmised that emerging adults with type 1 diabetes who have a negative focus on the past, are at high risk in terms of their future diabetes health outcomes.

The next chapter will detail the procedures and findings of the qualitative study that was conducted, to further explore the meaning behind these relationships.

Chapter 6. Phase II Qualitative Study

Introduction

The sequential explanatory design of this mixed methods project, started with a quantitative phase, for the purpose of identifying relationships between time perspective and the dependent variables of self-care and HbA1c. According to this type of mixed methods design, a rich sample taken from the same participant pool, would then be required for the qualitative study (153). Participants in the second phase should be able to provide explanations behind the relationships that were found quantitatively in the previous study.

In the Phase I study, the sample were found, on average, to score lower in future time perspective when compared with most of the other time perspectives. One of the reasons young people have been found to score lower in future time perspective, is that the cognitive ability to visualise a more expansive projection into the future, develops across late adolescence (11, 12). For example, it has been shown that emerging adults have greater ability to visualise a longer future timeline of their typical life-events, when compared with younger adolescents (11).

It could be expected that the ability to visualise an expansive future in this way, would be varied in the present sample, since capacity to do so is likely developing during this time. It is possible that many of the sample were not considering the expansive future. Qualitative research has suggested that emerging adults with type 1 find the concept of their long-term health, and the importance of the objective measure of HbA1c, hard to comprehend (245). It has also been reported that the prospect of complications serves as a source of fear and anxiety that can hinder self-care among emerging adults (45). For example, in a small study conducted in Sweden (n=8), participants aged 20-25 years had mixed views when asked about the prospect of future complications serving as a motivator for self-care (245). Some reported that thinking about their long-term health was a 'very abstract concept'. Others echoed this view in relation to the measure of HbA1c, stating that it too, was abstract. Conversely, in general adult samples the prospect of future complications has been

highlighted as a motivator for self-care, where self-care serves to reduce the risk of these happening later in life (246). From the Phase I study, a clear association has been shown between future time perspective and self-care behaviour, however the reason for this relationship is less clear, given the low mean score in future time perspective in the sample. If the prospect of future complications is something emerging adults find hard to conceive, it is possible the association between future time perspective and self-care is driven by something else.

Higher past negative perspective was associated with higher HbA1c in Phase I and this finding requires deeper exploration in the present study. As discussed in Chapter 5, it would seem plausible that the past negative view could be connected to living with diabetes. Given the higher clinical risk of emerging adults with type 1 diabetes (231), understanding the meaning behind these associations found with past negative perspective, could provide useful information for targeted interventions and support in diabetes care.

The present study therefore explored experiences of living with diabetes in a sample of the participants, to identify how these experiences related to time perspective. The following original research questions were addressed:

3. What experiences of living with type 1 diabetes are connected to time perspective?
4. What are the perceptions of future complications among emerging adults and how does this affect self-care in present time?

The themes generated from the present study were subsequently triangulated with the Phase I findings, to understand meaning behind the time perspective associations that were found. The integrated discussion following triangulation of the two datasets is presented in Chapter 7.

Methods

Recruitment and participants

Ethical approval was obtained for this study in October 2019, from University of Brighton PABS Research Ethics Committee (Appendix 11) and data collection ran from November 2019 until May 2020.

In Phase I, the most effective means of recruitment was via the Diabetes UK website and social media advertising, evidenced by an influx of completed questionnaires in the days following any new online posts connected to the study. This was therefore adopted as the sole method of recruitment for Phase II and considered sufficient to recruit the targeted 15-20 participants. To assist with planning and design of the study, representatives from the Diabetes UK Young Adults Panel were consulted.

The inclusion criteria were emerging adults aged 18-25 years, with type 1 diabetes that had been diagnosed at least 12 months previously. Ideally, people who had already completed Phase I were desired, however due to the anonymous nature of Phase I it was not possible to specifically identify these participants. Recruiting in the same way through the same pool of participants, increased the chance of identifying participants from the Phase I sample. Promotional materials therefore specifically targeted people who had completed the Phase I questionnaire. However, invitations were also extended to anyone who had not participated previously, since all individuals would be invited to complete the questionnaire before taking part in an interview. The questionnaire for Phase II contained an additional question asking participants to state whether they had completed the same questionnaire in Phase I. Those who had not, were added to the Phase I data set. For those who had taken part in Phase I (or anyone giving a 'don't know' response), the additional Phase II questionnaire was solely used to assist with interpretation of the fully integrated data.

Advertisements were placed on Diabetes UK's research web pages and magazines. Social media platforms such as Twitter™ and Instagram™ were

used by the research team and by Diabetes UK representatives to promote the study. All participant information was made available at the same dedicated study website used for Phase I. Participants provided electronic written consent and were asked to provide an email address and contact telephone number for the purposes of communication, these personal details were all deleted at the end of the study period. As thanks for their time, participants were offered a £20 e-shopping voucher at the end of the interview. Following participation, all interviewees were invited to promote the study in their respective online social media networks. This created a snowballing effect within the Diabetes Online Community. As data collection progressed, advertisements were amended to target specific participants who were under-represented; namely males and younger emerging adults under 20 years old. Full details of the participants can be found below in the results and discussion section. A copy of the questionnaire, participant information sheet and consent form can be found in Appendices 12, 13 and 14 respectively.

Interviews

Interviews were offered in person, or via the video chat platforms Skype™ and WhatsApp™. A dedicated mobile phone, email account and corresponding video chat accounts for the project were created to ensure security of personal information. Interviews were offered flexibly to accommodate participants, including evenings, weekends or anytime during business hours. From 23rd March 2020, due to the COVID-19 pandemic, it was no longer possible to conduct in-person interviews. The project website was therefore amended to advise potential participants that interviews would only be conducted by video chat from that point onwards.

Each interview was audio recorded using a voice recorder, then transcribed verbatim by the researcher. The duration of interview was typically around 45 minutes, but ranged between 30 minutes and 80 minutes.

The interview was designed to ‘walk’ participants through their diabetes journey, taking the temporal themes of past, present and future in turn. The topic guide began by exploring the events and memories around diagnosis and the

subsequent adjustment period. Participants were then asked to recount significant diabetes-related memories from the past, which led to discussions about living with type 1 diabetes and its impact more generally. This part of the interview was flexible, to allow for variation in age at diagnosis and therefore the extent of past diabetes experiences. Explorations of the present included questions about managing self-care independently and some of the challenges and successes around glycaemic control. In the final stage of the interview, participants' future time perspective was explored, by asking about their future self and what was important to them looking forward on their diabetes journey, from this point in their lives. If the subject of complications had not been discussed by this point, it was raised specifically, in order to explore perceptions about complications and how they might influence self-care. A copy of the detailed topic guide can be found in Appendix 15.

Interview preparation and reflexive practices

One member of the Young Adults Panel took part in a mock interview to allow pilot testing of the question guide and interview structure. In response to feedback, minor changes were made to the guide on the more sensitive issue of diabetes complications. Following the mock interview, a decision was also made to create a pre-interview checklist. The mock interview had been conducted at short notice and on a particularly busy day, meaning there was little time to prepare. This resulted in some procedural issues, for example forgetting to revisit the PIS and ask if the interviewee had further questions. This checklist can be viewed in Appendix 16.

As discussed earlier, reflexive practice was pertinent to the data collection and analysis processes. As such, it was decided that a short meditation would be an appropriate way to mentally prepare and focus prior to starting, since meditative practice was familiar to the researcher. This was designed following a period of reflection, inspiration was also taken from preparation techniques of Janesick's "Stretching Exercises for Qualitative Researchers" (247). The meditation was designed to be spoken out loud or read in silence, whilst concentrating on breathing. The words aimed to draw attention to the researcher's personal position within the interview. The researcher spent 15 minutes prior to each

interview dedicated to the meditation. This would always be in the room where the interview was taking place, the space was kept silent and only items for the interview would be in front of the researcher to avoid distractions. A copy of the meditation can be found in Appendix 17.

During interviews the researcher took notes to be used in addition to the transcripts, these enabled recording of non-verbal expressions, or any reflections about the researcher's situatedness whilst the interview was taking place. A reflective diary was also kept by the researcher. Following each interview an entry was made, the researcher freely journaled thoughts about the participant, the interview or herself within the process. Additional reflections were documented at other times throughout the data collection period.

Transcription

Transcription of all interviews took place between December 2019 and June 2020. This was done solely by the researcher and was viewed as an initial step in the analysis process. The acts of listening and recording each interview verbatim served as the first opportunity to digest and become familiar with the data. Interviews were transcribed as close to the interview as possible, to ensure clarity of memory. This was helpful, for example in deciphering parts where the audio recordings were slightly unclear. There is a paucity of information on good practice and quality of transcription production, however, recommendations were found in a single source and these were broadly followed for consistency across the transcripts (248).

For the purposes of validity, four participants were randomly selected and sent a copy of their transcript to agree accuracy of the record. This process of member checking is a recognised and recommended technique to enhance trustworthiness of the data and research process (249, 250). Each of the reviewed transcripts was approved by the participant as a true account of their interview.

Data Analysis

All transcripts were read several times before coding commenced. The thematic analysis was conducted in several stages, following the approach recommended by Braun & Clarke (2006) (221). To address the research question “what experiences of living with type 1 diabetes are connected to time perspective?”, it was necessary to code data for each of the five time perspectives separately, since these are individual constructs. Open codes were therefore attached to data extracts reflecting experiences or attitudes that connected to any of the five perspectives. These codes were then analysed further for characteristics. Taking each time perspective in turn, a set of initial semantic themes were generated (221). Semantic themes were then reviewed across the dataset and refined as appropriate. In the next stage, deeper analysis of the semantic themes was carried out for each time perspective to generate main themes. In the final stage, all themes were then tested using the transcripts, the researcher’s interview notes and the reflective diary. Thematic maps were generated and used to support development of the final themes. To address the research question “what are the perceptions of future complications among emerging adults and how does this affect self-care in present time?”, the same process was adopted.

Initially, coding was done manually by the researcher. However, to assist with management of the volume of coded data and subsequent stages of the thematic analyses, Nvivo Release 1.3 (August 2020) software was used. The lead supervisor independently coded a sample of transcript data following the same process. Inter-coder reliability was found to be very high, Cohen’s kappa = 0.94.

Results and Discussion

The results and discussion section for the qualitative study is broken down into two parts. The first part describes connections to the time perspectives through lived experiences, in response to research question 3. The second part outlines perceptions about complications, in response to research question 4.

Participants

A total of 21 emerging adults consented to take part in the interviews, however, three of these were unable to be further contacted for interview which left a final sample of 18 in the study. A single interview was conducted in-person, all others were conducted via video chat platforms. The participants were predominantly female ($n=13$), had a higher level of education ($n=16$ for > A-level) and a longer duration of diabetes ($n=12$ for >10 years), which was typical of the full sample from Phase I. In contrast to the full sample, Phase II participants were slightly older, with a mean age of 22.3 years ($SD = 1.63$). Just over half of the participants used a pump as their method of insulin delivery ($n=10$), compared with just under half in the full sample. All participants reported a recent HbA1c value and there was a wide range of values (range 45-196, mean = 69.8, $SD = 35.5$, median = 58.0 (all values expressed in mmol/mol)). There was a range in reported self-care scores across the participant group and variation in scores across the five different time perspective scales. Overall, this sample were considered to satisfactorily represent a range of typical cases from Phase I, with the added benefit of more extreme HbA1c values represented. However, despite several recruitment attempts made through targeted advertising and snowballing, there were no participants at the lower end of the age range and only a small number of males in the Phase II sample. A summary of the participant characteristics can be seen in Table 9, with a detailed comparison of the main characteristics data being presented in Chapter 7.

Table 9 Phase II participant characteristics

Participant No./ID	Age	Gender	Age diagnosed with type 1 diabetes (T1D)
1. O	24	Female	7
2. E	24	Female	6
3. A1	23	Female	2
4. S	20	Transgender	19
5. P	20	Female	6
6. M1	24	Female	19
7. F1	21	Female	15
8. B	23	Female	7
9. K1	21	Transgender	8
10. D1	23	Female	7
11. F2	20	Male	12
12. J1	21	Male	13
13. A2	23	Female	8
14. D2	24	Male	13
15. K2	24	Female	17
16. J2	22	Female	8
17. M2	24	Female	6
18. L	20	Female	5

Lived experiences

Research question 3: What experiences of living with type 1 diabetes are connected to time perspective?

Separate thematic analyses were conducted for each of the five time perspectives. To aid understanding, Table 10 below provides an overview of the characteristics of each time perspective (previously described in Chapter 3), alongside a summary of the themes identified in response to research question 3. The results and discussion on each of these, has been chronologically sectioned into the wider temporal frames of past, present and future. This was done because inter-related characteristics were found between the two past and the two present perspectives.

Table 10 Summary of time perspectives and identified themes

Time perspective	Characteristics	Associations	Identified themes
Past negative	An unfavourable or pessimistic view of the past, from actual experiences or negative reconstructions	Higher anxiety, depression & aggression. Lower emotional stability, impulse control & self-esteem	1. Mental & emotional health 2. Poor care support
Past positive	A favourable warm and nostalgic view of the past, from actual experiences or positive reconstructions	Higher self-esteem, happiness & friendliness. Lower anxiety & aggression	1. Normalising T1D 2. Good care support
Present hedonistic	A pleasure-seeking attitude with low regard for consequences	Higher sensation seeking, aggression & ego control. Lower consideration of future consequence, conscientiousness & preference for consistency	1. T1D limits enjoyment 2. Compromising between glycaemic control and being in the moment
Present fatalistic	An attitude of hopelessness towards the future, outcomes are out of one's control and down to fate	Higher depression, anxiety & novelty seeking. Lower self-esteem, conscientiousness & consideration of future consequence	1. No escape from illness 2. Future holds threat
Future	A focus on achieving goals, giving consideration to consequences and being motivated by future reward	Higher consideration of future consequence, conscientiousness, preference for consistency & reward. Lower sensation seeking, aggression & ego control	1. Short glycaemic control goals motivation 2. Truncated future perspective 3. Giving myself the best chance

References to the past

Participants' abilities to recall events around the time of diagnosis were dependent on their age at that time. Those diagnosed earlier in childhood, for example before the age of eight, had hazy memories and it was sometimes unclear whether they were recounting a true personal memory, or simply relaying stories they had been told. Similarly, some doubted the accuracy of earlier memories of events around diagnosis and initial adjustment to living with type 1 diabetes. However, every participant was able to describe clear and sometimes very vivid memories of significant experiences relating to living with diabetes in the past. When asked to recount such experiences, the majority automatically described negative experiences that were frightening, traumatic or had had a negative emotional impact. Only two participants did not immediately respond in this way, in both these cases the first response was to question whether positive or negative experiences were of interest to the researcher. Of the five time perspectives, past negative generated a considerably greater number of coded references compared with the others and most participants held a broadly negative view of living with diabetes. Despite this, they were equally able to describe positive past experiences that were due to having diabetes.

Past Negative (PN)

Previous diabetes-related experiences that had a significantly negative impact took many forms. Examples of some initial semantic themes found included diagnosis trauma, hospital stays, injection problems, diabetic ketoacidosis or severe hypoglycaemia. Even if participants had only experienced one or two episodes of severe hypoglycaemia in their lives, they were important memories. These events served as a reminder of the seriousness of their condition and the potential threat to their life:

F2: *I'd had a pretty hot shower and just collapsed, I like passed out because, I take it it was just like low blood sugar combined with the heat... another time that I was at a mate's house a similar event happened... probably those specific events made me more aware of hypos and how dangerous they actually are, as*

opposed to just having low blood sugar, eating some sweets to make yourself feel better

The most impacting past negative diabetes experiences were related to deeper feelings and stressors arising from living with diabetes, rather than specific incidents themselves. It was common for isolated events to have been notable examples of the wider negative impact on mental and emotional health. From the thematic analysis, mental and emotional health was therefore identified as a theme for past negative perspective. The second theme identified was poor care support. The development of these main themes can be seen in Figures 1 & 2 at the end of this chapter.

PN Theme 1: Mental & emotional health

All participants had, at some point, been affected mentally or emotionally due to living with diabetes. For a few participants, the impact had been transient and they were able to view this as an issue that had happened at a certain period in time. For example, F1 described such a time in her teens:

F1: *I didn't quite realise it at the time, but I went through a phase where I was like quite tearful a lot and definitely more withdrawn. Sort of came out of the other side of it, but looking back, thinking back about that, there definitely was a period afterwards where it impacted me in that sense*

For others, this was cited as having been the most impacting aspect of living with the diabetes, as summarised here by J1:

J1: *it is quite a big deal, like it does have a very big impact on your life and I think I've often in my head tried to minimise that... I guess it was just like, it is a lot of kind of daily background stress about having to think about things and sort them out*

In many cases, the mental health impact was serious and a substantial number had required treatment. Half of the sample (n=9) had received psychological or psychiatric intervention as a result of diabetes-related mental health disorders. A further three participants who did not report having received formal

psychological treatment, described experiencing severe diabetes distress or burnout in the past. Many examples of diabetes distress were discussed across the interviews. Sometimes this was caused by practical problems, such as injection or pump-related problems, difficulty keeping blood glucose in range and struggles with managing food. Other scenarios had emotional roots, for example the stressful impact their diagnosis had on their parents and family life. Repeatedly being in hospital, or identifying as always being unwell in childhood was another emotionally driven source of distress. However, a pertinent emotional problem was a sense of being different and feeling isolated as a result. In some cases, this was due to overt stigma or misperceptions about diabetes:

E: *the thing that has always really bothered me about diabetes is kind of the stigma around it... even recently I was on holiday, and I've got the Freestyle Libre... and someone came up to me and said what is that on your arm? I explained what it was, they turned around and they said, well that's what you get for eating too many sweets and just walked off, and that's something that I've kinda faced like basically the whole time*

More commonly, it arose from a personal desire to fit in, or to feel normal and be able to do what other peers could do, without limitations:

F2: *I think kind of wanting to fit in, that's definitely had the biggest impact... especially like going to parties and going out and that kind of thing... I think, not wanting to stand out, I wanted to just fit in to the kind of normal*

A behavioural consequence of diabetes distress was the avoidance of self-care. For a few people, such behaviour had been a phase in the past, for example lasting a couple of years during their teens. However, for others this had been more significant and resulted in a burnout syndrome and abandonment of self-care. For instance, M1 had become overwhelmed and required psychological intervention:

M1: *but I think I did experience a diabetes burnout like probably, 1 or 2 years after I was diagnosed and that was around the time, actually it was just after*

that that I saw the clinical psychologist, and I think I was like, I don't wanna do this, no, it's not my life, got really sick of doing it... my control got a lot worse and I was quite unhappy at the time

Out of all the participants in the sample, the only person who did not recount any past experiences connected to diabetes distress was S, who had been most recently diagnosed. This highlights how frequently the participants were impacted by this emotional disorder and supports previous studies which suggest the incidence of diabetes distress is higher in emerging adults, when compared with other age groups (68, 71). It is evident from the quotes above that the stressful impact of living with type 1 diabetes had deeply affected some of the participants and possibly contributed to a past negative view.

