TYPE 1 DIABETES AND ADOLESCENCE: AN EXPLORATION OF LIVED EXPERIENCES

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by Joy Spencer

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DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or institute of learning.

Joy Spencer

To my mother and father

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Abstract

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Joy Spencer

Type 1 diabetes (T1D) is the third most common chronic disease in childhood. Maintaining adequate control of blood glucose through insulin injections, blood glucose tests, controlled diet and exercise is essential to prevent complications. During adolescence there is evidence of deteriorating metabolic control, increasing risk of complications in later life. I conducted a review of the biomedical literature to define the self-management of T1D and paediatric care in the UK. This pinpointed a range of factors affecting blood glucose, suggesting the influence of much more than biomedical management alone. I then conducted a systematic review of qualitative studies of T1D in adolescence, alongside a review of the wider psychosocial literature. This further highlighted the need for rigorous qualitative research in the UK exploring the lived experiences of adolescents with T1D and their parents, underpinned by a synthesising framework that appreciates the many interdependent factors impacting on outcomes.

I highlighted complexity science as a novel theoretical framework, which embraced the multifaceted nature of T1D in adolescence. However, its metaphorical application to T1D management merited epistemological validation. I employed interpretive phenomenology as a research methodology to access the complexity of T1D in adolescence, through the exploration of lived experiences. The study had two aims: (i) to explore the lived experiences of adolescents with T1D and their parents using an interpretive phenomenological approach; (ii) to investigate the applicability of complexity science as a framework for understanding adolescent T1D management.

I recruited a maximum variation sample of twenty adolescents with T1D (age 13-16) and their parents/guardians from a North West clinic. I employed a multi-method, hermeneutic approach, which included the collection of clinical data, the development of an original computerised self-management diary, hermeneutic interviews with adolescents and their parents and validation focus groups. I analysed the data using a rigorous seven-step approach underpinned by interpretive phenomenology.

Four themes emerged from my interpretation of the data: (i) nomalisation, (ii) embodiment of T1D, (iii) learning through experience and (iv) relationships with significant others. All were underpinned by an on-going process of adaptation to T1D, and social interactions within adolescents' surrounding environments. I triangulated the findings with previous research and explored the application of complexity science to the lived experience of T1D in adolescence. This validated its use as a framework for T1D management in adolescence - a groundbreaking move beyond its current metaphorical application in the social and health sciences.

My findings provide an original contribution to understanding T1D in adolescence. Diabetes care warrants a transformative shift from a focus on the outcome of blood glucose control, towards educational needs assessment in relation to individual complex systems. This will enable an approach to diabetes care which adolescents and their families can translate into 'real life'. Further work is currently being undertaken to design a computerised individual learning needs assessment tool for adolescents with T1D. This has the potential to shift the focus of care towards a complexity model, and greatly improve blood glucose outcomes for young people with T1D.

Chapter 1: Type 1 diabetes from a biomedical perspective

Introduction

There are 2.5 million people with diabetes in the UK (QOF, 2008). Over 22 000 of these are under the age of seventeen and 97% have Type 1 diabetes (T1D). Just under 9 000 are aged between ten and fourteen years (Royal College of Paediatrics and Child Health, 2009), which is the peak age range for diagnosis (NHS, 2007). Ten per cent of the National Health Service (NHS) budget is currently spent on diabetes (£173 million/week) (NHS Confederation, 2009). The Diabetes Control and Complications Trial (DCCT, 1993) found that effective blood glucose control of T1D considerably reduces the risks of developing long-term complications. However, global evidence suggests that metabolic control deteriorates during adolescence (eg. Cardwell et al, 2005; Dabadghao et al, 2001; Scottish Group for the Care of the Young Diabetic, 2001; Thomsett et al, 1999) leaving young people at risk of complications in later life.

This has provoked a wealth of multi-disciplinary research on adolescents with T1D, showing that there are many individual, cultural, psychological and societal influences affecting the biomedical outcome of blood glucose control (Swift, 2004). Despite this evidence, diabetes care continues to be structured within a narrow biomedical model (Cooper and Geyer, 2007) and blood glucose control continues to deteriorate. Only fifteen per cent of under-fifteens with diabetes in the UK were achieving the recommended blood glucose levels of 7.5% in 2005 (Diabetes UK, 2005). This warrants a need for qualitative research to understand the lived experiences of adolescents with T1D, in order to delineate, reassess and improve future health outcomes.

In this chapter, I aim to describe T1D as it is biomedically defined. In Section 1, I focus on the disease epidemiology (clinical definition, prevalence, presenting symptoms, cause and prognosis). In Section 2, I describe the current care situation for adolescents with T1D in the UK within a policy context. In Section 3

I address the biomedical self-management of T1D and in Section 4 I define the problem of blood glucose control in adolescence and present determinants of blood glucose control from the literature. I conclude that the management of T1D in adolescence is more complex than a biomedical model of care can address, thus pinpointing a need to explore qualitative and wider psychosocial literature.

Section 1: Epidemiology

1.1 Definition

T1D is an autoimmune condition characterised by a long pre-clinical phase during which the insulin-producing beta-cells are destroyed (Couper, 2001) leading to an absolute requirement for insulin. Insulin must be injected in order to convert glucose from food into energy, along with following a controlled diet, self-testing blood glucose levels through a finger-prick test a number of times a day, and taking regular exercise. Diabetes management is constant, difficult and intrusive, monotonous, lifelong, erratic and unpredictable, and constantly changing throughout childhood and adolescence; along with changes in age, development, physiology and maturity (Swift, 2004). T1D is a chronic illness. Thus, it is long-term and has a profound influence on the life of the person (Locker, 1997).

1.2 Prevalence

T1D is the most common metabolic abnormality in young people (EURODIAB ACE Study Group, 2000). It affects 246 million people worldwide (Diabetes UK, 2009), with an annual incidence increase of three to four per cent (EURODIAB ACE Study Group, 2000) particularly in children aged nought to four years (Hirschorn, 2003), and it is continually presenting at an earlier age (Devendra et al, 2004). The reasons for this increase are not yet understood. In a study of twenty centres in seventeen European Union Member States (1989 to 2003), Patterson and colleagues (2009) found that the year-on-year increase was 5.4%

for the age group nought to four years, 4.3% for the age group five to nine years, and 2.9% for those aged between ten and fourteen. An estimated 15 000 new cases emerged in Europe in 2005: 24% for the age group between nought and four years; 37% for those aged between five and nine years; and 34% for those between the ages of ten and fourteen. The number of cases in European children under the age of five are predicted to double by 2020.

In England and Wales, 17/100 000 under-sixteens are diagnosed with diabetes each year (Greene, 2002) and the age of onset is decreasing (Feltbower et al, 2003). T1D has 4.41% prevalence in England, and this is higher in women (5.17%) than in men (3.61%) (Forouhi et al, 2005). The incidence of T1D was found to rise steadily at an annual average increase of 2.9% for nought to fourteen year olds in Yorkshire, UK, suggesting that more recent birth cohorts are at increased risk of developing the condition (Feltbower et al, 2003). In England and Wales the largest proportions of young people registered with T1D are between twelve and fifteen years old (National Clinical Audit Support Programme, 2006).

1.3 Presenting symptoms

T1D presents with the symptoms of hyperglycaemia (i.e. polyuria, polydipsia, weight loss and blurred vision) (Bui and Daneman, 2006; Roche et al, 2005). The peak presenting age in boys is twelve to thirteen years, and nine to twelve years in girls (Forouhi and Wareham, 2006). Secondary enuresis is also a common symptom in those under ten years, along with constipation in the under-five age group (Roche et al, 2005). A single blood glucose measurement is sufficient to make a diagnosis. Early diagnosis can prevent the occurrence of diabetic ketoacidosis (DKA) (Bui and Daneman, 2006). DKA occurs when there is an absolute or relative insulin deficiency along with an increase in catabolic hormones, resulting in hepatic overproduction of glucose and ketone bodies. It is commonly caused by infection, errors in diabetes management and newly-presenting T1D. Fifteen to 67% of children present in this state (Rewers et al, 2002), which can lead to coma and requires hospital admission and monitoring for up to five days.

1.4 Cause

The exact cause of T1D is unknown. Family and twin studies suggest that genetic factors determine susceptibility, and environmental, lifestyle and socioeconomic factors are 'triggers' (Hirschorn, 2003). Evidence for such causal factors is presented as follows.

Genetic factors

Those with a family history, a HLA-DR-DQ genotype (Couper, 2001) or diabetes-related autoantibodies at birth (Devendra et al, 2004) are considered to be at increased risk. The risk of the offspring of a parent with T1D developing the disease is approximately two per cent if the mother has T1D, eight per cent if the father has T1D and 30% if both parents have T1D. Siblings of individuals with T1D have a ten per cent risk of developing the disease (Diabetes UK, 2009). Despite these proven genetic associations, the heritability of diabetes is only 72% or less, implying that at least a quarter of the risk is due to other factors (Hirschorn, 2003).

Environmental factors

Immune responses leading to the later development of T1D frequently appear within the first few years of life, suggesting that causal environmental exposures are likely to occur early in development (Gale, 2002). Children in South Asia have a low incidence of diabetes, but migrants to the UK have similar overall rates to the indigenous population, suggesting that environmental factors are key (Feltbower et al, 2002). Increasing incidences and epidemics suggest that certain viruses may influence risk of T1D (Devendra et al, 2004). Many associations have been found including enteroviruses (Richardson et al, 2009; Dotta et al, 2007) and pertussis infections (Montgomery et al, 2002), although congenital rubella is the only proven direct causal virus (Devendra et al, 2004; Couper, 2001).

Diet

Some aspects of early childhood diet are thought to influence the development of T1D (Devendra et al, 2004), including the NO^3 strain of ion nitrate concentration (Moltchanova et al, 2004) and the relationship between zinc and magnesium in drinking water (Zhao et al, 2001). Northern European countries with a high rate of cow's milk consumption also have high rates of T1D (Hirschorn, 2003). As breast-feeding protects against enteroviruses, it is thought that early introduction of infants to cow's milk may increase risk (Feltbower et al, 1994).

Socioeconomic factors

No relationship has been found between deprivation and T1D (Evans et al, 2000), in fact it has been suggested that improved living standards and decreased exposure to microorganisms has increased the risk of autoimmune disease in childhood (Farouhi and Wareham, 2006; Marshall et al, 2004). Early infancy social mixing at day care centres during early infancy may confer protection against the development of T1D in childhood, as early infectious exposure may develop immunity against diabetes (McKinney et al, 2000).

Family/life events

Independent of family history of diabetes, serious life events such as divorce and violence have been linked to the induction or progression of T1D in children at two and a half years old (Sepa et al, 2005). Parent-reported stressful life events including parental death, divorce, parental job loss, problems at home (parental abuse, parental dispute) and school (poor performance) have also been linked to onset in children (Karavanaki et al, 2008).

1.5 Prognosis

Complications

Multiple microvascular complications are apparent in almost one fifth of patients with diabetes over the life course (Morgan et al, 2000), and occur as a result of maintained high blood glucose levels in the younger years (Carel and Levy-Marchel, 2008). Diabetes increases the risk of developing heart disease, stroke, blindness, kidney disease and amputations (Diabetes UK, 2005) and after twenty years of living with diabetes, the impact of atherosclerotic complications steadily increases (Laing et al, 1999a, 1999b). Diabetes is the most common cause of lower limb amputations (Amputee Statistical Database for the UK, 2005) and neuropathy affects up to 50% of people with diabetes (Boulton, 2005). In a study of a UK district health authority population with T1D (10 709 people), coronary heart disease was the most common complication (25.2%), followed by complications of the diabetic foot (18.1%), retinopathy (16.5%) and nephropathy (2%) (Morgan et al, 2001).

Blindness is ten to fifteen times more likely to occur in people with diabetes than those without (Hamilton et al, 1996). Duration of T1D has been found to be significantly related to retinopathy (Raile et al, 2007; Morgan et al, 2000) and nephropathy (Morgan et al, 2000). Patients with onset of T1D before the age of fifteen are predicted potentially worse renal outcome and are more likely to need laser treatment for retinopathy (Harvey and Allagoa, 2003).

Pregnancy also poses risks for women with T1D, with babies five times as likely to be stillborn, three times as likely to die in their first three months of life and twice as likely to have congenital abnormality (Diabetes UK, 2009). Early detection of complications may help to prevent their natural progression, therefore screening and regular health checks are of utmost importance (Stakos et al, 2005; Giusti, 2001).

Mortality

Diabetes is the fifth most common cause of death in the world (Roglic et al, 2005). Children with T1D have a higher mortality rate than the general population (Edge et al, 1999) and life expectancy is reduced by more than twenty years on average for people with T1D (Department of Health, 2001). Forty-four per cent of deaths in patients diagnosed with T1D before the age of 30 are caused by diabetes-related complications (Feltbower et al, 2008). A study of the deaths of patients with diabetes under twenty years of age from 1990-1996 in England, Wales and Scotland found that 71.5% of deaths were caused by diabetes. Forty per cent of these were found dead at home and the most common cause was DKA (Edge et al, 1999). Acute metabolic events have the greatest impact on mortality in the early years, with vascular effects dominating after the age of 30. Over 85% of cardiovascular deaths in 20-39 year olds can be attributed to the presence of diabetes (Paterson, 1999).

Section 2: Diabetes care for young people in the UK

1.6 Paediatric care provision

The National Service Framework for Diabetes (Department of Health, 2001a) states that an appropriately resourced and trained multidisciplinary team should manage children and adolescents with diabetes. This team should include a paediatrician with a special interest in diabetes, a paediatric diabetes specialist nurse, a paediatric dietician with expertise in diabetes, a senior paediatric diabetes ward nurse and easy access to services in psychology, psychiatry, podiatry and ophthalmology. The most instrumental member of this team is the diabetes nurse specialist, who provides education to the child and family both in the hospital and the community. Paediatric diabetes services have been shown to be inadequate thus inhibiting optimum diabetes control. In an average health district of 250 000 people, there are approximately 75 young people under the age of sixteen with T1D (Betts and Swift, 2003). The case-load of a paediatric diabetes nurse should not exceed 70 (Royal College of Nursing, 2006), but in practice it often does. Whilst services for children with diabetes have improved significantly over the past decade, there are still marked deficiencies and inequalities of care in the provision of the specialist diabetes team approach, mainly with regards to the provision of psychosocial support and transition services (Betts and Swift, 2003).

1.7 Psychosocial support

The National Institute of Clinical Excellence (NICE) (2004) recommend that psychosocial support should be offered to children and young people with T1D, with regard to emotional and behavioural problems, anxiety and depression, eating disorders, cognitive disorders in relation to frequent hypoglycaemia, non-adherence and family therapy. Diabetes care teams should have access to mental health professionals to support them in the assessment of psychological dysfunction and the delivery of psychosocial support. Diabetes UK (2005) noted a lack of psychological support in children's diabetes services. A number of psychosocial support interventions have been shown to be effective in enhancing psychological adjustment to diabetes, including psychosocial support and reinforcement, coping skills training, cognitive behaviour therapy and family behaviour therapy (Canadian Diabetes Association, 2003). Hampson and colleagues (2001) reviewed the effectiveness of behavioural interventions for adolescents with T1D. They found a small-to-medium-sized beneficial effect across a range of outcomes (psychosocial, knowledge, HbA_{1c}, self-management behaviours) but the persistence of improvement, and the extent to which it lowers the risk of complications, remains to be determined.

1.8 Transition to adult services

Most paediatric diabetes service in the UK provide care up to between sixteen and eighteen years (Logan et al, 2008). Moving from paediatric to adult services often incurs the loss of long-standing, trusted relationships with health professionals (Kirk, 2008). There are significant differences in the practice and the culture of adult clinics compared to the paediatric environment (Jones and

Hamilton, 2008). Paediatric care is usually multidisciplinary, family focused, prescriptive and involves parental input and consent; whereas adult care is often provided by a single doctor, is individually patient focused and requires autonomy on the part of the service user. Adult diabetes nurse specialists also have considerably larger case-loads and therefore care is less personalised (McGill, 2002).

The NSF for Diabetes Standards (Department of Health, 2001a) recommends that all young people with diabetes should experience a smooth transition to adult care. The transition should be organised in partnership with each individual, at an appropriate age for them (Department of Health, 2004). Although local services appear to reflect the policy guidelines for transition (Cooke, 2007), research has shown a 'gap' in the transition process between paediatric and adult services in the UK, due to the lack of a clear transition pathway and systemic support during the process (Jones and Hamilton, 2008). The transition process can be fraught with psychosocial barriers such as parents being suspicious of adult health professionals and anxieties about their child's quality of care (Fleming et al, 2002). A smooth transition is important as clinic non-attendance increases in late adolescence, leading to a decrease in blood glucose control (Bryden et al, 2001; Scott and Donnelly, 2001). In Oxford, UK, clinic attendance was found to decline from 94% (two years pre-transfer to adult services) to 57% (two years post-transfer), in 229 subjects from four paediatric clinics in the area (Kipps et al, 2002). Meanwhile, transition clinics for young adults have been found to have a positive effect on blood glucose control (Logan et al, 2008). Overall, all adolescents with T1D should have access to a monitored, high quality transition service, in order to remove the inequalities that exist for adolescents going through this process.

1.9 Education

Diabetes education is an integral part of diabetes care, as living with T1D requires adjustment to a particular 'way of living' in order to maximise future health with minimal restrictions on current behaviour. The new way of life may be very different to the lifestyle lived before diagnosis and therefore requires a significant amount of adaptation. Education at diagnosis should provide children/adolescents and their families with a kit of 'survival skills', including explanation of how the diagnosis has been made and reasons for symptoms; the uncertain cause of diabetes; insulin and blood glucose; insulin injections; blood testing and reasons for monitoring; basic dietetic advice; hypoglycaemia; diabetes during illnesses; DKA; diabetes at home and school; exercise; identity equipment; membership of support groups/associations; psychological adjustment and emergency telephone contacts (Swift, 2007). The responsibility of parent(s) or carer(s) to process this information on their child's behalf means that education at diagnosis is dominated initially by family teaching (Snoek and Skinner, 2000). Ongoing education should be a continued, structured programme covering these areas. Information must be accurate, consistent, support informed decision making; and be appropriate for the child/young person's age, maturity, culture, wishes, existing knowledge and special needs (NICE, 2004).

Section 3: Self-management

Self-management of T1D diabetes requires concordance to a self-administered management regime which includes insulin injections, blood glucose monitoring (3-4 tests daily), basic nutritional planning, regular exercise and hypo/hyperglycaemia detection and treatment (Bui and Daneman, 2006), with the goal of maintaining adequate blood glucose control. The components of self-management are described as follows.

1.10 Insulin therapy

The standard insulin regime for children in the UK is a 'twice-daily' regime (a mixture of short and long acting insulin). Daily insulin requirements in children with T1D are approximately 0.8 units/kg/24hour. In mid-puberty, requirements usually rise to between 1-1.5 units/kg/24hour, due to growth hormone hyper-secretion, and decline following puberty (Williams and Dunger, 2004). High mean insulin doses have been found to be related to poor glycaemic control in adolescents (Hanberger et al, 2007).

As insulin requirements increase with puberty and independence from parents increases, change to an 'intensive' multiple injection (basal bolus) regime (Williams and Dunger, 2004) is recommended (DCCT, 2001). This involves taking a long-acting insulin which lasts for 24 hours, and a short-acting insulin before or after every meal based on a calculation of the amount of carbohydrate consumed. This regime has been shown to reduce the incidence of diabetes-related complications (Massin et al, 2007; Mohsin et al, 2005; DCCT, 1993); the development and progression of all diabetes-specific complications by up to 76% (EDIC, 2005); severe episodes of hypoglycaemia and DKA (Nordfelt and Ludvigsson, 1999); and to influence good psychosocial outcomes in young adulthood (Insabella et al, 2007).

Intensive regimes are most effective when implemented early in the course of diabetes (EDIC, 2005) and health professionals are therefore keen to implement them during adolescence. However, despite its potentially less restrictive lifestyle advantages and options for better control, these regimes can complicate the dilemmas faced by adolescents with T1D as they manage the personal, situational and relational contexts of their self-management. Patients selected for basal bolus regimes should be highly motivated, have no needle-phobia, good family and friend support, and excellent diabetes education and understanding of T1D. Adolescents with significant family dysfunction, poor compliance, recurrent DKA and severe eating disorders are not considered suitable (Davidson et al, 2004).

1.11 Diet

There is no specific 'diet' prescribed for those living with T1D. The principles of a diabetes diet are largely the same as for healthy individuals. Diet should aim to prevent acute hypoglycaemia and reduce the risks of complications by moderating the intake of high sugar foods and saturated fat. In adults with T1D, total energy intake should be made up of 35% fat, 50-55% carbohydrates (accompanied by 30 grams of dietary fibre per day), 10-15% protein and no more than 6g sodium. Four hundred grams of foods naturally rich in antioxidants are also recommended. Timing and size of food portions is important, particularly for those on twice-daily insulin regimes. This is because a certain amount of insulin is given in advance, and the carbohydrate consumed must 'balance' out this dose. If too little carbohydrate is consumed, blood glucose levels may drop too low; if too much carbohydrate is consumed, blood glucose levels may rise too high (Ha and Lean, 1997).

Food intake should also depend on the amount of physical activity taken (Ha and Lean, 1998). As taking exercise utilises carbohydrate, a higher intake may be required to maintain balanced blood glucose. Fruit and vegetable intake is also related to self-control in adolescents, suggesting a relationship between intake and adherence (Wills et al, 2007). Parents have a direct influence on the dietary habits of their children. They shape them through implementing specific feeding behaviours and techniques and have direct control over the foods available in the home (Rhee, 2008). Despite this evidence, previous research has shown that the only correlate of fruit and vegetable intake in young adulthood across gender is taste preferences (Larson et al, 2008).

1.12 Physical Activity

The importance of lifestyle changes when a person is diagnosed with T1D are emphasised for both adults and children (Rachmiel et al, 2007). However, there is generally low stability of exercise in transitional life phases such as from childhood to adolescence (Telema, 2009), and children and adolescents (girls in particular) spend less time participating in exercise than their non-diabetic peers (Valerio et al, 2007). The Department of Health (2004) recommend that children and adolescents should undertake one hour of moderate physical activity per day to achieve optimum health. Although there is a risk of hypoglycaemia when undertaking physical activity, this can be managed through alteration of the treatment regime, for example by consuming carbohydrate before and/or after exercise, depending on the energy expended (American Diabetes Association, 2004). Barriers to taking exercise in a study of adults with T1D included perceived difficulty in taking part in exercise due to diabetes, feeling tired and being distracted by the television. Lack of time and local facilities were also contributing factors (Thomas et al, 2003).

1.13 Blood glucose monitoring

Blood glucose control is measured by the glycated haemoglobin (HbA_{1c}) test, which gives an average blood glucose reading over the previous three months. HbA_{1c} results are currently given as a percentage of millimoles per litre (mmol/litre), however from May 2011, HbA_{1c} will be given in millimoles per mol (mmol/mol). The aim of treatment is to maintain a blood glucose level of 6.5% mmol/litre or under (7.5% or under for those at risk of severe hypoglycaemia) (Diabetes UK, 2008a). Research from the Diabetes Control and Complications Trial (DCCT, 1993) proved that this can considerably reduce the risks of developing micro-vascular complications in adults. The risk of new eye disease can be reduced by 76%, early kidney disease by 54%, and nerve damage by 60% at preliminary follow-up. Findings from this trial show a 57% reduction in the combined end-point of fatal and non-fatal myocardial infarction and fatal and non-fatal strokes.

An important part of diabetes self-management is also the daily self-monitoring of blood glucose by a finger-stick test. Frequency recommendations are individual to each person with diabetes. Regular testing (four times per day) can allow people with T1D to see the immediate effect of their behaviour on their blood glucose (for example eating behaviours, physical exercise), provide confidence at critical times (for example when driving or at work), and promote a sense of well-being through feeling in control (National Diabetes Support Team, 2003).

1.14 Blood glucose control

Adolescents with T1D deal with blood glucose fluctuations on a daily basis. Hypoglycaemia (low blood glucose) is the primary complication of insulin therapy (Jones and Gill, 1997) and occurs when the brain is deprived of glucose. This is most commonly a result of injecting too much insulin, not consuming enough carbohydrate to compensate for insulin dose, taking exercise or developing insensitivity to symptoms over time (McAulay et al, 2001). Hypoglycaemia ('a hypo') is experienced as various physiological and neurological responses, which alert the person to their decline in blood glucose. Early warning symptoms usually allow the person to take appropriate action: to consume fast-acting carbohydrate, for example glucose. The eleven most commonly reported symptoms of hypoglycaemia are sweating, palpitations, shaking, hunger, confusion, drowsiness, 'odd' behaviour, speech difficulty, incoordination, headache and nausea (Deary et al, 1993). The character and intensity of symptoms are temporal and affected by numerous biological and psychosocial modifiers (McAulay et al, 2001).

Severity ranges from frequently occurring mild episodes to rare severe episodes that may result in a coma. Mild-moderate hypoglycaemia is the experience of symptoms that the patient is aware of and can respond to promptly. Children with relatively good glycaemic control usually experience one or two mild hypoglycaemic episodes per week (Bui and Daneman, 2006). Severe hypoglycaemia describes cases where the patient is unable to respond, is semi-conscious/unconscious and requires assistance (McAulay et al, 2006). Although hypoglycaemia does not cause severe damage to organs, it can put a person in danger through losing consciousness, for example if alone, or driving. Frequent hypoglycaemia has also been associated with psychological distress in young adults with T1D (Hislop et al, 2008).

Increased emphasis on strict blood glucose control may lead to increased hypoglycaemia, as patients aim for relatively low blood glucose levels. Therefore, attempts to reduce HbA_{1c} levels must be accompanied by efforts to reduce hypoglycaemia (Davis and Alonso, 2004). Kaufman and colleagues (2002) argue that if families are competent in diabetes management, it is possible for young children to achieve HbA_{1c} levels of less than eight per cent without increased risk of hypoglycaemia.

Hyperglycaemia (high blood glucose), can occur as a result of missing an insulin dose or taking insufficient insulin, eating too much carbohydrate in relation to insulin dose, counter-reaction to a hypo, stress, being unwell with an infection or change in activity levels. Symptoms include increased thirst and urination, headaches, lethargy and stomach pain (Diabetes UK, 2008). If hyperglycaemia is left untreated, it can result in DKA. DKA has an average mortality of five to ten per cent of episodes in Western countries (Krentz and Nattrass, 1997). Cerebral oedema, a result of DKA accounts for most hospital deaths of young children with T1D (Edge et al, 1999).

Section 4: Blood glucose control in adolescence

1.15 The 'problem' of blood glucose control in adolescence

Adolescence is a hazardous period for diabetes management, given frequent reports of deteriorating metabolic control (Cardwell et al, 2005; Scottish Study Group for the Care of the Young Diabetic, 2001; Thomsett et al, 1999; Mortensen et al, 1998). In the UK, only 17.5% of under-fifteen year olds in the UK are achieving the recommended blood glucose levels of 7.5% (Diabetes UK, 2005). The majority of adolescents have either constant (i.e. not improving) or deteriorating control (Dabadghao et al, 2001). Although metabolic control is likely to improve in young adulthood (Archarya et al, 2007), poor control during the adolescent years yields the threat of potential damage to organs in later life (Jones and Gill, 1997).

1.16 Determinants of blood glucose control in adolescence

There is a large body of empirical, quantitative evidence defining various factors affecting blood glucose control negatively during adolescence. These include biological factors such as hormone imbalances during puberty (Du Pasquier-Fediaevsky et al, 2004) and poor dietary compliance (Rosilio et al, 1998); sociological factors including female gender (Archarya et al, 2007; Hanberger et al, 2007; Hanna and Guthrie, 1999); lower socioeconomic status (Carter et al, 2008; McKinney et al, 2008) and minority-ethnicity (Carter et al, 2008; Povlsen et al, 2005; Gallegos-Macias et al, 2003). Psychological disorders have also been widely attributed as causal determinants of HbA_{1c} in adolescence (Nardi et al, 2008; Roy et al, 2007; Lustman and Clouse, 2005; Pinar, 2005; Whittemore et al, 2002). Positive influences on HbA_{1c} include intensive insulin regimes (Mortensen et al, 1997); taking regular, controlled exercise (Marrone et al, 2009; Valerio et al, 2007, Bernardini, 2004); dietary fibre intake and regular meal patterns (Overby et al, 2007).

Interestingly, self-monitoring of blood glucose through the finger-stick method has not been found to be any more beneficial to HbA_{1c} than continuous subcutaneous monitoring systems (Chetty et al, 2008; Golicki et al, 2008). These systems continuously measure glucose concentrations in subcutaneous tissue as an alternative to the finger-stick method (Chico et al, 2003). This suggests that frequency of blood glucose testing does not improve blood glucose control, indicating that it is underpinned by much more than biomedical adherence to the diabetes regimen.

1.17 Conclusion

From a biomedical perspective, living with T1D requires adherence to a strict self-management regime with the aim of maintaining a blood glucose level conducive to reducing the risk of developing complications in later life. Self-management of T1D is 'measured' by the HbA_{1c} level, which gives a calculation of average blood glucose control. Blood glucose control deteriorates during adolescence and quantitative studies have pinpointed causal determinants of blood glucose control in this age group, however there is a need to explore the social and individual contexts of these factors. Interestingly, recent evidence has shown that subcutaneous blood glucose monitoring does not improve HbA_{1c} in children and adults, suggesting that wider psychosocial factors aside from biomedical adherence must be of influence. From this, I suggest that the current biomedical model of care and attribution of control to HbA_{1c} levels, is not adequate to account for the complex nature of blood glucose control in adolescence. Thus, there is a need to explore wider psychosocial and qualitative research in this area to understand the experiences of adolescents with T1D. This will enable a move towards a better understanding of blood glucose control in this age group.

Chapter 2: Living with T1D in adolescence

Introduction

In Chapter 1, I suggested that the current biomedical model is not adequate to account for the complex nature of blood glucose control in adolescence, and defined a need to explore wider psychosocial and qualitative research in this area. In this chapter, I present an exploration of the psychosocial factors underpinning the self-management of T1D. As a starting point, I conducted a systematic review of qualitative studies of T1D in adolescence, with the aim of exploring research relating to the lived experiences of adolescents with T1D and identifying a specific direction for the study (Spencer et al, 2009). I searched electronic databases using all combinations of the terms 'Type 1 diabetes', 'adolescence', 'teenager', 'parents', 'family' and 'qualitative' for the period 1988-2008. My search yielded twenty qualitative studies, which were quality appraised and synthesised using a research integration approach (Sandelowski, 2004). Further detail of the methodology employed can be found in the supporting paper included at the end of the thesis. I categorised the findings of the studies into four themed sets:

1) Independence and autonomy for diabetes management

2) Living with T1D

3) Family relationships

4) Diabetes care

Alongside this, I also conducted a general literature review of T1D in adolescence. As the systematic review search was limited by specific search criteria, this ensured that relevant data sources beyond the scope of the review were acknowledged. The literature review illuminated a varied literature of quantitative and qualitative studies focusing on the psychosocial experience of T1D in adolescence. This included psychological theories of identity development, personal models of illness and psychological stress in parents, and sociological research relating to family relationships and theories of family adaptation and coping with chronic illness. I present this literature with reference to the four sets defined in the systematic review. Each set begins by setting the sociological context of the set. The sub-themes within each set are then discussed in relation to the wider literature. I conclude by considering the implications of the systematic review and the wider psychosocial literature for the direction of this study.

Set 1: Independence and autonomy for T1D management

2.1 Background: Autonomy in adolescence

The term 'autonomy' is used widely to refer to psychosocial development during adolescence and has been conceptualised in a variety of ways (Zimmer-Gembeck and Collins, 2006). Definitions include psychosocial maturity (Greenberger and Sorenson, 1974), the ability to express differences between the self and others (Grotevant and Cooper, 1986), self-responsibility for behaviour (Cittenden, 1990), control over one's life (Collins et al, 1997) and an independent sense of identity whilst preserving connection to parents (Herman et al, 1997). Autonomy is achieved through a gradual move away from reliance on parents towards becoming a responsible adult. For adolescents with T1D, autonomy also refers to their ability to take responsibility for self-management of their disease. Parental over-protectiveness of a child with a chronic illness may inhibit the normal process of autonomy development, with the parent constantly 'pulling' the child back in to their care. Adolescents may also refrain from exploring their independence due to anxiety about managing their disease without parental support (Helms, 2007).

In the systematic review, I found that autonomy development for adolescents with T1D was underpinned by psychological and emotional maturity, parental input and support, and support from peers and health professionals. As follows, I discuss these sub-themes with relation to theories of experiential learning, personal models of illness, parental 'miscarried helping' and the stigma of chronic illness. I also note the implications of increased adolescent autonomy for parents and adolescents.

2.2 Psychological and emotional maturity

Experiential learning

In the systematic review, I found that becoming emotionally ready to take responsibility for diabetes management was a complex process for adolescents, underpinned by gaining factual and experiential knowledge and problem-solving skills. Diabetes camps and school trips provided safe environments through which to gain self-management experience away from home (Karlsson et al, 2008; Christian and D'Auria, 1999), which led to an increase in self-esteem. This demonstrated that learning through experience was instrumental to the development of autonomy for T1D management in adolescence.

This is supported by claims that alongside education in the clinical setting, a large percentage of diabetes education is developed through experiential learning, which occurs through trial and error in relation to individual experiences and social contexts (Paterson and Thorne, 2000; Price, 1993). Knowledge and skills do not necessarily facilitate confidence without real life experience (Nicholson, 2001). Rather, people become experts of their own illness in terms of how self-management 'fits' into their psychosocial context (as recognised in the *Expert Patient*, Department of Health, 2001b). Learning is therefore an individualised process dependent on personal norms, beliefs and values (Swift, 2004).

Cognitive developmental theories suggest that experiential learning may not be appropriate for children and adolescents, who do not develop the capacity for analysis, synthesis and evaluation until adulthood, highlighting the need for parental input. These concepts are defined within the psychological literature, as instrumental to the ability to assess the outcomes of one's behaviour and relate these to future actions (Bloom, 1956).

Personal models of T1D

Adolescence is a critical period for psychosocial development. Evidence suggests that living with diabetes may have an impact on identity development and psychological wellbeing during this life-stage. Adolescents with T1D appear to be as well psychologically adjusted as those without, although reports suggest lower self-esteem than their peers (Jacobson et al, 1997). From a sociological perspective, coming to terms with a chronic condition such as diabetes can be a transformational process for both the child with diabetes and their parents, and perceptions of the illness and its effect on perceptions of the self may also impact on diabetes control.

Personal models research is concerned with identifying variables that patients themselves believe to be central to their experience of an illness and its management. Personal models change with experience, particularly during adolescence, when young people are learning to take responsibility for their own diabetes management (Skinner and Hampson, 2001). They are shaped mainly by family (Lau et al, 1990; Skinner et al, 2000) and peers and there is a link between family support and efficacy of diabetes management (Skinner and Hampson, 1998). For example, in the systematic review, Williams (1999) found that adolescent girls incorporated diabetes into their identities more than boys, for whom mothers took responsibility for their care. In another study, girls described T1D forcing them to be more independent and responsible than their peers (Dickinson and O'Reilly, 2004). This supports claims that personal models of T1D may be the underlying cause of individual differences in health/illness-related behaviours (Hampson et al, 1990).

Charmaz (2001) coined the term 'alert assistant' to refer to mothers who identify, anticipate and meet the needs of their sons. This behaviour is influenced by mother's perceptions of the self-care abilities of their sons and the gendered ways in which sons perceive their diabetes, i.e. as a threat to their masculinity (Williams, 1999). Research suggests that mothers have a greater input in sons' diabetes management than in daughters, which may lead to better blood glucose control in males, but better development of independence skills in girls (Williams, 1999). Differences in parental roles between mothers and fathers have implications for understanding parent-adolescent relations, as research has shown that the gender of parents and adolescents may be related to outcomes for adolescents (Bosco et al, 2003; Conrade and Ho, 2001).

Personal models beliefs have been found to be proximal determinants of self-care in people living with diabetes and thus may facilitate autonomy in adolescents. Adolescents have been found to perceive their diabetes as chronic, with high levels of personal control over their illness (Law, 2002) and girls report greater impact of diabetes, more worries and less satisfaction with life than boys (Graue et al, 2003). Treatment effectiveness beliefs have been associated cross-sectionally and prospectively with self-care in adolescents (Skinner et al, 2002; Griva et al, 2000; Skinner et al, 2000). Perceived treatment effectiveness to prevent complications in later life was predictive of frequency of blood glucose testing in a population aged twelve to thirty years (Skinner et al, 2002). Short-term effects of diabetes and its treatment rather than long-term outcomes have been found to be predictive of self-management and well-being in adolescents (Edgar and Skinner, 2003; Skinner and Hampson, 2001, 1998) and adults (Skinner et al, 2002). This suggests that focusing on long-term complications in education strategies may not be effective for motivating self-care. This is supported by Green and colleagues (1990), who found that the short-term threat of hypoglycaemia was associated with diabetes control in adolescents.

The evidence supporting the impact of personal models and self-perception on glyceamic control implies that, as adolescents take on increased responsibility for the management of their diabetes, parents and health professionals must take into account beliefs about diabetes as key factors influencing self-care, emotional well-being and glyceamic control (Skinner and Hampson, 2001).

2.3 Parental input as a barrier to autonomy

In the systematic review, I found that parents took an administrative role in adolescents' diabetes management, including monitoring medication, organising clinic appointments and liaising with health professionals (Carroll et al, 2007). Other research suggests that mothers are usually the main care giver to a child with T1D (Dashiff et al, 2008) and that mothers spend more time meeting their children's practical needs whilst fathers spend more time on recreational activities (Pleck, 1997; Hall et al, 1995). An American study of 272 parents found that mothers and fathers agreed that mothers had more responsibility for adolescents' discipline and daily care and were satisfied with this arrangement, suggesting a general acceptance of these different gender roles in parenting within Western society (Phares et al, 2009). Despite this, fathers' contribution to the family has shown associations with disease-management outcomes in young people (Dashiff et al, 2008). Parenting a child with a chronic illness may also serve as a catalyst for fathers to take a more meaningful involvement in their child's care (McNeill, 2007).

Maintaining a balance between diabetes management and a child's growth and development can pose a great challenge for parents (Sherifali and Ciliska, 2006). When a child is diagnosed at a young age, maternal involvement is crucial in decision making, planning and adherence to the daily regimen (DCCT, 1994). Despite the advantages of parental involvement, independent decision making has also been found to be significantly correlated to metabolic control (Hanna and Guthrie, 2003). Parents of children with chronic illnesses may engage in a variety of monitoring practices, from direct supervision to wider supervision through contact with others who engage with the child (Ellis et al, 2008). Parents may find it difficult to trust that their child will look after their diabetes adequately, related to fear for their child's future health (Ivey et al, 2009).

Parental grief, feelings of guilt and self-responsibility can result in an unhealthy dyadic relationship between mother and child, where the child becomes fixed in the position of being dependent on the mother (Seiffge-Krenke, 1998). Parental involvement can also cause stress and sleep disruptions for parents as a result of night time care giving and monitoring, leading to poor sleep quality, depression and anxiety (Meltzer and Moore, 2008). Adolescents' perceptions of maternal control were found to be associated with depressed mood and poorer self-efficacy among older adolescents, suggesting that excessive parental control may inhibit autonomy for diabetes management (Butler et al, 2008). Despite the suggestion that T1D may complicate the transition from adolescence to adulthood (Seiffge-Krenke, 1998), Pacaud and colleagues (2007) found no delay in psychosocial maturation in comparison with healthy controls.

'Miscarried helping'

Another issue to emerge from my synthesis in the systematic review was that conflict between parent and child was common, resulting from unnecessary parental input (Schilling et al, 2006). Adolescents also felt mistrusted as a consequence (Kyngas et al, 1998). Parents were aware that their reminders for self-management were annoying, but found it difficult to step back from assistance (Carroll et al, 2007). Teenagers with poor control had a more negative view of parental reminders and tended to ignore them rather than utilise the support. There was also a higher instance of parent-adolescent conflict in these young people compared to those with better control (Leonard et al, 2005). For adolescents with varied chronic illnesses, parents were found to be an important source of support with medical regimens but also source of tension and resentment. Over-protectiveness often restricted independence and led to conflict (Taylor et al, 2008).

Negative relationships between parents and adolescents may be underpinned by 'miscarried helping' (Anderson and Coyne, 1991). This involves an investment by parents to help their child with the aim of achieving better health outcomes, to benefit their needs rather than the needs of the child. In chronic illnesses such as diabetes, the parent may feel that their child's health is not improving despite their efforts and may feel a sense of failure and disappointment. This is communicated to their child, resulting in them feeling 'blamed' for their illness and leading to interpersonal conflict. Miscarried helping has been found to be related to parent-child conflict and parent non-support of diabetes treatment, and negatively with youth and parent-reported adjustment to diabetes and youth-reported adjustment to treatment (Harris et al, 2008). Higher levels of family conflict which may result from miscarried helping, relate negatively to adherence (Miller-Johnson et al, 1994; Wysocki, 1993; Bobrow et al, 1985) and glycaemic control (Lewendowski and Drotar, 2007; Moreland et al, 2004) in adolescents with diabetes.

2.4 Parental facilitation of autonomy

Parental involvement in T1D management has been shown to improve adherence in adolescents (Berg et al, 2007; Ellis et al, 2007; Anderson et al, 1999) and reduce diabetes-related hospital admissions (La Greca et al, 1995; Wysocki et al, 1995). Parental knowledge about diabetes has also been found to have a positive effect on glycaemic control (Butler et al, 2008), suggesting that parents have a vital role in guiding their child's diabetes education. Studies in the systematic review found that parental involvement in diabetes self-management gradually decreased as adolescents grew older (Schilling et al, 2006). Parental trust in adolescents' ability to manage their diabetes reduced anxiety about the consequences of poor management and enabled parents to give their child more freedom (Karlsson et al, 2008). This suggests that parent and adolescent collaboration at an interpersonal level could lead to better emotional adjustment and adherence (Berg et al, 2008a), although enjoyment of collaboration has been shown to decrease for both adolescents and mothers, with increasing adolescent age (Berg et al, 2008b). Despite the benefits of parental input, sharing responsibility for diabetes self-care between parent and child is associated with better psychological health, good self-care behaviour and good metabolic control in adolescents, whereas stronger child or parent responsibility is not (Helgeson et al, 2008).

2.5 Peer facilitation of autonomy

Although families provide the main support for self-management tasks, friends may provide a greater level of emotional support to adolescents than families (La Greca, 1995). Peer relationships are important and best friends provide vital support to adolescents with chronic illness (Taylor et al, 2008). This is important in relation to the developmental shift in perceptions of peer support as adolescence is reached and perceptions of family and peers change (La Greca et al, 1995). Shroff-Pendley and colleagues (2002) found that adolescents perceived greater diabetes-related peer support than pre-adolescent children. They also found that perceived peer and family support were not correlated with metabolic control. In the systematic review, I found that peer support was generally valued by adolescents, but too much interest from friends was also seen as intrusive (Carroll and Marrero, 2006a; Olsen and Sutton, 1997).

Adolescents with chronic illness have reported their peers to be supportive of their condition (Lightfoot et al, 1999; La Greca, 1992), with many stating that having a chronic illness made no difference to their relationships (Lightfoot et al, 1999). However, lower levels of pro-social peer support and higher rates of relational victimisation have also been found in children with diabetes in comparison to their peers without, which was positively associated with depression, anxiety and loneliness (Storch et al, 2004). Kyngas (2000) found that good motivation, a strong sense of normality, energy and willpower, support from parents, physicians and nurses, positive attitude towards diabetes and fears of complications were significantly related to good compliance in youths with diabetes. This suggests that with the correct psychosocial support, adolescents are able to achieve a good level of adherence and ultimately metabolic control.

Disclosing diabetes to peers

In the systematic review, I found that the demands of living with diabetes became greater as socialisation needs increased with age, leading to feelings of frustration and restriction (Christian and D'Auria, 1999). Adolescents felt that they had to take on more responsibilities than their peers (Carroll and Marrero, 2006a) and feeling comfortable and not different from peers was key to integrating diabetes into daily life (Karlsson et al, 2008) and independence (Karlsson et al, 2008; Christian and D'Auria, 1999). A systematic review of qualitative studies of chronic illness in adolescence found that medication regimes were often a burden and made adolescents feel 'different' (Taylor et al, 2008).

The concept of stigma is relevant to understanding the experience of chronic illness within society. Stigma refers to, *'a negatively defined condition, attribute, trait or behaviour conferring 'deviant' status, which is socially, culturally or historically visible'* (Gabe et al, 2004:68). It symbolises the ways in which the self is presented within society and pinpoints why adolescents with T1D may feel different from their peers. Chronic illness can disrupt the way that the self is presented to others, through visible physical symptoms and obvious self-management practices which deviate from the normal expectations of behaviour within particular social situations. Stigma occurs when there is a discrepancy between 'virtual social identity' (stereotyped expectations of the behaviour of others) and 'actual social identity' (the actual attributes possessed by individuals). Those with a chronic illness may endeavour to 'pass' i.e. hide the characteristics of their illness from others, in order to avoid a stigmatising label (Goffman, 1968). In relation to disability and illness, stigma occurs as a result of the difference between what is socially desirable in relation to a person's level of visible disability (Philips, 1990). These differences may become more prominent if people take it upon themselves to objectify these perceived differences of someone else in a public manner, through discrimination.

There are psychosocial implications of the decisions that people with diabetes make about disclosing their condition. T1D is 'invisible' to others unless disclosed, or acute symptoms occur in public ('spontaneous disclosure'). Some people are reluctant to disclose their chronic illness for fear that responses of others will be negative. If a person chooses not to disclose their condition to others, but is 'caught out' by spontaneous disclosure, they may experience stigma through others' reactions (Goffman, 1968).

Controlling blood glucose fluctuations is essential to avoid spontaneous disclosure of T1D. Rajaram (1997) argues that hypoglycaemic episodes cause disruption to the daily lives of people with T1D and upset self-worth through feelings of loss of control and failure. This threat to self-worth may influence some to maintain a high blood glucose level in order to avoid the disclosure of their disease to others. This is supported by findings that during mid-adolescence, it is common for adolescents with chronic illness to confront the limitations of their disease (for example rejecting their medication) in order to achieve normalcy with their peers (Taylor et al, 2008). In a study of 33 adolescents with chronic illness in the UK, over a third stated that they had been bullied because of their illness characteristics or being treated differently by teachers in school (Lightfoot et al, 1999). Shiu and colleagues (2003) suggest that when those with diabetes perceive the external environment as being non-supportive, they have difficulty transferring what they have learned about diabetes management into practice.

I found that in a number of studies in the systematic review, it was important for adolescents to disclose their diabetes to their friends (Carroll and Marrero, 2006a; Christian and D'Auria, 1999; Olsen and Sutton, 1997) as they felt 'safe' in the knowledge that their friends could cope in an emergency. This enabled them to 'forget' about their diabetes when with their peers (Karlsson et al, 2008), thus facilitating social autonomy (Spencer et al, 2009). As a reaction to the threat of stigma, 'protective disclosing' aims to make others aware of T1D. The adolescent is then in control of who knows about their diabetes and when they become aware of it. For example, adolescents with chronic illnesses stated that they told their peers about their condition so that they knew what to expect and what to do in an emergency (Lightfoot et al, 1999). 'Preventive disclosing' is a choice to disclose when there is a perceived high risk that the condition will become visible to others, e.g. if hypoglycaemia is a regular occurrence (Joachim and Acorn, 2000a). This may facilitate autonomy for self-management, as the barriers to self-management caused by perceived stigma are removed. Joachim and Acorn (2000b) suggest that 'normalisation' counteracts stigma, through the strategies that those with a chronic illness develop in order to cope and integrate within society and 'rise above' the limitations of their illness.

2.6 Biomedical facilitation of autonomy

In the systematic review, I illustrated that encouragement for independent decision making by health professionals was beneficial for autonomy. Basal bolus regimes (Christian and D'Auria, 1999) and insulin pumps (Low et al, 2006) benefited autonomy, lifestyle freedom and independence for some adolescents. However, research suggests that patients must be selected carefully for transfer to basal bolus regimes which involve multiple injections in relation to carbohydrate counting, as they are, *'difficult to learn, involve multiple injections, frequent blood glucose measurements and require considerable increased resources'* (Mortensen et al, 1998:758). Transference as a remedy to poor control may result in further decreases in control if the adolescent does not have the skills and motivation required (Davidson et al, 2004). An awareness of the social context of adolescents with T1D by health professionals is therefore beneficial in order to avoid transference to regimes which hinder self-management capability.

2.7 Implications of autonomy for adolescents and parents

As I found in the systematic review, many parents took personal responsibility for their child's diabetes, and interpreted the HbA_{1c} check at clinic appointments as confirmation of how they had discharged their parental responsibilities (Wennick and Hallstrom, 2007). Transferring responsibility over to their child was therefore often difficult. Parents felt that they had lost control, and had to deal with negative consequences of reducing their input, such as increased blood glucose fluctuations. Parents and adolescents worried about the burden of increased responsibility for adolescents, and adolescents recognised their parents' concerns. Despite this, adolescent autonomy positively relieved the burden of responsibility for parents, whilst adolescents enjoyed increased knowledge and confidence in their abilities, more freedom and the approval of others (Hanna and Guthrie, 2000a, 2000b). Successful self-management reduced worry for parents and adolescents and increased freedom (Herrman, 2006). Parents and adolescents described confidence and pride in adolescents' abilities to manage independently (Hanna and Guthrie, 2000a, 2000b).

Finding the correct balance between encouraging autonomy and providing adequate parental support is an ideal scenario for the development of adolescent autonomy, but is often difficult as emotional issues for both parent and child can impinge upon the natural process (Grey et al, 1998). Sharing responsibility for diabetes self-care between parent and child is associated with better psychological health, good self-care behaviour and good metabolic control in adolescents, whereas stronger child or parent responsibility is not (Helgeson et al, 2008). Team-based management strategies and cohesive family climate promote adherence to medical treatments over time in adolescents with chronic illness, whereas conflict and disengagement in family interactions disrupt adherence and lead to a decline in child health (Fiese and Everhart, 2006).

Set 2: Living with T1D

2.8 Background: Living with chronic illness in adolescence – a sociological perspective

The social construction of chronic illness

From a social constructionist perspective, illness is socially constructed through meanings and interpretations. This forms a long-standing debate over whether social problems are 'real' or whether they are purposively created by social actors. Biomedical knowledge defines a condition as a biological entity, but social constructionsim asks how and why a condition was identified at a certain time; why action was taken or not taken and how the person's experience of the illness affected the outcome or course of the disease (Brown, 1995). Thus the meanings and interpretations of the illness extend far beyond the biophysical symptoms of illness and affect daily life, social relationships and identity. Chronic illness is both a personal and public phenomenon shaped by the social, cultural and ideological context of a person's biography. The interpretation of an illness therefore contributes to the way in which it is experienced (Nettleton, 1995). Living with chronic illness is an individualised experience and thus qualitative research exploring lived experiences has the potential to understand the meaning-structures of individuals living with T1D.

From a functionalist perspective, Parson's concept of the 'sick role' (1951) argues that sickness is deviant in that it prevents a member of society from fulfilling their roles (ie. not being able to work or attend school). The person who is sick is not held responsible for their illness and is therefore excused from their usual social obligations, however they are expected to cooperate with medical help in order to become well as soon as possible and regain their active position within society. Chronic illness does not fit into this conception of disease (Gerhardt, 1987). It is life-long, and therefore the focus moves from cooperating with medical assistance in order to rectify health, to learning to self-manage illness whilst fulfilling expected and desired roles within society (Nettleton, 1995). The role of health professionals to provide 'medical help' is also limited to within the biomedical environment, when the reality of chronic illness involves relentless management within many environments and social situations. The diagnosis of a chronic illness therefore requires a range of adaptive processes in the face of disruption to the 'normal' functioning of the body, in order to accommodate the illness within the context of everyday life.

Biographical disruption

In 1982, Bury introduced the concept of 'biographical disruption'. Theories of biographical disruption recognise chronic illness as a disruptive life event followed by an ongoing process of adaptation to the new bodily state. The diagnosis of a chronic illness disrupts the structures of everyday life and the knowledge which underpins them, and introduces pain and suffering as well as the possibility of death. It may also represent a loss of personal control when daily activities are disrupted and a person becomes dependent on health professionals (Williams, 1996). The extent to which a life is disrupted by chronic illness depends on the individual context of the person (Locker, 2008). Bury (1982) defined three responses to the disruption caused by chronic illness:

(i) Disruption of taken-for-granted assumptions

Attention is drawn to bodily states that are normally taken for granted, through the experience of symptoms and the implementation of management practices. In normal daily life the body does not have a dominant presence unless a person chooses to focus on it, for example an athlete for whom bodily function has integrated significance in daily activities. For the majority, the body is a taken-for-granted medium through which life is experienced, and 'health' is taken-for-granted (Williams, 1996). Adolescents with T1D are required to control the functioning of their pancreas, which is taken-for-granted in those without diabetes. This is facilitated by the introduction of the biomedical environment and the definition of their condition as a biomedical disease.

(ii) Disruption of biography and self-concept

Identity and being is questioned in relation to the new bodily state, and a transformational process occurs as the person attempts to realign themselves within society with their 'new' body. Perceptions of how close others such as peers and relatives perceive them in their new bodily state may affect their sense of self-perception, which will be shaped by the interactions and reactions of others to the public demands of their illness. This is explored further below in with reference to the influence of peer and family relationships on self-management.

(iii) Mobilisation of resources

Social environments are rearranged to accommodate the chronic illness. For example, having to administer injections during the school day requires adaptation by an adolescent with T1D to incorporate this practice into the normal routine. It also requires adaptation by those within the school environment, including teachers and peers, in order to enable the adolescent's self-management practices to occur. These stages represent an on-going transformational process as people with chronic illness constantly meet new environments and interact with significant others. The lives of close family members are also disrupted and undergo a similar transformation as they accommodate the illness within their social contexts.

Chronic illness and adolescence

The life-stage of adolescence signifies the period between the end of childhood and the beginning of adulthood and is characterised by rapid biological, psychological and social development (Yeo and Sawyer, 2005). Adolescents with T1D have the same developmental issues as healthy young people. However, the disruption of T1D may have a chronic effect on life trajectory and biography, as significant aspects of a young person's surrounding world are affected by the illness. Negotiation through education, career planning, independence and friendship networks may take a different form (Grinyer, 2007). Psychosocial development can be disrupted by repeated hospitalisation and poor health status (Thomas and Gaslin, 2001). Likewise, the management of a chronic illness (i.e. blood glucose control) can be disrupted by developmental changes in the period of adolescence, such as puberty and independence (Yeo and Sawyer, 2005).

2.9 Managing conflict

As I reported in the systematic review, adolescents with T1D had to make decisions and manage a range of conflicts (Hayes-Bohn et al, 2004). These included whether to follow their management plan (Davidson et al, 2004; Dickinson and O'Reilly, 2004), be truthful about self-care action (Davidson et al, 2004), tell others about their diabetes (Davidson et al, 2004; Dickinson and O'Reilly, 2004), and ask for help (Davidson et al, 2004). Adolescents also reported emotional conflicts: being healthy yet invisibly ill, feeling acceptance yet frustration, independent yet supervised and confident yet insecure (Wennick and Hallstrom, 2007). Balfe (2009) has reported conflicts between the 'social body' (risk taking) and the 'healthy body' (reduction of bodily risk) in university students with T1D, based on Goffman's (1959) theory of the presentation of the self, where the body is seen as a source of identity. Identities are dependent on the abilities of individuals to sustain them, therefore a diagnosis of T1D may conflict with the identity the adolescent wants to portray to others. 'Body projects' refer to the ways in which people present certain identities in order to maintain normality (Giddens, 1991). T1D instigates boundaries which may restrict engagement in bodily practices which enforce normality. In Balfe's study, adolescents drank alcohol with their peers in order to conform to a shared ideal of how individuals should be, specific to their sociocultural context. Conflict occurred between the social body (risk taking) and the healthy body (reduction of bodily risk). Presenting the social body to others through risky health practices enabled them to construct desired identities in relation to their desired position within their social group (Balfe, 2009).

2.10 Facilitators of and barriers to self-management

In the systematic review, I highlighted that successful management of diabetes was related to knowledge and experience, adherence, exercise and parental support (Herrman, 2006). Confidence, knowledge and self-efficacy had a positive effect on health, emotions, social opportunities and relationships (Davidson et al, 2004), emphasising the important influence of experiential learning. Adolescents and parents felt that an implantable testing device which automatically tested blood glucose and administered insulin, and a blood glucose tester incorporated into a mobile telephone or personal digital assistant (PDA) would be beneficial to self-management, in line with adolescents' cultural norms (Carroll et al, 2007). This is supported by the findings of a systematic review of technology-based approaches to education for young people living with T1D. Such methods were found to be beneficial to knowledge and psychosocial well-being, with probable improvements to self-care behaviours (Cooper et al, 2009).

In the systematic review, I found that some adolescents saw T1D as a threat to their physical and psychosocial well-being (Kyngas and Barlow, 1995). Adolescents were aware of the potential health costs of not taking care of their diabetes (Herrman, 2006), however self-monitoring was inconvenient and disruptive, and negatively influenced by increase in age, school and peer influences and social stigma (Carroll et al, 2007). Adolescents were concerned with fitting in with the adolescent culture (Dickinson and O'Reilly, 2004) and some received unwanted attention when injecting or testing in public. Research with the general adolescent population has found that behaviours which receive peer group approval are likely to be repeated (Allen et al, 2005). Not taking care of diabetes had the perceived benefit of enabling some adolescents to fit in with their peers more adequately (Herrman, 2006). Viner (2009) has suggested that adolescents who are defined as 'non-adherent' in the biomedical setting are not without adherence entirely. The management of blood glucose in order to maintain invisibility of T1D in different aspects of their lives requires a high level of commitment and planning and therefore they are adherent to a regime in order to achieve this, albeit not a 'biomedically prescribed' one. Poor adherence to the biomedical regime did have consequences for blood glucose fluctuations (Herrman, 2006) and feelings of guilt (Davidson et al, 2004; Dickinson and O'Reilly, 2004).

2.11 Restrictions, stressors and coping

It is assumed that the burden of diabetes management may have a negative effect on quality of life, evidenced by reports that adolescents with diabetes have a worse quality of life and more frequent psychological disturbances than those without (Nardi et al, 2008). Poor quality of life has been found to be related to the development of diabetes-related complications (Hahl, 2002). In the systematic review, I found that diabetes was perceived as a difficult and demanding condition (Davidson et al, 2004) with inconvenient dietary restrictions and interruptions to daily life (Herrman, 2006). Some adolescents felt controlled by school staff, sports coaches and health care providers (Dickinson and O'Reilly, 2004). Despite the burden of self-management however, adolescents saw their diabetes as potentially manageable (Davidson et al, 2004).

Factors related to better quality of life in adolescents with T1D include parent responsiveness (Botello-Harbaum et al, 2008), younger age, (Wagner et al, 2005; Graue et al, 2003) good metabolic control, intensive insulin therapy (Wagner et al, 2005) and male gender (Graue et al, 2003). Insulin pump use and it's relation to quality of life has been studied extensively, however, in a systematic review of these studies, Barnard and colleagues (2007) found no strong evidence for or against the benefits of insulin pump therapy. Improved quality of life through the use of therapeutic educational tools has the potential to reduce HbA_{1c} levels (Debaty et al, 2008). Periodic discussion and monitoring of health-related quality of life in adolescents with diabetes was found to have a positive effect on their psychosocial well-being, except for those with the poorest control (de Wit et al, 2008), as were empowerment educational programmes (Forlani et al, 2006). In one study in the systematic review, adolescents described implementing a range of coping mechanisms including implementing routines for diabetes management, carrying supplies in preparation for potential blood glucose fluctuations, asking parents for help and thinking ahead regarding the possible implications of non-compliance (Davidson et al, 2004).

2.12 Psychological distress

In the systematic review, I found that anxiety was present in adolescents, caused by the threat of complications and poor HbA_{1c} results (Dickinson and O'Reilly, 2004). As I described in Chapter 1, research suggests that adolescents with T1D are at risk of psychological distress (Northam et al, 2006). Depression is almost twice as prevalent in people with T1D as it is in the general population (Katon et al, 2004). Poor metabolic control (Nardi et al, 2008; Northam et al, 2004, Seiffge-Krenke and Stemmler, 2002), pre-existing psychological problems at diagnosis and female gender are thought to increase the risk (Northam et al, 2004), although a number of reports have also found no gender association (Goldston, 1997; Blanz, 1993). As well as a causal factor in the development of psychological disorders (Seiffge-Krenke and Stemmler, 2002), poor metabolic control is also an outcome related to depression (Nardi et al, 2008; Roy et al, 2007; Lustman et al, 2005; Whittemore et al, 2002) and eating disorders (Pinar, 2005). Diabetes-related complications are more prevalent in relation to both disorders (Goebel-Fabbri et al, 2008; Takii et al, 2008; Grylli et al, 2005; Peveler et al, 2005; Stewart et al, 2005; Katon et al, 2004; De Groot et al, 2001; Rydall et al, 1997), as well as risk of increased hospitalisation from DKA (Stewart et al, 2005). In contrast, stable psychosocial resources (eg. education, being married, good coping styles) are related to good diabetes control over a prolonged period of time in adults, suggesting that psychosocial stress in other areas can negatively impact on blood glucose control (Kanner et al, 2003).

Set 3: Family relationships

2.13 Background: T1D and the family

The traditional concept of the family as a permanent unit consisting of a married couple and their children is no longer the norm in the UK due to increases in divorce, single-parent families, cohabitation, and employed mothers. In 2004 there were approximately seventeen million families in the UK, 70% of which were headed by a married couple. Between 1996 and 2004, the number of married couple families fell by 4%; the number of cohabiting families increased by over 50%; and the number of lone-mother families increased by 12%. Nearly 40% of married couples and cohabiting couple families had dependant children. In lone parent families, children were 90% more likely to live with their mother than their father (Office for National Statistics, 2004).

A long-standing issue in the study of families is the contribution of the family environment and the parent-child relationship to psychosocial development in adolescents (Callan and Noller, 1986). The family has an important influence on the educational outcomes of adolescents (Melby et al, 2008) and is their most important support system. Consequently, any dilutions to the family system such as changes within the adolescent (ie. the diagnosis of a chronic illness), parental separation, or negative parenting style, have implications for adolescent functioning and adjustment (Heaven, 1994).

T1D can have a greater impact on the family unit than on the individual adolescent alone. There may be benefits in drawing the family closer together as a unit, but the heightened parental roles required to care for an adolescent with T1D may damage the relationship between parents in two-parent families (Dashiff, 1993). It is also possible that having a child with diabetes in the family, influences parenting and family style. Seiffge-Krenke (1998) found that families with adolescents with diabetes had a highly structured family climate (high levels of family organisation, control and goal orientation), and families with healthy adolescents were closer, dealt with conflict more openly and offered more autonomy. Families of adolescents with diabetes had better interpersonal relationships when the adolescents had better metabolic control. Having an adolescent with T1D in the family was found to have a negative impact on fathers, who were found to have low communicative activity and initiative within the family, in comparison to a control group of fathers with healthy adolescents, although their styles of coping with non-illness specific problems were no different (Seiffge-Krenke, 2002). Siblings were found to assist their ill sibling in hiding their chronic illness from others, based on the perceptions they felt others may have about their siblings illness, and participated in tasks to help their sibling manage their condition (Gallo et al, 1991).

2.14 Family adaptation and learning

In the systematic review, Wennick and Hallstrom (2007) described family adaptation to T1D as a two-stage, on-going learning process for families:

(i) **'Learning about the inevitable':** acknowledgement of the symptoms of the child's diabetes pre-diagnosis, followed by feeling overwhelmed and powerless. Confidence emerged once they had experienced managing the child's diabetes at home.

(ii) **'Learning about the extent':** learning about the effect of the child's diabetes on family relationships, the restrictions imposed on family life, and anxiety about blood glucose fluctuations. This reflects a process of experiential learning facilitating adaptation within the family.

Snoek and Skinner (2000) suggest that family teaching dominates education at diagnosis, as parents(s) and carer(s) are responsible for processing educational information at diagnosis on their child's behalf. Parents are likely to take a primary caring role in their child's diabetes management until at least early adolescence, setting parents up as a necessary facilitator of diabetes care, mediating between health care professionals and their child. Family educational approaches to youth with T1D have shown promising effects on family communication, problem solving and clinical outcomes (Fisher et al, 2007). The focus on family teaching and learning means that experiential learning is a fundamental process for the whole family.

The diagnosis of a child with a chronic illness causes a significant disruption to family life which requires the structure and function of the family to change substantively through role and responsibility distribution (Hauenstein, 1990). The studies in the systematic review indicated that parents created new family routines following diagnosis (Wennick and Hallstrom, 2006) and changed their lifestyle (eg. reducing working hours), to cope with the demands of the diabetes regime (Mellin and Neumark-Sztainer, 2004). Adhering to routines reduced parental anxiety (Wennick and Hallstrom, 2006; Mellin and Neumark-Sztainer, 2004) but caused inconvenience for some siblings (Wennick and Hallstrom, 2007). Some adolescents perceived changes to family life as a 'cost', as conflicts and inconvenience were introduced (Herrman, 2006).

An adolescent with a chronic illness demands a higher level of support from their significant others than before their illness. Families can thus be a vital source of practical and emotional support, although the strains of family life can also be amplified (Nettleton, 1995). Adaptation is required by the person with chronic illness and their significant others, in order to enable the chronic illness to become normalised (ie. not disruptive to daily life). Nomalising behaviour within families involves an acknowledgement of the disease, a minimisation of the abnormalities relating to the chronic illness, defining the social consequences of the situation as minimal and demonstrating the normality of the family to others (Knafl and Deatrick, 1986). It also involves socialisation into the hospital environment and coping with periodic stress and crises (Canam, 1993). Normalisation of a child's illness within the family may facilitate acceptance of their difference to others and promote the confidence and self-assurance to manage the disease in external environments (Amer, 1999).

2.15 Parent-child relationships

Parenting style

Baumrind (1971, 1989) emphasised parenting style as a major influence on adolescent behaviour and personality development. Her model of three parenting styles has been applied in various studies to explain variations in patterns of adolescent development, including academic achievement, psychosocial development, behaviour problems and psychological symptoms (Steinberg et al, 1994). Research has shown that there are modest but predictable differences in the adjustment and psychosocial functioning of adolescents, depending on the style used (Lamborn et al, 1991).

The authoritarian style involves rigidly enforced rules with low acceptance. Parents are restrictive, punitive, expect the adolescent to follow their directions, respect work and effort, place limits and controls and offer little verbal give and take. Adolescents are likely to be anxious about social comparison, fail to initiate activity, be ineffective at social interaction (Santrock, 1990) and have poor school attainment (Dornbusch et al, 1987). Adolescents score reasonably well on measures of obedience and conformity to the standards of adults, but have relatively poor self-conceptions compared with other youngsters (Lamborn et al, 1991).

The authoritative style combines reasoned control with love and affection. Parents encourage adolescents to be independent, but still place limits and controls on the adolescent's actions, and are warm and nurturing. This style is associated with social competence, especially self-reliance and social responsibility (Santrock, 1990). Adolescents who characterise their parents as authoritative attain good school grades (Steinberg et al, 1989a; Dornbusch et al, 1987). It has been found that three main aspects of authoritative parenting – acceptance, psychological autonomy and behavioural control, make a contribution to achievement; and that this positive impact is mediated through the effects of authoritativeness on the development of a healthy sense of autonomy and a healthy psychological orientation towards work (Steinberg et al, 1989a). Adolescents parented with this style score highest on measures of psychosocial competence, and lowest on measures of psychological and behavioural dysfunction (Lamborn et al, 1991).

Permissive parenting, as defined by Baumrind (1989, 1971), has been developed further into two types of permissive behaviour (Maccoby and Martin, 1983). Permissive-indifferent parents are uninvolved in the adolescent's life. They are neglecting and non-responsive and this style is linked with a lack of self-control in adolescents. Adolescents score highest on measures of psychological dysfunction and lowest on measures of psychosocial competence (Lamborn et al, 1991). Permissive-indulgent parenting is undemanding but accepting and responsive. Parents are involved in the adolescent's life but allow excessive freedom and do not control negative behaviour. Adolescents are likely to disrespect rules and authority (Santrock, 1990), have a strong sense of self-confidence, a higher frequency of substance abuse and school misconduct and are less engaged in school (Lamborn et al, 1991). Both permissive parenting styles are associated with poor school grades (Dornbusch et al, 1987).

Lamborn and colleagues (1991) found clear advantages for adolescents raised in authoritative homes, clear disadvantages for those raised in permissive-indifferent homes and mixed outcomes for those raised in authoritative and permissive-indulgent households. Parental acceptance and involvement therefore, may be the primary contributors to the development of positive self-conceptions and well-being; and strictness and supervision may help to deter the development of behavioural problems and encourage achievement-related phenomena (Lamborn et al, 1991). Children reared with an authoritative parenting style are likely to be the most autonomous and content, whereas those reared permissively are likely to be less developed in these areas (Hendry et al, 1994).

Family functioning and adherence are strongly associated with metabolic control in adolescents with T1D (Lewin et al, 2006). A cohesive, well-structured and organised family environment with little conflict and positive encouragement of leisure activities and independence appears to be the most favourable in supporting adolescents with T1D (Seiffge-Krenke, 2001). Non-traditional family structure was found to be related to low levels of organisation, recreational activity, child-behaviour problems and poor metabolic control in children with diabetes (Overstreet et al, 1995). A number of studies have looked at the relationship between parenting style and diabetes regimen adherence. Authoritative parenting was found to be advantageous for regimen adherence and glycaemic control in school-aged and younger children (Davis et al, 2001), although parent-child discipline, warmth and behaviour supervision have also been found to be associated with diabetes outcome (Miller-Johnson et al, 1994). Higher child perceptions of parental warmth and caring in relation to the diabetes regimen were related to decreased odds of experiencing an episode of DKA, whereas higher parental negativity were associated with increased odds (Geffken et al, 2008). Parental responsiveness was also recently found to be related to improved quality of life in a sample of 81 children with diabetes (mean age 13.3 years) (Botello-Harbaum et al, 2008). Adolescent perceptions of parental psychological control have been found to be associated with increased depressed mood and poorer self-efficacy in adolescents with diabetes (Butler et al, 2007) and youths' perceptions of parenting as 'critical' have been found to have a negative impact on adherence to diabetes management (Duke et al, 2008).

