Challenges to Good Glycaemic Control in Young Adults with Type 1 Diabetes

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ABSTRACT

Type 1 Diabetes (Type 1 DM) is a chronic condition requiring complex self-care. Young adults with Type 1 DM have poor outcomes and are at serious risk of premature death. There is a lack of evidence regarding how young adults self-care and what challenges they face. This thesis aimed to investigate challenges to self-care in young adults with Type 1 DM.

Qualitative interviews were conducted with young adults (*n* = 26), their parents (*n* = 18) and staff (*n* = 13) from a Type 1 DM clinic. Young adults want to be responsible for their own self-care but often manage care inadequately. Parents fear diabetes related complications and consequently have difficulty releasing control of care. This can create family difficulties which staff are unsure how best to manage. Strong social priorities may explain inadequate self-care in young adults. When self-care compromises social image or activities it is neglected. However the quality of self-care may be improved by tailoring to individual lifestyles.

For some young adults eating problems may complicate self-care. A meta-analysis of 13 studies investigating the prevalence of eating problems in this population was conducted. No study used a diabetes-specific measure of eating problems. Therefore conclusions were drawn from studies that used generic measures that had been adapted for Type 1 DM. Eating problems were common (clinical eating disorders, 6.4% and disordered eating behaviour, 58.1%) and associated with suboptimal glycaemic control.

Finally a quantitative study was conducted to investigate prevalence and predictors of eating problems in this population using a diabetes-specific measure. Eating problems were common (*n* = 99; 36.1%) and were predicted by female gender, suboptimal glycaemic control, elevated BMI and (in the case of females) diabetes-specific distress. Eating problems were associated with suboptimal glycaemic control.

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ABBREVIATIONS

Abbreviation	**Meaning**
BMI	Body mass index
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
DCCT	Diabetes Control and Complications Trial
DDS	Diabetes Distress
DEPS-r	Diabetes eating problems scale
DSN	Diabetes specialist nurses
EDE	Eating Disorders Examination scale
EDE-Q	Eating Disorders Examinations - Questionnaire
EDIC	Epidemiology of Diabetes Interventions and Complications study
HbA1C	Glycated haemoglobin
NDA	National Diabetes Audit
NGH	Northern General Hospital
RHH	Royal Hallamshire Hospital
Type 1 DM	Type 1 Diabetes
Type 2 DM	Type 2 Diabetes

Preface

Statement of problem

Type 1 DM is a life changing chronic and progressive illness that requires multi-faceted, complex management (Norman, 2011c). The demands of self-care are intense and the consequences for suboptimal control of Type 1 DM potentially deadly (Smith-Marsh & Walker, 2010b; The Diabetes Control and Complications Trial Research Group, 2001). For any individual and their family, Type 1 DM places tremendous burden on nearly all areas of life. But for young adults with Type 1 DM this burden is amplified (Anderson, 2009). At what is already a complex and demanding time of life, young adults must prioritise a complex regimen of self-care (Harris, Freeman, & Duke, 2011). Type 1 DM is an unwanted intrusion on their lives, yet consequences of suboptimal management during this crucial time can be and often are, fatal for young adults (The NHS Information Centre, 2011). Suboptimal control of Type 1 DM during young adulthood can result in a lifetime of debilitating, painful or fatal medical complications in the longer term (The Diabetes Control and Complications Trial Research Group, 2001). For these reasons it is critical that the problem of suboptimal control in this age group is addressed as a matter of urgency.

A diagnosis of Type 1 DM is "a life sentence to a difficult therapeutic regimen that is only partially effective in preventing acute and chronic complications" (Devendra, Liu, & Eisenbarth, 2004, p750).

Case study

J is 17 years old and lives with her mother in the south of Sheffield. She has been diagnosed with Type 1 DM for 7 years. Her diagnosis occurred as a result of unusual behaviour a week before her 10th birthday. She had always been relatively healthy, but suddenly began to feel very thirsty, drinking excessive amounts of water and frequently urinating. After a day of symptoms, J's mother took her to the GP and J was diagnosed with a urinary tract infection. She was prescribed antibiotics, but symptoms persisted and she began to feel exhausted. Late on the third night of symptoms, her mother found her drinking water from the bathroom tap and called a doctor. J was admitted to hospital and subsequently diagnosed with Type 1 DM. She stayed in hospital to be rehydrated and a diabetes specialist nurse visited her several times. The nurse explained that J would have to inject insulin to treat her Type 1 DM for the rest of her life.