Other mental health consequences that are distinct from diabetes distress were described in the interviews, one of which was type 1 diabetes-related eating disorders. There were four participants who had received specialist treatment for this condition and a further two participants described experiences with disordered eating or unhealthy attitudes towards food and body image. These had typically started in the early teens and brought complexity to self-care. Those affected felt that there had been a lack of knowledge and awareness about eating disorders and that their problems could have been addressed sooner:

P: *I feel like they could have had more room to be aware that this {eating disorder} is the sort of thing that might happen and therefore pick up on it easier, so I think the diabetes team themselves could have maybe picked up on it and then passed on that information to the psychologist*

A single participant, A2, described a different mental health issue, where she had repeatedly self-induced diabetic ketoacidosis after being diagnosed with depression around the age of 13:

A2: *I got diagnosed with depression, anxiety, so I kind of like, basically always put myself in hospital, so I'd stop taking my insulin, I'd want to be in hospital to*

get away from it all... there was a time where I had kidney failure... that all kind of carried through until I was like 19

Another significant disorder described by M2, was debilitating anxiety and fear of hospital appointments. She believed this had developed due to having negative appointment experiences in her teens:

M2: *I probably stopped attending a lot of appointments when I was at college... I would just ring up and cancel on the day with any excuse under the sun ...so you're not meant to join the community team I think until you're about 25, but he {the GP} actually pulled me out of the hospital early because the anxiety was so bad about going to appointments, so he was like you just can't go there anymore*

The impact of these mental health problems had been so significant, that participants reported they continued to struggle with these issues in present time. The frequency of mental and emotional problems in this cohort was notable, with half of the participants having received psychological or psychiatric treatment, specifically for diabetes-related problems. A recent large-scale retrospective cohort study, showed that there was a significantly higher risk of psychiatric disturbance among adolescents and emerging adults with diabetes, compared with age-matched controls (251). The researchers found that young people with diabetes (n=3544), were more likely to experience any type of psychiatric disorder when compared with peers (adjusted hazard ratio 1.29 [95% CI 1.21-1.37] (251).

An important psychological issue raised here was eating disorders, which are reported to occur in young females with type 1 diabetes at twice the rate than those without this condition (252). Eating disorders are complex in people with type 1 diabetes, often arising from the unusual approach to food required for glycaemic control. The term 'diabulimia' has been coined from within the diabetes community and was used by participants in the interviews. It describes a unique type of eating disorder, where insulin is omitted to facilitate weight loss. In young people, previous studies have shown eating disorders have a negative impact on glycaemic control outcomes (253). Care recommendations

from NICE, advise that diabetes-related eating disorders require specialist multi-disciplinary management, due to their complexity (254). However, the participants typically felt that knowledge and experience about eating disorders within their immediate diabetes care team was lacking. A recent study involving participants aged between 15 and 58 years with a history of insulin misuse, produced similar findings, where participants felt that there was insufficient awareness from care providers and this resulted in negative care experiences (255). Although these conditions are well recognised in the diabetes literature, it would appear from lived experiences, that care providers still lack the specialist expertise required to support people with diabetes and co-existing eating disorders. In the present sample, negative past reconstructions arose from difficulties in coping with glycaemic control and the eating disorder combined. This was further compounded by a lack of awareness from carers.

PN Theme 2: Poor care support

The second theme of poor care support was closely connected to mental and emotional health, since negative care experiences often had an emotional impact. Participants also expressed that when they had been going through mental or emotional health problems, any deterioration in glycaemic control would often be met with negative reactions from care providers. One characteristic of poor care concerned the care systems themselves. It was common for systematic care problems to be encountered in adult services, after leaving paediatrics:

O: since leaving paediatrics I feel totally on my own, nothing flows, I haven't seen the same DSN more than once, I couldn't tell you who half the team members are

Some participants had found transitioning to adult care to be a negative experience. At times this was due to difficulty adapting to the adult care approach. For example, P described the switch in expected responsibility:

P: the paediatric team it was a lot more like actively giving you advice, helping you to look for those trends and everything... helping you to change the things you aren't doing the best. Whereas it felt like initially with that adult team, they

weren't really gonna change anything ... if you asked them specific questions they could give you answers, whereas the paediatrics team would raise those questions in the first place

D2 described his transitional experience as being difficult, because there had been a lack of information and support about issues that were important to him at that time:

D2: *adjusting in the adults' clinic and moving into college, alcohol, there's so much things like that, that wouldn't have been discussed with me or done with me that really should be... around sport or like why are my levels going high before a certain activity, why are they going lower with other activities... there's a lot of stuff like that I had to read up on myself*

The most significant and impacting negative experiences relating to care support, arose from participants feeling blamed. This was frequent and a large number (n=11) reported having experienced blame from care providers specifically. They often gave examples where blame had been apportioned to them if glycaemic control was not meeting desired targets. Some recalled this happening in childhood and it had made them fearful of their HbA1c tests when they were younger. At times they had been threatened regarding the risk of future complications:

K1: *I think it was just, like if my HbA1c's were high, they would be saying you know this could lead to eye problems, circulation problems, nerve damage etc... it was terrifying to be honest*

More recently, there were examples of differing expectations between participants and their adult care providers. Examples included times when participants had seen an improvement in their HbA1c, but were still met with a negative response from professionals:

K2: *...but the specific GP that had seen it {HbA1c test result}, was like 'it's still well above the government guidance' (mimicking voice), and I'm like yes, but it's gone down from 68 to 57! That's amazing achievement!*

The most extreme case of blame described by any of the participants, had been encountered by D1, who had experienced a very negative relationship with her diabetes consultant:

D1: *...but he {consultant} told me explicitly that you are a shit diabetic... that is what he said to me once... I had just moved up from the children's clinic into the adult clinic, I got my A1c down from like a hundred and something down to like the nineties... and I was going through a lot of burnout, I was just struggling a lot and he didn't help, he then signed me off the clinic for 2 years, he refused to see me*

Feeling blame around glycaemic control outcomes, has been described elsewhere in the literature. For example, qualitative research has reported that some children and adolescents worry about attending diabetes clinics, due to fears of negative reactions or confrontation about glycaemic control (256). It was concerning that past negative experiences arising from feeling blamed, was still causing emotional problems for some participants in present time. The fear and anxiety precipitated by these experiences, may continue to affect a patient as they develop through emerging adulthood.

In summary, many past negative diabetes-related experiences had impacted mental and emotional health. For a large number of participants, the impact of this had been significant and continued to affect them in present time. Most of the sample had experienced diabetes distress and many had required psychological intervention. Poor care support experiences, especially where participants had felt blamed by care providers, had additionally contributed to negative past perspectives of living with type 1 diabetes.

Past Positive (PP)

In the interviews, most participants had to be prompted about past positive diabetes experiences. There were some examples given of a memorable point in time that was positive, such as a period when the participant felt they'd had particularly good glycaemic control. For others, positive memories centred on

an event, for example taking part in an activity to raise funds for diabetes charities. From the collective semantic themes, two main themes were identified as being key to past positive diabetes experiences. These were normalising type 1 diabetes and good care support, as shown in the thematic map in Figure 3.

PP Theme 1: Normalising type 1 diabetes

Situations where living with type 1 diabetes had been normalised contributed to past positive experiences. This counteracted feelings of isolation, which had contributed to past negative perspectives of life with type 1 diabetes as previously described. Some participants felt very grateful for having had good family support, where their parents had made efforts to normalise their childhood experiences. For instance:

M2: *they {diabetes care team} didn't want me to have coco-pops for breakfast for example, but my mum was like, but she needs to eat, she's not gonna eat your bran flakes, so I'd rather she had the coco-pops, so I was quite lucky in that my mum was quite flexible with things like that*

An important characteristic of this theme, was having shared experiences and a sense of connectedness with other people who were also living with type 1 diabetes. A childhood experience described by four of the participants to highlight this, was attendance at diabetes camps, something they recalled with great enthusiasm. The camps had been thoroughly enjoyable and fun, but what was most positive in participants' memories, was how they had felt normal amongst the other children and families:

E: *I remember going to diabetes camp... I just had the best time - it was a week of people exactly like me, having to test their blood sugars before they eat and taking hypos, or having higher blood sugars and taking injections... so we went like, horse riding and we went paragliding, just doing all these kind of things just to show that we could do it... yeah just exposing me to a whole world of people that were living normal lives with type 1, was just amazing*

Sharing experiences and feeling a connectedness to others with type 1 diabetes remained important at this stage of life, some participants described this from the more recent past:

K1: *I think the best part of it {DAFNE course} was spending a week with a group of people who completely understood, meeting other people with diabetes, I'm still in touch with some of them, this must have been like 3 years ago now, that was really nice... hearing other people bring up issues that you've had yourself, like it stops you feeling so alienated*

A recent qualitative study found similar themes among emerging adult bloggers (257). Researchers analysed blog posts about living with type 1 diabetes written by 16 different authors, to identify themes in relation to positive facilitators for management and support. Normalisation of diabetes was noted to be found through connection to peers also living with the condition. Additionally, sharing experiences, such as problems around daily glycaemic control management, reduced feelings of isolation or being different (257). Another aspect of normalising life with type 1 diabetes for the present sample was related to new forms of technology. Many participants had been switched to a pump, or had received a flash glucose monitor or continuous glucose monitoring (CGM) device. For some of them, this event was so salient, they recalled the exact date when it had happened and held this in their memory as a key milestone on their diabetes journey:

K2: *but yeah, getting a pump that was a year later to the day... that was quite significant cos that marked the change in which I felt like my life became more normal and more like it used to... I can have a snack if I feel like it, you can vary your basal rate on it which means I can exercise or I can have a more active day, if I really don't wanna get out of bed I don't have to do much, I can just vary the basal rate... you're more in control*

These devices had helped them to live with an enhanced sense of freedom, or had attenuated feelings of being different or stigmatised. In another qualitative study exploring the nature and meaning of insulin pump use in emerging adults,

participants also expressed feeling a greater a sense of normalcy, through the more flexible lifestyle that an insulin pump enabled (258).

PP Theme 2: Good care support

For those who had received care from a paediatric diabetes team, experiences were overwhelmingly positive. A single participant, J1, described being dissatisfied with his care under paediatrics. This was due to his desire to manage self-care his own way and he felt he hadn't been permitted to do so. All others had a very positive perspective about the team and supportive care they had received in paediatrics. In many cases, they greatly appreciated the personal investment that had been made across their childhood and some felt sad to move to adult care. For example:

P: *it was really, really sad to leave the paediatrics team, cos they were just a group of people who were so amazing, and so lovely, and they'd been such a big part of my life so long... they know so much about me and help me literally to stay alive and then they're just not there anymore*

In more extreme cases, for example A2 who had experienced significant trauma and loss in her childhood, the paediatric diabetes team had been a lifeline at times:

A2: *my paediatrics team at [location 1] they were amazing... they really pushed to help me, they got me a psychiatrist and they just never gave up on me... they got me a place up in [location 2], so like it was a unit that helped with the physical and mental health together and that's when I really got better*

An important aspect of good supportive care, was where participants' independence had been nurtured, meaning responsibility was shared and they felt part of a team with all their care providers. For D1, this had happened right from diagnosis when she was just 7 years old:

D1: *so she {paediatric diabetes specialist nurse} really pushed for independence on everything like that, she didn't just talk to my mum... it was a conversation between me and her... I would say right, here's a pattern in my*

blood sugars I don't like this, we need to adjust this insulin, and my mum would say 'yep that's right'

Participant F2 spoke of how good supportive care from his paediatric team, had prepared him well for coping with transition and the independence expected once in adult care:

F2: *I think I was lucky that the paediatric team where I'm from... they were always completely supportive and they like made an effort with our families, so that made that {transition} really easy... in terms of being at uni, has made just that other switch into like a more independent kind of hospital team much easier than it maybe would have been otherwise*

It has been documented elsewhere in the literature, that shared decision-making facilitated by a familiar and supportive care team, positively contributes to self-efficacy and engagement with diabetes care in emerging adults (60, 259). From these lived experiences, nurturing independence has also contributed to positive care experiences in the past.

Technology provision was also cited as an aspect of good supportive care experiences. Participants described how their self-efficacy was enhanced by having access to comprehensive data or helpful software applications:

A2: *so with the Libre, it's just the simplicity of it, how I can get it on my phone and just quickly, quickly scan it and then with the PDM {personal diabetes manager}, like it does all the calculations for you and it's a lot, it would be a lot harder for me*

These results of the past positive thematic analysis overall, showed that experiences or events that served to normalise type 1 diabetes and prevent participants from feeling alienated, contributed to a positive perspective. Good care experiences, especially where the participants' independence had been supported was also key to past positive experiences and this was commonly encountered in paediatric services.

References to the present

When asked about present diabetes experiences, it was apparent that the emerging adults in the sample held a comprehensive view of what was meant by 'present' time. Many considered transition as being part of the present, rather than being a past event, even though it had normally occurred a few years prior to the interview. In relation to the time perspectives of present hedonism and present fatalism, the participants voiced some experiences of living with type 1 diabetes that were connected to each of these. Evidence for the identified themes are presented in the following sections and the thematic maps can be seen in Figures 4 & 5.

Present Hedonism (PH)

Examination of the data relating to a present hedonistic perspective, revealed two connected themes. The first, was that type 1 diabetes brings limitation to enjoyment and spontaneity, which sometimes impacted broader satisfaction with life. The second theme was compromising between glycaemic control needs and being in the moment. This was a complex balance that participants faced frequently in their daily lives and at times, it served as a source of diabetes distress. Coded references that were connected to present hedonism largely came from an inverse point of view, where opportunities that might foster present hedonism were being repressed due to having diabetes.

PH Theme 1: Type 1 diabetes limits enjoyment

The participants recounted a range of different scenarios and experiences showing how type 1 diabetes limits their enjoyment. For instance:

D2: *just wanting to be normal and stuff, wanting to, let's say go to a friend's house and order pizza, you just want to be like one of your friends and just eat it like, whereas, you have to plan, you have to carb count, everything like that, so it's just not, not that easy*

K2: *I really like cooking and if you're pricking your finger 10 times a day, that's made difficult because you're chopping a tomato, or a lime or just the heat over the pan, like tiny little things that seem really insignificant*

A semantic theme that was raised by several participants as pertinent during emerging adulthood was travelling. For example, J1 commented on how type 1 diabetes had detracted from being able to enjoy the spontaneity of travelling recently:

J1: *last summer I went on a long hiking holiday in [location] and just the kind of stress of having to manage my diabetes on these huge, huge hikes... I was having to make sure I had the right amount of food for my low blood sugars, just kind of like takes away from the overall experience*

In other examples, participants felt their diabetes was currently a barrier to the idea of travel or moving to a new location. For instance:

J2: *I had like thoughts about going to [overseas location]... but I just don't know what the healthcare system is like and it definitely just put me off, thinking to have to sort all of that out or pay for anything, I really just wanted to avoid any of that and so it just kind of meant that I didn't even try, I didn't even really do my research*

PH Theme 2: Compromising between glycaemic control and being in the moment

Participants frequently found themselves in situations where they were forced to make a compromise between dealing with glycaemic control duties and being in the moment. At times, they would reluctantly prioritise looking after their glycaemic control, at the expense of something that would bring enjoyment or satisfaction. For example:

F2: *if I'm like caught up in something or if I'm enjoying myself then I didn't want to, kind of taking time out of that to focus on something that I don't like... diabetes is always a negative*

Many described how this balance negatively impacted their social life and caused emotional distress:

E: *How hard it can be sometimes to keep them {blood sugars} in range and feel normal... not being able to go and have cocktails with my friends and things like that, it's hard sometimes to kind of find the balance of being careful and having good sugars, but also like living as a girl who's 24*

However, some opportunities were considered too important to miss out on, in which case being in the moment was prioritised over self-care responsibility. For example, D2 described taking conscious risks whilst back-packing, to make the most of the experience:

D2: *I was on the back of the bike for about 2 or 3 days, and obviously I had insulin supplies to last me the month... so they were on my back in like scorching 30 degree heat for 3 days, (both laughing) so, how effective that insulin was after that I don't know like... but that was one of the highlights of the trip*

In more extreme cases, conscious risk-taking had resulted in self-care avoidance and disregard for glycaemic control consequences, at least for a while. This was described by A1 as lasting for an extended time when she had attended university:

A1: *just didn't let it {diabetes} interfere with my life, which obviously is good but only to a certain extent... I would just go out, I went out a lot on nights out and stuff and didn't really think about my diabetes control, or I just you know, have some food before I went to bed and then hope I feel better later on... I lived like everyone else you know, did what my friends did*

Prioritising more desirable activities with friends at the expense of self-care, has been associated with higher HbA1c in previous emerging adult samples (260). From the reported increase in social risk-taking by emerging adults (10), it might be expected that people in this age group would be inclined to compromise glycaemic control needs, when faced with a more desirable opportunity.

However, the present sample seemed more inclined to prioritise self-care, albeit reluctantly. Comparable samples have voiced similar frustrations about how type 1 diabetes limits social freedom, examples cited include not being able to fully enjoy festivals with friends and managing alcohol (45). These findings would suggest that emerging adults are unlikely to be compromising glycaemic control regularly, in the 'devil may care' type of attitude associated with present hedonism. In the present sample, it was more common for participants to feel that type 1 diabetes limited spontaneity and that they couldn't afford to be cavalier with their decisions.

In summary, the thematic analysis for present hedonistic time perspective showed type 1 diabetes brought limitation to enjoyment or social opportunities. Participants were frequently being forced to prioritise between taking care of glycaemic control and being fully present in the moment. In total, 14 of the emerging adults highlighted this as being a problem at this stage of their lives. For most part, living with type 1 diabetes appeared to limit freedoms that might encourage a present hedonistic perspective. However, there were still some participants who described becoming completely avoidant of self-care and ignoring the potential consequences of this, which is characteristic of a present hedonistic perspective.

Present Fatalism (PF)

From the thematic analysis for present fatalistic time perspective, two main themes were identified. These were: having no escape from illness and that the future holds threat. The two themes shared some connected characteristics that left participants feeling powerless against type 1 diabetes.