Family structure

There is a lack of empirical research exploring single parenting and chronic illness (Brown et al, 2008). In the general population, without the additional impact of chronic illness, involvement in an adolescent's life by non-residential fathers reduces conduct problems in adolescents, suggesting that the paternal influence may serve to counter the low control and discipline manifested by some single mothers (Simons et al, 1994). Not taking into account the additional demands of chronic illness, research has also found that a partner's involvement and support makes a crucial difference to mothers' ability to manage (Backett-Milburn et al, 2001). In the absence of a father, grandparents provide vital support to single mothers to cover work commitments (Backett et al, 2001). Single parents have been found to experience difficulties negotiating time off work for children's sickness (Spencer-Dawe, 2005; Backett-Milburn et al, 2001). This is likely to be a more prominent issue for parents of adolescents with chronic illnesses, and thus suggests that single mothers may be under increased stress than mothers from two parent families when coping with a child's chronic illness. Evidence also suggests that significant stress may also exist for step-parents integrating into a formed family where an adolescent has T1D (Zarelli, 2009).

Conflict

In the systematic review, I found that adolescents felt supported by parents who reassured them about complications and blood glucose fluctuations (Weinger et al, 2001), and were motivated by positive parental feedback (Kyngas et al, 1998). Parent-adolescent conflict occurred as a result of non-adherence to the diabetes regimen and resulting parental anxiety (Schilling et al, 2006; Leonard et al, 2005; Mellin and Neumark-Sztainer, 2004; Weinger et al, 2001). Although such disagreement was common (Weinger et al, 2001), some parents felt close to their adolescent daughters and rarely experienced conflict (Mellin and Neumark-Sztainer, 2004). Research has shown that approximately one in five parents and adolescents engage in prolonged, intense, repeated family conflict (Santrock, 1990). Whilst high levels of continued family conflict are associated with poor outcomes, conflict in early adolescence is vital to help the adolescent achieve some of the necessary changes in roles and relationships (Noller and Callan, 1991).

Adolescent gender is thought to be a differentiating factor in parental-adolescent conflict (Allison and Schultz, 2004). Some authors have found more serious conflict between adolescents and mothers, than fathers (Paikoff and Brooks-Gunn, 1991; Smetana, 1989; Steinberg, 1989b; Montemaya, 1986). An eight year longitudinal study of 61 children and adolescents with T1D observed that girls with recurrent ketoacidosis had increased levels of behaviour problems and lower social competence, reported higher levels of family conflict and their parents reported lower levels of family cohesion, expressiveness and organisation (Dumont et al, 1995). However, Dashiff and colleagues (2005) also found no relationship between general family conflict and diabetes-specific family conflict, and adolescent self-care adherence.

In the systematic revirew, I found that the adolescents described conflict with their parents, resulting from intrusive behaviours and precipitated by parental anxiety (Weinger et al, 2001). A lack of confidence in adolescents' abilities to manage their diabetes led to negative adolescent-parent communications, and adolescents feeling mistrusted (Kyngas and Barlow, 1995) and that they had failed their parents (Wennick and Hallstrom, 2007; Weinger et al, 2001). This affected self-esteem, confidence, autonomous functioning and ultimately diabetes control, as adolescents sometimes compromised their self-management behaviour to avoid potential conflict and negative feedback (Carroll et al, 2007; Carroll and Marrero, 2006a; Weinger et al, 2001). Higher levels of family conflict have been found to be negatively related to adherence in adolescents with diabetes (Miller-Johnson et al, 1994; Wysocki et al, 1993; Bobrow et al, 1985) and glycaemic control (Lewendowski and Drotar, 2007; Moreland et al, 2004). Parents in the systematic review described changing their own behaviours and expectations of 'perfect' management, in order to reduce conflict with their child (Mellin and Neumark-Sztainer, 2004).

2.16 Parental anxiety

In the systematic review, I found that parents in the perceived their child's diabetes as more serious than the child (Carroll and Marrero, 2006b). Diabetes brought parents anxiety about complications, management away from home, quality of management and hypoglycaemia (Ivey et al, 2009; Mellin and Neumark-Sztainer, 2004). The literature suggests a reciprocal relationship between adolescent coping with chronic illness and parent adaptation; the child's illness impacts on the parents' functioning and the parents' functioning impacts on the child's adaptation (Brown et al, 2008). I also found this in the systematic review. Relationships between daughters and mothers were perceived as positive when daughters displayed 'responsible' behaviour, including being reliable and trustworthy in other areas of life as well as with diabetes (Mellin and Neumark-Sztainer, 2004). When daughters achieved good control of diabetes, relationships with mothers improved, as parents reported experiencing less stress (Leonard et al, 2005). This indicated that parental anxiety was underpinned by a concern for their child's health. The literature suggests that the diagnosis of a child with T1D has a severe emotional impact on parents. Anxiety for their child's well-being is therefore illuminated if the child's diabetes is not well controlled.

The emotional impact for parents of a child with T1D begins at diagnosis. The events preceding diagnosis are often tainted with a slight suspicion of diabetes, culminating in a climax of panic and urgency and resulting in potential trauma for parent and child (Lowes et al, 2004). The diagnosis of a child with a chronic illness has been linked to stress and negative psychological effects for parents (Cadman et al, 1991), which varies between individuals dependent on environmental and interpersonal factors (Lowes and Lyne, 1999). Parents of very young children may struggle with injecting and taking blood from their tiny infant (Snoek and Skinner, 2000). Evidence of post-traumatic stress disorder has been found in mothers and fathers of children with newly-diagnosed T1D (Ribi et al, 2007; Landolt et al, 2005) and other chronic (Cabizuca et al, 2009) and critical (Shudy et al, 2006) illnesses. In fathers, the prevalence decreased after six months (Ribi et al, 2007), but lasting effect has not been studied in mothers. There is also evidence of anxiety and depression following a child's diagnosis (Kovacs, 1985) linked to increased parenting stress (Streisand et al, 2008), particularly in single parents (Streisand et al, 2005).

In the systematic review, I found that parents coped with anxiety by maintaining a positive outlook and providing practical support to their child (Mellin and Neumark-Sztainer, 2004). Other parents have described dealing with emotional stress through various avenues, including distancing (taking a break or focusing elsewhere), communicating with one another about the illness, engaging with and overseeing the management regimen and accessing support (Dashiff, 1993). This highlights a need for psychosocial support for parents with regard to the day-to-day anxiety experienced when caring for a child with T1D. Parent support groups may act as a positive coping mechanism. Studies investigating father's perceptions are limited, although the importance of the support they provide to their female partners has been recognised by a number of authors (Wysocki and Gavin, 2004; Amer, 1999).

2.17 Chronic sorrow

Olshanky (1962) coined the term 'chronic sorrow' when he observed that parents of children with cognitive impairment experienced life-long, episodic sadness, underpinned by the guilt that they felt at initial diagnosis. Theoretical approaches to grief reactions in parents are situated between two debates. Time bound theories suggest that grief runs a natural course over time which culminates in resolution, whereas chronic sorrow theories propose that individuals enjoy periods of satisfaction and happiness (Hayes, 2001) with periods of grief reoccurring periodically, as certain situations bring the disease to the forefront (Lowes and Lyne, 2000). In contrast to the permanent loss of a child, having a disabled or chronically ill child is a living reminder of loss to the parents, meaning that such feelings are more difficult to resolve (Kornblum and

Anderson, 1982). A number of studies support chronic sorrow theory in relation to varied chronic conditions, including disabling orthopaedic problems (Buschmann, 1988), Down's syndrome (Damrosch and Perry, 1989), chronically ill and disabled children (Phillips, 1991), cognitive disability (Teel, 1991) and developmentally-disabled children (Mallow and Bechtel, 1999).

In a review of the literature relating to chronic sorrow in parents of children with newly diagnosed diabetes, Lowes and Lyne (2000) found that although a number of studies suggested that parents reached an end-point in their grief, the majority of studies supported chronic sorrow theory. Lowes and colleagues (2005) later found the experience of diagnosis for parents to contain characteristics of a 'psychosocial transition' event. Psychosocial transitions occur when discrepancies exist between the world 'that is' and the world that 'should be'. Parents experience a process of grief and adaptation in transit to a new way of life, suggesting an evolutionary, transformative process (Parkes, 1996, 1993). Parental grief should be taken into account in the biomedical setting, as it may impact on parents' responsibility for their child's diabetes management. It also indicates a need for psychosocial support for parents.

Set 4: Diabetes care

2.18 Background: Policy context

Underpinned by *The Children Act* (2004), the Green Paper *Every Child Matters* (Department for Children, Schools and Families, 2003) aims to give all children the support they need to be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic well-being. *The Children's Plan* (Department for Children, Schools and Families, 2007) is a ten-year strategy to make England the best place in the world for children and young people to grow up. Within this ethos, the *Children's National Service Framework (NSF)* (Department of Health, 2005a) aims to stimulate long-term and sustained improvement in children's health through services designed and delivered around the needs of children and families. The views of children are respected and accounted for in policy decisions relating to their health care needs, supported by the *Children Act* (2004) and *NICE Guidelines for Children and Young People with Type 1 Diabetes* (NICE, 2004). *The National Service Framework for Diabetes* (Department of Health, 2001a) emphasises the importance of patient-focused services, aiming to *"build care around the person with diabetes, seeing services from their perspective"*, a view set out by *The NHS Plan* (Department of Health, 2000) and *The Expert Patient* (Department of Health, 2001b). Standard 3 of the NSF aims to ensure that people with diabetes are empowered to enhance personal control over the day-to-day management of their diabetes. Standards 5 and 6 aim to ensure that the special needs of children and adolescents with diabetes are recognised and met (Department of Health, 2001a). *The Expert Patient* recognises that living with long-term conditions can often mean physical and psychological difficulties, socio-economic problems, reduced quality of life and social exclusion (Department of Health, 2001b).

2.19 Clinical care

Relationships with health professionals

In the systematic review, I found that adolescents described valuing health professionals who had a '*friendly*' manner and spoke to them about other things aside from diabetes (Carroll and Marrero, 2006a; Waller et al, 2005). They felt supported when health professionals made suggestions about insulin doses or food choices (Dickinson and O'Reilly, 2004) and when care was planned collaboratively with them (Kyngas and Barlow, 1995). Professional advice often did not conform to their real-life situation (Karlsson et al, 2008) and some felt they were treated as a '*disease*' rather than a person (Carroll and Marrero, 2006a). Some adolescents did not understand the information that health professionals gave them, and allowed their parents to interpret it for them (Waller et al, 2005). Others felt that some physicians worked to a specific, immutable model of care regardless of communication between the adolescent and physician (Kyngas and Barlow, 1995). Other qualitative evidence suggests that adolescents with various chronic illnesses appreciated health professionals focusing on them rather than their illness, as well as the implementation of flexible care plans (Taylor et al, 2008).

In the systematic review, older adolescents wanted communication in consultations to be directed towards them rather than their parents (Carroll and Marrero, 2006a). Teenagers did not completely trust the care plans issued to them by health professionals and wanted more input into their care decisions (Davidson et al, 2004). Clinic attendance tended to decline as adolescents got older and transition to adult services occurred. Efforts to engage adolescents at transition age should be made to prevent them losing contact (Olsen and Sutton, 1997).

Education

The recent Diabetes UK *Silent Assassin* campaign aims to raise awareness of complications and promote structured education for people with T1D (Diabetes UK, 2008c). As I mentioned in Chapter 1, structured education is an integral part of diabetes care for young people and their families. Group education was beneficial for adolescents in the systematic review, as it facilitated a support network. Adolescents disliked *'refresher sessions'* which covered the basics of diabetes management, as they did not learn anything *'new'*. They preferred education away from the hospital, presented in a simple manner without the pressure of tests and assessments, and enjoyed the incorporation of *'fun'* activities. Parents felt that practical exercises rather than didactic teaching were beneficial for adolescent learning and that the use of technology would encourage participation (Waller et al, 2005).

2.20 Diabetes care in schools

Self-management in school

There are at least 15 361 children (age five to fifteen) in schools in England with diabetes (Royal College of Paediatrics and Child Health, 2009), therefore care provision in schools is fundamental to self-management. Young people with T1D have to contend with diabetes management during school hours. For those on twice-daily regimes, this involves taking a carbohydrate snack mid-morning and eating a calorie-controlled lunch at a specific time so as to correspond with the time-action profile of the insulin dose, and testing blood glucose if necessary. For those using basal bolus regimes this should involve calculating carbohydrates, administering insulin injections and testing blood glucose.

The Schools (Health Support) Bill (2009) has recognised that many children suffer during school because they are not receiving adequate support for their health condition, underpinned by insufficient training of school staff. This leads to inequalities in education and could impact on a child's progress in later life. A recent Diabetes UK (2008d) report found that where schools are able to accommodate the specific needs of children with health conditions, this occurs in collaboration with the Primary Care Trust and Local Authority who provide training, resources to schools such as school nurses and community children's nurses, and appropriate indemnity insurance. However, there is no official policy and guidance to oversee this in all schools, meaning that many young people do not receive adequate care. Based on this, the *Schools (Health Support) Bill* (2009) aims to produce and implement medical conditions policies in line with current guidance and best practice. School staff are to receive appropriate support and training. NHS bodies, local authorities, primary care trusts (PCT's) and school inspections are to oversee the process, to ensure that schools fulfill their responsibilities.

School rules and restrictions, such as healthy food choices not being available can make diabetes management in school difficult. In the systematic review, I found that food choices conducive to 'healthy' diabetes management were poor in school canteens and adolescents sometimes struggled to meet school rules, which were insensitive to their needs (Hayes-Bohn et al, 2004). In other studies, families in the UK have described problems with the timing and content of meals in schools (Kauffman et al, 1990). In the USA, a study of parents' views found that most children were not allowed to check blood glucose levels or administer insulin during class (Jacquez et al, 2008). Another study of 69 young people with asthma and diabetes and their parents, found that the structure of the school day led to difficulties in maintaining their diabetes regimen. Participating in sport and school trips was challenging, but adolescents found strategies which enabled them to take part despite their medication regimes being restrictive and making them feel 'different' from their peers (Newbould et al, 2007).

Another finding from my systematic review synthesis, was that a lack of understanding about T1D from teachers in school was common. Adolescents were often questioned by teachers when blood testing and eating (Waller et al, 2005; Dickinson and O'Reilly, 2004; Hayes-Bohn et al, 2004). It is important for adolescents with T1D to feel supported in their school environment, as lower HbA_{1c} levels have been found to be related to greater satisfaction with school support in children aged nine to fourteen with diabetes (Lehmkuhl and Nabors, 2008). However, research with adolescents (Hayes-Bohn et al, 2004), teachers (Warne, 1988; Bradbury et al, 1983) and parents (Tatman and Lessing, 1993; Lessing et al, 1992) has shown that teachers have limited knowledge of diabetes. Parents have shown concern about awareness of their child's condition at school and the support available to them in a crisis (Newbould et al, 2007). In the UK, research has shown that parents were dissatisfied with the care of their child's diabetes at school. They were more satisfied if liaison with the school came from a paediatric diabetes service rather than an adult one (Tatman and Lessing, 1993). Children with various chronic illnesses valued teachers who were aware of their health condition, understood the impact it had on their school work and behaviour and made special arrangements for the child without 'making a fuss' (Lightfoot et al, 1999). A recent qualitative study of 20 parents of children and young people with T1D in the UK concluded that diabetes care plans should be provided for every child with T1D, along with guidance and training for blood glucose testing in schools (Wilson and Beskine, 2007).

Educational attainment

Evidence suggests that children with T1D could be at an educational disadvantage as a result of poor health, blood glucose fluctuations and resulting possible cognitive impairment and absence due to clinic appointments and diabetes-related illness (Aspey, 2001). A Swedish study of sixteen year olds' school attainment records found that those with diabetes attained slightly lower marks than those without (Dahlquist and Kallen, 2007). A Canadian study found that children with diabetes missed on average one more week of school than their siblings without the disease (Vetiska et al, 2000). Despite this international evidence, a systematic review of UK research found that many children with diabetes (in particular late-onset) perform equally well at school as their non-diabetic peers, despite increased rates of absence. This suggests that T1D does not affect educational attainment, although diabetes diagnosed in childhood does appear to disadvantage adult employment prospects (Milton et al, 2006).

2.21 Summary

The findings of a systematic review of qualitative studies of T1D in adolescence underpinned the structure of this literature review, which aimed to explore the psychosocial factors underpinning the self-management of T1D in adolescence, and identify areas for future research. The literature within the four sets is summarised as follows:

Set 1: Independence and autonomy

Autonomy in adolescence is characterised by a gradual move away from parental control towards becoming a responsible adult. For adolescents with T1D, autonomy also refers to their ability to take responsibility for the self-management of their disease. Autonomy for diabetes management is a complex process influenced by many psychosocial factors including psychological and emotional maturity, parental input; peer and health professional support and facilitation; experiential learning; personal models of illness; and miscarried helping by parents.

Increased autonomy relieves the burden of responsibility for parents and improves confidence and knowledge for adolescents, although the process also causes anxiety for parents and adolescents, as they adjust to decreased/increased responsibility. Sharing responsibility for diabetes management between parent and child is conducive to autonomy development and facilitates a healthy relationship between parents and adolescents.

Set 2: Living with T1D

From a sociological perspective, chronic illness is socially constructed and shaped by the social, cultural and ideological context of a person's biography. The diagnosis of chronic illness is a disruptive life event requiring ongoing transformational adaptation for adolescents and parents and therefore may have a profound impact on the developmental life-stage of adolescence. Living with T1D in adolescence involves conflict resolution on a daily basis with regard to decision making and emotions and may have a negative impact on quality of life and psychological well-being, leading to poor control. Successful self-management of T1D is related to knowledge and experience, adherence, exercise and parental support. Fitting in with the adolescent culture is a priority, and not taking care of diabetes may enable some adolescents to do this more adequately.

Set 3: Family relationships

Family adaptation to chronic illness is underpinned by experiential learning and adaptation in order to 'normalise' the illness within the family. Parenting style has an effect on diabetes management during adolescence. Adolescent-parent conflict is common resulting from unwanted parental input underpinned by parental anxiety for their child's future health. Parental grief for a child's diagnosis may never be fully resolved and single parents may experience higher levels of parenting stress due to a lack of partner support and difficulty negotiating care of their child as a priority.

Set 4: Diabetes care

Current UK policy aims to provide a family-centred care approach to paediatric diabetes services, underpinned by empowerment and personal control. Adolescents value individualised care and involvement in care planning. Group education incorporating activities is an effective way for adolescents to learn. Clinic attendance declines with increasing age and transition services are important to avoid losing contact. Adolescents with chronic illness are currently not receiving adequate support in school. This is important, as lower HbA_{1c} levels are related to greater satisfaction with school support. Teachers have limited knowledge of diabetes and many parents are dissatisfied with their child's care at school.

2.22 Conclusion

In this chapter, I aimed to explore the psychosocial factors underpinning the self-management of T1D in adolescence. I presented four thematic sets emerging from the systematic review in discussion with the wider psychosocial literature. This has provided a synthesis of current qualitative research on T1D in adolescence within a wider psychosocial context, thus presenting a holistic perspective of the experience of living with T1D during this life stage. In light of previous systematic reviews which found that continuous subcutaneous glucose monitoring is no more effective than finger-stick testing (Chetty et al, 2008; Gollicki et al, 2008), the findings of my review suggest that social relationships are a key factor in the management of T1D. Adolescents face juggling the different demands of their diabetes within the social spheres of the family, school, peers and clinic, alongside conflicting evidence surrounding the impact of T1D on psychosocial development during adolescence (Pacaud et al, 2007; Seiffge-Krenke, 1998). Teenagers' abilities to be independent in diabetes management are embedded within relationships with parents, peers, health professionals and teachers. This highlights a need to explore the lived experiences of adolescents with T1D and their parents.

Viewing the findings of my systematic review within the context of wider psychosocial literature has demonstrated that there are a range of multi-disciplinary theoretical approaches to understanding T1D management in adolescence, including biographical disruption, personal models, chronic sorrow and psychological distress. This is problematic for both academics and health professionals in understanding the nature of blood glucose control during this life stage, as they are overwhelmed with different theoretical approaches, making synthesis difficult. Therefore, there is a need for a theoretical approach which can embrace these varied theories and provide synthesis and direction for care.

The quality appraisal that I conducted as part of the systematic review (see supporting paper) highlighted the need for qualitative research in the UK and other settings, using rigorous qualitative research methodologies underpinned by epistemological tradition and novel theoretical frameworks, researcher reflexivity, triangulation of methods and member checking of interpretations. There is also a need to explore parents' as well as adolescents' perspectives, highlighted by the significance of family relationships in the findings of my review.

In Chapter 3, I introduce complexity science as a theoretical paradigm for the study of T1D management. I believe this has the potential to embrace the multi-theoretical nature of adolescent T1D management. Interpretive phenomenology is also introduced as an underpinning epistemological framework for exploring the lived experiences of adolescents with T1D, to ensure high quality and rigour in this study.

Chapter 3: Theory and Epistemology

Introduction

In Chapter 2, I defined a need for a theoretical paradigm which has the potential to embrace the multi-theoretical nature of adolescent T1D management, and rigorous qualitative research exploring the lived experiences of adolescents with T1D in the UK, grounded in epistemological tradition. In this chapter, I present the theoretical and epistemological basis for the study, to address these objectives.

In Section 1, I introduce and rationalise complexity science as a theoretical framework for the management of T1D. I present Cooper and Geyer's (2007) recent application of complexity science to diabetes management as a critique of the current reductionist, biomedical approach to diabetes care. This section also emphasises the need to acknowledge the many interacting factors that can impact on blood glucose control in the adolescent age group. I discuss the metaphorical nature and limitations of complexity science as a research methodology, and underline the need for an epistemological approach. In Section 2, I introduce interpretive phenomenology as an underpinning epistemological framework to explore the complexity of adolescent diabetes, through the study of the lived experiences of adolescents with T1D.

Section 1: Complexity science

3.1 Background

From the seventeenth to the nineteenth century, natural science was based on the principles of order, reductionism, predictability, determinism and linearity. These principles defined the creation of knowledge, i.e. if a result could be replicated and therefore predicted correctly, this was interpreted as truth. 'Cartesan dualism' (seeing the body as a mechanical entity of two parts: body and soul), Newtonian science, and the success of the industrial revolution in the eighteenth and nineteenth centuries were underpinned by this ordered vision of reality (Cooper and Geyer, 2007). This created a relatively simplistic approach to knowledge creation, in which there was an 'end-point' to understanding the world. This approach is embraced today within the quantitative research paradigm. Large samples and statistical tests aim to reduce phenomena in order to prove theories and predict outcomes. It assumes that replication of results leads to the validation of knowledge.

Scientific discoveries in the nineteenth and twentieth centuries by Einstein (1879-1955), Schrodinger (1887-1961) and Heisenberg (1901-1976) revealed that not all scientific phenomena behaved in such a predictable manner. Immanual Kant proposed that natural science could only offer mechanical explanations which were clearly inadequate in the study of organisms (Sweeney, 2004a). Non-linear systems such as weather patterns and fluid dynamics did not obey the simple rules of a reductionist approach, but produced complex and unexpected results (Cooper and Geyer, 2007).

Human science approaches also argued that human beings could not be easily quantified or 'reduced' into predictable explanations (Fjelland and Gjengedal, 2004), and the qualitative research paradigm emerged. Qualitative research does not believe in reducing phenomena into a predictable form, rather it aims to inductively explore the varied and individual experiences of participants. This recognition that knowledge does not always equal order, lead to greater prediction and control, or have an 'end point' also symbolised the emergence of complexity thinking.

Table 3.1 demonstrates the differences between the natural science and complexity science approaches to the concepts of order, reductionism, predictability and determinism. It highlights the move away from a purely linear approach, where an end point can be reached when the components making up a phenomena are 'known'. Complexity science embraces uncertainty, as it recognises that the relationships between the components of a phenomena can often not be predicted, meaning that outcomes are ambiguous.

Table 3.1: The characteristics of scientific phenomena: natural science vs complexity science

Concept	Natural Science Perspective	Complexity Science Perspective
Order	Causes always lead to known effects	Phenomena can exhibit both orderly and chaotic behaviours
Reductionism	The behaviour of a system can be understood by observing the behaviour of its parts	Not all phenomena are reducible to the behaviour of their parts
Predictability	Once the system is understood, the future course of events can be predicted	Phenomena can only be partially modeled, predicted and controlled
Determinism	Processes have clear beginnings and rational ends	The exact outcome of events is uncertain

3.2 A science of complexity

There is no single unified 'theory' of complexity, but several theories which have arisen through the study of complex systems in various natural science domains, including biology, chemistry, computer simulation, evolution, mathematics, physics (Mitleton-Kelly, 2003) nonlinear dynamics, systems theory and statistical mechanics (Heylighen et al, 2007). Complexity science is viewed as a useful tool for social science research (Matthews et al, 1999), however it utilises methods, models and metaphors from a variety of disciplines (Heylighen, 2007) and speculates about how these perspectives apply to society (Stewart, 2001), rather than applying empirical methods.

By definition, complexity science is the study of *complex systems*. It focuses on phenomena that are characterised neither by order or disorder, but sit somewhere in between. The global behaviour of a complex system is hard to predict but is also not completely random (Heylighen et al, 2007). Complexity science challenges the assumptions of natural science in recognising that many phenomena are directed by non-linear interactions that cannot always be understood by breaking systems down into their constituent elements and applying analytical rules (Kernick, 2002). In 1961, Edward Lorenz discovered that small discrepancies within the weather system experienced feedback and reinforced themselves in divergent ways, leading to unpredictable outcomes. This was a defining concept in the development of complexity science, named the 'butterfly effect': small movements by a butterfly in China could lead to a tornado in the USA given particular circumstances (Cooper and Geyer, 2007).

3.3 The simple, complicated and the complex

It is essential to define the difference between 'simple', 'complicated' and 'complex' systems. Simple problems require a form of mastery, but once the 'recipe' for success is understood, repeating the recipe will have a high success rate. An example of this might be developing a formula to solve a difficult algebraic equation. Complicated problems are made up of subsets of simple problems. Although solutions are generalisable, they are not purely reducible to the sum of the system's parts. For example, surgical procedures are related to the scale of the problem and also the expertise of the surgeon. Complex systems can encompass both simple and complex problems, but are not reducible to either. The local conditions, interactions between elements and historical background produce unpredictable outcomes. For example, although a company manager has knowledge of how to manage a team successfully, the historical context of the team members and their relationships with each other will affect the outcomes of the team. It is therefore the notion of unpredictability which sets complex systems apart from simple and complicated systems. Understanding complex systems retrospectively has the potential to inform ways in which to improve the performance of the system in the future (Martin, 2007).

3.4 Defining complex systems

Complexity exists in both physical and biological phenomena. Physical complexity refers to the complex systems of for example, gravity, fluid dynamics and weather patterns and biological complexity is inherent in plant and animal interaction and evolution (Cooper and Geyer, 2007). Complex systems exist all around us, from weather patterns, to biochemical reactions, ant colonies, human beings, the NHS, and the family. All complex systems share the same fundamental characteristics (adapted from Cooper and Geyer, 2007; Cilliers, 2005; Kernick, 2004):

- There are a large number of elements which **interact**
- There are **feedback loops** between elements which affect the behaviour of elements
- Interaction is **on-going** and **never static**
- They **share an environment** with and interact with other complex systems
- The **past influences present** behaviour
- The system **cannot be reduced** to the sum of its parts
- Outcomes **cannot be predicted**
- Behaviour **emerges** from interaction rather than external or internal control or characteristics inherent in the elements themselves.

Mitleton-Kelly (2003) provides a succinct summary of the principles of complex systems. They are compiled from a review of the work of key complexity thinkers over the past 25 years, merging the disciplines of complex adaptive systems (Santa Fe Institute (USA) and Europe); dissipative structures (Ilya Prigogine and co-authors); biology and autopoiesis (Maturana and Varela; Kauffman); chaos theory (Gleik) and economics (Arthur). They were developed for use in human organisational research, giving them particular relevance to human behaviour. I have organised Miltleton-Kelly's (2003) principles into three fundamental actions. These summarise the behaviour of complex systems, based on the following presumptions:

(i) There are three **fundamental characteristics** of complex systems (connectivity, feedback, and historicity), which are the essential components to facilitate the healthy growth, change and adaptation of the system. These principles describe the natural relationships which occur between the elements within the system.

(ii) As a result of these interactions as well as external influences, the system is pushed to a **critical point** (far-from-equilibrium) at which either new order is created or disorder occurs, and the path taken is established through the exploration of the space of possibilities and in the influence of positive feedback. Action must occur as a result of the system being far-from-equilibrium in order for the system to adapt and survive

(iii) Exploring the space of possibilities leads to **adaptation** of the system, in the form of emergence, self-organisation and co-evolution.

This three-step, ongoing process is demonstrated in Figure 3.1. As follows, I describe each principle as outlined by Miltleton-Kelly (2003), with reference to the theoretical development of each principle and its contribution to the healthy functioning of complex systems. This description demonstrates the formulation of complexity thinking from a number of theoretical disciplines, and its application to varied phenomena. It also demonstrates the interdependent nature of the interactions between principles in the ongoing functioning of a complex system, which is also conceptualised in Figure 3.1.

(i) Fundamental characteristics

Connectivity

Connectivity refers to the relationships between elements within a complex system and between the system and its environment. The theoretical origins of this principle derive from systems theory (Santa Fe Institute (USA) and Europe) as well as theories of biological co-evolution, in which the fitness of an organism/species depends on the characteristics of the other organisms/species it interacts with (Kauffman, 1993). All action by elements within the system have consequences for the rest of the system and other systems within the environment. One element trying to improve its fitness or position may result in a worsening of conditions for others. The extent to which the fitness of one agent depends on another agent is termed 'degrees of connectivity'. For example, a small change in one part of the system can have a massive effect elsewhere.

Historicity

Historicity refers to the fact that within a complex system, decisions about current actions are based on past experience. This is particularly relevant to looking at human behaviour as a complex system, as all human beings exist within a history. The principle of historicity originates from theories of dissipative structures; that paths taken at a critical point contribute to the future evolution of systems (Nicolis and Prigogine, 1989). Events are irreversible and inevitably affect the future evolution of the system and thus the form and direction of events depends on the sequence of previous events.

Feedback

The principle of feedback refers to reiterative feedback loops which exist within interactions between agents in a system. Historicity is a type of feedback, in that the effects of the agent's actions affect the way that the agent behaves in the future. Feedback changes potential action or behaviour of a system and it is not predictable. The degree of connectivity between different individuals, time and context will influence feedback, actions and behaviour.

(ii) Actions at a critical point

Far-from-equilibrium

Far from equilibrium' or 'edge of chaos' states occur when a system is pushed far from its established norms by external events. It reaches a critical point where it will either degrade into disorder, or create some new order and organisation. Positive feedback processes underlie such transformation. The Benard cell is an example of a physico-chemical dissipative structure which demonstrates the process of far-from-equilibrium. It is made up of two pararellel plates and a horizontal layer of liquid. When the temperature of the liquid is the same as the environment, the cell is at equilibrium (a homogenous state in which all parts are equal). When heat is applied to the bottom of the plate (an external constraint), the temperature is greater at the bottom of the wafer surface than at the top and at a critical point the fluid becomes unstable, entering a state of far-from-equilibrium (Nicolis and Prigogine, 1989). Being pushed far-from-equilibrium is healthy behaviour in a complex system, as it facilitates evolution and adaptation, leading to better ways of working.

Explore the space of possibilities

When a social entity is pushed far-from-equilibrium, it is forced to experiment and explore the 'space of possibilities', in order to discover and create new ways of working. This concept derives from theories of biological co-evolution. In an appropriate environment, novel functions of organisms are created due to selective significance of options during the natural selection process (Kauffman, 2000). Exploring the space of possibilities, before selecting a chosen path generates healthy variety within the system. The optimum strategy chosen is context dependent, therefore in order to survive, a system must constantly explore the range of possibilities available.

Positive feedback

Positive feedback processes underlie the creation of new order, as defined by Prigogine and Strengers (1985). In far-from-equilibrium conditions, positive reinforcing feedback underlies the creation of new order; whereas negative feedback maintains stability.

(iii) Adaptation

Emergence

The ultimate goal of a complex system is the creation of new order, which occurs through exploring the space of possibilities. Innovation takes place at a critical point where the existing order can no longer be sustained. The emergence of new states in relation to stressors is fundamental to the healthy adaptation of a complex system.

Self-organisation

Self-organisation refers to the spontaneous coming together of the parts of a system. When change is introduced from the outside, the system self-organises to adapt to the new environment. This concept emerged from theories of biological evolution, which state that natural selection is not the sole source of order in organisms. There is also spontaneous order which occurs in response to far-from-equilibrium states (Kauffman, 1993). Elements may not necessarily self-organise to the benefit of the system as a whole.

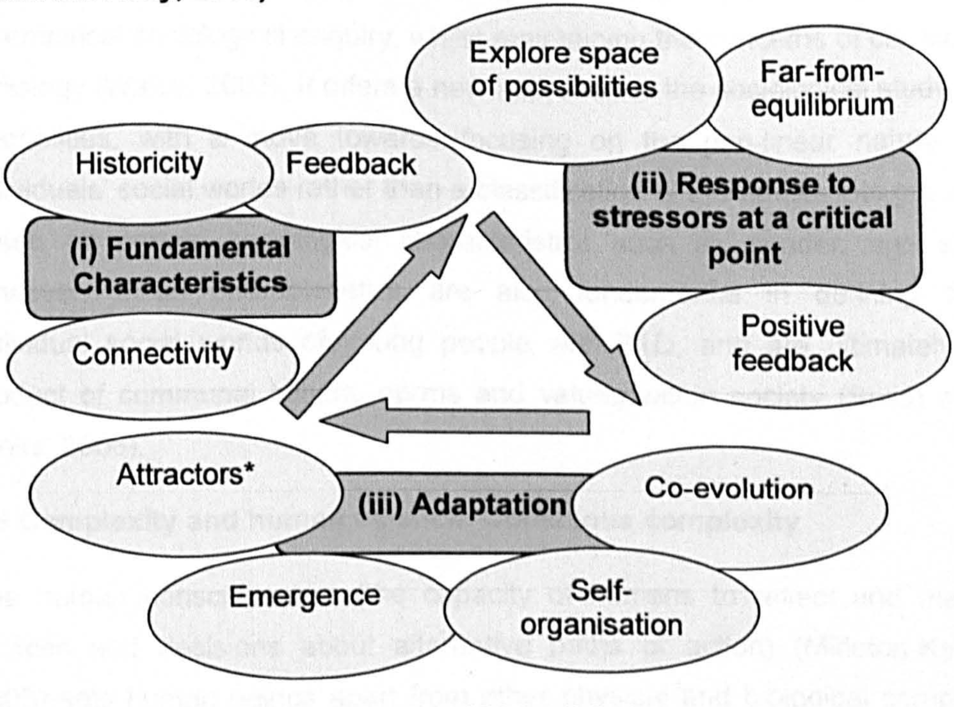
Attractors

Attractors are sets of patterns that hold the system together and prevent it from falling into total disorder (Luhman and Boje, 2001). Thus, emergence does not always occur as the result of a stressor. Attractors can prevent emergence, and revert the system to an old, more 'comfortable' state in order to avoid chaos.

Co-evolution

Complex systems exist within a universe of other complex systems and change in one complex system affects the landscape for others. The evolution of one complex system is therefore partially dependent on the evolution of other related complex systems, termed co-evolution. This is apparent in theories of biological co-evolution, where the evolution of one biological entity is partially dependent on the evolution of other related entities. Co-evolving complex systems can be individuals, teams, families, organisations and economies. Co-evolution is ultimately dependent on the degree of connectivity between the elements within the system.

Figure 3.1: The behaviour of complex systems (adapted from Mitleton-Kelly, 2003)



* This principle is not acknowledged by Mitleton-Kelly, but was adapted from the work of Luhman and Boje (2001) and Sotolongo (2002).

3.5 Complexity and sociological theory

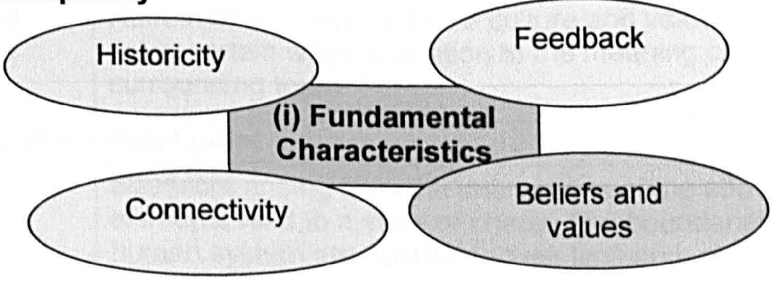
Complexity science constitutes a challenge to traditional sociological theory, offering new perspectives on social change and inequalities. Sociology has traditionally been concerned with breaking down society into systems and models in order to understand human behaviour. Relationships between systems and their environments are re-evaluated from a complexity science approach. With resonance to a postmodernist viewpoint, it rejects the causal relationships within systems embraced in the modernist era (Walby, 2007); instead it embraces order and disorder within social systems (Urry, 2005).

Complexity science advocates the merging of different theoretical disciplines. It combines an understanding of both the individual and the social structure and embraces the self-reflexivity of the human subject, whilst theorising with reference to the social totality. Complexity science therefore has implications for empirical sociological enquiry, whilst maintaining the concerns of classical sociology (Walby, 2003). It offers a new approach to the sociological study of inequalities, with a move towards focusing on the non-linear nature of individuals' social worlds rather than a classification of individuals into groups based on certain sociological characteristics such as gender, age etc. However, these characteristics are also fundamental in defining the individual social worlds of young people with T1D, and are ultimately a product of communal beliefs, norms and values within society (Smith and Jenks, 2006).

3.6 Complexity and human science: Conscious complexity

The human consciousness (the capacity of humans to reflect and make choices and decisions about alternative paths of action) (Mitleton-Kelly, 2003) sets human beings apart from other physical and biological complex systems. The individuality of the consciousness and capacity for interpretation, makes human behaviour unpredictable. The interpretive nature of human beings allows them to be self-aware, understand the components of their complex system and make choices and decisions based on past experiences, culture, knowledge and relationships with others (Cooper and Geyer, 2007). Thus, when applying complexity to human behaviour, a new element *'Beliefs and values'* is introduced to the fundamental characteristics of complex systems, shown in Figure 3.2. This recognises that all human beings exist within a context, in which things have meaning, and cultural and personal beliefs and interpretations underlie all human behaviour. Human beings act because something is *meaningful* to them, which adds a fundamental aspect to the study of human complex systems.

Figure 3.2: The added dimension of 'beliefs and values' in conscious (human) complexity



When a human being is conceptualised as a complex system, human action is affected in the ways shown in Table 3.2.

3.7 Complexity, human science and health

Table 3.2 demonstrates that human action can be metaphorically explained as a complex system. The applicability of complexity science to the nature of human behaviour has led to its wide application within the humanities disciplines, particularly in the exploration of family systems (Granic and Patterson, 2006) and the health care and management literature (eg. Steinberg, 2005; Kernick, 2004; Sweeney, 2004; Battram, 2002; Lissack, 2002; Stacey, 2000, 1996). Humans are complex systems because interactions between elements within a human system are affected by multiple factors existing in their immediate and more distant environment. This produces unpredictable and individualised outcomes (Heylighen et al, 2007).

Table 3.2: The principles of complexity and their affect on human action

Characteristic of complex systems	Influence on human action
(i) Fundamental characteristics	
Connectivity	There are many biological, social and psychological elements in a person's complex system which affect actions, including relationships, environments, bodily functions, activities
Historicity	Human beings act on the basis of their past experiences, and future orientations
Feedback	Positive and negative feedback about actions taken, from elements in the system will affect future actions
Beliefs and values	Human beings exist within a culture and value system and act in certain ways in relation to the meaning of the objects surrounding them
(ii) Actions at a critical point	
Far-from-equilibrium	Stressors arising from the interactions of the above four elements lead to a state of chaos. The boundaries of the human system are pushed to their limit and change is needed for the system to survive
Explore the space of possibilities	Humans explore many possibilities of actions before deciding on one course of action. The decision will be influenced by the four fundamental characteristics.
Positive feedback	In particular, positive feedback about the successful outcome of an action will influence the decision to take that action
(iii) Adaptation	
Emergence	In response to far-from-equilibrium, a new state, or way of being emerges, which becomes part of the human system's history and affects future actions
Self-organisation	The emergence of the new way of being is a spontaneous, unpredictable occurrence based on the outcome of actions at a critical point
Attractors	Emergence of new ways of being can sometimes be prevented, if the actor reverts to previous ways of working in order to avoid chaos. Social expectations and norms may serve as limits preventing certain 'socially undesirable' behaviours (Sotolongo, 2002)
Co-evolution	The evolution of a human system occurs in relation to other human systems in the surrounding environment (ecosystem). A human ecosystem includes the social, cultural, technical, geographic and economic dimensions.

Within the organisational science community, complexity has been seen as a route to a possible theory of organisation and also as a powerful metaphorical lens through which to view organisations. The non-linearity of healthcare and healthcare systems has been recognised by a number of authors (e.g. Steinberg, 2005; Sweeney, 2004; Kernick, 2002). Health care systems are complex because they are composed of individuals, patients and clinicians who have the capacity to learn and change as a result of their experience. Their actions are not always predictable, and tend to change both their local and larger environments (Harris et al, 1999).

Complexity science suggests that the current biomedical model, based on scientific positivism and reductionism, is not a sufficient method alone to enable health professionals to support patients in today's society. It advocates the need for a broader approach, which addresses and incorporates unpredictability and non-linearity (Sweeney and Griffiths, 2002), drawing parallels with the biopsychosocial model of health, which takes into account a range of factors including the patient's lifestyle, socio-economic factors, the external environment and health beliefs and attitudes (Bogg and Geyer, 2007). The emphasis moves away from prediction and control, towards understanding the relationships of the system's components, and the creation of patterns of order between them (Kernick, 2002).

3.8 Complexity and diabetes management

Traditional diabetes care is based on a biomedical model (reductionist) approach in a secondary care setting (Cooper and Geyer, 2007). As I described in Chapter 1, the management of T1D involves four main 'biomedical' components (insulin administration, blood glucose monitoring physical activity and diet). Treatment is based on linear, predictable relationships between these components of diabetes management to produce the outcome of blood glucose control.

Research has advocated the need for a non-linear approach to blood glucose management in T1D (Holt, 2002; Kroll, 1999), recognising that although biological reactions to blood glucose are largely predictable, they are also individualised and largely unpredictable. The biomedical model does not take this into account, as well as the influence of biopsychosocial factors and the individuality and unpredictability of life events which can impact on blood glucose control.

Cooper and Geyer (2007) present a critique of the biomedical model of diabetes care, and provide an alternative view from a complexity science perspective. Table 3.3 compares the medical model assumptions of diabetes management to the complexity model assumptions. This view is more applicable to the nature of living with T1D, as it takes unpredictability into account and demonstrates the constraints that the medical model perspective can place on its management. It focuses on the ongoing journey of T1D, the continuous learning it entails and focuses on the person with T1D as an expert of their disease, embracing an 'empowerment' rather than a 'top down' approach to education and care.

3.9 Fitness landscapes

Cooper and Geyer (2007) use the concept of fitness landscapes to describe living with diabetes as a 'journey of highs and lows'. The concept was introduced by Wright in 1931 (Kernick, 2004) and was originally used by complexity scientists to model chemical and species interactions (Gell-Mann, 1994). Fitness landscapes are three-dimensional diagrams where raised areas represent areas of the system's high fitness, dropped areas represent areas of poor fitness and flatlands represent areas of neutral fitness (Cooper and Geyer, 2007). The aim of the evolution of a system is to move out of the valleys to a higher peak (Kernick, 2004). In relation to diabetes, the raised areas represent zones of good control, the dropped areas poor control and the flatlands uneven areas of control. The primary tactics of people with diabetes working through their fitness landscape are adaptability, flexibility, learning and balance (Cooper and Geyer, 2009). This on-going process of continual learning and adaptation is represented by the illustration in Figure 3.3.

Table 3.3: The medical model vs complexity model of diabetes management (adapted from Cooper and Geyer, 2007)

Orderly Perspective (Medical Model)	Complexity Science Perspective
Causality Managed diet, activity levels and insulin usage lead to good blood glucose control	**Partial causality** Basic management is important, but *more* does not lead to greater control
Reductionism Different aspects of diabetes management (eg. diet, exercise, drug treatment) can be separated and addressed individually	**Reductionism and holism** Different aspects of diabetes management (eg. diet, temperature, activity, mood etc.) all **interact** to influence blood glucose levels
Predictability More management → greater control → improved health	**Predictability and uncertainty** Fundamental strategies do matter (eg. healthy diet), but minor actions such as changing an injection site can have an impact on outcome
Determinism More management → greater control → improved health LONG TERM	**Probabilistic** The long-term impact of strategies is unknown, plus it is impossible to predict future life events that may affect blood glucose
No equivalent	**Emergence** Life changes (eg. puberty, pregnancy, menopause) require different management strategies
No equivalent	**Interpretation** Individual and public opinion shape diabetes management

Figure 3.3: The fitness landscape of living with T1D

(Illustration: Cooper and Geyer, 2007.)

3.10 Implications for diabetes research

Complexity science recognises that human illness and behaviour are unpredictable and that neither can be modelled in a simple cause and effect system. Random effects of life along with the patient's ability to self-manage their diabetes are recognised as key influences on blood glucose control. Complex systems cannot thrive when there is too much central control (i.e. from health professionals). Control should be distributed throughout the system, recognising the integral role the patient plays in the effectiveness of care decisions (Cilliers, 2000). Taking a complexity science approach to diabetes care encourages practitioners to focus on the individual rather than the disease and embraces the ongoing nature of learning to live with diabetes. When viewing diabetes in this manner, the assumptions about its management change. The focus moves to creating adaptive and evolving responses to diabetes rather than responses which give an ultimate 'end result'. Complexity embraces patient education through experience and self-expertise, and mistakes are expected within the normal learning process (Cooper and Geyer, 2007).

Complexity science promotes the use of qualitative and quantitative enquiry, to explore and uncover the complex, non-linear world of adolescent diabetes. It advocates the need to focus on emergence and interpretation in research rather than prediction and control, and advocates the use of contrasting qualitative and quantitative mixed methods in order to illuminate the complex nature of phenomena. It also embraces the ongoing nature of the creation of knowledge. Quantitative methods are needed to investigate the linear aspects of social phenomena through approaches such as predictive statistical and ideal type modeling, whilst qualitative approaches such as constructivist methods and historical narratives enable the investigation of the more alinear aspects of social phenomena (Cooper et al, 2004). Qualitative methods embrace the ability of the human consciousness to place interpretation on experience, and thus influence future behaviour and actions.

As a starting point for research with adolescents, complexity builds on the conclusions of the literature review in recognising that diabetes is not a singular entity with a simple cause and effect model for treatment, but rather is linked to and affected by many other elements in a young person's social world. Thus, the study of conscious complexity has the potential to uncover the potential influences on blood glucose control, through a qualitative approach (Cooper and Geyer, 2007).

3.11 Complexity science: an epistemological problem

A sociologist's philosophical presuppositions (both conscious and unconscious) influence the way he or she defines and limits their perspective (Kienzle, 1970). Epistemology refers to the nature, sources and limits of knowledge, i.e. *how* things come to be true (Klein, 2005). The definition of a social problem and the methodology used to study it involve philosophical assumptions about how knowledge is created (Kienzle, 1970). Epistemology thus underpins a researcher's orientation to the phenomenon they are studying, and allows them to shape their definitions of social phenomena (Klein, 2005).

Conducting qualitative research grounded in epistemological tradition is essential to give validity and trustworthiness to research findings and conclusions. Transparency is essential in qualitative research, so that the reader can make a judgment regarding the validity of the findings, based on sufficient knowledge of the assumptions of the researcher and the methods used. Transparency of method should allow other researchers to conduct a similar study using the same methods.

Although complexity science is viewed as a useful tool for social science research (Matthews et al, 1999), critics have described it as little more than an amalgam of methods, models and metaphors from a variety of disciplines rather than an integrated science. The complexity paradigm is in need of assimilation and validation by academic philosophy (Heylieghen, 2007). Popular and reputable scientists' accounts of complexity often provide speculative models of how complexity perspectives *might* apply to society (Stewart, 2001). Although metaphors and analogies may facilitate transitional thinking when faced with new ideas and concepts, it does not enable an understanding of the fundamental nature of a particular system under study (Mitleton-Kelly, 2003). There is no evidence that complexity science has validity in explaining or describing empirical observation and there is a need for substantive reasoning and evidence for such claims (Fuller and Moran, 2000). Allowing metaphors to dominate a field of study holds the risk of lowering the credibility of the field in mainstream science and hinders the resources for future development (Phelan, 2001).

The complexity of adolescent T1D management could be studied by taking the principles of complex systems as underpinning methodology. If the principles of complex systems and their relationship to diabetes management were taken as validated, semi-structured interviews could be constructed to enquire about the different elements of the adolescent complex system, i.e. connectivity, feedback, exploration of the space of possibilities. However, in relation to diabetes management, complexity science currently provides a set of presuppositions rather than a distinct epistemology for exploring the phenomena (Luhman and Boje, 2001). It provides a logical starting point in that it addresses the complex issue of the many interacting factors affecting blood glucose control. However, it is yet to be integrated (i) as a basis for empirical qualitative research (Kovandzic and Cooper, 2009) and (ii) for the study of diabetes in this age group. Therefore, applying complexity science as a methodology would be naïve as it would assume the validity of the approach in the study of adolescent diabetes. Empirical evidence is therefore necessary in order to validate the application of complexity science to T1D management, if it is to develop beyond its current position as a metaphorical tool. In Section 2 I discuss the application of interpretive phenomenology as an epistemology which will allow access to conscious complexity, through the exploration of lived experiences.

Section 2: Interpretive phenomenology

3.12 Background

In Section 1, I described how conscious complexity sets humans apart from other complex systems, and is defined by humans' ability to interpret experiences and shape future behaviour. Complexity is therefore situated within the arena of interpretation. As an epistemology, interpretive phenomenology developed through influence from the phenomenological and hermeneutic traditions, and is underpinned by the belief that all human knowledge is created through a process of interpretation.

Phenomenology is the study of lived experiences (the lifeworld); the taken-for granted experience of objects by the consciousness (Russell, 2006). As an epistemological discipline, phenomenology is rooted in a critique of scientific reductionism. Social reality is not conceived as a fixed and objective external reality. Rather, individuals attribute meaning to objects and experiences through the experience of their individual lifeworlds (Overgaard and Zahavi, 2009). In the early days of phenomenological thought, William Dilthey strove to explain knowledge as an interrelationship between experience, expression and understanding (Rapport, 2005) in contrast to scientific reductionism (Fjelland and Gjengedal, 2004). Phenomenologists do not reject natural science, but rather see science as something that people 'do' to make theoretical sense, or bring meaning to the world, rather than it being the 'sole judge' of what is real and what is not (Overgaard and Zahavi, 2009).

Social reality therefore, is a product of human activity, i.e. it is socially constructed. Phenomenology differs from the social constructionist view of reality, by seeing it is an individually constructed entity rather than a product of the relations between individual subjects (intersubjectivity). However, although the phenomenological lifeworld relates to the *individual's* experience, it is also *dependent on intersubjectivity* – the world experience of other subjects surrounding the individual (Overgaard and Zahavi, 2009). In this sense, phenomenology sits within sociological thought, as it explores the individual meanings that constitute the collective, intersubjective actions which underlie the functioning of society as a whole. Without intersubjectivity, there is no lifeworld and no social reality (Overgaard and Zahavi, 2009).

3.13 Descriptive phenomenology

Phenomenological research is based on the premise that a person cannot observe their own lived experience, because their lifeworld is 'taken for granted'. It is only to a stranger (the researcher) who observes another's lifeworld, that the practices of their everyday life become apparent (Schutz, 1944). There are two traditions of phenomenological thought: descriptive and interpretive. Husserl (the 'founding father' of descriptive phenomenology) believed that by suspending (or 'bracketing') the influence of the outer world, it was possible to examine objects (both concrete and experiential objects including feelings, thoughts, emotions and fantasies (Rapport, 2005), in the form that they appear to the consciousness. This enables descriptions of experiences of phenomena 'as they are lived' by those describing them. When taking this approach, researchers should be aware of previous assumptions and place them to one side when conducting research (Schutz, 1944).

3.14 Interpretive phenomenology

Interpretive phenomenology emerged from a critique of the descriptive tradition, in arguing that the meanings of objects are not inherent in their descriptions. Rather, the researcher must *interpret* meaning from the description of the object or phenomena, in order to move beyond what is simply a description of the data. Martin Heidegger (1889-1938) questioned the ability of Husserl's phenomenology to elucidate the meaning of objects. He saw interpretation as foundational to man's being (Rapport, 2005). Humans are always involved in the practical world of experience and therefore consciousness can never be pre-suppositionless. Heidegger termed the taken-for-granted lifeworld which Husserl described, the 'ready-to-hand mode'. This experience of the world without interpretation is what gives anything we do *meaning*, and is the object of study in interpretive phenomenological research. The researcher accesses the ready-to-hand mode of participants through in-depth interviews and then applies their 'present-to-hand mode' (theoretical knowledge) to the experience in order to interpret the experience and apply meaning to it (Johnson, 2000).

Hermeneutics (interpretation)

The focus on interpretation derives from the ancient hermeneutic discipline; the concept of bringing things to understanding through language (Leonard, 1994). Culture and language shape the way knowledge is formed and the way in which we communicate and interpret each other's actions and behaviour within society. Hans-George Gadamer (1900-2002) located understanding in language and speech (Chadderton, 2004) and saw language, interpretation and understanding as inextricably linked (Rapport, 2005). Instead of aiming to bracket preconceptions, Gadamer saw prejudices as positive, inherent in our linguistic experience and necessary in order make understanding possible.

Humans are viewed as beings for which interpretation is the essence of existence, and this interpretation is influenced by five elements of the human consciousness, as described by Heidegger. These elements affect the way that humans interpret both their own experiences and the experiences of others, and they influence the process of interpretation between researcher and participant in the research interview. The research interview encounter is seen as a two-way process between participant and researcher, and the researcher's lifeworld cannot be removed or 'bracketed' from the interpretation they place on the participant's experience. I describe the influence of the five components of the consciousness on the process of interpretation during the research interview as follows.

(i) Humans exist within a lifeworld

A person's 'lifeworld' is made up of a meaningful set of relationships, practices and language, underpinned by the culture in which he/she lives, and their history. This world is taken-for-granted, or 'ready-to-hand' - it is what gives anything we do *meaning.* In the research interview, a participant's interpretation of their experience is influenced by his/her relationships, language, culture and history. Similarly, the researcher's interpretation of the participant's experience is contextualised by his/her relationships, language, culture and history.

(ii) Humans are beings for which things have significance and value

Actions are carried out based on some meaning of working towards the future, but are always shaped by the past. To understand a person's behaviour, he/she must be studied in a context (Leonard, 1994). A participant's interpretation of his/her experience is embedded within the context of their world, and a researcher's interpretation of a participant's description of their experience is embedded within the context of his/her world. Thus, the meaning of a single experience cannot be understood as an isolated object but must be seen as embedded within a contextual whole.

(iii) Humans are self-interpreting

All human beings are engaged in and constituted by on-going interpretive understanding. The lifeworld cannot be studied as it is actually lived, therefore any description of what an experience was like is a product of self-interpretation (Leonard, 1994). A participant's description of his/her experience to a researcher is a reflective, self-interpretation of what that experience was like. The researcher's interpretation is a secondary interpretation of the participant's reflective self-interpretation of an experience, and is therefore can never be completely accurate.

(iv) Humans exist within a body

Human beings are seen as embodied, and common practices are based on shared perceptions of what it is like to be in a body (Leonard, 1994). A participant's existence within a body influences the way they experience and interpret phenomena. A researcher's interpretation of a participant's experience is influenced by (his/her) experience of existing within a body as well as providing a common ground to relate to the participant.

(v) Humans exist within time

A human being exists in terms of what has happened in the past and what matters to them in the future (Leonard, 1994). Thus, humans are always 'becoming', i.e. living in relative absence, lack or need. It is through this need that humans are faced with a choice of possibilities, and meaningfully and purposefully live with and among others (Johnson, 2000). This means that a participant's interpretation of his/her experience is based on their past experiences and their beliefs relating to the future. A researcher's interpretation of a participant's experience is based on his/her past experiences and his/her beliefs relating to the future. Thus, interpretations of experience are only relevant to the moment in time they are gathered.

This process of interpretation inherent in the research interview encounter, demonstrates a two-way process of knowledge creation through interpretation, and shows how a participant's description of their experience is influenced by the way that they interpret the world based on their contextual history, culture and relationships. The researcher's interpretation of the participant's experience is also influenced by their own contextual history, culture and relationships.

3.15 Interpretive phenomenology as a methodological approach to the study of conscious complexity

Conscious complexity is inherent in adolescent diabetes management only as it is described by those living with the disease and as it is interpreted by the researcher. Complexity is derivative, rather than inherent in phenomena (McIntyre, 1998) meaning that it only exists through the interpretation of phenomena by humans (Stewart, 2001). Interpretive phenomenology focuses on gathering descriptions of individual experiences and therefore allows the emergence of the complexities and uniqueness of an individual's lifeworld - their culture, relationships, beliefs, history and future orientation, whilst acknowledging the researcher's influence on the interpretation of the experience. The process of interpretation embraces the historicity and contextual nature of human action, the process of feedback between researcher and participant in the creation (emergence) of new knowledge and the temporality of new knowledge. It also allows for the recognition of relationships between meaningful factors in a person's life which affect outcomes. The ongoing creation of new knowledge is embraced along with the assumption that there is no 'end point' to experience and outcomes of human action because interpretation is on-going and constant.

An interpretive approach also allows for the recognition that descriptions of complex systems are variable, context specific and relative to the perspective from which the description was made. Complexity exists only as it is described by the participant and interpreted by the researcher. Therefore it is never possible to fully understand a complex system in its entirety, as this would involve understanding the complete environment within which the system is situated, which is complex in itself. The exhaustive complexity of a complex system is beyond the interpretive capacity of the researcher (Cilliers, 2005). Thus, I take the view that complexity science is a theoretical tool which may enhance the understanding of lived experiences within the health care field, rather than an overarching grand theory which aims to reduce lived experiences into pre-defined categories.

Methodological assumptions

Interpretive phenomenology does not provide a workable 'method' for qualitative research as such. Rather, the researcher embraces the philosophical underpinnings of interpretive enquiry and orients to these throughout the research process. This influence can be summarised in three assumptions from the work of Heidegger (1962) and Gadamer (1960), which orient the researcher to data collection and analysis:

1. Knowledge is a product of interpretation, influenced by individual context and history (the lifeworld), and instrumented by language.

2. The researcher plays an active role in the research process and the formation of knowledge, as bracketing of the lifeworld is not possible.

3. Findings are not transferable to other populations, and are temporal. The interpretation of experience is relevant only to the particular individuals being studied by the particular researcher at that moment in time.

These assumptions relate to the way in which interpretive phenomenologists view the creation of knowledge through their research. Findings cannot claim to be any more than the researcher's interpretation of the participant's interpretation of their experience at the moment in time the interview was conducted. It is impossible to get any 'closer' to the true meaning of the experience, as it is impossible to study lived experience as it is *actually lived through* (the ready-to-hand mode). The closest we can get to knowing what an experience was like for someone is through their reflective description. Although the 'product' of interpretive phenomenological research is subjective, this approach enables the in-depth exploration of lived experiences as they are naturally interpreted by participant and researcher, thus yielding rich descriptive data and an in-depth insight into the experience of a particular phenomenon by individuals.

Exploring the lifeworlds of participants

Hermeneutic phenomenology as a research method aims to uncover an understanding from the presentation of an experience to the researcher (Johnson, 2000). The starting point of phenomenological enquiry is to identify a phenomenon of interest, which can be defined as something that human beings live through (van Manen, 1997). The next stage is to formulate a phenomenological question in which the researcher asks what the experience of the phenomenon is really *like* (van Manen, 1997), for example, *What is it **like** to live as an adolescent with T1D?* The ready-to-hand mode of life as defined by Heidegger (Plager, 1994) is most commonly accessed through a dialogue of conversation with the participant. In-depth interviews bring forth stories or narrative about actual events or episodes, which are transcribed to become the text for interpretation.

Max van Manen (1997) provides four existentials which can provide a guide for reflection throughout the research process. Building on the work of Heidegger, Merleau-Ponty (1962) described these existentials as the components of the 'lifeworld'. Table 3.4 describes the four existentials and their function in the research interview. Exploring these existentials in relation to the phenomenological question allows the researcher to build a composite picture of the participant's experience. It also gives potential for the complexity inherent in a phenomenon to emerge through the exploration of the person's lifeworld.

As well as influencing the research encounter, the four existentials can also provide a guide for exploring the lived experiences of participants. For example, when exploring and analysing the lived experience of T1D, the lived space of participants allows access to the experience of living with T1D in different environments such as the home, school and the clinic. The lived body allows for the emergence of factors relating to the physical experience of diabetes, such as the physical symptoms of blood glucose fluctuations. Lived time allows for the exploration of how past experiences, such as diagnosis, and future conceptions of diabetes affecting present behavior. Lived relations allows for the exploration of relationships with significant others and the effect on diabetes management and control. Applying the four existentials in methodology can therefore provide access to the elements of an adolescent's complex system through descriptions of their lived experiences.

Lived body and chronic illness

Lived body is particularly relevant in the study of chronic illness. Human beings experience and interpret their surrounding world through the bodies they inhabit, thus bridging the gap between body and soul. As described in Chapter 2, in normal daily life the body does not have a dominant presence unless a person chooses to focus on it, such as an athlete for which bodily

Table 3.4: Function of the four existentials in the research interview

Existential	Definition	Function in the research interview
(i) Lived space (spatiality)	• The felt spaces that surround us • Enquiry into the ways people experience the affairs of their day-to-day existence	• When wanting to understand about a person's experience, we ask him/her about their profession, interests, background, childhood etc • These things tell the story of a person's surrounding world and this can help us to uncover the fundamental meaning dimensions of lived life
(ii) Lived body (corporeality)	• We are all embodied human beings and we experience other human beings through their bodies. • Bodies can reveal things about a person, whilst also concealing the inner-self	• A person's experience of being in a body will affect the way that he/she interprets the world and the way that others interpret them • People experience physical symptoms of illness through their bodies. How a person copes and deals with symptoms and what happens as a result, defines their experience of living with an illness
(iii) Lived time (temporality)	• The temporal way of being in the world and the conceptualisation of the past and the future	• Conceptions of the past involve memories, social practices learned from family and friends, and language and behaviour • The past and the future influences how a person interprets his/herself in the present
(iv) Lived other (relationality)	• The lived relations maintained with other human beings in the interpersonal spaces shared with them	• A person approaches others with an impression of what that person is like, which influences how he/she acts towards them.

function has integrated significance in daily activities. For the majority, the body is a taken-for-granted medium through which life is experienced, and 'health' is taken-for-granted. The diagnosis of a chronic illness divides the duality of the mind and the body, as the body is required to 'take over' the taken-for-granted function of the body and the body rapidly becomes an object of attention (Williams, 1996).

The adolescent with T1D has a commitment to their body as the control of blood glucose defines their existence. Physical symptoms of blood glucose fluctuations create new boundaries; they provide 'alarm clocks' which demand the attention of the adolescent to the physical needs of their bodies and tear them away from other social experiences. Dys-embodiment (feeling betrayed by the body) leads to a psycho-physical dualism between body and mind. In this sense, human existence returns towards the Cartesian notion of the body as a machine, separated from the adolescent, their self and their society. The alienation of the body triggers coping strategies which enable a person to realign this relationship, moving back towards a more taken-for-granted bodily existence (Williams, 1996). 'Narrative reconstruction' (telling meaningful stories about the experience of the illness) (Williams, 1984), can assist the process of the reintegration of the new body-with-chronic-illness within the self and wider society (Gabe et al, 2004) through a reorganisation of biography to account for the onset of the illness (Locker, 1997).

3.16 Methodological rigour in interpretive phenomenological research

In an interpretive phenomenological study, the researcher cannot be separated from the research process, and their influence is instrumental to the findings. A value-oriented approach is unavoidable because all research contains pre-understanding which originates in the researcher's historical context (Koch, 1995). The nature of reductionist science strives for a value-free approach in which the researcher sits outside the research process, rather than being embedded within it, in order to eliminate bias. Theoretical and practical procedures and rules and routines are followed and the aim is to produce objective and standardised results that can be replicated and generalised (Plager, 1994). Value-orientation can be seen as a fundamental flaw, but interpretive phenomenologists would argue that it is unavoidable, because interpretation is the very means by which human experience exists.

In order for interpretive phenomenological research to stand up against reductionist science, methodological rigour is essential so that the reader can understand how the interpretation of the phenomenon in question came about. This is achieved through reflexivity, facilitated by transparency throughout the research process.

Transparency

Transparency refers to the researcher's explicitness of pre-understandings, presuppositions, theories, assumptions and beliefs relating to the phenomenon under study, throughout the research process (van Manen, 1997). This can be achieved through literature review and personal reflection, whilst being mindful of not decontextualising the interpretation of the original experience by focusing too specifically on these (Benner, 1994). Taking this into account is a dialogical process that requires openness, sensitivity, and scrutiny so that the world disclosed in the interpretation provides an understanding and not a 'misunderstanding' of the families' lived experiences. Throughout the research process, critical reflection of bias, possible blind spots and the questions being asked throughout the research process, allows a greater understanding of the process of interpretation.

Phenomenological writing

Writing is the instrument which allows the essential understanding of a phenomenon (van Manen, 1997). Descriptions of experience should aim to accurately represent the voice of the participants (Benner, 1994) and bridge the gap between theoretical abstractions and the concrete reality of lived experience through the use of anecdotes and stories. Themes extracted in the analysis should allow the reader to see the deeper meaning of the phenomenon. Anecdotal narratives are an effective demonstration of the phenomena because stories compel us and grab our willing attention and lead us to reflect and search for significance. They involve the reader/listener personally, as one searches for the meaning of the story via one's own meanings. They also encourage transformation, as one may be touched, outraged, or moved by a story. Ultimately they allow people to make interpretive sense of the phemonena and come to an understanding (van Manen, 1997). If the interpreter's own views have not been challenged or extended through reading the text then the quality of the account is questioned (Benner, 1994).

3.17 Summary and conclusions

In this chapter, I have presented the theoretical and epistemological basis for the study, in order to address the research gaps defined in Chapters 1 and 2. I introduced complexity science as a metaphorical tool for conceptualising the multifaceted nature of blood glucose control in adolescence. In line with the conclusion of Chapter 1, this framework recognises the need to move away from a reductionist, biomedical approach to diabetes care. Although complexity science appears to be relevant to T1D management, I defined a need for epistemological grounding and validated methodology to access the complexity of T1D management in adolescents and to validate complexity science as a theoretical approach to the study of T1D.

Interpretive phenomenology provides an appropriate epistemological approach. Both disciplines see interpretation as fundamental to human 'being'. In complexity science, interpretation sets human beings apart from other complex systems, as they have an additional layer of 'conscious' complexity within their nature, derived from the ability of the conscious to interpret and give meaning to actions within the system. Interpretive phenomenology sees interpretation as the very means by which human knowledge is created. Both believe that human action is underpinned by context and history and both see human experience as individual and temporal. Complexity can therefore be embraced through the self-interpretation and description of participant's experiences.

The provision of individuality in descriptions of experiences encourages movement away from a homogenous model of diabetes care, as suggested by Cooper and Geyer (2007) and towards a recognition of the complexity of individual experience and it's affect on the outcome of blood glucose control.

In Chapter 4, I present and discuss the aims and objectives of the study and the methodological approach employed.

Chapter 4: Methodology

Introduction

In Chapter 1, I defined a need to explore beyond the biomedical model, in order to understand the nature of blood glucose control in adolescence. In Chapter 2, I explored the psychosocial factors underpinning the self-management of T1D in adolescence, through the discussion of wider psychosocial literature in relation to the findings of a systematic review of qualitative studies of T1D in adolescence. From this, I defined three objectives for further research:

1) A need to explore the lived experiences of adolescents with T1D and their parents, to understand the factors affecting the biomedical outcome of blood glucose control.
2) A need for qualitative research in the UK, underpinned by rigorous qualitative research methodologies and epistemological tradition
3) A need for a novel theoretical approach which can embrace the multifaceted nature of T1D management in adolescence.

In Chapter 3, I introduced complexity science as a theoretical paradigm for the study of diabetes management. It defines the need to move away from a reductionist model of diabetes care, towards a complexity model which embraces the multifaceted nature of blood glucose control. This recognises ongoing learning through experience and the need for individualised care. As an epistemological approach, interpretive phenomenology provides access to the conscious complexity of the human experience of living with T1D. By exploring the lived experiences of adolescents with T1D, and investigating the applicability of complexity science to these experiences, I aim to explore its current application as a metaphorical approach, to enable a move towards validating (or invalidating) complexity science as an approach to understanding adolescent T1D management.

In Section 1, I describe the research process, including the research aims, questions and objectives, the sampling process and research methods.

Section 2 will address ethical issues and methodological rigour.

Section 1: The research process

4.1 Research aims, questions and objectives

The primary aim of the study was to explore the lived experiences of adolescents with T1D and their parents, with regard to two research questions. I explored the first question, '*What are the biomedical self-management practices of adolescents with T1D?*' through collecting quantitative data regarding the self-management behaviour of adolescents with T1D. This consisted of background data from clinic notes to investigate the medical status of adolescents with T1D including: HbA_{1c} levels, age at diagnosis, date of birth, and gender. In addition, I gathered data on the biomedical self-management practices of adolescents with T1D using a specifically-designed computer diary tool. I addressed the second research question, '*What are the lived experiences of adolescents with T1D and their parents?*' by exploring the lived experiences of adolescents through an interpretive phenomenological approach to data collection and analysis. This consisted of hermeneutic interviews and focus groups with adolescents with T1D and their parents.

The secondary research aim was to investigate the applicability of complexity science as a theoretical framework for understanding adolescent T1D management, underpinned by the research question, *Are the principles of complexity science applicable to the lived experiences of adolescents with T1D and their parents?* The objective was to explore the lived experience data in relation to the principles of complex systems as defined by Mitleton-Kelly (2003).

In this chapter, I address the methodology employed to meet the primary aim of exploring the lived experiences of adolescents with T1D and their parents; taking account of strengths and limitations, ethical issues and rigour. The secondary aim of *investigating the applicability of complexity science as a theoretical framework for adolescent T1D management*, will be addressed in Chapter 6, where I will discuss the findings in relation to the principles of complexity science.

4.2 Sampling

Sampling in qualitative research is purposive rather than random. It allows the researcher to choose particular cases because they illustrate some feature or process of interest (Silverman, 2009), aims to answer the proposed research questions and uncover multiple realities (Kuzel, 1992). Purposively selecting participants acknowledges the complexity of human and social phenomena as well as recognising the limits of generalisability (Maykut and Morehouse, 1994). The recruitment of my sample was an inductive process which adapted to the low success rate of the initial methods employed. I describe the process as follows.

Selecting a population

The first stage of the sampling process was to select a particular site from which to recruit participants, in order to maximise access and the success of recruitment (Marshall and Rossman, 1995). I approached a paediatric diabetes clinic in the North West of England, who agreed to participate in the study. All correspondence, data access and recruitment was facilitated through a diabetes nurse specialist at this site who acted as the lead contact.

Defining the criteria for participants

In order that family relationships could be explored within the data, it was important that at least one parent/guardian took part alongside each adolescent. Therefore, I excluded adolescents and parents from the study if their counterpart (mother or father) did not wish to participate. Adolescents receiving treatment for psychiatric conditions were also excluded to avoid emotional distress, as well as adolescents with other chronic conditions which would affect their diabetes management significantly, such as cystic fibrosis. The Local Research Ethics Committee (LREC) approved the sample inclusion and exclusion criteria, shown in Table 4.1.

Table 4.1: Sample inclusion and exclusion criteria

	Adolescent	**Parent**
Inclusion Criteria	• Age 13-16 • Has T1D • Attend the diabetes clinic taking part • At least one parent/ guardian also wishes to take part	• Has a child age 13-16 with T1D who wishes to take part
Exclusion Criteria	• Currently receiving treatment for a psychiatric condition • Has another chronic condition • Parent/guardian(s) do not wish to take part	• Child with T1D does not wish to take part in the study

Planning the sample size

In qualitative research it is common for data saturation to determine the sample size. This refers to the point at which new data collection becomes redundant (Maykut and Morehouse, 1994), i.e. nothing 'new' is emerging from the data. This method is mostly applicable to grounded theory studies, which aim to develop new theory through the validation of concepts in relation to them appearing more than once in the data set. An interpretive phenomenological approach posits that each individual exists within a unique lifeworld, making interpretations of experiences unique to the participant and the researcher. Interpretive enquiry presents an example of the experience of a phenomenon for a group of participants. The philosophy maintains the essence of individual experiences whilst exploring commonalities and differences within participants' descriptions of their experience, in order to come to an understanding of the phenomenon (Heidegger, 1962). The diversity of human experience makes it extremely unlikely that a person's experience will occur more than once to facilitate data saturation, although there may well be commonalities between the facets of experience that individuals describe. Saturation is even less likely when combining adolescent and parent experiences together as a family unit due to the complex nature of family relationships.

Although data saturation was strived for, I therefore anticipated that it may not occur within a manageable sample size. Thus, it was necessary to set limits on the number of participants I recruited for realistic data manageability. I set the limit for the total number of participants (including adolescents and parents) at approximately 20 families, but no more than 50 participants in total (adolescents and parents), as I was unsure of the number of parents that would participate alongside each adolescent. A total number of participants greater than 50 may have affected the quality of data collection and analysis within the specified time-frame (Ritchie and Lewis, 2003).

Stage 1: Maximum variation sampling

In qualitative research, epistemology underpins the research process from beginning to end. I chose a maximum variation approach to sampling, as it reflected the values of interpretive phenomenology in enabling the recruitment of participants from a range of different contexts and settings (Maykut and Morehouse, 1994), allowing the exploration of a range of experiences. A sampling frame was constructed to provide a comprehensive and inclusive basis from which to select potential participants, based on four contextual characteristics of the clinic population provided by the lead contact at the clinic: age, gender, HbA_{1c} and age at diagnosis. Whilst this reflected the reductive nature of categorisation within the biomedical setting, these categories were not used in a reductive manner in the collection and analysis of data. Rather they enabled the inductive exploration of real lived experiences in relation to the categories which define education and treatment within the clinical setting. I divided each characteristic into categories for sampling (shown in Table 4.2) and each adolescent was assigned a category for each characteristic. I included all adolescents who met the inclusion criteria from the clinic population in the sample frame (n=117).

Table 4.2: Sample frame characteristics and categories

Characteristic	Function of Maximum Variation	Categories
Age	To explore the experiences of adolescents at different ages	• 13 • 14 • 15 • 16
Gender	To explore the experiences of male and female adolescents	• Male • Female
HbA_{1c} *	To explore the experiences of adolescents with good to poor blood glucose control	• Good (6-8%) • Moderate (8.1-9.9%) • Poor (10%+)
Age at diagnosis	To explore the experiences of adolescents living with T1D for different durations of time	• 0 -5 years • 5 - 10 years • 10 years +

* An average HbA_{1c} level was calculated for each adolescent based on the mean of their previous four HbA_{1c} results. This covered a period of approximately 1 year based on the norm of regular three monthly clinic appointments, where the HbA_{1c} test was taken. The categories of 'Good', 'Moderate' and 'Poor' were adapted from the Clinic's definition of HbA_{1c} levels.

I divided the categories into a number of groups, giving a total of 72 possible different combinations of categories. The categories for all participants aged thirteen and male are shown in Figure 4.1, as an example:

Figure 4.1: Maximum variation categories for 13 year old males

Age 13 / Male / Good control / Diagnosed < 5 years
Age 13 / Male / Good control / Diagnosed 5-10 years
Age 13 / Male / Good control / Diagnosed 10 + year
Age 13 / Male / Moderate control / Diagnosed < 5 years
Age 13 / Male / Moderate control / Diagnosed 5-10 years
Age 13 / Male / Moderate control / Diagnosed 10 + years
Age 13 / Male / Poor control / Diagnosed < 5 years
Age 13 / Male / Poor control / Diagnosed 5-10 years
Age 13 / Male / Poor control / Diagnosed 10 + years

Although it was impossible to recruit one adolescent from each of the 72 categories, using this sample frame as a guide ensured that the characteristics were balanced across the participants. For example, within the age thirteen group, I strived for a balance of male and female, levels of control and ages of diagnosis.

I selected 20 families from the population using the sample frame to ensure variability. Each family was sent a recruitment pack approved by the LREC (including invitation letters, adolescent and parent/guardian information sheets and consent/assent forms), by the lead contact at the clinic (Appendix I: Note that the adolescent information sheet alone is included in the appendix; the parent sheet took a similar format). In the invitation letter, I asked families to read through the information sheets and to sign and return the consent/assent forms in a pre-paid envelope by a date two weeks in advance, if they wished to take part in the study. I provided contact details for the researcher, and families were urged to contact me with any questions. The response rate was nil. Repeating this method was unrealistic given that data collection was due to begin in four months time.

Stage 2: Self-selection

Due to the nil response rate in Stage 1, I tried a self-selecting approach, as it met the need of generating a sample within the time constraints. I invited all remaining families to take part, and aimed to select a maximum variation sample from those who opted to participate. This approach is termed 'convenience sampling', as the sample is generated based on participants putting themselves forward rather than the researcher's selection (Ritchie and Lewis, 2003). Although effective in meeting the time constraints, a limitation of this method is that the researcher has little control over the participants, and therefore the variation hoped for in the sample may be lost.

I sent recruitment packs to the remaining families (n=87), with the aim of selecting a maximum variation sample from those interested in taking part. As this method held the possibility of turning some families away if more responded positively than could be accommodated within the planned sample size, I changed the wording on the information sheet to state that if the families were interested in taking part, they may be selected to participate. The envelopes were addressed to the child and their parents, with the aim of encouraging the parent to involve the child in the decision making process to facilitate informed consent (Miller, 2000). 'Interest in participation' forms were enclosed for return, rather than consent forms, which would be sent to selected participants at a later date. The response rate to Stage 2 was also poor (n=2). I plotted the two consenting families on the sample frame.

Stage 3: Face-to-face recruitment

The lead contact at the clinic suggested that face-to-face recruitment at clinic appointments may be a more effective method of recruitment. I obtained clinic schedule information for the following three months, which allowed me to target cases of interest during weekly clinics, thus maintaining the variation strived for. For example, once ten female participants had been recruited, only males were targeted. Because the males already recruited were all of ages thirteen and fourteen, I only approached males aged fifteen and sixteen.

I approached families in the clinic waiting area. During their appointment, the adolescents saw three different health professionals, which gave approximately one hour for me to explain the study to the adolescents and their parents and for them to read through the information sheets and ask any questions. The nurses in the clinic introduced me to each family as a researcher from the University of Liverpool. Following this, I sat with the family and explained the aims and objectives of the study. I went on to describe what would be involved should they wish to take part. I explained that in the first instance, I would visit their home with a computerised diary tool and the adolescent would be asked to use this for one week. I had one of the computer tools with me and demonstrated this to the adolescent, letting them have a go at using it. I went on to explain that the second stage would involve separate interviews with the adolescent and parent(s) about what it is like to live with diabetes. Finally, I stated that clinical data would be obtained from the clinic should the family agree to take part and that optional focus groups would be held at the end of the study to discuss the findings.

I explained that I would use what they told me, to write a report about living with T1D in adolescence, and that the health professionals in the clinic, staff at the University and the wider public would be able to read this as it would be published in medical journals. I assured them that confidentiality would be maintained through the use of pseudonyms in the research report, but that it may be possible for family members and health professionals to identify what they had said if they knew them well. I also assured them that their data would be kept in a locked filing cabinet and under password-protected computer files.

Finally, I informed the families that they could withdraw from the study at any time and that this would not affect their clinical care in any way. This protected the participants from the risk that some may have felt pressured to give consent by their counterpart giving consent. Families were also advised that if they were to tell me that a child under 16 was at risk of harm, I would be required to break confidentiality and pass this information on to an appropriate health professional. I then left the adolescent and their parent(s)/guardian(s) with the information sheets to read through and advised them to ask me any questions they may have. After their clinic appointment, I asked if they wished to take part in the study and obtained signed consent/assent if they wished to participate. Eighteen families were recruited in this stage, giving a total of 20.

Reflections on the recruitment process

The success of face-to-face recruitment in relation to the previous stages was due to the fact that I met families in person and was therefore able to explain the aims of the research project and what would be involved, in a non-threatening manner. The lack of response to the postal methods supports previous findings that face-to-face recruitment is more effective than letters or phone-calls (Maheux et al, 1989). This suggests that people do not respond well to being sent a large amount of information which they are required to read.

It was particularly important to have the opportunity to explain the study to the adolescents. In studies involving minors, parents are important gatekeepers. Sending the information in the post held the risk that parents may have read the information and made a decision about the family's participation without consulting the adolescent, or not passed the information on the adolescent at all (Miller, 2000).

Face-to-face recruitment also meant that I was there to answer any questions or doubts which may have prevented potential participants from considering the research. For example, one mother asked me if they would have to travel to the clinic for the interviews, to which I replied that I would come to their house, or other preferred venue, or could meet them at the clinic if this was more convenient. The presumption that her family's participation would involve travel may have prevented her from reading the information sheets, had she received the information in the post.

Gatekeepers are instrumental for recruitment at health-care sites (Logsdon and Gohmann, 2008) and the nurse's introduction was vital to successful recruitment in this study. Further recruitment work I have undertaken in similar settings has confirmed this. Introduction by a trusted health professional validates potential participants' trust in the research study and in the researcher. In this study, parents acted as a second gatekeeper to the participation of the adolescent and thus gaining their trust was of particular importance (Miller, 2000). A number of studies have found trust to be a vital motivating factor in participant motivation (Murphy, 1993; Newberg et al, 1992) as well as altruism (Peel et al, 2006; Murphy, 1993), perceiving the importance of the research (Murphy, 1993) and recruitment taking place in a positive, comfortable and safe environment (Crosby et al, 1991).

Despite the advantage of the nurse introduction to recruitment, it was noted that the dual role of the nurse (as a care-giver and an active participant in the recruitment process) may confuse potential participants (Logsdon and Gohmann, 2008). I therefore stressed to the families that I was an external researcher and that participation was entirely voluntary and would not affect their care at the clinic, to ensure that they did not feel obliged to participate. I was also aware that the computerised diary tool attracted some adolescents to participate in the study. This 'adolescent-friendly' (Steinbeck et al, 2009) aspect of the methodology may have increased interest in the study. When recruiting in the clinical setting, I was conscious of using lay language and communicating with families in a non-threatening manner. I wore casual clothes and tried to present myself as a 'young' person that the adolescents would feel comfortable talking to.

Most of the adolescents I approached in the clinic were with their mother. Previous sociological research on the family has tended to be based on interviews with women, as the 'figurehead' of domestic life. Gaining the father's perspective has the potential to expose, *'the negotiated and contested nature of household relationships, and so contribute to the development of...complex...understandings of gender relations'* (Valentine, 1999:67). Thus, I strived for paternal participation in consenting families with two parents. In order to optimise recruitment of fathers, I asked if there was a male guardian in the family that might be interested in taking part and followed this up when contacting the family to arrange the initial visit. Recruitment of fathers was most successful when the father was present with the adolescent in the clinic, which is resonant with other findings that 'snowballing' from one family member to another is less effective than approaching them in their own right (McCarthy et al, 2003).

4.3 Methods

A multiple method approach was taken to data collection encompassing primarily qualitative methods. Interpretive phenomenology posits that all knowledge is created through a process of interpretation. Qualitative methods were chosen as they enable the investigation of the meaning of social action. Quantitative methods involve coding the social worlds of the participants into quantified variables, which inhibits the inductive emergence of the meaning of experiences (Marshall and Rossman, 1995) and therefore would not be appropriate in the study of lived experiences.

A key assumption of interpretive phenomenology is that the way humans interpret their own experiences and the experiences of others is influenced by their individual context and history (the lifeworld). Based on this assumption, through the central method of hermeneutic interviews with adolescents (described on p110), I aimed to explore the lived experiences of adolescents with T1D. Three additional methods aimed to provide contextual data within which the lived experience data could be situated: a computerised diary tool, hermeneutic interviews with parents and background data supplied by the clinic. Following data analysis, focus groups with all of the participants aimed to validate the interpretations of the researcher.

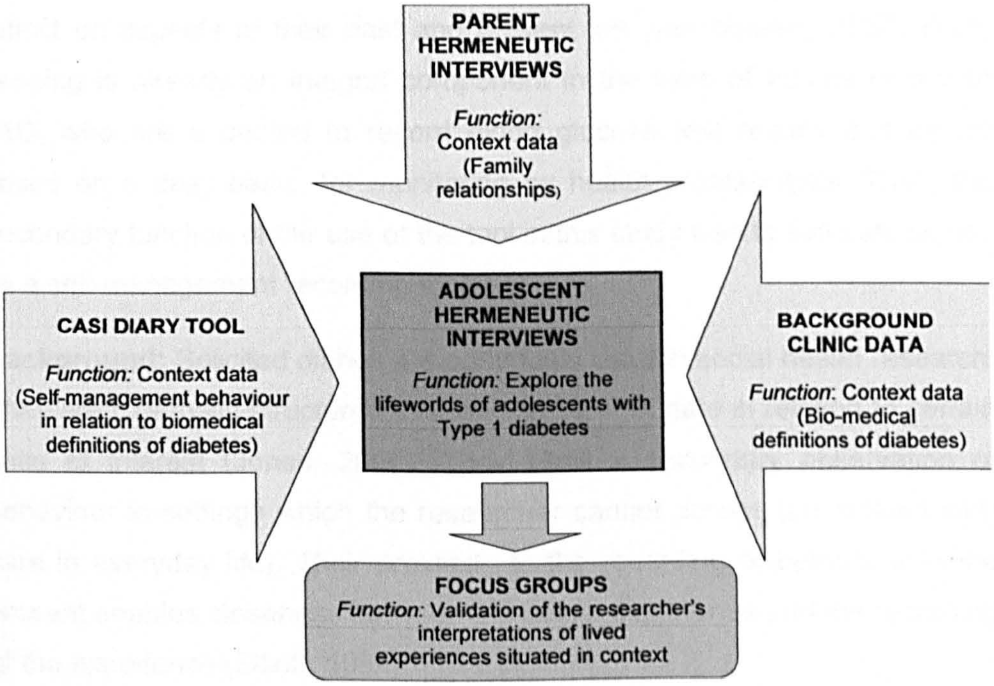
I divided the participants into four cohorts. Data collection followed a six week schedule for each cohort, as shown in Table 4.3.

Table 4.3: Data collection and preliminary analysis schedule for each cohort

WEEK 1	WEEK 2	WEEK 3	WEEK 4	WEEK 5	WEEK 6
Adolescents complete computerised diary Tool		Hermeneutic interviews with adolescents and parents		Transcription of interviews and summary of computerised diary tool data	

As well as providing valuable contextual data within which to situate the lived experiences of adolescents with T1D, triangulation of methods also had the benefit of improving understanding in the study of complex concepts and providing scientific rigour (Jones and Bugge, 2006), and thus addressed the research gap I had highlighted in the systematic review (Spencer et al, 2009). The methods were actively constructed to suit the research question in order to facilitate the production of new knowledge (Kincheloe and Berry, 2004). The data collection process is illustrated in Figure 4.2, which also details the function of each method within the process of gaining an interpretation of what it is like to live with T1D in adolescence. The data collection methods are described in detail below.

Figure 4.2: Data collection



(i) Background data

Objective: I obtained data regarding the age, gender, age at diagnosis, HbA_{1c} level and insulin regime from clinic notes, and this was recorded. This met the primary objective of gathering quantitative data regarding the self-management behaviour of adolescents with T1D and providing demographic context data in relation to the adolescents' experiences.

Implementation: I had collected this background data when constructing the sampling frame. This was extracted for each consenting participant and stored in an anonymised, username and password protected database.

(ii) CASI diary tool

Objective: I developed the CASI (computer-assisted-self-interviewing) diary tool to provide contextual data on adolescents' self-management behaviour as it is biomedically defined, i.e. adherence to insulin injections, blood glucose testing, regular exercise and a dietary plan. The most appropriate way to access such information was through diary keeping. In phenomenological research, diaries are useful tools for allowing a person to reflect on aspects of their past and present life (van Manen, 1997). Diary keeping is already an integral component in the lives of adolescents with T1D, who are expected to record blood glucose test results and insulin doses on a daily basis, for monitoring by health professionals. Thus, the secondary function of the use of the tool in this study was to evaluate its use as a self-management recording tool.

Background: Solicited diaries are commonly used in social health research. They are externally structured to allow the input of data in relation to certain units of interest (Jones, 2000). They allow a secondary observation of behaviour in settings which the researcher cannot access (i.e. patient self-care in everyday life). Their proximity to the recording of behaviour in the present enables closeness between the actual experience and the recording of the experience (Elliott, 1997).

Self-management competence in young people with T1D could be assisted through the use of information technology (IT) (Cooper et al, 2009). Adherence in a study of haemophilia patients was improved by the use of handheld computers and all participants preferred this method to paper diaries (Arnold et al, 2005), suggesting that the use of IT could provide motivation for the completion of a diary tool relating to self-management. CASI (questionnaires loaded onto computers for participants to complete) yields good response rates in research with adolescents, and its anonymity encourages honesty in response (Paperney et al, 1996).

Development of the tool: I developed the tool based on the assumption that completing a diary on a hand-held computer such as a personal digital assistant (PDA) would be interactive, fun and easily transportable for adolescents, thus improving response rates.

The design of the tool aimed to meet the following specified criteria:

- A recording device for blood glucose test results, insulin doses, diet and physical activity data

- Free text diary function for adolescents to write their thoughts and feelings
- Installable on a PDA device
- Username and password protected to ensure confidentiality
- Fun, easy to use and appealing to adolescent age group
- Straightforward transfer of data from PDA to Excel database.

An independent software designer was recruited to produce a software package of the specification. It was designed for installation on HP iPAQ rx1950 PDAs (2.78" x 4.47" with colour screens) which were operated with a touch screen and stylus. Seven PDAs were purchased through an internal University grant.

The diary tool enabled adolescents to input quantitative data regarding their self-management decisions. Figure 4.3 demonstrates the process of entering a blood glucose result, as described in the instruction manual. The process was similar for the input of insulin doses, diet data and physical activity. The original specification for the tool can also be found in Appendix II, to give an example of the screen design.

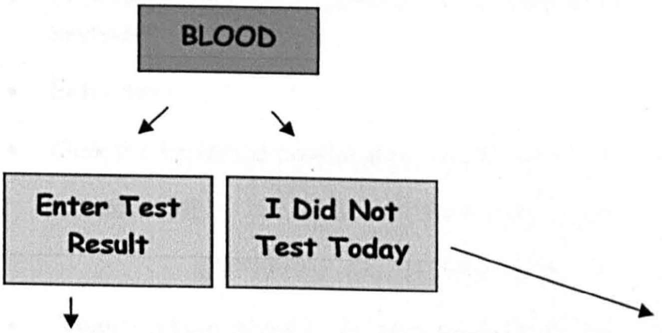
The software programme was password protected to ensure participant confidentiality. All of the previous user's data was removed from the PDA before the next participant's use and each participant had a unique user number assigned to access use.

Pilot: Before use in the study, the tool was piloted by two fifteen year old adolescents (one male and one female) and one twenty year old female. All had T1D and were members of the Research Advisory Group for the study (see p132). Participants were briefed, gave signed consent for their data to be used in the pilot, and were assured of confidentiality.

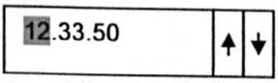
All three found the device easy to use. The male adolescent reported feeling motivated to test his blood glucose levels more frequently. Suggestions for improvement were made, and the following functions were added before use

Figure 4.3: Instructions for entering a blood glucose test result in the CASI diary tool

- On the main screen click 'BLOOD' and then 'ENTER TEST RESULT' or 'I DID NOT TEST TODAY' if you haven't tested your blood glucose at all that day



1) <u>Enter the time of your test</u>



- Click to highlight the hour
- Use the up and down arrows
- Do the same for the minutes

1) <u>Describe why you did not test your blood glucose</u>

- Click on the keyboard symbol at the bottom of the screen to bring up the keyboard
- Write down why you did not test your blood glucose along with any thoughts or feelings you might have about this
- Click the keyboard symbol again to get rid of the keyboard
- Click SAVE

2) <u>Enter the date of your test</u>

- Do this in the same way as entering the time of test (see above)

3) <u>Enter your test result</u>

- Click in the Test Result box
- Click on the keyboard symbol at the bottom of the screen to bring up the keyboard
- Enter your test result
- Click the keyboard symbol again to get rid of the keyboard

4) <u>In School/College?</u>

- If you tested your blood glucose in school, click in the box to tick it

Figure 4.3 (continued)

5) How do you feel about the results?

- You can use this box to write down how you felt about doing the test or the test result
- Click in the large text box
- Click on the keyboard symbol at the bottom of the screen to bring up the keyboard
- Enter text
- Click the keyboard symbol again to get rid of the keyboard

CLICK THE ☐ SAVE BUTTON WHEN YOU HAVE FINISHED ENTERING ALL YOUR BLOOD TEST INFORMATION

- When you have saved it will take you back to the Enter Test Result screen. To get back to the main menu, press OK in the top right corner

in the study:

1. A 'view entries' function to look back over previous entries
2. A delete function for incorrect entries.

Implementation: I visited the participant's homes to deliver the PDA's. I briefed the adolescents on the use of the tool and gave them an instruction booklet and obtained signed consent for use of the data entered into the PDA in the research study. The adolescents used the diary tool for a period of one week. They were asked to record every blood glucose test, insulin injection, activity and all food and drink consumed. Following completion, I collected the PDA's from the adolescents' homes and data was downloaded from the PDA into Excel databases on a university computer with username and password protected access.

Data analysis: I created self-management profiles for each participant, to show their daily self-management decisions and the relationships between insulin doses, blood glucose test results, diet and physical activity. Data from each self-management behaviour were extracted under a number of different categories, shown in Table 4.4. These quantitative data along with the background clinic data were used to explore the four self-management variables in relation to issues raised in the qualitative interviews, for example, age at diagnosis in relation to HbA_{1c} levels and perceptions of control.

Table 4.4: Data extracted for self-management profiles

Self-management Behaviour	Data Extracted
Blood	• Average number of blood tests per day • % of hypoglycaemic results (<4 mmols/L) • % of normoglycaemic results (4-9.9 mmols/L) • % of hyperglycaemic results (10-14.9 mmols/L) • % of results > 15 • Range of blood glucose test results • Mean fasting level (before breakfast test result) • Recorded hypos
Insulin	• Insulin regime • Injection site rotation • Injections done in school?
Activity	• Number of days with physical activity • Number of hours of physical activity per week • Types of exercise taken
Food and drink	• Amount of fruit/vegetables consumed per day • Amount of high sugar foods consumed per day • Number of takeaways consumed per week • Regularity of meal pattern • Healthy snack choices

Reflections on the CASI diary tool method: The use of CASI in the healthcare setting provides an original contribution to research, although as a relatively new method it is in need of further validation. The tool yielded a large amount of insightful data in relation to the realities of living with diabetes for individuals on a daily basis, and was interactive and fun for adolescents to use. It provided a meaningful tool of communication with the adolescent age group (Miller, 2000). It acted as an 'ice-breaker' in preparation for the hermeneutic interviews described in the following section, given that rapport may be more difficult to establish between and adult researcher and a young person due to power relations (Kirk, 2006). Use of the CASI diary tool prior to the interviews meant that the researcher had already visited the young persons' homes twice before visiting a third time to conduct the interview. Thus a trusting relationship (Westcott and Littleton, 2005) had already been established between the researcher and participant, making the interview conversation more comfortable and natural for both parties.

The CASI diary tool met the aim of providing contextual data in relation to the biomedical management of diabetes advocated through the clinical setting. Reliability may have been lost through misrepresentation which is common in most methods of data collection (participants entering what they feel to be the desirable answer, rather than the truth) (Jones, 2000). There were inconsistencies in the amount of data the adolescents entered into the diaries, with the number of entries ranging from 2 to 16 entries per day. This meant that quantitative analysis and comparison across the data set was impossible. I did not assume that data input reflected adherence to diabetes management, as it was likely that the data did not give a true reflection of 'normal' behaviour. On reflection some of the adolescents stated that using the tool motivated them to indulge in increased self-management behaviour. It is also possible that the data entered represented under or over-recording of behaviours (Jones, 2000).

Evaluation of the CASI diary as a self-management tool: At the end of the interviews (described in the following section), I asked adolescents and parents about their opinions of using the CASI diary as a self-management tool. Responses were analysed thematically using NVIVO, and are summarised as follows. I have used pseudonyms to protect the participants' identities. A description of the participants can be found in Chapter 5.

Using the CASI diary tool was enjoyable for most of the adolescents, who found it easy to use. A number of parents and adolescents stated that using the tool had improved their motivation to self-manage their diabetes during the time they were using it, in particular for those with poor adherence to their regime. As one female stated:

"It made you want to do your blood more and keep on top of doing your needles...on time" (Emily Dougherty, 15).

It was more appealing than the traditional pen and paper diary as a method of recording blood glucose test results, and provided a good recording device which enabled tidy storage of data and analysis of self-management in relation to blood glucose levels, diet, injection sites and physical activity. One mother felt that it provided an outlet for feelings of frustration for her daughter:

"Sarah say's it asks you questions how you're feeling...so instead of saying it to us, she can say it to the diary...say how you feel instead of getting all irritable" (Mother, Morris family).

Despite its positive traits, some adolescents found the tool confusing, annoying and time-consuming, for example:

"It was just like time consuming writing in it all the time" (James Butcher, 15).

There were some technical issues, which resulted in data loss. Some found it difficult to use, and others suggested that an editing feature would make it more user-friendly. Adolescents suggested adding a range of functions to the device in order to improve its use as a self-management tool, including blood glucose testers and insulin pens.

The range of frequency of data entry across the sample illustrated that some adolescents were more prone to engage with this type of self-management tool than others. Although the tool had motivational properties in terms of encouraging blood glucose testing, many adolescents thought that the novelty of using it would be short-lived, as this female stated:

"As soon as I saw it I thought woah this is cool, but then when you get used to it it's sort of like just there *kind of thing"* (Holly Thomas, 15).

Although frequency of data input could not be taken as an indicator of adherence, the adolescents who were the most adherent to data entry tended to be those with better blood glucose control. These adolescents found the tool to be an extra burden because the need for its assistance was low. I concluded that the tool has the potential to be a useful motivational/educational aid for newly diagnosed patients or for those who were experiencing periods of low motivation, and could also serve as a monitoring tool for health professionals, as this adolescent male stated:

> *"I don't think if you had it all the time but maybe if you had it for...people who have just got* (diabetes), *because it would be able to help the nurses keep track of them"* (Ian Collins 13).

Despite its motivational properties, there were a number of functional limitations to the functioning of the CASI Diary Tool. It therefore warrants further development, taking into account the adolescents' suggestions for improved function and its use as a short-term motivational/educational aid.

(iii) Hermeneutic interviews

Objective: I conducted hermeneutic interviews with adolescents and parents to meet the primary objective of exploring their lived experiences through an interpretive phenomenological approach. I interviewed both adolescents and parents, in order to combine the unique perspectives of family members to give a broader picture of the reality (Deal, 1995) of living with adolescent diabetes within the family environment.

Background: The lived experiences of individuals are best explored through in-depth interviews (Marshall and Rossman, 1995). An interview guide may be developed, based on some pre-determined topics, but respondents are allowed to direct and shape the interviews according to their own responses. This allows the participants' perspectives of the phenomenon to unfold as they view it rather than in response to how the researcher views it. The interview process must be shaped by the fundamental phenomenological question, 'What is the experience *like?'* The experience of participants should be described in such a way that the meaning structures of this experience as it was *lived through* are brought back. This enables the recognition of the description as an interpretation of that experience. The researcher's task is then to construct a possible interpretation of the nature of human experience through phenomenological writing (van Manen, 1997).

Design: The aim of the interviews was to gain in-depth accounts of the participants' lived experiences. An interview guide was developed to facilitate discussion if needed during the interview (Appendix III). The need for this was based on the presumption that the adolescents (and parents) may have found the in-depth interview situation unnatural. Young people have expectations about what is required of them when interacting with adults. They maybe rarely listened to in-depth, unless they have done something 'wrong' and therefore may find being asked to describe their experiences an unfamiliar situation. They are used to teachers initiating a discussion, usually with a question to which the young person is expected to initiate a response for which they will then receive feedback (Westcott and Littleton, 2005).

I based the design of the interview guide on Merleu-Ponty's four existentials, as defined by van Manen (1997). These existentials make up the structure of the lifeworld. Exploring these allows the researcher to build up a detailed picture of a participant's lived experience. Each existential facilitated open-ended questions about each area of the lifeworld. I designed the questions with the age of the participants in mind and prioritised simple language. I did not aim to implement the guide in a structured fashion with each participant. Rather, I asked the participant to lead the conversation and referred to the guide if certain areas if necessary.

Pilot: I conducted five pilot interviews with a male and female adolescent (age fifteen) with T1D, a twenty year old female with T1D, and two mothers of adolescents with T1D. All were members of the Research Advisory Group. As the interviews were to be unstructured, the aim of the pilot was to rehearse the method rather than to test the schedules. Participants piloting the interviews were briefed before the interview, signed consent for the interview to be recorded was obtained, and participants were assured of confidentiality.

The overall method was successful and the group felt comfortable with the questions asked and interpreted the questions as I had intended. I subsequently revised the interview schedules to add in some additional areas which the group felt were missing from the schedule based on their personal experience of living with T1D. These included career aspirations, relationships with boyfriends/girlfriends and managing blood glucose around physical activity.

Implementation: I gave the participants the choice of three venues for the interview - their home, the university or the diabetes clinic, in order to ensure that they felt comfortable and to allow them optimum control over the situation (Mauthner, 1997). All families chose the home, which had the advantage of ensuring the participants felt comfortable in their surroundings. I conducted the interviews at a time of day suitable for the individuals. Two parents took part in seven of the families. In most families with two parents taking part, I interviewed the parents together as they felt this to be more convenient. Two out of the seven families with two parents participating agreed to be interviewed separately.

I interviewed nineteen of the twenty adolescents, as one adolescent female refused. Most of the interviews were approximately one hour long, with a range of between 40 minutes and three hours. The parent interviews were typically longer than the adolescent interviews, and I had to use more prompts with some adolescents, as expected. The content of the accounts varied due to differing individual experiences.

I conducted each interview visit in relation to Legard and colleagues' (2003) description of the interview encounter, shown in Table 4.5. The aim was to ensure that the participant felt respected and at ease, whilst enabling me to gather sufficient data at the same time as maintaining respect and ethical standards. All interviews were digitally recorded with the permission of the participants. Additional notes were not taken during the interview so as not

Table 4.5: Five stages of the interview encounter (adapted from Legard et al, 2003)

Stage	Function	Researcher Actions
(i) Arrival	Establishing relationship between researcher and participant	• Act as the guest whilst putting the participant at ease • Make conversation whilst being mindful to avoid the research topic. • Allow the participant to feel comfortable
(ii) Introducing the research	Introducing the research topic and interview brief	• Ensure that the research environment is suitably private and comfortable • Ensure that the participant fully understands and is happy with the interview brief
(iii) Beginning the interview	Easing into the first interview questions	• Gather background information • Begin with 'easier' questions
(iv) During the interview	Guide participant through the interview guide	• Active listening • Prompt for further information when needed
(v) Ending the interview	Return to a normal level of social interaction at the end of the interview	• Signal the approach of the end of the interview • Check if there is anything important that they have not yet expressed during the interview.

to interrupt the flow of conversation and the listening process. I recorded field notes immediately after the interview in a field note diary. The stages of the interview process are explained as follows.

(i) Arrival and (ii) Introducing the research

I took my appearance into account when preparing for an interview visit as participants' perceptions of an interviewer can influence their willingness to disclose their real-life experience. I dressed informally and aimed to present myself as a non-threatening character to the participant. I had the advantage of already having met the families on at least one occasion before the interview took place (in the clinic if recruited this way, and in the home when delivering and collecting the CASI diary tool). This gave me the opportunity to establish a comfortable relationship with the participant before the interview encounter, allowing the participant to feel more at ease.

I gave the participants a briefing sheet before the interview began. The adolescent brief is shown in Appendix IV; the parent brief took a similar format. I guided the participant through this and gave them the opportunity to ask questions. I obtained signed consent before the interview began to indicate that the information sheet was understood and that the participant agreed to the interview being digitally recorded. I took a pen and paper to every interview, should the participant prefer not to be recorded, but all consented to this.

(iii) Beginning the interview

I began the interview by asking the participants a number of opening questions, to help the interview situation to feel as 'natural' as possible (Robson, 1993). For the adolescents, these included, '*How old are you? 'How long have you had diabetes for?'* and *'Does any one else in your family have diabetes?'* For the parents, *'How long has your son/daughter had diabetes?'* and '*Does any one else in your family have diabetes?'* Following this I asked them to think back to the diagnosis of diabetes, with the presumption that reflecting on the events which began their experience of living with T1D would enable them to build a story of what had happened in their life from diagnosis until the present day. This functioned in exploring 'lived time', but also eased the participants into the interview through the process of reflection. Some participants led the flow of conversation from this starting point, with little influence from myself, whereas others needed more guidance in relation to the interview guide. The adolescents generally needed more guidance than the parents. This was expected as adults have the capacity to reflect on the meaning of their experiences, whereas adolescents are still developing their capacity for critical thinking (Nielson et al, 1996).

(iv) During the interview

The interpretive phenomenological interview is a two-way process. The researcher must place themselves in the participant's situation in order to merit understanding of their experience (Johnson, 2000). Listening and personal interaction skills are essential to conduct effective in-depth interviews. I was careful not to ask leading questions which would encourage the participant to respond in a certain way (David and Sutton, 2004). Open-ended questions, such as, *"Tell me about a typical day in your life"*, leave the direction of the conversation open for the participant to explore (Seidman, 1998). This was achieved by asking questions as they were planned in the interview guide.

I employed the skill of active listening to assess if the amount of detail given was adequate and to avoid descriptions relating to participants' 'outer' rather than 'inner' voices. The outer voice refers to stereotypical statements which participants may feel are the norm in describing their experience, for example, *"Living with diabetes is a challenge"*. In order to explore their inner voice, the researcher should ask the participant to elaborate, for example, *"In what way is it a challenge?"* (Seidman,1998). I was also mindful of non-verbal cues such as time, the amount left to cover and the participant's energy levels, in order to move the interview forward if necessary. Body language such as tone of voice, manner and actions can often give clues to where more depth can be found (Legard et al, 2003).

(v) Ending the interview

Once I was satisfied that they had gained an adequate description of the participant's experience, or as a response to cues that the participant may be becoming tired, I signalled that the interview was coming to an end. I asked the participant if they were satisfied with their description and if there was anything else which they felt needed to be covered. The confidentiality agreement was reiterated at the end. Due to the sensitive nature of the research topic, I advised participants to inform myself or the lead contact at the clinic if any issues had arisen for which they needed further emotional support.

Interviewing families: Interviewing family members can increase the complexity and sophistication of the accounts collected by the researcher, add depth by exposing conflicts and the processes underlying decision making and enable dynamics to be explored (Valentine, 1999). In families were two parents/guardians participated in the study, I interviewed some as a couple, and others separately, although the majority (n=7), were interviewed together. This was the family's choice based on what was most convenient for them, or what they felt most comfortable with. Both approaches to interviewing have strengths and limitations and affect the quality and substance of the data gathered, and the subsequent analysis. Involving multiple family members in research thus requires a recognition when analysing the data, that the account gained may have been very different had the interview been conducted with/without a partner present (Beitin, 2008).

Joint interviewing allows access to a single, collaborative account created through a process of negotiation and mediation, which can give insights into the dynamics of the household (Valentine, 1999). This provides access to the interaction between the couples in the creation of their account, which would be unobtainable in individual interviews (Allan, 1980). One partner is likely to be the dominant speaker, but the other partner can add something to their account which introduces new themes without the interviewer having to intervene. Thus, the account is shaped by the dynamics of the partners' interaction, is spontaneous and shaped by the validation and modification of discussion rather than the interviewer's agenda. Joint accounts can also illuminate the processes through which the household operates, based on the tendencies of partners to lead when talking about particular topics (Valentine, 1999). Although the result is one account, it can illuminate and reflect the different realities experienced by the two spouses (Allan, 1980).

When interviewing couples together, there is a risk that conflict may occur during the interview (Valentine, 1999). Such disagreement did not occur in the interviews I conducted. However, it is possible that the accounts gained did not give a true representation of the individual partners' accounts of their experiences. One reason for this is that partners may hold back on their true feelings or experiences in order to maintain a 'status quo' within their relationship. The moral basis of kinship may mean that individuals give answers which reflect their normative rather than actual behaviour (Allan 1980). Another is that participants strive to hide their real life, 'backstage' behaviour in order to maintain a view of what they perceive to be 'good parenting' (Valentine, 1999) and thus protect themselves from the critical scrutiny of the researcher (Allan, 1980). Despite the limitations of interviewing parents together, fathers may have been more inclined to participate in an interview with their partner rather than alone, due to expectations that the mother is the 'figurehead' for the discussion of household issues (Valentine, 1999). Thus, if the interviews had been stipulated as individual only, even less fathers may have participated.

Interviewing parents separately gives participants more freedom to express their individual views (Valentine, 1999) and expand upon a topic fully without being interrupted (Beitin, 2008). This lends more privacy to the discussion (Valentine, 1999) and may generate deeper, more uninhibited accounts of family life. However, it is possible for individuals to present a joint opinion of the family based on their own experience and views, with the use of 'we'. This should be clarified to distinguish an individual's perspective from that of other family members' (Beitin, 2008). Separate interviews may also generate anxiety between couples, about the image that one has presented about the other.

Situational influences such as the appearance and gender of the researcher (Williams and Heikes, 1993), and the environment in which the interviews were conducted may have impacted on the participants' interpretation of the situation and the data they provided (David and Sutton, 2004). In one situation, the father of an adolescent female entered the room during his daughter's interview and remained for the duration. I was not in a position of power to ask him to leave and therefore the quality of the data was affected. I could not be sure if the daughter's and parents' accounts were a true reflection of their experiences. This had to be taken into account in the data analysis, and meant that data relating to parent-adolescent relationships could not be used for this family.

Data analysis: Each interview was digitally recorded and transcribed verbatim either by myself or an independent transcription assistant employed by the University. Interviews transcribed by the assistant were checked for errors against the recorded interviews. A small number of errors were found, which mainly occurred when the transcriber was unable to distinguish certain words. In the majority of cases, I was able to distinguish these words.

The phenomenological description of lived experiences is based on a co-construction of meaning between the participant and researcher (Westcott and Littleton, 2005). Thus, my interpretation of the participants' experiences was based on the fact that I was once an adolescent, aspire one day to be a parent and have been parented myself (Danaher and Briod, 2005); and also my experience of having a chronic illness as an adolescent. It has been argued that adult researchers cannot understand the world from a child or adolescents' point of view (Christensen, 2004). Kirk (2006) points out that coming from a different generation means that adults cannot relate to a child or adolescent's experience exactly, due to a cross-generational culture shift in what it means to be an adolescent. It was therefore also important to distinguish between adolescents' experiences and parents' accounts of their child's experiences in the analysis to uncover these multiple perspectives. It was also impossible for me to understand exactly what it is like to be a parent, as I had not yet had this experience. However, I was able to draw on my own relationship with my parents and the issues that as an adult, I was now able to 'see' they faced.

Writing a biographical note (Appendix V) before undertaking this study enabled me to reflect on my personal history and experiences. This enabled me to interpret the participants' experience with reference to my own personal context and experiences of 'being.' Thus, the outcome of my analysis was the collaboration of the perspectives of adolescence, fatherhood and motherhood, but only as my life experience and perspective allowed me to situate these in relation to my own context.

Thematic data analysis followed a rigorous seven-step process informed by the assumptions of interpretive phenomenology, the work of van Manen (1997) and the study aim. The study sought to create an in-depth insight into the experience of living with T1D, rather than to build new theory based on reoccurring patterns of themes across the participants (van Manen, 1997). It focused on building a picture of multiple family perspectives between individuals within families, between individuals in the sample as a whole, between families and between myself and the participants (McCarthy, 2003). Through thematic analysis, I did not intend to extract the most common themes, but rather to provide a range of examples of the experience of living with T1D in adolescence in order to explore the ways in which various individuals constructed similar or divergent realities (McCarthy, 2003). For example in Stage 2, I analysed each transcript as an individual text and not in relation to the themes already extracted from other transcripts. My analysis also aimed to combine the experiences of adolescents and parents/guardians to explore the data within the family context. The analysis process for each family data set is demonstrated in Figure 4.4 and described as follows.

(i) Contact summaries

Following each interview, I drafted a summary of the main issues raised, listing events, situations and actors (Miles and Huberman, 1994). This enabled an understanding of the general experience being described and the main actors involved, in preparation for a more in-depth thematic analysis.

(ii) and (iii) Thematic analysis of adolescent and parent interviews focusing on individual experience

I analysed the transcripts in family sets. I began the thematic analysis by reading through each transcript from start to finish, making reference to the contact summaries. Each page of the transcript was read through line-by-line (van Manen, 1997) and initial themes were noted using highlighting pens and notes in the text. Once the text had been highlighted, each theme was numbered, noted and described in a separate document, to produce a collaboration of themes for each transcript. A numbered list of themes was

Figure 4.4: Data analysis process for each family data set

(i) Contact summary

(ii) Thematic analysis of adolescent interview focusing on individual experience

(iii) Thematic analysis of parent interview focusing on individual experience

(iv) Exploration of adolescent interview data in relation to context data (background, CASI and parent interview data)

(v) Synthesis of adolescent, parent and context data

(vi) Data organisation: NVIVO

(vii) Extraction of final sets, themes and sub-themes

(viii) Exploration of the sets, themes and sub-themes in relation to the four existentials of the lifeworld (van Manen, 1997) and the generation of four thematic categories.

compiled as the themes emerged and multiple instances of themes were categorised together.

(iv) Exploration of adolescent interview data in relation to contextual data

I explored the adolescent interview data in relation to the data generated by the supporting methods of background data, the CASI diary tool and the parent interviews, with the aim of situating the adolescents' lived experiences within the context of diabetes management and family relationships.

(v) Synthesis of adolescent and parent data

Following the individual analysis of adolescent and parent transcripts, I synthesised the data to provide a synopsis of issues relating to the management of T1D within the family unit. In this stage of analysis, it was important to take note of the interplay of multiple family perspectives, and recognise the different voices and views of experience. Individuals within families speak from different positions, underpinned by gender, generation, history and personality. Some of the themes were distinguished by adolescents' voices alone, other by parents' voices alone, and others referred to supporting or conflicting perspectives which portrayed family behaviour or relationships in particular households (McCarthy et al, 2003). Parents cannot be assumed to give valid accounts of a child's world and vice versa. Their views are very different, and both contribute important insights (Miller, 2000). It was therefore important to distinguish when parents were talking about adolescents' behaviour and not to confuse this with adolescents' own views of their behaviour.

McCarthy et al (2003) distinguish a number of avenues for making sense of multiple family perspectives during interpretive analysis, which I took into account during this stage of analysis. Firstly, when individual accounts tell similar stories, this does not necessarily confirm reality and thus should not signal the close of interpretation. It should be questioned whether the agreement reflects a jointly constructed version of reality, and if this is grounded in the reality of their lives, or a superficial 'family script'. Secondly, when we hear multiple stories, we are able to fill in the gaps and draw an overall interpretation. The researcher must be mindful of the gaps which still remain and the process which enabled them to reach the overall interpretation. Thirdly, it is important to mindful of whether we are describing a 'family culture' or the existence of quite different individual realties within the family. Bearing these interpretive issues in mind during analysis ensured that quality was maintained in the data analysis and that the different voices of parents, adolescents and the family were preserved.

(vi) Organising the data: NVIVO

I imported the transcripts into an NVIVO database, and coded them with reference to the individual themes distinguished in stages (ii) and (iii). This enabled collaboration of the individual themes across the data set into categories and themes, and the building of new themes through comparison of individual experiences. NVIVO was not employed at an earlier stage in the analysis process as it is more suited to a constant comparative approach to data analysis characteristic of grounded theory studies, in which themes are derived through a process of attending back and forth to the data. Analysing the transcripts individually by hand in the first instance and using the software as a data organisation tool allowed the individuality of experiences to be preserved without the influence of other participants' experiences, before they were collaborated across the data set.

(vii) Sets, themes and sub-themes

I compiled a number of sets from the themes identified in the NVIVO database. I extracted coded data from the database into tables headed by each category. This enabled me to refine a large number of themes from the NVIVO database into more organised categories. The categories formed the basis for the phenomenological interpretation of the findings.

(viii) Exploration of the sets, themes and sub-themes in relation to the four existentials of the lifeworld (van Manen, 1997) and the generation of four thematic categories

As the aim of the study was to explore the lifeworlds of the participants, I explored the above themes and sub-themes in relation to the four existentials of the lifeworld (Van Manen, 1997) described in Chapter 3: lived space, lived body; lived time and lived other. This enabled me to establish an understanding of my interpretation of the lived experiences in relation to the facets of the lifeworld, thus facilitating theoretical rigour. Four categories emerged once the data had been organised in this way, which are presented in Chapter 6.

Reflections on the hermeneutic interview method: In-depth interviews allowed the exploration of lived experiences from the perspective of the participants, with an emphasis on their experience rather than my agenda. Interviews can be time consuming, as they require the researcher to visit each participant individually for one to two hours. However, the in-depth dialogue and the wealth of rich, descriptive data gathered would have been difficult to obtain through any other method (Robson, 1993).

Interpretive phenomenology does not advocate a specific method for data analysis. This could be seen as a limitation, as there will be variability between different studies applying the approach. I developed a method in relation to the philosophical underpinnings of the approach and to meet the aims of the study. The breakdown of the process into a number of steps allowed for transparency and potential replication of method.

Interpretive phenomenological interviews generate findings which are temporal and non-transferable to other populations, or to the same population at a later date (Heidegger, 1962). If an interview took place at a later date, the interpretation would be different as events occurring after the interview could influence the interpretations of both researcher and participant. This could be seen as a limitation to the validity of the findings, however interpretive phenomenological studies do not claim to generate more than a 'snapshot' of what an experience is like for a particular population, interpreted by a particular researcher, at a particular moment in time. This snapshot is underpinned by the uniqueness of the human being, and is instrumental to understanding the way in which a particular phenomenon is experienced by individuals (Johnson, 2000).

(iv) Focus groups

Objective: A researcher's interpretation of a participant's experience is influenced by the researcher's lifeworld. I planned to conduct focus groups separately with adolescents and parents to facilitate participant validation through discussion of findings. This aimed to reduce interpretation bias through member checking, which was found to be lacking in other qualitative studies of T1D in adolescence (Spencer et al, 2009).

Background: Focus groups are often used to modify enquiry after individual interviews, to discuss the themes that have emerged (Bloor et al, 2001) and clarify results (David and Sutton, 2004). Findings can be presented to the group, allowing feedback and validation (Flick, 2006). Focus groups require different skills to individual interviews, as group dynamics can influence responses and the validity of the data (Frey and Fontana, 1993). The researcher's role is to facilitate interactions between participants and to prevent domination of the discussion by single participants or groups of participants. It is usual for two researchers to be present; one to act as facilitator and one to take notes relating to content of the discussion or interactions between participants. In a validation focus group, the researcher 'steers the dynamics' of the interaction by using provocative questions to support the dynamics and functioning of the group (Flick, 2006).

Design: The aim of the focus groups was data validation rather than the generation of new data. The groups were structured around activities which aimed to serve this purpose. The structure of the adolescent and parent groups were different and tailored to an appropriate level for the participants, but both aimed to present the participants with the interpretive themes for their discussion and validation.

I designed the adolescent focus group exercise to maintain the interest of the adolescents and encourage interaction, as adolescents may be reluctant to interact confidently in an unfamiliar group situation. Texts and images can be a useful way to stimulate further discussion (Flick, 2006) and therefore I used posters as a visual aid. The eight emerging categories from the interpretive phenomenological analysis were presented on A0 size posters, and placed on the wall around the room. Six quotations were presented on each poster to demonstrate the themes within each category, and the participants were asked to select two themes from each category which had the most meaning for them. For the parent group, posters were produced in the same format, but were presented as a booklet rather than as a poster.

Recruitment: All of the participating families were invited to participate via a letter. They were asked to contact me if they were interested in taking part. If there was no response, I contacted the family after a two-week period. I hoped that all participants would participate in the focus group exercise in order for the exercise to serve as a validation device, however only six parents and adolescents participated, which limited the validity of this as a method of member-checking.

Implementation: The adolescent and parent focus groups were held separately in a seminar room at the clinic. I chose this venue as it was easily accessible and familiar to the families. The participants, myself and another facilitator sat around a central table and the discussion was digitally recorded with the consent of the participants. Each participant was subsidised £20 to cover travel to and from the venue and refreshments were provided.

A focus group rule sheet was developed which provided a summary of the study so far, and the intended structure of the focus group. The adolescent rule sheet can be found in Appendix VI; the parent sheet took a similar format. It outlined important considerations surrounding group dynamics, and ethical issues including informed consent and right to withdraw. As an ice-breaker, I asked each participant to introduce themselves to the group and give a brief description of their experience of living with diabetes. Participants were given green stickers and asked to place them on each poster to represent the two quotations that they related to most strongly. If they strongly disagreed with any quotes they were asked to label these with a red sticker. The themes from each category with the most red and green stickers were then discussed within the group.

Data analysis: Verbatim transcription of the focus groups was not necessary, given that the purpose was validation rather than the generation of new themes. The number of stickers placed on quotations in the adolescent focus group was recorded in a table. I listened to the digital recording of the discussion again and quotations were added to the table to support the findings, under the pre-defined themes of the validation discussion.

Reflections on the focus group method: The interactive poster method in the adolescent focus group was successful for collecting opinions on the themes and quotations. However, the discussion became limited towards the end of the meeting and my input was instrumental to stimulating further discussion. Domination and peer pressure can be problematic when holding groups with adolescents (Bloor et al, 2001) and there is the possibility that group members may over-conform to the majority decision of the group (Frey and Fontana, 1993).

The method employed in the parent group was also successful for exploring the findings, however the unaffiliated group discussion before the validation exercise took place lasted for approximately two hours. Late-comers to the meeting meant that previous discussion was reiterated, as the other parents were interested in the newcomer's experiences. This was positive, as the discussion was guided by the participant's own initiatives. However, on a practical level some of the participants became anxious to leave near the end of the meeting whilst completing the validation workbooks, which could have affected their response.

Due to limited recruitment to the focus group sessions, I was unable to use them as a member-checking device. In hindsight, individual follow-up interviews would have been more appropriate to check my interpretation of each individual participant's experience and thus reduce interpretation bias. However, I chose focus groups as they were cost and time-effective (Bloor et al, 2001), and it was anticipated that all participants would attend. Due to these limitations, the focus group data was used as additional data to support or contradict the themes emerging from the individual interviews, not as a validation of my interpretation of the interview data, as originally planned. Despite this, the focus groups served as an effective dissemination tool to those who participated and provided a forum for positive discussion and empowerment.

Section 2: Ethics and rigour

Throughout the research process, I implemented a number of measures in order to maintain good ethical practice and ensure methodological rigour, with the aim of producing high quality research. Social researchers have a responsibility to take account of the effects of their actions upon the subjects of their research and to preserve their rights and dignity. Ethical principles regulate the relationship between researchers and participants to ensure just practice in the interests of the participants (Gilbert, 2001).

4.4 Ethical issues

There were four main ethical issues that merited attention throughout the study, described as follows.

Informed consent

Participants consenting to participation in a research study should have sufficient understanding and intelligence to understand what is proposed; have the ability to make a decision in their own interests (Gillick, 1984); be adequately informed about what will be required of them; and able to give their consent voluntarily (Allmark, 2003). In the information sheets, I stated the aims of the research, the commitment required, what would happen to the results, and assurance of confidentiality (Hill, 2005). To ensure that potential participants were competent to give informed consent, I presented the information sheets in clear language, with any terms explained clearly. For example, I explained confidentiality in the following way in the information sheet (see Appendix I): *'All the information that you give me will be kept confidential. This means that nobody will see it apart from the research team and that you will not be named. Anything about you will have your name and address removed so that no one will know it is about you.'*

I explained the contents of the information sheets verbally at the clinic during face-to-face recruitment, where the parents and adolescents had the chance to ask questions about anything they did not understand. I emphasised that their participation was entirely voluntary, and allowed them time to make a decision whilst they were waiting in the clinic. If they wanted more time to consider taking part, I offered to telephone a week later. Following these procedures ensured that participants were adequately informed about the study in a way they could easily understand, and they were therefore able to make an informed decision about their voluntary participation.

There is a risk that adolescents may find it difficult to refuse to take part in a proposed study, due to adults having an ascribed authority over children. They may find it difficult to disagree or say things which they perceive an adult will think are unacceptable (Hill, 2005). Although this difference in social status could not be avoided, I strived to minimise authority by using informal language and sitting in a position comfortable for the child (Alderson, 1995), i.e. at the same level as them.

It is commonly debated whether participants under the age of sixteen can give valid consent on their own behalf (Alderson and Morrow, 2004), although children who are of sufficient understanding to make an informed decision currently have the right to refuse medical examinations and care orders (Children Act, 2004). As the legal situation is unclear (ESDS, 2005), English medical research guidelines advise obtaining parental consent for all minors under 18, whilst respecting the minor's refusal and gaining their assent for participation (Alderson and Morrow, 2004). In line with this, parents/guardians gave consent for themselves and for their child to take part and the adolescents gave assent for themselves and their parents to take part. Gaining parental consent and adolescent assent ensured that parental approval was gained whilst respecting the adolescents' growing self-awareness and independence for decision making. This process also ensured that all members of the family agreed to take part in the study.

Confidentiality

Researchers have a responsibility for the integrity and confidentiality of clinical records and data generated by the study (DoH, 2005b), in line with the Data Protection Act (OPSI, 1998). To ensure data protection, I protected CASI and all other computer files with a password and username, needed for access. I removed all participant names and replaced them with codes known only to myself. I stored all personal details, including consent forms, separately from the data in locked filing cabinets.

Participants or organisations should not be identifiable in research reports (DoH, 2005b). I did not identify individual participants and the clinic specifically identified in the research report and I took care to reduce the risk of identification by close others. However, the lead contact at the clinic was aware of who was taking part in the study; and therefore may have been able to identify families when reading the research report. There was also a danger that the participants would be easily identified by themselves and close others (parents and health professionals) due to the individual nature of the lived experience data collected. I informed the participants of this in the information sheet (Appendix I) and verbally at the point of consent, and assured them of data protection.

Protection

Priority must be given to the dignity, rights and safety of research participants and the benefits of conducting the study must outweigh the risk of harm to participants. Asking about sensitive topics can cause emotional harm including anxiety, distress, embarrassment and mental discomfort (Alderson and Morrow, 2004). I ensured that measures were in place to minimise harm to participants and guarantee that support was available to them should emotional distress occur as a result of taking part in the study. I informed them in the interview brief that they could stop the interview/focus group at any time, and could refuse to answer any questions they did not feel comfortable with. I recruited two psychologists to the Research Advisory Group (RAG) to provide support to participants if needed. In the interview and focus group briefs, I assured participants of access to support should they feel distressed.

The relationship between the researcher and the participant in qualitative health research is complex (Peel et al, 2006) and the line between research and therapeutic interviews is often not clear (Beitin, 2008), particularly when researching a sensitive subject matter such as this. For example, one mother commented to me that she was rarely asked about how she felt about her son's diabetes and that talking about it had made her realise how concerned she was for his future health. I recommended that she talk to her son's nurse if she felt she needed further support and she agreed that she would. Peel and colleagues (2006) also found that adults with Type 2 diabetes found participation in interviews about their experiences therapeutic in relation to addressing an unmet service need.

Although it was impossible to foresee participants' emotional responses to questions, I was sensitive to verbal and non-verbal cues during the interviews and did not probe participants further if they appeared to be distressed by a particular question. Three of the parents became upset during their interviews, suggesting emotional distress. When this happened, I asked them if they wished to stop the interview, but all wished to continue. All parents and adolescents were informed at the end of the interview that they should talk to myself or their specialist nurse should they feel they needed further support with any of the issues raised. There was also the potential that the sensitive nature of the topic could cause distress to myself, in concern for the welfare of the participants. For example, the psychologists on the RAG provided me with advice and support in the following situation.

There was a possibility that during the course of the interviews, an adolescent or parent could disclose an incident of harm to a minor (Hill, 2005). I had a duty of child protection if a child or young person divulged to me that they or others were at risk of significant harm (Alderson and Morrow, 2004). The information sheets and interview/focus group briefs stated that confidentiality would not be maintained if information suggesting risk of harm to a young person emerged. The lead contact at the clinic was the point of contact should this situation occur. During the data collection process, an incident occurred which led me to question the definition of 'harm to minors'. In the Salisbury family, the daughter completed the CASI diary tool but refused to take part in an interview. On interviewing her parents, they disclosed to me that she rarely tested her blood, often refused to inject her insulin and was often found to be drinking alcohol with friends. The parents also disclosed that they found it difficult to cope with their daughter's diabetes emotionally.

The literature generally defines harm to minors as reports of abuse (Hill, 2005). Although this adolescent was not being deliberately harmed by an adult, I questioned whether her behaviour could be defined as 'self-harm' in terms of the damage she was causing to herself by not looking after her diabetes. I also felt concerned that her parents' distress indicated that they were not able to support her adequately and was concerned that I had a moral duty to pass this information on to the hospital.

I made an appointment to visit one of the psychologists from the RAG and without naming the family, asked their advice on what I should do. They advised me to talk to the specialist nurse without naming the family and ask whether, given the situation she felt that this amounted to an incident of harm that merited disclosure. The nurse was aware of the families taking part in the study, and when I told her about the situation, she informed me that if I was referring to one particular family, then she was fully aware of the situation. This was in fact the family that I was concerned about and was therefore relieved of the ethical responsibility I felt for the adolescent's welfare, without breaking the confidentiality agreement.

My safety as a researcher in the field also had to be taken into account, as fieldwork involves entering unknown environments with unknown participants (Oliver, 2003). Visiting participants in their homes for interviews posed a risk to my safety, even though a certain amount of confidence could be gained from knowing that the families were familiar to the nurse at the hospital. Therefore, a safety protocol was followed when visiting participants' homes. Before each visit, I gave the name, address and telephone number of the participant to my supervisor in a sealed envelope, only to be opened should an emergency occur. I also informed her of the time of the visit. Once I had left the participant's home, I sent a text message to my supervisor. Had my supervisor not received a text within two hours and thirty minutes (three hours if two interviews were taking place in succession) from the start time of the visit, she was to telephone me to confirm my safety. If I did not answer, she was then to open the sealed envelope and telephone the participant's house. Should they not answer, the emergency services were to be informed. Such a situation did not occur during the study, however on two occasions I had to text my supervisor during the interview to inform her that I was running late.

4.5 Research governance

NHS approval

All research conducted with NHS staff or patients must be granted ethical approval from the LREC in accordance with the Research Governance Framework (Department of Health, 2005b). Ethical permission was granted and I held an honorary contract with the NHS site to allow legitimate interaction with the participants (Department of Health, 2005b). Addressing these issues at the beginning of the study enabled sound ethical practice throughout the research process.

Research Advisory Group

I recruited a Research Advisory Group (RAG) with the objective of overseeing the progress of the study and facilitating ethical transparency in the research process in terms of the issues discussed in Table 4.8.

The terms of reference for the group aimed to:

1. Bring together a range of stakeholders to discuss the progress of the above named research project
2. Recognise the lay experience of each member of the group
3. Ensure that the research project was conducted to the highest ethical standards.
4. Provide the researcher with a forum where expert advice could be sought on:
    - the progress of the research.
    - methodology
    - theoretical framework
5. Identify options for strengthening the research project.

The group was comprised of a range of lay, academic and clinician stakeholders to ensure a wide-range of view-points and expertise within the group. Group membership is shown in Table 4.8. Members were aware of the terms of reference, in order to ensure the objective of ethical governance for the study was met. The group met every three months whilst the study was being conducted and assisted with issues such as the structure of the interview guidelines and the design of the CASI software. The lay members of the group piloted the CASI Diary Tool and interview guidelines and the clinical psychologists provided support to the researcher and participants as described in Table 4.6. The lay group members were compensated £20 for attendance at each meeting, with regard to the recommendations of the National Children's Bureau (2003).

Table 4.6: RAG Membership

Member Affiliation	Member Roles/Professions	Number of Members	Total
Lay Members	Adolescent male with T1D	1	
	Adolescent females with T1D	1	
	Mother of adolescent with T1D	2	
	Young adult with T1D	1	5
Clinicians	Diabetes specialist	2	
	paediatrician	1	
	Diabetes specialist nurse	1	
	Diabetes specialist dietician	1	
	Consultant clinical psychologist	1	6
	Diabetes specialist psychologist		
Academics	Researcher	1	
	Research supervisor	2	
	Clinical psychologist	2	
	Complexity science expert	1	6
Total			**17**

4.6 Rigour

Qualitative research in the medical field has been criticised as subjective in a discipline dominated by clinical trials of a reductionist nature (Mahoney, 1997). In Chapter 3 I discussed the particular importance of transparency in the research process when conducting an interpretive phenomenological study, due to the subjectivity inherent in the influence of the researcher on the research process. Rigour was ensured throughout the study in the following ways:

- A number of data collection methods were combined to facilitate triangulation.
- I kept a detailed audit trail record, which detailed the recruitment, data collection and analysis process, as well as a research diary to facilitate and document development of thinking and self-reflection. I have used this to reflect on the methods employed throughout the

current chapter.

- This chapter documents a detailed description of the research methodology, which acknowledges the strengths and limitations of the methods used.
- Chapters 1-3 provided a description of my preconceptions, which are critically reflected upon in the discussion in Chapter 7.

Although interpretive accounts are inherently value-laden by the nature of interpretation, adhering to these measures and taking a reflexive approach to the research process ensures that the study can be replicated by other researchers. It also ensures that the reader is able to make an informed judgement on the validity of the interpretation of experience based on a detailed knowledge of the research process and influence of the researcher.

4.7 Summary and conclusions

This study aimed to explore the lived experiences of adolescents with T1D, the psychosocial factors exploring blood glucose control and the applicability of complexity science to the study of adolescent diabetes management. In this chapter I have described the methodology employed to meet the primary objective of exploring the lived experiences of adolescents with T1D through an interpretive phenomenological approach. I have described the research process as well as ethical issues and methodological rigour.

The research methods chosen were underpinned by the philosophy of interpretive phenomenology. I recruited a maximum variation sample with the aim of exploring a wide and varied range of lived experiences. I constructed an original, multi-method approach to interpretive phenomenological research to suit the research question, with the aim of facilitating the production of new knowledge. As well as providing a range of contextual data within which to situate the lived experiences of adolescents, triangulation of methods and participants (adolescents and parents) also had the benefit of improving understanding in the study of a complex phenomenon, and providing scientific rigour.

I explored the lifeworlds of adolescents with T1D through the central method of hermeneutic interviews, underpinned by the four existentials of the lifeworld. Background data obtained from the clinic, the CASI Diary Tool and hermeneutic interviews with parents provided important contextual data within which to situate the adolescent lived experience data. Data analysis took a rigorous, seven-step approach influenced by interpretive phenomenological theory and the aims of the study. I conducted focus groups with the aim of data validation, but poor recruitment meant that the data could be used in a supporting sense only. I ensured scientific quality of the findings through reflexivity and good ethical practice to maintain methodological rigour throughout.

This multi-method qualitative approach to data collection and analysis enabled the exploration of the lived experiences of adolescents with T1D, with reference to contextual factors within the lifeworld. It provided a range of contextual data within which to situate the lived experiences of adolescents, and triangulation of methods and participants (adolescents and parents) improved scientific rigour. The data provided a 'snapshot' of the experience of living with T1D for a group of adolescents and their parents, based on my interpretation. This interpretation was based on the previous life experiences I was able to relate to when hearing the participants' stories. Recognition of my interpretive position can be found in the biographical note in Appendix V. This rich, lived experience data provided a description of the lived experiences of adolescents with T1D, which can be explored in relation to the second research question:

- *Are the principles of complexity science applicable to lived experiences of adolescents with T1D?*

My knowledge of complexity science and its influence on data collection and analysis was acknowledged as influential to the research process, as my world and preconceptions could not be 'bracketed' during the interpretation process. However in meeting the primary objective of the study, the focus of the methodology was to explore the lived experiences of adolescents with T1D. Knowledge of complexity science positively influenced me to be open to the complex nature of living with diabetes and the many possible psychosocial factors affecting blood glucose control. However, the principles of *complex systems* were not taken into account in the analysis of the lived experience data, but will form the basis for discussion in Chapter 7. Preceding this, in the following two chapters I describe the participants and the findings of the study.

Chapter 5: The families

Introduction

In Chapter 4 I discussed the methodology employed to study the lived experiences of adolescents with T1D. Applying a multi-method qualitative approach guided by the philosophy of interpretive phenomenology enabled the exploration of the lifeworlds of adolescents with T1D, with the aim of gathering high quality data to provide a platform for the investigation of the applicability of complexity science to the management of T1D in adolescence. In Section 1 of this chapter, I present the outcome of the sampling process; in Section 2 I describe the biomedical and social characteristics of the participating families.

5.1 Recruitment: response rates and attrition

Table 5.1 illustrates the response rates in the four stages of the recruitment process. Recruitment in stage 1 was unsuccessful due to the small number of families invited (n=30) and the postal method employed. When I increased the invited population in stage 2, the response rate improved slightly. As discussed in the previous chapter, stage 3 was the most successful method due to face-to-face contact with participants. I approached twenty-five families in the clinic over eight weeks and recruited a sample of twenty adolescents and their parents (n=27) (60% response rate). This sample size (n=47) was adequate to represent participants from a range of contexts and backgrounds whilst maintaining quality in data analysis. It must be noted that those I approached in stage 3 had already received an invitation letter in either stage 1 or stage 2. Therefore the numbers shown in the 'Approached' column in Table 5.1 do not reflect the total number of participants invited, but rather the amount of times potential participants were asked to participate.

Following the withdrawal of seven participants before data collection began, I implemented a fourth stage of recruitment to maintain the sample size. Reasons for withdrawal included moving away from the area and emotional difficulties. I recruited further participants in relation to the characteristics missing from the sample frame following the withdrawals.

The total number of families approached across the four stages was 152. A total of 27 were recruited giving a 17.8% response rate. Thirty-two per cent of the families later withdrew from the study for the reasons described above, leaving a total of twenty families (twenty adolescents and twenty-seven parents).

5.2 Sample characteristics

The characteristics of the recruited sample are shown in Table 5.1. The balance of characteristics shows that the sampling technique was successful in obtaining a maximum variation sample. It was important to achieve this balance in order to explore the experience of living with T1D in adolescence in a varied range of contexts.

I recruited slightly more females than males (n=9/11) and the four age groups were moderately balanced (with slightly more fifteen year olds than the other age groups).

Blood glucose control was categorised in the clinic as shown in Table 5.1. Ten of the adolescents needed to improve their HbA_{1c} levels, with eight posing a risk to their health in the 'Risk zone' and 'Your health is now at risk' categories. Ten had good control of their diabetes, with one defined as excellent (<7.4%). Only two had a mean HbA_{1c} level of the recommended 7.5% or under and two had a dangerously high average HbA_{1c} of over ten per cent.