PF Theme 1: No escape from illness

It was evident from some of the discussions that a few participants believed things would never improve in relation to their diabetes. As an example, O explained that accepting this to be a reality had led her to stop psychological therapy:

O: ...there was no improvement {in mental health} over about a year and half again... the reason there was no improvement is because nothing ever changes... I'm never gonna get rid of type 1 diabetes, and although that wasn't the only problem, but the root causes of my anxiety and stuff are things that I can't take away and are actually ingrained in me, so I basically just said to her {psychologist} look, I'm kind of wasting your time

Other participants talked about hope for a potential cure for type 1, that is often expressed from within the diabetes community. Several in the sample did not believe there was any hope for a cure in their lifetime:

A2: there's not gonna be a cure... I'm never hoping for a cure, the JDRF {Juvenile Diabetes Research Foundation} are always like, yeah strive [inaudible] for a cure, there's not gonna be a cure

A large number (n=10) described a sense of powerlessness with regards to glycaemic control. They explained that this was simply an impossible task and despite considerable efforts towards self-care, there was no way to avoid out of range blood glucose. For instance:

J1: the effort that I put into it {self-care} has been fairly consistent, I'm always trying around the same amount, but sometimes putting in that amount of effort will mean that I'm just constantly having to deal with loads of highs and lows and that's awful, and sometimes putting in that amount of effort just means I'm kind of stable, you know, don't even need to think about it

There were some participants who had other physical illnesses that are associated with diabetes. These participants expressed a sense of inevitability about having related physical conditions. For example, L demonstrated this when reflecting on being diagnosed with ovarian cysts:

L: I went to the gynaecologist and she said that it's cysts and I said, well what can I do to prevent this happening and she said because you're diabetic you're probably just more likely to have it... I think as diabetics we just kind of accept

that a lot of things aren't in our favour but we don't question why, so even to this day like I don't know why diabetics are more prone to have cysts...

Feeling powerless against type 1 diabetes has been reflected in this way by previous samples. In quantitative research, powerlessness was found to be a significant source of diabetes distress unique to those with type 1 (71). The impossible task of keeping blood glucose in range has been specifically highlighted. For instance, in a qualitative study involving parents caring for children with type 1, the parents expressed feeling powerless because of the disconnect between the amount of daily control effort and actual blood glucose outcomes (261). In another adult sample, participants described living 'at the mercy of insulin' and expressed that efforts to self-manage were not worthwhile, due to uncontrollable fluctuations (262). The impact these struggles have on mental health, was described by several participants in the present sample as an endless battle between physical and mental health. It was clear that this left them feeling very despairing at times:

K1: *I'd really, really like to get to a point where I'm managing it better and having my blood sugars in range a lot more, cos I just think it would improve my quality of life in general... I think it's hard, because when I do get to a point where I'm managing my blood sugars better, I feel like it takes up so much of my time and so much of my thought, like it's a really involved thing to try and do*

PF Theme 2: Future holds threat

Feeling powerless against glycaemic control was not just a problem relating to the daily grind of self-care. Being unable to combat daily glycaemic control fluctuations contributed to a deeper sense that the outlook for the future was bleak. Participant E described how this made her feel:

E: *finding out what my HbA1c is, is usually quite a tearful process for me... it's just horrible to think what that number means for the future... it's just so unfair to think about all the different things that can go wrong because of high blood sugars, how hard it can be sometimes to keep them in range*

Many of the participants associated their inability to maintain glycaemic control with the risk of developing complications in the future. There was a shared view that complications were self-caused. For example:

D1: *I mean obviously I'm hoping no complications, I think that's a bit of a wide hope though, because the years of bad control that I did have*

Despite this, some emerging adults in the sample did not believe that maintaining tight glycaemic control could necessarily protect them from future health risks. The picture ahead was not clear and some participants felt future outcomes were largely out of their control:

L: *I think of the future a lot, but I think I also know very well that I can't control my future, and I can put myself in position to make it good and be healthy, but that isn't a linear process of me being like, I'm gonna be good, I'm gonna be healthy, I'm gonna have a good future, because you don't know what's gonna happen*

Overall, experiences linked to present fatalistic perspective typically involved beliefs that there was minimal hope for the future. This resulted in participants feeling powerless against the mental and physical health consequences of diabetes. There was a shared view that complications would be self-caused due to previous struggles with glycaemic control. Some believed this to be a likely future threat, however a small number felt that their future is not something they can control.

References to the future

Since discussions about the future were theoretical in nature and not about experiences as such, there was risk the data would be limited in its ability to answer research question 3. However, it was evident the participants' perceptions about the future had often been formed through past and present lived experiences.

Future time perspective (F)

It was apparent that the motivation behind goals for self-care was variable across the sample. For example, some participants were motivated by longer-term future health outcomes and others were not at all. Three themes were identified from the analysis, as can be seen in Figure 6. The first theme was being motivated by short or immediate glycaemic control goals, which was referred to by most participants. The second theme was a truncated future time perspective and the final theme was giving myself the best chance for the future. The themes shared some common characteristics, as described below.

F Theme 1: Short glycaemic control goals motivation

The majority of participants (n=17) described being motivated by immediate or shorter-term glycaemic control goals. All participants paid attention to daily self-care, they described numerous experiences relating to blood glucose monitoring and making adjustments to keep in range. All were aware of their HbA1c results, however not all participants found this marker useful or motivational as a glycaemic control goal. They were more motivated by seeing progress in their daily blood glucose levels, it was satisfying to them when they could see their commitment to self-care bringing positive results. For example, J2 was finding this rewarding:

J2: *it's a completely new outlook on it than I'd ever expected before going to uni, so now I really enjoy food, I really enjoy looking after myself and if I take up exercise, I notice that my blood sugars are doing a lot better and it's a pretty gratifying experience*

A different motivation behind shorter glycaemic control goals was described by B. This was to stay feeling well enough to be able to get the best out of life, since being out of range often had a negative physical or emotional impact:

B: *I tend to get a little irritable when I'm high and so... I want to be you know, in a better, not mood, but I wanna feel well, you know so that I can be in the moment, and be, not worried about it all the time*

For some participants, technology was empowering them to successfully meet short glycaemic control goals. For example, J1 described how it was much easier to anticipate changes in blood glucose before they happened:

J1: *it's easier to manage what's going to happen, so for example, just using the data I know that if my blood sugar's around 8 before breakfast, I give myself insulin for breakfast around half an hour beforehand... but if I eat with a blood sugar of like between 4 and 5, then it's not gonna spike... and I know that thanks to all the data*

A number of participants were using HbA1c as a goal, however the reasons behind this were variable. In most cases, it was deemed to be a useful average or benchmark. However, very few participants were motivated by nationally recommended clinical targets. It was common for participants to feel stressed by these targets and interpret HbA1c their own way:

P: *I generally like it {HbA1c}, I like to know it and I like it as an aim as well, I don't like giving myself specific aims, like oh it should be below this, you know that stresses me out a lot, but I think it's useful when I see it, especially when it's like higher than previous... it gives me that confirmation that actually I can be working harder*

For a few participants, the diabetes distress brought about by the burden of glycaemic control meant that having very proximal goals was the only way they could operate. In extreme cases, it was not possible to focus beyond daily goals:

M2: *my only goal for diabetes is just to make it through each day, I think that's literally all you can do, because every day is so different... I go through weeks where I take insulin and it works perfectly well and then two days later I'm insulin resistant due to hormones ... I aim to be within range, but for me, I just need to get through the day really*

It was interesting that the emerging adults in the present sample were not inclined to focus on the recommended target for HbA1c as their goal. This

would suggest their priorities are different from those of their clinical care providers. The relationship emerging adults have with HbA1c is not something that has been previously investigated. The previous finding that HbA1c is abstract for emerging adults to comprehend (245), was not echoed by the present sample. In fact, most participants were clear about the purpose of HbA1c and many were keen to receive their results, even when they found it very stressful. This novel finding would merit further exploration. Understanding how emerging adults evaluate HbA1c alongside their daily blood glucose levels, could provide new insights for care teams supporting this population. This theme suggests that focusing on daily time in range with HbA1c as an average reference point, could be more motivational than aiming for long-term standardised targets.

F Theme 2: Truncated future time perspective

The thematic analysis showed that having a more proximal future focus, was not solely related to glycaemic control. It was common for participants in the sample to have a shortened future view more generally. One reason for this was deliberate avoidance of thinking about the long-term future, due to fear and anxiety about complications:

M1: *I tend to plan ahead and kind of like to know what's going on in the future, probably not years and years in the future, maybe like up to a year, something like that...I think it's more the immediate future... yeah I would worry a lot about serious complications that happen to people later in life, but I've got used to the fact that I don't need to worry about that right now and I shouldn't let myself get stressed about it*

Deliberate avoidance of future thinking was also described as a consequence of having been diagnosed with a chronic condition. This made some participants want to focus more on the present:

F2: *I like to take life as it comes, just because, I think in terms of having to deal with illness and that kind of thing throughout my life, has made me think about my future so much that I want to kind of like enjoy life*

However, in other cases it was a lack of capacity to view an expansive future, that was causing a foreshortened future perspective. These participants reported that diabetes clouded visions of their future self. Living with the knowledge that their condition might impact their health and well-being in the future, meant they were unable to picture themselves older:

J1: *it's very, very likely that I'm gonna live to be like 40 or 50, but I've got no idea what health problems I could have at that age, so it's kind of, the fact that it's theoretical, conceiving it, like the health problems and complications I'll have, just makes it much more difficult to do*

As previously reported, it has been proposed that denial about future diabetes complications truncates future time perspective in adults with type 1 diabetes (263). This is reflected in some of the quotes shown above, for example deliberately avoiding long-term thinking because of fears about complications. However, a limited expansive future view in the present sample could also be explained by age. Since emerging adulthood has been recognised as the period when the capacity to view one's expansive future develops (11, 12), perhaps some of these findings are simply a reflection of developmental variations at this time.

F Theme 3: Giving myself the best chance

Variability in future expansiveness was further evident in the sample, because a small number of participants reported that reducing the risk of complications in the distant future, was indeed motivating them towards good self-care at this point in time. These participants appeared to focus on both proximal and longer-term glycaemic control goals:

A1: *within the next 10 years I would like to have kids and hopefully not be complications, in you know pregnancy ... and then obviously long, long term I hope, I hope to have no complications at all (laughs), yeah it's obvious but it's just to like, bear in mind I guess... it isn't a major worry, but it's like a motivation to keep quite controlled*

Becoming cognisant that good self-care now could benefit them in future, was a recent realisation for many of the participants. This applied to both participants who did and did not have an expansive future perspective. For example, several who avoided future thinking due to complications fears, still believed that maintaining self-care in present time would confer some level of future health benefit. D2 voiced that his future focus had recently become more expansive and he believed this was down to maturity, because it was not something he had been aware of when he was an adolescent:

D2: *like all the potential complication with it in the future, it's probably something I've become conscious of recently... and it was just becoming more mature... trying to manage your diabetes as best as you can now, for the future if you get me... that's not something you think of when you're 15 or 16... and that comes with maturity*

Nonetheless, investing in self-care now to give themselves the best chance later, was not usually related to the distant future. This theme was also characterised by more proximal goals and as can be seen in the quote from A2 above, a pertinent subject was having children. At this stage of their lives, it was common for participants to be considering this in the near future and they wanted to give themselves the best chance for reproductive and pregnancy health. For instance:

M2: *looking more forwards, having babies and things like that, that's gonna be a challenge, I'm dreading it, but being managed enough that's safe and it's healthy, like it's safe for me to have children... I think that's another reason why I wanna get it more managed*

In summary, there was variation in the expansiveness of future time perspective. The participants were typically motivated by shorter-term glycaemic control goals and felt rewarded when they saw progress in these goals. A small number of participants reported their self-care was motivated by reducing the risk of complications in the distant future. However, it was more common for them to be focusing on the proximal future and in some cases, participants were unable to visualise the longer-term or had deliberately chosen

not to focus on it. Regardless, many of the participants believed investing in their self-care in present time would benefit them later on.

Complications perceptions

Research question 4: What are the perceptions of future complications among emerging adults and how does this affect self-care in present time?

Some of the data reported above in response to research question 3, has already provided data in support of research question 4. For example, from the present fatalistic and future time perspective analyses, it has been established that the emerging adults had worries about complications and for some, this posed a significant future threat and caused anxiety. It has also been discussed that self-care in present time was motivated by giving themselves the best chance later. These themes reflect perceptions about complications and the influence they have on present self-care. However, additional distinct themes relating to complications perceptions were found from the analysis. These were that the participants held a broad view of what complications are, that they were typically self-assessing their own risks and that there is a lack of information regarding complications. The themes are visually represented in Figure 7.

Theme 1: A broader view of complications

The subject of complications was raised in the context of screening appointments in the interviews, therefore annual checks for microvascular complications was a common discussion topic in response to this. However, many participants additionally discussed some of the wider impacts diabetes has, as part of conversations about complications. For instance, B raised scarring from injection sites as a complication:

B: *one conversation we had for example, was just making sure that I'm rotating my infusion sites, to make sure I'm not building up any scar tissue and that sort of thing, cos that was one thing that I was always not great about and I've been trying to get better with*

Some participants reflected that diabetes-related mental health disorder was a complication, captured in this example by O:

O: I really do see quite a mixture of people with complications, people without complications, and I mean, we don't talk about mental health as being a complication, but I would say that needs to be talked about a lot more

The importance of complications around pregnancy and reproductive health has been discussed in the previous section. However, there were additional concerns raised within this subject, about potential genetic links with diabetes:

E: I think a big thing for me as well, is thinking about like starting a family and stuff when I'm older, and how much harder that's gonna be, the extra strain that that's gonna put on my body, and then what if they have diabetes as well?

These quotes demonstrate that emerging adults consider some of the wider impacts of diabetes to be complications, beyond the established set of microvascular and macrovascular complications.

Theme 2: Self-assessing risks

Participants used both prior knowledge and lived experiences to self-assess their personal risks. Since the majority of the sample believed that complications would be a result of their own actions, this was a source of significant anxiety for some of them:

E: I'm worried about what my HbA1c is gonna be like, I think for me higher numbers are more terrifying, thinking about all the complications that can happen... there was one point where my HbA1c was sitting at 11, which thinking about now makes me feel quite sick

Conversely, one participant who had low HbA1c levels at this stage, expressed he believed he was unlikely to develop complications:

F2: *having my diabetes quite well controlled has made me not really think about it {complications} because it's, like I'm in the mindset that if I keep doing this then it shouldn't happen to me*

Participants typically reflected about time scales and a characteristic of self-assessing complications risks, was that duration mattered. There were differences in the way this was expressed, in many cases those with a long duration of diabetes felt they were at increased risk. However, in other cases, personal risk was seen as low because of their young age in present time:

J1: *it's pretty difficult to be thinking that long term, but when I do think about it, it can be quite scary, but at the same time it's just like so removed... if I do ever get complications that's gonna be a person 40 years from now... like it's irrational to worry about it now*

Several participants described experiences from their youth, where complications had been used as a scare tactic. The impact of these traumatic experiences, played a part in their self-assessment of the risks now, meaning they felt more likely to develop a complication they had been warned about. An example was given by E, who had specifically developed worries about the risk of kidney disease:

E: *growing up I can remember one event, when I was maybe like 13, 14 and I was really struggling with it, my consultant suggested taking a walk around the renal unit... I just don't think taking a 14 year old to a ward of people who are seriously ill with kidney failure is acceptable... a lot of my fears kind of stem from that, the consultant that day was like, this is what's gonna happen to you*

Experiences of future complications being used as a scare tactic have been reported in another recent qualitative sample (264). In this mixed sample of adolescents (n = 22) and parents of adolescents with type 1 (n = 25), participants reported they felt that use of complications as a threat in this way had not been constructive, and that complications conversations need to be handled with better sensitivity, (264).

Theme 3: Lack of information

The ability to accurately self-assess personal risk of complications requires sufficient knowledge, yet participants reported there was a lack of information about complications. It was highlighted by many of them that future complications are not discussed by care providers, they reflected that the issue is too sensitive and is therefore not raised in their appointments. Some participants even reflected that this had been the case across their whole diabetes journey:

J1: *I'll have my feet tested, I'll have my eyes tested, so it's, like I'm made aware of the complications, but it's not like it's explicitly discussed, I don't think it's ever been explicitly discussed*

Complications were also deemed to be a sensitive subject amongst the diabetes community and as a result, the subject wasn't discussed within the peer group either:

F2: *in terms of like talking with my peers about it, it just doesn't really get brought up, because it's quite like, yeah as you said delicate so, it's got a bit of a stigma around it, like people don't want to think about it*

A topic that was particularly pertinent, was background retinopathy. At the point of interview, a total of eight participants had been recently diagnosed with this. Participants reported they had received very little information about background retinopathy, or what it meant for their health:

E: *there are slight diabetic changes, and I was just distraught and in tears, and the doctor basically said you've had diabetes for 16 years, that's just it, there are gonna be changes, and I was like so, do I need to be worried about it, I don't really understand then, like slight, what does that mean, does that mean I am gonna lose my eyesight, or can I treat myself?*

A frequent response to the lack of information about background retinopathy, was for participants to try and find out about it themselves. They did this either

by doing their own reading or seeking help from others within the type 1 diabetes community:

M2: *I think even now, so I've got mild retinopathy in my left eye, but that's not even been discussed with me either, they haven't even really told me what it is (laughing), I had to Google it myself*

Self-driven research due to a lack of information leaves emerging adults open to misinformation or misinterpretation. Some of the participants specifically stated that at this point in time, they desired to have more information about complications from their care providers, despite the sensitivity around this topic. It has recently been recognised that complications are not discussed in general adult diabetes care settings either (265). This has led to a dialogue between prominent community representatives and policy-makers, about the need for more open and non-judgemental conversations to take place (266). Since the participants felt this issue is becoming more relevant for them at this stage of their lives, avoidance of the topic in emerging adult care settings is not supportive. New ways of framing these messages and communicating with patients need to be found, so that emerging adults can be appropriately informed without feeling blamed or overly anxious about the future. Further qualitative research involving emerging adults and their diabetes care providers, would be a way to facilitate this.

In summary, perceptions about complications were broad and included those related to glycaemic control, such as retinopathy or foot problems. However, participants also perceived some of the wider impacts of diabetes unrelated to glycaemic control to be a complication, for example mental health disorder and the impact on reproductive health. It was evident that the emerging adults were self-assessing their own likelihood of developing complications and mostly believed that this was partially influenced by their own actions. For some, this was motivational for self-care, but for others it caused anxiety and distress, particularly if care providers had previously used complications as a scare tactic. There was deemed to be a lack of information from care providers with regards to complications and some participants reported a desire for more

information at this stage of their lives. The lack of information had led them to carry out their own research, particularly in relation to background retinopathy.