The participants used three different insulin regimes. Seven used a basal bolus regime, eight used twice daily injections, and five were using a combined regime, consisting of 24 hour basal insulin, a long acting insulin given in the morning to cover the school day and a fast-acting taken with their evening meal.

Most of the adolescents were diagnosed over the age of ten (n=11), but a fifth were diagnosed under the age of five (n=4) and five between the ages of five and ten.

Table 5.1: Sample characteristics

Maximum Variation Characteristic	Number of Participants (%)
Gender	
Male	9 (45)
Female	11 (55)
Age	
13	4 (20)
14	5 (25)
15	7 (35)
16	4 (20)
Insulin regime	
Twice daily	8 (40)
Basal bolus	7 (35)
Combined	5 (25)
HbA_{1c} (Clinic classification categories)	
Excellent control (6-7.4%)	1 (5)
Good to reasonable control (7.5-8.5%)	9 (45)
Needs improving NOW (8.6-9%)	2 (10)
Risk zone (9.1-9.9%)	6 (30)
Your health is NOW at risk (10% +)	2 (10)
Age at diagnosis (years)	
<5	4 (20)
5-10	5 (25)
<10	11 (55)
Family characteristics	
Living with birth mother and father	12 (60)
Living with birth mother alone	6 (30)
Living with birth mother and step-father	2 (10)
Parent/guardian participation	
Mother/female guardian and father/male guardian	7 (35)
Mother/female guardian alone	13 (65)

Twelve of the adolescents lived with two parents, six lived with their mother alone and two lived with their mother and step-father, which gave a good representation of different family types. Despite striving for optimum father/male guardian participation, the female parent/guardian alone took part in thirteen of the families and both parents took part in seven of the families. Difficulties in the recruitment of men to qualitative research within the household have also been documented by other researchers (Daly, 1992).

5.3 Focus group recruitment and participants

The characteristics of the focus group participants are shown in Table 5.3. One family responded to the focus group invitation letter; I contacted the remaining families two weeks following the sending of the letters and seven agreed to participate. The group included eight adolescents (four female and four male), five mothers and three mother and father couples. One family withdrew by email two days before the event due to personal circumstances (one adolescent female and her two parents), and one male did not turn up to the adolescent meeting. Six adolescents and six parents attended the focus groups on the day, shown in table 5.3

Table 5.2: Focus group attendees

Participant (pseudonym) and Age	Parents Attending
Tom Butcher, 15	Mother
Samantha Makin, 15	Mother
Anthony Mather, 15	Mother
James Pickering, 15	Mother & father
Jenny Dutton, 17	Mother
Jane Fletcher, 13	0

5.4 Introducing the families

Drawing on the clinical, interview and CASI data, I have compiled the following synopses of each family's characteristics to provide the context within which to situate the lived experience findings that follow in Chapter 6. Pseudonyms have been used to protect the identities of the participants.

The Butcher family

Tom Butcher was a fifteen year old male who lived at home with his parents and twelve year old brother. His mother and father both worked full-time, but his father worked shifts so that one parent was always at home with the children. He was diagnosed with T1D at the age of eight and was currently using a combined insulin regime. Tom's HbA_{1c} was 7.5%, meaning that he had excellent control of his diabetes. He was adherent to the CASI diary tool, in which he reported testing his blood glucose three times a day, eating four portions of fruit and vegetables over the week and taking four hours of exercise. He was fairly active, participating in PE and football after school. He acknowledged that his diabetes caused restrictions to social activities occasionally, but otherwise felt he coped with it well and saw it as a natural part of his daily life. Tom's mother also participated in the study. She took a controlling role in her son's diabetes management and was anxious about him managing away from home.

The Ratledge family

Sean Ratledge was a fifteen year old male, who had been diagnosed with T1D aged five. He lived at home with his parents, who were fostering an eight year old girl and also looked after his ten year old female cousin. His father worked full-time and his mother stayed at home. Sean's HbA_{1c} was in the risk zone at 9.9%, although he reported testing his blood regularly in the CASI diary tool three times a day. He recorded eating eight portions of fruit and vegetables over the week and participated in a range of sports including kick-boxing, football and athletics. Sean used a twice-daily insulin regime. Both of his parents participated in the study and were interviewed separately about their experiences. The family found it difficult to control Sean's blood glucose and unpredictable blood glucose fluctuations caused anxiety for his parents. They believed that the diabetes clinic gave conflicting advice and therefore preferred to look after his diabetes their own way.

The Stanley family

Stewart Stanley was a sixteen year old male who had T1D since the age of three. He lived at home with his parents and had four sisters aged 24, 21, 15 and 13 (the two elder sisters had left home). His father worked full time and his mother stayed at home to care for her children and granddaughter. Stewart's HbA_{1c} was 8.5%, which represented good to reasonable control. He used a combined insulin regime. He reported 6.5 hours of exercise in the CASI diary but only two portions of fruit and vegetables over the week. He reported testing his blood three times per day. Stewart was very dependent on his mother for the self-management of his diabetes, and she took control. He did not participate in many social activities outside the family, apart from playing golf with his father. Stewart's mother also participated in the study. She was extremely concerned for her son's future health and preferred to keep him within the home environment where she felt he was safe.

The Salisbury family

Beth Salisbury was a thirteen year old female who lived with her parents and her younger brother, age eight. Her father worked part-time and her mother stayed at home. Beth had been diagnosed with T1D at the age of four. A HbA_{1c} level of 10.7% meant that her health was at risk, and she reported very little data in the CASI diary tool. Beth used a twice-daily insulin regime. Her parents' reported that she very rarely tested her blood glucose, only injected insulin when her parents prepared the needles for her, rarely participated in physical activity and ate a poor diet. She had also recently started drinking alcohol with her friends. Both parents participated in the study and were interviewed together. They were anxious and concerned as they felt Beth did not accept her diabetes. They wanted her self-management to improve, but felt helpless. Beth completed the CASI diary tool but withdrew from the interview, which may have reflected her difficulty in coming to terms with her disease.

The Bingham family

Emma Bingham was a sixteen year old female who had been diagnosed with T1D age five. She lived with her mother and younger brother, age nine. Her parents divorced three years ago and she rarely saw her father. Emma's HbA_{1c} was 8.5%, reflecting good to reasonable control, however she had experienced a number of severe hypoglycaemic events during the past four years. She was adherent to the CASI diary tool and recorded testing her blood glucose three times a day. She only reported eating two portions of fruit and vegetables in the week and did not undertake any exercise. She used a basal-bolus regime. Emma's mother also took part in the study. She trusted her daughter to manage her diabetes independently and it was evident that Emma did not need to rely on her mother for help.

The Brookes family

Lisa Brookes was a sixteen year old female who lived with her mother and eighteen year old sister. Her parents divorced when she was nine and she saw her father occasionally. Lisa had been diagnosed at the age of seven. She used a twice-daily regime and had a good to reasonable HbA_{1c} level of 8.1%. She was not adherent to the CASI diary tool and entered little data over the week period. She also reported rarely testing her blood glucose. However, she accepted diabetes as part of her life and never missed an insulin injection. Lisa's mother also took part in the study. She felt her daughter managed her diabetes well, however her mother found it hard to deal with blood glucose fluctuations and relied on Lisa's sister to assist with hypoglycaemia. Lisa had violent mood swings, and although she was now doing well at school, had been expelled in the first year of secondary school for bad behaviour. He mother attributed this behaviour to her diabetes.

The Jones family

Russell Jones was a fourteen year old male who had been diagnosed with T1D aged eleven. His HbA_{1c} was 8.7% (good to reasonable control) despite his sporadic self-management behaviour on the basal bolus regime. He rarely tested his blood glucose and described missing meals and injections on a regular basis, if other priorities (i.e. playing in a band with his friends) took over. He entered little data into the CASI diary. Russell lived with his mother and his twelve year old sister. He went to stay with his father and step-mother every weekend, where he reported going out with his friends and drinking alcohol. His mother was fairly young, and described a chaotic and untidy lifestyle in which she felt she did not have the energy to cope with the demands of her children. She wanted her son to be independent in his diabetes management, as she felt it was another pressure she had to deal with as a single mother. However without her help, his diabetes was an inconvenience and was pushed into the background as he was not ready to take responsibility.

The Collins family

Ian Collins was a thirteen year old male who had been diagnosed with T1D aged eleven. He lived with his parents and two-year old brother, and his father also had T1D. He was extremely adherent to the CASI diary tool and reported testing his blood glucose twice a day. He was self-disciplined and independent in his self-management, demonstrated by his ability to test and inject away from home and manage his diabetes around an active lifestyle. He only reported one hour of physical activity in the CASI diary tool, although in his interview he reported taking part in a range of different sports teams including rugby and football. Despite his adherence and acceptance of his diabetes, his HbA_{1c} level was 9.1%, placing him in the risk zone. Both of Ian's parents participated and were interviewed separately. Both worked full-time and Ian's grandmother often looked after him and his brother after school, and accompanied him to his clinic appointments. T1D had been a normal part of daily life for this family before Ian was diagnosed and therefore felt he had adapted to living with the disease fairly quickly.

The Makin family

Samantha Makin was a fifteen year old female who had lived with T1D since the age of four. She had a good to reasonable HbA_{1c} level of 7.5% and reported that she had always maintained good control of her diabetes. She used a twice-daily insulin regime and reported testing her blood three times a day. She did not participate in sport apart fro PE in school, but reported walking a mile to school and back each day. She reported eating nine fruit and vegetable portions over the week. Samantha lived with her birth parents, her sister (age thirteen) and her brother (age eleven) who also had diabetes. Samantha blamed herself for her brother's diagnosis and felt it her responsibility to encourage him to maintain good blood glucose control. Samantha's mother also took part in the study. She worked part-time whilst her husband kept a full-time job. She described diabetes taking over family life sometimes on outings and holidays, but also described a routine of management that they had become accustomed to with two of their children living with the disease. Samantha's mother was concerned that Samantha had recently become concerned about her weight and had reduced her food intake, leading to more frequent hypos.

The Morris family

Sarah Morris was a fifteen year old female who had lived with T1D since age three. Her HbA_{1c} level was in the risk zone at 9.8%. She lived with her mother and younger brother aged nine. Her parents had divorced when she was five. Her mother was unemployed but was a full-time carer to her mother and brother who both had disabilities. Sarah did not enter any data into the CASI diary and this reflected her lack of adherence to her diabetes regime. She had recently transferred from a twice-daily to a basal bolus regime and her new 'freedom' enabled her to stay out with her friends for long periods of time without injecting insulin, meaning that her blood glucose was high most of the time. Sarah's mother took part in the study. She respected her daughter's independence but wished she would take more responsibility for her diabetes as she worried for her future health. Sarah reported drinking alcohol with her friends most weekends, which had led to severe hypoglycaemia on few occasions.

The Collier family

Darrell Collier was a thirteen year old male. He was the most recently diagnosed, less than one year ago. His HbA_{1c} was eight per cent, indicating that he was managing to achieve good to reasonable control of his diabetes.

He reported testing his blood glucose twice a day and undertook four hours of physical activity during the week. Darrell had good control of his blood glucose, but diabetes had altered his life and his independence. He used a basal bolus regime, but went to his grandmother's house each lunch time from school to inject and his mother reported him spending less time with his friends since his diagnosis. Darrell lived at home with his birth parents and two older sisters (age seventeen and nineteen). His mother worked part time in the evenings and his father worked full time. His mother participated in the study.

The Mather family

Anthony Mather was a fifteen year old male who had been diagnosed at the age of thirteen. He lived with his mother and twelve year old sister, but spent a lot of time at his grandmother's house as his mother worked full-time. He used a twice daily regime and had a good to reasonable HbA_{1c} level of 8.3%. He did not enter any data into the CASI diary tool but stated that it had encouraged him to think more about his diabetes management. Anthony's mother also took part in the study. She worried that her son appeared to cope with his diabetes in order to protect her, when deep down he struggled to come to terms with it. His mother worried for his safety when he was away from home and felt that she could not leave him alone in the house in case hypoglycaemia occurred, which restricted his independence.

The Dougherty family

Emily Dougherty was a fifteen year old female who had lived with T1D since the age of ten. She had a good to reasonable blood glucose control level of 7.6%. She lived with her birth parents and older brother who was eighteen. Emily's father also had T1D and her mother worked in health care, meaning that she was well supported. She reported eating the most fruit and vegetable portions in the sample (n=16) and was fairly active, participating in 4.5 hours of physical activity during the week she kept the CASI diary. She used a basal bolus regime and reported testing her blood three times a day. Emily's parents both took part in the study, and all family members reported that Emily's diabetes was well managed and did not cause her any restrictions. However the data from this family had to be viewed in light of the fact that Emily's father sat in on Emily's interview, and Emily sat in on her parents' interview. This may have restricted their responses considerably and therefore data relating to family relationships could not be used.

The Pickering family

James Pickering was a fifteen year old male who lived with his birth parents and older brother (seventeen). James's father also had T1D, and James had been diagnosed at the age of six. His HbA_{1c} of 8.5%, reflected good to moderate control. He reported testing his blood twice a day during the week he kept the CASI diary, eating three portions of fruit and vegetables and participating in five hours of physical activity, which mainly consisted of football. He used a combined insulin regime and described how he had overcome his fear of injecting when he was younger through counselling. His father worked part-time and his mother was unemployed. Both parents took part in the study and were interviewed together. They worried for James's future health as his father had experienced discrimination and complications despite maintaining better blood glucose control than his son.

The Thomas family

Holly Thomas was a fifteen year old female who had lived with T1D since the age of eleven. Her HbA_{1c} was 8.1%, reflecting good to reasonable control. She lived with her mother and older sister (age eighteen). Her parents were divorced and she spent two evenings a week with her father. Holly's mother also took part in the study. Holly was independent in her diabetes management and used a basal bolus regime, although her mother reported taking a greater role in her daughter's management since a severe episode of hypoglycaemia had occurred. She felt that she had trusted her daughter's independence too soon and that her input was still needed in order to maintain good blood glucose control. Holly reported testing her blood glucose three times a day in the CASI diary and was fairly active, spending four hours a week doing exercise. She reported eating four portions of fruit and vegetables during the week. Holly felt that her diabetes shaped her social life as she preferred to spend time at home with her family where she felt in control.

The Edwards family

Martin Edwards was a fourteen year old male who had been diagnosed at the age of eleven. His HbA_{1c} level was 7.8% (good to reasonable control). He was very active, reporting 7.5 hours of physical activity in the week he kept the CASI diary. He managed his active lifestyle by carrying glucose tablets and snacks with him. He used a twice-daily regime and reported testing his blood glucose three times a day. He lived with his parents and older brother, age sixteen. His father worked full-time and his mother part-time. His mother took part in the study. She voiced her concern that her son had a poor diet and often missed his lunch to play football with his friends. Overall, Martin felt he coped well with his diabetes, although he felt his mother restricted him sometimes on going on school outings and other social activities.

The Dutton family

Jenny Dutton was a fourteen year old female who was diagnosed aged ten. She had the highest HbA_{1c} in the sample of 11.4%, meaning that her health was at risk. She entered limited data into the PDA diary but stated that she wanted to gain better control of her diabetes. She lived at home with her mother and younger brother (age two) saw her father occasionally. Her mother was unemployed. Jenny used a twice-daily regime but reported rarely testing her blood. She had experienced a severe episode of DKA earlier that year and had been in hospital for over a week. This had scared her and made her realise the implications to her health if she did not maintain good control of her diabetes. Her mother desperately wanted her to test her blood glucose more regularly in order to gain better control.

The Gibbons family

Steven Gibbons was a sixteen year old male who had lived with T1D since the age of thirteen. His HbA_{1c} level was 8.3%, reflecting good to reasonable control. He lived with his birth parents and younger sister (age five). He did not report any fruit and vegetable intake in the CASI diary, although he did report three hours of exercise during the week and testing his blood glucose twice a day. He used a twice-daily regime and felt that he managed his diabetes well. Steven's mother also took part in the study. She described her anxieties about his self-management, independence and future health and found it difficult to let him go. Steven felt that his mother worried too much about his diabetes and often found her input frustrating.

The Fletcher family

Jane Fletcher was a thirteen year old female who had been diagnosed with T1D at the age of eight. Her HbA_{1c} level was 9.6%, which was situated in the risk zone. She lived with her birth mother and step-father, and older brother (sixteen). She used a combined regime and reported testing her blood glucose twice a day, no exercise and the consumption of three portions of fruit and vegetables over the week. Jane's mother and step-father took part in the study and were interviewed together. Her step-father described his integration into a family were T1D was a way of life and the learning process involved. Her parents felt anxious about Jane participating in school activities, but were wary not to restrict her independence because of her diabetes. Jane had experienced severe hypo and hyperglyaemic events and gave in-depth recollections of her experiences.

The Jeffs family

Neil Jeffs was a fourteen year old male who had T1D since the age of ten. His HbA_{1c} was 8.9% and therefore needed improving. However, he appeared to have good control of his diabetes, demonstrated by his adherence to the CASI diary tool. He reported testing his blood glucose three times a day, and was fairly active, taking part in five hours of physical activity per week. He lived with his birth parents, older brother (age eighteen) and twin sisters (age twenty-one). Both of his parents took part in the study and were interviewed together. They described how they took on the management of Neil's diabetes as a family team, and Neil described appreciating this support. His parents described feeling they had become too anxious about blood glucose testing, but had managed to reach a balance where diabetes was managed within the family environment. The basal bolus regime had benefited the family lifestyle in bringing more freedom.

5.5 Conclusion

In this chapter, I have described the outcome of the maximum variation sampling technique employed. Twenty families with varied characteristics participated in the study, and six parents and adolescents participated in the focus groups. I presented the biomedical and social characteristics of the families to enable familiarity with the participants preceding the findings presented in the following chapter.

Chapter 6: Findings

Introduction

In this chapter, I present my interpretation of the lived experience of T1D in adolescence, as described to me by the adolescents and parents. In stage 7 of the hermeneutic analysis process, I inductively generated nine categories, incorporating themes and sub-themes within each category:

- Acceptance and coping
- Adolescence: independence and autonomy
- Care journey
- Embodiment
- Family dynamics
- Learning diabetes
- Managing diabetes (biomedical)
- Managing diabetes in context
- Perceptions of diabetes.

In stage 8, I explored the above themes and sub-themes in relation to the four existentials (Van Manen, 1997) to establish an understanding of my interpretation of the lived experiences in relation to the facets of the lifeworld. In this chapter, I describe the four categories that emerged from this stage of analysis:

- Normalisation
- Embodiment
- Learning through experiences
- Relationships with significant others

I present a number of themes and sub-themes within each category and discuss these with reference to the wider literature. I also discuss the relationship of each theme to the biomedical outcome of blood glucose control.

Category 1: Normalisation

(The normalisation of T1D within surrounding environments)

'Lived space' refers to the felt spaces surrounding us, and the ways that people experience their day-to-day existence through the environments they inhabit (van Manen, 1997). This category relates to the normalisation of T1D within the key environments surrounding adolescents which represent four themes: the home (family); the hospital (biomedical); the school (teachers and friends) and the social environment (friends). I explore further sub-themes within these.

My interpretation of the families' experiences was that a diagnosis of T1D led to significant disruptions within these environments, with the introduction of a new biomedical environment compounding these disruptions. The adolescents and their significant others had to adapt to T1D within these environments in order to integrate T1D within their lives.

6.1 Normalisation Theme 1: The experience of T1D in the home (family) environment

The families described how living with T1D in adolescence disrupted the family environment in a number of ways, mainly by instigating a new focus on dietary restrictions and scheduled meal times, blood glucose tests and injections, which had an impact on family activities. For example, usual family outings such as day trips and holidays required a great deal of planning. This mother (who had two children with T1D) described the preparation involved when going away as a family:

> *"When you go away it's a mini operation, you've got to do all this and all that ...and days out we always make sure we've got the medicine"* (Mother, Makin family).

I interpreted a number of adaptation strategies that families employed to cope with the disruption caused. These, as well as the outcomes of adaptation are described in the following sub-themes.

(i) Adapting to disruption

The families described implementing various strategies in order to adapt to the disruption of T1D within the family, outlined as follows.

Changes to family lifestyle

Other research has shown families implementing lifestyle changes (eg. reducing working hours) to cope with the demands of the new diabetes regime (Mellin and Neumark-Sztainer, 2004). In this study, the parents described positive changes to family eating habits, in order to support the adolescents' dietary restrictions, including the elimination of processed foods, consuming diet rather than full sugar soft drinks, and changing attitudes to the consumption of 'junk' food, such as crisps and biscuits. This mother described how such foods were now seen as treats to be enjoyed now and again rather than as a part of the daily diet:

> *"It used to be no crisps, no biscuits, no junk...I didn't like the idea of eating all that in front of him knowing he can't...now we've adapted to it, you can have biscuits and stuff, just not excessively"* (Mother, Gibbons family).

Routine

Data from the adolescents and parents suggested that routine was beneficial to facilitate the diabetes regime, in support of other qualitative studies showing the creation of new family routines following diagnosis (Wennick and Hallstrom, 2006). Routine appeared to give parents a sense of control over diabetes. I interpreted that this was due to the minimisation of uncertainty, through which the impact of T1D on family life was reduced. For example, this mother described the benefit of the school-day routine for her daughter's diabetes management, in contrast to the summer holidays, when days were often unstructured:

> *"I'm really looking forward to her going back* (to school) *tomorrow because I know it's back to a regular thing with her and that's fine then isn't it because she doesn't go out of a school night...it's just once that weekend comes, you know it's going to be stay out until half past ten and I'm sitting*

here like this, where is she...I mean they might go shopping to town but then all the Subway meals will start and like you know then the diet cokes and that, there's no like home made food getting done for her and things and that's where she slips..." (Mother, Salisbury family).

The importance of routine to the management of T1D was also demonstrated by the implementation of routine by certain adolescents using a basal bolus regime. This regime gave freedom from the restrictive insulin and food schedule of the twice-daily regime, however adolescents with good control on this regime described implementing a routine characteristic of the twice-daily schedule:

> *"Before I go to school I'd sort of work out what I'm going to eat so that I can just inject like whatever I need to do for whatever I eat...and normally we eat whatever like a normal sort of regime or something like that so that I know what things are"* (Holly Thomas, 15).

Despite the potential benefit of routine, many of the adolescents described the routine of self-management as a burden, for example:

> *"I hate coming in and taking* (insulin) *and I hate taking my blood sugars...getting up early in the mornings and I feel sick and I have to take my insulin and have something to eat...I just hate the routine"* (Jenny Dutton, 14).

Parents' roles in self-management

Mothers described having significant organisational roles to play in their child's self-management of T1D, including setting up injections, recording blood test results and collecting prescriptions and medication. This supports previous findings that mothers are usually the main caregiver to a child with T1D (Dashiff et al, 2008). Some parents mentioned occasionally administering insulin injections to their child if the site was difficult to reach, or to relieve the pressure of multiple injections on the basal bolus regime, as this mother described:

> *"He does six injections a day...and the first one every morning we try and relieve the pressure a bit by giving him the injection before he wakes up, so it's one less"* (Mother, Jeffs family).

Parents also had a role to play in reminding their child about their self-management behaviours, and providing meals. Despite other adolescents describing parental reminders as annoying (Schilling et al, 2006), this adolescent male described them as instrumental to him maintaining a healthy lifestyle:

> *"I think I could cope for a week or two weeks or something (without my mum) but not full time...mainly because your meals are cooked for you so it's easy...when I've had to do my own dinner I've just had soup...but my mum does different meals"* (Ian Collins, 13).

Siblings' roles

Most of the adolescents and parents did not describe siblings having a fundamental role in their diabetes management, and many described them as having no role at all. Other research has shown that the diagnosis of a sibling with T1D improved sibling relationships, and a sense of the family *'working together'* (Herrman, 2006). When I asked about sibling support, some of the adolescents described their siblings being aware of their diabetes needs and knowing what to do in an emergency, for example:

> *"I'm confident that if there was a problem, like if I had collapsed or something, he* (brother) *would know what to do"* (Tom Butcher, 15).

A small number of siblings actively reminded their sibling with diabetes about their diabetes management and had a significant input in this way. Some took a more practical role in helping their siblings to do their injections, particularly if the parents were absent for a period of time:

> *"Sometimes my sister does it in the morning, say if my mum and dad aren't here...sometimes my brother reminds me and things like that. So they do help out but it's only when they need to really"* (Neil Jeffs, 14).

In this way, siblings provided a 'safety net' for parents, who knew they could rely on them for assistance in an emergency. Parents even described much younger siblings having an awareness of their siblings needs:

> *"She knows when he's going low 'cause she can see it in his eyes or he goes pale and things, so it's just one of those things, a daily routine"* (Mother, Ratledge family).

Some adolescents described negative comments from siblings in relation to their diabetes. They described their siblings using their diabetes against them in situations of conflict, for example:

> *"It does cause a lot of arguments between me and my sister 'cause she'll skit me about being diabetic but like she won't mean it...like if I start arguing she'll just use my diabetes against me and we'll just get into a big argument...she just likes to skit it"* (Lisa Brookes, 16).

This supports other findings that the diagnosis of an adolescent with T1D was perceived as a 'cost' to family life by siblings (Wennick and Hallstrom, 2007).

(ii) Outcomes of adaptation

Adapting new lifestyle behaviours within the family environment meant that adolescents with T1D felt supported by their families and that their diabetes was normalised to a certain extent. The adaptation processes demonstrated by families in this study are supported by Knafl and Deatrick's (1986) definition of nomalising behaviour within families following the diagnosis of a child's chronic illness. Families acknowledge the disease, minimise the abnormalities of the chronic illness, and define the social consequences of their situation as minimal, through demonstrating the normality of their family to others. For the Collins, Thomas and Pickering families, the impact on the family following diagnosis was less substantial as the adolescents' fathers also had T1D. Therefore the diabetes routine was already integrated within the family environment. The following quotes from the father and son in the Collins family demonstrate this:

(i) "I think that helped Ian a lot...I knew the everyday routine of a diabetic... rather than someone getting it...where no one in the family's got it and it's like new to everyone. It wasn't new to me and my wife, plus he's seen me doing it when he didn't have diabetes..." (Father, Collins family).

(ii) "How did you feel at the time when you were told you were diagnosed...? (Joy)

"...I wasn't that bothered because I'd seen my dad doing it loads so I understood basically what they were telling me...it wasn't as bad because I knew quite a lot about it already (Ian Collins, 13).

Maintaining routine within the family environment was beneficial for the integration of diabetes within this environment, as it enabled the timely implication of blood glucose tests, injections and the provision of food. Some families already functioned within a routine, however others described having to 'learn' new more organised approaches to daily living. This mother described how her daughter's diabetes had a positive impact on her parenting style:

"I was a very chaotic person, emotionally and also in how I managed my life and the children...I was very, very laid back...it was very unstructured...this has forced me as a parent to look at things like...being organised, managing time, managing looking after the family, ensuring everything's in place...so it taught me a lot, it made me become a lot more disciplined, a lot more focused and changed all my priorities as well" (Mother, Fletcher family).

Being 'in control' of diabetes through organisation and routine allowed it to be situated in the background of the family environment. The importance of this sense of predictability was emphasised by parents' descriptions of disruptions to the ordered environment caused by severe hypo or hyperlgycaemic events. This caused anxiety and stress within the family and impacted on the family's ability to manage the disease. For example, the Fletcher family described an episode of DKA in their daughter whilst on a family holiday:

> *"We've just been away on holiday...and a few of the kids were just off colour...one particular day and Jane was the same, but it just escalated and escalated with Jane and by the next day all the other kids were fine and Jane had to be rushed into hospital"* (Step-father, Fletcher family).

The family had to cut their holiday short and Jane was taken to hospital. Such experiences affect the family's perceptions of their ability to continue with activities outside the family home such as family holidays. This event instigated anxiety in the parents about their daughter staying away from home in the future:

> *"I know the teachers will look after Jane very well, they understand the diabetes but it's a totally different regime to what she's used to here really...it's going to be so active and that's the worry. We really want her to go* (on a skiing trip with school) *because it's the chance of a lifetime...but at the same time we don't want her to go..."* (Step-father, Fletcher family).

In support of my interpretation, routine has been shown to contribute towards the normalisation of T1D within the family (Clawson, 1996; Heaman, 1995), through decreasing parental anxiety (Wennick and Hallstrom, 2006; Mellin and Neumark-Sztainer, 2004) and minimising impact on life outside the family. It has also been argued that family adoption of a normalised view of chronic illness may lead to the child/adolescent feeling more confident in situations outside the family home (Amer, 1999). This was demonstrated as many of the adolescents who stated that they did not notice much change to their family life, as this female stated:

> *"I don't think it has changed anything really, I mean they're* (family) *careful, always watching when I'm eating sweets and stuff but they don't really...I haven't noticed a massive change, we do things normally"* (Holly Thomas, 15).

6.2 Normalisation Theme 2: The experience of T1D in the biomedical environment

The biomedical environments of the hospital and diabetes clinic were new environments 'imposed' on the adolescents and their families following their diagnosis of T1D in relation to three main events: diagnosis, readmission to hospital as a result of serious hyper or hypoglycaemic events and ongoing outpatient clinic appointments. In this theme, I examine how experiences of the biomedical environment related to the adolescents' experiences of living with T1D through the following sub-themes: experiences of diagnosis; the clinic as a forum for education; readmission to hospital following diagnosis; ongoing care and transition to adult services.

(i) Experiences of diagnosis

Parents' experiences of the hospital environment at diagnosis appeared to be determined by the severity of the adolescents' presenting symptoms. The majority of the sample did not present in a critical condition. In these cases, mothers took their children to their GP with symptoms which were causing concern, the child's blood was tested and they were referred to the hospital. One mother described her daughter's condition at diagnosis as 'normal',

> *"Her blood sugars were 39 and she was just normal. The doctor said...we had a grown man in here the other day with a blood sugar of 38, he was in a coma, and she was just sitting there like, what, eh?"* (Mother, Dutton family).

Adolescents and parents from families where the adolescent did not present in a critical condition generally described a positive experience of care at diagnosis, apart from one family who felt they were left alone for a number of hours with no information.

Four adolescents in the sample were diagnosed in a state of DKA. As a result of misdiagnosis at the GP surgery, symptoms of diabetes had been attributed to urine infections, viruses and growth spurts. One mother was turned away from her GP twice before her three year old son was admitted to hospital in a critical condition:

> *"My doctor didn't take any notice of me, I actually went to (hospital) and we had a scan on his head, they told me that was clear and he'd lost so much weight it was untrue...the bed was so wet and he was fitting of a night...he done his wee and he said – diabetes and then we got him to the*

hospital straight away and he was very, very poorly...he was in hospital for a week...we came out...for 48 hours and he was taken back in again because he'd hypo'd really bad, he was unconscious. Got him back into hospital he was in for another three days, brought him out and the same happened again..." (Mother, Stanley family).

I interpreted that the adolescents' conditions at diagnosis determined parents' experiences of the biomedical environment and also influenced adolescents' perceptions of their diabetes. Although the diagnosis of diabetes was traumatic for parents regardless of whether their child was critical at diagnosis or not, the experience of having a critically ill child was an added trauma for many parents, as this mother described:

"He looked really, really ill, his eyes were sunken, he'd lost so much weight and I literally I had to carry him out of the bath...I took him to the medical centre to see a doctor, they checked his blood sugars and basically said take him straight to hospital, by the time we got to the hospital he couldn't walk by then so we took him in a wheel chair to A and E, he was seen by a triage nurse who immediately took him into majors and then it was all doctors all round basically doing various different tests because he was very, very ill at that point" (Mother, Mather family).

It is possible that traumatic experiences such as these influenced parents' perceptions of the hospital environment as 'safe' and 'protective'. It has been recognised elsewhere that events leading up to a diabetes diagnosis are often tainted with a slight suspicion of diabetes, culminating in a climax of urgency and panic once the diagnosis is made (Lowes et al, 2004). Parents were thrust into uncertainty with regards to their child's health and therefore when they arrived at the hospital, the environment was perceived as a safe haven to care for the child, as this mother stated:

"I managed to get him into (hospital) *and everything was just wonderful – because they just came in and put him on a drip and you know, sorted him out. And we had people there that understood...everything was lovely...and there were lots of nurses there that I could talk to"* (Mother, Stanley family).

(ii) The clinic as a forum for education

Adolescents stayed in hospital following diagnosis for between four and fourteen days. During this time the hospital environment facilitated education and learning for both adolescents and parents, to equip them with the skills to manage their diabetes in other environments, as this male described:

> "*During the time I was staying in hospital, they were giving me lessons on how to manage my diabetes and how to work needles and blood testers and things like that, learning about what foods I'd be able to eat as much as I want of, and what foods contain carbohydrates and things like that...*" (Russell Jones, 14).

The age of the child affected the education received, as with younger patients the focus was on educating the parents, who were responsible for processing educational information at diagnosis on their child's behalf (Snoek and Skinner, 2000). Parents were generally satisfied with the education they received at diagnosis, although some reported feeling overwhelmed with the amount of information they had to take in. This supports findings that there is a 'right' time to learn for every individual, and diagnosis may not be an appropriate time for everyone (Cooper et al, 2004), as this mother described:

> "(The hospital) *were really good at explaining but I just couldn't take it in. It took me ages to think my god what am I going to do and all the things they give you, you know all the paper, I thought I don't believe this, I just couldn't believe it...I was walking round in a dream world...I don't think I took anything in because I just couldn't think straight really*" (Mother, Edwards family).

Another family praised the hospital for their delivery of education at diagnosis, at the 'right' level. They were given the essential facts at diagnosis, which gave them room to come to terms with the diagnosis before they were given any in-depth information. A year following diagnosis, this family became keen to learn about blood glucose fluctuations as their son was playing football frequently. As they had come to terms with his diagnosis at this stage, they were able to take on board the additional information:

> *"Of late...* (the dietician will) *go into a bit more detail about the effect of insulin or the effect of glucose in the blood and you realise, this is very, very complex, what actually goes on...and yet what you get taught at the beginning is exactly the right level to make you understand what is going on"* (Father, Jeffs family).

This demonstrates the importance of the timing of education in order to facilitate optimum impact (Cooper et al, 2004). Ongoing education was also important as adolescents also described feeling motivated following education received from the hospital, but also losing that motivation soon after:

> *"It usually happens just after I come out of the clinic just like the novelty of doing well with your diabetes, that only lasts for about two weeks because I'll do my blood and I'll have a full sheet of it and then it will only take like once for me to say something like oh I'll do my blood tomorrow...and then tomorrow will just become tomorrow again and it'll go on like that..."* (Russell Jones, 14).

The majority of the adolescents and parents were satisfied with the education that they received. Many commented particularly on the usefulness of the advice given to them by the dietician, as this adolescent stated:

> *"The one who gives me the most advice is my dietician...she helps me, I always go and see her about my eating and stuff and she gives me a folder with everything to do with it, food, injections and every time I go they give me more leaflets to put in it...and all stuff like diabetes in school and diabetes when you're sick and everything else"* (Martin Edwards, 14).

The health professionals also approached health education areas specific to adolescence such as alcohol and drugs, demonstrating in line with the *NSF for Diabetes* (Department of Health, 2001a) that education was tailored to meet individual need and perspectives:

> *"They give me stuff like when you're older about drinking and getting tattoos...I think it says in one of the leaflets it says eat a meal before you drink and after you drink to keep the blood sugar the same...eat a lot before and a lot after"* (James Pickering, 15).

(iii) Readmission to hosptial

The biomedical experience of severe hypoglycaemia was determined by parents' ability to treat the hypo at home. In many cases, parents called an ambulance for assistance. Once the paramedics had treated the hypo, they did not routinely take the child into hospital but twenty per cent of the adolescents had been admitted to hospital with severe hypoglycaemia. Parents saw the hospital as a 'safe' place which provided reassurance of their child's health and insisted their child be admitted in some cases for peace of mind, as this mother stated:

> *"The ambulance men were saying oh she'll* (be fine), *but they're obviously used to diabetics a lot more than I am...you know we won't bother taking her to hospital and I said, no you don't understand she's never been like this, I want her to go to (hospital), oh she'll be alright...they rang one of the diabetic nurses in the end and...they put her on to me and she said what do you think? And I just said if they go away I am going to personally put her in the back of my car and bring her because she is bad, she's never been like this and they're treating it like I'm being hysterical"* (Mother, Thomas family).

Twenty-five per cent of the sample had been admitted to hospital with DKA (excluding diagnosis). Two adolescents had been admitted with both hypoglycaemia and DKA. Sixty per cent of those admitted with DKA had HbA_{1c} levels classified in the 'Risk Zone' whereas 80% of those who had been admitted with severe hypoglycaemia fell within the 'Good to moderate' HbA_{1c} zone (apart from the two who had also been admitted with DKA who had HbA_{1c}'s of 8.9 and 9.8). This suggests that maintaining low blood glucose levels poses the risk of hypoglycaemia.

At diagnosis and at readmission, adolescents' experiences of staying in hospital were generally positive. The hospital staff created a child-centred environment which reduced the impact of the situation:

> *"I was there on Christmas day, came out for new year and I got like loads of presents off the hospital, I got like lip glosses and IPOD shuffle, I got all things like that, the hospital treated me good actually"* (Jenny Dutton, 14).

Some adolescents had never been readmitted to hospital following their diagnosis. My interpretation was that the individual experience of the biomedical environment appeared to affect adolescents' perceptions of their diabetes. Visits to hospital appeared to illuminate the seriousness of their disease and defined the experience of living with diabetes through a number of serious events, for example:

> *"I was in hospital...I was like sitting there spewing my guts up and people were looking at me...and the woman next to me, she was going why are you in, I said I got ketone acidosis...it's where your blood's too high and your body rejects anything that you eat or drink...my sick was always black...I never understood it. I had water and I threw that up, and they had to feed me off a drip, it was horrible. I was in for a couple of days, because when I stopped being sick, my throat was all inflamed, so I couldn't swallow or nothing...they had to wake me up every hour to test my blood"* (Sean Ratledge, 15).

It may be that those who are never readmitted perceive their diabetes in a less medically intrusive way. Visits to hospital emphasised T1D as a biomedical disease rather than a lifestyle. This supports personal models theory, which suggests that personal models of diabetes are developed through emotional responses to the illness experience (Hampson et al, 1990). In line with this, this study thus suggests that extended experience of the biomedical environment amplifies the physical implications and limitations of the disease.

Serious events such as hospital admission also illuminated poor blood glucose control. Such visits had the power to alter adolescents' and parents' perceptions of diabetes and the importance of control for their future health. This was particularly relevant for Jenny Dutton (14), whose 'near death' experience had influenced her to take more care of her diabetes. She stated:

> *"When I had ketone acidosis...I just remember I couldn't breathe so I had a mask on and I went in on the Friday night and then the Saturday was the worst day ever. I was very sick that day...(I was) so close to dying. And they said that was one of the crucial days and then all my family was there and I had hearing but I couldn't respond...it's showed me to look after myself more and be careful what you do, it was a scary time"* (Jenny Dutton, 14).

(iv) Ongoing care

Within this theme, parents and adolescents talked about their satisfaction with the diabetes care they received, as well as the benefit of activity weekends provided by the clinic.

Satisfaction with care

Other research has shown that socialisation into the hospital environment is important for adaptation to a diagnosis of T1D, as it becomes a significant part of the family's social world (Canam, 1993). Ongoing outpatient care was provided at three-monthly appointments in the diabetes clinic. The diabetes specialist nurses also made visits to the home and school for newly diagnosed patients and those experiencing difficulties. Adolescent and parent perceptions of the clinic environment were positive in most cases and families were extremely satisfied with the care they had received, as this mother stated:

> *"There can't be many people who would complain about...the service you get, because it's brilliant"* (Mother, Thomas family).

Adolescents described how the nurses were interested in their lives aside from their diabetes. Their friendly approach and interest facilitated a comfortable clinic environment and trustworthy relationships between the health professional and patient:

"They...just talk to you, not like a normal person but as if like...they don't just talk to you about your diabetes, like your holidays and things that you've done and stuff so it's not totally based around diabetes so you feel more normal anyway sort of thing" (Holly Thomas, 15).

In contrast, other research has found a lack of trust by teenagers in the care plans issued to teenagers by health professionals (Karlsson et al, 2008) and adolescents wanting more input into their care decisions (Davidson et al, 2004).

Parents also felt supported by the clinic nurses, who took a family-centred approach to care:

"I was very, very impressed with (hospital)*...I was so impressed by the nurses, the dietician, and the doctors, it was like you felt protected, it was like they really cared and they were looking out for me as well as Holly, because I've split up from my husband, well my ex, we're divorced and so I felt quite isolated"* (Holly Thomas, 15).

Despite the majority of patients appreciating the 'one-to-one' level of communication between the adolescents and nurses, a number of parents described frustrations that the care provided in the clinical setting did not translate into 'real life'. This mother felt that health professionals sometimes gave advice which was difficult to implement due to situational factors which they were unable to foresee:

"Most of the time I think they're okay, maybe there's the odd time when I think... they don't live with it day to day... as an example we were talking to the dietician the other day and Emma was saying that her blood could be high at tea time...she said well if you check your blood two hours after lunch and then if that's okay you'll know you've had the right amount of insulin...but it's not always easy to do that...if she's in school she can't do it and that's that" (Mother, Bingham family).

Adolescents in the focus group felt that the nurses were *"more approachable"* (Samantha Makin, 15) and delivered care at a more understandable level than the doctors. Families felt safe and protected in the knowledge that there was always help at hand should they need it. The clinic staff facilitated this through their warm and friendly manner, and had a good relationship with most of the families:

"I suppose with it being a children's hospital, it just has that friendliness doesn't it, the warmth..." (Mother, Stanley family).

However, others felt that the child-centred environment was inappropriate for adolescents:

"Every time you go there, there always seems to be young children...there's all toys and things for the little ones...she's grown up isn't she" (Mother, Morris family).

Activity weekends

Parents and adolescents described the clinic staff organised activities outside of the clinic for the adolescents, including activity weekends away, trips to theme parks, Christmas parties and an annual fun day. This study as well as others (Karlsson et al, 2008; Christian and D'Auria, 1999) advocates hospital activity weekends as a facilitator of positive relationships between health professionals and patients. Some of the adolescents regularly attended these activity weekends and found being in contact with other adolescents with diabetes a valuable learning experience, as this adolescent described:

"It's good because you get to talk to different people and learn more and find out how they control it and stuff and you see the different opinions...and you get to know people...even though no one knows you, you've all got something in common because you're diabetic" (Samantha Makin, 15).

For others, the thought of mixing with others with diabetes was not an environment they wished to be situated within. They did not tolerate the idea of diabetes defining their environment. One mother felt that her son avoided this situation, as mixing with others with diabetes would make the reality of his disease more poignant:

"I don't think he wants to be associated with people like him...I think it brings it to life more doesn't it..." (Mother, Jones family).

For those that attended, the activity weekends provided a 'safe' environment for adolescents to practice their self-management away from the secure environments of the home and the clinic.

(v) Transition

The prospect of transition to the adult clinic was a daunting prospect for many of the adolescents, as it meant moving away from a safe environment which they had grown to be comfortable in:

"I've been with them since I was a kid so it will be horrible moving into a new place" (Sarah Morris, 15).

The adolescents in the focus group agreed, as one stated:

"This is my second home, I'm always here" (Jane Fletcher, 14).

A number of adolescents and parents wanted to gain control of diabetes before leaving the peadiatric clinic:

"My diabetes isn't under control and I want to get it under control before I go" (James Pickering, 14).

The experience of impending transition by the families in this study supports other findings that the process is underpinned with psychosocial barriers, including parents being suspicious of adult health professionals and anxieties about their child's quality of care (Fleming et al, 2002). This suggests that the psychosocial needs of parents and adolescents during the transition process are not always met and this needs to be addressed.

6.3 Normalisation Theme 3: The experience of living with T1D in the school environment

.A diagnosis of T1D impacts on the daily routine of adolescents and therefore self-management has to be taken into account in the school environment. This section focuses on the disruptions caused by T1D to the adolescents' school life, as well as the disruptions caused to the self-management of T1D by the school environment. I present two sub-themes, focusing on the management of T1D during school, school attendance and educational outcomes.

(i) Managing T1D during school

Most of the adolescents used a twice-daily or combined insulin regime which meant that no injections were necessary during the school day. For these adolescents, self-management involved eating a snack and their lunch at certain times to adhere to the peaks of their insulin, eating additional carbohydrate when participating in physical activity and occasionally treating hypoglycaemia. Most of the adolescents felt that their diabetes was not usually an issue during school, as this well-controlled male described:

> "*It's nothing to worry about 'cause it's something personal to me and it's not something they all (teachers) need to know about*" (Tom Butcher, 15).

Those using basal bolus regimes had to inject insulin at lunch time and they were provided with a room to use. Although this support was appreciated, having to leave their friends to inject also made the adolescents feel different and even 'naughty' in this case:

> "*The head teacher for the year said just come to my office and take your injection in my office...he must have felt a bit awkward, going into an office at lunch time and break time to do injections, especially because she's so strict as well, they were all terrified of her!*" (Mother, Jeffs family).

One male described how he would sometimes miss his injections as they interfered with his lunch time activities:

> "*I used to do it quite a lot, forget about my dinner time injection because I'd want to just go off to the music block for a practice, so I'd forget quite a lot and I'd come back from school in a mood because my blood would be about twenty from my dinner*" (Russell Jones, 14).

One female overcame the barrier of leaving her friends by injecting in the playground with her friends, as she felt that they accepted her diabetes:

"They did tell me I had to do my injections by the office or where they thought I'd be happy doing it but there's always teachers and stuff walking around and people just coming up, so I just do it outside because my mates don't care about me doing it...I just get on with it" (Holly Thomas, 15).

Teachers were described as supportive of adolescents' self-management needs by parents primarily, illustrating that they had confidence in the school's ability to manage their child's diabetes. Supportive practices included:

- Giving the adolescent a dinner pass to enable them to go to the front of the queue if they needed to eat urgently: *"If she needs any food she's got a special dinner pass so that if she needs to go for dinner early, she can jump to the front of the queue"* (Mother, Thomas family).
- Putting a photo of the adolescent on the staff room wall so that teachers were aware of their diabetes: *"They have photographs stuck on the staff room wall with 'this girl has diabetes' and what to do if anything happens"* (Mother, Bingham family).
- Providing diabetes 'mentors' to newly diagnosed pupils: *"Whenever someone else comes like diabetic...they always say to me would you like to talk to them...if they need any help I'm the person to come to"* (Holly Thomas, 15).
- Understanding school absence due to diabetes: *"School are really good because he will go to school but maybe about 11 o' clock...or if it's worse that day he'll have the day off...the school send work home and they keep things he's missed from the lesson, he collects it and catches up that way"* (Mother, Stanley family).
- Keeping 'hypo boxes' for the adolescent in the staff room: *"We have a box with his name on in the staff room...explaining all about* (son) *and I put his name clearly on, diabetic with things in it, just in case he forgets whatever in his bag, and usually at the end of term we get the box back and renew it"* (Mother, Edwards family).

- Teachers being aware of hypo symptoms: *"They are very watchful, she's had a couple of hypos and the teachers know what to look out for"* (Mother, Thomas family).
- Monitoring the adolescents' diabetes on school trips: *"The school were very helpful...when they were going on field trips...you know obviously they had to take her insulin"* (Mother, Dutton family).

Despite the teachers' support perceived by parents, a number of adolescents described barriers to their self-management at school. Many described situations where they had needed to treat a hypo during class and teachers had questioned their need. As this adolescent female stated:

> *"If I felt low, a few teachers won't let me have...something to get it up, there's always been a few arguments about letting me go out and have something...there was a few teachers that wouldn't let me go even if I gave them the note"* (Lisa Brookes, 16).

Some parents were concerned that teachers were unaware of their child's diabetes within the school setting. This was demonstrated in a number of cases, where adolescents had been punished for trying to meet their self-management needs, as this mother described:

> *"I got a phone call to say we're not very pleased with Steven, we're going to keep him on detention because he's demanded to get in the front of the dinner queue telling the dinner lady that he's diabetic and I said, well he is, she went what? They didn't know. Now this was two years later, they had no record that he was"* (Mother, Gibbons family).

Detentions also caused an issue if they interfered with the adolescents' management schedule. One parent worried about their child being kept behind on detention when they needed to do an injection or eat. Some teachers were unsympathetic to the child's needs and refused to let them complete the detention at a more suitable time:

> *"I don't like the way they kept him behind...I'm not saying let them get away with things but have a bit of you know, keep them in at play time or*

something instead of after school" (Mother, Gibbons family).

These disruptions to diabetes self-management caused barriers to the management of T1D in the school environment. One mother was concerned that her son would avoid treating his hypos for fear of a negative reaction from teachers:

> *"I worried about school at first and one time, he came home upset because the teacher had told him off for taking dextrose in class...although we sorted it out in school, I thought, because he's never in trouble...he might think twice now about doing that in another lesson and then he might end up collapsed on the floor"* (Mother, Jeffs family).

These incidences were underpinned by a lack of knowledge about T1D on the teachers' part. One parent described how he had been called out of work by the school when his step-daughter had a hypo. He became extremely frustrated when he felt that the treatment procedure could have been easily implemented by a member of staff at the school:

> *"There was a time that Jane didn't have any Lucozade in school and she was very low and the school phoned me. I was at work and I said well it's going to take me twenty minutes to get there, can someone run to the shop and get her some? No we're not allowed to do that. And I was like well if you don't do that you're going to end up with an ambulance on your doorstep having to cart her to hospital...to save all that just run the shop, no, we're not allowed to do that...I was thinking...how dare you let this happen to a child!"* (Step-father, Fletcher family).

One mother described how her son was restricted from going on a trip away with school because the teachers were unaware of how to deal with his diabetes:

> *"In the first year of juniors, James was diagnosed with the diabetes and they said he couldn't go...with him being diabetic...*(the teacher) *said tell him that we put his name in a hat and his name never come out, I said you won't, you will tell him the truth"* (Mother, Pickering family).

This lack of knowledge and confidence to deal with T1D appeared to be underpinned by a lack of communication between staff about the adolescents' diabetes. At diagnosis, a specialist nurse from the clinic visited the school to educate staff about their medical needs, but it was evident that this knowledge was not passed on to all staff, giving rise to situations in which teachers were unaware of their condition and did not how to give assistance if needed. The following quotations demonstrate this common unawareness:

> *"If I'd tell them I feel sick they'd say oh come back in half an hour see how you feel, I'd say I'm diabetic and they'd say well go downstairs and get a bar of chocolate...but it's not like that"* (Jenny Dutton, 14).

The lack of diabetes knowledge in schools described by the participants in this study is supported by the findings of a number of other studies conducted in the UK (Newbould et al, 2007; Waller et al, 2005; Hayes-Bohn et al, 2004; Dickinson and O'Reilly, 2004; Tatman and Lessing, 1993; Lessing et al, 1992; Warne, 1988; Bradbury et al, 1983). Overall, adolescents and parents felt that more awareness from teachers about T1D was needed in order to make self-management easier for adolescents and enable parents to feel confident that their child is in a safe and supportive environment when they are at school. This mother summarised:

> *"I think they need to be more aware in the schools, to take that bit of worry away from the parents, because you have got a lot of worry when it first happens and it would be a bit easier if schools already were aware of it"* (Mother, Jeffs family).

(ii) School attendance and educational attainment

School absence as a result of T1D was not common in the sample, apart from missing a morning every three months for their clinic appointments. These findings contradict previous research linking T1D to increased school absence (Aspey, 2001). However, one adolescent female missed school more than most because of the sickness she experienced as a result of her high blood glucose levels. Her mother stated:

"She has had time off school...she's been sick quite a bit...she always seems to be sick, always throwing up" (Mother, Morris family).

A recently diagnosed male also missed school occasionally due to emotional issues with coming to terms with his diabetes, as his mother reported:

"We've had a couple of days where he's refused to go to school just because he's got himself so stressed out...I phoned school and just said to them look he's dead stressed that's why he's not in" (Mother, Collier family).

One parent described their child being sent home from school with hypoglycemia, again due to teacher's lack of knowledge of how to deal with it:

"The senior school he's in, I mean he's had a couple of hypos, whenever he had a hypo in his other school they dealt with it, they just phone us and send him home" (Father, Ratledge family).

Evidence suggests that that increased school absence may be present in adolescents with T1D (Aspey, 2001) and that educational attainment is not equal for young adults with and without disabilities in the United States (Shandra and Hogan, 2009). Despite this, a systematic review recently found that children with T1D perform equally well at school as their non-diabetic peers, despite increased rates of absence (Milton et al, 2006).

One possible effect on school attainment was the effect of hypoglycaemia on concentration, as this male described:

"If I do go low in class I think you lose concentration and your handwriting gets all scruffy and messed up" (Martin Edwards, 14).

One female also described hypoglycaemia affecting her academic performance in a test:

"I was in an exam the other day I couldn't read the questions because I was having a hypo...I just sat through it and I think I've done rubbish in the exam" (Holly Thomas, 15).

One mother believed that hypoglycemia had a direct impact on her son's attainment:

"He might have a few days in the week where he's hypo, it'll probably be coming towards lunch time and his concentration goes with that...he is a clever lad but his grades aren't showing that....we've now put measures in place where he'll go ten minutes before morning break to the office and check his blood sugars...so we can see what's going on during the day" (Mother, Mather family).

This supports previous findings that some aspects of cognitive functioning are altered during experimentally induced hypoglycaemia (Gold et al, 1995; Maran et al, 1995; Cox et al, 1993). As well as having a potential negative effect on short-term educational outcomes, this also causes concern for future health, as a recent literature review hypothesised that hyperglycaemia-associated microvascular changes in the brain are responsible for the long-term cognitive decline in patients with T1D (Wessels et al, 2008).

Families also described blood glucose fluctuations affecting the mood and motivation of adolescents in school. This male described his lack of motivation when his blood glucose was running high:

"When I'm on a high I just can't be bothered doing anything. I've been in lessons on a high and just going to sleep in lessons and that, just can't be bothered to do anything, listening and all that on a high...as long as you keep the blood sugars down it's alright in school" (Anthony Mather, 15).

One adolescent female had been expelled from secondary school on grounds of bad behaviour. This could have had an impact on her school attainment, as she missed a significant proportion of school before her GCSE's. Her mother felt that her daughter's bad behaviour was due to mood swings caused by fluctuations in her blood glucose as well as teachers' lack of understanding. She stated:

"She used to lose her temper in school, eventually she got expelled...If she wanted a drink or a snack, she couldn't have it...but I'm diabetic, who said you are? was one reply" (Mother, Brooks family).

Another mother had removed her daughter from her secondary school because she believed that she was being bullied by one of the teachers about her diabetes. She stated:

"We had problems at school, one of the teachers was bullying her over her diabetes and so I took her out of the school" (Mother, Dutton family).

This mother was charged in court for keeping her daughter off school illegally, and the adolescent now attended a unit for children with special needs. Although traumatic for the family, the situation had worked out well for the teenager in relation to her diabetes needs. She felt much more comfortable and supported in her diabetes needs in the unit, as she described:

"I love the unit because the teachers there are like your friends, you can call them by their proper names and you can talk to them and tell them anything you want, they're always there for you, so I prefer that. If anyone asked where I would rather go, school or the unit I'd say the unit, they understand about everything, when I tell them about my diabetes they understand" (Jenny Dutton, 14).

The impact of T1D on behaviour merits further exploration, but highlights that chronic illness may cause disruption for some adolescents in terms of integrating within the school environment. This is important to prevent low educational attainment in adulthood, based on findings that school achievement is a strongest predictors of low educational level in adulthood is a strong predictor of this (Hurre, 2006).

6.4 Normalisation Theme 4: The experience of T1D in the social environment

A diagnosis of T1D also has an impact on the social environment of adolescents, i.e. the time they spend outside the family home with their peers. Diabetes management may restrict participation in certain activities, and affect the adolescents' and others' perceptions of the adolescent within society (Goffman, 1968). This section focuses on the disruptions caused by T1D to the adolescents' social environments and how they dealt with these disruptions. I describe three sub-themes, which explore the barriers to normalisation occurring in the social environment, the participants' perceptions of discrimination in relation to diabetes, as well as facilitators to normalisation and drinking alcohol.

(i) Disclosing diabetes to others

Many of the adolescents described situations in which their diabetes made them feel different from their friends. These were mostly situations in which their self-management behaviour brought them unwanted attention. Parents also recognised this, as these participants described:

"I think it's just made him...feel he's different from the others by getting the biscuits out, and the others go ooh we want to get a biscuit, the fact that he has to makes him different from them, he just wants to be like the rest of them" (Mother, Pickering family).

Many of these situations occurred within the school environment. Adolescents were sometimes asked to talk about their diabetes in class, drawing unwanted attention to their diabetes, sent home when experiencing hypoglycaemia, unable to participate in the same activities as their peers and having to eat in class, for example:

"Sometimes he doesn't have time for his dinner and he's got to eat so he'd have to miss the basketball or whatever so that used to upset him" (Mother, Jeffs family).

Others perceived their difference to others as a novelty rather than as a negative:

"I wasn't really bothered when I got diabetes actually, I was more excited because my Nan had it, I don't know why (laughs) I was like yaaaaay" (Russell Jones, 14).

The unexpected disclosure of T1D to others through blood glucose fluctuations caused perceived negative reactions from others, as this male described:

> *"In assembly when I had a hypo, they used to look at me as if I was the world's worst...people always look at me as if I'm an alien or something different"* (Sean Ratledge, 15).

Injecting insulin in public was embedded within perceptions of how others would react to the sight of injections. Some did not wish to inject in public, whereas others, such as this male, demonstrated confidence to do so:

> *"I do it anywhere really it doesn't bother me where I do it, its like whether anyone's like looking or anything like that sometimes I even just like do it in lesson underneath the table if I can't be bothered going all the way to the office"* (Russell Jones, 14).

Confidence to inject in public developed over time and frequent experience of the situation, as these parents described:

> *"At one time he was hiding away doing his insulin at the match..."* (Father, Jeffs family)

"...Oh yeah he was hiding away and we said, what you hiding for, you don't have to hide anything, just do it there, and he was getting looks off some people...but he's got that perception now, I don't care, you can look all you want!" (Mother, Jeffs family).

Not disclosing diabetes to friends had the potential of leading to dangerous situations, for example:

> *"When I was out with my mates one time, I was sitting on the couch and I was having a hypo and she didn't know what was going on because I'd only known her for a day, she said to me are you alright and I was saying yeah because I felt shady saying well no I'm not alright...I ending up going into a diabetic coma"* (Sarah Morris, 15).

Knowing that their child did not disclose their diabetes to friends caused anxiety for some parents. Some felt a responsibility to disclose their child's diabetes to their friends, or friends' parents on their behalf, in order to ensure their safety, as this mother described:

"When she stays at her friends, I mean there's certain friends and she goes, oh no I don't want to tell them, well they're your friends, I've got to give the information to parents..." (Mother, Salisbury family).

As a disease, T1D is 'invisible' to others unless it is disclosed verbally or through physical actions such as injecting or testing blood glucose in public, or if acute symptoms occur in public. Therefore adolescents have the choice of how 'visible' or 'invisible' they make their condition to others. Many adolescents demonstrated 'passing' behaviour, as defined by Goffman (1968), in order to avoid a stigmatising label. Not disclosing diabetes to others was common, and many preferred to manage their diabetes within the home environment. This meant not injecting or testing in public, and for many not carrying any diabetes-related equipment around with them, from ID jewelry and cards, to glucose tablets, as this parent described:

"He hasn't got a necklace on him to say he's diabetic...it's easy enough to carry a card around but he won't even do that, so someone like an ambulance person will just think he's drunk" (Mother, Jones family).

However for others, identification of their diabetes was important and they willingly carried identification with them:

"I take my insulin everywhere...I carry this little card round, which says like I have diabetes and then my name and all my details, so like if I'm on my own...and something happens to me they just look at my card" (Emma Bingham, 16).

Reluctance to disclose T1D was embedded within the reactions of others and their acceptance of their self-management behaviours. This mother recognised her daughter's need to fit in with her peers during school:

"Of late she's been saying that she doesn't like to be obvious that there's something different about her...I think we all do, we don't want to stick out especially when we're at school, so she kind of keeps quiet about her diabetes" (Mother, Thomas family).

(ii) Peer support and acceptance

Despite the social advantages of non-adherence for some adolescents in this study, other qualitative studies support the finding that that disclosure of diabetes to friends is important (Carroll and Marrero, 2006a; Christian and D'Auria, 1999; Olsen and Sutton, 1997), and advocates a feeling of safety. La Greca (1992) and Lightfoot and colleagues (1999) also found that peers were generally supportive of adolescents' diabetes. Adolescents can *'forget'* about their diabetes when with their peers (Karlsson et al, 2008), thus facilitating normalisation of T1D in the social environment. The negative impact of unsupportive peers on adolescents' self-management was evident in this study, supported by evidence that poor psychosocial support impacts on adherence to the diabetes regimen (Kyngas, 2000).

Most of the adolescents described their friends as supportive to their diabetes needs. It was positive when peers recognised that the adolescents were restricted by their diabetes in certain activities, as this male described:

"What about like your close mates in your group, how are they...? (Joy)

"... (My friends) *understand that I'm not exactly the same as them and they understand that it does prevent me doing the same things as them*" (Sean Ratledge, 15).

Supportive peers meant that self-management practices were easier to adhere to, without the obstacle of peer-approval to negotiate. This enabled the normalisation of the adolecents' diabetes within the peer group, as this adolescent stated:

"(My friends are) *good, they look after me, they make sure I do it and they always make sure that I'm feeling ok and I've had enough to eat so they're fine, it doesn't really bother them like they don't really say much about it because it's just normal really*" (Lisa Brookes, 16).

Friends demonstrated their supportiveness in a number of ways. Some adolescents described how their friends had assisted them with treating hypos, as this adolescent described:

> *"In our school we've got a box with all Lucozade and tablets in it if I've got none with me, if something happens to me, one of them can go and get it and the person where the box is knows all of them"* (Martin Edwards, 14).

Others described how their friends were sensitive to their diabetes needs when they were playing sports. One adolescent male told how his friends agreed to play football at a certain time of the day in order to fit in with his management regime:

> *"We'd organise* (football) *in the middle of the day so that there was nothing interfering with it...if I needed to* (inject) *my mates would just say yeah alright just go in here and do it and then weren't too bothered"* (Tom Butcher, 15).

One adolescent female described how she was grateful to her friend for staying with her when she had an episode of DKA:

> *"My mate was saying, stay awake, stay awake, she was trying to distract me saying, oh your Christmas tree's nice, the Christmas lights are lovely, and I was in real bad pain, I've never had a pain worse than that actually, and then my mate phoned an ambulance and then I got told at that point I only had a few hours left, and I respect her so much for staying with me..."* (Jenny Dutton, 14).

Others talked about their friends being sensitive to the restrictions that living with diabetes sometimes placed on them, for example, not being able to eat certain foods, as this adolescent female stated:

> *"When we used to go to the beach and they used to get all the sugar dummies and rock, I'd just be sitting there eating my packet of crisps...they'd go I feel dead sly and they're hiding it away from me, but I didn't mind"* (Emma Bingham, 16).

Some adolescents described how their friends were interested in their diabetes and often asked them questions about it. Although this was interpreted as positive interest, some found it frustrating, as this adolescent male described:

"Have you ever been in a situation when you've found that people don't understand about your diabetes...? (Joy)

"*...Most of the time people like listening, they ask me questions it does my head in, they ask me questions on it like do you inject yourself and all stuff like that, it's like oh my god yeah I've told you about five times!*" (Russell Jones, 14).

Some also found it annoying when their friends tried to help them. This adolescent interpreted her friends' helping behaviours as interfering:

"*I hate it when I know what I'm doing, when people come up to me and say have you took your insulin, have you done this...I know what I'm doing, I hate people trying to control it for me...*" (Jenny Dutton, 14).

It was therefore appreciated when adolescents were given space and time to deal with their diabetes, as this male explained:

"*I feel they're quite good mates to me because they will like wait for me or something, they will give me the time to do what I need to do*" (Tom Butcher, 15).

One adolescent female described her friends' unsupportive reaction to her blood glucose fluctuations:

"*When I'm on the streets with my mates, and I say I feel high or I feel sick, they say it's not bad and walk away. Like a few of them are alright and come over to me, but like when they're not out, a few of them just walk away and leave me, they're walking away from me and they're meant to be my mates*" (Sarah Morris, 15).

Her mother reported that she avoided diabetes management when she was with her friends, maintaining high blood glucose levels on a daily basis as a consequence. She recognised her daughters' need to fit in with others, underpinned by her perception of herself as not 'normal':

> *"She does want to be like her friends...she doesn't class herself as being one of them...as she says she'd like to be ordinary like them, normal like them. So I say she is normal, you are normal, it's just you have to do these things, but it just doesn't register with her"* (Mother, Morris family).

Thus, her peers' unsupportive reactions may have been due to a lack of understanding about their friend's diabetes, due to her lack of disclosure of the condition to them. One adolescent male in the focus group discussion stated that he also often missed insulin injections through avoidance of injecting whilst with his friends:

> *"I do that all the time...I never take* (injection) *out with me... It's finding a place to do it"* (James Pickering, 14).

Research with the general adolescent population has found that behaviours which receive approval from the peer group are likely to be repeated (Allen et al, 2005) and qualitative evidence suggests that adolescents with T1D are concerned with fitting in with the adolescent culture (Dickinson and O'Reilly, 2004). This explains why some adolescents prioritise social behaviours over diabetes self-management in order to integrate within the peer group. As in this study, non-adherence has been found to have the perceived benefit of enabling some adolescents to fit in with their peers more adequately (Herrman, 2006).

Viner (2009) has suggested that adolescents who are defined as 'non-adherent' in the biomedical setting are not necessarily so. They may not be adherent to the biomedically-defined variables of diabetes self-management. However, the management of blood glucose in order to maintain invisibility of T1D in different aspects of their lives requires a high level of commitment and planning. This warrants a need to explore the meaning of 'adherence' in relation to adolescents' motivations for T1D management and an avoidance of the assumption that poor adherence to the diabetes regime is caused by lack of clinical education or psychosocial 'problems'.

Adolescents did not prioritise peer acceptance over diabetes management in all cases. One adolescent male did not wish to disclose his diabetes to others, however he prioritised his diabetes management over being with his friends, and restricted his social life in order to adhere to his self-management regime, as his mother described:

> *"I've heard him on the phone to his friends who've wanted to go to the cinema in the afternoon and he's made an excuse up that he can't go, but not because he has to have his insulin, he'll say something else because he's obviously embarrassed...he doesn't want them to know"* (Mother, Mather family).

'Preventive disclosing' (Joachim and Acorn, 2000a) of T1D to peers had the positive effect of enabling peers to assist with self-management and gave parents peace of mind for their child's safety. Peer acceptance facilitated positive self-management behaviour, as practices were easier to adhere to without the obstacle of peer approval to negotiate. Informing others about T1D was a positive action, as it enabled adolescents' surrounding peers to assist them when blood glucose fluctuations occurred and the situation was beyond the adolescents' control. Most of the adolescents stated that they felt safe when they were with their friends. Although they did not have an in-depth knowledge about diabetes, they were confident that they knew what to do in an emergency, as this male stated:

> *"Nothing's ever happened but they all know if I ever go into a coma or anything, they'd phone my mum and get me a sugary drink, they know bits about it"* (Steven Gibbons, 16).

It also gave peace of mind to parents, who could be confident that their child's friends were capable of assisting their child in such situations, as this mother described:

> "Do you think his friends, how his friends have been in school – are they quite good with him...? (Joy)
>
> *"...They've always got like a bottle of Lucozade in case he goes low...they are quite good with him so it's a weight off my mind they can deal with it as well"* (Mother, Ratledge family).

These findings are supported by other reports of adolescents receiving unwanted attention when testing or injecting in public (Herrman, 2006), jeopardising their ability to fulfil their self-management regimes as a consequence (Carroll et al, 2007). Shiu and colleagues (2003) suggest that when those with diabetes perceive the external environment as non-supportive, they have difficulty transferring what they have learned about diabetes management into practice. This highlights the need to find a balance between diabetes management and other aspects of social life. If one aspect is more prominent, this can lead to restrictions elsewhere, whether this is socialising or blood glucose control. The findings suggest that peer support is instrumental to the management of T1D outside the home environment. Lack of peer support or adolescents' perceptions of negative peer reactions may explain reports of reduced adherence to the diabetes regimen during adolescence (Timms and Lowes, 1999; Jacobson et al, 1990).

(iii) Drinking alcohol

Consuming alcohol was a normalised practice within the social environment for Russell Jones (14), Sarah Morris (15) and James Pickering (15). For example Sarah stated:

"I used to always stay out but my mum stopped it 'cause I used to come home every morning feeling sick and be in bed all day the next day so I've stopped staying out..." (Sarah Morris, 15).

"...So what used to happen when you were ill the next day? Why was that...? (Joy)

"...I'll be honest I do have a little drink now and again. Like every couple of weeks it depends, or on special occasions or like when everyone's having a laugh, having a little drink" (Sarah).

Six families also mentioned that adolescents had drunk alcohol with their friends before (Stewart Stanley (16), Lisa Brookes (16), Holly Thomas (15), Jenny Dutton (14), Beth Salisbury (13)) and one had drank alcohol with family members (Jenny Dutton (14)). Most of the adolescents had never tried alcohol and many stated they would not want to because of its negative health effects, for example:

"I don't really want to drink I've got mates that have done it since they were ten, they think they're all like hard and that but when they cough you can hear it, and when you've had a bit too much to drink and you've got a hangover, I just think what's the point in doing all that 'cause it's just ruining your body" (Sean Ratledge, 15).

Balfe (2009) suggests that adolescents experience conflict between their social body (risk taking behaviour such as drinking alcohol) and their healthy body (reduction of bodily risk) as they pursue the construction of a desired identity in relation to their desired position within their social group.

Parents expressed their concerns about their child drinking alcohol with their friends. They recognised the temptation if their peers were doing it but worried for their child's health because of the effects of alcohol on blood glucose and the risk of severe hypo occurring. This mother stated:

"She's going to a party later, I do worry, as getting to the age that she is...and I think what I was doing when I was seventeen, I think oh my god you know...is she going to start drinking?" (Mother, Bingham family).

Parents recognised the influence of peers on adolescents' decisions to drink alcohol (Allen et al, 2005). These fathers recognised the difficulty their children may experience in saying no, when all their friends are doing it:

"I just know they're at that age where they're all having a go at doing it and there again I suppose she doesn't want to go well I can't 'cause I'm diabetic...it's easier said than done when they're all having a go" (Father, Salisbury family).

One adolescent female described the opposite, that her friends supported her in not being able to drink alcohol, and refrained from drinking themselves so that she would not feel pressurised to join in:

"My friends don't really drink, they support me with that, only on special occasions like if we go out to a party or we have a party in the house,

that's the only time we drink really" (Jenny Dutton, 14).

Sarah Morris, Martin Edwards and Beth Salisbury had experienced severe hypoglycaemia as a result of consuming alcohol. As James Pickering's father described:

> *"For a normal person...let him be sick that's fine, I had to stay up all night and test his blood every two hours. It's different than in a normal family, you'd be annoyed and say ah he's ok now, put him to bed let him sleep, just sleep it off..."* (Father, Pickering family).

One adolescent female described experiencing DKA after forgetting to inject her insulin after drinking alcohol the previous evening. She stated:

> *"Well I was drinking a few days before I went to hospital, I was drinking for two days with my Nan and that and I missed my insulin three or four times..."* (Jenny Dutton, 14).

Some parents worried that their child may be mistaken for being drunk when hypoglycaemic because of impact of symptoms on awareness and character, as this mother described:

> *"If he flakes out...someone like an ambulance person will just think he's drunk"* (Mother, Jones family).

This was also discussed in the parent focus group, as one mother stated:

> "(When he is having a hypo)...*he'll look at me and his face has gone all funny, and that's what worries me because if he's in the street he looks like he's drunk or on drugs or something..."* (Mother, Mather family).

Those adolescents who did drink alcohol were aware of how to drink safely, in order to reduce the risk of hypoglycaemia occurring. The hospital informed adolescents how to drink safely which involves eating whilst drinking and/or reducing insulin intake. As this adolescent male confirmed:

> *"It makes your blood lower when you drink alcohol...when I do drink I don't take a needle for my supper 'cause I go low in the night, If I take a needle at my supper and I have something to eat before I go to bed then I'm*

fine" (James Pickering, 15).

Beth Salisbury's father found himself in a predicament when he discovered his thirteen year old daughter had been drinking alcohol with her friends. He wanted to advise her on how to drink alcohol safely, however he felt that if he did this she would then think he was giving her his blessing to drink. He agonised:

> *"It's either saying, lower your insulin but is that then giving her the go ahead to go well, I don't mind you drinking, I don't want her drinking full stop but I just think well if she's going to go out and do it anyway behind your back...but I don't want to give her the green light to go out and get bevvied on a Friday night...you just don't know what to do for the best with her"* (Father, Salisbury family).

Sarah Morris's mother also felt that the hospital's education regarding alcohol gave her daughter 'permission' to drink. This indicates a difficulty in determining the best approach regarding alcohol education in adolescents with T1D. Education is necessary in order to avoid severe hypoglycaemia, however there is a danger that such education may lead adolescents to believe that their perception of alcohol consumption is approved of by health professionals and parents.

(iv) Perceptions of discrimination

Parents described the adolescents experiencing discrimination in a number of ways, including one male not being able to go on a school trip because of his diabetes and another not being allowed a lunch break when he was on work experience. This led to him having to withdraw from work experience and hence he missed out on this vital part of his education as the school could not provide him with another placement at short notice. His mother described:

> *"He had to fill in the form where there's health requirements and I said Martin must eat his dinner and be allowed snacks during the day and he's got to carry glucose tablets. The feller he was with was really horrible. He said you won't be having a dinner hour for the rest of the week...and he was*

running all around, it was like a fitness day for other schools to come and he's like putting the equipment out, it was really strenuous, he was using his body all day... he had six hypos that day because he hadn't stopped to eat...he said I'm not going back, I can't do that every day, no lunch...I thought I'm not risking his health, so can you get him somewhere else and they couldn't so he missed the whole work experience thing...sometimes he will miss out on certain things like that, and that bothers me and I think it bothers him as well" (Mother, Edwards family).

Some adolescents described having experienced bullying with regards to their diabetes, for example:

"What about like her friends in school, were they supportive or did she have any problems...? (Joy)

"...If they'd see her going to the ice cream van they'd say, oh Jenny's a smack head, go and take your needles...it fizzled out, it's just kids isn't it, they outgrow it" (Mother, Dutton family).

A study of 33 adolescents with chronic illness in the UK found that over a third had been bullied because of their illness characteristics or been treated differently by teachers in school (Lightfoot et al, 1999), suggesting that stigma exists. One adolescent described how bullying by his peers led to him getting into trouble at school, when he retaliated to their comments. He stated:

"I always had people skitting me about it but I mean, I took so much and then I'd had enough, that's when I started getting in trouble because of it...there was this lad...he was going on at me and I hit him in the face and then he went and told the teacher, the teacher told me off" (Sean Ratledge, 15).

Discrimination in sports was also an issue for two of the adolescent males, as this male described:

"In my old school, they wouldn't let me join in on any sports teams...in case we have a match and I have a hypo and collapse...but that shouldn't be

a problem 'cause I control my sugar...they're not that bothered now 'cause they understand I can control it so they let me on more teams and that" (Sean Ratledge, 15).

One mother believed that her son had not been accepted into a football team because of his diabetes. She stated:

> *"They never phoned back and I always wonder, although Steven was supposed to contact him I know that, but I thought if he was really keen he'd have rung up but I thought was it because I'd ticked diabetes?"* (Mother, Gibbons family).

Others described positive reactions from sports teams, and the CASI data demonstrated that many adolescents enjoyed an active sporting life. This mother stated:

> *"When she was in the first year she was trying for all these teams and what bothered her the most was I won't be able to get into the teams because I've got diabetes, but they said oh no we're pleased to have you"* (Mother, Thomas family).

The different perceptions of mothers around this issue suggests that discrimination may be perceived rather than actual in some cases where adolescents' and parents' expectations of how they think others will react dominate their interpretation of situations. Some parents worried that their adolescent would experience discrimination in later life as a result of having diabetes. In the Pickering family this was related to the father's own experience of living with diabetes:

> *"I worry...because right away after you're diagnosed with diabetes they treat you differently anyhow, work wise you can't join the forces, can't be a policeman, can't all that type of stuff so that's an ordeal that the kids have got to go through when they get older, get the knock back and that...* (Mother, Pickering family)

> *"...I had a lot of knock backs...I don't tell people I'm diabetic 'cause as soon as they know I'm diabetic...* (Father)

"*...They sort of shy away from you...* (Mother)

"*...I've had that all my life because I'm one of the top referees, if they know I'm a diabetic, I won't get the games*" (Father).

Although in other families, a parent with diabetes appeared to have a positive affect on adolescents' self-management, in this case the father's experiences affected the parents' outlook on their child's future in a negative way.

The label of 'disabled' caused some distress to some parents who felt uncomfortable labeling their child in this way because of the risk of discrediting responses from others (Goffman, 1968). One mother described how she felt uncomfortable when her son was given a high level of financial support when applying for the Disability Living Allowance (DLA):

> "*When he was very first diagnosed and we filled all these forms...one for the living disability allowance...he got the higher level allowance and it struck home that he's got something really bad...that really upset me...it's actually come down now...he gets the lower rate now, which made me feel better really because I felt like you know, he's not that bad after all*" (Mother, Jeffs family).

This adolescent female described how knowing that she had a 'disability' made her think negatively about her career prospects:

> "*I always wanted to be a model and I used to think I couldn't because of my diabetes but my mum said it's nothing to do with that...I always used to think there's loads of things you can't do if you're a diabetic with a disability*" (Jenny Dutton, 14).

This demonstrates the social construction of the defining characteristics of illnesses within society (Nettleton, 1995). Mrs Jeffs perceived her son's diabetes as less serious when the allowance was reduced. She also stated that she did not inform her son of the allowance for fear that he would interpret the label of 'disabled' as him being different from his peers.

6.5 Normalisation: Impact on blood glucose control

Through exploring the management of T1D within the home, biomedical, school and social environments, I interpreted that blood glucose control is underpinned by the different spatial environments inhibited by adolescents in their daily lives, and the 'normalisation' of T1D within these environments. Established environments including the family home, school and the social environment are disrupted when T1D is diagnosed, as normal practices become restricted with the demands of the diabetes regime. Alongside this, adolescents and their families are introduced to a new biomedical environment – the hospital and diabetes clinic. T1D is already normalised within the clinical environment, as it is medically defined, however it is often perceived as an alien environment in relation to the 'real life' experience of T1D.

Following the initial disruption of T1D within the home environment, families gradually adapt to the demands of the disease and integrate it within family life, meaning that T1D also becomes normalised within the family environment. The initial disruption is large and T1D is visible to family members who witness the self-management regime, blood glucose fluctuations and raw emotional and psychological effects on the adolescent. Parents are likely to control this adaptation process as they re-evaluate their caring role towards the child with diabetes and their other children. Adaptation is necessary in order to maintain a balance within the functioning of the family. The unbalance caused by a diagnosis of T1D can lead to conflict within the family environment, as discussed later in the *Relationships with significant others* category. Therefore adaptation within the family is necessary and meaningful to all family members.

Within the school and social environments, normalisation of diabetes does not occur as readily, as there are a number of barriers restricting this. Firstly, the adaptation of these environments to T1D may not be as meaningful to the actors within them as it is to actors within the family. For example, the well-being of one adolescent within a school of 3 000 pupils does not directly impact on the well-being of another individual pupil. However, in a close peer group it may be more meaningful to normalise the adolescents diabetes in order to minimise its effect on peer group activities. Secondly, the adolescent may create barriers to normalisation, through maintaining 'invisibility' of their disease, which acts towards preventing the meaningfulness of their diabetes to others. Thirdly, invisibility of T1D is maintained by adolescents because of the perceived and actual negative reactions of others to the visible characteristics of their disease, including reactions to blood glucose fluctuations and injecting, and discrimination. Feeling 'different' because of diabetes was embedded within the reactions of others. Acceptance of diabetes was encouraged when others around the adolescent appeared to integrate and accept their diabetes as 'normal'. When diabetes was normalised, it was easier for the adolescents to integrate self-management into daily life and therefore many of the adolescents described situating their self-management within the 'safe' environment of the home, and this appeared to restrict independence for some.

Finally, the meaningful aspects of the spatial environments to the adolescent will also affect their self-management decisions within the environments, in terms of what they prioritise as most important. For example, Russell Jones told how he would often miss his lunch time injection in order to spend time with his peers in the music block suggesting that immediate concerns about fitting in with the peer group may outweigh long-term concerns for future health for this age group, in relation to their cognitive developmental level. It was therefore apparent that blood glucose control was influenced by the *level of normalisation* of T1D within the different spatial environments of the adolescents' lifeworlds. The following two case studies demonstrate the extremes of this phenomenon.

Case Study 1: The Collins Family

Ian Collin's father had lived with T1D since the age of fifteen. The family members spoke of the prompt adaptation to the adolescent's diabetes within the family when Ian was diagnosed. The following quotation illustrates that the T1D lifestyle was already integrated within family practices, and therefore already normalised for the adolescent, removing many of the barriers to acceptance:

> *"With my dad having it for so long I've seen it from like four, when I started noticing it and then I got used to it...I wasn't that bothered because I'd seen my dad doing it loads"* (Ian Collins, 13).

The father took a mentoring role towards his son, and guided him through self-management based on his own experiences, as the following quotations demonstrated:

> *"He's my star pupil (laughs)...I always tell him to take Lucozade because I think Lucozade gets into your sugar faster and it seems to bring you out the hypo a lot quicker that eating a chocolate bar or anything like that"* (Father, Collins family).

> *"Because my dad's got it himself...he understands it completely...I think my mum does as well but not like to the same level, as my dad's experienced it and still is"* (Ian Collins, 13).

This empathetic understanding of his disease by his father enabled the adolescent to feel confident, guided and most importantly, not isolated or different within the family environment. This confidence extended to other environments and facilitated his ability to commit to the self-management of his diabetes. In comparison to families who were unfamiliar with T1D, this mother described a more minimal impact on her son's life:

> *"He's seen a lot of it with his dad so it's part of life...it hasn't been a terrible shock...he knows it's not the end of the world, so it's not that life changing"* (Mother, Collins family)

The normalisation of this male's T1D within the family environment appeared to have a positive impact on his perceptions of his self-management and his ability to self-manage his diabetes away from the family home. He reported blood glucose testing frequently in the CASI diary tool and described successfully managing his diabetes around a range of sporting activities in the school and social environments, for example:

> *"I went away for a week last year skiing so I was alright then but when I was out there I bought a few bottles of Lucozade so I if I did need to have anything I had it"* (Ian Collins, 13).

Having T1D already in the family also facilitated parental coping. The impact of T1D on the functioning of the family environment was less, and required less adaptation by family members in order to regulate the environment. Ian's mother explained:

> *"Obviously (with my husband) having it your always conscious...about food, there has to be carbohydrates within the meal...and signs to look for if somebody's going into a hypo and all the various things that are just automatically a part of the way of life. So in that way I can honestly say from our point of view it probably has not been that disruptive"* (Mother, Collins family).

Ian used a basal bolus regime and injected and tested his blood glucose in school, and was keen to move onto an insulin pump in order to minimise the impact of T1D on his lifestyle further. This attitude may have been influenced by his father's belief in the value of balancing living with T1D and quality of life, as he described here:

> *"I think with diabetes you've still got to live your life like you'd live it if you didn't have diabetes even though you've got to control it. I don't think you can let it hold you back in life. If you are going to do something, do it, don't not do it because you've got diabetes, I think that's a negative attitude if you do it like that"* (Father, Collins family).

Ian's mother also described his autonomy and ability to manage blood glucose fluctuations confidently away from the family environment, as this quotation demonstrated:

"I think one time he got sherbet coating or something, he hadn't realised and it sent his sugars really high, he'd rang me from his friends, I think it was a party...so he took some insulin and I said ring me back in an hour and he kept ringing me back, it came down gradually...to be honest he is good with it...the one thing I've never had to worry about with him with his insulin because he's so sensible with it..." (Mother, Collins family).

The positive impact of the support of others with T1D in the same environment as the adolescents was also demonstrated in a number of other cases, where fathers (Emily Dougherty and James Pickering), siblings (Samantha Makin) and peers (Jenny Dutton) with T1D influenced normalisation through the commonality of the disease. As Jenny described:

> *"There's a lad that I hang round with and he's got diabetes as well...so I feel comfortable telling him when I feel sick because he's like had it for thirteen years...and we feel the same, we're dead comfortable around each other. I didn't used to feel comfortable telling people about it, but now because he's there I don't feel any different"* (Jenny Dutton, 14).

Ian had an average HbA_{1c} of 9.1%, which was slightly higher than the 'Good to moderate' category. Although this merited improvement, his adherence to the CASI diary tool and descriptions of his good coping skills by himself and his parents self-efficacy for his diabetes management. This enabled Ian to engage in environments external to the family without the perception of barriers to his self-management, as he saw his dad living an unrestricted life with T1D. His self-management was also assisted by the supportiveness of his school and peer environments. Ian's relatively high HbA_{1c} level suggests that this level of control may have been accepted within the family, embedded within his father's ethos of balancing the enjoyment of life with the demands of T1D. It would therefore be interesting to explore his father's HbA_{1c} levels in relation to Ian's, and suggests that although normalisation in the family may have positive psychosocial effects, this does not necessarily have a positive impact on HbA_{1c}.

Case study 2: The Morris family

As described in the *Normalisation* category, Sarah Morris received negative feedback from her friends in relation to the visible symptoms of blood glucose fluctuations, in particular hypoglycaemia. Her mother described her daughter's need to be "normal" (the same as her friends) within her social environment. The negative feedback she received from her friends prevented the normalisation of her diabetes within her peer group. This adolescent prioritised her need for peer acceptance over T1D control and it was therefore necessary to 'eliminate' diabetes from her persona when with her peers.

Sarah's recent transference to a basal bolus regime gave her the freedom to do this, as she was able to be with her friends for long periods of time without the threat of spontaneous disclosure of her diabetes through hypoglycaemia. Instead, she maintained high blood glucose levels for long periods of time each day in an attempt to avoid hypoglycaemia. She would routinely eat from the chip shop with her friends and not inject insulin for up to five hours later, when she returned to the 'safe' environment of the home. Here, diabetes was normalised and also invisible to her peers, however her maintained high blood glucose levels were detrimental to her future health, putting her at risk of complications and resulting in an average HbA_{1c} of 9.8%. Negative attributions of friends' reactions have previously been shown to be related to poor adherence and diabetes stress in adolescents.

Like Sarah, many other adolescents described the interference of T1D to peer activities:

> *"Basically it just gets in your way, it's something that you don't really need when you've got other things to do"* (Russell Jones, 14).

The barriers to normalisation of this teenager's diabetes within her social environment were perceptions of her peers' reactions to her diabetes, based on previous negative experiences. The meaning of diabetes control for this adolescent was the avoidance of low blood glucose to facilitate integration within her peer group. In order to confirm her identity it was important that she inhabited the same characteristics as her friends. Diabetes alienated her from her peer group through difference. Therefore, rather than being motivated by the biomedical model of good blood glucose control to maintain her health, diabetes management was meaningful to this adolescent in terms of her ability to maintain invisibility of her disease within the social environment.

6.6. Normalisation: Summary

My interpretation of the lived experiences of the sample, in discussion with the findings of other studies, suggests that living with T1D involves negotiating a variety of barriers within different environments, which have the potential to inhibit normalisation. Negotiation of these barriers is based on norms, values and the prioritisation of the adolescent of personal goals within the environment. The normalisation of T1D within an adolescent's surrounding environments influences self-management and promotes good blood glucose control through the absence of negative feedback in relation to self-management behaviour. Normalisation is most likely to occur in the diabetes clinic, where T1D is biomedically defined through medical terminology and language; and in the home environment, where it is meaningful to family members to adapt to T1D in order to maintain family structure.

A balanced family environment enables experiential learning for the adolescent and family members, which contributes to the normalisation of

T1D within the family and external settings and adolescent independence for T1D management. Routine is therefore absolutely necessary for parental well-being, family functioning and experiential learning when a child has T1D. The normalisation of T1D as a positive family trait may have negative implications for blood glucose control, whereas normalisation of T1D as a negative family trait has the potential to affect the psychosocial well-being, motivation and perceptions of adequate blood glucose control. Thus, normalisation is not a homogenous process for all families. It can take many different forms and have various psychosocial and biomedical outcomes, depending on a range of interpersonal and structural factors.

Normalisation is less common in the social and school environments, where need is not meaningful to other individuals. This causes barriers which inhibit self-management through negative feedback and ultimately inhibit blood glucose control. Disclosure of T1D to others within the social setting is underpinned by a complex process of weighing up the costs and benefits of disclosure in relation to the social objectives of the adolescent. This leads to daily conflicts and self-management may suffer if social acceptance is prioritised over health needs. Meanings and motivations underpinned by environmental constraints and facilitators for diabetes self-management are of utmost importance in understanding the self-management behaviour of adolescents and how this has the potential to ultimately impact on blood glucose control.

Category 2: Embodiment

(The integration of T1D within the self and parental embodiment of a child's T1D)

This theme emerged from my interpretation of how adolescents embodied living with T1D in adolescence and integrated the disease within the self, in relation to theories of the embodiment of chronic illness discussed in Chapter 2. It is divided into two themes: the embodied experience of T1D and the phenomenon of parental embodiment.

6.7 Embodiment Theme 1: The embodied experience of T1D

Experiencing T1D within the body was characterised by the manifestation of new physical symptoms within the body, which disrupted its taken-for-granted 'healthy' state. This state was replaced with a 'new' body. The functions of the pancreas were brought to the attention of the mind and had to be controlled 'externally' be the adolescent. The experience of adjusting to the embodied state of T1D was underpinned by a number of factors explored in the following further sub-themes: the disruption caused by diagnosis, the biomedical management of T1D, the process of redefining bodily existence, diet and physical activity and body image.

(i) The disruption of diagnosis

Symptoms preceding the diagnosis of T1D were the first 'signs' of abnormality in the taken-for-granted bodily functioning of the adolescents. All of the adolescents presented with physical symptoms before diagnosis, but the majority of parents (apart from those who had previous experience of diabetes), were not aware of their significance at the time. The most common symptoms experienced were the physiological responses to decreasing insulin production in the body: frequent urinating, extreme thirst and fatigue. As this adolescent male stated:

"When you were first diagnosed with diabetes, what's your first memory of what happened...? (Joy)

"...I was going to the toilet all the time in the night and drinking loads of drinks...I couldn't last that long in footy and was having to like sit out" (Steven Gibbons, 16).

Entrance into the biomedical environment at diagnosis symbolised a new conception of the body as 'out of control'. Symptoms, diagnosis and treatment underpinned a new world of understanding that had to be taken on board by both the adolescent and their parents in order to survive. Some adolescents described being put on an insulin drip in hospital, representing the inability of the body to function alone without assistance, as described here:

"I got taken to the doctors and then got referred to (hospital), then I was put on a drip...then when I was better off the drip again I was took off it and then I had the first injection" (Anthony Mather, 15).

My interpretation of the reactions to diagnosis of those who were old enough to remember the event, was a process of redefining themselves. Their embodied identity was questioned, and they began to query their existence in relation to the taken-for-granted practices within their daily lives, as the following quotations depict:

(i) "I just felt different from everyone else and I felt I don't know, different to my mates" (Jenny Dutton, 14).

(ii) "(I was) *devastated really 'cause I'd have sweets all the time...I didn't like it at all because I couldn't have what I used to have*" (Martin Edwards, 14).

The threat of death became a reality following diagnosis for one male. The mother described the following reaction in her son:

"I can remember him coming into the room where we were being educated and he said, does this mean I'm going to die? And that was very upsetting" (Mother, Butcher family).

This demonstrates the uncertainty a diagnosis of chronic illness can bring, with regards to health and perceptions of the life-course. Following a diagnosis of T1D, adolescents are forced to redefine themselves and their identity in relation to their new body and its new limits.

(ii) Redefining bodily existence

As the theme of 'normalisation demonstrated, the biomedical definition of T1D was often alien within external social environments and warranted the adaptation of others within the environments. However, the process of normalisation of T1D within these environments was also underpinned by the adolescents' coping strategies, which functioned to enable them to 'tolerate' their illness and maintain a sense of personal worth (Bury, 1982). As a result, adolescents' lived experiences were redefined by the regulation of their blood glucose levels. Within the theme of redefining bodily existence, I described two further sub-themes: adapting to the diabetes body and positive integration of T1D within the self.

Adapting to the diabetes body

This adolescent female described how her daily activities were always meaningfully directed towards the regulation of her blood glucose:

"Can you talk me through what you actually have to do to manage your diabetes in a typical day?... (Joy)

"I make sure I've done an activity in the day to make sure it's not going too high...and make sure I've had something to eat at lunch to make sure it stays up and then just make sure I eat at the right times and do my needle when I get in later on..." (Lisa Brookes, 16).

Many of the adolescents found self-management a chore. However, complete non-adherence to the diabetes regime was restricted by the physical manifestation of blood glucose fluctuations. These were experienced by adolescents in the form of various physical symptoms, which acted as barriers to the escalation of blood glucose to a severe level. Some interpreted these as useful warnings, but they were also an inescapable and constant reminder of T1D. It is common for children with relatively good glycaemic control to experience one to two mild hypoglycaemic episodes per week. Most of the adolescents in this study experienced low blood glucose symptoms on a daily basis. Even those who appeared to be the most well controlled, experienced symptoms of hypoglycaemia three to four times per week (Emily Dougherty, 15), or *"most of the time"* (Samantha Makin, 15). Other adolescents very rarely experienced hypos, and some only experienced them at night, as this female explained:

"I've never had one whilst I was awake, it's always been when I've been asleep...I'll go into one in the middle of the night and then just wake up and be sick... and the headache as well" (Lisa Brookes, 16).

At the other extreme, five of the families described high blood glucose readings as *"normal"*. This was mainly due to issues with adherence. As described in, *The experience of T1D in the social environment* (6.4), the visibility of low blood glucose symptoms influenced some adolescents to maintain high blood glucose in order to avoid involuntary disclosure of their diabetes. For these adolescents, their bodies had the potential to betray them unexpectedly. The maintenance of high blood glucose levels enabled control in the social environment, but posed a risk to future health.

The embodied experience of blood glucose fluctuations varied between adolescents. Table 6.1 shows the most commonly described symptoms of hypo and hyperglycaemia. This demonstrates the variability of symptoms across the sample and also the overlapping of some symptoms in the experience of both hypo and hyperglycaemia. Experiencing the symptoms of hypo and hyperglycaemia enabled the adolescents to attune to the physical needs of their bodies. For some, this reduced the impact of T1D on their daily lives through preventative measures, such as taking extra carbohydrate when participating in sport and not missing meals. This was important, as some adolescents described an adverse affect on their concentration which could affect their academic performance. Others described how they relied on embodied indications of blood glucose fluctuations, rather than preventative blood glucose testing:

> *"She says she knows how she feels when it's low, so she doesn't need to test"* (Mother, Morris family).

The overlapping of symptoms described indicated that reliance on physical symptoms did not provide an accurate definition of blood glucose levels. This may be problematic for blood glucose control, as a recent study found that children aged 6-11 years with T1D failed to recognise 60% of hyper and hypoglycaemic symptoms (Gonder-Frederick, 2008), which could lead to dangerous blood glucose fluctuations if blood is not checked regularly. A number of adolescents reported not always experiencing symptoms which emphasised the importance of regular testing. However, reported blood glucose testing in the CASI diary tool was extremely variable throughout the

Table 6.1: Embodied symptoms of hypo and hyperglycaemia

Embodied Symptoms of Hypoglycaemia	Embodied Symptoms of Hyperglycaemia
Fatigue: *"You just want to sit down and go to sleep"* (Holly Thomas, 15) **Loss of concentration:** *"It's like you're trying to concentrate on something but it won't let you..."* (Russell Jones, 14) **Pain:** "*I get a pain in my head*" (Ian Collins, 13) **Changes in body temperature:** *"You feel dead cold like you're freezing, shaking..."* (Ian Collins, 13) **Nausea:** *"...Dizzy and sick"* (Sarah Morris, 15) **Hunger:** *"I went straight to the cupboard and just started eating honey"* (Anthony Mather, 15) **Loss of balance**: *"My legs are about to go at any minute...my legs just do their own thing"* (Russell Jones, 14) **Shaking and sweating:** "I feel a bit shaky and sweaty" (Ian Collins, 13)	**Fatigue:** *"I've got no energy and I can't be bothered doing anything"* (Emily Dougherty, 15) **Loss of concentration:** *"In tests sometimes I'm high or something, it can affect your concentration"* (Mother, Collier family) **Pain:** *"He knows when he's high 'cause he gets headaches with it"* (Mother, Collier family) **Changes in body temperature:** *"I just get tired and hot"* (Martin Edwards, 14) **Vomiting:** *"She'll start throwing up and going to the toilet"* (Mother, Morris family) **Loss of appetite:** *"I'm not hungry...it goes alright after about an hour of doing my jab though"* (Martin Edwards, 13) **Dehydration:** *"If it does get too high I start getting thirsty"* (Emma Bingham, 16) **Frequent urinating:** *"If he's really high he'll be going to the toilet a lot more"* (Mother, Edwards family)

group; the mean number of entries across the week for blood testing was 14.7 with a standard deviation of 5.7 and a range of 4-24. Some adolescents rigorously tested their blood throughout the day, whereas others reported rarely testing, for example:

(i) "I get up, test my blood and have my breakfast, take my insulin...test my blood at lunch...I usually check it before sport...after lunch I play football...then come home and test my bloods, test my blood for my tea

and then...at night test it before bed" (Ian Collins, 13).

(ii) "I don't really do my blood that much, I do it but I'm not one of them people to do it all the time. I'll miss it, but I'll miss it like a couple of days...it's just hard to remember most of the time, if you're going out as well" (Lisa Brookes, 16).

Some adolescents had experienced severe hypoglycaemia and DKA as a result of poor blood glucose control. This adolescent female described her experience of severe hypoglycaemia:

"I went to the gym with my mum and then I had a bit of Lucozade because I was four before I went to bed and then I think I just dropped you know through the night...and then my mum was telling me that I was awake but I can't remember anything...and I was about to get in the bath and I slipped on the mat and hit my head against the sink and then I started having fits on the floor, so my mum phoned the ambulance men and they came out...my mum asked to me to go in and I was on a drip when I woke up" (Jane Fletcher, 14).

The varying experience of severe symptoms and the hospitalisation of some adolescents meant that the way in which the adolescents experienced the embodiment of their disease was not homogenous. Those experiencing more severe symptoms were more likely to have a more biomedically-defined view of their bodies. Such events also acted as individual disruptive events in their own right, leading to a similar displacement of the self as that experienced at diagnosis. This is addressed in more detail in the following category, *Experiential learning.*

The findings suggest that chronic illness may represent a loss of personal control when daily activities are disrupted and a person becomes dependent on health professionals. This may affect a person's sense of self and identity and have a particular psychological impact during the developmental period of adolescence (Grinyer, 2007). Despite this, previous research has found that adolescents with T1D appear to be as well psychologically adjusted as those without a chronic illness, and in support this study did not find evidence of psychological disorders in the sample (although methods did not aim to detect this specifically). Psychosocial barriers may be experienced as adolescents attempt to redefine their identities with integration of their illness, but with guidance and support from family and health professionals, 'pushing boundaries' has the potential to increase confidence and self-esteem and thus facilitate normalisation in the home and other environments.

Positive integration of T1D within the self

Many adolescents demonstrated a positive integration of T1D within the self, through improved lifestyle, a view to not take health for granted and a non-judgmental view of others and the description of positive outcomes of the disease. These included improved lifestyle and not taking their health for granted, as the following quotations demonstrated:

(i) "Do you think anything positive at all has come from you having diabetes...? (Joy)

"*...I always used to eat chocolate every day and now I feel more healthy, I feel more energetic...I'm not eating junk food like all the time, it's better*" (Jenny Dutton, 14).

(ii) "It's made me like appreciate stuff more because you moan about having it but you see other people in worse conditions, people in wheel chairs, so it's made me appreciate stuff like that" (Ian Collins, 13).

One adolescent also described how it had changed the way he viewed other people:

"It's made me a better person like because I always think you can't insult people because you don't know how hard they've got it" (Sean Ratledge, 15).

Adolescents were comfortable with managing their diabetes in public when situational barriers were reduced by the acceptance of diabetes by others and the self-esteem and confidence of adolescents. This appeared to increase with duration of diabetes as Emma Bingham described:

"I used to go to the toilet and do my injection but now I just sit there at the table injecting and some people you get staring at you, seeing what you're doing and I don't look I just go whatever, I just put it in me, they just get used to it" (Emma Bingham, 16).

When asked if they felt diabetes had had any positive influences on their family, parents scribed various positive psychosocial outcomes for their adolescent in relation to living with diabetes, including a number of positive personality traits:

- Maturity: *"I think it's made him more patient and it's really helped him to grow up"* (Mother, Edwards family).
- Determination: *"She'll have a go at things, she won't let something stop her, she won't say, I can't do this it's I'm going to do that and nothing's stopping me, so its built her up in that sense"* (Mother, Makin family).
- Discipline: *"In a way, having diabetes can make you disciplined and I think that is a good thing really"* (Mother, Dougherty family).
- Independence: *"I think she's gained her independence a lot quicker in a lot of ways...she's had to grow up quicker 'cause she's had to behave in a different way"* (Mother, Makin family).
- Positive coping: *"The way he's coped with it...I think he's been very positive from day one...I think he's like accepted it and got on with it"* (Mother, Ratledge family).

This suggests that a diagnosis of T1D may have a positive impact on self-development in adolescence, as observed by parents, although it is also acknowledged that parents were directly asked for this information and therefore may have offered a positive trait to balance out the preceding discussion of difficult issues. This is supported by evidence that personal models of T1D are inextricably linked to the transformation of the self in response to T1D, and could have a key impact on adherence and blood glucose control. Treatment effectiveness beliefs have been associated cross-sectionally and prospectively with self-care in adolescents (Skinner et al, 2002; Skinner et al, 2000; Griva et al, 2000; Hampson et al, 1990).

(iii) The biomedical management of T1D

Following diagnosis, adolescents were monitored in hospital for a number of days, before they were released from the biomedical environment into the environments of the home, school and the social. Their lifeworlds were severely disrupted, as they were forced to take on the responsibility for the normally taken-for-granted production of insulin by the pancreas. This was achieved through adherence to an insulin regime. Most of the adolescents began their diabetes treatment on twice-daily insulin, but the diabetes clinic aimed to transfer all adolescents onto a basal bolus regime based on its proven benefits for control and long-term outcomes. Forty per cent (n=8) of the adolescents were using this regime.

Each insulin regime had benefits and limitations which were individualised in relation to lifestyle preferences. Adolescents on the twice-daily regime appreciated the predictable daily routine it facilitated. It appeared to give them a certain amount of control over their diabetes and enabled them to predict outcomes more easily. This was reflected in one adolescent female's reluctance to move to the basal bolus regime:

"*Well when I went yesterday to the hospital they said they wanted to put me on four injections a day...* (Samantha Makin, 15)

"...How do you feel about that...? (Joy)

"*...I don't know 'cause, I don't think I'd like to do four injections... 'cause she said do four at the weekends and then three in the week but I'd just forget... (Samantha)*

"...So when will you be taking your other injections then...? (Joy)

"*...One at lunch time...* (Samantha)

"...So don't you fancy doing that in school...? (Joy)

"*No, it gets confusing. 'Cause say I only do it at the weekends then I might* *just forget..."* (Samantha).

Some adolescents rarely needed to test their blood on this regime, and I believed that this may have been due to them thinking they would know what the outcome would be. Some families also described feeling restricted on this regime. This related to not being able to eat what they wanted due to a restricted carbohydrate intake, and also having to eat too much at times in order to meet the peak of their insulin dose. Adolescents on the basal bolus regime therefore enjoyed the freedom of being able to eat what they wanted, when they wanted, and inject insulin accordingly. For some this meant eating foods that had previously been restricted; for others it had the benefit of a reduced calorie intake and weight loss, as Jane described:

> *"I used to have to eat every two hours on my old medication and people would be really thin and I always used to think, oh I want to lose weight...* (The basal bolus regime) *gave me more freedom and I wouldn't have to snack every two hours, I lost weight because I didn't have to snack..."* (Jane Fletcher, 13).

The basal bolus regime also benefitted adolescents in reducing the amount of carbohydrate needed to treat hypoglycaemia and improve blood glucose control. This regime has been shown to reduce the incidence (Massin et al, 2007; Mohsin et al, 2005; DCCT, 1993) and progression of diabetes-related complications (EDIC, 2005), severe episodes of hypoglycaemia and DKA (Nordfelt and Ludvigsson, 1999) and influence good psychosocial outcomes in young adulthood (Insabella et al, 2007). The majority of adolescents using it benefitted from increased lifestyle freedom and independence, supported by previous reports of increased freedom in comparison to twice daily regimes (Nordfelt and Ludvigsson, 1999; Mortensen et al, 1997), improved blood glucose control, fewer hypoglycaemic episodes (Nordfelt and Ludvigsson, 1999) and increased independence.

Most of the adolescents did not mind the increased amount of injections on the basal bolus regime, in exchange for the increased freedom it brought. However, this was a deterrent to some adolescents to transfer from twice daily to basal bolus. It was also a limitation for some on the basal bolus regime:

"I sometimes feel a bit down about having diabetes...like having to do a needle with every little thing that I have" (Darrell Collier, 13).

Some parents were concerned that their child avoided eating to avoid injecting insulin, as this mother explained:

"He'll either eat his dinner and not do his insulin or he might not even bother eating his dinner because he thinks if he doesn't eat his dinner then he's alright for some reason...he'll say well if I haven't ate nothing I don't have to give myself nothing" (Mother, Jones family).

The basal bolus regime required motivation and commitment from the patient and some adolescents felt tired of this at times. Many felt that is was time consuming and difficult working out the amount of carbohydrate in everything eaten:

"Sometimes it can be annoying and time consuming when you've got to work it out and I get bored sometimes...sometimes you just inject whatever just to get it out the way..." (Holly Thomas, 15).

"I do worry that we don't carbohydrate count on the system because I can't get it into my mind, especially if you weigh everything, so I do tend to shy away from it, we've, guesstimated what we should inject and it seems to work" (Mother, Butcher family).

Family support was important due to the level of organisation required. Many families made a list of certain meals and the carbohydrate amounts they contained in order to make working out insulin doses at meal times an easier task. A team work approach between parent and adolescent was also valuable:

"My mum would help out more and like buy foods that I like, because I'm counting the carbohydrates, so she picks things that I like and we remember what they are" (Holly Thomas, 15).

The combined insulin regime, united the advantage of not having to inject during school by injecting a slow acting insulin to cover them for the school day, with the freedom of using a fast acting insulin to cover their evening meal and additional snacks. It therefore provided a middle-ground for adolescents transferring from twice-daily to basal bolus.

Adolescents on basal bolus and combined regimes generally reported testing their blood glucose more regularly that those on the twice-daily regimes, however two adolescents on this regime had the lowest rates of adherence to blood glucose testing recorded in the CASI diary (Russell Jones, 14 and Sarah Morris, 15). Low levels of commitment and family support plus a lack of carbohydrate counting meant that their blood glucose control deteriorated following transference to this regime. The adolescents' HbA_{1c} levels were in the 'Needs improving now' and 'Risk zone' categories (8.7 and 9.1 respectively). Not testing their blood glucose led an unknown state and often led to chaotic and 'risky' situations, as Russell described:

> *"Most days* (I have a hypo)*...I've got this book that measures carbohydrates and I haven't took it lately so I end up giving myself too much insulin, so I'll have a hypo probably...between the end of school and going home...usually it's at the bus stop so I'll wait...I know that I'll last because the bus takes like two minutes and there's a shop just around the corner from the bus stop when I get off, so I'll just end up getting something* (to eat) *from there"* (Russell Jones, 14).

This supports Davidson and colleagues' (2004) findings that a number of psychosocial factors need to be considered for suitability to the regime including motivation, absence of needle-phobia, family and friend support and diabetes education. Those who succeeded in managing their diabetes on the basal bolus regime implemented a structured routine similar to that of the twice-daily regime. For example, Holly Thomas (15) described planning her meals for the day and Ian Collins' father described the importance of Ian getting up early so that his meal pattern did not fall out of sync:

> *(i) "I sort of work out what I'm going to eat so that I can just inject like whatever I need to do for whatever I eat, and then it's annoying 'cause like if*

I have snacks or something, I've got to work it out then on the spot but when I come home...and normally we eat whatever like a normal sort regime or something like that so that I know what things are" (Holly Thomas, 15).

(ii) "I like him up around the 8 o'clock mark, 9 o'clock so his meals fall in with each other. If he gets up at, you know some kids get up at 12 o'clock don't they, if he's having his breakfast at 12 o'clock his next meal's like, dinner time so basically he knows he's got to get up out of bed. So I'm a bit regimental on that (laughs)" (Father, Collins family).

This suggests that routine is a key factor in the successful self-management of T1D regardless of regime. It also implies that basal bolus regimes may not necessarily be the best option for all adolescents, depending on attitude, lifestyle, family support and views about injecting. This supports findings that patients must be selected carefully for transfer to basal bolus regimes as they are, *'difficult to learn, involve multiple injections, frequent blood glucose measurements and require considerable increased resources'* (Mortensen et al, 1998:758). Transference as a remedy to poor control may result in further deterioration of control if adolescents do not have the skills and motivation required (Davidson et al, 2004).

There was evidence to suggest that regular blood glucose testing led to increased feelings of control. Following a 'rough patch' of poor control, Holly Thomas (15) and her mother followed a rigorous regime in order to regain control of her blood glucose. As a result, her self-esteem increased and she felt more confident to manage her diabetes. Her mother stated:

"Her bloods since she's been monitoring her food, have been spot on. You can see the improvement - between four and seven, she might have the odd glitch but they've come back in line and she said she's feeling much better, she feels in control because she was feeling guilty, she knew she wasn't doing it right and that's why she was trying to hide it a little bit" (Mother, Thomas family).

In this and a number of other cases, parental input had a positive influence on blood glucose testing and it is well documented that parental involvement improves adherence in adolescents with T1D (Berg et al, 2007; Ellis et al, 2007; Grey et al, 1998; Anderson et al, 1997). However, there was also evidence to suggest that one adolescent female avoided testing her blood glucose when she believed the result would be high, to avoid negative input from her parents. Her mother described:

> *"She wouldn't do her blood sugar before her insulin yesterday so she took her insulin then and as we're doing her some breakfast she said I feel shaky now so she was obviously very low and then she's took her insulin, where really she's got to do her blood sugars first but I don't know what it is, she's either terrified of the meter or I think it's 'cause, maybe 'cause we moan at her when she is low and maybe we shouldn't you know"* (Mother, Salisbury family).

Previous studies have found that negative parental communications left adolescents feeling mistrusted (Kyngas et al 1998), or as if they had failed their parents (Wennick and Hallstrom, 2007; Weinger et al 2001). As in the case of Beth, other adolescents have been found to indulge in or avoid self-management behaviour to evade conflict and negative feedback from their parents (Carroll et al 2007, 2006; Weinger et al 2001).

(iv) Diet and physical activity

Fruit and vegetable consumption was poor in this study. The highest incidence of fruit and vegetable consumption in the CASI Diary Tool (2.3 portions per day) was less than half the amount recommended by the UK NHS, in order to maintain a healthy weight, protect against heart disease, stroke and some cancers (NHS, 2009a). The one adolescent who reported consuming more than two portions of fruit and vegetables per day (Emily Dougherty, 15) also had one of the lowest HbA_{1c}'s of 7.6%, suggesting that awareness and maintaining a healthy lifestyle may be linked to blood glucose control. Access to 'healthy' food was an important influential factor in adolescents' food choices. Parental control of diet was also important, in terms of routine and also limitation of 'treats' such as chocolate, sweets and takeaway food. Some parents felt that they lost control of their child's diet when they transferred onto the basal bolus regime, when the child perceived that they had more freedom to eat once-forbidden foods. Knowledge about the importance of 'healthy' eating was influential to food choices.

Low fruit and vegetable intake is a cause for concern in relation to blood glucose control, as high fibre intake and high intake of fruit and vegetables is characteristic of people with HbA_{1c}'s of less than 7.5% (Overby et al, 2007). Fruit and vegetable intake has also been found to be related to general self-control in adolescents, suggesting a relationship between fruit and vegetable intake and personality types characteristic of adherent behaviour (Wills et al, 2007). In criticism of the influences of access, awareness and parental control on food choices, previous research has shown that the only correlate of fruit and vegetable intake in young adulthood across gender is taste preferences (Larson et al, 2008). However, it is acknowledged that parents have a direct influence on the dietary habits of their children. They shape dietary habits through implementing specific feeding behaviours and techniques and have direct control over the foods available to their child in the home (Rhee, 2008).

Sixty minutes of exercise is recommended per day for children, in order to maintain a healthy weight and protect against heart disease, stroke and some cancers (NHS, 2009b). There is evidence that controlled exercise has a positive impact on glycaemic control in adolescents with T1D (Valerio et al 2007; Bernardini, 2004). Only one adolescent male (Neil Jeffs) reported this level of activity in the CASI Diary Tool. Many of the adolescents participated in physical activity during school hours and some competed in sports teams outside of school. Some adolescents recorded physical activity as part of their daily routine in the CASI diary, such as walking to school and walking with friends. Two adolescent girls (Emily Dougherty, 15 and Lisa Brookes, 16) made a conscious effort to integrate physical activity into their lifestyles in order to control their blood, for example:

> *"I make sure that I do an activity in the day to make sure it's not going too high"* (Laura Brookes, 16).

Taking part in physical activity appeared to have a positive impact on blood glucose control for a number of adolescents, as Martin Edwards described:

"(On holiday), *I'll be in the pool all day doing more exercise so it's different from when I'm here, it's better because it keeps my blood glucose around four, last time I went on holiday...the hotel was up a hill so...we'd have to walk down it and go up it and it was keeping it low*" (Martin Edwards, 14).

Adolescents who integrated exercise into their daily lives reported a positive impact on blood glucose control, apart from Sean Ratledge who experienced substantial and disruptive blood glucose fluctuations after exercise, causing stress for him and his parents. Previous research has found barriers to taking exercise to be perceived difficulty in taking part in exercise, feeling tired, being distracted by the television, lack of time and poor local facilities (Thomas et al, 2004). However in this study, participating in physical activity was underpinned by whether adolescents enjoyed exercise, preferred other activities, had access to sport, or participated in low impact activity (such as walking) as part of their daily routine. None of the adolescents stated that having diabetes directly prevented them from taking part in exercise, but this could have been an underlying factor for why some adolescents preferred other, non-impact activities (such as art lessons). T1D appeared to impact on adolescents' and parents' perceptions of sporting ability for two males who were keen footballers.

The low levels of fruit and vegetable consumption and physical activity in this sample of adolescents suggests that adolescents did not perceive these activities as meaningful to their social world, however the underlying reasons for levels of fruit and vegetable intake and physical activity were individualised and context-specific. This highlights that national recommendations may be irrelevant in relation to the psychosocial context of adolescents, suggesting a need for individualised assessment and education.

(v) Body image

There is a wealth of evidence suggesting a relationship between T1D in adolescence and eating disorders (Ackard et al, 2008; Helgeson et al, 2007; Pollock-BarZiv and Davis, 2006; Manucci et al, 2005; Pinar, 2005; Northam et al, 2004; Maharaj et al, 2003; Maharaj et al, 2001; Jones et al, 2000; Engstrom et al, 1999; Herpetz, 1998; Affenito et al, 1997; Rydall et al, 1997; Pollock et al, 1995). Two families described an awareness of weight issues in adolescent females, demonstrating an increased awareness of the calorie content of food and body image. Samantha Makin (15) experienced hypos most of the time *("I'm always low")*. Her mother believed this was due to an increased consciousness of her diet and weight and a subsequent reduction in food intake. She explained:

"Ok, so you mentioned that you think she's finding it a little bit more difficult now at the age that she is, what sort of things do you think...? (Joy)

"...I think it's because of her body image...it's not that she's overweight but because she's tall and her dad's got big bones...I think a lot of girls would be like that at this age...her dads saying to her now look you're having to take more Lucozade now 'cause you're not eating properly...she's having hypo's more now than she ever has, nothing thank goodness where she's collapsed or anything but she's feeling low at times" (Mother, Makin family).

Other parents mentioned the weight-increasing side effects of insulin, for example:

"She's going on about her weight, but they said the insulin can make them all that. The doctor was saying if you do enough blood sugars...then you could lower your insulin and then maybe not be eating as much then" (Father, Salisbury family).

In the Thomas family, Holly had taken ownership of her diabetes from a young age and always been independent in her self-management. After changing to the basal bolus regime from twice-daily, her mother believed that she was capable to manage on her own, but did not know that her daughter was over-compensating on insulin because she believed that it would help her to lose weight. It was when her daughter had a severe hypo and was admitted to hospital that her mother realised that there was a problem. Holly described:

> *"Sometimes I'd inject more insulin because I always thought if I was low and I didn't treat the hypo then it'd take like sugar from like the fat...to make me lose weight but it never worked. But then I started losing weight by doing it properly, so it's better if you just do things right than to mess around doing it stupid"* (Holly Thomas, 15).

She also described her dislike of being weighed at the diabetes clinic, as she was conscious of her weight:

> *"Whenever I go to the hospital it's disgraceful when I have to go on the scales, I feel dead embarrassed,* (the nurse has) *got the graph and it's just gone up and up, I feel dead embarrassed and they always say it'd be good if you lost a bit of weight...so I try and it just doesn't work"* (Holly Thomas, 15).

This indicates that weight may be a sensitive issue for some adolescents and this issue may be accentuated due to the weight-gaining side-effects of insulin. This also demonstrates a conflict between the social body and the healthy body as described by Balfe (2009). In order to achieve the desired physical appearance (social body), blood glucose control (healthy body) is jeopardised. Some would argue that T1D instigates a level of awareness about food that is characteristic of eating disorders (Steel et al, 1990), and body consciousness as well as weight and shape concern (Maharaj et al, 2003) are causal factors in the development of eating disorders in this age group with T1D. However, despite the large amount of evidence suggesting a relationship between T1D in adolescence and eating disorders (Ackard et al, 2008; Helgeson et al, 2007; Pollock-BarZiv and Davis, 2006; Manucci et al, 2005; Pinar, 2005; Northam et al, 2004; Maharaj et al, 2003; Maharaj et al, 2001; Jones et al, 2000; Engstrom et al, 1999; Herpetz, 1998; Affenito et al, 1997; Rydall et al, 1997; Pollock et al, 1995) they were not found to be prevalent in this small sample of adolescents. However, the findings do highlight that 'normal' dieting behaviour (i.e. a reduction in calorie intake, increased exercise) has implications for blood glucose control for adolescents with T1D and adolescents should provide adequate support if striving to reduce calorie intake.

6.8 Embodiment Theme 2: Parental embodiment of a child's T1D

T1D requires an assumption of responsibility for the taken-for-granted secretion of insulin by the pancreas by the mind. It involves monitoring blood glucose, insulin calculations, and routine injections in order to maintain blood glucose control. This process of disruption is synonymous with the personal transformation described by biographical disruption theory (Bury, 1982). This level of commitment to the body requires a certain level of cognitive capacity and an ability to make informed decisions, think symbolically, consider different options and reason critically about behaviour.

It is recognised that parents are likely to take a primary caring role in their child's diabetes management until at least early adolescence (Snoek and Skinner, 2000). Many of the adolescents were children when they were diagnosed with T1D, meaning that they did not have the cognitive capacity to self-manage their disease at diagnosis. It was therefore the responsibility of the parent to 'embody' the responsibility of their child's illness and take on the role of the child's mind in controlling their blood glucose. Parents had to come to terms with the loss of their child's 'healthy' body and had to redefine their child's surrounding social world on their behalf. Families undertake a reflective process of learning following the diagnosis of a child with T1D, which enables the family to come to terms with the diagnosis through the identification of narrative points of reference between the experience of the illness and their society. Identifying common areas of experience, and being able to communicate about the experience to others in this way enables the experience to become meaningful and therefore be understood. This theme focuses on the nature of 'parental embodiment' and the narrative reconstruction process as a coping function for parents.

From my interpretation of the lived experience findings, and triangulation with other theoretical literature, parental embodiment was constituted by three characteristics: the parental input in T1D management and conflicts with autonomy development, narrative reconstruction (Williams, 1984) to make sense of the child's illness, and chronic sorrow. This theme is broken down into further sub-themes to explore the relationship between parental input and autonomy development, the process of narrative reconstruction in parents and the impact of chronic sorrow.

(i) Parental input and autonomy development

When a child is diagnosed with T1D at a young age, parental involvement in management is crucial in decision making, planning and adherence (DCCT, 1994). Adolescents and parents described a high frequency of parental reminders for blood glucose tests and injections, and some adolescents recognised that their parents' input was instrumental to their adherence to blood glucose testing, as this male stated:

> *"If it wasn't for my mum, I probably wouldn't do my blood at all"* (Russell Jones, 14).

Although parental involvement has been shown to improve adherence in adolescents with T1D in this study and others (Berg et al, 2008a; Ellis et al, 2007; Grey et al, 2001; Anderson et al, 1997), this study and previous findings have shown that adolescent autonomy has the positive impact of relieving the burden of responsibility for parents, whilst adolescents benefit from increased knowledge and confidence in their own abilities, more freedom and the approval of others (Hanna and Guthrie, 2000a, 2000b). Therefore, parental input should naturally decrease as the child enters adolescence.

Adolescents who described being adherent to testing and injecting had parents who believed in the development of adolescent autonomy, such as Samantha Makin's mother:

> "(When) *she went to senior school I did give her a bit more freedom...she's taken on more and more in the past year or so I've just left her, and when she goes to the hospital if she hasn't filled her blood glucose book in, I've just sat there and said well I haven't filled the book in, or she's sorry not me she wouldn't fill the book in, because it's her doing it"* (Mother, Makin family).

It was therefore important for parents to find a middle ground between providing enough and too much support, in order to enable the development of adolescent autonomy. Parental embodiment of a child's diabetes had the potential to restrict this process.

In cases where the adolescent was diagnosed at a young age, parents fulfilled the function of 'mind over body' with the administering of injections, testing blood glucose and diet control. For one set of parents whose son had a phobia of needles, this involved administering his injections twice daily from his diagnosis age six, up until the age of nine. They described a traumatic rigmarole in which they felt they inflicted pain and discomfort on her son by injecting him. In this sense, they felt that they were the cause of his bodily pain and discomfort, rather than the diabetes itself, and such feelings could manifest in further parental responsibility and guilt. This was particularly difficult for the father who had diabetes himself:

"We'd have to sit him our knee and it was terrible, the child didn't want to have the injection, it was just horrendous. Every morning every night... (Mother, Pickering family)

"...I used to have to do it and having to give your son about six injections all the time then doing your own was awful" (Father, Pickering family).

A number of parents described how they continued to take responsibility for their child's diabetes during adolescence, although this was at a lesser level of input. The previous section described how the physical symptoms of blood glucose fluctuations acted as personal signals to the adolescents about their blood glucose levels. For parents, controlling blood glucose fluctuations was a difficult task without the embodied experience of physical symptoms, and many described external signs which they looked for in their child, as an alternative. For example:

"Can you tell if he's blood sugar's high or low? Are there certain things about him that you notice...? (Joy)

"If his bloods are high he's a bit snappy and argumentative...but when his bloods go low, he goes very like pale and his freckles disappear, it looks like

he's going to burst out crying so that's our sign, so we can react to that quicker than the high ones obviously" (Mother, Ratledge family).

This led to parents developing a heightened awareness of their child's health through the interpretation of physical and behavioural signs, in order to monitor and attend to their health needs.

(ii) Narrative reconstruction

To give meaning to the biographical disruption of their child by T1D, parents demonstrated a process of 'narrativisation' (turning an alien illness into a meaningful story) (Williams, 1996). One of the ways in which they did this was through searching for a meaning for their child's diagnosis in order to make chronological sense of their experience. The ability to describe an experience to others in relation to normative reference points, situates the experience within societal norms and facilitates understanding (Williams 1996). This enabled parehts to define a cause that was acceptable within family norms. Parents described a range of causal ideas relating to their child's diagnosis. When there was a history of T1D in the family, genetic susceptibility was a definitive reference. For those without, lay and biomedical suggestions were combined, underpinned by emotional and psychosocial factors.

When adolescents and parents were asked about their experiences of diagnosis, the parents told detailed 'stories' of their experiences, demonstrating a process of narrative reconstruction. Although some adolescents demonstrated a narrative capacity in the descriptions of their experiences, their accounts tended to be much shorter and lacked the detail of reflection and the attribution of meaning to experiences that the parents' descriptions held. The ability to analysis, synthesise and evaluate experiences may only be reached in adulthood (Arnett, 2000). This emphasised the importance of health professionals and parents in assisting with reflection on experiences in the process of coming to terms with chronic illness. These excerpts from a parent and child's recollection of the same diagnosis event demonstrate this and highlight the generational gap which can exist in the interpretation of the same event by different family members

(Kirk, 2006). The adolescent quote represents her full description of the diagnosis, whereas the parent quote is an excerpt of the first paragraph of a two-page description:

> *"Well my mum noticed all the symptoms of getting tired and feeling weak all the time, so she took me to the doctors, but there was a big kafuffle with it because we had to wait until the last minute because we didn't have an appointment...they tested my urine and they said it was not normal and they said go straight to the hospital and then I spent five days in hospital"* (Holly Thomas, 15).

> *"It was extremely traumatic when she was diagnosed because I knew that something was wrong, she started saying I feel tired, I feel weak and she shared a room with her sister and when I got up in the morning there'd be all kinds of lemonade glasses, I was blaming the two of them, I was saying, will you stop drinking all the lemonade, just stop drinking it, you know look at all these glasses, every day there was six glasses up there and in the end the eldest girl just said, mum I'm not drinking any lemonade, it's not me and it was Holly and also she was starting to buy her drinks with her pocket money you know so she was having as much drinks as she could have because her body was obviously trying to swill all the toxins and the sugars away, so I made an appointment to go to the doctors and the was a bit of a mix up and they got me in the emergency appointments, I waited half an hour with her and the doctor said well, she said what is it that's brought you here that's made you think it's an emergency and I said well I've been waiting a week to see you and they've put me in the wrong clinic but there's no-one else I can see so you know I am very worried about her..."* (Mother, Thomas family).

Although some adolescents demonstrated a narrative capacity in the descriptions of their experiences, meaningful stories were more characteristic of parents' accounts. One of the ways in which parents attempted to come to terms with the disruption of their child's illness was by searching for the meaning of the diagnosis. Sixty per cent of the adolescents did not know why they had got diabetes, but their parents described a range of various ideas. The adolescents who did describe causal factors, described the same factors as their parents, indicating that the concluding cause had been defined within the family as a narrative reference point for the experience. Parents attempted to identify cause through the connection of lay theories and biomedical explanations. In families with a parent with T1D, or other family history of the disease, perceived cause was more definitely linked to genetic susceptibility than those with no obvious genetic link. In one family however, the mother refused to accept that her husband was to 'blame' for her son's diagnosis. By attributing the diagnosis to another reference point (a 'shock'), this enabled the family to cope emotionally with the son's diabetes:

"How did you react at the time to the diagnosis...? (Joy)

"*...The worst thing is when he got it, people were saying to hmi, oh your dad's got it, you must have got it 'cause your dad's got it but* (wife) *won't accept that...everyone said it was the genes but* (wife) *said no it wasn't, it was the shock*" (Father, Pickering family).

This illustrates that the meanings people attribute to their experience through narrative points of reference are influenced by interpersonal relationships and other psychosocial factors in their surrounding environments. The mother in the Pickering family employed these points of causal reference allay feelings of responsibility from her husband. This functioned to create a narrative which met their emotional and coping needs - in this case the protection of the father from blame.

Parents also made reference to their child's health before their diagnosis, in an attempt to link the diagnosis to previous events. A common interpretation was that the child had been predisposed to the development of T1D, or that they had been "*sickly as a child*" (Butcher family). Some mothers blamed their own actions, or health for their child's diagnosis including eclampsia (Salisbury family), diet during pregnancy (Ratledge and Bingham families). Other possible environmental triggers included lactose intolerance (Collier family), the MMR injection (Stanley family), being a large baby (Salisbury family) and a 'shock', as this mother described:

"We were on holiday down south and James cut his knee, the blood was just everywhere and he was in a such a state with the shock...he needed five stitches in his knee, that was the only time he's ever been in hospital, next thing he's diagnosed with diabetes" (Mother, Pickering family).

The reference made here to, *"the only time he's ever been in hospital"* demonstrates that this mother assumed there must be a biomedical cause for her son's disease. As her son had no history of ill health before the shock, this attribution makes sense to her based on her belief system in relation to cause and effect. As mentioned, this cause also enabled her to deviate from the belief of genetic susceptibility passed on from her husband.

(iii) Chronic sorrow

The embodiment of a child's T1D was influenced by parental responsibility for their child's health, underpinned by self-blame, grief and guilt for the diagnosis. Many parents described a feeling of self-responsibility for their child's future health, as demonstrated by this quotation:

"How do you think Stewart's dad feels about his diabetes...? (Joy)

"...Oh he was devastated when he was diagnosed, absolutely devastated. Even now he still gets upset you know, but, he copes well. It's just the worrying isn't it as they get older...that is the main concern. Not looking after yourself now, what is going to happen to you later on in life...people say to me just let him go and see what happens but I can't do that...something will happen and he'll end up in hospital...and I think well why should I put that on him when there's no need to" (Mother, Stanley family).

Theories of chronic sorrow (Olshanky et al, 1962) suggest that parents never fully come to terms with the diagnosis of their child with diabetes, as emerging discrepancies or triggers over time emphasise the reality of their child's condition. There was evidence of chronic sorrow in the parents in this study, when their accustomed ways of dealing with T1D were disrupted by new situations, which were unfamiliar to the usual routine, i.e. holidays, day trips, severe hypo/hyperglycaemic events. Three parents cried during their interview, indicating their emotional response to recalling stressful situations.

Significant events, such as severe hypoglycaemia, starting a new school and going on holiday brought diabetes to the parents' attention as they negotiated dealing with the new situation, as this parent explained:

> *"You get to a point and everything goes ok and then she might have an unwell day or a hypo, so that would send me back down for a couple of months, worrying if it's going to happen again"* (Mother, Bingham family).

This parent described the impact of severe hypoglycaemia resulting in unconsciousness:

> *"He has had a couple of big fits which were really distressing to see, because I didn't know that diabetics could have a fit. I went to wake him up one morning and...he was trying to put his trousers on but every time he tried to put his foot in the trouser leg he fell over. We picked him up and put him on the bed and then he just had a full fit which I'd never seen before and it really did distress me, it was awful"* (Mother, Mather family).

When severe hypoglycaemia occurred, the child usually had no recollection of the experience, although the parent witnessed unpleasant effects, such as fitting. Discussion at the parent focus group supported this theme. Therefore, as well as the embodied responsibility of their child's blood glucose fluctuations, parents also had to experience the severities of the fluctuations, which remained absent to the adolescents. In response, parents developed almost a 'sixth sense', attuned to their child's bodily needs. Control of their child's blood glucose became an essential cognitive function and some parents described not sleeping properly in order to keep a constant check on their child's blood glucose. One mother in the focus group discussion described her actions following her son's experience of a severe hypo:

> *"There's been times when I slept on his bedroom floor but that was because he had some severe hypos and he was low going to bed and I thought I can't sleep, so I just slept in the room on the floor"* (Mother, Mather family).

Another mother described how going on holiday had caused a disruption to their usual care routine. The self-blaming implications of forgetting her son's injection were apparent, as she took personal responsibility for his future health:

"When we went on holiday in France I forgot his insulin...and he became very, very moody and by ten o' clock, you just know this isn't Tom...and then we realised ... it is worrying because you think to yourself, I'm damaging him" (Mother, Butcher family).

Many other parents stated that they felt responsible for their child's future health in this way, for example:

"What is it that worries you the most...? (Joy)

"*...I worry that he'll die before he should, that he might lose limbs or I can't even say because I get all upset thinking about it...what the future holds for him, and I won't always be there right behind him because I have to make him independent"* (Mother, Mather family).

The ongoing grief for the loss of their child's health plus the responsibility they felt for the diagnosis manifested in feelings of constant anxiety, with some parents stating that their anxiety levels had increased as a result of their child's diagnosis. As this mother stated:

"I think it's made me more a worrying person, I'm more of a worrier now...even the girls know I'm worried sick of everything they do...I don't know whether I'm worried about something happening to them 'cause I think something could happen to him...it's made me a worrier, it's made me worse" (Mother, Gibbons family).

Anxiety was increased for mothers of less-adherent adolescents, as this mother described, whereas other mothers felt that the worry they felt for their child was the same as any mother of a teenager, regardless of diabetes:

"I think if she was to do that (carry insulin and dextrose) *I'd be more relaxed in myself, I know she'd be fine, she's got her insulin with her, she's got her blood monitor, she feels low, but I think that's why I feel sick and worry all the time with her because she's not doing it"* (Mother, Morris family).

"It's probably the same as being a parent to any teenager - they're swines, they drive you nuts and the diabetes is just part of it to be honest" (Mother, Collins family).

It was apparent that parental grief was underpinned by a sense of responsibility for the child's diagnosis in many cases, and manifested in constant anxiety regarding complications, management away from home, quality of management and hypoglycaemia, as found by Low and colleagues (2006). Many adolescents gave descriptions of constant parental reminders, which demonstrated the resonance of the anxiety present in the embodiment of their child's blood glucose control. This mother described the difficulty she experienced in 'letting go' of controlling her child's disease:

"She can manage it now but I don't think she realises the implications if she doesn't manage it...at this moment in time I would be uneasy to let go...I know I've got to let her go but I think it will always be in the back of my mind thinking, I hope she hasn't lost her insulin, lost her bag, it's always going to be there" (Mother, Thomas family).

Although parents may come to terms with the diagnosis of their child's diabetes, disruptive situations are an integral part of learning to live with T1D. Such events which bring diabetes to the forefront may trigger grief to emerge periodically (Lowes et al, 2005). Thus, living with T1D for both adolescents and parents is an on-going, continually shifting process in which people experience recurrent shifts in perspectives about the disease which allow them to make sense of their experiences (Paterson, 1998). Based on this, the transference of responsibility from parent to child characteristic of adolescence, can be seen as a complex emotional process for parents in which they have to 'disembody' the responsibility for their child's self-management, which for some has defined their existence for many years. This can feel like a great loss to parents who are intuitively aware of their child's diabetes day to day, as this mother described:

"It's a big part of my day, I think about it in the morning and I think about it at tea time and I think about it at ten o' clock, and if he has any other reason to have another injection" (Mother, Butcher family).

The evident restrictions to autonomy development caused by parental embodiment are supported by evidence that maintaining a balance between diabetes management and a child's growth and development can pose a great challenge for parents (Sherifali and Ciliska, 2006). This conflicts with previous evidence that there is no delay in psychosocial maturation in adolescents with T1D, but is supported by findings that T1D may complicate the natural transition from adolescence to adulthood (Seiffge-Krenke, 1998). Adolescents' perceptions of maternal control have been found to be associated with depressed mood and poorer self-efficacy among older adolescents, suggesting that excessive parental control may inhibit autonomy for diabetes management (Butler et al, 2008).

Research has shown that sharing responsibility for self-care between parent and child is associated with better psychological health, good self-care behaviour and good metabolic control in adolescents, whereas stronger child or parent responsibility is not (Helgeson et al, 2008). Although this has been shown to be the ideal scenario in a number of studies (Hanna and Guthrie, 2001; Christian and D'Auria, 1999; Kyngas et al, 1998), emotional issues for both parent and child can often impinge upon the natural process of autonomy (Grey et al, 1998). The concept of parental embodiment demonstrates that it is often difficult for families to find a balance between encouraging autonomy and providing adequate parental support as management of their child's disease is integrated within their persona. This indicates a need to take into account the complex relationships existing between parents and adolescents, particularly when the adolescent was diagnosed with T1D at a young age.

6.9 Embodiment: Impact on blood glucose control

T1D requires an attunement of the mind with bodily mechanisms and symptoms and a re-evaluation of the position of the self within society, as defined by Bury (1985). The embodied experience of a person with T1D is also related to their level of cognitive ability to reflect and make sense of their experience. A diagnosis of T1D in adolescence is a very different experience to a diagnosis of T1D in early childhood. The child does not have the capacity to undergo the complex reflection process required for the renegotiation of the self within society. Therefore, the parent undergoes this process on their behalf (Snoek and Skinner, 2000) whilst the child 'grows up' with the disease. In terms of integrating T1D within self-identity, a number of the adolescents diagnosed at a young age described the integration of T1D into their bodily selves. As they could not recall any previous existence to their existence as a body with T1D, their body with T1D was as 'taken-for-granted' as someone without T1D:

(i) "So have you ever had any problems or anything in school that you can think of...? (Joy)

"...I've never had any problems with my diabetes. It's just, this is the way it sort of acts in all of me, it's just there, it's something I've got to deal with, it's there and that's it" (Tom Butcher, 15).

(ii) "Are there any times that you can think of when you feel like having diabetes has been difficult for you...? (Joy)

"...It's just natural daily life, I don't even think about it" (Emma Bingham, 16).

For these adolescents, 'normal' life was life with T1D and therefore the restrictions it imposed were not necessarily welcome, but were familiar. These adolescents did not experience the sudden loss of 'life as it once was' to the same degree as adolescents diagnosed nearer to or during adolescence. At this age, norms of behaviour are established and have to change, and cognitive capacity has increased to allow for the natural development of independence, meaning that disruption to the self is experienced with full impact.

Case Study 3 explores the experience of a recently diagnosed thirteen year old adolescent male, and the issues he addressed in the discovery of his new embodied 'self'. Case Study 4 goes on to explore the parental embodiment of an adolescent male's diabetes, and the impact of this on the development of his independence.

Case Study 3: The Collier Family

Darrell Collier (13) was the most recently diagnosed adolescent in the sample. His response to the bodily disruption of his diabetes diagnosis is demonstrated. He demonstrated behaviour characteristic of the first stage of adaptation to chronic illness - a recognition of the disruption of taken-for-granted assumptions and behaviours, and an awareness of bodily states not usually brought to consciousness. For example, he recognised the new demands of his body and their impact on his daily routine, with particular regard to eating and sleeping. This was embedded in a sense of loss for his old life, as this quotation demonstrated:

> *"I felt more sad really because at the time, when they started me on the two injections a day, normally I just used to go to like the cupboards and just sit and eat cakes, but I couldn't do that anymore...and then I had to get up early to do a jab, even in the summer holidays, get up at eight thirty to do my jab and have something to eat, which I'm not used to"* (Darrell Collier, 13).

It was apparent that his diagnosis of T1D had disrupted his social environment, as his mother described:

> *"He doesn't see any of his friends out of school, he doesn't do anything over the weekend he doesn't do anything of a night...the summer before he was diagnosed I couldn't keep him in he was out all the time...I think its got a lot to do with why he doesn't go out really because I think he thinks my mum will make me take all this stuff with me...he's not ready to do that yet"* (Mother, Collier family).

She also noted an effect on his behaviour at school, demonstrating the potential psychosocial impact of bodily disruption:

> *"His attitude to school is absolutely terrible, he's been in all kinds of trouble, detentions and everything, where he never was like that before"* (Mother, Collier family).

Darrell's mother described him going on holiday with his uncle where he was able to 'practice' his self-management in a comfortable environment. He participated in an activity course and tested his blood glucose throughout. Such situations may facilitate successful embodiment, as they enable adolescents to become familiar with the bodily manifestation of their disease, thus enabling them to gradually regain control over the unknown bodily state since diagnosis.

The psychosocial issues this adolescent male experienced as a result of his diagnosis demonstrated a process of personal transformation, as he worked through the barriers created by his new bodily needs in order to integrate the limitations imposed by the disease and facilitate an acceptance of his new 'self'. Darrell struggled to negotiate his daily life due to a lack of confidence in controlling his blood glucose beyond the home environment; the presentation of his new bodily state in relation to different situations was still unknown. Although he struggled emotionally to come to terms with this, he also demonstrated the positive influence of 'pushing his boundaries,' to manage his diabetes away from home. The clinic noted the issues this adolescent was experiencing with adjustment and recommended psychological support, although he was reluctant to accept this. This adolescent's experience links back to the issue of normalisation within external environments, and his preference to stay at home where his self-management can be safely adhered to.