Limitations

Limitations of this study included the under-representation of males and lack of younger age emerging adults, when compared with the full Phase I sample. The present participants were all post-transition, or had been diagnosed over the age of 18 and therefore never treated under paediatrics. If there had been younger participants actively going through transition at point of interview, perhaps additional themes may have been identified. As with all qualitative studies, the small number of participants means the personal journeys and meaning of experiences for those included, may not reflect those of other emerging adults. However, since the purpose of qualitative investigation is interpretative, generalisability is not the objective. Moreover, although genuine saturation cannot be guaranteed, data were deemed to be thematically saturated around the eleventh interview and the original target sample size was obtained. Many of the interviews took place in April and May of 2020, when the first national lockdown had been implemented due to the COVID-19 pandemic. This significant external stressor may have had an influence on the present time thoughts and feelings of some participants. Finally, the researcher had limited experience with conducting qualitative research, which could have limited the ability to extract and interpret the data. Additionally, the researcher's prior clinical and practice experience of young people with type 1 diabetes, could have influenced both the nature of questioning in the interviews and analysis of the data. However, careful steps were taken in the procedures to mitigate these risks, such as using a clear questioning guide and carrying out a meditation prior to each interview, which was designed to focus attention on reflexivity.

Reflexivity statement

It was previously discussed in Chapter 4, that a salient issue in my case was approaching this research as someone who has a clinical background. This meant that I was bringing to the research extensive knowledge about type 1 diabetes and the challenges young people face living with this condition. In

addition, my scientific background meant that I was naturally more at ease with quantitative research and this likely played a part in my formation of the main research questions. Even though my original questions regarding future perceptions aligned with a qualitative approach, I was equally drawn to the idea of psychometric testing against time perspective theory, resulting in the decision to use mixed methods and the subsequent direction of the study overall. Without my scientific background, it is possible I would have developed questions of an entirely qualitative nature and not considered quantitative research as being relevant at all. It is therefore very likely that my knowledge and experience as a clinician, shaped this research towards its dual purpose of trying to identify generalisable results that can translate to policy, and meaningful results that can help me better understand the individual perspective of a patient.

I was therefore mindful I needed to approach this qualitative study, not as a specialist pharmacist or clinician, but as an independent qualitative researcher. Use of the pre-interview meditation certainly helped me to shelve my clinical-scientific side and enter the interviews in the mindset of a researcher, I felt open and impartial towards each participant and their response to my questions. At the same time, it is not possible to completely separate ourselves from our background. I saw the impact of this through my interview with participant S. I had conducted three interviews prior to this one and felt I was becoming familiar with the process and with my interview questioning guide. However, S was very different in that they had only been diagnosed the year before. As we talked, it became apparent to me that S was still processing their diagnosis and coming to terms with it. The onset and presentation of their type 1 diabetes had been atypical and spanned many years, S was very keen to share this story with me and I was immediately interested. However, my interest was in the details of S as a clinical case and my focus quickly switched from qualitative researcher to clinician. As the interview progressed this escalated further, it was clear that S was seeking information and I was providing it for them. When I realised this was happening during the interview, I was able to re-focus and switch back to my role as independent researcher. Reflecting on this later, I saw that the experience enabled me to recognise the influence of my background, and also to recognise that the process of research participation is therapeutic for some

people. Perhaps this is what S wanted from the interview all along, or perhaps my interest in the clinical details provided an opening, where our shared space began to feel more like a clinical consultation and this led S to treat it as such. This was a valuable experience for me in my development as a qualitative researcher. For all subsequent interviews, I decided not to share anything about my clinical background or experiences, unless directly asked by a participant. I had no further experiences like this one and I became far more aware of myself and how my presence can influence the interviews.

Conclusions

There were many experiences of living with type 1 diabetes that were connected to time perspective and the most commonly cited events related to past negative experiences. The participants typically held a negative view towards diabetes and many had lived with significant challenges caused by their condition. In particular, the mental and emotional impact of diabetes had been a pertinent source of distress. In present time, living with diabetes brought limitations to the typical freedom of emerging adulthood. Many participants were struggling to manage self-care, whilst at the same time living a fulfilling life. Future perspectives were found to be variable in the sample. However, it was common for participants to have a shorter future focus and be working towards proximal glycaemic control goals, rather than longer-term goals. Participants were fearful of complications and there were varied responses to this. A small number believed self-care in present time could influence outcomes in relation to future complications, whereas others felt they had no control over them, or that they were inevitable due to suboptimal glycaemic control in the past.

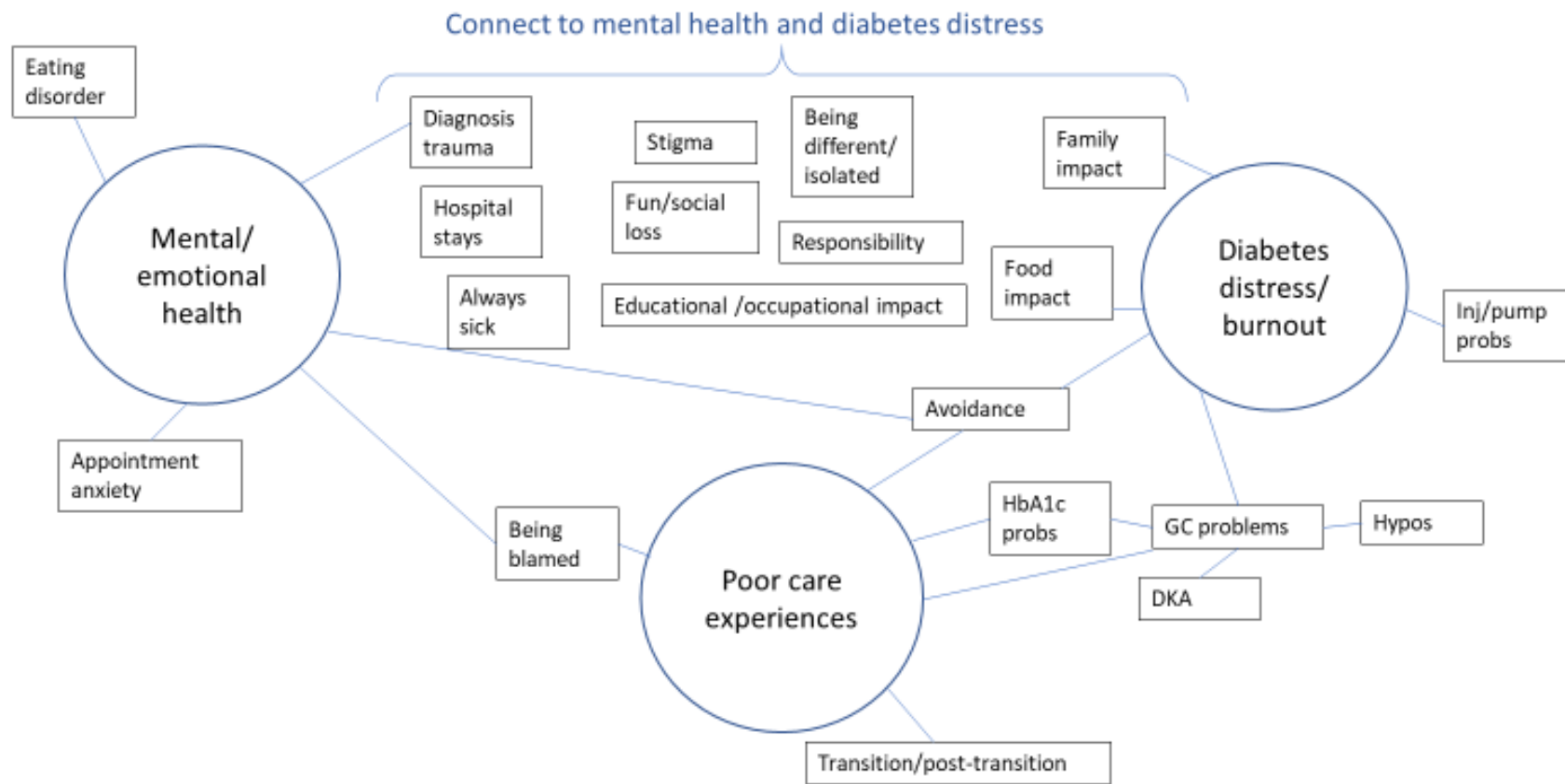


Figure 1 Development of the past negative perspective themes

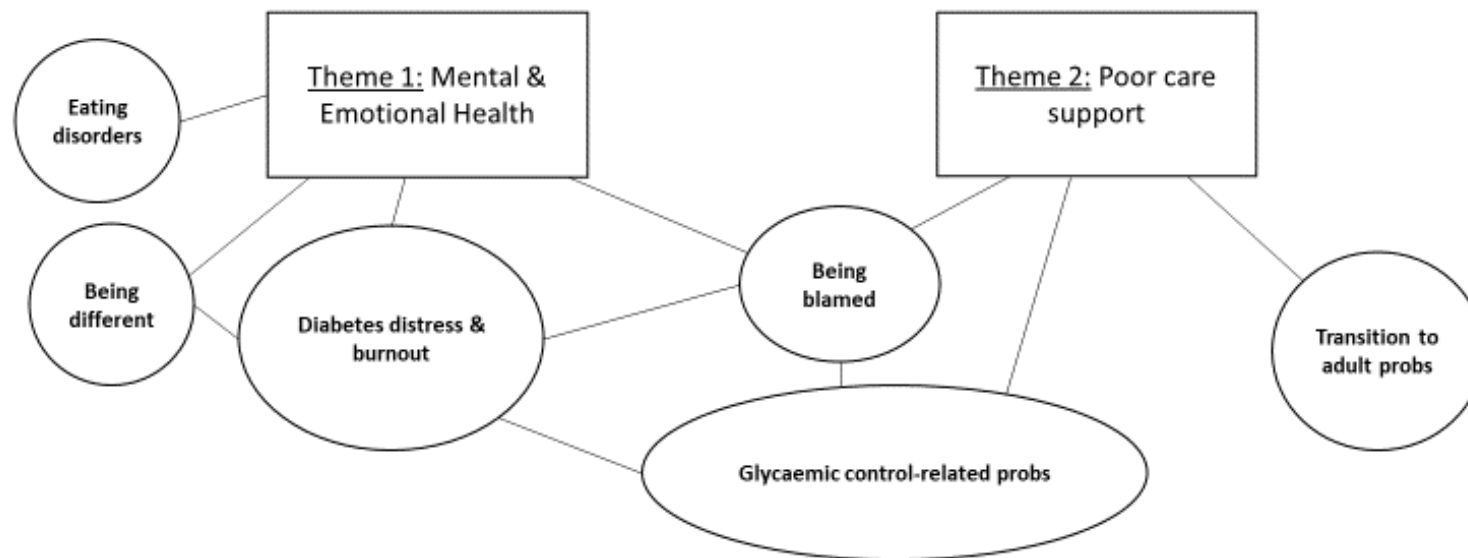


Figure 2 Past negative perspective thematic map, showing the two final themes.

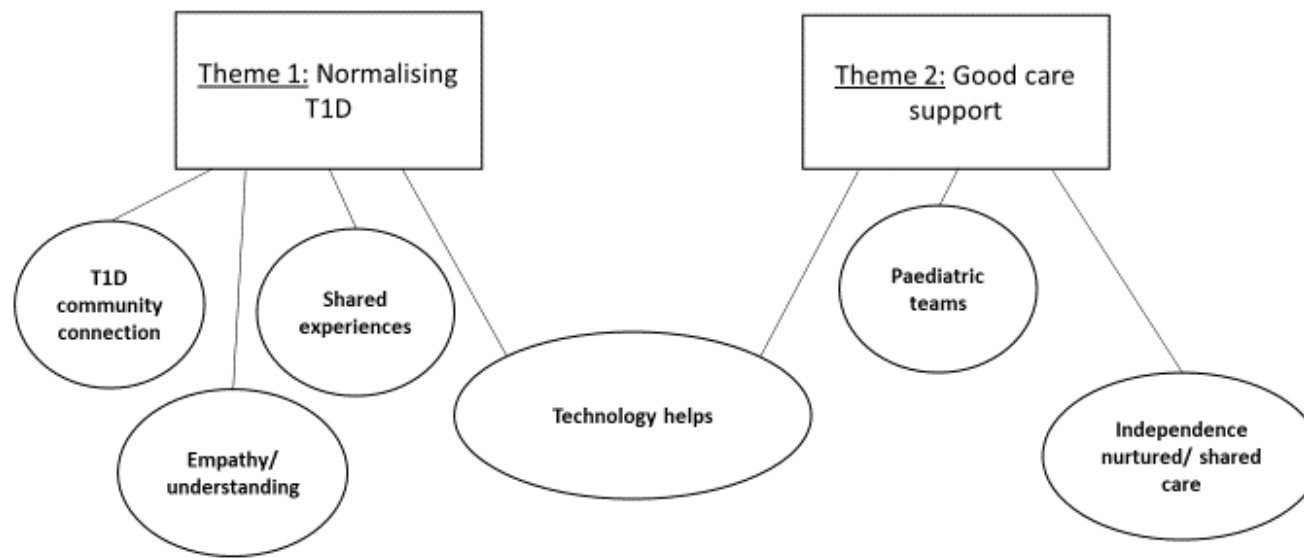


Figure 3 Past positive perspective thematic map, showing the two themes.

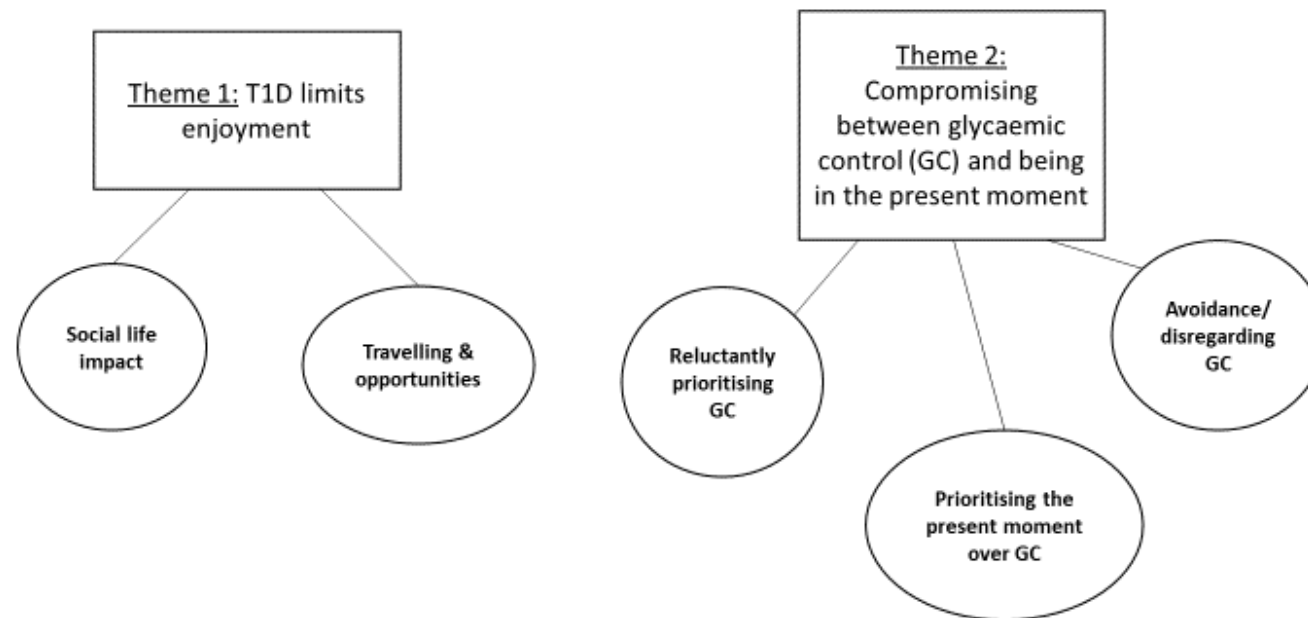


Figure 4 Present hedonistic perspective thematic map, showing the two themes.

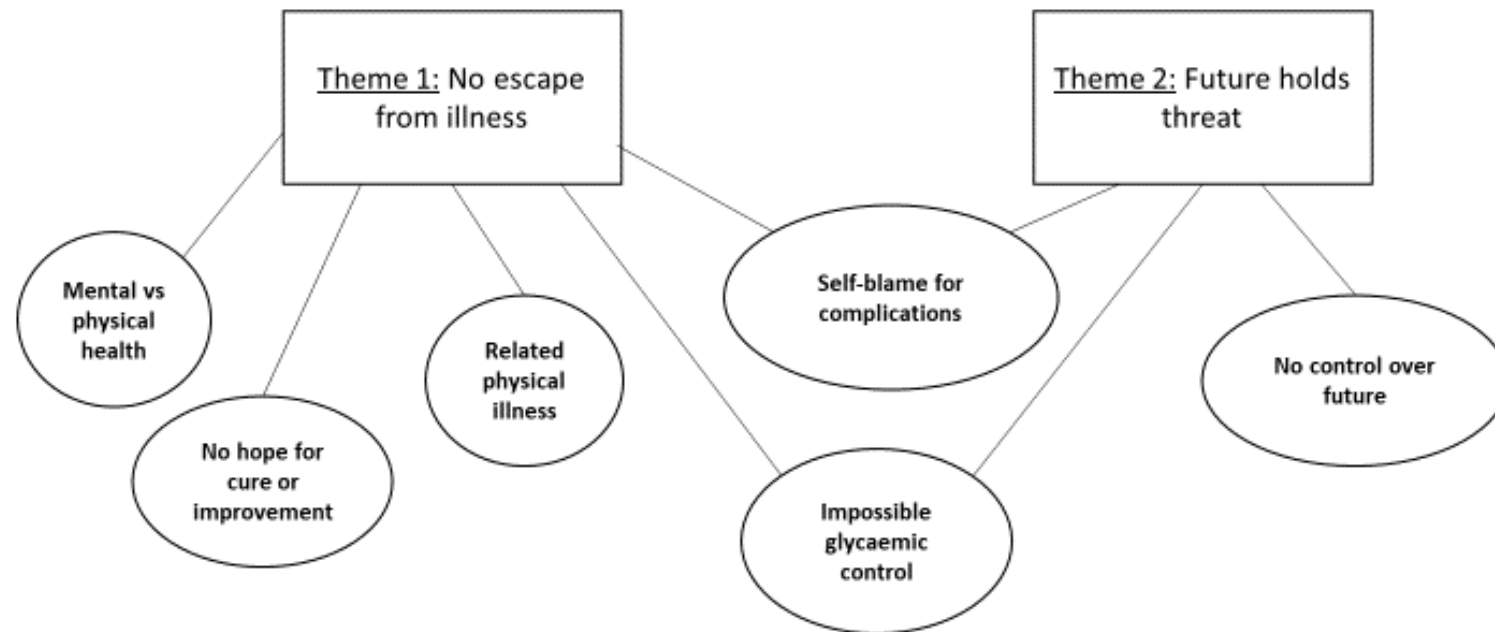


Figure 5 Present fatalistic perspective thematic map, showing the two themes.