This process of disruption and adaptation was synonymous with biographical disruption theory (Bury, 1982). This process of self-transformation was encapsulated in the case study of Darrell Collier. He demonstrated behaviour characteristic of the first stage of adaptation to chronic illness defined by Bury (1982) – a recognition of taken-for granted assumptions and behaviours, and an awareness of bodily states not usually brought to consciousness. T1D impacted on his independence as he spent more time in the safe environment of the home than with his friends. Spending time away from peers could affect identity development, as peer interactions are paramount to this process (Jaffe, 1998). Despite these barriers, Darrell also demonstrated 'pushing his boundaries' in safe situations, in order to adapt to his new embodied state and overcome the uncertainty he encountered, which conveyed a positive developmental transformation (Williams, 1996).

Case Study 4: The Stanley Family

Stewart Stanley was diagnosed with T1D at the age of three. The diagnosis was extremely traumatic for his mother, as he was misdiagnosed a number of times before a correct diagnosis was made. She described how she was aware of the long-term dangers of his disease from onset. This defined her responsibility for his future health, in order to protect him from such dangers:

> "*I was devastated, totally devastated because of the illness, and I know how severe, you know, problems long term - what can happen*" (Mother, Stanley family).

Due to her son's young age at diagnosis, this parent took full responsibility for her son's blood glucose control following diagnosis. However, this process had restricted the development of his independence for his diabetes management, as his mother was still taking sole responsibility for his care at the age of sixteen. His mother demonstrated the 'embodiment' of her son's disease through the control she implemented over his social life. She retained him within 'safe' environments including the school and golf club, where she had a degree of control over his diabetes:

> "*He's a little home bird so in that respect I'm very lucky but I don't know if that's because I've nurtured him in that respect, and I bring people to him*" (Mother, Stanley family).

She also took control of his self-management, often giving him insulin injections and testing his blood in the middle of the night:

> *"I still give some of his injections, of a morning, I will do his blood before school, because when he's lying in bed it's just easier. I know I shouldn't - but I do...and of a night-time, I go in, I check his blood I do it about two o' clock and see if he needs more insulin. If he needs more insulin I'll give it to him or if he's low I'll give him something to eat"* (Mother, Stanley family).

This mother noted that as her son grew older, she had less control over his diet, and described a direct link between her decreasing control and his ability to self-manage his condition, indicating that he has not developed the adequate skills to take care of himself:

> *"I'd say it's getting harder now he's older, because I can't control what he eats...when he was at you know, school, primary school, everything was so easy and the dinner ladies used to write everything down he'd eaten, I'd take his food in"* (Mother, Stanley family).

Stewart's mother's ownership of his diabetes had influenced him to become complacent in his self-management and completely reliant on his mother in terms of his diabetes needs. His mother described his lack of competence for self-management. He would often not inject without her reminders, which created a vicious circle of her not being able to trust him to manage without her and therefore being unable to restrict her input. As a result, she referred to him as a pre-school child, meaning that she could not yet see him as an independent adult:

> *"It's still like having a pre-school child, it's still the same, I can't let him go because I still look after his blood because he still has quite a few hypos of a night, or he'll say he's had his supper and he hasn't had his supper and I have to keep a check on him like that"* (Mother, Stanley family).

All parents will experience difficulty 'letting go' of their children during adolescence, but this normal process is magnified when a child has T1D (Ivey et al, 2009). Another parent whose son was diagnosed at the age of eight described similar anxiety about losing control of her son's diabetes:

> *"I think it's more frightening when he gets older and he is on his own and he goes out with his friends. Then I've got no control... because you've looked after somebody for that long and they're still your child, you still can't take the responsibility off your shoulder and say oh he's sixteen now, there you go!"* (Mother, Butcher family).

Parental embodiment was more common in mothers of adolescent boys than adolescent girls, suggesting that there could be a gendered explanation within the mother-son dyad. Research suggests that mothers have a greater input in sons' diabetes management than in daughters, which may hinder the development of independence skills in males (Williams, 1999b). Similar protective behaviour was demonstrated in the Butcher family between mother and son, although Tom was not dependent on his mother to the same extent as Stewart. Mothers of sons with T1D have also been found to identify, anticipate and meet the needs of their sons, termed 'alert assistants' (Charmaz, 1991). This behaviour is influenced by mother's perceptions of the self-care abilities of their sons and the gendered ways sons perceive their diabetes, i.e. as a threat to their masculinity (Williams, 2000). Qualitative studies have also found that adolescent girls incorporated diabetes into their identities more than boys (Williams, 1999b) and that girls described T1D forcing them to be more independent and responsible than their peers (Dickinson and O'Reilly, 2004). The majority of females in this study appeared to be more independent in their diabetes management than the males. These findings suggest that gender differences in parent-adolescent relationships may relate to independence.

The case of the Stanley family demonstrates the potential negative effect of a parent's embodiment of their child's diabetes. Maternal embodiment restricted the integration of the son's condition within his identity as he passively received his mother's input. As a result, he refused to integrate

T1D into his identity, as this quote from his mother demonstrated:

> *"He won't take any identification with him...he tells me he's not a dog, he won't have anything on him, and he won't take any glucose tablets or anything with him at all"* (Mother, Stanley family).

The son's blood glucose control was in need of improvement at a level of 9.6%. His mother thought that this could be improved if he changed to a basal bolus regime, however he refused as this would mean administering his own injections in school. This refusal to take responsibility for his diabetes control could hinder his independence greatly during the next five years of his life, when going to university or beginning employment. His mother's anxiety of 'letting go', underpinned by responsibility for their child's future health and lack of trust in the child to manage alone can be detrimental to an adolescents' autonomy for diabetes self-management, future independence and blood glucose control. The parental grief instigated by disruptive situations is naturally integral to the process of redefining the self within society in response to chronic illness (Williams, 1996). However, unresolved parental grief following diagnosis may contribute to maladaptive parental behaviours towards the child, such as the over-protectiveness or enmeshment (extreme emotional bonding in which family members are over-involved with each other) (Almeida, 1995), characteristic of parental embodiment.

6.10 Embodiment: Summary

Within my interpretation of the lived experiences of adolescents and parents, T1D disrupting the taken-for-granted functioning of the body was an important theme in explaining the integration of T1D within the self and the complexities underpinning parent-child relationships in relation to self-management. A diagnosis of T1D requires the mind to 'take over' the functioning of the pancreas, synonymous with theories of biographical disruption (Bury, 1985). Adolescents had to redefine their self and their identity in order to 'fit' their new bodily existence. The process of realigning the self following the diagnosis of T1D, can cause psychosocial adjustment problems in newly-diagnosed adolescents which may affect blood glucose control negatively, until resolved. This new definition of the bodily self, characterised by various physical symptoms, causes feelings of displacement in surrounding environments, when relationships with others alter and barriers are created in relation to the new body.

Parental embodiment may occur when a young child is diagnosed with T1D and does not have the cognitive capacity to adapt the self to diagnosis. The parent 'embodies' the child's diabetes and becomes responsible for blood glucose management. This has implications for adolescent independence and blood glucose control if the parent finds it difficult to disengage from this responsibility when the child reaches adolescence, due to feelings of anxiety, chronic sorrow and the need for control. This was only prevalent in mother-son dyads in this study, which may suggest an underlying gender influence.

Category 3: Experiential learning

(Learning through past experiences and acting on what is meaningful in the future)

The third category emerged from the ways in which participants described their past, present and future experiences. This relates to the phenomenological existential of 'lived time' - the temporal way of being in the world. This relates to the ways in which a person conceptualises their past and future and how this affects their interpretation of their experiences in the present. There are two themes within this category, which explore the process of experiential learning through past experience and through orientation to the future.

6.11 Theme 1: Experiential learning through past experience

Case Studies 1 and 2 (the Collins and Morris families) demonstrated that normalisation within different environments is underpinned by adolescents' perceptions of how others will react to their diabetes, and that this is influenced by past experiences. In the Collins family (Case Study 1), the families' past experience of T1D facilitated normalisation and the adolescent male was able to integrate T1D into his life with ease. For Sarah Morris (Case Study 2), negative reactions from an adolescent female's friends in the past prevented her from achieving good blood glucose control in the present, as she was terrified of the symptoms of hypoglycaemia disclosing her diabetes to her friends. These cases show that learning to live with T1D is an individualised learning process dependent on personal norms, beliefs, values and past experiences. The experiences of each individual and the barriers these create affect the ways in which adolescents are able to self-manage their diabetes. This theme explores the temporal process of experiential learning in diabetes self-management, parents' experiences of learning after serious events and parental grief in relation to the concept of 'chronic sorrow', through the further sub-themes of adolescent learning and parental learning.

(i) Adolescent learning

Living with T1D requires life-long self-management and therefore education is on-going when living with the disease. I interpreted the development of experiential learning as an individualised process, evidenced by the apparent influence of adolescents' and parents' past experiences on their behaviour in the present. One example of this was time, which had an effect on learning in a number of ways.

Firstly, some adolescents described learning through their mistakes. Through this process of trial and error, they found new ways of working their lifestyle around their diabetes needs. As this male described during the interview:

"Have you ever been in any situations when you've had a bad hypo or anything around your mates...? (Joy)

"*...No, I've never really had a bad one...* (Steven Gibbons, 16).

"...What about high blood sugar...? (Joy)

"*...There was one time at footy and I drank two Lucozades and then I was getting sent off for it, cause I thought if I drank more Lucozade that I'd be able to like last longer and play better, and then the next time I spoke to the dietician like she explained and then like I was alright after that...*(Steven).

"...So how did you feel at the time when that happened...? (Joy)

"...I was a bit gutted 'cause like I got sent off and that but like I understood like after the dietician explained to me that it wouldn't help me play better" (Steven).

This father with T1D also recognised the significance of learning through mistakes:

> *"The thing with diabetes, it's having the knowledge about it, I think there's no better knowledge than when you've got it, you learn by your mistakes when you've got it"* (Father, Collins family).

Pushing boundaries in unfamiliar situations was seen as a positive for learning, as this mother explained:

> *"It's not the sort of condition that you should need to avoid anything...the more you do, the better you are"* (Mother, Butcher family).

Secondly, the individualised nature of blood glucose fluctuations and the varied activity levels of adolescents meant that in many cases it was necessary to experiment with different self-management strategies in order to arrive at the best strategy for them, as this mother described:

> *"Sometimes you've got to mess around with the insulin and get that right, it might take a few days, it needs adjusting if he's been doing more sport, more activities then it's got to be changed for that"* (Mother, Mather family).

Thirdly, living with T1D for a length of time facilitated learning through the natural accumulation of experiences, and made the self-management of T1D easier. As described in the embodiment theme, time also facilitated integration of diabetes within the self for a number of adolescents. Adolescents described becoming more familiar with different situations over time. This male recognised that his actions in the present would affect his ability to manage his diabetes in the future, as a product of experiential learning:

> *"I just think if I can handle it now then I can handle it easier in the future because I'll have that much more experience then"* (Neil Jeffs, 14).

Experiential learning was facilitated through support from the family and the diabetes clinic, as this male described:

> *"We didn't quite understand how it worked at the start, but as we* (family) *went through it, it got better and easier because we all just worked together"* (Tom Butcher, 15).

Adolescents with a parent with T1D appeared to benefit from the learned experiences of their parents. However, as described in the normalisation theme, it was also possible for parental experience to have a negative effect on self-management. In the case of the Pickering family, the father's experiences of complications and discrimination affected the family's outlook for their son's future as they expected their son to foresee the same difficulties. A history of diabetes complications among relatives can significantly affect the outlook of both children with diabetes and their families. The father's experience of complications despite maintaining 'good control' meant that he worried about the future for his son. He stated:

> *"They do say you're better...keeping your bloods low, between seven, eight and nine and you won't get the complications, but I've had them... after...ten, fifteen, years I started getting some but I still kept stable, I still kept strict and not many people are like me, I'm very strict in what I do"* (Father, Pickering family).

Adolescents also learned through reflective discussions with the diabetes nurse specialists about their past experiences. Through describing events, the nurse and adolescent were able to work through the situation and explore alternative solutions for the future. This was facilitated by positive relationships between the nurses and the adolescents. When adolescents felt they could be honest about their past behaviour, they were able to transfer this into a positive orientation for the future, as this adolescent female explained:

> *"Say if I told* (the nurses) *something like I was drinking last month, they'd say well did you do this and I go no, well this can happen if you don't or this happens when you do"* (Jenny Dutton, 14).

Learning through experience did not necessarily lead to positive behaviour change and some adolescents demonstrated learning negative behaviours. My interpretation of Sarah Morris' poor control was that she had learned that maintaining high blood glucose enabled her to integrate with her friends without the interference of T1D. My interpretation of Stewart Stanley's lack of independence in Case Study 4 was that he had learned that his mother took responsibility for his diabetes management. In such cases, it may take a disruptive event to change the person's belief system, as described in the following section.

The influence of the past on the present behaviour of adolescents was synonymous with the interpretive phenomenological assumption that a person's interpretation of his/her experience is based on past experiences and beliefs relating to the future (Heidegger, 1962). This temporal interpretation of experience influences how a person behaves in the present and thus learning to live with diabetes emerged as an individualised process dependent on personal norms, beliefs and values (Cooper and Geyer, 2007). This supports claims that experiential learning is fundamental to diabetes education, and occurs through trial and error in relation to individual experiences and social contexts (Paterson and Thorne, 2000; Price, 1993).

In support of Cooper and Geyer's (2007) suggestion that the biomedical model of diabetes care conceptualises mistakes in a negative way, 'mistakes' were shown to be instrumental to the learning experience, as they made learning meaningful. Participants felt that the more they pushed themselves in different situations, the more confident they became with their diabetes management. Diabetes education must be based on personal experience and be meaningful in the sense that the person believes that their actions will be successful, in order to be effective (Cooper et al, 2004). In light of this theory, the findings of this study suggest that there is a 'right' time for individuals to learn (Cooper and Geyer, 2007) and that education may be most effective following a meaningful event.

(ii) Parental learning

As most parents had a large degree of responsibility for the management of their child's T1D, they also described a process of experiential learning. The process of experiential learning and adaptation to T1D was apparent in the Fletcher family, where the step-father described his experience of integrating into a family where his partner's adolescent daughter had T1D. He described how his behaviour when he was first introduced into the family, was insensitive to the needs of his step-daughter:

> *"It's only when I actually became part of the family and I was around a lot more, it was just simple things I was bringing deserts round when we were having tea together and even* (wife) *was saying to me, don't keep doing this, it's a treat it's got to be one-offs"* (Step-father, Fletcher family).

He described how his position as an outsider, and his lack of knowledge and understanding about diabetes, meant that he stood back and let his partner and her daughter deal with the diabetes at first. This was comfortable for a period of time, however when his step-daughter experienced a severe hypo, he realised that he needed to improve his knowledge to enable him to assist and support his wife. He stated:

> *"Seeing those hypos, it really hit home. And after the first one, even though I'd listened and I'd taken everything in, I needed to know more, just so I knew if* (wife) *wasn't around, I was totally confident...I thought, oh my god I've got to get my head clued up here, it wasn't just for Jane but seeing what happened to* (wife), *daughter's on the floor, mother's upset - you've got to get involved and understand it"* (Step-father, Fletcher family).

He began to take more of an input into his step-daughter's diabetes management and built his knowledge through attended clinic appointments with her. On reflection realised that he was pressurising his step-daughter more by taking an input, in order to deal with his own anxieties. He stated:

> *"I started realising what I was doing then, I was watching Jane doing her insulin, how much have you taken? Have you taken it at the right time? What have you eaten? So then it was putting pressure on her - it was*

because I was afraid of that (hypoglycaemia) *happening again*" (Step-father, Fletcher family).

This process represented a learning curve for the step-father. He entered the family unit as a stranger, realised the seriousness of diabetes and the trauma it could inflict on his wife and gradually adapted to living with diabetes through increasing his input in his step-daughter's management, knowledge and understanding. When he realised his input was in fact disrupting his step-daughter's routine, he then took a step back. This approach meant that he did not disrupt the care dynamic between his wife and her daughter, but had the confidence to assist if his help was needed. Through this realisation, a comfortable family dynamic was restored in the family unit. He described his current approach:

> "*When Jane comes in from school, I'll just step back and let her talk to her mum and I'll just have a look at her, is she dead moody or is she tired looking, and it will be a case of go and test yourself, a little quite nudge, we're going to have tea now, and then that will be when we'll find out if she's ok or not, but if you go in and say are you feeling ill, are you this, it's too much for her*" (Step-father, Fletcher family).

The advantage of gaining knowledge through experience was demonstrated by parents' experiences of serious hypo/hyperglycaemic events. A prominent theme to emerge from the parent interviews was the trauma caused to parents as a result of unexpected severe reactions to blood glucose fluctuations in their children. A serious cause of anxiety for parents was the thought of finding their child in a coma as a result of hypoglycaemia, as this mother stated:

> "*The worst scenario would be I'd find him in a coma or slipping into a coma, that is my worst fear*" (Mother, Mather family).

Other parents described not knowing how to deal with such situations and having to call for medical assistance. Many of the parents felt that after experiencing such an event, they were better equipped to deal with such incidences in the future:

> *"I'd probably be ok if I had another* (hypo) *to deal with because I'd know what to expect"* (Mother, Mather family).

One mother whose husband had T1D described how experiencing hypoglycaemia previously with her husband equipped her with the knowledge to cope with situation should such a situation occur with her son:

> "Is that a support for him having his dad having it as well...? (Joy)

"...It takes the frightening bit out...I know from my husband if something did happen, if he passed out or whatever, I'd know what I'd have to do" (Mother, Collins family).

However, the trauma of the unexpected event also led to anxiety for some parents, manifesting in a fear that it may happen again. This mother described how she would not leave her son unattended at the age of fifteen following his severe hypo, which had the potential to restrict his independence:

> *"I can't go to work and leave him in bed and he's fifteen, he should be able to stay in the house but he has to get up and come* (to his nan's) *because if he was hypo there would be no-one there to look after him, things like that worry me...if he ever went on holiday with his friends..."* (Mother, Mather family).

Parents generally wanted more information to prepare them for hypoglycaemic events:

> *"The only criticism...is preparing you for things that can happen to them. I know you can't give us too much information at first, but I wish I'd known a bit more, I think you're subconsciously prepared then"* (Mother, Mather family).

Despite the felt need for more education, parents described receiving education from the clinic regarding how to deal with severe hypoglycaemia. However, because they had no experience of the actual event until it had occurred, it was likely that the education they received was not meaningful at the time. A quotation from this mother demonstrates that despite her knowledge about what to do in an emergency, she felt great anxiety about how she would actually react should the event occur:

> *"I still don't know, with the orange stuff, glucagon, I worry in case if I ever have to do that, I remember one time saying to the nurse, do you put the whole end of the needle right in? And they went no don't be silly!...I've had some that are out of date, so I practice using them rather than dump them, and I can never get it right, it's always full of air and I worry thinking, if I injected that air into him would he die?"* (Mother, Gibbons family).

It was apparent that following a serious event, such education was meaningful, as parents were able to relate this to personal experience. This suggests that although the experience of events was traumatic for parents, they also provided an experience which facilitated learning new behaviours for future situations. Despite receiving education about what to do in emergency situations; without experience of the event, the information did not hold meaning for parents.

6.12 Theme 2: Orientation to the future

T1D has implications for future health if it is not controlled adequately (Diabetes UK, 2005) and therefore perceptions of the future are important in order to understand self-management behaviour. This section explores adolescents' and parents' perceptions of the future in relation to diabetes-related complications, addressing complications and career ambitions.

(i) Perceptions of diabetes-related complications

Parents appeared to show more anxiety about future complications than the adolescents. All of the parents stated this as a major concern, for example:

> *"I just worry when she's older...I've just got this thing that something's going to go wrong or something's going to happen"* (Mother, Morris family).

This adolescent male recognised his mother's concern for his future health and the effect of this on her underpinning anxiety and behaviour towards him:

"Do you think that your mum sees your diabetes in the same way as you do?" (Joy)

"My mum sees it as more dangerous...I see it as normal and she sees it as , you've got to do these things or you could lose your life to it and lose your limbs, so she's always in my face basically to look after myself" (Jenny Dutton, 14).

In comparison, only one adolescent male and one female stated that they were worried about complications when asked about their future, for example:

"I've been told if I don't like get my blood sugars down, they've said it can lead to going blind, losing your limbs, the worst death and that just scares me. I just want to get my blood sugars under control and I can't" (Jenny Dutton, 14).

Others stated that they were unaware of the potential health effects of T1D, for example:

"I don't really know what it affects, I know it affects your blood and it can affect your kidneys and your liver...but I don't know whether it can affect anything else, so I'm never really worried about it 'cause I don't know what it can do to you" (Sean Ratledge, 15).

Many adolescents described hoping for the development of a cure during their lifetime, for example:

"I've seen things on the news that have been promising, about some of the things that they've thought of which could cure it, it's not definite and I'm not depending on that to happen but it's always good to like hear stuff like that" (Neil Jeffs, 14).

Focusing on this may have acted as a way of coping with the threat of complications. One mother also described her daughter's unrealistic perceptions of the future as a coping mechanism for facing a life with T1D:

"She says...when she's older she's going to be fine. She's got this thing that she's going to go on tablets...she's not going to have to take injections" (Mother, Morris family).

Lack of concern about the future implications of T1D was expected in this age group, as adolescents lack the life experience needed to commit to long-term goals and therefore focus on more immediate goals such as integrating within the adolescent culture (Dickinson and O'Reilly, 2004). My interpretation of the adolescents' lack of expressed concern over their future health, was that it was not necessarily that the adolescents were not *aware* of the threat of complications, but rather that they did not perceive them as meaningful. The insidious development of organ damage meant that the threat of complications was not relevant to the 'here and now', as this quote demonstrated:

"I used to be worried about going blind and losing my legs...but now that doesn't really bother me...I think I've just got used to the idea...I do what I want to do and I know how important diabetes is but for some reason other things just take over, because I can sort of feel the effects when I have hypos and things like that but because it's like a slow thing you can't really tell what damage you're doing to yourself at the time" (Russell Jones, 14).

The threat of complications has been found to cause anxiety for parents in a number of studies (Low et al, 2006; La Greca et al, 1995; Dashiff, 1993), and appeared to be overwhelming for some of the parents in this study. Their grief and anxiety was underpinned by the loss of their child's 'perfect' health and the uncertainty the future held. This mother described the grief she experienced at clinic appointments when complications were mentioned:

"You said before about how you won't go to the hospital together...? (Joy)

"...I find it very upsetting Joy, I really do. It's when you sit in the clinic...once they tell me about the bad sides of it, you know the eyes...I just break down, it is upsetting" (Mother, Salisbury family).

Despite the threat of complications, there was also hope reignited in the fact that complications were preventable through maintaining good control of diabetes, as this mother stated. However this also increased parental responsibility for care of their child's diabetes, as a coping mechanism for dealing with the threat. This enabled them to apply a degree of control to a situation which was beyond their control in many ways. This mother stated:

> *"...But he can stop it can't he, if he looks after himself, it's not as if it's going to happen, he can stop it, he doesn't have to go down that road"* (Mother, Stanley family).

Adopting a 'here and now' approach may also have functioned to eliminate anxiety for parents, through a process of avoidance and focusing on the adolescent's present health rather than what may occur in the future. This father described his tendency to block out his worries and focus on the present, in order to cope with the potential threats to his son's health:

> *"You hear stories about problems with feet and eyes and often you don't really want to know, you know you can go on the internet and find out about potential blindness and all that later on in life, but you try and block out a bit and just get on with it"* (Father, Jeffs family).

(ii) Addressing complications

Addressing complications with their son/daughter was an issue for most parents, as they strived to balance ensuring their child was aware of the dangers of maintaining high blood glucose levels without burdening the child with worry and concern for their future. This quotation demonstrates the impact of parental warning on an adolescent's anxiety about complications:

"What do you think *(your mum's)* worried about...? (Joy)

"...The long term, what's going to happen in the future if I don't get my bloods down..." (James Pickering, 14)

"...Do you worry about that...? (Joy)

"...I do now since she's told me" (James).

Parents described strategies for getting the information across to their child using sensitive tactics, without directly warning them about complications:

(i) "He knows what can happen when he's older, I haven't really said...well I have said you've really got to watch what you eat now for when you're older. He does know that but I don't think he knows what can happen" (Mother, Edwards family).

(ii) "We say to him things like this thing with your eyes, you know you've got to be careful you know if you're high in the future kind of, but we would never actually say that to him, we would say to him, you could end up having to wear glasses and all kinds of problems with your eyes" (Mother, Jeffs family).

Addressing complications was seen as less necessary if adolescents had good control of their diabetes, as this mother stated:

"At this stage we don't think there's any need for him to know, but he's looking after himself anyway, if he wasn't looking after himself then I think you'd have to take it a stage further to frighten him into doing it" (Mother, Jeffs family)

However, if the adolescent's self-management was a concern to parents, addressing complications was employed in order to provoke motivation for better control. This was apparent in the Thomas family, following the adolescent's experience of a severe hypo. Holly's mother also described how she felt she had a duty to let her daughter know the potential dangers to her future health if she did not take control of her diabetes:

"They're children and they're diagnosed with it, you don't want to tell them this could do this to you, this could do that to you, but I think it reaches the stage where if you don't tell them and they don't know it could ruin their kidneys later on in life, they could wake up blind one day...you want to protect them but you can't, you've got to let them know" (Mother, Thomas family).

This evidence points to the assumption that parents were caught in a conflict between protecting their children by withholding information and looking after their future health by letting them know about potential complications.

6.13 Experiential learning: Impact on blood glucose control

Past experience

The average HbA_{1c} levels for the sample suggests that being diagnosed with T1D at a young age facilitates good blood glucose control in adolescence. Living with T1D for a longer period of time meant that adolescents had more opportunity for experiential learning. Three out of the four adolescents diagnosed under the age of five had the three lowest HbA_{1c}'s in the sample: 7.2 (Tom Butcher); 7.5 (Samantha Makin) and 7.6 (Emily Dougherty). The fourth adolescent (Stewart Staniforth) had a HbA_{1c} of 9.6 which is defined as the 'risk zone'. There were only five adolescents in the sample with a higher HbA_{1c} than this. A possible explanation for this adolescent's poor control was his mother's ownership of his diabetes, as described in the *Embodiment* category.

I rationalised that adolescents' and parents' interpretations of their past experiences and future orientations affected their behaviour, although this was underpinned by differences in meaning from adult to child. Past experiences affected adolescents' self-management behaviour in terms of their expectations of the outcomes of their behaviour in the present, and parents experienced recurring grief for the loss of their child's health over time. Parents perceived the future as threatening, as a result of a fusion of responsibility for their child's diagnosis in the past and anxiety for their future health. The relationship between past, present and future indicates that learning to live with T1D is underpinned by individual context and experience. Therefore, for education to be effective, it has to be meaningful in relation to the person's situated context. Case Study 5 demonstrates how the events of the past have the potential to elicit behaviour change if a meaningful chord is struck with the adolescent.

Case Study 5: The Dutton family

Jenny Dutton had generally poor control of her diabetes, illustrated by her average HbA_{1c} level of 10.7%. She described her lack of motivation to test her blood and difficulty in controlling her blood glucose. Following an episode of DKA, the threat of death had struck a meaningful chord with this adolescent. As described in the 'Lived body' section, her experience in hospital influenced her perceptions of T1D in a biomedical manner. Before the episode, it had just been something that she lived with whereas now it posed a real threat to her life. She described in the CASI diary journal how the incident had influenced her attitude and her behaviour:

> *"It was hard in the beginning coming to terms with Type 1 diabetes but now it's not so hard dealing with it because in the beginning I felt different and didn't understand It. I have had some bad experiences with diabetes, over Christmas I was in hospital with ketoacidosis and was close to dying, the doctors estimated that If I never came into hospital I would have died within two hours because I missed my insulin four times because I was drinking alcohol, and when I was in hospital I was vomiting and was in bad pain with my kidneys. That is why I agreed doing this (research) with you, to tell you it is hard having diabetes but it is not as hard looking after myself"* (Jenny Dutton, 14).

She also stated her outlook for the future:

> *"I want to be better controlled and then I can be healthy in the future, because they said if I don't control it now I won't be healthy in the future, and I want to be healthy, that's what I want"* (Jenny Dutton, 14).

This demonstrates the temporal nature of learning throughout the course of living with T1D and the importance of meaningful events for positive behaviour change and the potential for improved blood glucose control. As with the mothers experiencing hypoglycaemic events with their children, it was only after the event had occurred that the education given by the clinic became meaningful to them. For this adolescent female, blood glucose control became meaningful when she came close to losing her life.

In contrast, future health was not meaningful to Sarah Morris (Case Study 2). Her self-management behaviour was meaningful in relation to a need to fit in with her peers rather than a concern for the damage her high blood glucose levels would cause to her future health. Motivation for blood glucose control within a biomedical model is the preservation of future health, however this may not be true for the majority of adolescents who are more concerned with breaking down the barriers their diabetes impinges on them in the present. For Sarah Morris, the meaning of blood glucose control was not going 'low' in front of her friends; for two of the adolescent males (Steven Gibbons and Neil Jeffs), the meaning of blood glucose control was being able to play football without their performance being hindered by T1D. This demonstrates the need for health professionals to access the deep structures of the meaning of self-management for adolescents and to recognise the importance of past experiences and future orientation on present behaviour. When a meaningful chord is struck with the adolescent, in relation to their past and future, behaviour has the potential to change positively and blood glucose has the potential to improve.

Psychological theories of cognitive development suggest that experiential learning may not be appropriate for children and adolescents in relation to their cognitive developmental level (Arnett, 2000). Concepts of analysis, synthesis and evaluation required for experiential learning are only reached in adulthood, and are instrumental in the ability to assess one's behaviour and outcomes and relate these to future self-management decisions (Bloom, 1956). In contrast, the case study of Jenny Dutton however, demonstrated her ability as a 14 year old, to reflect on her experience of DKA in relation to her future health. It also demonstrated that self-management became meaningful to her when she was faced with the threat of death. This demonstrated that adolescents are capable of learning through their experiences. For Jenny, experience of the biomedical environment when she was admitted to hospital and the education she received following the event, influenced her motivation for behaviour change.

Future orientation

In terms of future orientation, perceptions of future effects of T1D were different for adolescents and parents. Most of the adolescents did not voice their concern about the long-term effects of T1D, whereas for most parents it was a cause of anxiety, supported by previous findings that parents were likely to perceive their child's diabetes as more serious than the child (Carroll and Marrero, 2006b). The threat of complications has been found to cause anxiety for parents in a number of studies (Low et al, 2006; La Greca et al, 1995; Dashiff, 1993). There are three possible explanations for parents' greater concern for complications:

(i) Complications were not addressed in the clinical setting

The NICE guidelines (2004) do not include a recommendation that children and young people with T1D and their families should be offered a structured programme of education that includes complications, suggesting that current paediatric care follows this view. Although omitting discussion of serious complications may be potentially positive for psychosocial adjustment, there is the danger that if complications are not addressed, knowledge is unable to influence self-management behaviour in a positive way if adolescents are unaware of the impact of their present actions on their future health.

(ii) Complications were not addressed by parents

Many of the parents took personal responsibility for their child's diabetes and their main concern was the impact of diabetes on their child's future health. They saw the development of complications in their child as an indication of parental failure. Linked to the process of parental embodiment discussed earlier, parents may have protected their child from knowledge about complications, in order for T1D to be normalised within the family environment. Some parents were conscious of the need to inform their child of the risks of poor control, but were also aware of the psychological burden of such information. My interpretation of this conflict is that broaching complications with adolescents had the potential to cause further biographical disruption to the adolescent and parent and therefore may have been avoided in order to maintain the status quo within the family. Some parents highlighted that it was not as necessary to talk about complications when the adolescent had good blood glucose control, which could explain why some adolescents had a limited knowledge of future health concerns.

(iii) Complications were not 'meaningful' to adolescents

A third possibility is that adolescents do not focus on future outcomes, supported by evidence that the short-term effects of diabetes and its treatment rather than long-term outcomes have been found to be predictive of self-management (Skinner and Hampson, 1998; 2001; Edgar and Skinner, 2003). This suggests that focusing on long-term complications in education strategies with young people may not be meaningful to adolescents in the form it is currently delivered.

The findings suggested that perceptions of the future and adolescent motivations for self-management behaviour are underpinned by complex structures of meaning within their social worlds. The literature suggests that young people typically lack the life experience needed to commit to long-term goals, and focus on more immediate concerns such as peer relationships and social activities (Jaffe, 1998), rather than concerns for future health (Timms and Lowes, 1999). However, the adolescents talked about their career ambitions which indicated that conceptualisation of the future was not impossible. Rather, future health in relation to diabetes was not necessarily *meaningful* to them. Interpretive phenomenology suggests that present behaviour is always oriented to meaning, based on past experiences, the context within which an adolescent is situated, and their beliefs and values (van Manen, 1997). Certain things held meaning for adolescents because they enabled them to integrate within a certain social environment without the disruption of T1D. Education about complications may well have been given in the clinical setting and by parents, but not taken on board because it was not meaningful at the time in the context of adolescent life.

For example, Jenny Dutton (Case Study 5) demonstrated how an episode of DKA made education about self-management from the clinic meaningful, as she found new motivation in the goal of maintaining her future health.

Similarly, Neil Jeffs (14) demonstrated a keen interest in advice from the dietician in order to maximise his ability to perform well in sport. For other adolescents, peer group acceptance was a priority, meaning that self-management took a back seat as it inhibited normalisation within the peer environment. The differences between parent and child short and long-term perceptions of the future demonstrate that behaviour is always influenced by past experiences and oriented towards expectations of the future. Therefore, what is meaningful to individuals will depend on their social world and the perceived barriers surrounding them.

This evidence shows that living with T1D is underpinned by a process of experiential learning for both parents and adolescents. This provides a critique of psychological theories of cognitive development, which suggest that adolescents lack the cognitive capacity to reflect on their experiences, and supports Cooper and Geyer's (2007) claim that learning to live with T1D is an ongoing, individualised and sometimes unpredictable journey. Learning through experience is vital for all people living with T1D, regardless of their age or cognitive developmental level. However, the following theme goes on to describe how input from parents and health professionals is vital in collaboration with adolescents, in order to convert experience into positive behaviour change. Their greater life experience and knowledge means they are instrumental in guiding children and adolescents' learning in the 'right' direction.

6.14 Experiential learning: Summary

My interpretation of the process of learning to live with T1D with reference to the literature, was that it is an on-going process underpinned by past experiences. It was apparent from the data presented that the adolescents and parents explained and rationalised present behaviour in terms of past events and beliefs in the future. This implied that it is often necessary to experience unpleasant situations in order to be better equipped and prepared to deal with such situations in the future. Experiential learning allows families to adapt to the self-management of T1D, but also to the effect of diabetes on the family unit and relationships within it, as demonstrated by the step-father's experience in the Fletcher family. The findings suggest that education preparing adolescents and parents for serious events such as hypo and hyperglycaemia may often not be meaningful until the person has experienced the situation for themselves. Experience of such events has the potential to change perceptions of T1D and motivation for self-management.

Adolescents' and parents' perceptions of the future were very different. Parental anxiety and subsequent behaviour was underpinned by the threat of future complications, which underpinned their anxieties about self-management and prompted them to remind and assist their child. Adolescents' perceptions of self-management often did not relate to the future or to parents' perceptions, but were underpinned by other meaningful structures in the social worlds, such as peer integration. This implies that diabetes education must be meaningful and based on experience in order to be effective and taken on board by adolescents. Meanings and motivations for diabetes control in adolescence are underpinned by individual contexts in terms of the past, present and future of the adolescents and their significant others.

Category 4: Relationships with significant others

(Relationships with parents, peers, teachers and health professionals)

In the normalisation theme, I described the influence of different environments on the experience of living with T1D. This category refers to the influence that relationships with others within these environments have on diabetes self-management and experiential learning in adolescence. I describe two themes, focusing on family relationships and parenting and relationships with health professionals.

6.15 Theme 1: Family relationships and parenting

Within the data, I looked for descriptions of the roles of parents in relation to adolescents' diabetes management. Caring responsibilities appeared to be underpinned by relationships between parents, the roles they took within the family in relation to their child's diabetes management and differences in the roles of parents in two-parent and single-parent families. This theme explores the further sub-themes of caring responsibilities in two-parent, single parent and step-parent families, the influence of parenting style on blood glucose control and family conflict.

(i) Caring responsibilities and parenting roles in two-parent families

Twelve of the adolescents lived with their birth mother and father and were therefore classed as two-parent families. In two-parent families, mothers usually took on the main caring responsibilities for their child's diabetes. Some adolescents described their mothers being more involved and in control of monitoring their self-management behaviour than fathers, who provided help with sport and activities, as this adolescent male stated:

> *"If I have a hypo or I'm not feeling too well, my mum will always look after me or she'll always make sure like I have the right amount of stuff if I'm going out. My dad, he looks after my diet and exercise and that, makes sure that I do the right amount...if I'm bored or something, he'll take me somewhere"* (Sean Ratledge, 15).

Other researchers have also found mothers to be the main caregiver to a child with T1D (Dashiff et al, 2008). Research with the general adolescent population suggests that in two-parent families, mothers spend more time meeting their children's practical needs (Pleck, 1997) and spend more time with adolescents (Phares et al, 2009), whereas fathers tend to spend more time in play activities (Pleck, 1997; Hall et al, 1995). This was reflected in the activities fathers participated in with their children (i.e. sporting activities, days out), as opposed to the daily tasks integral to diabetes management (eg. blood testing, injecting, diet), which mothers took on board. However, the mother did not take the main caring role in all families. In other two-parent families, a dominant mother role was not described, suggesting a more equal approach to diabetes management between parents.

Those mothers that did take on the responsibility for the practical side of T1D appeared to be anxious about their child's blood glucose control. The important role played by fathers in supporting their female partners in caring for a child with T1D has been recognised by a number of authors (Gavin and

Wysocki, 2006; Hanna and Guthrie, 2001; Amer, 1999; Christian and D'Auria, 1999; Kyngas et al, 1998). In this study, fathers often provided a more relaxed viewpoint which balanced out mother's anxious behaviour. They relieved some of the caring burden for mothers by taking a more relaxed approach to diabetes management and taking responsibility for more lifestyle-related care duties such as diet and exercise. This was stated by mothers, adolescents and fathers, for example:

"Do you think your diabetes affected anybody else in the house at all...? (Joy)

"*...My mum, she worries more like. My dad, he knows I'm alright and if I need something I'll ask him or my mum, but my mum just worries too much about everything*" (Steven Gibbons, 16).

Some adolescents described their fathers encouraging independence, which made them feel trusted, as this adolescent male described:

"My dad's more laid back, he accepts that I know what to do and lets me do it, he'll say have you done everything and I'll just say yeah and it's alright then. My mum's going into more details with it, my dad just sort of lets me get on with it and I tell him if I've got a problem and he'll sort it out" (Anthony Mather, 15).

When two parents had a different approach to diabetes, this appeared to assist parental coping, particularly for mothers. One mother described how her husband's calmer nature balanced out her panicking and encouraged her to act more rationally in certain situations:

"(My husband)'s *more chilled out than me. I'm like arghh panicking, he's just dead calm...takes everything in his stride. Which I suppose it's good in one way because he calms me down"* (Mother, Ratledge family).

In one family, the family structure (father working full-time and mother at home in primary caring role) meant that the father had little role in his son's diabetes care at all:

"What about your husband, what's his role in...? (Joy)

"...He doesn't, men don't...he'll look after him when they go out you know when they play golf and everything else he takes care of him that way, making sure he has his insulin and everything else but on a day-to-day basis it's me" (Mother, Stanley family).

Another mother stated that her husband felt guilty that his working hours meant he could not help with his son and daughters' diabetes. Each morning, he set up their insulin injections, arranged the collection of their medication and took a more 'hands on' role at weekends when he was at home. These roles in the daily routine enabled him to feel he was contributing to their care and supported the mother in her 'full time' duties. She stated:

"I mean her dad still sets the pen up in the morning ... he organises their medicine ...that's the role he seems to have taken on...because with him working full time he can't always be there to help...when we're on holiday he takes over, checking this and that...it's as equal as it can be given the situation, but he does more on that side and I'm more on the hands on with them, then at the weekend we tend to change it over" (Mother, Makin family).

(ii) Caring responsibilities and parenting roles in single-parent families

My interpretation of the experiences of two-parent families was that parents often took differing approaches to diabetes management, underpinned by different caring responsibilities and that this enabled a balanced environment which assisted parent coping. Six of the adolescents were from a single-parent family. In all cases, the adolescent lived with the mother full-time. This was expected, as 90% of children in single-parent families are more likely to live with their mother than their father (National Statistics, 2004).

Previous research suggests that single parents are at increased risk of anxiety and depression and increased parenting stress, following a child's diagnosis of T1D (Streisand et al, 2005), however parent stress in this study did not appear to be any greater in single parent than in two-parent families. The lack of a partner to assist with lifestyle activities, may mean that single parents are under increased pressure as they strive to deal with daily management tasks alongside lifestyle activities. Other findings suggest that single parents experience increased stress following diagnosis of their child's diabetes, in comparison to parents in two-parent families (Streisand et al, 2005). This may lead to some areas of diabetes care being neglected, due to lack of time and resources. Previous research has shown that single parents may suffer more due to evidence that the family system benefits when a chronically ill child's parents support each other (Hatton et al, 1995). Lack of support from a partner meant that Russell Jones' mother did not have enough time or energy to input into her son's diabetes management at the level he needed, as her time was split between many priorities. She stated:

> *"I just think it makes it twice as hard basically...it's hard enough anyway being a single parent, I might be different to some of the other families, they might have a mum and a dad in their houses...I've got more things to worry about than just him...of course I worry about him all the time but there's only so much I can do"* (Mother, Jones family).

She described not having the time to go running with her son when he wanted to do exercise, and disassociation with him in the mornings when he was getting ready for school in order to avoid conflict:

> *(i) "I need to maybe go jogging with him so that he'll go jogging...it's all a big responsibility...we never end up doing it because I'm not very good at routine...if I was to say right Monday, Wednesday Friday I'll go jogging with you that wouldn't be very realistic cause I couldn't see it happening he might say to me like on the day, do you want to go jogging? I'll go, yeah and I might go but then other times I might say I'll go then it'll come to the time and I just won't go, it's just the way it goes"* (Mother, Jones family).

> *(ii) "I don't get up with him, because he's not a morning person, he's up at half 6 that's for his little ritual what he does with all his cleanliness, and that's it really, I don't get up with him because of that"* (Mother, Jones family).

In most cases adolescents and their mothers described the absent fathers having little input in the adolescent's diabetes management. However, this must be taken with caution as the absent fathers were not interviewed, and mothers' perceptions of their lack of input may not be accurate given that they would likely not be present when the father spent time with their son or daughter. This adolescent female described the infrequency of her father's input:

> *"I don't see my dad very often like, frequently but not all the time...he doesn't really have a big role in* (diabetes)*, it's mainly my mum who's there for me"* (Jenny Dutton, 14).

As found in previous studies (Spencer-Dawe, 2005; Backett-Milburn et al, 2001), the single mothers in this study described finding it difficult to negotiate time off work when their child was ill. In such situations an understanding employer was vital:

> *"I made the decision if ever she was off I had to be off work...if she's got a cold fair enough if she's still eating but anything to do with stomach upsets or diarrhea...I just made the decision that I've got to be off. Work, they've been understanding about it and about the time I need off to take her to the clinic, but it's always there, I've only ever had to take about four days off but it's still a pressure where you think you know you've got to be prepared to have time off"* (Mother, Thomas family).

Some mothers and adolescents in single-parent families also perceived the absent father to have a lack of knowledge about diabetes. However, as an outsider to the household, fathers were not able to develop their knowledge through experience. This adolescent female felt annoyed when her father tried to advise her because she felt he was not knowledgeable about her diabetes,

> "(Dad's) *absolutely awful, he doesn't have a clue, he still thinks I'm on the two injections...every now and again he'll make a comment like, are you meant to be eating that? and things like that...he doesn't get involved at all, but he thinks he knows all about it...he'd say you're eating well too much, are*

you sure you're taking control of yourself and things like that" (Holly Thomas, 15).

This perceived lack of knowledge caused concern for some mothers, when their child stayed with their father, as they were worried blood glucose fluctuations would go unnoticed:

> *"Me and his dad are divorced so I'm the main carer...and any problems if he's with his dad he'll ring me, he doesn't really know how to adjust anything they rely on me to do it. I think he sort of buries his head in the sand and doesn't really fully accept the abnormity of the illness or how important his insulin and his health are...he didn't pick up on the signs that I would pick up on when he started to act a bit strange...I would have known he was hypo, his dad thought he was just being silly"* (Mother, Mather family).

This mother felt the same, but understood the difficulty her ex-husband had in keeping up to date with their child's diabetes when he was not around all of the time:

> *"I don't think he understands as much and I think that's the danger because we've split up that's what naturally happens because when the parent hasn't got custody of the children he loses touch with them a little bit and every other weekend isn't enough to keep in touch with the normal, what's happening with school, never mind diabetes...it's a bit more like an uncle relationship he's got rather than a father"* (Mother, Thomas family).

This demonstrates the importance of experiential learning in the management of chronic illness (Paterson and Thorne, 2000; Price, 1993). The experience of the step-father in the Fletcher family demonstrated a rich learning process underpinned by family dynamics. When fathers lacked the opportunity to learn about diabetes through regular contact with the child, their knowledge was incomplete which may have affected their ability to care for their child. However it must be acknowledged that the absent fathers were not interviewed in this study and therefore their lack of knowledge is purely the interpretation of the mothers and adolescents describing their experience. A recent systematic review found a lack of empirical research looking at single parenting and chronic illness (Brown et al, 2008), and therefore this finding relating to experiential learning is an important contribution to understanding absent fathers' experiences.

In families without a co-habiting father, grandparents provided vital support to single mothers to cover work commitments (also found by Backett et al, 2001) and also assisted with childcare in two-parent families when parents had work commitments or were going away. They provided respite care for the child when parents were away and in some of the families, grandparents took on the main care role whilst the parents were at work. This was particularly vital in single parent families, as a secondary support role. Their assistance provided peace of mind for some parents who were too anxious to leave their child alone, for fear of hypoglycaemia, as this mother explained:

> *"While I'm at work they're here* (at grandmother's), *I don't leave him in the house on his own...with the diabetes you've always got to keep tab on where he is and has he had his lunch and has he had his tea...so he loses that sort of independence I suppose"* (Mother, Mather family).

(iii) Step-parent families

Two of the adolescents lived with their mother and step-father. In the *Experiential learning* theme, I described the adjustment of a step-father entering a family in which his step-daughter had T1D. The transformational process he portrayed underpinned by experiential learning, illustrates how absent fathers could miss out on the essential learning process. Zarelli (2009) suggests that integrating into a formed family, adjusting to step parenting and learning about caring for T1D may lead to a constant state of transition for step-fathers, leading to significant stress. From an interpretive phenomenological perspective, the fusion of two families begins with a blending of history and experiences, which influence the role expectations of individuals. The transformation of T1D from an issue that his step-daughter and wife addressed, to a part of the step-father's daily life, captures the process of integration and adaptation of the father to the norms of the new family. In this situation, diabetes was already normalised within the family environment and the introduction of the step-father disruption the functioning of the family. Through experiential learning, Jane's step-father was able to adjust to the new family environment and eventually the family structure settled, relationships and expectations were balanced, and a status quo within the family was reached. This demonstrated that diabetes knowledge was instrumental to this step-father fulfilling his new role within the family, emphasising the impact of T1D on all family members (Dashiff, 1993).

(iv) Parenting styles

There is a substantial body of evidence to suggest that family relationships (Lewendowski and Drotar, 2007; Moreland et al, 2004; Miller-Johnson et al, 1994; Wysocki et al, 1993; Bobrow et al, 1985), parenting style (Davis et al, 2001; Overstreet et al, 1995; Miller-Johnson et al, 1994; Lamborn et al, 1991), and structure (Lewin et al, 2006) affect blood glucose control in adolescents with T1D. Previous studies have shown that authoritative parenting, parent-child discipline, warmth and behaviour supervision may be advantageous for diabetes regimen adherence and glycaemic control in young people with T1D (Davis et al, 2001; Miller-Johnson et al, 1994), and that family functioning and adherence are strongly associated with metabolic control (Lewin et al, 2008). This suggests that parental involvement and discipline are integral to successful diabetes management. I explored this within the findings of this study, in relation to the four parenting styles defined by Baumrind (1989, 1971) and the metabolic control of the adolescents within the families.

The authoritative style

The authoritative style is characteristic of finding a balance between the encouragement of autonomy and discipline and protection. Parents encourage their adolescents to be independent, but also place limits and controls on their actions (Baumrind, 1989, 1971). These characteristics were apparent in the Bingham, Collins, Makin and Dougherty families. For example, Samantha and Emily's mothers described how from a young age, their daughters were encouraged to lead an active lifestyle without restriction:

(i) "She was doing Irish dancing, she was doing athletics, everything she would've done she carried on doing so she didn't stop anything because of her diabetes if anything we pushed her to say yeah ok so your diabetic, it's not stopping you doing this not stopping you doing that" (Mother, Makin family).

(ii) "So what's the story since diagnosis, have there been any major issues that spring to mind...? (Joy)

"I always remember the head teacher saying to me, do you want to come with her just in case there's a problem but we said no, none of the other children were having to do that so we don't feel Emily should have her parents with her and no she goes on the skiing trips with school and just encourage her to be the same as everybody else and let her manage her own diabetes, just support from us" (Mother, Dougherty family).

Jane Makin's mother also described disciplining her daughter firmly, and not allowing diabetes to be used as an excuse for bad behavior:

"In some ways I'd feel quite hard on her but you know if she'd been badly behaved we wouldn't say when we got to know some people oh she's having a hypo, no she's not having a hypo that's bad behavior - it'd be proper behaviour first, we didn't want anyone to say to her or about her well she's getting away with something because she's got a condition" (Mother, Makin family).

Alongside this, she also described encouraging her daughter to be autonomous in her diabetes management, showing that the development of independence in her daughter was a priority:

"Now I have to take the backward step where when we go into clinic...sometimes I find it's the night before and Samantha will panic she's not written anything in her book (laughs)*...I let her do it...if the doctors ask why it's not done I say, ask Samantha!"* (Mother, Makin family).

Emma Bingham's and Ian Collins' mothers also described how they had encouraged independence in their children from a young age, although they were mindful to keep an eye on their diabetes and give input when necessary:

> *(i) "She does need a boot up the bum, sometimes just a little one, just to remind her of certain things like if her blood sugar's going a bit hay wire and I'll have to say right we have to do this we've to alter it a little bit. But she, she, does it all...and she always has, after her first year, 'cause I remember Alder Hey saying to us they'd be able to do their own injections and their own blood sugars within a year and I was thinking god, you know at the time...I'm thinking I couldn't imagine her when she's 6 doing all this by herself, but she did"* (Mother, Bingham family).

> *(ii) "Obviously we always check on him but as I say from day one he's always done his own injections and to me that was important because if I'm not around I need to know he can look after himself and so it was important to be like that"* (Mother, Collins family).

The parenting values apparent in these families appeared to influence independence for diabetes, as all of the adolescents mentioned were able to manage their diabetes successfully away from home and with minimal parental input. This style was therefore characteristic of an ideal environment for the development of autonomy, in line with its association with social competence, especially self-reliance and social responsibility (Santrock, 1990). This supports findings that sharing responsibility for diabetes self-care between parent and child is associated with better psychological health, good self-care behaviour and good metabolic control (Helgeson et al, 2008).

The authoritarian style

Mothers who demonstrated parental embodiment of their child's diabetes, were characteristic of the authoritarian style, involving rigidly enforced rules with low acceptance (Baumrind, 1989, 1971). Authoritarian parents are restrictive, expect the adolescent to follow their directions, place limits and controls and offer little verbal give and take between the adolescent the parent. The behaviour of Stewart Stanley's mother demonstrated in Case Study 4 represented this style, as she had total control over her son's self-management behaviour. Tom Butcher's mother also took a similar approach in expecting James to follow her rules of diabetes management. She described her anxiety about him being beyond her control if he gained more independence, and how she enclosed his social world to one familiar to her so to enable such control.

"Tom is still being nurtured, he's still even now we still, he's not as independent as maybe he should be...we haven't really let go maybe where other children have, but maybe that's our negative...I think it's more frightening when he gets older and he is on his own and he goes out with his friends and things like that, that's a frightening thought...I don't think I would have been any freer with him really (if he didn't have diabetes), *he doesn't go out and not come back and I don't know where, and we don't have a lot of people, I don't have boys turning up that I don't know..."* (Mother, Butcher family).

Research has shown adolescents with raised with an authoritarian style score reasonably well on measures indexing obedience and conformity to the standards of adults, but have relatively poorer self-conceptions in comparison to other youngsters (Lamborn et al, 1991), which may impact on their ability to develop independence adequately. In agreement with this, parental control appeared to restrict natural autonomy development for both Stewart and Tom. However, such controlling characteristics may be beneficial for diabetes control in the short-term. Holly Thomas' mother described how she allowed her daughter to be to independent in her self-management too soon, leading to poor control of her diabetes:

"I think you've got to empower them to take responsibility...but I just feel that parents should be made more aware about keeping an eye on things...ok she's got to take control but I'm her parent, I've got to be a lot more responsible because things can go drastically wrong...make sure...you don't become blasé like I was where you trust them to do all this and then all of a sudden they're not telling you" (Mother, Thomas family).

During this stage, the mother took an authoritative approach to parenting her daughter, allowing her to be independent. However, without her mother's input this led to a demise in her control, and her mother described adopting a more authoritarian approach involving rules and restrictions, to gain better control of her daughter's blood glucose:

> *"She's been having a few lows of late and we sorted it out that she's got to test her blood every night now, it's more of a regime you know I feel like, she say's I'm bullying her, I'm not bullying her and I think I've made her understand, I've got to still stay in there with her and I might have to do this for a few more years yet"* (Mother, Thomas family).

Permissive-indulgent and permissive-neglectful styles

In the Morris family, Sarah's mother was interested and involved in her daughter's diabetes management, but she also had a 'friend-like' relationship with her daughter lacking in parental discipline. This resulted in her daughter having a lot of freedom outside the family home, plus sole responsibility of her diabetes management. This 'friend-like' style of parenting is characteristic of permissive indulgent parenting. Parents are involved in the adolescent's life but allow excessive freedom and do not control negative behaviour, demonstrated by the mother's lack of ability to prevent her daughter from neglecting her diabetes when she was out with her friends. Adolescents with this style are likely to disrespect rules and authority (Santrock, 1990); have a strong sense of self-confidence; a higher frequency of substance abuse and school misconduct and are less engaged in school (Lamborn et al, 1991). These characteristics were all present in Sarah, who often neglected her self-management:

> *"She should be taking say five injections a day but now it's slacked off now...that's why her blood sugars are going higher now because she's suited when she wants to eat (on the basal bolus regime) so she'll be out now eating away not a care in the world come in and go mum I feel sick"* (Mother, Morris family).

Her mother also described her disrespect for her mothers' curfew rules and her drinking alcohol with her friends. She had also chosen to leave school to attend a community college. Her approach to parenting Sarah is summarised in the following quotation:

> *"I would like to give her all the independence she wants. I think she gets a lot of independence do you know what I mean, it's just that I'd like her to let me know where she is, what she's doing and things like that. Not leave me notes, come home when I'm sleeping, leaving me a little note saying that mum I'm staying out and things like that"* (Mother, Morris family).

Permissive indifferent parents are uninvolved in the adolescent's life, neglecting and non-responsive. The mother in the Jones family had little involvement in her son's life, lack of time to be involved in his diabetes management and a 'friend-like' relationship with him that lacked parental discipline and respect. Russell's mother's style of parenting was characteristic of adolescents who characterise their parents as neglectful. Russell described having low blood glucose frequently:

> "Erm, about feeling low - does it happen a lot...? (Joy)

"I go low most days yeah because I haven't been taking, I got this book that like measure carbohydrates and I haven't took it to school with me lately so I end up giving myself like too much insulin, so like I'll have a hypo probably just at the end of school between the end of school and going home I'll probably have one" (Russell Jones, 14).

This implied a lack of self-control through having little of adherence to his self-management regime (Lamborn et al, 1991).

(v) Family conflict

Minor conflict between parents and adolescents was common as a result of blood glucose fluctuations and parental reminders for self-management. The management of T1D appeared to have an effect on parent-child relationships in some families. This was most commonly due to parental reminders about self-management, as this mother explained:

"I think the relationship with the mother and dad and the child, that sort of breaks down at times...instead of being a good relationship, because the mother or the dad is saying you need to do this, you need to do that, have you done your needle, have you done that, they get annoyed because you're nagging all the time, so it's really, really hard" (Mother, Pickering family).

Conflict as a result of parental reminders supports previous findings (Schilling et al, 2006) and the theory of 'miscarried helping' (Anderson and Coyne, 1991). Some parents demonstrated helping behaviours as a result of their own anxieties for their child's future health, rather than the benefit to the child. This is supported by findings that parents are often aware that their reminders are annoying, but find it difficult to step back from assistance (Carroll et al, 2007). Unnecessary parental input may result in the child feeling 'blamed' for their illness (Low et al, 2006; Mellin and Neumark-Sztainer, 2004a; Kyngas and Barlow, 1995) and result in conflict between parent and adolescent (Schilling et al, 2006). Miscarried helping has been found to be related to parent-child conflict and parent non-support of diabetes treatment, and negatively with youth and parent-reported adjustment to diabetes and youth-reported adjustment to treatment (Harris et al, 2008), and therefore it is important to address parental anxiety to avoid it manifesting in this way.

Some adolescents also described blood glucose fluctuations having an effect on their mood, leading to family conflict, as this female and mother described:

(i) "I just have a go at everyone when I'm high, it annoys me that it won't go back down, so I end up having a go at anyone who's there really" (Lisa Brookes, 16).

(ii) "Bad temper, very bad temper, throwing things, language...I've literally had to sit her down and make her eat something" (Mother, Dutton family).

Some adolescents described feeling guilty following such angry outbursts:

"Do you think that you blood sugar affects your mood at all...? (Joy)

"...*Yeah, big...* (Jenny Dutton, 14)

"...In what way...? (Joy)

"...*If I have a hypo I go mad and I can't stop it, and after it I feel guilty 'cause I can't really remember much*" (Jenny).

Adolescent-instigated conflict as a result of blood glucose fluctuations was soon resolved, as parents were sympathetic to its cause. Parents usually took an understanding attitude to their behaviour, as they recognised that it was often beyond the adolescents' control, as these quotations demonstrate:

(i) "I sort of overlook it and I won't argue too much with him when he's in an argumentative mood" (Mother, Jones family).

(ii) "Later she'll say look I'm sorry about before and I say, It's okay, 'cause I know if she hasn't had a snack or something she gets really angry... we all understand where she's coming from when that happens" (Mother, Dutton family).

One parent noted the effect of her divorce on her daughter's blood glucose control, indicating that conflict and stress within the family could have a psychosocial influence on blood glucose control. She explained:

"I think a lot of the problems when she was having frequent hypos was down to the fact that me and her dad were having a pretty stressful time... there were a lot of arguments...obviously that all affects the kids...she was in hospital a few times and they'd say to us is everything ok in school, yeah, everything ok at home, I'd go yeah and looking back I think no actually it wasn't" (Mother, Bingham family).

This is supported by findings that family functioning and adherence are strongly associated with metabolic control in adolescents with T1D (Lewin et al, 2008). Despite evidence of minor conflicts, high levels of parent-adolescent conflict were not reported in the sample and therefore the risk of a negative impact on adherence (Miller-Johnson et al, 1994; Wysocki et al, 1993; Bobrow et al, 1985) and glycaemic control (Lewendowski and Drotar, 2007; Moreland et al, 2004) was not a cause for concern.

6.16 Theme 2: Relationships with health professionals

In the *Normalisation* category, I addressed relationships with significant others in the school and social environments. I found that poor relationships with teachers in relation to teacher knowledge about diabetes had a negative effect on self-management behaviour. Positive relationships with peers and acceptance of T1D facilitated self-management. Lack of acceptance led to avoidance of self-management in order to preserve the 'invisibility' of T1D and avoid negative peer reactions. In this theme, I concentrate on relationships between families and the staff at the diabetes clinic. As the clinic was a specialist paediatric unit, care was family-centred and therefore relationships between the family and clinic staff were instrumental to care delivery. I address further sub-themes exploring positive relationships established between the families and the diabetes specialist nurses, the way in which they delivered care to the family and incidences of conflict between the clinic and families.

(i) Positive relationships between nurses and family

As I described in the *Normalisation* theme, the panic of diagnosis meant that positive relationships between the hospital and the family were established from diagnosis in the majority of families. Most of the parents valued the service they received from the hospital and many of the teenagers had a positive and trustworthy relationship with the diabetes nurse specialists, as these quotations demonstrated:

"Is there anything that could be improved about the service they provide there...? (Joy)

"*...Hand on heart, I couldn't have had a better service...I just felt cared for. When I walk in that hospital, I feel as if someone just put their arms around us and just took everything away and sorted everything out*" (Mother, Stanley family).

Adolescents felt they could trust the nurses which enabled them to be open and honest with the nurses in clinic. The open relationship that the nurses encouraged between themselves and their patients meant that the adolescents received realistic and accurate advice for diabetes management in various situations, as this female described:

> *"Say if I told them something like I was drinking last month...they'd say well did you do this and I'd go no, well this can happen if you don't... if you lie to them then you won't get the thing you need to know"* (Jenny Dutton, 14).

As most of the adolescents had been diagnosed with T1D for a number of years, this relationship of trust was established through continuing contact and familiarity with the nurses. There were a number of factors relating to familiarity that contributed to the trust that families had in the clinic: The adolescents felt welcomed and comfortable in the hospital due to the friendly approach of the clinic staff, *"They're all friendly and when I go in they know my name straight off"* (Tom Butcher, 15); the clinic staff had been there for a long time and the family always saw the same nurses at every appointment, *"You'd always seem to see the same staff which is nice... we go and in and they'll go, oh alright Emma..."* (Mother, Bingham family); the nurses had known the adolescents since they had been diagnosed, sometimes at a very young age, *"They've seen me grow up, so I know them pretty well...I'm just comfortable there"* (Tom Butcher, 15).

Positive relationships were maintained between families and the diabetes clinic in most cases, based on trustworthy relationships established based on familiarity and longevity of the family's association with the clinic and mediated through the specialist nurses' role. This style of care is characteristic of the paediatric setting. The nurses provided 24 hour support to families and always made time to listen to the family's concerns. It was this attentive approach to care that families stated they would miss when transferring to adult services, supported by previous findings (Fleming et al, 2002).

Evidence suggests that trust between patients and health professionals mediates therapeutic processes and influences health outcomes through patient satisfaction, adherence to treatment and communication with the health practitioner. Trust between patients and health professionals encourages patients to access health services (Calnan and Rowe, 2008). This could explain the decline in attendance following transition (Kipps et al, 2002; Bryden et al, 2001; Scott and Donnelly, 2001), if the trustworthy relationship is lost during this process.

The importance of familiarity was reinforced by parents' statements relating to dissatisfaction with seeing different consultants each time at clinic. Some parents were not satisfied with seeing different doctors in the clinic at each appointment, and felt more comfortable approaching nurses if they had a problem as the following quotes demonstrated:

> *"They seem to have loads of consultants coming in all the time...which is good and it's bad because sometimes you can go see a consultant and then you won't see them again..."* (Mother, Bingham family).

> *"Emily has known the staff from day one, and I mean the doctors are changing all the time...we both find it easier to approach the nurses"* (Mother, Dougherty family).

(ii) Care delivery

Health professionals were praised for their sensitive yet direct approach to care delivery at an understandable level. The delivery of care was individualised to suit achievable goals and encouraged independence, in line with NICE recommendations (2004). This trustworthy relationship provided an excellent forum for the delivery of education to both adolescents and their parents. Previous findings have shown that older adolescents desire communication in consultations to be directed towards them rather than their parents (Carroll and Marrero, 2006a), and this was demonstrated by the health professionals at this paediatric clinic.

The health professionals were praised by parents for their sensitive approach to communication, with regards to issues such as puberty and emotional acceptance:

"They took into consideration that when he did reach puberty that he might feel embarrassed about certain things and didn't want them to investigate when they wanted to and they were very good, no he doesn't want to, we'll leave it this time..." (Mother, Butcher family).

"He got so emotional...(nurse) *was just so good, she stood at the door, stay there 'til you're ready...s*he was really good talking to us and saying right we need to talk to the psychologist" (Mother, Collier family).

Most adolescents respected the health professionals' advice in the clinic, and took on board their expertise and knowledge, as this adolescent female stated:

"Do you think that the clinic staff see your diabetes in the same way as you...? (Joy)

"...I sort of agree with them because I know that they're sort of right so I don't like to say that you're wrong or anything like that 'cause they have more experience or they know like more about it than me, but I don't really think any different, what they tell me goes, they totally rule whatever I do" (Holly Thomas, 15).

The nurses were praised for being 'straight talking' to adolescents about the importance of their self-management, for example:

"When I've had low blood sugars and that they were describing to me how low blood sugars felt...and none of them have got it so I think that's good the way they understand it so much but like you know what I mean, they haven't got it" (Anthony Mather, 15).

However, one parent felt that the nurses should approach the dangers of neglecting self-management more forcefully with her daughter:

"They need to explain exactly what could happen, why it's important to get these tests done...she just thinks they're poking at her all the time for nothing. They should explain well we're doing this test to make sure this is

still right, we're doing this one to see what's going on here...I think if they explained a but more to her, she wouldn't do half the things like the drinking and the smoking..." (Mother, Morris family).

Nurses communicated at an understandable and familiar level with the adolescents but some found it difficult to understand the consultants:

> *"They talk about stuff and I just don't think I understand it and that. It's all stuff I can't understand, he like doesn't explain it"* (Darrell Collier, 13).

> "(The Doctor)*'s very nice, but when you go in and see him you come out head spinning a bit"* (Mother, Collier family).

Although this was not true in all cases, as this mother iterated:

> *"What's so nice about the doctors is that they speak to you on a level, they're not Mr. high and mighty, they're just ordinary people, they're lovely"* (Mother, Stanley family).

Nurses provided vital support to parents, who were comforted in the knowledge that they had 24 hour support from the clinic. This support was instrumental to parental coping, particularly following diagnosis when parents were often unsure of what action to take and needed reassurance, as this mother explained:

> *"When he was first diagnosed, all the worries you can have and you can just get in touch with* (nurse), *if she wasn't there it was the ward, so I never had a problem there"* (Mother, Edwards family).

Parents also felt that the nurses would always make time for parents' and adolescents' concerns regardless of their workload, as this mother stated,

> *"They'll make time, if they haven't got time then they'll say, well there's a diary, lets sit down and work out when we can see you, but usually they can see me then"* (Mother, Stanley family).

The nurses were sympathetic to the family situation, and actively aimed to adapt diabetes care to suit individual needs. This quote from one mother demonstrated that the nurses took into account individual needs when recommending care plans, and aimed to set achievable targets rather than unrealistic goals:

> *"The last agreement was the nurse said, alright if you don't want to do it (blood test) every day, she's trying to cut him some slack, she said do it twice a day, three times a week"* (Mother, Jones family).

Nurses also encouraged independence in adolescents through the child rather than the parent in consultations. This assisted parents in their attempts to transfer responsibility for diabetes management from themselves to the child. As these parents described:

> *"She's very independent and from day one, with the support of the staff on the ward we've encouraged her to manage her own diabetes herself"* (Mother, Dougherty family).

> *"What I like about the hospital is, Ian likes to do all his own talking and we go with him, they talk to him...they ask Ian the questions, so it just reinforces what I've done, it's about him taking it for him and not about me sitting there going well he does this he does that"* (Mother, Collins family).

However, other parents disliked this approach and felt 'pushed out' when health professionals addressed their child rather than them, as they were not yet ready to let go of their care responsibilities:

> *"The nurses talk to James not to the mum and dad...but I think they've gone too much towards the child now...they wanted to give the child a bit more power but they've given the child too much power"* (Mother, Pickering family).

(iii) Conflict

The majority of families described positive relationships between themselves and the health professionals, and appreciated the encouragement of independence by health professionals. However, some families also described situations of conflict when health professionals prioritised teenagers' independence needs over parental control. Sarah Morris's mother described how she felt undermined by clinic staff in relation to her daughter drinking alcohol. The nurses valued the Sarah's honesty about her drinking and educated her on how to drink alcohol safely. Her mother felt that this gave her daughter 'permission' to drink alcohol, when she mother disagreed with her behaviour. Although the mother understood the nurses' motive in ensuring her daughter was safe when drinking, she felt that the hospital were putting Sarah's lifestyle needs before parental discipline. This left her feeling that her authority as a parent had been undermined by the hospital staff. She explained:

> *"She told them she was drinking. They said it was fine as long as she does it safe, she eats, she checks her blood sugars. I don't agree with that, where I was saying no, you're not allowed to drink, and now she knows how many units she takes with alcohol, so she thinks it's okay now to drink, that gives her a bit more independence, where I was saying all along no you can't...but now everyone's saying as long as you play it safe it's fine...I was annoyed...I thought it was still a young age"* (Mother, Morris family).

In the Pickering family, the mother also felt that her authority had been undermined when her adolescent son was transferred from a twice daily insulin regime to a basal bolus regime to benefit his independence. The suggestion was made to her son before consulting her and her husband, and the mother subsequently disagreed with her son's decision. She stated:

> *"They should have spoke to us first and then tell us that they're going to mention this to James but it didn't work like that did it"* (Mother, Pickering family).

Although the majority of parents praised the support they gained from the clinic, some felt that there was a need for more specific therapeutic support for parents. As one mother explained:

> *"We campaigned for (a therapist) to be on the diabetic ward, when people get diagnosed, not just for the child, I think for the parents as well...I didn't think we got that support"* (Mother, Pickering family).

Another mother suggested the introduction of parent mentors to meet this need in providing extra support to parents of newly diagnosed children and adolescents:

> *"There should be just something where...you're put in touch with people who've gone through it...I wouldn't mind just being a mentor to someone...just to say this is what I went through, you may have different experiences but they tend to be slightly the same and I'd watch out for this, I'd watch out for that"* (Mother, Thomas family).

6.17 Relationships with significant others: Impact on blood glucose control

Parenting style

The adolescents which I attributed to being parented in an authoritative style (Emma Bingham, Samantha Makin and Emily Dougherty) all had HbA_{1c} levels representative of good to reasonable control (7.5-8.5%), aside from Ian Collings. Ian's was slightly higher at a level of 9.1, but he did demonstrate an autonomous attitude to his diabetes management.

It also appeared that the authoritarian style may benefit blood glucose control for adolescents in the short-term. Holly Thomas, James Butcher and Stewart Stanley all had HbA1c levels representing good to reasonable control (7.5-8.5%). However, the negative influence parental control can have on independence supports the need for parents to find a balance between encouraging freedom and monitoring their adolescent's diabetes, to attain optimum psychosocial and medical outcomes (Helgeson et al, 2008).

Both Russell Jones and Sarah Morris had HbA_{1c} levels in need of improvement (8.7 and 9.8 respectively), suggesting that the permissive style of parenting was less beneficial for blood glucose control in this sample of families. It is a possibility that these single-parent families demonstrated negative parenting characteristics because of the lack of paternal input. However, other single parent families demonstrated the authoritative parenting style (eg. The Thomas family), suggesting that it is possible for mothers to achieve autonomy and responsibility for their adolescent with T1D without the support of a male partner. Therefore, it is more likely to be the individual personalities of parents which influence the style of parenting they portray.

This discussion of parenting styles in relation to the blood glucose control of adolescents with T1D must be regarded with caution, as in-depth interviews only provide a snapshot of data from which to draw comparisons of parenting behaviours to that of Baumrind's (1989, 1971) parenting styles. However, it does appear that authoritarian and authoritative styles may be related to better blood glucose control in adolescents with T1D, in line with previous findings (Lewin et al, 2008; Davis et al, 2001; Miller-Johnson et al, 1994). The authoritarian style is likely to be the most successful approach to parenting an adolescent with T1D, as this also encourages independence for self-management, whilst allowing parents to support the experiential learning of their child. Although good blood glucose control was shown to be achieved with the authoritarian style, this was due to parental control. The case of the Thomas family demonstrated that different aspects of these styles may be more appropriate for different adolescents at different times during adolescence, and that parenting is unlikely to fit one particular style throughout childhood and adolescence.

The necessary input of parents in experiential learning was demonstrated by Russell Jones. He had learned risky behaviours (missing injections, drinking alcohol, bingeing on sweets and chocolate), which were detrimental to his diabetes control. His mother was not involved in his diabetes self-management and did not intervene in the learning process. As a result, these behaviours became normalised. Families who took a collaborative approach to the adolescent's self-management provided support and guidance, and influenced the adolescent's perceptions of their behaviour in relation to meaningful goals conducive of good self-management. This approach to parenting is synonymous of the authoritative style, which was found to be advantageous for regimen adherence and glycaemic control in school-aged and younger children with T1D (Davis et al, 2001). The Jones family characterised a permissive indifferent style of parenting, which is linked to psychological dysfunction and psychosocial incompetence (Lamborn et al, 1991). This is also supported by findings that parent support assists experiential learning (Herrman, 2006) and parental involvement improves adherence in adolescents (Berg et al, 2008; Ellis et al, 2007; Grey et al, 2001; Anderson et al, 1997). Findings that parental knowledge about diabetes has a positive effect on glycaemic control (Butler et al, 2008) also suggest that parents have a vital role in guiding their child's diabetes education.

Relationships with health professionals

Case Study 6 identifies the negative effects of a poor family-clinic relationship on an adolescent male's blood glucose control.

Case Study 6: The Ratledge family

The Ratledge family had a long-standing negative relationship with staff in the clinic. They did not trust the advice they were given by health professionals as they believed that they received conflicting advice from the clinic, which led to a state of confusion regarding the adolescent's diabetes care. The father stated:

> *"Different doctors will tell you different things. Some doctors will say it's not the high (blood sugars) you have to worry about it's the low ones, but the diabetic nurses will tell you it's the high ones because they do the long term damage....and you get all these fact sheets, but these fact sheets are contradicting each other as you're reading them"* (Father, Ratledge family).

This lack of trust between the clinic and the family meant that the mother adjusted her son's insulin herself despite advice from the hospital and the son adapted a similar distrustful attitude towards the advice he received from the dietician in clinic:

> *"We used to get told he's not doing enough exercise and he was on quite a lot of insulin, but now he is doing more exercise, I've dropped his insulin myself...we always bring him home and do what we've always done anyway"* (Mother, Ratledge family).

"The dietician I used to go to was alright, this one just feeds you a load of bull. Tells me I need more carbs and I need to do more exercise, go back and I'm doing too much exercise and need to eat more protein, I don't do it because my dad says it's a load of bull" (Sean Ratledge, 15).

Although the mother stated that she maintained the same regime with her son despite hospital advice to change, the father described feeling 'blamed' for his son's poor control despite following the clinic's advice, which reinforced the family's negative perception of the care they received:

"You go back to them the next time and say it's higher and you say, right I've done what you've asked me to do, it's gone higher and then they say oh it must be something you've done...I'm only doing what you said to do" (Father, Ratledge family).

Lack of communication and trust between health professionals and this family meant the adolescent's care was implemented based on family experience alone. Although experiential learning has an instrumental role in self-management, it is important that it takes place alongside the guidance and input of medical experts. Lack of communication meant that the family were unaware of some vital aspects of self-management. For example, this quotation demonstrates their confusion in managing the adolescent's blood glucose levels following sport, as there was often a delay in the dropping of blood glucose levels:

"The hardest bit is actually keeping his blood glucose level within what the hospital say, because it definitely doesn't play by the rules diabetes, you can go months where his blood's fine, you might not change his diet or his exercise and its up and down. Like last night it was something like 30 and he's just come from two hours of doing martial arts - hang on a minute, it should be low!" (Father, Ratledge family).

The delay in the dropping of blood glucose following exercise was commonly discussed amongst other adolescents, as the following quotations demonstrated:

> *"Sometimes if I'm doing a workout, my blood sugar might drop a bit later on and I'll have to have something to eat...like a couple of hours"* (Emily Dougherty, 15)

This suggests that this aspect of blood glucose management was covered in the diabetes education delivered at the clinic. On the basis of their criticism of the advice they received from the clinic, it is likely that this information was given, but not taken on board by the family. As a result, Sean's blood glucose control was poor (HbA$_{1c}$: 9.2%), his blood glucose was unpredictable and unmanageable, and this caused considerable stress to the family.

My interpretation of the poor relationship between this family and the clinic leads to the presumption that education was not absorbed by the family. Reflecting on their experiences with health professionals may have enabled the family them to learn from their mistakes and reduce the effects of physical activity on blood glucose control in the future. In support of this family's experiences, lack of trust in health professionals has been found in a previous study of adolescents with T1D (Herrman, 2006). This supports previous qualitative findings that adolescents felt supported when care was planned collaboratively with them (Hanna and Guthrie, 2000b).

This highlights that relationships between health professionals and families constitute one influential factor on blood glucose control, but it must be noted that there may have been other factors influencing Sean's diabetes management alongside this, such as puberty (Williams and Dunger, 2004) and relationships with peers and family members (Spencer et al, 2009). In effect, this provides one snapshot of the bigger picture in relation to blood glucose control for Sean.

In the *Experiential learning* category, I critiqued psychological theories which suggest that adolescents are incapable of experiential learning due to lack of cognitive capacity. The above two case studies further emphasise the importance of significant others (i.e. parents and health professionals) in assisting with reflection of experiences and the transformation of the outcomes of experience to positive future behaviour.

6.18 Relationships with significant others: Summary

My interpretation of the lived experience findings in discussion with the wider literature, has led to the conclusion that family structure, parenting style and relationships with significant others (peers, teachers and health professionals) have the potential to affect self-management and blood glucose control. Parental support is key to adolescent experiential learning and positive communication with clinic staff is instrumental to provide a forum education alongside this. The nurses were instrumental in instigating a trustful relationship between themselves and families, indicating that they were striving to employ a holistic approach to patient care which moved beyond the traditional biomedical approach. Poor communication between the clinic and families can leave gaps in knowledge which can impact, alongside other psychosocial factors, on the care needs of adolescents and ultimately prevent the achievement of adequate blood glucose control.

6.19 Conclusion

In this chapter, I have presented the lived experience findings, discussed in relation to other literature. Through exploring of the lifeworlds of adolescents and their parents, I have uncovered the complex nature of the management of T1D in adolescence. This highlights the individuality of each adolescent's social world and the impact of their individual context, history and relationships on their capacity to self-manage their diabetes. The following conclusions are drawn from my interpretations of the accounts of adolescents and their parents, with reference to the work of others discussed in this chapter.

T1D disrupts the lives of the adolescents and their families by disturbing taken-for-granted daily practices and introducing the biomedical environment to family life. The biomedical environment implements structure in the chaos caused by T1D. Contact with this environment determines how adolescents and their parents perceive their disease throughout its course.

Nomalisation of T1D within surrounding environments is dependent on the knowledge and understanding of others. It is an ongoing and contested social process based on individual conceptions of what constitutes normality, underpinned by the need to constitute equilibrium between family members. It has the potential to eliminate barriers to self-management, which are underpinned by the structure of daily practices or perceptions others held about diabetes. Relationships with significant others enable a balance between the management of T1D and the function of usual social practices and thus have the potential to shape self-management behaviour.

Adaptation to T1D within the family is an on-going process in which parental roles shift and routine acts as a coping strategy in the face of the unknown. Families implement various strategies of adaptation, which are grounded within previous theories of biographical disruption and adaptation to chronic illness. Normalisation of T1D is most likely to occur in the family environment, where it is meaningful to family members to adapt to T1D in order to maintain family structure and functioning.

Parental embodiment explains the difficulties underpinning the transference of responsibility for T1D management from parent to child in adolescence. This phenomenon also underpins parental anxiety and recurring grief (chronic sorrow) for the loss of their child's health and concern for their future.

Experiential learning and future orientation are fundamental to the experience of living with T1D in adolescence, through the attribution of meaning to experience. This process of learning through mistake-making is instrumental to the transition of adolescents to functioning as independent managers of their diabetes. Education was most effective for adolescents and parents following disruptive events.

These conclusions demonstrate that living with T1D in adolescence is underpinned by a combination of adaptive processes which are dependent on many psychosocial factors, meaning that self-management is an individualised phenomenon. The current biomedical model of care does not account for these influences on the outcome of blood glucose control. This advocates the need for an encompassing theory which recognises the unpredictable nature of living with T1D, supporting Cooper and Geyer's (2007) suggestion that complexity science provides such a theoretical framework. In discussion, in Chapter 7 I explore the principles of complexity science in relation to the conclusions of this study, drawn from a rigorous interpretive phenomenological approach. This is an original attempt to ground the metaphorical principles of complexity science within qualitative evidence, in order to move beyond its current application in a metaphorical form.

Chapter 7: Application of complexity science to the lived experiences of adolescents with T1D

Introduction

In Chapter 3, I defined the principles of complex systems and their application to human behaviour. In Chapter 6, I concluded that the biomedical model does not adequately account for the relationships between various psychosocial influences on blood glucose control in adolescence. Complexity science advocates a more realistic approach to diabetes management. Individual random effects of life along with the patient's ability to self-manage their diabetes can be recognised as key influences on blood glucose control. Conceptualising adolescents with T1D as complex systems may have the potential to lead to an improved understanding of blood glucose control. In this chapter, I discuss the lived experience findings in relation to the principles of complexity science, to explore if these principles can be grounded in the empirical evidence gathered in this study. The discussion is structured around the three groups of principles defined in Chapter 3:

(i) Fundamental characteristics of complex systems
  - Connectivity
  - Historicity, feedback and beliefs and values

(ii) Stressors at a critical point
  - Far-from-equilibrium
  - Exploring the space of possibilities
  - Positive feedback

(iii) Adaptation
  - Emergence
  - Attractors
  - Co-evolution

7.1 Fundamental characteristics of complex systems

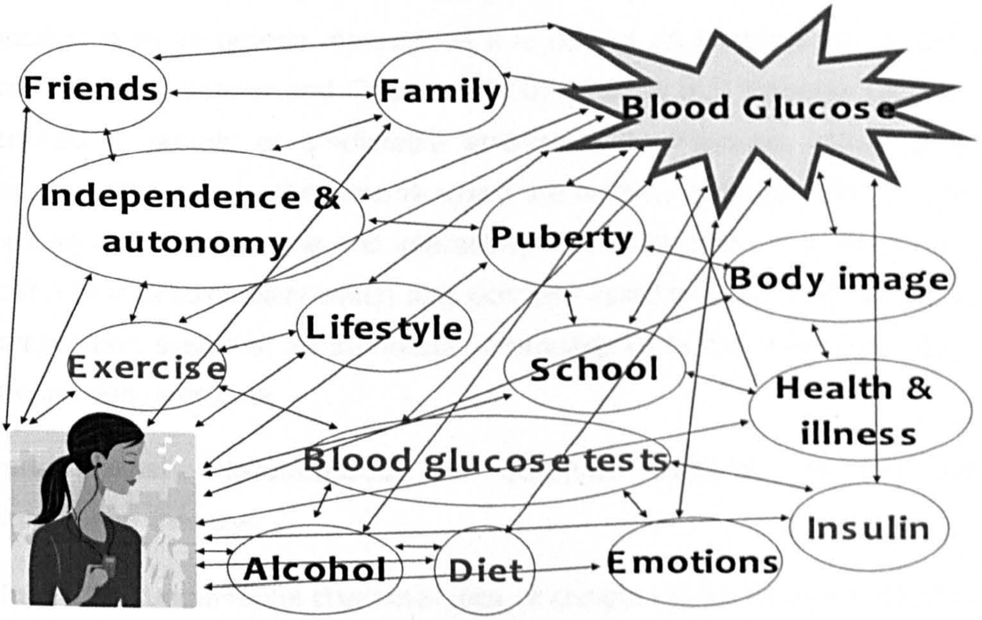
The first set of complexity principles describes the basic functioning of human complex systems: connectivity, historicity, feedback and beliefs and values. These components are essential in facilitating the healthy growth, change and adaptation of a system.

Connectivity

Connectivity refers to the relationships between elements within a complex system and between the system and its environment (Mitleton-Kelly, 2003). These relationships form the basic interactions through which complex behaviour occurs. Chapters 1 and 2 defined many individual, cultural and societal influences on metabolic control in adolescence, including gender (Hanberger et al, 2008), developmental level (Timms and Lowes, 1999); illness perceptions (Skinner et al, 2002), school support (Lehmkuhl and Nabors, 2008), peers (La Greca et al, 1995) and the family (Helgeson and Novak, 2007). These make up some of the elements of connectivity within the adolescent complex system, depicted in Figure 7.1, along with the biomedical requirements of self-management (highlighted in red). The poor blood glucose levels of the sample indicated a need to explore the interactions between these elements, to understand what was at stake for the adolescents in self-managing their diabetes. Complexity science encouraged me to take account of the interactions between these psychosocial factors and recognise that every individual is a unique complex system with unique interactions.

In the lived experience findings, there were different levels of connectivity within adolescents' complex systems. A small change in one part of the system can have a massive effect elsewhere and some parts of the system have a greater influence on behaviour than others. Some interactions may produce ordered behaviours, whereas others are more disordered. One example of connectivity from the findings is the theme of parental embodiment. This demonstrated that parents' coping mechanisms affect adolescents' self-management behaviour, which has an ongoing effect on blood glucose control and independence.

Figure 7.1: Variations of connectivity within the complex adaptive system of an adolescent with T1D



Historicity, feedback and beliefs and values

Historicity, feedback and beliefs and values describe the mechanisms by which connectivity interactions instigate change within a complex system. Feedback refers to information relating to the outcomes of actions in the past and the influence of these on behaviour. Negative (stable) feedback and positive (amplifying) feedback give rise to non-linearity which leads to innovation and unpredictability within the system (Kernick, 2004). From an interpretive phenomenological perspective, beliefs and values underpin historicity and feedback. They define the way in which humans interpret the outcomes of their actions as positive or negative feedback, and believe their behaviour will affect future actions. Positive feedback increases the chance that a behaviour or strategy will be applied in response to similar stressors in the future. Negative feedback does not rectify disorder, and encourages the exploration of further possibilities in order to find the best strategy to meet the needs of the system. Therefore an adolescent may interpret the outcome of maintaining invisibility in the social environment as positive if it enables them to integrate within their peer environment. However, if this has a negative impact on their blood glucose control, then it is defined as negative feedback within the complex system, as it instigates disorder elsewhere. It is possible for some parts of the system to exist in disorder if others are functioning in an orderly manner, as it is part of an evolving way of being. This supports Cooper and Geyer's (2009) premise that diabetes cannot be reduced to orderly or predictable arrangements. Physical, biological and social worlds contain phenomena which are orderly, complex and disorderly, existing at the same time and interacting with each other. It is therefore the notion of unpredictability which sets complex systems apart from simple and complicated systems, as numerous interacting units can evolve in multiple unexpected directions.

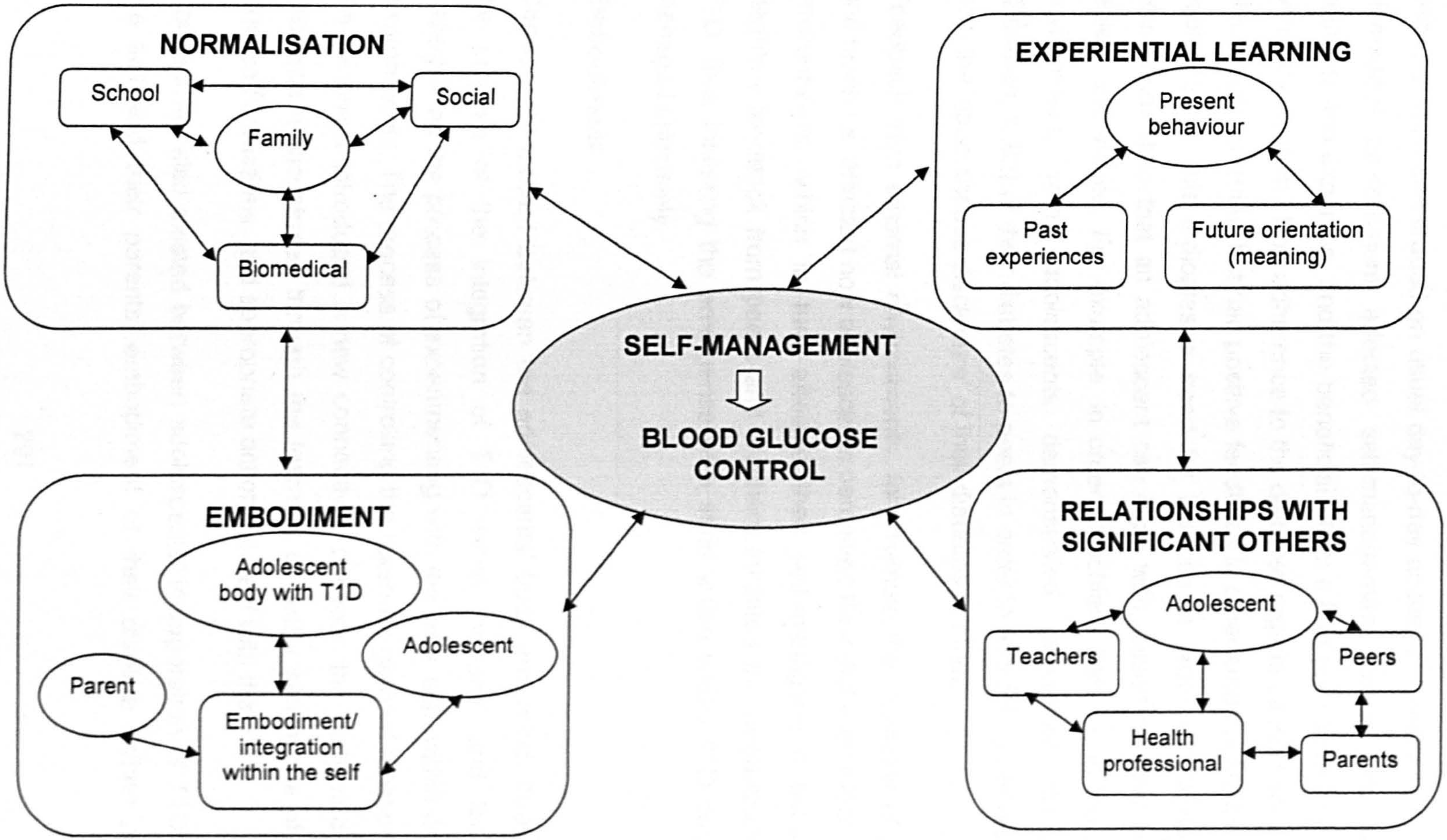
Fundamental characteristics of complex systems in the lived experience themes

I found the fundamental characteristics of complex systems to be inherent in the thematic constructs derived from the lived experience data. Figure 7.2 shows the connective relationships between elements within each of the themes at the micro level. Each theme interacts at the macro level, produces feedback and affects self-management behaviour and blood glucose control. Each theme has an affective feedback relationship with the other constructs, to 'make up' the overall experience of living with T1D. For example, the integration of T1D within an adolescent's persona will be related to their parent's embodiment of T1D. The extent to which a parent embodies their child's diabetes is dependent on family structure and the relationship between parent and child, and will affect the adolescent's self-management behaviour based on their expectations of parental input in the past. Evidence of the fundamental characteristics of complex systems in the lived experience themes is discussed as follows.

Normalisation

The process of normalisation within the family was underpinned by a network of complex family interactions. Figure 7.2 depicts the family as the central element integral to normalisation, as normalisation with the family influenced

Figure 7.2: Connectivity and feedback in the lived experience themes: Impact on self-management behaviour



behaviour and blood glucose control.

The introduction of the biomedical environment was characterised by control and order, with the function of regulating blood glucose. This new environment had a connective influence on surrounding environments, as the diabetes regimen intruded on usual day-to-day activities. Feedback from the biomedical environment affected self-management, based on medical authority and expertise, and the beneficial effect it had on maintaining order within the system. Non-adherence to the diabetes regime caused disorder to blood glucose levels, but had positive feedback in other areas of life for some adolescents. This indicates a need for balance in order to maintain an equilibrium state that an adolescent can cope with, based on their current beliefs and values. For example, in order to achieve balance in the social environment, some adolescents demonstrated 'preventive disclosing' (Goffman, 1962) of their diabetes to peers in order to avoid disorder resulting from the 'spontaneous disclosure' of their diabetes to others.

Feedback from external environments, for example the reactions of peers and teachers, affected how adolescents perceived their diabetes within these environments, which in turn affected their self-management behaviour. Negative feedback from peers and teachers inhibited the normalisation of T1D, thus inhibiting the emergence of a state within which T1D could be managed effectively.

Embodiment

Connectivity existed between the adolescents' body and mind, throughout the process of the integration of T1D within the self, and feedback underpinned the process of experimenting with the new 'self' within different environments. The process of controlling the taken-for-granted functioning of the pancreas introduced a new connectivity between the body and mind. This was demonstrated through the learning of bodily sensations of blood glucose fluctuations, and appropriate actions to deal with them.

Connectivity also existed between adolescents' incorporation of T1D within the self and their parents' embodiment of their disease. When parents embodied a child's diabetes, connectivity also existed between the parent's mind and the child's body. Parental embodiment was underpinned by a process of feedback to the adolescent, which reiterated the role of the parent caring for the child and restricted the development of autonomy. Historicity also influenced this process as it reflected the caring role mothers had established with their children over time. This supported the claim that some elements within an adolescent's complex system have a stronger connection than others. It was evident that parents had an important impact on adolescents' self-management behaviour, and mothers usually had more of an impact than fathers. Peers were another potentially strong connective relationship.

Experiential learning

Connectivity existed between the past, present and the future. Learning to live with T1D was a process reliant on past experiences, feedback from the outcomes of previous actions and beliefs, and beliefs about the outcomes of future actions. Feedback had the potential to change the beliefs and values of an adolescent. Historicity was important, as a greater depth and breadth of experience was gathered over time with diabetes, making self-management decisions easier based on expected outcomes.

Historicity also influenced chronic sorrow in parents. Grief reoccurred in response to stressors within the system, based on past experiences of their child's diagnosis. Negative feedback from the impact of hypo/hyperglycaemia influenced positive behaviour in parents, who were more prepared to deal with such situations in the future.

Relationships with significant others

Relationships with family, friends, peers, teachers and health professionals were interlinked. Relationships with peers were influenced by parental control and the allowing of freedom outside the family home. Lack of connectivity between the diabetes clinic and the family in the Ratledge family hindered the development of knowledge through a breakdown of communication and a lack of potential for feedback. Positive relationships between clinic staff and families were thus of utmost importance to fulfil the function of positive feedback for experiential learning from the biomedical environment.

Negative feedback from parental communications impacted self-management behaviour negatively. In the Salisbury family, Beth expected negative reactions to high blood glucose results from her parents, based on past experience and therefore avoided blood glucose testing. On the contrary, praise for a task well done gives adolescents and parents confidence in the ability of the adolescent to complete the task again, and initiates trust within the relationship (Granic and Patterson, 2006).

Negative feedback was also present in the discrimination that adolescents and parents experienced, or perceived they experienced. This influenced the way they expected others would react to their diabetes, and affected their behaviour accordingly. For example, Steven Gibbons' mother believed that he as not accepted into a football team because he had diabetes. Her perceptions of discrimination may have influenced his confidence in his ability the future. In the Pickering family, the negative experiences of James' father affected his parents' and his perceptions of diabetes. This ultimately affected their approach to self-management.

7.2 Response to stressors at a critical point

The second group of complexity principles describe the processes that occur when a system is pushed to a critical point (far-from-equilibrium) by an external or internal stressor.

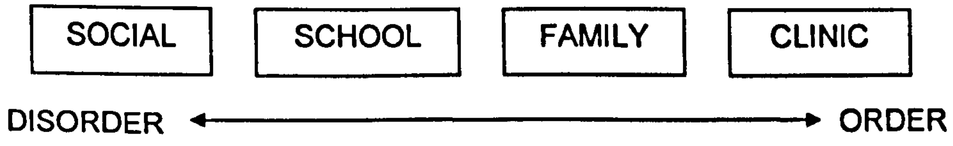
Far-from-equilibrium, exploring the space of possibilities and positive feedback

When a system functions at an equilibrium state, the system is running smoothly. For a complex system to be healthy, disruption must occur to force the system to adapt and change within its environment. When systems are pushed far-from-equilibrium, they are able to create new structures and order. The on-going functioning of a complex system is therefore characterised by periods of order and disorder (Mitleton-Kelly, 2003).

Following a diagnosis of T1D, a person's physical, social and mental state is pushed far away from established norms, procedures, ways of working and relating, and they have to adjust to this change and find new ways of 'being'. Similarly, when a person has lived with diabetes for a period of time, something may happen in 'real life' which disturbs their self-management practices, such as parent-adolescent conflict, exams at school, parental divorce, a bereavement, or a holiday abroad (Cooper and Geyer, 2007).

Elements within a complex system also differ in the levels of order and disorder they influence on the system. Interactions between different elements influence the level of equilibrium with the system. Figure 7.3 demonstrates the different degrees of order within the adolescents' surrounding environments. The biomedical environment was the most ordered, and had the function of controlling disorder through the implementation of the diabetes regimen. The family implemented a greater deal of order than the school and social environments, through monitoring and administering the regime recommended by the biomedical environment. The social and school environments were often consumed with barriers, instigating disorder to the self-management regime.

Figure 7.3: Ordered and disordered aspects of an adolescents' social environment



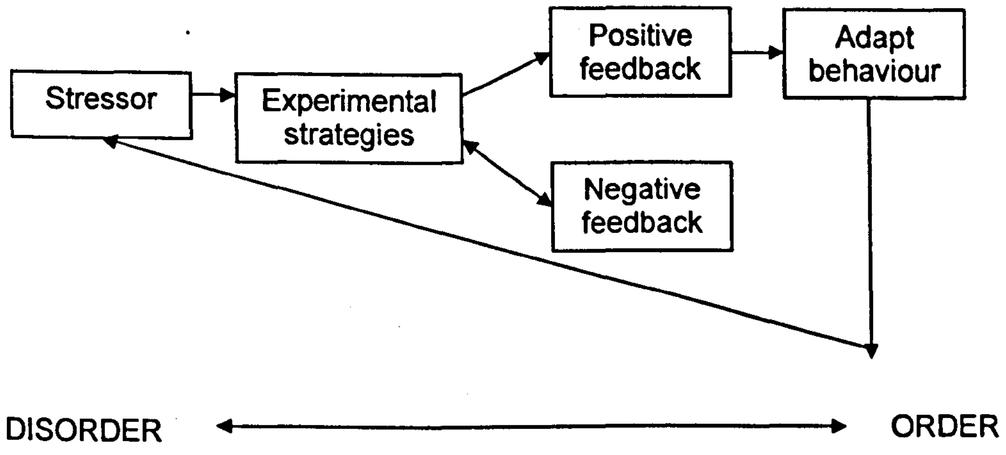
Exploring the space of possibilities involves exploring new options and ways of working and relating, eg. trying different ways to manage diabetes (feedback will play an integral part in this). 'Exaptation' is the emergence of a novel function of a part of the system in a new context (Mitleton-Kelly, 2003), i.e. a new strategy for management that works well for the individual. For example, experimenting with different insulin regimes may be necessary before one that suits the patient is found. The findings demonstrated that transference to the basal bolus regime instigated disorder to diabetes management for some adolescents who did not have the organisational skills, discipline or family support to manage it effectively, supporting the findings of other authors (Davidson et al 2004: Mortensen et al, 1998). Complexity science moves beyond this in providing a framework for understanding *why* certain regimes may not be effective for particular individuals. Sarah Morris and Russell Jones were both in a state of disorder following their transference to this regime, compounded by a number of psychosocial factors for both adolescents, including family structure, parenting style, peer relationships, maturity and perceptions of diabetes.

When such disorder occurs, new strategies for self-management must be explored in order to regain order, to avoid chaos in relation to blood glucose control. When a stressor pushes a complex system far-from-equilibrium, either new order is created or disorder occurs and the system enters a state of chaos. Behaviour in response to stressors is chosen through an exploration of the space of possibilities (different options in response to the stressor) and the influence of positive feedback in response to the various options. If an option receives negative feedback, more possibilities must be explored until a suitable path is chosen. Figure 7.4 demonstrates this process of transformative learning. Feedback may come directly from significant others or the outcomes of situations.

Response to stressors at a critical point in the lived experience themes

Within the four emerging themes, there was evidence of stressors pushing systems far-from-equilibrium, adolescents and parents exploring the space of possibilities in order to cope with the stressors, and positive feedback influencing the path taken in response to the stressor. It is worth noting that historicity and beliefs and values also underpin this process, as they influence the options that a person experiments with, as well as their interpretation of the feedback from these experiments.

Figure 7.4: Exploring the space of possibilities in response to stressors in a complex system



Normalisation

A diagnosis of T1D caused disruptions within the adolescents' surrounding environments, which disturbed the equilibrium of their system. In response to the disruption, adolescents explored different ways of coping with T1D in different environmental settings. For example, for Sarah Morris, following the diabetes regime and injecting insulin at the correct times warranted perceived negative feedback through the risk of hypoglycaemia. Not injecting insulin led to perceived positive feedback, as she was not at risk of spontaneous disclosure. This demonstrates that positive feedback does not necessarily produce a positive outcome for the system as a whole and is dependent on the phenomenological interpretation of the feedback, based on an individual's beliefs and values.

Families demonstrated adaptive changes to family roles and lifestyle practices, in order to cope with T1D. One of the main coping mechanisms was the implementation of routine within the family. In a situation of chaos and disorder, when the family system has been pushed far-from-equilibrium, routine established a degree of predictability which enabled the family to function at a state of regained equilibrium. In families with low routine, chaotic behaviour was apparent (eg. lack of meal time schedule, lack of meal planning, lack of parent-child quality time, lack of discipline) and this had an adverse effect on blood glucose control. When routine practices establish order, this is interpreted as positive feedback by the family, and therefore the practices are likely to be continually applied in order to maintain an equilibrium state.

The introduction of a step-parent into the Fletcher family demonstrated the family system being pushed far-from-equilibrium. The step-father explored different strategies of coping with his step-daughter's diabetes, some of which were disruptive. After exploring various ways of integration, a new state of order emerged in which he was able to assist and cope with his step-daughter's diabetes without causing disruptions to the family environment. The mother, daughter and step-father co-evolved to reach a new state of being, in response to the disruption caused by the introduction of a new member to the family.

The process of transition to adult services symbolised far-from-equilibrium, as families were threatened with uncertainty about care in the adult environment. This threat of disorder caused anxiety for parents and adolescents, as they felt that they were losing control of a part of their system they had come to rely on to provide predictability and care. The good relationships built up with clinic staff through positive feedback emphasised the threat of uncertainty.

Embodiment

A diagnosis of T1D pushed the complex system of adolescents far from its equilibrium state. Far-from-equilibrium describes the process of biographical disruption as defined by Bury (1982). Darrell Collier demonstrated exploring the space of possibilities as he adapted his lifestyle in response to his diabetes. His mother described Darrell's experimentation with glucose tablets during physical activity, as he looked for ways to control the unknown fluctuations of blood glucose within his body.

Further disruptions to equilibrium within the body included the experience of severe hypo/hyperglycaemic events. From a complexity perspective, unexpected events which contribute to the history of the complex system are termed 'frozen accidents' (Cooper and Geyer, 2007). Such events had the potential to alter adolescents' and parents' perceptions of diabetes and their future behaviour and strengthen the family unit through pushing the limits of its boundaries (Clawson, 1996).

Experiential learning

Exploring the space of possibilities and positive feedback encapsulates the process of experiential learning. Learning through experience was an integral part of learning to live with T1D. Parents learned about how to manage hypoglycaemia through exploring strategies when such events occurred. Other examples of experiential learning from the findings include adolescents experimenting with different treatments for mild hypoglycaemia and Neil Jeffs experimenting with different blood glucose management strategies whilst playing football. The mother of Holly Thomas also described her experimentation with strategies to accommodate her daughter's independence. Having more involvement in her daughter's self-management led to positive outcomes, as her HbA_{1c} level and self-esteem improved. Based on this feedback, the mother concluded that his was the most effective strategy to maintain good control of her daughter's diabetes.

Relationships with significant others

The Ratledge family explored the best ways of coping with Sean's diabetes. They interpreted advice from the clinic as negative for Sean's blood glucose control. When they implemented their own strategies of self-management, disorder was avoided and feedback was positive for the family, as outcomes were more predictable and enabled them to feel in control of their son's disease. However, this had a negative effect on the system as a whole, as the family where unable to manage the adolescent's blood glucose control to their full potential without the input of the clinic.

7.3 Adaptation

Exploring the space of possibilities leads to the adaptation of the system to the stressor, in the form of emergence, self-organisation and co-evolution. The ultimate goal of a complex system is the creation of new order which occurs through exploring the space of possibilities. Innovation takes place at a critical point where the existing order can no longer be sustained (Mitleton-Kelly, 2003).

Emergence

Emergence is the potential within complex systems to develop behaviours which create emergent properties (Sweeney, 2004). It occurs when interactions within the system create new organisational forms which become part of the history of individuals and affect their further evolution (Mitleton-Kelly, 2003). In a social context, individuals make decisions from several possible alternatives, which are constrained by the person's current state and the landscape the person occupies. The emergent behaviour is not a matter of chance, but a result of the selection of a particular set of choices, shaped by a person's history of past choices (Mitleton-Kelly, 2003). A person with T1D is constantly creating new levels of coping with their condition, based on their interactions with people and situations and their previous experiences. Emergence was key to the adaptation of living with T1D, as demonstrated in the lived experience themes.

Attractors, co-evolution and self-organisation

Attractors are varied movements which lead to change and are part of sets of patterns that hold the system together and prevent it from falling into total disorder (Luhman and Boje, 2001). For example, a clinician may advise an adolescent on how to improve diabetes control, involving a change in behaviour. The adolescent may implement this new behaviour for a number of weeks but then become attracted back to their old regime when it becomes difficult to manage, in order to avoid chaos. Thus, attractors can cause patterns of negative behaviour (Granic et al, 2006).

Co-evolution occurs when one domain in a system changes in the context of another (Mitleton-Kelly, 2003). For example a patient's self-management behaviour changes in relation to what is going on in another part of the system. The clinic may recommend a new self-management regime, which affects the adolescent's freedom in their social environment. Changes within the family, school or social environments may warrant changes to the diabetes regimen. The positive influence of normalisation within the family on the normalisation of T1D within other environments also demonstrates a process of co-evolution.

Self-organisation refers to the spontaneous coming together of parts in a system to create new order (Mitleton-Kelly, 2003). Self-organisation is the product of all of the interactions of the principles of a complex system, and is the outcome of the process of adaptation in the face of a disruption to the system. It cannot be predicted as there are too many potentially influential factors (Sweeney, 2004).

Adaptation in the lived experience themes

Normalisation

The concept of emergence relates to the normalisation of T1D with the family and other environments. Following the disruption of T1D to the family, establishing routine and parental input in self-management behaviour led to the emergence of new family environments within which T1D was normalised. Family environments continued to adapt to further stressors in order to maintain order within the family system. Overcoming barriers to self-management within the school and social environments enabled the system to move towards a more ordered state of control.

All human behaviour aims to maintain order within the social world, based on what a person perceives to be the norm in that environment. Within the social environment, an equilibrium state emerged when adolescents integrated with their peers and diabetes was accepted in the peer group. If there were barriers to normalisation within the peer group, the social environment remained in a state of disorder until these were overcome. The implementation of routine within the family, and the maintenance of high blood glucose to avoid hypoglycaemia acted as a protective strategies to maintain order and control and avoid chaos.

The diagnosis of T1D influenced how adolescents integrated with their home, school and social environments. Emma Bingham's mother described a period of disorder when she and her husband divorced. Emma's blood glucose control improved following this period of disruption, indicating that when the family environment settled, her blood glucose control in the biomedical environment returned to a more ordered state.

Attractor behaviour was evident in adolescents who preferred to manage their diabetes within the safe environment of the home, rather than push their boundaries in external environments. The twice daily regime acted as an attractor for diabetes management during school. The long-acting insulin dose enabled adolescents to go through the whole school day without needing an injection, meaning that self-management could remain within the safe environment of the home. However, staying on this regime could have negative implications for independence in the future, in preventing the emergence of new coping states.

Embodiment

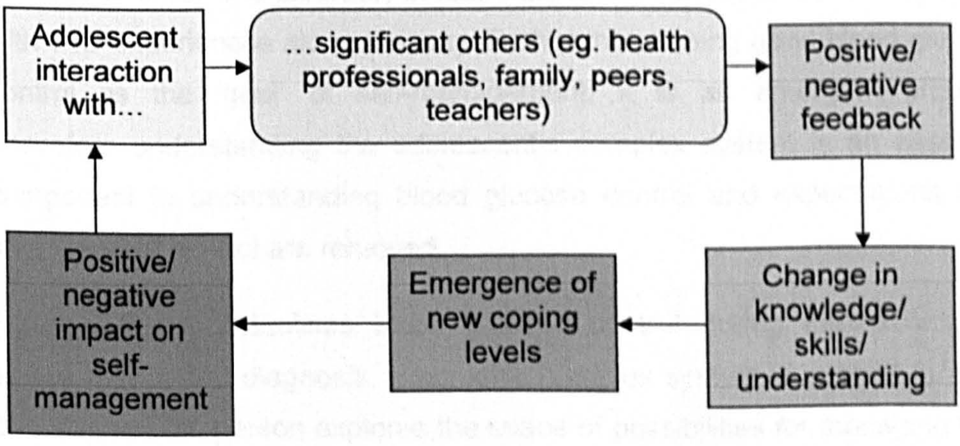
Integration of T1D within the self and experiential learning were on-going developmental processes. New levels of integration and coping emerged through self-organisation when interactions between elements instigated feedback reactions. The outcome of the process of redefining the self in response to T1D is the emergence of an adapted, 'transformed' self which incorporates the bodily existence of T1D. Changing taken-for-granted assumptions and learning about how the diabetes body behaves are explored until the adolescent reaches a state of being which he or she is comfortable with and able to integrate within daily life. Further disruptions, such as hyper/hypoglycaemic events may bring T1D to the forefront and require further adaptation strategies in response.

Parental embodiment demonstrated a process of co-evolution between parent and adolescent complex systems. Attractors were apparent when it was more comfortable for mothers to continue embodying their child's diabetes rather than risk the disorder that may follow should they step back. Another example was the ways in which parents approached complications with adolescents. They were wary of causing disruption to their child's belief system with the burden of complications and tended to broach the subject only if they felt it necessary (ie. if blood glucose control was poor).

Experiential learning

Experiential learning is underpinned by the emergence of new knowledge and coping strategies based on feedback about past experiences. Therefore learning is an emergent and on-going process throughout the life with T1D. Knowledge can never reach an end-point, as future experiences are unpredictable. For example, Figure 7.5 demonstrates how interactions (connectivity) between different elements in a patient's social world will influence learning and understanding. The adolescent receives positive or negative feedback from such interactions which may lead to a change in behaviour that has a positive or negative impact on self-management, and new levels of coping emerge. Once a new level of coping emerges, interaction between elements is ongoing and the process of emergence continues.

Figure 7.5: The emergence of knowledge as a complex system



Relationships with significant others

Relationships with significant others are constantly emerging. For example, the findings demonstrated that the influence of parenting style leads to the emergence of certain behavioural characteristics in adolescents, and that positive feedback from peers can lead to the emergence of the normalisation of T1D within the social environment. Adolescent and parent complex systems evolved within the contexts of each other, in a process of co-evolution underpinned by parent-child relationships. This was evident in the conflict caused by the miscarried helping of parents as a result of underlying anxieties about their child's future health, brought to the surface by the adolescent's need for independence and participation in new activities which push the boundaries of normal self-management.

The influence of attractors was evident in the Ratledge family. When the health professional's advice did not appear to be effective, the family reverted back to employing the self-management factors which they knew to be effective. The influence of attractors may prevent chaos within the system in the short term, but long term may have a negative effect on experiential learning, as it is such disruptions to equilibrium which force the system to change and adapt to its environment to its full potential.

7.4 'Zones of good control'

'Fitness landscapes' were introduced in Chapter 3, to conceptualise the life-long journey of living with T1D. They represent the highs and lows of life (periods of order and disorder) in response to the various stressors a person with T1D experiences along the way. Rather than seeing good blood glucose control as the 'goal' of self-management, it is an emergent product. Therefore understanding the adolescent's complex system is an essential component to understanding blood glucose control and expectations of a static level of control are removed.

Figure 7.6 conceptualises blood glucose control during adolescence. It shows that at first diagnosis, a person's complex system is pushed far-from equilibrium. The person explores the space of possibilities for managing their disease through interaction with significant others within their surrounding environments. When self-organisation occurs as a result of positive feedback (boundaries are broken down between the elements within the environments) a period of 'good self-management' may then occur. However this is not static as the cycle of feedback and emergence continues (interaction between the elements in the system) in response to further stressors. Boundaries and conflicts may form again as random life events occur, leading to disruption and the system being pushed further from equilibrium on an irregular basis. This is supported by findings (Holt, 2002; Kroll, 1999), that although biological reactions to blood glucose are largely predictable in patients with T1D, they are individualised and unpredictable to a large extent.

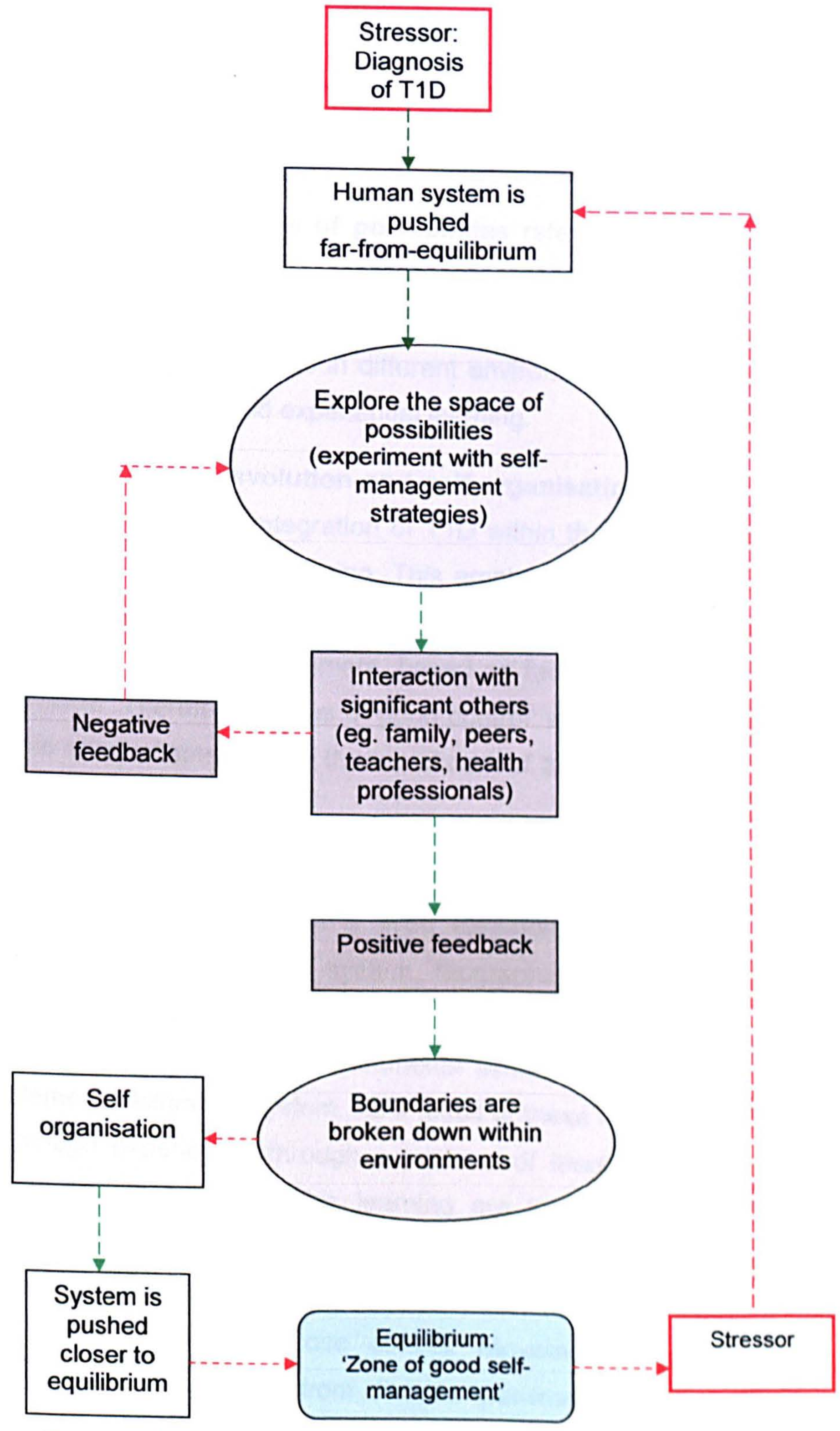
7.5 Summary

In this chapter, I aimed to explore the applicability of the principles of complexity science to the lived experience of T1D in adolescence. I have demonstrated that the principles of complexity science do have relevance to the lived experience findings. The association between the phenomenon of living with T1D in adolescence and the behaviour of complex system is summarised as follows.

The principle of **connectivity** recognised the interactions between the psychosocial elements in a young person's social world, in support of previous findings that there are many influential factors on the outcome of blood glucose control. This provides a framework for acknowledging the connections between these different psychosocial factors. Connective relationships were identified within each of the lived experience constructs. Each adolescent existed within a unique complex system and their self-management behaviours were therefore unique based on interactions within the system.

Historicity, feedback and beliefs and values underpinned the process of learning to live with T1D, and the ongoing adaptation to changes in the adolescent's surrounding environment. Interactions between the different elements within adolescents' social worlds produced feedback which was

Figure 7.6: Zones of good control in the self-management of T1D



Key: - - → **Moving towards equilibrium**

- - → **Moving away from equilibrium**

interpreted based on beliefs and values, influenced future actions and contributed to the history of the system.

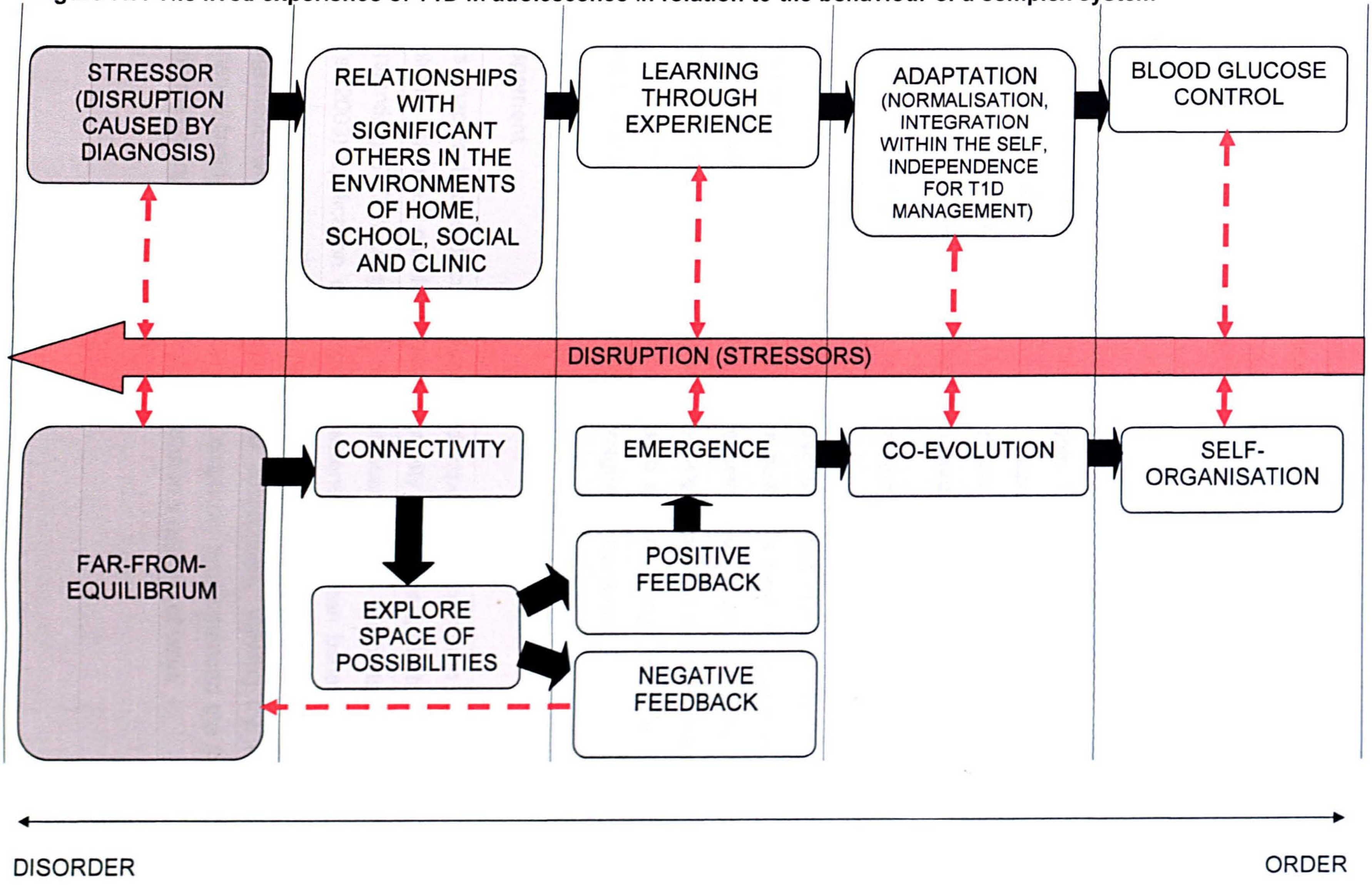
Far-from-equilibrium conceptualised the disruption caused by a diagnosis of T1D, and further disruptions caused by living with the disease along the way, including blood glucose fluctuations and adjusting to new environments.

Exploring the space of possibilities referenced the process of trial and error inherent in learning to live with T1D. The experimentation of different selves in integrating T1D within the self and experimenting with different self-management strategies in different environments to facilitate the processes of normalisation and experiential learning.

Emergence, co-evolution and self-organisation defined the outcomes of normalisation, the integration of T1D within the self, and knowledge gained through experiential learning. This emphasises the ongoing nature of these phenomena and recognises that a person with T1D is constantly adapting to changes in their environment, based on feedback from elements within the system. Therefore, 'zones of good control' will emerge and retract based on the affect of stressors on the equilibrium of the adolescent's complex system.

The relationship between complexity science and the lived experience findings is further depicted in Figure 7.7, which shows the adaptation process following diagnosis from a lived experience perspective, alongside the behaviour of a complex system. Biographical disruption represents a far-from-equilibrium state. Following diagnosis, interactions with significant others within different environments symbolises the connectivity between elements within the system. As a result of these interactions, learning occurs through experience, through a process of feedback and emergence. The emergent products of this learning are the normalisation of T1D within different environments, the integration of T1D within the self and independence for T1D management. These facets co-evolve to influence the outcome of blood glucose control. Movement through this process is symbolised by a move from disorder (far-from-equilibrium at diagnosis) to order (self-organisation). Further disruptions can occur within the system at any time in the process, to revert the system back to a far-from-equilibrium

Figure 7.7: The lived experience of T1D in adolescence in relation to the behaviour of a complex system



state (disorder), represented by the large red arrow. Some individuals may never reach a self-organised state and remain at the disordered end of the scale for long periods of time, if disruptions continue to occur. The turbulent nature of adolescence means that this is likely for some adolescents during this life stage. Positive interactions and feedback from relationships with significant others and the surrounding environment are key to moving towards a more ordered system.

7.6 Conclusion

The lived experience findings gave an insight into the lives of twenty adolescents living with T1D and their parents. The phenomenon emerged as an on-going process of adaptation to the diagnosis of T1D, underpinned by social interactions within the environments adolescents inhabit. The processes of normalisation and integration were individualised and

dependent on the psychosocial factors making up an adolescent's social world, including family structure, parent coping and grief, parenting style, peer relationships, relationships with clinic staff and diabetes, care and support within school. These relationships built up a past of experience for adolescents with T1D, which affected the self-management decisions they made in the future based on what was *meaningful* to them at that moment in time. Further experience had the potential to alter meaning over time, thus leading to a change in priority and self-management behaviour.

The value of complexity science to understanding adolescent diabetes management

In this chapter, I have discussed the lived experience findings in relation to complexity science. I conclude that complexity science is advantageous for understanding T1D management in adolescence. This supports Mitleton-Kelly's (2003) application of complexity science to human behaviour, and Cooper and Geyer's (2007) application of complexity science to T1D management, with particular reference to adolescents. Viewing the lived experience findings through the lens of complexity has enhanced the lived experience findings beyond their original form in a number of ways.

First of all, complexity science emphasises that living with T1D in adolescence is individualised and unique for every young person and their family members. Although many aspects of T1D may be ordered (eg. the self-management regime) outcomes are unpredictable to a large extent. It recognises the connectivity between the four lived experience themes. Normalisation, integration, learning through experience and relationships with significant others are not homogenous concepts but rather indicate the nature of the underlying processes of living with diabetes for every individual. The experience of each construct by individuals is defined by their unique complex system.

Viewed through the lens of complexity, a diagnosis of T1D causes chaos and disorder within the body, when the pancreas fails to function and regaining control of blood glucose symbolises order. The experience of living with T1D therefore represents a person's journey between the states of order and disorder as they learn about how to manage their disease in the face of unknown situations. The adjustment processes inherent in normalisation, embodiment and learning through experience never reach an end-point, but are ongoing in response to further disturbances to equilibrium. The outcome of blood glucose control is underpinned by complex interactions within the adolescent system, and the relationship of these interactions to the adolescent's history and context, through the feedback they receive.

Disruptions (for example hypoglycaemia, entering a new social environment, puberty, family conflict) are a normal part of life. A system has to be pushed to its limits in order to change. Adaptation to disruptions improves the overall fitness of a complex system, and therefore 'mistakes' are essential in the process of experiential learning. The 'meaningfulness' of self-management behaviour is open to change at any time, as past experiences build up and influence future orientation. Education has most relevance following an event which upset the equilibrium of a person's social world.

To conclude, viewing the lived experience through the complexity lens shifts the interpretation of the meaning of living with T1D from a developmental process with an end-point (i.e. control), to an on-going journey of highs and lows underpinned by rich and individualised learning processes. It is a valuable framework through which to translate the phenomenological lived experience of adolescent diabetes into practice, as it provides a model which embraces the unpredictability and individuality of diabetes management for young people. Chapter 8 notes the implications of these findings for clinical care, policy and future research, describes the strengths and limitations of the study, and draws final conclusions.

Chapter 8: Conclusions and recommendations for policy and practice

Introduction

I open this final chapter with a summary of the thesis. I the address the contribution this study has made to knowledge about the lived experience of T1D in adolescence and the theoretical application of complexity science to T1D. In the final section, I explore the implications of the findings for policy, clinical practice and further research.

8.1 Summary of the thesis

My primary research aim was to explore the lived experiences of adolescents with T1D and their parents. I took an interpretive phenomenological approach, which allowed me to explore the taken-for granted lifeworlds of the participants (twenty adolescents with T1D and twenty-seven parents). Within this epistemological framework, I employed a novel, multi-method, primarily qualitative research design to gather rich, in-depth data about what it is like to live with T1D, based on the assumption that the way humans interpret their experiences and the experiences of others is influenced by their individual context and history (the lifeworld). My central method, hermeneutic interviews with adolescents, aimed to explore the lived experiences of adolescents with T1D. I employed three additional methods to provide contextual data (CASI Diary Tool, hermeneutic interviews with parents and background data supplied by the clinic), along with facilitating triangulation. I also facilitated triangulation through discussion of the findings in relation to previous research.

I introduced complexity science at the beginning of the thesis, as a theoretical starting point for understanding the management of T1D. Although metaphorically applicable, it lacked validation as an approach to understanding T1D management and as a research methodology. Thus, my secondary research aim was to investigate the applicability of complexity science as a theoretical framework for understanding adolescent T1D management. I discussed the principles of complexity science in relation to the interpretive phenomenological findings. I concluded that Complexity science does have relevance for understanding the management of T1D in adolescence. Viewing the lived experience findings through the lens of complexity provided a framework for drawing together the multi-faceted and individual nature of blood glucose control, and provides a framework that can be used in practice to account for the individuality of patient need. This highlights the need for a new approach and way of understanding diabetes care for young people, with the aim of delivering meaningful, individualised education.

8.2 The experience of living with T1D in adolescence

Addressing a research gap

I began this thesis by outlining a need to understand why metabolic control deteriorates in adolescents with T1D, in order to improve health outcomes in later life through reducing the risks of complications. In Chapter 1, I presented the body of literature addressing the biomedical management of T1D in adolescence, in order to explore factors influencing deteriorating control. In Chapter 2, I reported the results of a systematic review exploring qualitative studies of T1D in adolescence. I also addressed the wider psychosocial literature in relation to the themes emerging from the synthesis of findings in the review. I concluded that social relationships and the different environments adolescents inhabit influence independence for T1D management in adolescence. My review also highlighted a need for further qualitative research to explore adolescents' experiences of living with T1D. This study addressed this research gap, by further investigating the social relationships and environments of adolescents and their parents with T1D.

The quality appraisal I conducted in the systematic review highlighted a need for high-quality qualitative research, due to a paucity of epistemologically grounded qualitative research in this subject area internationally. I also defined a specific need for research in the UK, as only one qualitative study was conducted in the UK in the past ten years and this focused on an evaluation of an educational programme rather than adolescents' lived experiences (Waller et al, 2005). Poor quality was due to a number of methodological limitations, which I addressed in this study. Table 8.1 pinpoints the main methodological limitations of the studies in the systematic review and demonstrates how this study filled these highlighted gaps, thus contributing positively to the quality of research in this subject area as strengthening the findings of this study.

Table 8.1: Methodological gaps addressed in the study

Systematic review: Methodological limitations	**How the limitations were addressed in this study**
The majority of studies did not ground their research within qualitative epistemological tradition	This study was grounded in the epistemological tradition of interpretive phenomenology
The majority of studies did not employ an underpinning theoretical framework	This study was underpinned by the theoretical paradigm of complexity science
Researcher reflexivity was under-reported in the majority of studies	Interpretive phenomenology recognises the influence of the researcher's lifeworld on their interpretation of the experiences of participants
Only two studies incorporated triangulation in the form of multiple methods	An original, multi-method approach was employed to facilitate triangulation
Member checking to reduce interpretation bias was scarce	Focus groups were conducted to ensure member-checking of the findings

Contribution to knowledge

In the systematic review, I concluded that social relationships are a key factor in the management of T1D. This study added to these findings, as it has provided in-depth data on how these relationships manifest within the family and other environments to influence self-management and blood glucose control. The biomedical literature review I conducted in Chapter 1 highlighted the reductionist view of T1D. Exploring the lived experiences of adolescents and their parents thus led to an in-depth understanding of the wider psychosocial underpinnings of adherence and blood glucose control. Adaptation was key to learning to live with T1D in the following ways.

Family adaptation underpinned a process of normalisation which facilitated self-management. Where normalisation was scarce in external environments, barriers existed which inhibited adolescents' self-management and independence.

Adolescents and parents had to redefine themselves within society following the disruption of T1D, as the function of adolescent body was redefined as the function of the pancreas had to be controlled by the mind. Parents often took on this responsibility through parental embodiment.

Learning was an ongoing process underpinned by past experiences and future orientation. This meant that all self-management behaviour was underpinned by meaningful action, which highlighted a need to access what is meaningful for adolescents in order to better understand self-management behaviour.

Epistemological strengths and limitations

My findings must be viewed alongside the following epistemological and methodological strengths and limitations. Taking an interpretive phenomenological approach strengthened this study as it allowed for the in-depth exploration of the lifeworlds of adolescents and their parents, in order to understand the phenomenon of living with T1D in adolescence. Gathering the primary data in this way allowed for a rich interpretation of what it is like to live with diabetes in adolescence Hermeneutic interviews are primarily unstructured and this allows the participant to describe their experience from their own view-point. However, as myself and the participant both exist within a lifeworld, the products of the interview encounters were the result of an interaction between myself and the participants, underpinned by our individual contexts and histories. My interpretation of their experiences was therefore based on my life experience, which allowed me to interpret the data in a meaningful way. Personal histories continually develop over time. This means that the findings are my interpretation of the experience of living with T1D for this group of individuals at the moment in time the interview was conducted. Thus, they give a reflective 'snap shot' of the experience of T1D in adolescence as it was lived through by this particular population. This could be viewed as a limitation, as transferability of the findings to other populations is not possible.

My findings are grounded within a unique and original multi-method approach, which served to strengthen the study through methodological triangulation. This provided contextual data within which to situate the lived experience data gathered through hermeneutic interviews. My methods included the development of a novel self-management diary tool, which has the potential to be developed as a motivational self-management aid, based on the participants' evaluation. The contextual data I gathered facilitated in-depth descriptions of participants, their family structure and self-management behaviour, and supported transparency. The rigorous seven-step analysis process I employed minimised interpretation bias. Triangulation of the findings with previous literature also grounded my interpretation within theory and previous research work. I reached data saturation was reached within the sample. The theory generated through the rigorous methodology applied is therefore highly applicable beyond this sample of families and within clinical practice.

8.3 The application of complexity science to T1D in adolescence

Addressing a research gap

Complexity science is a theoretical paradigm which views the world as a network of complex adaptive systems. Conscious complexity sets humans apart from other complex systems, defined by humans' ability to interpret experiences and shape future behaviour. Complexity science has been widely applied within the humanities disciplines, particularly in the exploration of family systems and the health care and management literature, albeit metaphorically. Recently, it has been applied to the management of T1D (Cooper and Geyer, 2007). From this approach, living with T1D is viewed as an individualised learning process. The outcome of blood glucose control cannot be attained through biomedical treatment alone.

Complexity science provided a relevant starting point for this study, as the literature review concluded that there are many interacting factors which influence the outcome of blood glucose control in a person with T1D. Complexity science recognises that the self-management of T1D is an individual, on-going and often chaotic process, and that the current biomedical model of diabetes care is inadequate to incorporate the variety of influential factors. It therefore provides a theoretical framework which has the potential to encompass the many theoretical approaches to T1D in adolescence defined in the literature.

Although a relevant starting point for the qualitative exploration of the lived experience of T1D in adolescence, criticisms of complexity science as a purely metaphorical analogy meant that it was not validated as a research methodology. This identified a need for empirical research to validate or invalidate the application of complexity science to understanding the management of T1D. I addressed this gap by employing a validated epistemological approach (interpretive phenomenology) to data collection and analysis, which was effective in collecting rich data which could be explored in relation to Complexity science. As an epistemology, interpretive phenomenology is underpinned by the belief that all human knowledge is created through the process of interpretation. It therefore enabled me to access the conscious complexity of human behaviour and gather rich, lived experience data. It also privileged individual experiences in the first stages of data analysis, which provided an opportunity to explore the adolescents' and parents' social worlds as individual complex systems. I was then able to analyse this data in relation to the principles of complex systems defined by Mitleton-Kelly (2003), in order to define its relevance to the real lived experiences of adolescents with T1D.

Contribution to knowledge

In this study, I have validated complexity science as a theoretical paradigm, through empirical data gathered through a grounded epistemological approach. This is a ground-breaking step towards moving beyond purely metaphorical analogy, towards establishing complexity science as a methodological approach in its own right. Viewing the lived experience findings through the lens of complexity enabled me to gain a more holistic understanding of the findings and of the connective relationships between the emerging themes. Thus, I believe it enabled a deeper understanding of the processes of adaptation (normalisation, embodiment and learning) and the recognition that complex feedback interactions within an adolescent's complex system affect the self-management practices that emerge from these adaptation processes. The individual nature of each adolescent's context and history are recognised as influential to self-management behaviour, as well as the on-going process of learning through experience which underpins self-management behaviour.

Theoretical strengths and limitations

The strength of this study is that it represents a unique endeavour to ground the metaphorical application of complexity science to human behaviour within empirical qualitative data. This is beneficial not only for the application of complexity science to understanding the management of T1D, but for understanding human behaviour in a wider context. However, this contribution must be viewed alongside the limitation that the lived experience findings were a context-specific interpretation of T1D in adolescence by myself alone, and there is therefore a need to explore the application of complexity science to T1D in other settings. Although I strived for impartiality when exploring the relevance of complexity science to the lived experience findings, it is possible that I was influenced in my analysis, as complexity science had been explored as a starting point for the research study. However, the rigorous data collection and analysis methods employed ensured that the lived experiences of adolescents and parents were privileged throughout the research process.

8.4 Implications for policy

The lived experience findings highlighted a need for improved diabetes care in schools for adolescents with T1D, based on the finding that the school environment often held barriers to self-management. A recent qualitative study of twenty parents of children and young people with T1D in the UK also concluded that diabetes care plans should be provided for every child with T1D, and guidance and training for blood glucose testing in schools (Wilson and Beskine, 2007). This issue is currently being addressed by the Schools (Health Support) Bill (2009). Schools are required to produce and implement medical conditions policies and school staff will receive appropriate support and training to support children with health conditions, overseen by NHS bodies, local authorities and primary care trusts. This is a step towards improving diabetes care for children in schools. However the findings from this study also highlighted the need for peer education within the school environment, in order to break down barriers to normalisation, and improve independence for self-management at school.

Viewing diabetes management from a complexity perspective encourages focusing on the patient as a being within a complex and individual social world, rather than a person who is failing to attain the recommended blood glucose levels set within the biomedical environment. This has implications for both policy and clinical practice. Government targets are unachievable if the way in which patients are encouraged to meet these targets is in a linear and orderly fashion which does not reflect the unpredictability of real life. Until the gap is bridged between the biomedical model of T1D and reality of the integration of T1D within the interrelated complex systems of real life, the translation of guidelines into practice may never happen.

8.5 Implications for clinical practice

Blood glucose control

Blood glucose control in the sample was poor, with only 10% achieving the recommended level of under 7.5%. This reflected national statistics, suggesting that the current biomedical model of diabetes care is not effective in improving blood glucose control in adolescence. To fully understand this requires acknowledging all of the connective relationships between elements in a young person's social world. Predicting the outcome of the interactions between elements is a near impossible task, but if the basic connections can be mapped, this can form a basis for better understanding of what is at stake for that adolescent. This approach encourages health professionals to take a more holistic view of the patient, and not to omit any potential influences on blood glucose control from their surrounding environment, no matter how insignificant they may seem. This was emphasised by the finding that some adolescents manipulated the basal bolus regime in relation to their structures of meaning, supporting the claim that health professionals must take caution when prescribing this regime to adolescents. Health professionals should also take account of the impact of family structure and parenting styles on adolescents' abilities to self-manage their diabetes, particularly with regard to single parent families were parenting stress is often high in the absence of the support of a partner. This suggests a need for education which focuses on the family as a learning unit.

Transition services

The Department of Health (2001, 2004) recommends that all young people with diabetes should experience a smooth transition to adult care as a guided, educational and therapeutic process. The findings highlighted a need for a transition clinic for patients between the ages of sixteen and eighteen to bridge the gap between adult and child-centred care services, as anxiety about transition was apparent for both adolescents and parents. A smooth transition is important as clinic non-attendance increases in late adolescence, leading to an increase in HbA_{1c} (Kipps et al, 2002; Bryden et al, 2001; Scott and Donnelly, 2001). The main anxiety for adolescents and parents was the change in environment from child-centred to adult centred care, and the loss of familiarity it would bring. Jones and Hamilton (2008) recommend that the transition process should begin early, awareness of the process should increase, on-going education programmes should be provided, and the role of a nurse coordinator should be developed. Alongside this, these findings suggest that a transition clinic ran by paediatric nurses but held at the adult hospital may be beneficial for adolescents. This would introduce them to the environment of the adult hospital whilst maintaining the care ethic of the adolescent clinic up until the age of 18. This would minimise the disrupting effect of transition for families and may improve HbA_{1c} (Logan et al, 2008).