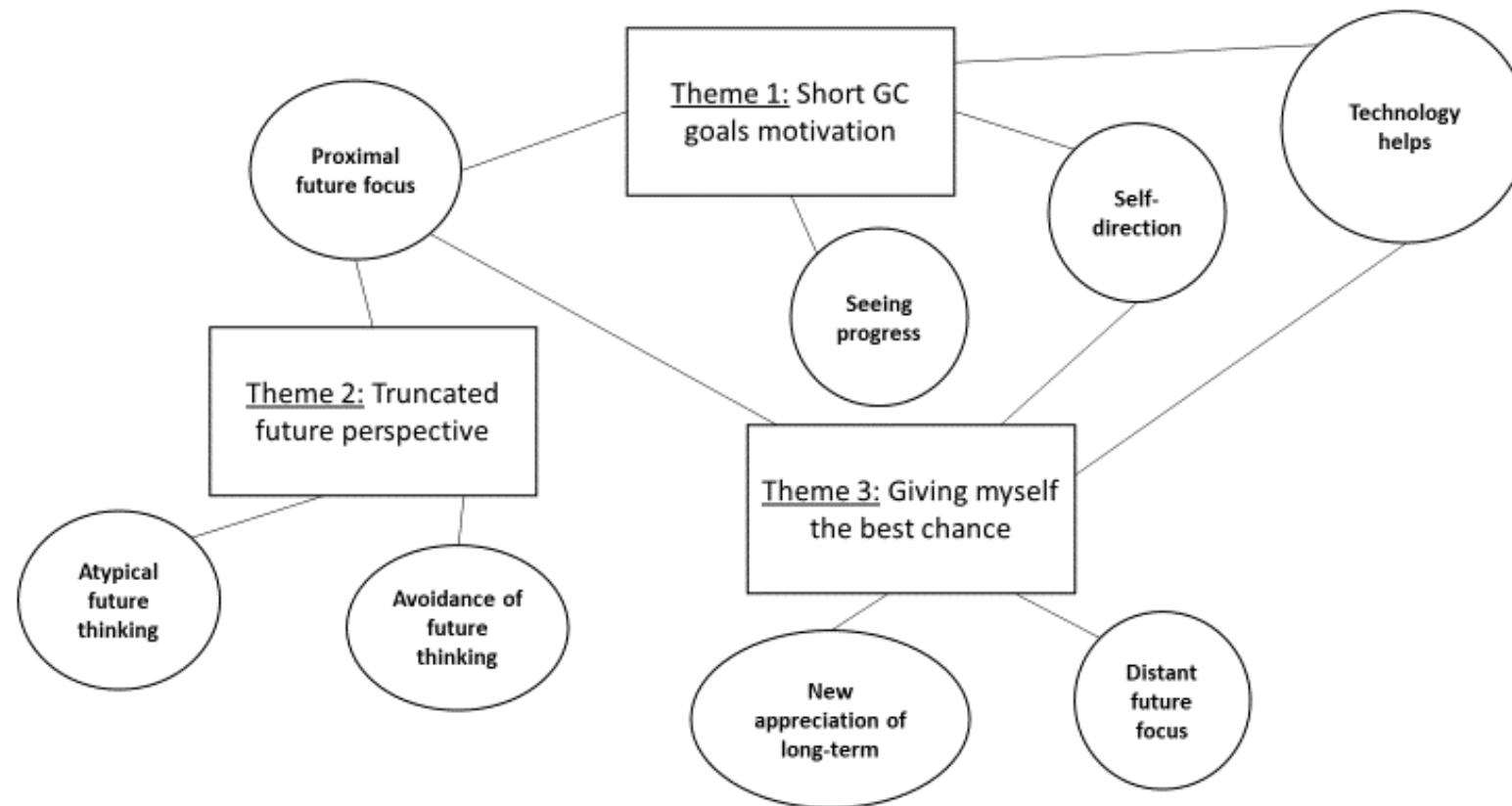


Figure 6 Future time perspective thematic map, showing the three themes.

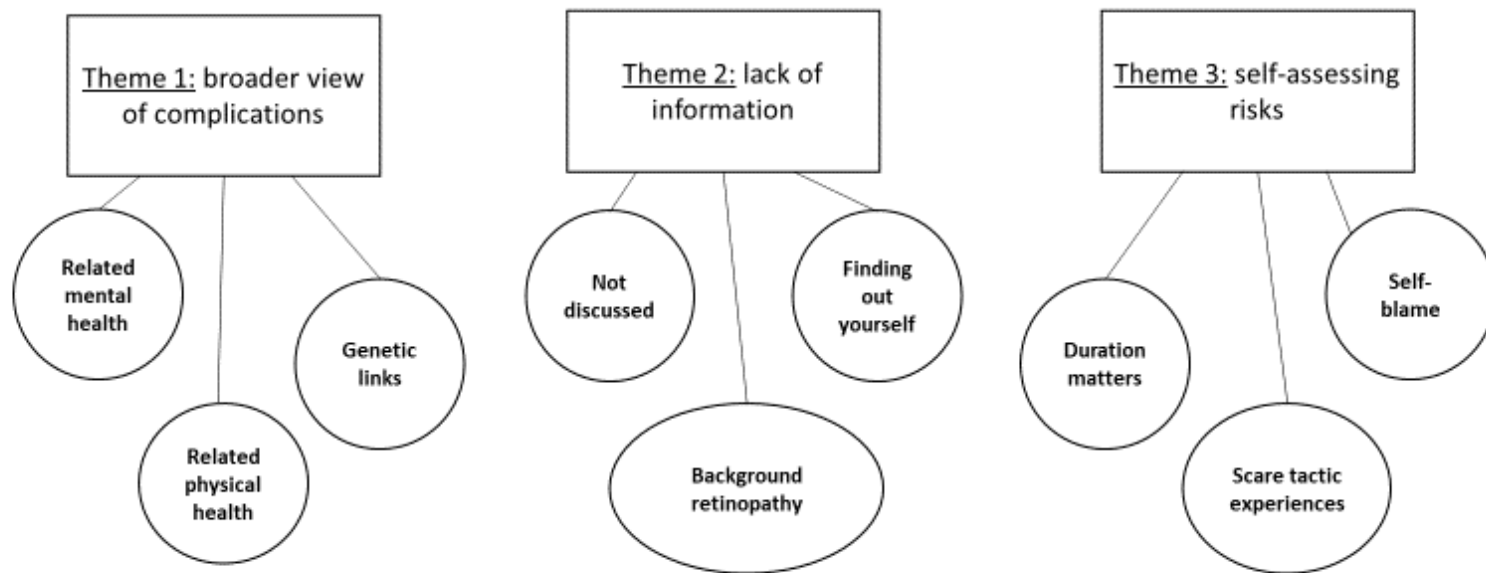


Figure 7 *Complications perceptions thematic map, showing the three themes.*

Chapter 7. Integration of Phase I and Phase II data

In this concluding chapter of the thesis, the datasets from the two studies will be used to form an integrated discussion and provide some explanation to the main findings from this research. The approach to integration of the data is described below. Following this, there is a discussion and possible explanation for the associations found between future time perspective, self-care and HbA1c. Next, a similar discussion and explanation is offered for the findings between past negative perspective and the dependent variables. Finally, the main thesis conclusions and some key recommendations for clinical practice based on the findings, are presented.

Overview of the approach to integration

The aim of integration of the two datasets was to explain key findings from Phase I. Firstly, the qualitative data was used to identify possible reasons why future time perspective was significantly associated with self-care and inversely associated with HbA1c in this cohort. Secondly, explanations why past negative time perspective was associated with higher HbA1c and lower reported self-care, were sought.

The questionnaire results for the Phase II participants were not analysed until after the thematic analysis had been generated from the interviews. This was to avoid knowledge of participants' quantitative data influencing the researcher, whilst the thematic analysis was being conducted.

Phase II quantitative data were examined to find participants scoring higher in future or past negative perspectives, whose self-care and HbA1c values reflected the significant relationships from Phase I. Four cases were identified as offering the most useful data for future time perspective. For the past negative associations, three cases were deemed most suitable. These selected cases were evaluated alongside the qualitative themes, to provide some explanations for the Phase I findings.

Quantitative data comparisons Phase I and Phase II

As can be seen below in Table 11, the Phase II sample provided good representation of typical characteristics found in the Phase I sample. However, there were some differences in mean scores of time perspective profiles. The Phase II sample had higher mean scores in past negative and future perspectives, with these forming the first and second highest biases, respectively. This was desirable in order to help explain the significant relationships with self-care and HbA1c.

Table 11 Main characteristics for both Phase I and Phase II

	<u>Phase I, n = 75</u>	<u>Phase II, n = 18</u>
Characteristic	Mean (SD) / prevalence %	Mean (SD) / prevalence %
Age	21.79 (1.97)	22.3 (1.63)
Gender		
Male	21.3	16.7
Female	77.3	72.2
Transgender	1.3	11.1
Education level		
Up to 5 GCSE	9.3	5.5
Apprenticeship	4.0	5.5
A level or above	86.7	89.0
Duration of diabetes		
1-10 years	41.3	33.4
>10 years	58.7	66.6
Insulin regimen		
Multiple daily injections (MDI)	50.7	44.5
Continuous insulin infusion (pump)	49.3	55.5
Complications present (yes response)	20	22.2
Past positive	3.57 (.74)	3.32 (.54)
Past negative	3.42 (.83)	3.66 (.89)
Present hedonistic	3.40 (.55)	3.32 (.54)
Present fatalistic	3.07 (.64)	2.79 (.78)
Future	3.29 (.67)	3.49 (.66)
Self-care	3.77 (.50)	3.87 (.59)
HbA1c (mmol/mol)	63.33 (13.71)	69.8 (35.5)*

*Due to outlier inclusion, median = 58.0 mmol/mol

Associations with future time perspective

Identification of cases

Cases were deliberately sought that reflected the significant associations found with future time perspective. This meant that in addition to a higher future time perspective score, these participants also needed to have a relatively high score on the SCI and relatively low HbA1c. For the time perspective and SCI score to be deemed high, threshold values of >4.0 were pragmatically chosen by the researcher. This was on the basis of sample distribution data, due to the lack of consensus in the literature regarding SCI thresholds (previously discussed in Chapter 4). The recent HbA1c value would ideally be below, or near to national target values (e.g. <53 mmol/mol (7.0%)), to be representative of desirable glycaemic control. For reference, the main questionnaire results for each participant in Phase II can be viewed in Appendix 18.

Initially, six participants were identified as scoring above 4.0 in future time perspective. Two participants were discounted due to having higher HbA1c and below desired threshold SCI scores. The remaining four participants were chosen as the most suitable cases, these were A1, B, D2 and J2. Participant A1 had slightly higher HbA1c (55 mmol/mol (7.2%)), however, she described how her HbA1c had been continuously dropping since her recent attendance on the DAFNE programme. Participant B was further examined due to scoring 4.0 in past negative time perspective, which was high compared to the other three cases. Both A1 and D2 scored low in past negative and J2 was comparable with the mean. Participant B was noted to have scored equally in past negative and past positive. On reviewing her past diabetes journey, she had recounted some minor negative diabetes experiences, but did not appear to have experienced significant problems living with diabetes up to this point. It was therefore assumed that the higher past negative score was not especially related to diabetes, making her a suitable case for review. For reference, a summary of the key variables for the cases with future dominance are shown in Table 12 below.

Table 12 Summary of data for the cases with future dominance

Participant	HbA1c	SCI score	Past Pos	Past Neg	Pres Hed	Pres Fat	Future
A1	55	4.00	4.20	2.00	2.80	2.75	4.17
B	49	4.27	4.00	4.00	3.40	2.25	4.17
D2	46	4.20	3.80	1.60	2.80	1.75	4.00
J2	45	4.60	3.60	3.60	3.00	2.00	4.33

Past pos = past positive, past neg = past negative, pres hed = present hedonistic, pres fat = present fatalistic

Future time perspective and main outcomes

When compared to others in the sample, the interview data provided some evidence that the cases with future dominance were able to visualise a more expansive future. For example, A1 and D2 had both explicitly stated how their present self-care was being motivated by reducing the risk of complications in the future. Participant B had described the importance of ensuring both daily numbers and longer-term average data, remained optimal. In the case of J2, a positive and hopeful outlook towards the longer future was expressed. These characteristics contrasted with others in the sample. It was more typical to be focused on immediate glycaemic control goals. Since many of the participants did not, or could not focus on an expansive future, it was common to have a truncated future perspective. Moreover, the cases with future dominance believed they were able to influence their future health outcomes in a positive way and this was motivating their present time self-care. Others in the sample with a less expansive view, were not convinced their future health outcomes were so controllable.

The significant positive association found between self-care and future time perspective, could therefore be explained by the desire to give themselves the best chance for the future. The cases with future dominance reflected this

phenomenon, in relation to the distant future and reducing the risk of complications. However, those who had a less expansive future view, still set self-care goals they believed would benefit them in the proximal future, for example with regards to starting a family. This further supports the explanation that giving themselves the best chance in future, was why self-care and future time perspective were associated.

A previously mentioned, variation in the expansiveness of future outlook within the sample, could be due to variations in age. Since the four cases with future dominance were all above the sample mean age (22.3 ± 1.63), perhaps a greater future expansiveness brought about by maturity, explains their data. However, when examining some other older participants in the sample, this does not appear to be consistent. For example, E, D1 and K2 were all aged 23-24 and each of them scored considerably lower on future time perspective (see Appendix 15). Additionally, it appeared from interview data that these participants either did not, or could not, think about longer-term health outcomes. For example, D1 expressed a fatalistic view towards the future and deliberately chose to focus on the present instead. Both E and K2 had significant anxieties about future complications and neither were convinced the risk of developing complications was something they could control.

Previous research has shown that denial, used as a coping mechanism in adults with type 1 diabetes, is associated with a truncated future time perspective (263). It has also been shown that the sense of a foreshortened future was associated with stressful emotional reactions predictive of PTSD, in another chronic disease that carries a future threat (242). More recently, a small study compared time perspective profiles of 30 adults with asthma, against 30 adults with type 1 diabetes (mean age 27.4 ± 10.9 yrs) (267). It was found that the diabetes group scored significantly higher in present fatalistic perspective and lower in future perspective, compared with the asthma and control groups. The authors concluded that the daily management burden of diabetes combined with a helpless future attitude, led to high fatalism in the present and a lower future expansion (267).

In the present sample, the cases with future dominance all scored below mean in present fatalism and above mean in future perspective. It is therefore likely that participants' attitudes towards the future is having an impact on their future expansiveness, aside from age or maturity. It can be posited that beliefs about future complications risks, and whether these are controllable by behaviour in present time, contribute to the expansiveness of future time perspective. These attitudes play a role in the relationship between future time perspective and self-care of diabetes and would appear to contribute to the individual time perspective profiles themselves.

In summary, the data suggests that the reason future time perspective had a positive association with self-care, was through an individual's desire to give themselves the best chance in the future. However, it seems that attitudes towards the future and whether outcomes are controllable or not, play an important role in the expansiveness of future time perspective.

The inverse association between future time perspective and HbA1c was as expected. As originally hypothesised, this appeared to triangulate with the self-care behaviours. It is therefore likely that self-care behaviour was mediating the relationship between higher future time perspective and lower HbA1c.

Associations with past negative time perspective

Identification of cases

For the second integrated evaluation, participants who scored high in past negative, lower on the SCI and had high HbA1c were desirable. To identify the most representative cases, a score >4.0 on past negative perspective was chosen, to mirror the process followed for the cases with future dominance. Since there are no upper threshold clinical risk categories for HbA1c, the decision was made to review all higher scorers in past negative and identify any low SCI and high HbA1c scores alongside this. Initially a total of eight participants were identified as scoring >4.0 on past negative perspective. Participant S was excluded as they had only been diagnosed for 12 months and had not yet lived through experiences described by the other participants.

Additionally, although they had the highest outlying HbA1c level of 196 mmol/mol (20%), this value represented the hyperglycaemic events leading up to their diagnosis and HbA1c had not been re-measured since. It was therefore not reflective of self-care. The second case to be excluded was B; as described in the previous section, the higher past negative score did not appear to be clearly related to past diabetes events. Of the remaining six, three further exclusions were made due to lower HbA1c and/or higher SCI scores. The three final cases were chosen: K1, A2 and L. These participants had the highest past negative scores of the sample, the highest HbA1c values (after excluding S) and the lowest SCI scores. The summary of their profiles is shown below in Table 13.

Table 13 Summary of data for the cases with past negative dominance

Participant	HbA1c	SCI score	Past Pos	Past Neg	Pres Hed	Pres Fat	Future
K1	110	2.80	2.60	4.80	3.80	3.25	2.50
A2	88	3.33	1.20	4.60	3.20	4.00	3.00
L	78	3.13	3.80	4.60	4.00	3.50	3.00

Past pos = past positive, past neg = past negative, pres hed = present hedonistic, pres fat = present fatalistic

Past negative perspective and main outcomes

It cannot be assumed that the past negative perspective of these cases is exclusively connected to diabetes. Negatively reconstructed events from any aspect of their lives could contribute to the score on the past negative scale, since the ZTPI is a generic scale. Indeed, A2 and L both shared that they had lived through traumatic family problems in their youth, which had seriously affected their mental health and well-being. However, when looking for commonality between the past diabetes journeys of these participants, it was clear they had lived through a catalogue of negative experiences due to diabetes. Each of them reported having serious diabetes-related mental health disorders including diabulimia, in addition they were the only participants in the

sample who had received psychiatric care whilst still in paediatrics. Over the years, all of them had been admitted to hospital numerous times with DKA episodes. Additionally, A2 and L expressed that they have frequently lost occupational and educational time, due to diabetes-related illness. These repeatedly negative experiences, provide good support that diabetes is implicated in the past negative perspective of the three participants, at least partially.

Comparing the cases with past negative dominance to those who had future dominance outlined above, it was notable that these three participants scored considerably lower in future time perspective, but higher than average in present fatalistic perspective. This was in opposition to the cases with future dominance and is suggestive that they are not able to look ahead with hope, it is likely they feel that they have little control over future outcomes. Instead, their future perspective is truncated and evidence from their interview data, suggested that they believe their future is in jeopardy. These findings of participants scoring lower in future time perspective and higher present fatalistic perspective, support the findings of the previous study described above, where time perspective profiles of people with diabetes were compared to those with asthma (267). However, the previous study did not include past time perspectives within their sample, meaning the additional connection to past negative perspective found in the present research, would merit further exploration.

Past negative diabetes experiences may have contributed to negative or fatalistic attitudes towards the future. For example, being blamed by care providers, meant that they believed the risks that lie ahead are a result of their own self-care failings. K1 reported 'terrifying' experiences in paediatrics, where complications were used as a threat in response to suboptimal glycaemic control. Both A2 and L similarly reported negative future health outcomes being used as a scare tactic, they too had experienced blame for past glycaemic control behaviours. Perhaps the inverse correlation between past negative perspective and self-care, can be explained by this phenomenon. Past negative blame experiences could have facilitated negative future attitudes, which makes it harder to comprehend that investing in self-care now will be protective later

on. This is supported by their data showing a higher fatalistic present perspective. Participant L even vocalised this in her interview: she believed she could not control her future and didn't accept that certain behaviour would equate to a particular outcome. Since self-care and glycaemic control are such a daily burden, it seems feasible that it would be hard to sustain these behaviours, if you did not fully accept they serve to benefit in the future.

However, there may be a more straightforward explanation for the inverse association between past negative perspective and self-care, in relation to mental health. Since mental health was such a prominent theme for past negative perspective, it is plausible that mental health provides an explanation for the relationship between past negative and lower diabetes self-care. The characteristic associations between past negative perspective and mental health problems, have previously been highlighted (3). Additionally, it has previously been shown that mental health problems in emerging adults with type 1 diabetes, are associated with lower levels of self-care and higher HbA1c (67, 71). The cases with past negative dominance expressed that the impact of mental health disturbance often affects their diabetes self-care. Both K1 and A2 described this as being an internal battle. On one side, they have intrusive fear and anxiety about the future health consequences, if they do not fulfil self-care requirements. However, on the other side they are frequently dealing with intrusive thoughts to omit insulin and completely abandon self-care. These conflicting thoughts have to be negotiated regularly, as often as daily when mental illness symptoms are severe.

Interestingly, despite having low SCI scores, it was evident that none of the cases with past negative dominance were disengaged with self-care or glycaemic control. Indeed, all three were very aware of their own blood glucose patterns and insulin management. The SCI questionnaire asks participants to report on whether they are carrying out behaviours 'as recommended'. Perhaps the lower SCI scores are a reflection of this. However, if they were not carrying out self-care as recommended by their clinics, this does not necessarily mean they were not carrying out self-care at all. They may have been managing activities in their own way and this could falsely give the impression of disengagement. The problem for these participants did not appear to be a lack

of desire or motivation for self-care. The issue was whether they were able to follow through and carry out the appropriate actions, which was entirely dependent on their mental state. It is therefore likely that mental health mediates the relationship between past negative perspective and lower self-care. This was supported by data from K1's interview. At the time of the interview, she revealed that she was struggling to cope with self-care due to her eating disorder. She described being acutely aware of her self-care needs and was checking her blood glucose levels frequently, yet she was unable to action the required insulin changes, due to deteriorating mental health.

In summary, the inverse relationship between past negative perspective and self-care, could possibly be explained by prior negative experiences contributing to a hopeless future view. However, it could also be a reflection of associated mental health problems presenting a barrier to self-care in present time.

The association between past negative perspective and HbA1c was stronger than the correlation found between past negative perspective and reported self-care behaviour, suggesting this construct could have an independent relationship with the biomarker, aside from self-care behaviour. A limitation of this type of correlational analysis, is that it is not possible to determine the direction of this relationship. It is possible that having had repeatedly high HbA1c during childhood and adolescence could have led to more negative memories or reconstructions, since this was frequently met with a negative response. However, it is also possible that the past negative perspective is affecting HbA1c by physiological mechanisms, through the presence of underlying mental stress. As described above, the anxiety burden brought about by managing co-existing mental health disorders alongside type 1 diabetes is profound. It is likely that repeated mental and emotional distress, would contribute to glycaemic control disturbance. Chronic stress has been associated with the dysregulation of many physiological parameters, resulting from a maladaptive shift in homeostatic processes (268). This includes metabolic processes and in people without diabetes, chronic stress has been associated with elevation in both fasting blood glucose and HbA1c levels (269). In those who do have diabetes, it is well recognised that mental health problems including diabetes distress, are associated with higher HbA1c (67, 71, 270).

Additionally, it has been suggested that the mechanism behind the association between mental health disorder and higher HbA1c in diabetes, is a result of these physiological changes induced by chronic stress (270). Therefore, it is possible that mental health is also involved in the relationship between past negative perspective and HbA1c found in Phase I. If the presence of chronic stress due to mental health disorder has resulted in metabolic dysregulation, there could be an independent impact on HbA1c, aside from the effects of self-care behaviours. The three cases with past negative dominance described the most severe mental health illness of all and they had the highest HbA1c levels. Indeed, all participants who had HbA1c levels >60 mmol/mol (7.6%) in the sample, had experienced diabetes-related mental health problems requiring psychological or psychiatric intervention. In contrast, none of the cases with future dominance reported having had any serious mental health problems related to diabetes in the past. Perhaps this had also been reflected in their HbA1c, where the absence of chronic stress impact, meant that their self-care activities were more effectively keeping HbA1c levels lower.

In summary, it is probable that for many of these participants, a past negative perspective is partly due to having diabetes. Negative diabetes-related experiences had contributed to alterations in attitudes towards the future, which may explain lower levels of self-care associated with past negative perspective. However, a more likely explanation is that the presence of diabetes-related mental health disorders is having a detrimental impact on the ability to sustain self-care activities. The effects of poor mental health could also explain why past negative perspective was associated with higher HbA1c, both through lower self-care ability and the physiological changes arising from chronic psychological stress.

Thesis Conclusions

This study set out to investigate the role of time perspective in self-care behaviours for type 1 diabetes, in an emerging adult population. The original research questions for this sequential explanatory mixed methods study were:

1. Is future time perspective associated with higher levels of self-care activity? It is hypothesised that scores in future time perspective will be positively associated with self-care and negatively associated with HbA1c level
2. Are other time perspectives associated with self-care or HbA1c and in what ways?
3. What experiences of living with type 1 diabetes are connected to time perspective?
4. What are the perceptions of future complications among emerging adults and how does this affect self-care in present time?

Time perspective was found to be connected to both self-care and HbA1c, from the research studies conducted. As was originally hypothesised, future time perspective was associated with higher scores in reported diabetes self-care and with lower HbA1c. This was a novel finding and contributes to the existing time perspective and diabetes literature. The main reason for this identified from the qualitative study, was that they were seeking to give themselves the best chance in the future. However, this was not always in relation to the prevention of chronic diabetes complications in the distant future. Indeed, many of the emerging adults did not have an expansive future view and it seemed that attitudes towards complications and whether they were controllable, played a part in the development of an expansive future view. Living with type 1 diabetes and its potential future threats, may be changing the time perspective of emerging adults.

Past negative time perspective also played a role, where this time perspective was found to be associated with lower reported self-care of diabetes and higher HbA1c. Again, this was a novel finding and adds new knowledge to the existing literature. Of the many past negative diabetes-related experiences reported by

the participants, the impact diabetes has on mental and emotional health was an important problem for participants in the sample. It is very likely that the impact on mental health was a key reason for having a past negative perspective. It could also provide an explanation for lower self-care and higher HbA1c. The former, due to struggles with managing the burden of self-care duties alongside anxiety and other mental health symptoms. The latter, could be a reflection of reduced self-care behaviours, or could be from consequential physiological changes in glycaemic control, arising from the presence of chronic stress. Another possible explanation for these associations, is that past negative diabetes experiences have contributed to the formation of negative future attitudes and a more fatalistic present outlook. This could attenuate motivation towards self-care as a means to protect health in the future, if it was not perceived as offering likely protection.

Past and present experiences of living with type 1 diabetes, were found to be connected to the different time perspectives. For example, significant experiences of care support that had been either positive or negative, had made a lasting impact on the participants. In present time, diabetes appeared to be a barrier to a present hedonistic perspective characteristic of emerging adults, these participants were less able to freely engage in pleasure-seeking on account of their condition. As described above, some past negative experiences appeared to change perceptions of the future, towards a less expansive and more fatalistic perspective. Where participants had experienced blame for suboptimal glycaemic control, or if they believed complications were not controllable, it was typical to have a truncated future outlook and a fear of future threats.

These apparent changes to time perspective were typically linked to perceptions about complications. The emerging adults held a broad view of what diabetes complications were. This included problems arising from diabetes that are unrelated to glycaemic control, as well as those related to glycaemic control. Based on prior knowledge and lived experiences, the participants were often self-assessing their personal likelihood of developing complications. However, the sample did not consistently believe that their present time self-care could influence this outcome. There was deemed to be a lack of

information about diabetes complications. Despite this difficult subject not being addressed in practice, many expressed a desire for more information about complications at this stage of their lives.

Recommendations for policy, practice and further research

The findings of this study support the position that emerging adults with type 1 diabetes have care needs that are unique to this group (44). As such, some recommendations for practice and further research can be made. These are outlined in the sections below.

Mental health

It was clear that diabetes-related mental health disturbance was both common and impacting for participants in this sample. Although not tested quantitatively, interpretation of the qualitative data was suggestive that those with more severe mental health problems, had the most significant challenges with self-care and clinical glycaemic control. This fits with previous literature, showing that mental health disturbance is a barrier to self-care and optimal glycaemic control in emerging adults (67, 71, 197). In view of this, it is recommended that psychological care should be a priority for diabetes care providers who are treating emerging adults. Since past negative perspective was associated with lower self-care and higher HbA1c, it would be of interest to further explore the possible relationship between past negative perspective and mental health within this population. Future studies could investigate whether the relationship between past negative perspective and the diabetes outcomes is mediated by mental health.

Participants who had co-existing eating disorders that are uniquely found in people with type 1 reported that in their experience, diabetes clinic staff lacked sufficient expertise to appropriately support them. Other samples have reported similar experiences in previous qualitative research (255). It has been recognised that the underlying pathology of diabetes-specific eating disorders is poorly understood (271) and that there is a need for more targeted support of patients with these conditions. It has been recently suggested that early intervention would be of benefit (272). However, research in this specialist area is lacking and future direction could include the evaluation of early intervention or prevention programmes.

Glycaemic control targets and feeling blamed

There had been considerable impact on the participants arising from negative reactions to glycaemic control. This had caused anxiety, diabetes distress and fear. In many cases, current beliefs about complications, such as whether these are controllable or not, or what their personal risk of developing them is, had been formed from previous negative experiences with care teams. Blaming younger patients for suboptimal glycaemic control is not appropriate and is unlikely to produce the desired motivational response (264). It has been suggested that this leads to an over magnification of the risks and that young people would respond better to positive messages focused on prevention (264).

The present study showed there was a difference in the way emerging adults were interpreting HbA1c. The participants did not use the national target of 48 mmol/mol (6.5%) as a goal, but set their own shorter goals and tended to use HbA1c as a general benchmark. It was not always possible for them to think about longer-term targets and only a small minority in the sample were motivated by potential health benefits that lay far in the future. From the care providers' perspective, the purpose of HbA1c monitoring is to continually aim for target, with the main goal being to reduce the risk of morbidity later in life. This disconnect presents a problem for policy makers. At this high-risk stage of life, clinical care providers would be right to prioritise target HbA1c according to the evidence-base, as a means to protect the patient's future health. However, this is not motivational for emerging adults who are focused on the proximal future. Moreover, from the experiences described by participants in the current research, the insistence on targets appears to be a common source of diabetes distress. This supports previous literature, showing that problems with achieving glycaemic control was one of the most significant sources of diabetes distress in type 1 diabetes (71). It would be more advisable for emerging adult care teams to focus on shorter glycaemic control goals, such as daily time in range. Perhaps a more sensitive approach is required, where the emphasis is moved away from recommended targets. At this life stage, treatment plans should temporarily focus on shorter glycaemic control goals, until such times when the emerging adult can more easily visualise the distant future. This could prevent

stress caused by feeling blamed and may prove to be more motivational in the longer-term.

Collaborative support post-transition

The participants shared many challenging experiences they had faced when they were new to the adult care environment. These clearly reflected qualitative findings in previous transition literature, for example struggling to navigate systems, feeling the teams didn't know them and feeling overwhelmed by independent responsibility (53, 54, 60, 62).

Recognition of the problems associated with transition, has led to global consensus on good practice and transitional care standards for young people with type 1 diabetes (44). There are many examples in the literature of innovative transition programmes and interventions, some of which have shown improvements on measured outcomes post-transition, including HbA1c and clinic attendance (273-275). However, the interventions in previous studies are multi-factorial and typically involve a combination of supportive, practical and educational resources. For example, use of a nominated systems navigator, various education-based resources and use of digital technologies to support blood glucose management, have all featured across a range of processes (273-276). It is therefore difficult to assess which of these is having most impact. Few of these studies have been randomised-controlled trials and there is high heterogeneity between the interventions, it is therefore difficult to collectively assess their effectiveness (276). Moreover, most of the longitudinal intervention studies have not collected measures beyond 12 months post-transition and are more focused towards the peri-transitional period. Relating this evidence back to findings from the present sample, highlights a clear gap.

It was notable that the participants considered transition as being a present time, rather than a past event, yet none of the participants in Phase II were currently going through transition. They were all in adult care at the point of interview and some of them had already been in adult care for several years. It is possible that emerging adults who have moved from paediatric to adult care, perceive transition to be an extended process that continues post-transition,

possibly for a period of many years. This is not likely to be recognised by care providers and there is risk that adult care teams lack understanding of the needs of emerging adults. For example, in a recent study among adult diabetes care physicians in Canada, over 50% of respondents believed that paediatric teams needed to better prepare emerging adults in the areas of their self-management skills, ability to navigate adult care systems and understanding the different approach to care, compared with paediatrics (59). This suggests that many adult care providers expect newly transitioned emerging adults to arrive ready for the adult environment. From previous literature and the present study findings, this is not typically the case.

There is therefore a need for further examination of the extended post-transition period. Rather than assuming autonomy once the transition process has been completed, care support needs to continue to be collaborative and individualised, depending on whether the emerging adult is ready for full responsibility or not. For those who do need additional support with self-care post-transition, providing individualised care in this way could prevent the deterioration in glycaemic control or disengagement with diabetes services, that is associated with this population (42, 43).

Talking about complications

The issue of chronic complications was important for the participants at this stage in their lives and they reported that this was something that had recently changed. For those with long duration of diabetes, emerging adulthood is a time when disease-related changes are more likely (7) and background retinopathy was a current issue for many of the participants. For the emerging adults in the present research, many had never had an open conversation with healthcare professionals about complications, despite regular conversations about HbA1c targets and attendance at annual screening appointments. It seemed that previous mention of complications had always come from a negative stance, due to suboptimal control. It is important for emerging adults to understand the relevance of their health outcome measures, without feeling blamed. It is also important that they feel able to seek information about complications in a supportive environment. At present, they seemed unable to access the

information they seek from their care providers and were instead searching for this on the internet or through the online diabetes community. There is a lack of evidence about how emerging adults with diabetes are seeking health-related information. One study conducted in a general adult sample (n=203), found that patients under 40 years old with type 1, were more likely to use the internet for health information and that 'complications' was a frequently searched topic (277). In a systematic review of information-seeking behaviours among people with diabetes, it was highlighted that although the internet is a common information source for younger people, studies suggest that they still wish to have information verified by their healthcare professionals (278).

Care providers need to find new ways to have open, non-judgemental conversations with emerging adult patients about diabetes complications. The current initiative regarding talking about complications in adult care (266), should be expanded to include the specific care needs of emerging adults, so that this sensitive subject can be appropriately discussed in clinic settings.

Further research

Finding ways to have constructive, supportive discussions about complications would require further research, this must involve all stakeholders and could be facilitated by both quantitative and qualitative methods. With regards to time perspective, the findings from this series of studies suggest there are changes to time perspective profiles in the sample, due to having type 1 diabetes. These were, that past negative experiences and fear of complications had possibly contributed to a more fatalistic outlook and foreshortened view of the future. This could be further explored quantitatively, using age-matched samples. Additionally, the mental health theme identified as being connected to past negative perspective, could also be quantitatively tested to identify a generalisable association and to investigate a possible mediational relationship. Time perspective constructs could potentially be used to identify emerging adults who are at particular risk and therefore used as a tool in psychological care. Further, time perspective intervention studies may provide useful new knowledge, since these could identify directionality of the relationships found in the present research.

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Appendices

Appendix 1. Problematic diabetes language with recommended alternatives

Problematic terminology	Recommended alternative words/phrase(s)
Diabetic (in relation to a person)	Person with diabetes, people with diabetes (Use person-first language)
Suffer, suffers from, suffering	Has diabetes Live/living with diabetes
Disease	Condition
Normal (glucose level, blood tests etc)	Within range Above/below target Optimal or suboptimal
Healthy (person)	Person/people without diabetes
Control of diabetes or treatment of diabetes	Management, managing diabetes
Good control, poor or bad control (of blood glucose or diabetes)	Stable/unstable Optimal/suboptimal Within range Above/below target
Compliance or non-compliance Adherence or non-adherence	Self-management, self-care Management, managing diabetes (Describe collaborative goal setting and empowered self-management, depending on context)

The Study Questionnaire

Part 1. General questions about you and your diabetes

What is your age? _____ yrs				
Are you:	Male <input type="checkbox"/>	Female <input type="checkbox"/>	Transgender <input type="checkbox"/>	Prefer not to say <input type="checkbox"/>
Which of the following best represents your highest level of qualification?				
1-4 GCSEs or equivalent <input type="checkbox"/>	5+ GCSEs or equivalent <input type="checkbox"/>	Apprenticeship <input type="checkbox"/>	2+ A levels or equivalent <input type="checkbox"/>	Degree level or above <input type="checkbox"/>
How long have you had type 1 diabetes?				
	1-5 yrs <input type="checkbox"/>	6-10 yrs <input type="checkbox"/>	Over 10 yrs <input type="checkbox"/>	
What is/are the name of your prescribed insulin(s)? _____ _____ _____				
What injection device(s) do you use? (e.g. pen, pump, InnoLet™) _____ _____				
<i>If you have signed a consent form for your clinic to provide your HbA1c later on, skip the questions about HbA1c below. If you know your recent result, please enter it below.</i>				
What was your last HbA1c result? (if known)		When was this HbA1c checked? _____		
Do you have complications of diabetes? Yes <input type="checkbox"/> No <input type="checkbox"/>				
If yes, please tick any that apply:				
Eye problems <input type="checkbox"/>	Foot problems <input type="checkbox"/>	Nerve problems (pain or tingling) <input type="checkbox"/>		
Kidney problems <input type="checkbox"/>	Heart problems <input type="checkbox"/>	High blood pressure <input type="checkbox"/>		
Any other complications not listed above <input type="checkbox"/>				

Part 2. Questions about your diabetes self-care

Please rate the statements below, selecting the response that is most true for you.
In the ***past month***, how frequently have you followed recommendations for:

		Never	Some- times, not often	About 50% of the time	Usually, with occasional lapses	Always, every day without fail
1	Checking blood glucose					
2	Recording blood glucose					
3	Checking ketones when glucose is high					
4	Administering correct insulin dose					
5	Administering insulin at the right time					
6	Adjusting insulin based on glucose level					
7	Eating the proper foods; sticking to the meal plans					
8	Eating meals/snacks on time					
9	Keeping food records					
10	Carrying quick acting sugar to treat hypoglycaemia					
11	Attending a diabetes appointment					
12	Wearing a medic alert identification					
13	Exercising regularly					

In the ***past month***, how frequently have you:

		Never	Some- times, not often	About 50% of the time	Often	Very often
1	Skipped meals					
2	Skipped insulin injections					
3	Eaten foods that should be avoided					
4	Rotated injection sites					
5	Counted carbohydrate content of food					
6	Made up glucose level because results were too high					
7	Made up glucose level because results weren't tested					
8	Taken extra insulin because of eating inappropriate food or binge eating					

Part 3. Questions about your time perspective

Please rate the statements below, selecting the response that is most true for you:

		Very untrue of me	Untrue of me	Neutral, not sure	True of me	Very true of me
1	Familiar childhood sights, sounds, smells often bring back a flood of wonderful memories.					
2	I believe that a person's day should be planned ahead each morning.					
3	It gives me pleasure to think about my past.					
4	On balance, there is much more good to recall than bad in my past.					
5	When listening to my favourite music, I often lose all track of time.					
6	Meeting tomorrow's deadlines and doing other necessary work comes before tonight's play.					
7	I enjoy stories about how things used to be in the "good old times"					
8	Painful past experiences keep being replayed in my mind.					
9	I try to live my life as fully as possible, one day at a time.					
10	Ideally, I would live each day as if it were my last.					
11	I meet my obligations to friends and authorities on time.					
12	I've taken my share of abuse and rejection in the past.					
13	I take each day as it is rather than try to plan it out.					
14	The past has too many unpleasant memories that I prefer not to think about.					
15	I've made mistakes in the past that I wish I could undo.					
16	I feel that it's more important to enjoy what you're doing than to get work done on time.					
17	Even when I am enjoying the present, I am drawn back to comparisons with similar past experiences.					
18	You can't really plan for the future because things change so much.					
19	It doesn't make sense to worry about the future, since there is nothing that I can do about it anyway.					
20	I complete projects on time by making steady progress.					
21	I find myself getting swept up in the excitement of the moment.					