Delivering patient education

Complexity science has implications for the way in which education is delivered within the clinical setting. The findings demonstrated that health professionals assist with the process of experiential learning through providing guidance to the way in which the adolescent interprets his/her experience. Their advice is important, but health professionals are just one factor in the complex system of an adolescent's social world. Therefore the current 'top-down' approach (health professional as expert, patient as listener) to patient education is not effective as there are many other feedback influences that will affect the path an adolescent takes.

Relationships between families and health professionals were key to the successful delivery of diabetes education to adolescents, as the findings demonstrated that parents were key in the process of reflection inherent in experiential learning during adolescence. Advice received in clinic does not always translate to real life situations, illuminating a discrepancy between the ordered biomedical environment and the complexity of 'real life'. The adoption of a complexity approach to care may work towards breaking down these barriers. There is also a need for health professionals to find a balance between consulting with parents and encouraging independence in adolescents, in order to avoid parents feeling undermined. Activity weekends away with the hospital were beneficial for promoting positive relationships between staff and adolescents, and also promoted the development of autonomy.

The nurses strived to employ a holistic approach to patient care, manifested in their positive relationships with the families. This already moves beyond the traditional biomedical approach, but is constrained by the lack of resources and guidelines which do not allow access the individual complexity of each patient. Integrating complexity science within clinical care has the potential to enable their holistic approach to thrive. If care is assessed on the merit of individual psychosocial outcomes and more than just HbA1c, their holistic approach to care will have maximum impact for patients and their families.

It was apparent that parents did not absorb information regarding the treatment of hypo/hyperglycaemia until after the event occurred, suggesting that there was a 'right' time for them to learn and that information was better absorbed when it had meaning in relation to their experience. This indicates that to better understand self-management in adolescence, we need to explore what is meaningful to adolescents with T1D. Education can address areas where knowledge is lacking in order to influence meaning, however it is often only when a crisis occurs that meaning changes for adolescents, as they redefine the consequences of their actions in order to stabilise their social world. This calls for a different approach to diabetes care, in which blood glucose levels are not the main target. Rather, the process of experiential learning throughout the period of adolescence should be monitored and reflected on, and opportunities to deliver education after disruptive events should be embraced.

Parents would benefit from education courses which are structured around the duration of their child's diabetes, and which provide a discussion forum to discuss experiences and gain guidance from health professionals. Such a forum would provide particular support to parents who did not live with their child full-time (such as fathers who have separated from their child's mother), and new step-parents entering a family. Health professionals are working within a tightly restrained NHS, where resources and time are very limited. Therefore in order to embrace complexity within the clinical setting, there is a need for individual needs- assessed education for young people with T1D. This will ensure that the education they receive within the clinical setting is meaningful in relation to their past experiences and developmental level, and focuses on their knowledge gaps.

Multidisciplinary care

The findings demonstrated that living with T1D is an ongoing process of adaptation. Following diagnosis, adolescents and parents experience self-adjustment in response to the demands of controlling the diabetes body. This can lead to anxiety and confidence issues for adolescents and parents. Although NICE (2004) recommends that diabetes care teams should have appropriate access to mental health professionals, it is essential that psychological care is provided to adolescents and families as an integrated component of care, rather than as crisis support. This would serve to minimise the impact of disruptive events in relation to the psychological impact of T1D and maintain equilibrium within the complex systems of adolescents and parents.

The findings demonstrated that family structure and parenting style were key to the management of T1D in adolescence. Parental embodiment hindered the process of autonomy development in some adolescents. Parents found it difficult to let go of the responsibility they held for their child's health, and adolescents were restricted in the process of learning through their experiences when parents took control. Family therapy may benefit families where parental embodiment is restricting autonomy. Parental embodiment takes away these disruptions and allows the adolescent to function in state of order controlled by his or parents. However, if the parent was to be removed from the management of their diabetes, their system would plunge into utter chaos without the learned tools for independent self-management. Therefore it is important for the parent to step back and let their child learn for themselves. Parents should be encouraged to view their child's diabetes from a complexity rather than a biomedical perspective. This would allow them to recognise that some disorder has positive implications for their adolescent child, as it allows them to learn through their mistakes.

The poor fruit and vegetable intake and physical activity levels in the sample also highlighted the importance of input from a dietician in the care of adolescents with T1D. However, all adolescents in the study were receiving this support at every clinic visit, suggesting that dietetic input currently lacks meaning for young people, given that there are other psychosocial influences affecting these practices.

8.6 Recommendations for further work

The findings of this study have generated a number of recommendations for future work. The family environment emerged as key to understanding the process of normalisation of T1D. Siblings also had a role to play within the family environment, and the diagnosis of a sibling with T1D disrupts the family environment for the siblings as well as parents and adolescents. Including siblings may have given a different view of adaptation within the family environment and therefore further studies of lived experiences would benefit from including siblings. Further qualitative work is also required to investigate the impact of family types and structure on the management of T1D. A comparative study would also provide the opportunity to investigate the process of normalisation within the family in more depth. It would also be interesting to explore differences in parent-adolescent relationships and parental embodiment in relation to gender dyads. The CASI diary tool was a novel approach to collecting data on the self-management decisions of adolescents with T1D developed in this study. The tool warrants further development as a motivational self-management aid for adolescents, based on evaluation data collected from the adolescents in this study.

Further investigation of the way adolescents self-manage their diabetes in environments external to the family is also required. Interviews with health professionals to explore their experiences of providing care to adolescents within the biomedical framework have been conducted and analysed and are currently awaiting synthesis with the data from this study. There is also a need to explore ways in which complexity science can be implemented to shape and improve biomedical care.

Ethnographic research in schools and adolescents' social environments has the potential to lead to an improved understanding of the barriers to self-management which exist within these environmental settings. It would also be beneficial to explore diet and frequency of physical activity in more depth and in relation to quantitative data depicting blood glucose levels, as these factors have been shown to have a positive influence on blood glucose control (Overby et al, 2009; Valerio et al 2007, Bernardini, 2004). Alcohol intake in adolescents with T1D and the effects of this on blood glucose control also merits further investigation. The findings demonstrated that a number of adolescents were drinking alcohol on a regular basis, but there was a paucity of literature on this subject.

This study has implemented a step towards the validation of complexity science as a tool to understand the management of T1D and also human behaviour in general. I have provided a basis for the development of a methodological approach which combines interpretive phenomenology with complexity science, in the study of human complex systems. This methodology was shown to be effective in generating rich data which revealed the conscious complexity of living with diabetes for adolescents and parents. Further work is required to validate complexity science with reference to other phenomena relating to human behaviour (for example other chronic illnesses and family systems) and in relation to other epistemological frameworks, if it is to move beyond metaphorical application to a science in its own right.

8.7 Conclusions

The study has explored the lived experiences of adolescents with T1D and their parents, utilising a unique, multi-method, qualitative approach underpinned by interpretive phenomenology. I took a pioneering move towards to the validation of complexity science to the understanding of T1D management, through exploring the interpretive phenomenological findings in relation to the principles of complexity science.

This has generated revealed ground-breaking evidence that the experience of living with T1D in adolescence reflects the behaviour of a complex system. The processes of self and environmental adaptation and learning emerged from the lived experience findings, as the essence of the experience of living with T1D. Viewing these findings through the lens of complexity science highlighted the individuality of each adolescent's experience and led to the recognition that the processes of adaptation defined in the lived experience findings were underpinned by complex feedback interactions within adolescents' complex systems.

This confirms that the outcome of blood glucose control can not be understood through the current biomedical model of care, as it does not take into account this multitude of interacting factors. Therefore, there are gaps in diabetes education for adolescents, as the current model does not account for what is 'meaningful' to them. From a complexity perspective, learning through experience is essential for ongoing adaptation to new situations, relationships and environments. This encourages a shift away from a focus on the outcome of blood glucose control, to a focus on balancing T1D with many other meaningful elements of life during adolescence.

Taking this view-point within the clinical setting will enable an approach to diabetes care which adolescents and their families can translate into 'real life'. This can be achieved through adolescents defining their own learning needs, in relation to their individual complex systems and developmental level. Further work is currently being undertaken which aims to design a computerised individual learning needs assessment tool for adolescents with T1D. It will provide an alternative environment for learning outside the clinical setting by directing adolescents to learning resources relevant to their unique experience of living with T1D. This has the potential to shift the focus of care towards a complexity model, and greatly improve blood glucose outcomes for young people with T1D.

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Appendices

Appendix I: Recruitment packs sent to families

(Hospital Logo/Address)

"Type 1 Diabetes and Adolescence: An Exploration of Lived Experiences."

(*Date*)

Dear Parent/Guardian,

A research study is being carried out in the diabetes clinic at *(Hospital)* by Dr. Helen Cooper, Dr. Beth Milton and Joy Spencer (a PhD student), who are based at the University of Liverpool. The aim of the study is to find out what it is like to live as an adolescent (age 13-16) with diabetes and what it is like for parents or guardians to care for a young person with diabetes.

As your child attends the diabetes clinic at *(Hospital)*, I would like to invite both them and you to consider participating in the study. It is hoped that the results of the study will help to improve services for young people with diabetes in the future.

Please find enclosed 2 information sheets, one for parents/guardians and one for your son/daughter. These information sheets explain to you what the study is about and what will be involved if you decide to take part. Please read through them carefully.

If you decide that you and your child would like to take part in the study, please complete the consent forms enclosed and return them in the pre-paid envelope by *(date)*. If there are 2 parents or guardians in your family, we would ideally like both to take part. **Once all replies from families wishing to take part have been received, twenty families will be selected to**

participate in the research. You will be notified within two weeks whether or not you have been selected to take part.

Thank you for taking the time to read this letter and we hope to hear from you soon. If you have any queries please feel free to contact *(Diabetes Nurse Specialist)* on *(telephone number)* or Joy Spencer (Researcher) on *(telephone number)*.

Yours sincerely,

Diabetes Nurse Specialist
Paediatrician

Diabetes Specialist

"Type 1 Diabetes and Adolescence: An Exploration of Lived Experiences"

TAKING PART IN RESEARCH

INFORMATION FOR PATIENTS

You and your parents/guardians are being asked to take part in a research study. Before you decide if you want to take part, it is important for you to understand why the research is being done and what will happen.

Please take your time to read this sheet, and discuss it with your parent(s) or guardian(s), a doctor or nurse and/or your friends if you wish. Your parent/guardian has also been asked to take part and will be aware of your involvement in the study.

Please ask us if there is anything that you do not understand or if you would just like more information. Take your time to decide whether or not you want to take part.

Who is doing the study?

Joy Spencer, a student at the University of Liverpool.

Dr. Helen Cooper and Dr. Beth Milton, who work at the University of Liverpool.

What is the study about?

We are trying to find out about what it is like to be a young person who has diabetes. We want to know what is important to you so that what you say can be used to make health services better for young people with diabetes. We also want to speak to your parent(s) or guardian(s) about what they think.

Why have I been chosen?

You have been asked to take part in this study because you come to the diabetes clinic at *(Hospital)*, and because you are aged between 13 and 16. We are looking for 20-30 families to take part in the study.

Do I have to take part?

No. It is up to you. You do not have to take part if you don't want to.

If you decide to take part you will be asked to sign a form to say that you have agreed to speak to us. Your parent or guardian will also have to sign the form to say that they agree you can take part, so please make sure they read this. You will also be asked to sign your parent's or guardian's form to say that you agree to them taking part in the study.

If you change your mind later you can stop taking part at any time without giving a reason. This will not affect the care you get at *(Hospital)* at all.

What will happen to me if I take part?

Your participation in the study will last no longer than 13 months. There are four different things that you will be asked to do during this time:

- For two weeks you will be lent a hand-held computer (PDA). You can use this to record things like your doses of insulin, food you have eaten, and any exercise you have taken part in. We will show you how to use the PDA so don't worry if you haven't seen one before.

- Joy Spencer, the researcher, will meet you either at home, at your school or at *(Hospital)*, to interview you about having diabetes. The interview will last for a maximum of 1 hour and 30 minutes. If the interview is not finished in this time, the researcher will ask you if you can carry on another day. The interview will be tape recorded and transcribed, so that the researcher can look over what you have said later on.

- If you agree, we will also ask the diabetes clinic at *(Hospital)* for your recent HbA1c (blood glucose test), **eye and feet screening results.** We will also collect information on your weight, height and medication status. We will not see any of your medical notes or other personal information. You will not have to have any extra medical tests to take part in the study.

- On another day, a focus group of young people will be getting together at *(Hospital)* to talk about having diabetes and what has been found in the study so far. You may be asked to come along and join in. The group will be meeting for about an hour and will also be tape recorded and transcribed.

What happens if there are any questions I don't want to answer?

We will ask you about what it is like to have diabetes and how it affects your life. You do not have to answer any questions that you do not want to and we will stop asking questions if you ask us to.

Will people know what I have said or who I am?

All the information that you give me will be kept confidential. This means that nobody will see it apart from the research team and that you will not be named in the report about the research. Anything about you will have your name and address removed and you will be given a fake name. *(Hospital)* will not be named in the report, however full anonymity can not be assured, as it may be possible for people to guess the hospital being studied. It may also be possible for people who know you well such as the nurses and doctors at the hospital and your family members, to identify what you have said from the report. This is because they may recognise the situations you have told me about.

Please note that if you did tell me about something that meant you were in danger or could come to any harm, we would have to tell *(Diabetes Nurse Specialist at Hospital)* about it.

What will happen to the results?

After the study is finished, the views of everyone taking part will be put together to write a PhD thesis, and this will be stored at the University of Liverpool. The main findings will be submitted to medical journals, and will also be presented at conferences. The aim of reporting the findings is to improve diabetes services for adolescents in the future.

Annual reports on the progress of the research will be given to the staff involved in diabetes care at *(Hospital)*. The progress of the research will also be presented to at the *(Hospital)* Annual Fun Day at the *(Leisure Centre)*.

Pretend names will be used in all of the reports, publications and presentations so that nobody will know who the views have come from.

What if I am not happy with the way I am treated during the study?

If you have any complaints about the research, please contact

Diabetes Nurse Specialist
(Address and telephone number)

Who is organising and paying for the research?

The University of Liverpool is organising and paying for the research as a student fellowship.

Who has looked at the study and said that it is okay to do?

The study has been approved by the *(Hospital)* Research Review Committee and the *(City)* Paediatric NHS Research Ethics Committee. It is being sponsored by the University of Liverpool.

How can I find out more?

Just get in touch with:

Joy Spencer	**Dr. Helen Cooper**	**Dr. Beth Milton**
PhD student who will be carrying out the research	Principal Investigator and student supervisor	Co-researcher and student supervisor
Tel:	Tel:	Tel:
Email:	Email:	Email:

What do I do if I want to take part?

If you and your parent(s) or guardian(s) decide that you want to take part in the study, please go through this information sheet with a parent or guardian and then sign (and ask a parent or guardian to also sign) the enclosed consent forms. You will be given a copy of this information sheet and the signed consent form to keep.

Please remember that you can stop taking part in the study at any time and this will not affect your care at the diabetes clinic at *(Hospital)*.

Thank you for reading this!

ASSENT FORM FOR PATIENTS

Title of Project

"Type 1 Diabetes and Adolescents:
An Exploration of Lived Experiences."

Name of Investigators

Joy Spencer	**Dr. Helen Cooper**	**Dr. Beth Milton**
(PhD student who will be carrying out the research)	(Research lead and supervisor)	(Supervisor)
Tel:	Tel:	Tel:
Email:	Email:	Email:

Please read the statements below with a parent/guardian and sign the next page if you agree.

- I have read the information sheet and understand that I can ask Joy Spencer, Helen Cooper or Beth Milton for information if I need it.

- I agree to taking part in this study.

- I understand that the researchers will ask the diabetes clinic at *(Hospital)* for my recent HbA1c (blood glucose test), eye and feet screening results, along with information on my weight, height and medication status

- I understand that if I want to I can decide not to carry on taking part without giving a reason and know that I will still receive the best possible treatment.

- I am happy for my parent(s) or guardian(s) to take part in the above study.

Name of patient ....
(please print)

Name of parent(s)/guardian(s) taking part in the study

....

....
(please print)

Signature ....

Date ....

Signature of Researcher
....

Date ....

A copy of this form will be kept by:
1) Your family
2) Joy Spencer, University of Liverpool
3) *(Hospital)*

CONSENT FORM FOR PARENTS/GUARDIANS

Title of Project

"Type 1 Diabetes and Adolescents:
An Exploration of Lived Experiences."

Name of Investigators

Joy Spencer	**Dr. Helen Cooper**	**Dr. Beth Milton**
(PhD student who will be carrying out the research)	(Research lead and supervisor)	(Supervisor)
Tel:	Tel:	Tel:
Email:	Email:	Email:

Please read the statements below and sign the next page if you agree.

- I have read and understood the Information Sheet.
- I understand that my child and I can stop taking part in the study at any time without giving a reason and that my child will still receive the best possible treatment.
- I agree for my child and I to take part in the above study.
- I understand that the researchers will ask the diabetes clinic at *(Hospital)* for my child's recent HbA1c (blood glucose test), eye and feet screening results, along with information on their weight, height and medication status
- I understand that if I want to I can decide not to carry on taking part without giving a reason and know that I will still receive the best possible treatment.

Name of child ....
(please print)

Name of parent/guardian 1...
(please print)

Signature ....

Date ....

Name of parent/guardian 2...
(please print)

Signature ....

Date ....

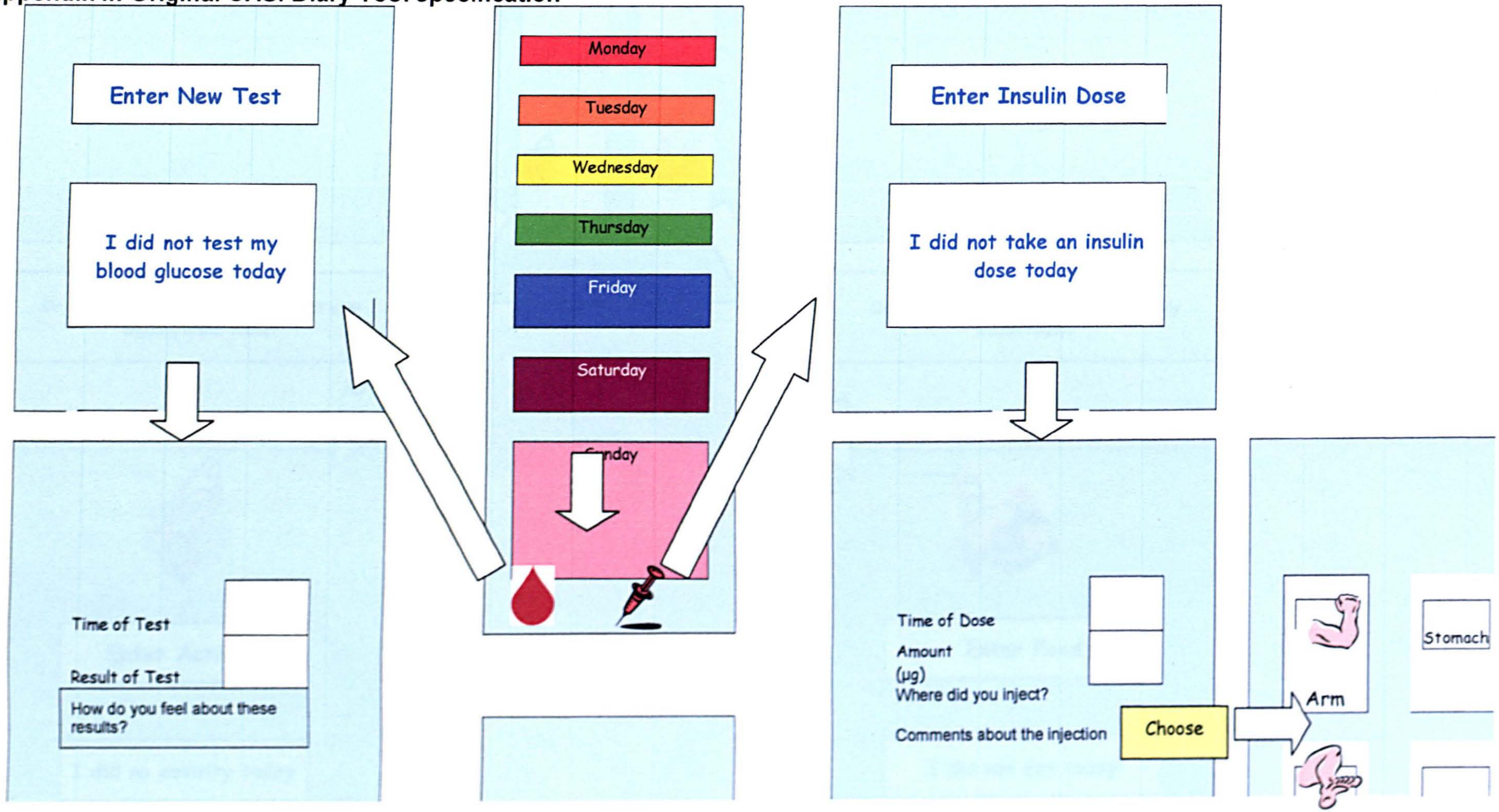
Signature of Researcher

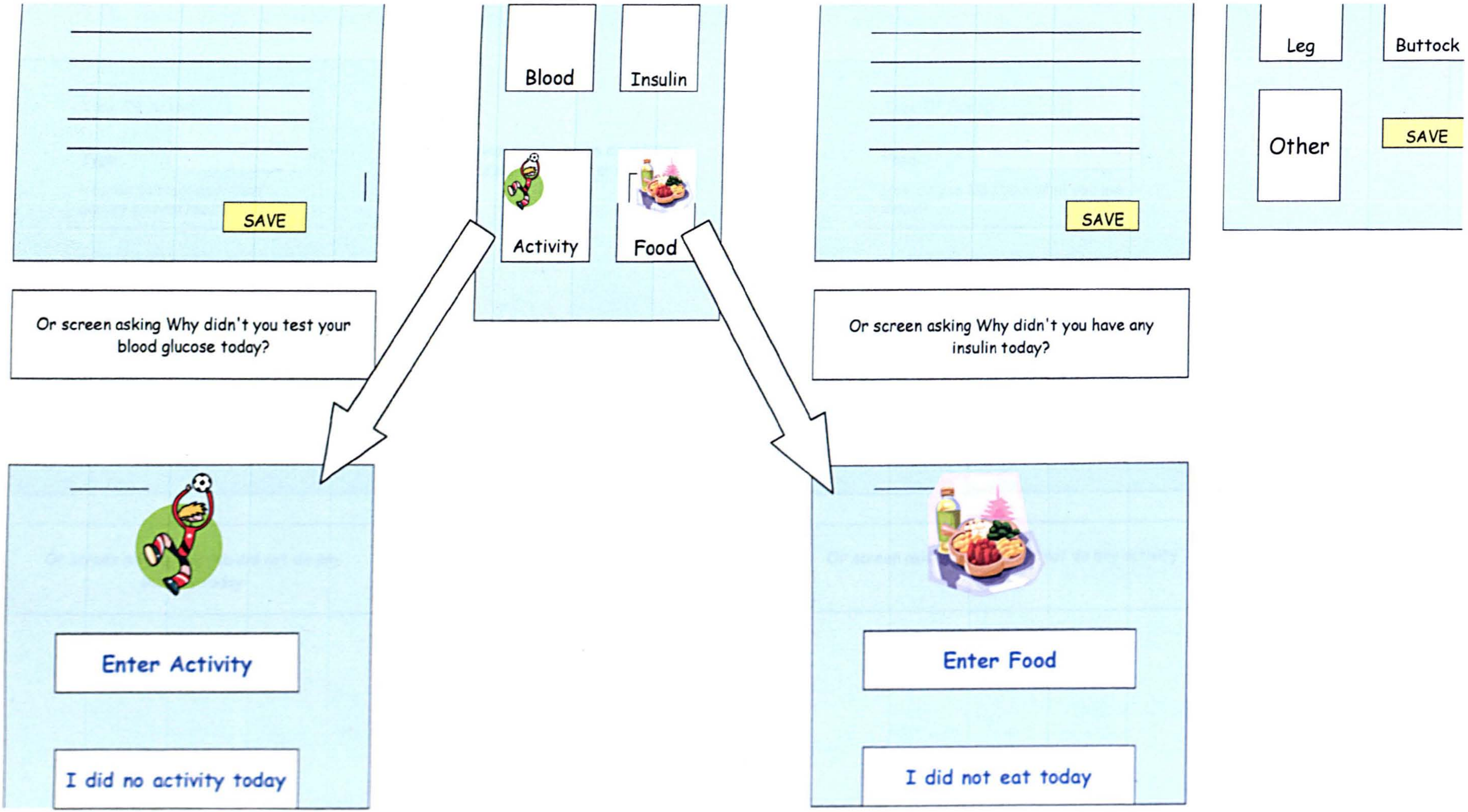
....

Date ....

A copy of this form will be kept by:
1) Your family
2) Joy Spencer, University of Liverpool
3) *(Hospital)*

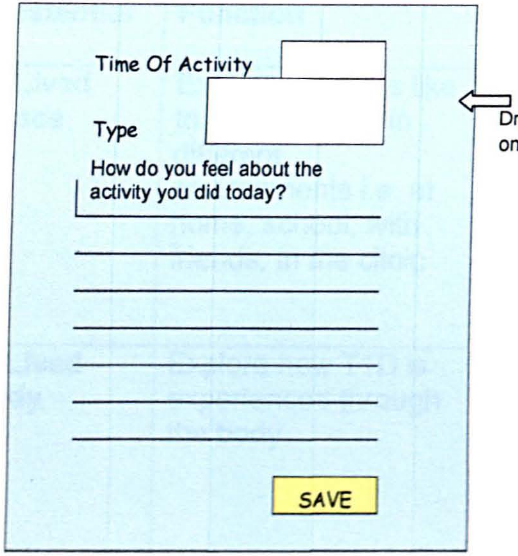
Appendix II: Original CASI Diary Tool specification





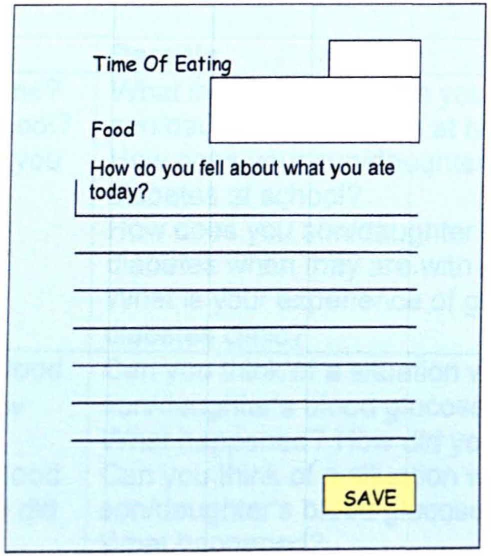
Or screen asking Why didn't you test your blood glucose today?

Or screen asking Why didn't you have any insulin today?



Drop down with activity types depending on whether it's a school day or weekend

Or screen asking why you did not do any activity today



Or screen asking why you did not do any activity today

Appendix III: In-depth interview guides informed by the four existentials of the lifeworld (van Manen, 1997)

Existential	**Function**	**Interview guide**	
		Adolescents	**Parents**
1. Lived space	Explore what it is like to live with T1D in different environments i.e. at home, school, with friends, in the clinic	What is it like to live with diabetes at home? What is it like to live with diabetes at school? What is it like to live with diabetes when you are with your friends? What is it like at the diabetes clinic?	What is it like to live with your son/daughter's diabetes at home? How does your son/daughter manage their diabetes at school? How does you son/daughter manage their diabetes when they are with their friends? What is your experience of going to the diabetes clinic?
2. Lived body	Explore how T1D is experienced through the body	Can you think of a situation when your blood glucose was high? What happened? How did you feel? Can you think of a situation when your blood glucose was low? What happened? How did you feel?	Can you think of a situation when your son/daughter's blood glucose was high? What happened? How did you feel? Can you think of a situation when your son/daughter's blood glucose was low? What happened?
3. Lived time	Explore the past, present and future in relation to living with T1D	*Past* What was it like when you were diagnosed with diabetes? *Present* How does your diabetes fit in with everyday life? *Future* How do you see your diabetes in the future?	*Past* What was it like for you when your son/daughter was diagnosed with diabetes? *Present* How does your son/daughter's diabetes fit in you're your everyday life? *Future* How do you see your son/daughter's diabetes in the future?

4. Lived other	Explore how relationships with others affect the experience of living with T1D	How do your friends feel about your diabetes? How do your family members feel about your diabetes?	How does your son/daughter's diabetes fir in with family life? Does your son/daughter's diabetes have an affect on your relationship with them?

Appendix IV: Interview brief (adolescents)

About the Interview

The aim of this interview is for you to tell me the story of **what it is like for you to live with diabetes.** A good way to tell your story is to think of situations or examples and describe them.

- I have some questions to guide the interview but it is more of a chat about what is important to you.

- You might like to think about the following things:

What is it like to be you?

- Where you go to school and what you like doing at school
- Your interests/hobbies
- What is your family like?

What was it like when you found out you had diabetes?

How do you manage your diabetes day-to-day and how does it fit in...

- At home with your family
- At school
- With friends

What is your parents'/guardians' role in your diabetes?

What is it like to test your blood glucose and give yourself insulin?

How does having diabetes affect what you eat and your activities and exercise?

What is it like going to the clinic at *(Hospital)*?

Interview Consent Form

Please read the following carefully:

- The interview should take about 1 hour.
- I am going to record our interview so that I can listen to it again later. If you are not happy with this let me know.
- You don't have to answer anything you don't want to.
- You can stop the interview at any time.
- Everything you tell me will be kept strictly confidential and anonymous. This means that you will not be named when I write up my research and I will not tell **anyone**, including your parents or the hospital what you have said.
- If you tell me that you have been harmed or that you are in danger, I will have to pass this information on to the Hospital.
- If there is anything that we discuss that you feel you would like further support with, please take this up with your Specialist Nurse.

I understand the information above and agree for the interview to be recorded.

Signed ....

Name ....

Date ....

Researcher signature ....

Date ....

Appendix V: Biographical note

I am 26 years old as I write this note. I was born in Chester and have spent my life growing up in this small, quiet city. I had a pleasant childhood, brought up by my parents Eileen and Robert, with my sister Zoe who is four years my junior. She has always been and still is my best friend. My mum is from Caenarvon, North Wales and my dad is from Huyton, Liverpool. Unfortunately both my grandfathers passed away before I was born, but I spent a lot of time with my grandmothers in Wales and Liverpool and they brought a great deal of pleasure to my childhood. My Welsh Nanna passed away when I was eleven and my Grandma when I was sixteen. Memories of my childhood at home, up until my teens consist mainly of playing outside in our road with our friends, which was a cul-de-sac and therefore perfect for games of football, 'curby' and 'tick and help'. I loved reading from a very young age. I used to visit the library on a Saturday with my Dad, take out eight books and read them all by the end of the weekend! My parents could not afford to take us on holidays abroad, but we had lots of fun holidays in various parts of the UK.

In adolescence, I attended a mainstream high school, half an hour walk from my home. Here I had a large circle of friends but was always aware that my parents were quite strict with me in comparison to many of the more 'cool' kids in my year. Looking back, I realise the power of peer pressure during adolescence, as I would have done anything to have the same clothes as them and be seen as part of this group. My group of friends started drinking alcohol around the age of fifteen. We spent many a Friday night sat in the village park where my friends lived, drinking strong cider. I was never allowed out past 10pm but still managed to join in! From the age of about 16 we started going to bars in town, if we could get in. There was one club which was notorious for an under-age crowd and we used to go there a lot, it was like a youth club in there!

Also at the age of fifteen, I was diagnosed with a chronic illness: Grave's Disease (an over-active thyroid gland). My mum had suffered from the condition after giving birth to me, and had been on the look-out for symptoms in myself and Zoe as she had inherited it from my Nanna. My behaviour deteriorated in school, I lost a lot of weight and I was constantly tired. I can remember having to phone my mum on a number of occasions at lunch time in school – she had to come and pick me up because I was so exhausted and I would sleep all afternoon. My mum said to me that my heart was beating as if I was running a marathon when I was sitting still. I can also remember waking up in the night with heart palpitations and the protruding goitre on my neck which ruined my school photo – I remember being shocked when I saw it. My mum had her suspicions and took me for a blood test and Grave's Disease was confirmed. I was prescribed a combination of two drugs: Carbimazole to reduce thyroid activity and Thyroxine to counter-act this in order to avoid under-activity. Once I had been on this combination for about a year and my thyroxine levels had stabilised, I was taken off the drugs in the hope that my thyroid would now continue to function normally.

I did well in my GCSE's, despite my mildly rebellious streak and my illness. All of my group of friends were staying on at school to do A Levels, with aspirations to go to University and I did the same. Most of the 'cool kids' left school and six of the girls were pregnant within the year. I can't believe they have ten year old children now, but I can see how it happened. I was lucky enough to have a supportive family and friends who valued education, which made staying on at school a credible thing to do. Going to university became the social norm in my peer group. I took Art, Psychology and English Language at A Level. I enjoyed sixth form. The best thing about it was that I met my fiancé Anthony whilst studying there. He came to my sixth form from another school and was in my form. I had had other boyfriends before him, but I knew when I met him he was 'the one'.

I chose to go to the University of Liverpool to study Sociology following sixth form. This was influenced by not wanting to be too far from Ant. I lived in halls for the first semester but moved home after Christmas of my first year, as my thyroid became over-active again. In June 2002 I had radioactive iodine treatment to stop my thyroid functioning altogether and I now have to take thyroxine every day for the rest of my life. I don't mind this. Having now explored the lived experiences of young people with diabetes, I feel very fortunate that my condition can be managed quite simply in comparison.

In terms of the psychosocial impact of Grave's Disease, I did not necessarily feel 'different' from my peers, as I did not have to self-manage my disease throughout the day, as adolescents with diabetes have to. However, I do remember feeling self-conscious of my weight around the ages of eighteen to twenty one, when people often used to comment that I must have an eating disorder as I was so slim – a side-effect of taking Thyroxine. I can relate to the families in this study where a parent and adolescent both had diabetes. For me, having the same condition as my mum made me feel special and more 'like her'. I also knew that my mum fully understood what I was going through, and I didn't feel worried about being ill because I knew that she was okay. I also did not question having radioactive iodine treatment over an operation because my mum had had it herself. In summary, it took the scariness of what I was going through away and I was definitely influenced the way that my mother had dealt with her illness.

I commuted to Liverpool for the remainder of my degree. My university years were filled with clubbing in Liverpool and Manchester. I really felt part of a distinct cultural group and wrote my dissertation on clubbing as a youth subculture. Ant was a budding DJ when I met him and has been Cream resident for the past seven years, for which I am immensely proud of him. I graduated in 2004 with a first class honours. It was amazing to see how proud my parents were of me.

During our ten years together, Ant and I have spent a lot of time on the Island of Ibiza, Spain, which I see as my spiritual home. I love the bohemian lifestyle, mixed with the hedonistic nightclubs, beautiful beaches, cosmopolitan Ibiza town and Mediterranean cuisine. We worked there for three summer seasons whilst I was at university. Ant worked in promotions, on a record stall and achieved a residency at Cream Ibiza in our third year. I worked in bars and on jewellery stalls. I had the time of my life and we visit the island every year without fail. We made so many amazing friends there. Ant proposed to me on a boat by the mystical rock of Es Vedra in June 2007 and we plan to marry in Ibiza in June 2012.

Following my graduation, I began an MSc in Health Promotion at the University of Chester. I suspended my studies after the first semester in January 2004 when I got a job in the Faculty of Health and Social Care as a Research Assistant. My role was to evaluate the effectiveness of a Sure Start programme in Birkenhead. I enjoyed research and soon realised that attaining a PhD was my goal if I was to pursue a career in this field. I applied for this studentship at the University of Liverpool, which I felt drew together my interest in health issues and young people. This thesis is the result of four years of hard yet thoroughly enjoyable work. I developed in many academic, professional and personal ways with the support of my two supervisors.

Exploring the experiences of families in this research study has highlighted to me that I have a lot to thank my parents for, in terms of what I have achieved in my life. In a sense, I have had a very 'normal' and privileged upbringing. My parents stayed together, took the time to educate me when I was young, and were typical 'authoritative' parents during adolescence. I did not live in poverty, resided in a nice area, attended excellent schools, and had a close bond with my sister. I have also been in a stable relationship from the age of sixteen, which I feel reflects the values my parents instilled in me through their relationship with each other. These factors have been an important source of support in allowing me to pursue my academic goals.

I currently live with Anthony in an apartment in Chester, which we bought two years ago. After ten years of working in the financial sector, Anthony began a degree in Events Management this year and is a successful DJ as well as a promoter of dance music events in Chester. I am now working at the University of Chester with my PhD supervisor Prof. Helen Cooper, on a study which aims to improve education for young people with T1D based on the findings of this study.

Joy Spencer
January 2010

Appendix VI: Focus group rule sheet (adolescents)

Type 1 Diabetes and Adolescence: An Exploration of Lived Experiences

Adolescent Focus Group

Monday 25th February 2008, *(Hospital)*

- Firstly - thank you for coming!
- Introductions

Summary of the Research Project

Aim: To find out about the experiences of adolescents with Type 1 diabetes and their parents

So far:

- 20 families have taken part
- You have used a PDA diary tool for one week
- You have taken part in an interview about your experiences
- Your parent(s)/guardian(s) have taken part in an interview about their experiences
- I have looked at all the teenagers' and parents' experiences and drawn out the main themes

Today:

- You are taking part in a focus group
- The aim of the focus group is for you to hear some of the findings from the study and discuss these with each other
- The discussion should last for approximately 1 hour

How will it work?

- There are 8 posters around the room, each representing a different theme from the research. These are:

  1. Perceptions of Diabetes
  2. Being Independent
  3. Managing Diabetes: From the Medical Perspective
  4. Managing Diabetes: in Real Life
  5. Living with Diabetes
  6. Family
  7. Clinic
  8. PDA

- On each poster there are a number of speech bubbles, with quotes from the teenagers who have taken part
- Have a walk around the room and read the speech bubbles
- You will be given some coloured stickers - on each poster put a sticker on the 2 speech bubbles which you feel are most important to YOU
- We will then have a break and a drink/snack
- After, we will have a discussion about the speech bubbles with the most stickers

Important considerations:

- Your views are very important. Don't hold back on saying what you think.
- Disagreeing is just as important as agreeing! If you feel your view varies from most of the people round the table, don't stay quiet. It is important to us to know differing opinions.
- This is a discussion. Although we may raise questions, we hope you will feel able to discuss amongst each other rather than always direct all your comments back to me.
- The discussion is being taped and your views will be used to check that the

conclusions I have come to are right.

- Please respect others in the group and let them have their say.
- Confidentiality is important to us all – no one individual will be named in the report – general phrases may be used e.g. one adolescent commented...

Any questions before we start?

Consent and Confidentiality Agreement

- In research, it is important that we maintain confidentiality
- This means that when writing up research, the researcher does not use names or anything that makes it easy to identify that a particular person has said something
- Please respect everyone's individual opinions
- Please keep the discussion we have within this room today
- I agree to this discussion being recorded

Signed ....

Date ....

Pediatric Diabetes

ISPAD

Pediatric Diabetes 2009
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Pediatric Diabetes

Review Article

Qualitative studies of type 1 diabetes in adolescence: a systematic literature review

Spencer J, Cooper H, Milton B. Qualitative studies of type 1 diabetes in adolescence: a systematic literature review.
Pediatric Diabetes 2009.

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Key words: adolescent – qualitative research – systematic review – type 1 diabetes

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Background

T1D is the third most common chronic illness in childhood following asthma and cerebral palsy (1), affecting 237 000 people in the UK, 20 000 of whom are under the age of 15 (2). Diabetes management is lifelong and unpredictable (3). It changes throughout childhood and adolescence alongside age, psychological development, physiology and maturity (4). It may impact on identity development and psychological well-being, and increase risk of depression (5) and eating disorders (6).

Multiple complications are present in almost one fifth of patients with diabetes (7) as a result of maintained high blood glucose levels in the younger years (8). Effective blood glucose control can considerably reduce the risks of developing micro-vascular complications (9). There is global evidence to suggest that metabolic control deteriorates during the period of adolescence (10–12) and only 15% of under-fifteens with diabetes in the UK are currently achieving recommended blood glucose levels (as defined by glycated haemoglobin/HbA1c) of 7.5% (13). This has provoked a wealth of research into factors affecting adolescent metabolic control with findings suggesting many individual, cultural and societal influences. These include gender (14), developmental level (15), illness perceptions (16), school support (17), peers (18) and the family (19).

A literature review of T1D in adolescence was conducted to explore the causal factors of deteriorating metabolic control in adolescents with T1D. Recent systematic reviews have highlighted that continuous subcutaneous glucose monitoring is no more effective in reducing HbA1c than finger-stick monitoring in both adults (20) and children (21), implying a need to explore wider psychosocial factors as determinants of poor control. This identified a need for qualitative research to explore adolescents' experiences of living with T1D, but no existing systematic reviews were found. This systematic review fills this gap, identifies areas for future research and has informed empirical qualitative research exploring the experiences of adolescents with T1D and their parents (22).

Search methods

Electronic databases were searched using all combinations of the terms 'Type 1 diabetes', 'adolescence', 'teenager', 'parents', 'family' and 'qualitative' for the period 1988–2008. Databases included Medline, Web of Science, British Nursing Index, CINHAL, PsychInfo, Science Direct, and Scopus. Grey literature was searched using the National Research Register, FADE and Proquest Dissertations and Theses. Qualitative studies of adolescents aged 13–16 years and their parents, published in English since 1988, were included. Quantitative studies, qualitative studies of adolescents and/or parents with T1D younger than 13 or older than 16, published in languages other than English and before 1988 were excluded. Mixed methods studies were included only if qualitative methods were prioritized.

Our searches identified 73 studies, including duplicates. After screening titles and abstracts for relevance, 38 full papers were obtained. The full text of these papers was then examined again against the inclusion/exclusion criteria. A total of 28 papers remained, relating to 20 individual studies (23–48). A second researcher was consulted when decisions regarding inclusion/exclusion were unclear.

Quality appraisal

All studies were systematically evaluated using Attree and Milton's checklist (49) (Appendix 1), chosen because of its balance between providing a comprehensive list of quality markers, whilst remaining meaningful and simple to administer. Two studies were excluded based on poor quality.

Data extraction and synthesis of evidence

A qualitative research integration approach aimed to provide a description, comparison and critique of current research and identify areas for further research (50). Data were extracted from computer-based forms developed for the review, and synthesized. The quality appraisal revealed varied methodological approaches, numbers of participants, reporting of participant characteristics, theoretical foundations, and settings. Epistemological grounding was not explicit in the majority of papers; therefore, a meta-synthesis was not attempted as findings were not transferable. The studies were grouped into 'sets' in relation to aims and content, and findings were compared, contrasted and discussed with reference to methodological issues emerging from the quality appraisal. Table 1 provides a detailed summary of each study.

Results: quality appraisal

Epistemology and theoretical framework

Epistemological grounding and theoretical basis are essential in qualitative research to facilitate methodological rigour. Data collection and analysis are grounded within a validated theoretical approach, thus improving the transparency and validity of the findings. Only six studies explicitly stated an epistemological viewpoint (24, 28–30, 36, 44, 47) and only three reported applying a theoretical framework (30, 35, 40–42). One study stated an ethnographic approach, but no evidence of ethnographic methods (i.e., observation) was described (30).

Sampling and population

The sample sizes of all studies, apart from Christian and D'Auria (44) and Davidson and colleagues (35) (four and six, respectively), ranged from 10 to 59. Most of the studies clearly described and justified their sampling strategy, aside from Carroll and colleagues (25–27). All of the studies implemented a purposive strategy, recruiting participants of a certain age and duration of diabetes from diabetes clinics. Authors applied a range of strategies within this approach including convenience (24, 28–30, 32, 33, 35, 36, 43, 46, 47), self-selecting (31, 33, 48), theoretical (23) and maximum variation (45) sampling. Olsen and Sutton described employing a stratified sampling technique in order to facilitate age-banding within their focus groups. Adolescents then self-selected from the stratified groups (48). Mellin and colleagues (37–39) recruited participants from a larger study, although it was not clear how these adolescents were selected, or how the sample was originally recruited. Two of the studies involved a secondary analysis of previously collected data: Ivey and colleagues (23) selected interaction transcripts based on HbA1c classifications; Davidson and colleagues (35) took a convenience approach to the selection of transcripts from coping skills training workshops.

Methods

Interviews were the primary method of data collection reported in 19 of the studies, including semi-structured in grounded theory and studies defined as 'qualitative' (30–32, 37, 39–42, 46, 47), and unstructured in phenomenological studies (24, 28, 29, 36). Other methods of data collection included focus groups (25–27, 34, 43, 48), drawings (47), and accessing the transcripts of coping skills training sessions (35).

Only three of the studies incorporated triangulation into their methodology in the form of multiple methods (39, 47, 48), thus reducing interpretation bias (60). Eight studies utilized multiple groups of participants (i.e., adolescents, parents, and siblings) (23, 25–29, 31, 33, 34, 37–39, 40–42) and one (28, 29) investigated family experiences by interviewing both adolescents and parents and analysing the data in terms of family narratives. Three studies explored family perspectives

Table 1. Studies included in the review

Study	Primary Focus	Epistemology	Theoretical Framework	Sampling Method and Population	Methods	Data Analysis	Integration Sets
Ivey et al. (23) USA	Parent/teen communication in relation to diabetes management	Not stated	Not stated	*Theoretical: metabolic control* Adolescents aged 11–15 (n = 28) and their parents (n = 28)	Secondary content analysis of interaction transcripts	Content analysis	3
Karlsson et al. (24) Sweden	Lived experiences of teenagers, focussing on the transition towards autonomy in diabetes self-management	Descriptive phenomenology	Not stated	*Convenience* Adolescents aged 13–17 (n = 32)	In-depth interviews	Halldorsdittir (51)	1, 4
(i) Carroll et al. (25); (ii) Carroll and Marrero (26); (ii) (27) USA	(i) Mobile monitoring technology for self-management assistance and adolescent–parent conflict (ii) Adolescents' perceptions of diabetes influence on quality of life and relationships with others (iii) Parents' perceptions of their child's well-being, parent–child relations, peer influence and school on their child's diabetes management	Not stated	Not stated	*Not clear* Adolescents aged 13–18 (n = 31) and their parents (n = 28)	Focus groups: adolescents and parents	(i) Five step analysis process (52); 3 researcher team	1, 2, 3, 4
Wennick and Hallstrom (i) (28); (ii) (29) Sweden	Families' lived experiences at diagnosis and one year after	Hermeneutic phenomenology	Not stated	*Convenience* Children/ adolescents aged 9–14 (n = 11), their parents (n = 21) and siblings (n = 6)	In-depth interviews	van Manen (53); family narratives compared	1, 2, 3
Herrman (30) USA	Costs and rewards of living with diabetes	Ethnography	Social exchange theory	*Convenience* Children/ adolescents aged 8–15 (n = 17)	Semi-structured interviews	Thematic analysis underpinned by social exchange theory	1, 2, 3
Schilling et al. (31) USA	Differences in self-management responsibility across adolescent developmental stages	Not stated	Not stated	*Self-selecting* Children/ adolescents aged 8–19 (n = 22) and their parents (n = 22)	Semi-structured interviews	Content analysis	1, 3

Table 1. Continued

Leonard et al. (32) USA	Teens' views of their parents' involvement in diabetes management	Not stated	Not stated	*Convenience* Adolescents aged 14–16 (n = 18)	Semi-structured interviews	Content analysis	1, 3
Low et al. (33) USA	Experience of insulin pump use	Not stated	Not stated	*Convenience/self-selecting* Adolescents aged 11–18 (n = 18) and their parents (n = 21)	Semi-structured interviews	Content analysis	1, 3
Waller et al. (34) UK	Perceived acceptability of the Dose Adjustment For Normal Eating (DAFNE) programme (64) for adolescents and parents	Not stated	Not stated	*Self-selecting* Adolescents aged 11–16 (n = 24) and their parents (n = 29)	Focus groups	Specific focus group analysis method (54)	4
Davidson et al. (35) USA	Stressors and self-care challenges reported by adolescents undergoing initiation of intensive management	Not stated	Hymovich and Hagopian's stress-adaptation model (55)	*Convenience* Adolescents aged 12–20 (n = 34)	Coping skills training sessions	Content analysis	1, 2, 4
Dickinson and O'Reilly (36) USA	Lived experiences of females	Hermeneutic phenomenology	Not stated	*Convenience* Adolescents aged 16–17 (n = 10)	In-depth interviews	van Manen (53)	1, 2, 4
(i) Hayes-Bohn et al. (37); (ii) Mellin and Neumark-Sztainer (38); (iii) Mellin et al. (39) USA	(i) Diabetes care at school (ii) Experiences of parenting (iii) Familial interactions regarding food and eating patterns	Not stated	Not stated	*Purposive* Adolescent females/ young adults aged 13–20 (n = 30) and their parents	(i) and (ii) Semi-structured interviews (iii) Disordered eating questionnaire; semi-structured interviews	Content analysis	3, 4
Hanna and Guthrie (i) (40); (ii) (41); (iii) (42) USA	(i) Dimensions of support related to assumption of T1D management responsibility (ii) Influences on the assumption of diabetes management from parents (iii) Parents' perceived benefits and barriers to transferring diabetes management to adolescents	Not stated	(i) Barrera and Ainlay's social support dimensions (56) (ii) and (iii) Janis and Mann's decisional balance sheet (57)	*Purposive* Adolescents aged 11–18 (n = 16) and their parents (n = 17)	Semi-structured interviews	Content analysis	1
Weinger et al. (43) USA	Sources of diabetes-related conflict and support within families	Not stated	Not stated	*Convenience* Adolescents aged 13–15 (n = 24)	Focus groups	Focus group analysis	3

Table 1. Continued

Study	Primary Focus	Epistemology	Theoretical Framework	Sampling Method and Population	Methods	Data Analysis	Integration Sets
Christian and D'Auria (44) USA	The experience of living with T1D in relation to taking on responsibility for care	Grounded theory	Not stated	*Purposive* Adolescents aged 15–17 (n = 4)	In-depth interviews	Constant comparative method (58)	1
Williams (45) UK	Impact of gender on the meanings and management of diabetes	Not stated	Not stated	*Maximum variation* Adolescents aged 15–18 (n = 20)	In-depth interviews	Open coding (59)	1
(i) Kyngas et al. (46); (ii) Kyngas & Barlow (47) Finland	(i) Adolescents' perceptions of the actions of physicians, nurses, parents and friends and their relationship to compliance (ii) Personal meaning and perceived impact of diabetes	(i) Not stated (ii) Grounded theory	Not stated	*Convenience* Adolescents aged 13–17 (n = 51)	(i) Semi-structured interviews (ii) Semi-structured interviews and drawings	(i) Content analysis (ii) Constant comparative method (58)	1, 2, 3, 4
Olsen and Sutton (48) UK	Family relationships and interactions with formal routine health care	Not stated	Not stated	*Stratified/ self-selecting* Adolescents aged 14–17 (n = 21)	In-depth interviews and focus groups	Framework analysis	1, 4

but published the findings from parents and adolescents as separate papers (26, 27, 38, 39, 41, 42).

Data analysis

Of the studies which did not state an epistemological stance, eight described a content analysis approach (23, 31–33, 35, 37–42, 46). This is the most basic type of qualitative analysis. The content of the data is analysed in order to categorize the recurrent or common themes (61), and thus it has been described as 'quantitative' description of qualitative material (62). Content analysis can be applied in a deductive manner which introduces a degree of bias. Interpretation and new meaning are minimal, as the findings provide a description of the data close to the form in which it was given (63). This was apparent in Shilling and colleagues' study (31), in which themes were predefined from the research questions. In an attempt to improve rigour, Low and colleagues (33) utilized a content analysis approach combined with the constant comparison method usually utilized in grounded theory studies, with a function of *"testing provisional hypotheses as additional cases were reviewed"* (33, p. 24). Three of the focus group studies applied specific authors' frameworks to their data analysis (25–27, 34, 43, 48). Carroll and Marrero (25–27) applied a basic thematic approach to analysis, but the validity of this study was improved as the analysis was collaborative, thus reducing interpretation bias. Bias was also reduced through member checking in one study (48).

The phenomenological studies utilized two different approaches to data analysis, grounded in the phenomenological tradition. Karlsson and colleagues (24) described an eight-step descriptive method based on Halldorsdottir's (51) approach and both of the interpretive phenomenological studies (28, 29, 36) utilized van Manen's (53) approach. The two grounded theory studies (44, 47) utilized open coding (59) and constant comparison (58).

The studies which utilized a content analysis approach were generally descriptive in their presentation of the findings. The validated approaches to analysis in the epistemologically-grounded studies moved the findings beyond pure description towards an interpretation of the meaning of the phenomena. This allowed for the inductive transformation of the data from its original form, towards a 'new' interpretation of the phenomena (63). Subjective meaning was privileged (49) and thus improved the transparency and validity of the findings.

Synthesis of findings

Four sets emerged from the integration of studies and each set was divided into sub-sets. Some studies' findings covered more than one set, as detailed in Table 1. The total number of studies in each set are as follows:

(i) Independence and autonomy for diabetes management (n = 14);
(ii) Living with T1D (n = 5);
(iii) Family relationships (n = 10);
(iv) Diabetes care (n = 8).

Set 1: Independence and autonomy for diabetes management

Psychological and emotional maturity

Becoming emotionally ready to take responsibility for diabetes management was a complex process underpinned by gaining factual, experiential knowledge and problem-solving skills. Diabetes camps and school trips provided safe environments to gain such experience away from home (24, 44). Self-esteem increased as a by-product of successful self-management, suggesting that confidence may facilitate independence (24, 30, 32); however, being away from home also caused stress for some (35).

Adolescent girls incorporated diabetes into their identities more than boys, for whom mothers took on most of the responsibility for their care (45). Girls described T1D forcing them to be more independent and responsible than their peers (36). This suggests that gender differences in developmental level may relate to cognitive capacity for independence.

Parental input as a barrier to autonomy

Parents took an administrative role in adolescents' diabetes management, including monitoring medication, organizing clinic appointments and liaising with health professionals (25). Unnecessary parental input often resulted in conflict between parent and child (31) and adolescents felt mistrusted as a consequence (46). Parents were aware that their reminders were annoying, but found it difficult to step back from assistance (25). Teenagers with poor control had a more negative view of parental reminders and tended to ignore them rather than utilizing the support. There was also a higher instance of parent–adolescent conflict in these young people compared to those with better control (32).

Parental facilitation of autonomy

Parental involvement gradually decreased as adolescents grew older (31). Parental trust in adolescents' ability to manage their diabetes reduced anxiety about the consequences of poor management and enabled parents to give their child more freedom (24). Allowing adolescents to build the confidence to manage their diabetes independently whilst giving background support (40, 44, 46) was the ideal scenario. The process of gaining autonomy for diabetes management was characterized by *'hovering'* between individual actions and the support of parents (24).

Peer facilitation of autonomy

The demands of living with diabetes became greater as socialization needs increased with age, leading to feelings of frustration and restriction (44). Adolescents felt that they had to take on more responsibilities than their peers (26). Feeling comfortable and not different from peers was key to integration of diabetes into daily life (24) and independence (24, 44). It was important for adolescents to disclose their diabetes to friends (26, 44, 48) as they felt *'safe'* in the knowledge that their friends could cope in an emergency. This enabled them to *'forget'* about their diabetes when with their peers (24). Peer support was generally valued, but too much interest from friends was also seen as intrusive and patronizing (26, 48).

Biomedical facilitation of autonomy

Encouragement for independent decision-making by health professionals was beneficial for autonomy. Basal bolus insulin regimes (44) and insulin pumps (33) benefited autonomy, lifestyle freedom and independence for some adolescents.

Implications of autonomy for adolescents and parents

Many parents took personal responsibility for their child's diabetes, and interpreted the HbA1c check at clinic appointments as confirmation of how they had discharged their parental responsibilities (28). Transferring responsibility over to their child was therefore often difficult. Parents felt that they had lost control, and had to deal with negative consequences of reducing their input, such as increased blood glucose fluctuations. Parents and adolescents worried about the burden of increased responsibility for adolescents. Adolescents recognized that their parents felt guilty and worried as they took on more responsibility (41, 42).

Adolescent autonomy positively relieved the burden of responsibility for parents, whilst adolescents enjoyed increased knowledge and confidence in their own abilities, more freedom and the approval of others (41, 42). Successful self-management had the benefit of reducing worry for parents and adolescents and increasing freedom (30). Parents and adolescents described confidence and pride in adolescents' abilities to manage independently (41, 42).

Set 2: Living with T1D

Managing conflict

Living with diabetes meant having to make decisions and manage conflicts (37), including whether to follow their management plan (35, 36), be truthful about self-care action (35), tell others about their diabetes (35, 36), and ask for help (35). Adolescents also reported emotional conflicts: being healthy yet invisibly ill, feeling acceptance yet frustration, independent yet supervised, and confident yet insecure (28).

Facilitators of self-management

Successful management of diabetes was related to knowledge and experience, adherence, exercise and parental support (30). Confidence, knowledge, and self-efficacy had a positive effect on health, emotions, social opportunities, and relationships (35).

Adolescents and parents felt that an implantable testing device which automatically tested blood glucose and administered insulin, and a blood glucose tester incorporated into a mobile telephone or personal digital assistant (PDA) would be beneficial to self-management. Desired functions were calculation of insulin dose based on blood glucose levels, storage of data, automatic upload onto a website which could be accessed by parents and health professionals, and alarmed reminders for blood glucose testing (25).

Barriers to self-management

Some adolescents saw T1D as a threat to their physical and psychosocial well-being (47). Adolescents were aware of the potential health costs of not taking care of their diabetes (30); however, self-monitoring was inconvenient and disruptive, and negatively influenced by increase in age, school and peer influences and social stigma (25). They were concerned with fitting in with the adolescent culture (36) and some received unwanted attention when injecting or testing in public. Not taking care of diabetes had the perceived benefit of enabling some adolescents to fit in with their peers more adequately; however, poor adherence also led to blood glucose fluctuations (30) and feelings of guilt (35, 36).

Restrictions, stressors, and coping

Diabetes was perceived as a difficult and demanding condition (35) with inconvenient dietary restrictions and interruptions to daily life (30), but also as potentially manageable (35). Some adolescents felt controlled by school staff, sports coaches and health care providers. Anxiety was caused by the threat of complications and poor HbA1c results (36). Coping mechanisms included implementing routines for diabetes management, carrying supplies in preparation for potential blood glucose fluctuations, asking parents for help and thinking ahead regarding the possible implications of non-compliance (35).

Set 3: Family relationships

Family adaptation and learning

Adapting to T1D was an on-going learning process for families which occurred in two stages. (i) *'Learning about the inevitable'*: acknowledgement of the symptoms of the child's diabetes prediagnosis, followed by feeling overwhelmed and powerless. Confidence emerged once they had experienced managing the child's diabetes at home. (ii) *'Learning about the extent'*: learning about the effect of the child's diabetes on family relationships, the restrictions imposed on family life, and anxiety about blood glucose fluctuations (28).

Parents created new family routines following diagnosis (29) and changed their lifestyle (e.g., reducing working hours), to cope with the demands of the diabetes regime (38). Adhering to routines reduced feelings of parental anxiety (29, 38) but caused inconvenience for some siblings (28). Some adolescents perceived changes to family life as a *'cost'*, as conflicts and inconvenience were introduced (30). T1D also had positive effects for some families, including improved diet (30, 38), increased exercise, smoking cessation (38), improved sibling relationships, and a sense of the family *'working together'* (30). Negative family meal time behaviour was thought to influence disordered eating in adolescents, whereas maintaining structure for meals and focussing on positive eating behaviours served as a protective function (39).

Parent–child relationships

Adolescents felt supported by parents who reassured them about complications and blood glucose fluctuations (43), and felt motivated by positive parental feedback (46). Parent–adolescent conflict occurred as a result of non-adherence to the diabetes regimen and resulting parental anxiety (31, 32, 38, 43). Although such disagreement was common (43), some parents felt close to their adolescent daughters and rarely experienced conflict (38). Relationships between adolescent daughters and mothers were perceived as positive when daughters displayed 'responsible' behaviour including being reliable and trustworthy in other areas of life as well as with diabetes (38). When daughters achieved good control of diabetes, relationships with mothers improved as parents reported experiencing less stress (32).

Parental anxiety

Parents were likely to perceive their child's diabetes as more serious than the child (27). Diabetes brought parents increased anxiety about complications, management away from home, quality of management and hypoglycaemia (23, 38). Parents reported increased stress in the initial adjustment period when their child began using an insulin pump (33). Parents coped with anxiety by maintaining a positive outlook and providing practical support (38).

Intrusive behaviours precipitated by parental anxiety (43) and a lack of confidence in the adolescent's ability to manage their diabetes led to negative adolescent–parent communications, and left adolescents feeling mistrusted (47) and as if they had failed their parents (28, 43). This affected self-esteem, confidence, autonomous functioning and ultimately diabetes control, as adolescents sometimes compromised their self-management behaviour in order to avoid potential conflict and negative feedback from parents (25, 26, 43). Parents described changing their own behaviours and expectations of *'perfect'* management, in order to reduce conflict (38).

Set 4: Diabetes care

Clinical care

Adolescents valued health professionals who had a *'friendly'* manner and spoke to them about other things aside from their diabetes (26, 34). They felt supported when health professionals made suggestions about insulin doses or food choices (36) and when care was planned collaboratively with them (47). Professional advice often did not conform to their real-life situation (24) and some felt they were treated as a *'disease'* rather than a person (26). Some adolescents did not understand the information that health professionals gave them, and allowed their parents to interpret it for them (34). Others felt that some physicians worked to a specific, immutable model of care regardless of communication between the adolescent and physician (47). Older adolescents wanted communication in consultations to be directed towards them rather than their parents (26).

Teenagers did not completely trust the care plans issued to them by health professionals and wanted more input into their care decisions (35). Clinic attendance tended to decline as adolescents get older and transition to adult service occurred. Efforts to engage adolescents at transition age should be made to prevent them losing contact at this complex time in their lives (48).

Education

Group education was beneficial, as it facilitated a support network. Adolescents disliked *'refresher sessions'* which covered the basics of diabetes management, as they did not learn anything *'new'*. They preferred education away from the hospital, presented in a simple manner without the pressure of tests and assessments, and enjoyed the incorporation of *'fun'* activities. Parents felt that practical exercises rather than didactic teaching were beneficial for adolescent learning and that the use of technology would encourage participation (34).

Diabetes care in schools

Lack of understanding about T1D from teachers in school was common. Adolescents were often questioned by teachers during blood testing and eating (36, 37). Food choices conducive to 'healthy' diabetes management were poor in school canteens and adolescents sometimes struggled to meet school rules, which they felt were insensitive to their needs. Transitions to new school settings caused stress, with new challenges and care resources in an unfamiliar situation (37).

Discussion

Twenty quality-assessed studies of adolescent diabetes were reviewed in this research integration exercise. Findings, centred around four sets, are summarized as follows:

- Developing autonomy for diabetes management is a complex process influenced by many psychosocial factors including psychological and emotional maturity and gender. It was inhibited by intrusive parental input and facilitated by parents finding a balance between holding back on input and providing background support. Adolescents felt safe in the company of peers who had diabetes knowledge but who also gave them space. Encouragement of autonomy by health professionals was beneficial, and basal bolus and pump regimes had a positive influence. Increased autonomy relieved a burden for some parents and improved confidence and knowledge for adolescents, although the process caused anxiety for parents and adolescents as they adjusted to decreased/increased responsibility.
- Living with T1D involved conflict resolution on a daily basis regarding decision-making and emotions. Knowledge, experience, and parental support facilitated effective self-management and adherence; not fitting in with peers was a barrier. Poor adherence led to blood glucose fluctuations and guilt. Some felt controlled, anxious and restricted by T1D.
- Living with adolescent T1D was an on-going learning process for all family members. Routine and positive parental support improved adolescent adherence and blood glucose control, whereas negative adolescent–parent communication negatively influenced self-efficacy, confidence, autonomy, and control. Adolescent–parent conflict was common; parental

anxiety was reduced when blood glucose control was good.

- Adolescents valued individualized care and involvement in care planning. Group education incorporating activities was an effective way for adolescents to learn. Clinic attendance declined with increasing age; transition services were important to avoid losing contact. Schools did not always provide an environment conducive to diabetes management.

Research gaps and methodological limitations

These findings must be viewed alongside the following limitations: (i) there were considerable inconsistencies between the research settings and methodologies of the studies; (ii) the reviewer's secondary interpretation of the included papers meant that the findings were subjective; (iii) limiting the search to studies published in English meant that studies in different cultural contexts were not included.

The quality appraisal highlighted a number of methodological issues, which have served to identify the following research gaps. However, it must be noted that the appraisal was based solely on the methods reported in papers and therefore may not accurately reflect the actual research process. Word-length limits in peer-reviewed publications can lead to poor quality in the reporting of research methods, although some papers provided more detail than others. Authors were not contacted for clarification of the methodology employed when epistemological approach and methods were unclear.

(i) The majority of papers described studies conducted in the USA (n = 18). These findings are not transferable to adolescents in other counties/settings where health care provision, education, and culture differ. Only one qualitative study was conducted in the UK in the past 10 years (34) and this focussed on an evaluation of a DAFNE-style (64) programme rather than adolescents' lived experiences. There is therefore a need for qualitative research exploring the lived experiences of adolescents with T1D in other countries/settings.

(ii) The findings suggest that significant others within the family, school, and clinic are paramount to managing the demands of living with diabetes in adolescence alongside the development of personal autonomy. Eight studies reported adolescents' and parents' perceptions of diabetes (23, 25–29, 31, 33, 34, 37–42), and one combined adolescents', parents' and siblings' perceptions (28, 29). The importance of parent–child beliefs and interactions in relation to adolescent diabetes management and autonomy was apparent. Family perspectives in future research are therefore needed.

(iii) Measures should be taken to improve the validity of qualitative research in this area. Researcher reflexivity was under-reported in the majority of studies and only three incorporated triangulation in the form of multiple methods (39, 47, 48). The study of adolescent diabetes requires a combination of qualitative methods to give greater diversity. Although analysis was checked by other researchers in some studies (24, 30, 46), there is also a need for member checking in order to reduce interpretation bias.

(iv) Qualitative research in this area should be grounded in epistemological traditions and underpinned by theory. Only six studies explicitly stated an epistemological viewpoint (24, 28–30, 36, 44, 45, 47) and only three of the studies applied a theoretical framework (30, 35, 40). Findings from high-quality, trustworthy studies can lead to a better understanding of the factors that inhibit good blood glucose control in the adolescent age group, and the potential impact on care provision.

Conclusion

This systematic review met the aim of integrating the research findings in reports of qualitative studies of T1D and adolescence in order to define the content of the literature to date and identify research gaps. In light of previous systematic reviews which found that subcutaneous glucose monitoring is no more effective than finger-stick testing (20, 21), the findings indicate that social relationships are a key factor in the management of T1D. Adolescents face juggling the different demands of their diabetes within the social spheres of the family, school, peers and clinic. Teenagers' abilities to be independent in diabetes management are embedded within relationships with parents, peers, health professionals and teachers. This warrants further investigation in the UK and other settings, using rigorous qualitative research methodologies underpinned by epistemological tradition and novel theoretical frameworks. This will enable a better understanding and new perspectives of what it is like for adolescents and their significant others to live with T1D and the complex social interactions surrounding self-management in this age group, with the ultimate aim of improving blood glucose control and future health outcomes.

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Appendix 1. Quality Appraisal Checklist (49)

Checklist for the quality appraisal of qualitative research

Quality scoring system:

A: No flaws;

B: Some flaws;

C: Considerable flaws, study still of some value;

D: Significant flaws that threaten the validity of the whole study.

Methodological Area	Key Criteria	Yes	No	Quality Score
Background of research	Source of funding (relationship to findings?)...........................			
	Name of study..			
	Is the connection of the research to an existing body of knowledge or theory clear?			
Aims and objectives	Is there a clear statement of the aims of the research?			
	Are the research questions clear?			
Context	Is the context or setting adequately described?			
Appropriateness of design	Are qualitative methods appropriate?			
	Is the research design appropriate to address the research aims? Is it 'fit for purpose'?			
Sampling	Sampling strategy..			
	Is the sampling strategy appropriate to address the research aims?			
	Criteria used to select the sample......................................			
	Does the sample include an adequate range of possible cases or settings?			
	Sample size..			
	Is the sample size justified? (Data saturation)			
	Did any participants choose not to take part in the study?			
	If so, why?...			
Data collection	How were data collected, and by whom?			
	Is the form of data clear (e.g., tape recordings, fieldnotes etc.)?			
	Were any methods modified during the research process?			
	If so, why?...			
	Does data collection involve triangulation (of multiple methods or data sources)?			
	Is there evidence that data collection was systematic (e.g., an audit trail)?			
Data analysis and findings	How was the analysis carried out?....................................			
	Are sufficient data presented to support the findings?			
	How were data selected for inclusion in the report?...			
	Are data annotated with demographic details of contributors?			
	Do the findings directly address the research question?			
	Does the research privilege subjective meaning?			
	What steps are taken to demonstrate the trustworthiness of the findings (e.g., negative cases, respondent validation)?.........................			
	Have the limitations of the study and their impact on the findings been taken into account?			
Reflexivity	Has the relationship between researchers and participants been adequately considered?			
	Do the researchers reflect on their personal viewpoints and experience that they bring to the research setting?			
How valuable or useful is the research?	Does the research add to knowledge, or increase the confidence with which existing knowledge is regarded?			
	Is there a discussion of how findings relate to wider theory; consideration of rival explanations?			
	What are the implications for policy and practice–how is it 'fit for purpose'?..			
Ethics	How have ethical issues been taken into consideration (e.g., consent, confidentiality, anonymity, distress to participants)?.....................			
	OVERALL STUDY SCORE			