22	Life today is too complicated; I would prefer the simpler life of the past.					
23	I think about the bad things that have happened to me in the past.					
24	Spending what I earn on pleasures today is better than saving for tomorrow's security.					
25	There will always be time to catch up on my work.					

**End of questionnaire.
Thank you for taking part.**

Appendix 3. Phase 1 Participant Information Sheet (general version)

Participant Information Sheet

Study title

The role of time perspective in self-care in people with type 1 diabetes

Invitation paragraph

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. This research is being conducted by Elaine Sharp, a University of Brighton doctoral research student. Please ask if there is anything unclear, or if you would like more information (contact details are below). Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Young adults with type 1 diabetes can sometimes struggle with their daily self-care activities. This can put them at risk of serious complications in the future (for instance eye, kidney or heart problems). We all have the ability to think about the future but psychologists believe that some people find imagining the future much easier than others. This 'time perspective' (the extent to which we think about our past, present and future) has been shown to predict a range of things including our health choices, but little is known on how it might influence managing self-care activities. Therefore the purpose of this study is to investigate whether time perspective is related to the way people with type 1 diabetes carry out self-care activities.

Why have I been chosen?

You have been chosen because you are a young adult aged between 18-25 years with type 1 diabetes. You have been identified through involvement with either the Brighton Area Diabetes UK Volunteers Group, or via Diabetes UK and affiliated Diabetes UK social media. This study will include about 77 people.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any aspect of your diabetes treatment or care.

What will happen to me if I take part?

If you choose to take part, you will be asked to complete a questionnaire that will take approximately 10-15 minutes of your time. The questionnaire is anonymous, but does ask for some of your personal details such as age, education background and details about your prescribed diabetes treatment and recent HbA1c result. There are questions about your self-care and a set of questions to establish your time perspective. Your consent will be assumed by completion of the questionnaire. You will not be asked to give your name or any other personal details.

What do I have to do?

You will only have to complete questionnaire, as described above. Questionnaires can be completed electronically using the link provided. You can request a paper copy by contacting the researcher, a stamped addressed envelope will be provided with paper copies. Please answer the questions as honestly as you can.

What are the possible disadvantages and risks of taking part?

There are no risks to you if you choose to take part. The information will not be passed on to your diabetes care team, or used by anyone other than the researchers. Additionally, you will not be named on the questionnaire. Some of the time perspective questions may make you think about difficult things that have happened to you, but you will not be asked for any details about your past. If you are concerned about any of the questions or your self-care, you can talk to your diabetes care team.

What are the possible benefits of taking part?

There are no potential benefits to you personally if you take part. However, the results may be used in future to find new ways to help support young adults with their diabetes self-care. If you wish, you can provide an email address to be entered in to a prize draw for a £20 Amazon gift voucher. This email address will not be used for any other purpose and will be deleted from the records at the end of the study.

What will happen if I don't want to carry on with the study?

Taking part is completely voluntary, you can choose to withdraw at any time and this will not affect you in any way.

Will my taking part in this study be kept confidential?

The questionnaire will not contain your name. All the anonymous information you provide will be transferred electronically and stored in a password protected database. Paper copies will be retained in a locked drawer at the university. Only the researcher and named supervisors will have access to the information, which will be retained for 10 years then disposed of securely.

What will happen to the results of the research study?

The results of the study will only be used for research purposes, which may include publication of the study in an academic journal. If you wish to receive a summary of the results when the project has finished, contact Elaine Sharp by email.

What if there is a problem?

If there is a problem or you wish to complain about any aspect of this study, you can contact one of the project supervisors, or the Pharmacy School office who will be able to address your concerns.

Main Contact Details: Mrs Elaine Sharp, Lecturer in Pharmacy Practice. es136@brighton.ac.uk 01273 641918		
Supervisor: Dr Sian Williams, Senior Lecturer in Health Psychology sew13@brighton.ac.uk 01273 643961	Supervisor: Dr Wendy Macfarlane, Reader in Molecular Biology, Brighton Diabetes Research Group w.m.macfarlane@brighton.ac.uk 01273 642101	Pharmacy School Office 01273 642090

Appendix 4. Phase 1 Participant Information Sheet (NHS clinic version)

Participant Information Sheet

IRAS ID: 222292

Study title

The role of time perspective in self-care in people with type 1 diabetes

Invitation paragraph

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. This research is being conducted by Elaine Sharp, a University of Brighton doctoral research student. Please ask if there is anything unclear, or if you would like more information (contact details are below). Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Young adults with type 1 diabetes can sometimes struggle with their daily self-care activities. This can put them at risk of serious complications in the future (for instance eye, kidney or heart problems). We all have the ability to think about the future but psychologists believe that some people find imagining the future much easier than others. This 'time perspective' (the extent to which we think about our past, present and future) has been shown to predict a range of things including our health choices, but little is known on how it might influence managing self-care activities. Therefore the purpose of this study is to investigate whether time perspective is related to the way people with type 1 diabetes carry out self-care activities.

Why have I been chosen?

You have been chosen because you are a young adult aged between 18-25 years with type 1 diabetes. You have been identified through the Diabetes Care for You service or the Brighton Area Diabetes Group. This study will include about 77 people.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and asked to sign a consent form saying that you agree for NHS clinics to provide your HbA1c result. You are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any aspect of your diabetes treatment or care.

What will happen to me if I take part?

If you choose to take part, you will be asked to complete a questionnaire that will take approximately 10-15 minutes of your time. The questionnaire is anonymous, but does ask for some of your personal details such as age, education background and details about your prescribed diabetes treatment. There are questions about your diabetes self-care and a set of questions to establish your time perspective. You will be given a Participant Unique Identification Number for the study, the clinic staff will match this number with your recent

HbA1c result and share this with the researcher. The researcher will not be given your name or any other personal details.

What do I have to do?

You will only have to answer the questions on the questionnaire, as described above. Questionnaires can be completed on paper and returned using the envelope provided, or they can be completed electronically using the link provided. If you complete the questions online, enter your Participant Unique Identification Number when requested. Please answer the questions as honestly as you can.

What are the possible disadvantages and risks of taking part?

There are no risks to you if you choose to take part. The information will not be passed on to your diabetes care team, or used by anyone other than the researchers. Additionally, you will not be named on the questionnaire. Some of the time perspective questions may make you think about difficult things that have happened to you, but you will not be asked for any details about your past. If you are concerned about any of the questions or your self-care, you can talk to your diabetes care team.

What are the possible benefits of taking part?

There are no potential benefits to you personally if you take part. However, the results may be used in future to find new ways to help support young adults with their diabetes self-care. If you wish, you can provide an email address to be entered in to a prize draw for a £20 Amazon gift voucher. This email address will not be used for any other purpose and will be deleted from the records at the end of the study.

What will happen if I don't want to carry on with the study?

Taking part is completely voluntary, you can choose to withdraw at any time and this will not affect you in any way.

Will my taking part in this study be kept confidential?

The questionnaire and HbA1c result will not contain your name. All the anonymous information you provide will be transferred electronically and stored in a password protected database. Paper copies will be retained in a locked drawer at the university. Only the researcher and named supervisors will have access to the information, which will be retained for 10 years then disposed of securely.

What will happen to the results of the research study?

The results of the study will only be used for research purposes, which may include publication of the study in an academic journal. If you wish to receive a summary of the results when the project has finished, contact Elaine Sharp by email.

What if there is a problem?

If there is a problem or you wish to complain about any aspect of this study, you can contact one of the project supervisors, or the Pharmacy School office who will be able to address your concerns.

Main Contact Details: Mrs Elaine Sharp, Lecturer in Pharmacy Practice. es136@brighton.ac.uk 01273 641918		
Supervisor: Dr Sian Williams, Senior Lecturer in Health Psychology sew13@brighton.ac.uk 01273 643961	Supervisor: Dr Wendy Macfarlane, Reader in Molecular Biology, Brighton Diabetes Research Group w.m.macfarlane@brighton.ac.uk 01273 642101	Pharmacy School Office 01273 642090

Appendix 5. Phase 1 consent form (for NHS clinic use)

CONSENT FORM

Participant Unique Identification Number:
IRAS ID: 222292

Title of Project: **The role of time perspective in self-care in people with type 1 diabetes**

Name of Researcher: Elaine Sharp

Please initial
box

1. I confirm that I have read the information sheet dated...June 2017...
(version...1.1....) for the
above study. 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 understand that the clinic will share my recent HbA1c result with the
researcher and that this will be matched to my participant unique
identification number, not my name. I give permission for the clinic to
provide my anonymous HbA1c result.

4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix 6. University of Brighton PABS Research Ethics Committee Phase I approval



University of Brighton

School of Pharmacy & Biomolecular Sciences

Huxley Building

Moulsecoomb

Brighton BN2 4GJ

pabs.ethics@brighton.ac.uk

6th June 2017

APPLICATION FOR ETHICAL APPROVAL FOR PROJECT PROPOSAL – Change Notification
Is time perspective associated with adherence to self-care activities in people with type 1 diabetes?

The School Ethics Committee has approved the requested change to the above application. There are no ethical issues with this new proposal.

The new End date for your project is **30th April 2018**. If, towards the end of your project, you realise it will over-run you must apply for an extension, allowing plenty of time for ethics approval.

Yours sincerely,

Dr Fergus Guppy

Chair, School of Pharmacy and Biomolecular Sciences Research Ethics Committee



Health Research Authority

Mrs Elaine Sharp Senior Lecturer University of Brighton

School of Pharmacy & Biomolecular Sciences Lewes Road Email: hra.approval@nhs.net

Brighton BN2 4GJ

17 November 2017 Dear Mrs Sharp

Letter of HRA Approval

Study title: An investigation of the role of psychological time perspective in self-care behaviours in emerging adults aged 18-25 years with type 1 diabetes

IRAS project ID: 222292

REC reference: 17/LO/1897

Sponsor University of Brighton

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability.

Please read *Appendix B* carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the

time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from the [HRA website](#).

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The 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.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the

HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.

- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found through [IRAS](#).

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application

procedure. If you wish to make your views known please use the feedback form available on the [HRA website](#).

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details on the [HRA website](#).

Your IRAS project ID is **222292**. Please quote this on all correspondence.

Yours sincerely

Joanna Ho Assessor

Email: hra.approval@nhs.net

*Copy to: Dr Lucy Redhead, Sponsor Representative, University of Brighton
Helen Vaughan, Sussex Community NHS Foundation Trust,
Dr Sian Williams, Academic Supervisor, University of Brighton*

Appendix 8. HRA favourable ethical opinion

London - Riverside Research Ethics Committee

Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048044

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

10 November 2017

Mrs Elaine Sharp Senior Lecturer University of Brighton
School of Pharmacy & Biomolecular Sciences Lewes Road
Brighton BN2 4GJ

Dear Mrs Sharp

Study title: An investigation of the role of psychological time perspective in self-care behaviours in emerging adults aged 18-25 years with type 1 diabetes

REC reference: 17/LO/1897

IRAS project ID: 222292

The Proportionate Review Sub-committee of the London - Riverside Research Ethics Committee reviewed the above application on 01 November 2017.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical Opinion

On behalf of the Committee, the sub-committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion”).

Summary of discussion at the meeting (if applicable)

The PR Sub Committee stated that is a straightforward study. There are no major ethical concerns. The study sounds useful and achievable, the supervisors are well qualified and the data will be anonymised.

Approved documents

The documents reviewed and approved were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Promotional poster]	1.1	23 June 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance]		19 July 2017
IRAS Application Form [IRAS_Form_17102017]		17 October 2017
IRAS Checklist XML [Checklist_31102017]		31 October 2017
Other [RE 222292 17LO1897 - PR - Valid Under		25 October 2017
Participant consent form [Consent Form]	1.1	23 June 2017
Participant information sheet (PIS) [PIS]	1.1	23 June 2017
Referee's report or other scientific critique report [Internal review outcome]	1	26 July 2017
Research protocol or project proposal [Research Protocol]	1.1	28 September
Summary CV for Chief Investigator (CI) [CV for CI]	2017	28 September
Summary CV for Chief Investigator (CI) [CI CV]	2017	28 September
Summary CV for student [CI/student CV]	2017	28 September
Summary CV for supervisor (student research) [CV supervisor]	2017	15 April 2017
Summary CV for supervisor (student research) [CV supervisor]	2017	15 April 2017
Validated questionnaire [Study Questionnaire]	3	15 February 2017

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

Progress and safety reports
Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

17/LO/1897	Please quote this number on all correspondence
-------------------	---

Yours sincerely

Pp 

Dr Margaret Jones Chair

Email: nrescommittee.london-riverside@nhs.net

*Enclosures: List of names and professions of members who took part in the review
"After ethical review – guidance for researchers"*

*Copy to: Dr Lucy Redhead
Helen Vaughan, Sussex Community NHS Foundation Trust*

London - Riverside Research Ethics Committee

Attendance at PRS Sub-Committee of the REC meeting on 01 November 2017

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr Nuria Gonzalez-Cinca	Clinical Study Manager	Yes	
Ms Alison Higgs	Ex-Lecturer in Social Work	Yes	
Dr Margaret Jones	Retired General Practitioner	Yes	Chair of meeting

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Tina Cavaliere	REC Manager
Miss Charlotte Ferris	REC Assistant

Appendix 9. Original Self-Care Inventory (192)

Please rate each of the items according to **HOW WELL YOU FOLLOWED YOUR PRESCRIBED REGIMEN FOR DIABETES CARE** in the *past month*.

Use the following scale:

- 1 = Never do it
- 2 = Sometimes follow recommendations; mostly not
- 3 = Follow recommendations about 50% of the time
- 4 = Usually do this as recommended; occasional lapses
- 5 = Always do this as recommended without fail

NA = Cannot rate this item/ Not applicable

In the *past month*, how well have you followed recommendations for:

1. Glucose testing	1	2	3	4	5	NA
2. Glucose recording	1	2	3	4	5	NA
3. Ketone testing	1	2	3	4	5	NA
4. Administering correct insulin dose	1	2	3	4	5	NA
5. Administering insulin at right time	1	2	3	4	5	NA
6. Adjusting insulin intake based on blood glucose values	1	2	3	4	5	NA
7. Eating the proper foods; sticking to meal plan	1	2	3	4	5	NA
8. Eating meals on time	1	2	3	4	5	NA
9. Eating regular snacks	1	2	3	4	5	NA
10. Carrying quick-acting sugar to treat reactions	1	2	3	4	5	NA
11. Coming in for appointments	1	2	3	4	5	NA
12. Wearing a medic alert ID	1	2	3	4	5	NA
13. Exercising regularly	1	2	3	4	5	NA
14. Exercising strenuously	1	2	3	4	5	NA

Appendix 10. Original Zimbardo Time Perspective Inventory (3)

Appendix

Zimbardo Time Perspective Inventory Items

1. I believe that getting together with one's friends to party is one of life's important pleasures.
2. Familiar childhood sights, sounds, smells often bring back a flood of wonderful memories.
3. Fate determines much in my life.
4. I often think of what I should have done differently in my life.
5. My decisions are mostly influenced by people and things around me.
6. I believe that a person's day should be planned ahead each morning.
7. It gives me pleasure to think about my past.
8. I do things impulsively.
9. If things don't get done on time, I don't worry about it.
10. When I want to achieve something, I set goals and consider specific means for reaching those goals.
11. On balance, there is much more good to recall than bad in my past.
12. When listening to my favorite music, I often lose all track of time.
13. Meeting tomorrow's deadlines and doing other necessary work comes before tonight's play.
14. Since whatever will be will be, it doesn't really matter what I do.
15. I enjoy stories about how things used to be in the "good old times."
16. Painful past experiences keep being replayed in my mind.
17. I try to live my life as fully as possible, one day at a time.
18. It upsets me to be late for appointments.
19. Ideally, I would live each day as if it were my last.
20. Happy memories of good times spring readily to mind.
21. I meet my obligations to friends and authorities on time.
22. I've taken my share of abuse and rejection in the past.
23. I make decisions on the spur of the moment.
24. I take each day as it is rather than try to plan it out.
25. The past has too many unpleasant memories that I prefer not to think about.
26. It is important to put excitement in my life.
27. I've made mistakes in the past that I wish I could undo.
28. I feel that it's more important to enjoy what you're doing than to get work done on time.
29. I get nostalgic about my childhood.
30. Before making a decision, I weigh the costs against the benefits.
31. Taking risks keeps my life from becoming boring.
32. It is more important for me to enjoy life's journey than to focus only on the destination.
33. Things rarely work out as I expected.
34. It's hard for me to forget unpleasant images of my youth.
35. It takes joy out of the process and flow of my activities, if I have to think about goals, outcomes, and products.
36. Even when I am enjoying the present, I am drawn back to comparisons with similar past experiences.
37. You can't really plan for the future because things change so much.
38. My life path is controlled by forces I cannot influence.
39. It doesn't make sense to worry about the future, since there is nothing that I can do about it anyway.
40. I complete projects on time by making steady progress.
41. I find myself tuning out when family members talk about the way things used to be.
42. I take risks to put excitement in my life.
43. I make lists of things to do.
44. I often follow my heart more than my head.
45. I am able to resist temptations when I know that there is work to be done.
46. I find myself getting swept up in the excitement of the moment.
47. Life today is too complicated; I would prefer the simpler life of the past.
48. I prefer friends who are spontaneous rather than predictable.
49. I like family rituals and traditions that are regularly repeated.

(Appendix continues)

50. I think about the bad things that have happened to me in the past.
51. I keep working at difficult, uninteresting tasks if they will help me get ahead.
52. Spending what I earn on pleasures today is better than saving for tomorrow's security.
53. Often luck pays off better than hard work.
54. I think about the good things that I have missed out on in my life.
55. I like my close relationships to be passionate.
56. There will always be time to catch up on my work.

Note. Respondents are asked to read each item and, as honestly as they can, answer the following question: "How characteristic or true is this of you?" (1 = *very uncharacteristic*, 2 = *uncharacteristic*, 3 = *neutral*, 4 = *characteristic*, 5 = *very characteristic*).

Received May 12, 1998
Revision received May 17, 1999
Accepted June 3, 1999 ■

Appendix 11. University of Brighton PABS Research Ethics Committee Phase II approval

PABS Research Ethics Panel

School of Pharmacy and Biomolecular Sciences
Huxley Building
Moulsecoomb
Brighton
BN2 4GJ

11/10/2019

Ref: 2019-2304-Sharp The role of Time Perspective in self-care in emerging adults with Type 1 diabetes

Dear Elaine

The PABS Research Ethics Panel are happy to offer a favourable ethical opinion for this study.

[A favourable ethical opinion is subject to the following conditions:](#)

Title	Comment
Ethical issues and risks	As the researcher is conducting the interviews alone there should be a risk assessment or a check in point to make sure they get home safe etc.in case something unexpected happens in the interview. Please provide a lone worker safety plan to the committee at your earliest convenience.

Favourable ethical opinion is given on the basis of the information provided in your application, including a project end date of 05/04/2021. Please note that the PABS Research Ethics Panel must be informed of any changes to the research process after a favourable ethical opinion has been given. If you need to make changes to your proposal, including requesting an extension, please complete and submit a change request form in order that the PABS Research Ethics Panel can determine whether the changes will necessitate any further ethical review.

We wish you all the best with your research and hope that your research study is successful. Best wishes



Dr Fergus Guppy

Chair, PABS Research Ethics Panel

Appendix 12. Phase II questionnaire

Part 1. General questions about you and your diabetes

Please enter your name:

Please enter your email address (this will only be used to arrange an interview):

Please enter a contact phone number (this will only be used to arrange an interview):

What is your age? _____ yrs

Are you: Male Female Transgender Prefer not to say

Which of the following best represents your highest level of qualification?

1-4 GCSEs or 5+ GCSEs or Apprenticeship 2+ A levels or Degree level
equivalent equivalent equivalent or above

How long have you had type 1 diabetes? 1-5 yrs 6-10 yrs Over 10 yrs

What is/are the name of your prescribed insulin(s)?

What injection device(s) do you use? (e.g. pen, pump, InnoLet™)

What was your last HbA1c result? (if known)

When was this HbA1c checked?

Do you have complications of diabetes? Yes No

If yes, please tick any that apply:

Eye problems Foot problems Nerve problems (pain or tingling)

Kidney problems Heart problems High blood pressure

□	□	□
Any other complications not listed above □		

Part 2. Questions about your diabetes self-care

Please rate the statements below, selecting the response that is most true for you.

In the ***past month***, how frequently have you followed recommendations for:

		Never	Some-times, not often	About 50% of the time	Usually, with occasional lapses	Always, every day without fail
1	Checking blood glucose					
2	Recording blood glucose					
3	Checking ketones when glucose is high					
4	Administering correct insulin dose					
5	Administering insulin at the right time					
6	Adjusting insulin based on glucose level					
7	Eating the proper foods; sticking to the meal plans					
8	Eating meals/snacks on time					
9	Keeping food records					
10	Carrying quick acting sugar to treat hypoglycaemia					
11	Attending a diabetes appointment					
12	Wearing a medic alert identification					
13	Exercising regularly					

In the ***past month***, how frequently have you:

		Never	Some-times, not often	About 50% of the time	Often	Very often
1	Skipped meals					
2	Skipped insulin injections					
3	Eaten foods that should be avoided					
4	Rotated injection sites					
5	Counted carbohydrate content of food					
6	Made up glucose level because results were too high					
7	Made up glucose level because results weren't tested					
8	Taken extra insulin because of eating inappropriate food or binge eating					

Part 3. Questions about your time perspective

Please rate the statements below, selecting the response that is most true for you:

		Very untrue of me	Untrue of me	Neutral, not sure	True of me	Very true of me
1	Familiar childhood sights, sounds, smells often bring back a flood of wonderful memories.					
2	I believe that a person's day should be planned ahead each morning.					
3	It gives me pleasure to think about my past.					
4	On balance, there is much more good to recall than bad in my past.					
5	When listening to my favourite music, I often lose all track of time.					
6	Meeting tomorrow's deadlines and doing other necessary work comes before tonight's play.					
7	I enjoy stories about how things used to be in the "good old times"					
8	Painful past experiences keep being replayed in my mind.					
9	I try to live my life as fully as possible, one day at a time.					
10	Ideally, I would live each day as if it were my last.					
11	I meet my obligations to friends and authorities on time.					
12	I've taken my share of abuse and rejection in the past.					
13	I take each day as it is rather than try to plan it out.					
14	The past has too many unpleasant memories that I prefer not to think about.					
15	I've made mistakes in the past that I wish I could undo.					
16	I feel that it's more important to enjoy what you're doing than to get work done on time.					
17	Even when I am enjoying the present, I am drawn back to comparisons with similar past experiences.					
18	You can't really plan for the future because things change so much.					
19	It doesn't make sense to worry about the future, since there is nothing that I can do about it anyway.					
20	I complete projects on time by making steady progress.					
21	I find myself getting swept up in the excitement of the moment.					

22	Life today is too complicated; I would prefer the simpler life of the past.					
23	I think about the bad things that have happened to me in the past.					
24	Spending what I earn on pleasures today is better than saving for tomorrow's security.					
25	There will always be time to catch up on my work.					

Have you completed this questionnaire previously in 2017 or 2018, when the researchers were conducting their first study?

Yes, I have previously completed this questionnaire

No, I have never completed this questionnaire before

I am not sure if I have completed this questionnaire before

End of questionnaire.

Thank you for taking part.

Appendix 13. Phase II Participant Information Sheet

Title of Study

The role of time perspective in self-care with Type 1 diabetes

Introduction and what is the purpose of the study/project?

This study is being conducted by Elaine Sharp, a doctoral research student at University of Brighton.

Time perspective is the extent to which we think about past, present or future and how these thoughts influence our behaviour. Time perspective has been shown to play a role in people's choices about their health. This study is the second in a series, looking at ways in which time perspective is linked to carrying out diabetes self-care in young adults aged 18-25 years, who have Type 1 diabetes. The first study showed us there are some links between time perspective and self-care. In this second study, we are hoping to understand more about why these things are connected. We aim to do this by asking about some of your thoughts and experiences of being a young adult who lives with Type 1 diabetes.

Invitation paragraph

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. This should take a few minutes. Talk to others about the study if you wish, and ask us if there is anything that is not clear. You will be given time to think about whether you wish to take part before making a decision. You may also download and save a copy of this information sheet from the study website

<https://blogs.brighton.ac.uk/youngt1peeps/>

Why have I been invited to participate?

You have been chosen because you are aged 18-25 years old and have Type 1 diabetes, which was diagnosed more than 12 months ago. You have been identified through Diabetes UK or its affiliated social media sites, or through the Brighton Area Diabetes Group. It is likely that around 20 young adults will take part in this study.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect any aspect of your diabetes treatment or care.

What will happen to me if I take part?

If you choose to take part, you will first be asked to provide written consent, this can be done on paper or electronically. You will then be asked to complete a short questionnaire taking about 10-15 minutes of your time. The questionnaire asks for some information about you, your diabetes self-care, your recent HbA1c result and your time perspective. You may have already completed the questionnaire in the first study last year, but for this study we will ask you to complete it again. Questionnaires can be completed online or on paper. You will then be asked to take part in an interview with the researcher. This will be a one-off interview, lasting no more than an hour. Interviews can be done in person if you live near to the Brighton area, or they can be done by video chat. Interviews will be audio recorded then transcribed. You may be contacted after the interview and asked to check that the transcription is a correct record of the details you gave. Once the interviews have been transcribed all recordings will be deleted.

Will I be paid for taking part?

You will not be paid for taking part. However, as thanks for giving us your time, each interview participant will receive a £20 gift voucher.

What are the potential disadvantages or risks of taking part?

There are no direct risks to you if you choose to take part. The information will not be passed on to your diabetes care team, or used by anyone other than the research team. However, it is possible that some of the questions about your diabetes journey may make you think about difficult things that have happened to you. You will not be put under any pressure to discuss things that make you uncomfortable. If any conversations become upsetting for you, the interviewer will stop the interview and only proceed if you give permission to do so. If any of the questions about your diabetes or self-care were to leave you feeling concerned afterwards, you can talk to your diabetes care team.

What are the potential benefits of taking part?

There are no benefits to you personally if you take part. However, it is hoped that the results may be used in future to find new ways to support young adults with their diabetes self-care.

Will my taking part in the study/project be kept confidential?

During the study, the researcher will keep a record of your name, a contact email address and phone number. These personal details will be held on a password protected spreadsheet on a secure server, and will only be accessible to the researcher for the purpose of communicating with you. You will be allocated an anonymous participant number, your responses to the questionnaire and interview questions will be associated with this number and not with your personal information. The anonymised information will also be stored in a password protected database on a secure server, separate from your personal information. At the end of the study, your personal contact details will be deleted from records and the anonymised questionnaires and transcripts will be kept for 10 years. Anonymised responses will be accessible to the research team only, this includes any research students working under them.

What will happen if I don't want to carry on with the study?

Taking part is completely voluntary, you can choose to withdraw at any time and this will not affect you in any way. If you had provided some responses and then decided to withdraw, for example you completed part of the questionnaire or started the interview but then changed your mind, the researcher will ask you if you are happy for this data to be used. We will only include your responses if you give us permission to do so.

What will happen to the results of the project?

The results of this study will only be used for research purposes. This will include reporting the anonymised results in the researcher's doctoral dissertation, and possibly publication of the anonymised results in an academic journal. If you wish to receive a summary of the results when the project has finished, contact Elaine Sharp by email to request.

What if I have a question or concern?

If there is a problem or you wish to complain about any aspect of this study, you can contact one of the project supervisors, or the Pharmacy School office who will be able to address your concerns. Contact details are provided below.

Contact details

Main Contact Details: Mrs Elaine Sharp, PhD Researcher es136@brighton.ac.uk 01273 641918
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Supervisor: Dr Sian Williams, Senior Lecturer in Health Psychology sew13@brighton.ac.uk 01273 643961	Supervisor: Dr Wendy Macfarlane, Reader in Molecular Biology, Brighton Diabetes Research Group w.m.macfarlane@brighton.ac.uk 01273 642101	Pharmacy School Office 01273 642090 Head of School: Prof. David Timson pabs-pahos@brighton.ac.uk
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Who has reviewed the study?

This study has been reviewed and given a favourable ethical opinion by the School of Pharmacy & Biomolecular Sciences Research Ethics Committee, University of Brighton.

Appendix 14. Phase II consent form

Participant Consent Form

Title of Project: The role of time perspective in self-care with Type 1 diabetes

Name of Researcher: Elaine Sharp

	Please initial or tick box
I have read and understood the information sheet for the above study, and have had the opportunity to consider the information and ask questions.	<input type="checkbox"/>
The researcher has explained to my satisfaction the purpose, principles and procedures of the study and any possible risks involved.	<input type="checkbox"/>
I am aware that I will be asked to complete a short questionnaire, taking about 10-15 minutes.	<input type="checkbox"/>
I am aware that I will be asked to take part in an interview, lasting up to one hour. I am aware this interview will be audio recorded and then transcribed. I give my permission for the interview to be recorded.	<input type="checkbox"/>
I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without any consequences.	<input type="checkbox"/>
I understand how the collected data will be used, and that any confidential information will be seen only by the researchers and will not be revealed to anyone else.	<input type="checkbox"/>
I agree to take part in the above study.	<input type="checkbox"/>

.....
Name of participant, signature & date

.....
Name of researcher, signature & date

Appendix 15. Phase II study interview topic guide

Interview Topic Guide – Sep 19 (following PPI input and practice interview)

Questions connected to past

1. How old were you when you were diagnosed with T1D? Tell me what you can remember about it (if appropriate). If too long ago: have you heard stories about what happened?

2. What was it like at first?

Probes:

- Adjusting to the change
- Managing daily routine
- New learning/getting to grips with rules, tech etc
- **Impact** on self, activities, family etc

3. Were there significant diabetes-related events or memories? Discuss examples that stand out

Probes:

- Positive experiences
- Negative experiences
- Why? What impact they've had

4. If not already covered: get a sense of the biggest impact diabetes self-care's had on life in the past

Questions connected to present

1. What is it like living with T1D at this point?

Probes:

- Transition if age appropriate
- Comparisons with past experience
- What impact it has right now

2. How are you finding independent self-care?

Probes:

- Discuss daily routine e.g. what does a normal day look like etc
- How self-care impacts everyday life
- **Challenges** – what challenges are experienced? What is most challenging (probe if doesn't come up in discussion)
- If person cites many negative experiences: how negative past experiences influence self-care now?

3. If hasn't already been mentioned – raise HbA1c e.g. 'when discussing management HbA1c often comes up in conversation...'

Probes:

- How do you feel about this measure?
- What does it mean to you?

Questions connected to future

1. Discussion on complications – can pick up again on HbA1c as the connection. Or something like ‘for people with DM, future thoughts often involve the subject of complications’

For sensitivity can use:

- Does this subject get raised much e.g. in diabetes appointments/ support communities/ peer groups etc?
- What’s your understanding of complications?
- How does it make you feel when it’s raised/discussed? Probe general feelings about complications.

Keep in background the issue of HCP self-care messages being future focused as another possible lead-in to discussions

Positive encouragements that could help if upsetting:

‘not everyone develops complications’

‘sounds like you are doing your best with management’

2. To what extent do you think about your future?

Probes:

- How much does it feature in your thinking/decisions? (Ask generally)
- Use past examples – education, career choice, where to live etc

3. What do you hope it will be like for you? (can be general, but probe health-related if not mentioned)

Probes:

- Explore best ‘future self’ visions
- Give timelines for visualisation e.g. ‘can you see yourself as a 40 year old? What do you see?’ If participant not able to visualise – ‘what would you hope to see?’

Ending

Thank you for sharing all this with me.

- Is this what you thought I would ask you about?
- Is there anything else important you want to say?

Reflect on the importance of the spoken data, ‘capturing the voice’ of those living a young adult life with T1D. Potential benefit of diabetes professionals understanding their journey better. End positive in this way.

- How did you hear about the study?
- Snowballing request within DOC/networks
- Shopping voucher info

Appendix 16. Phase II pre-interview checklist

Pre-Interview introduction checklist

1. Revisit PIS – any further questions?
2. Voluntary, confidential, anonymous
3. Audio recording (show)
4. May be sent a transcript later on to confirm it's accurate
5. Walk through your journey with Type 1 past, present and future, interview in 3 parts
6. This is your story - no right/wrong, no judgement or expectations
7. I'll take some notes in addition to recording – show notebook
8. Got drink, snacks, hypo kit etc
9. Quick break before starting if needed...

START RECORDER WHEN READY

Appendix 17. Pre-interview meditation to aid reflexivity

15 minutes before interview start time, take a few minutes of silence and concentrate on breathing.

Meditations:

- I am the research tool
- I am humbled to be a vessel for this participant's story and lived experiences
- I make no assumptions about their views, beliefs, attitudes or experiences
- I will listen and let them speak freely
- There is no need to fill silence, I don't fear it and will let it breathe
- I will minimise my noise, be attentive to my speech, body language and rapport and will not cause distraction
- I acknowledge my own interpretation of their world and will leave it outside of the interview
- I acknowledge my beliefs and expectations of new data the interview will generate and will leave these outside of the interview
- I will be attentive to my own responses and interactions with this participant and document them honestly

Appendix 18. Main questionnaire data for individual participants in Phase II

Participant No./ID	Age	Gender	Age diagnosed with T1D	HbA1c	SCI score	Past Pos	Past Neg	Pres Hed	Pres Fat	Future
1. O	24	F	7	59	3.47	3.40	3.60	3.80	4.00	4.50
2. E	24	F	6	63	3.60	3.60	3.40	3.00	2.25	3.33
3. A1	23	F	2	55	4.00	4.20	2.00	2.80	2.75	4.17
4. S	20	T	19	196	4.80	3.00	4.40	4.20	3.50	3.50
5. P	20	F	6	66	3.47	2.40	3.00	3.20	2.00	3.50
6. M1	24	F	19	74	3.73	3.80	3.60	2.20	1.50	4.17
7. F1	21	F	15	49	4.13	4.00	2.80	3.60	2.00	3.67
8. B	23	F	7	49	4.27	4.00	4.00	3.40	2.25	4.17
9. K1	21	T	8	110	2.80	2.60	4.80	3.80	3.25	2.50
10. D1	23	F	7	56	3.00	3.60	4.60	3.60	3.50	2.33
11. F2	20	M	12	55	4.27	4.00	3.60	3.60	2.50	2.83
12. J1	21	M	13	49	4.60	2.60	4.40	3.40	3.25	2.67
13. A2	23	F	8	88	3.33	1.20	4.60	3.20	4.00	3.00
14. D2	24	M	13	46	4.20	3.80	1.60	2.80	1.75	4.00
15. K2	24	F	17	57	4.07	3.00	4.00	3.80	3.25	3.33
16. J2	22	F	8	45	4.60	3.60	3.60	3.00	2.00	4.33
17. M2	24	F	6	62	3.47	3.20	3.40	2.40	3.00	3.83
18. L	20	F	5	78	3.13	3.80	4.60	4.00	3.50	3.00

Past pos = past positive, past neg = past negative, pres hed = present hedonistic, pres fat = present fatalistic