In the weeks that followed, J and her parents learnt all they could about Type 1 DM care. Her family (especially her mother) were initially overwhelmed by the amount of tasks necessary every day. J and her family learnt about the Type 1 DM diet, calculating the amount of carbohydrate in food, calculating and injecting the correct amount of insulin at the right times, needle hygiene and disposal, looking after injection sites, blood glucose testing equipment and how to test, correcting high blood sugar levels, treating low blood sugar levels, what to do when ill, emergencies and educating friends, families and school. At first, J's Type 1 DM consumed most of her family's time because they were inexperienced at the required tasks. Gradually, they became more practiced but self-care was still very time consuming. Her mother felt that J's Type 1 DM was her responsibility and she worried a lot about the complications that the doctors had described if J's Type 1 DM was not well managed.

As J got older, she increasingly injected insulin herself and took on more responsibility for care. Her mother still helped her a lot and oversaw the whole process. J found that as she got older social situations became harder. When she moved to high school, teachers and peers were not as supportive or interested as at her previous school. She started to resent that Type 1 DM made her stand out and tried to draw as little attention as possible to it at school. When J moved into her second year at high school, her parents divorced and her dad subsequently moved away from Sheffield. J had difficulty adjusting to the change and her mother believes that the event signalled the beginning of J disengaging from self-care. J became increasingly reluctant to care for her Type 1 DM and her mother found that she had to frequently remind J to complete care tasks. Specifically, J decreased the amount of blood glucose tests she performed until she did virtually none. This meant that she could not inject appropriate amounts of insulin for her blood sugar levels.

Now J admits that she rarely tests her blood glucose, guesses insulin doses and misses injections. She says she is sick and tired of Type 1 DM and if she let it, it would dictate her life. She refuses to manage self-care as prescribed and only injects enough insulin to keep herself out of hospital. J is unhappy with her weight and her doctors agree she is overweight. She has made frequent attempts to lose weight through exercise and diet as recommended by her doctors, but each time she loses motivation. When J has overeaten, she often misses insulin to counteract the excessive calorie intake. J thinks that this contributes to the poor control she has of her Type 1 DM, but reducing her weight is currently more important to her than having good control of her condition.

J's Type 1 DM is a source of conflict with her mother. J feels that her mother doesn't understand how hard it is for her and when J genuinely tries to improve her control, it goes unrecognised. Her mother is desperately worried and does not think J will live the full life that she wants her to. J's problems with her Type 1 DM are reflected in her clinical test results and she already has background retinopathy.

J wants to improve her control, but does not want her whole life to centre around Type 1 DM or self-care. She knows how to manage self-care but does not feel that it can be well managed in conjunction with her other priorities. To J, it is more important to have the social life she wants, to drink alcohol and to minimise weight gain.

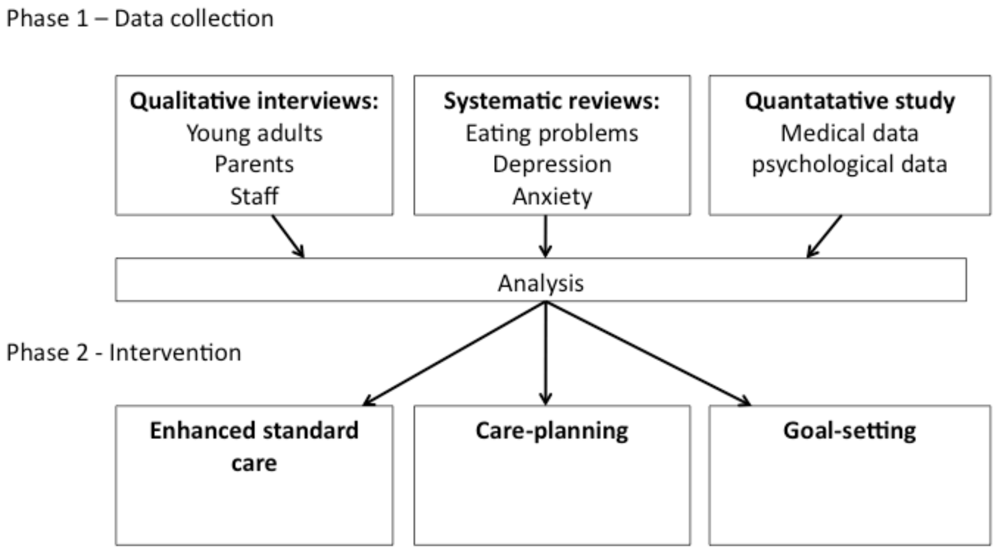
Background to thesis and CLAHRC project

Given the unique impact of Type 1 DM and self-care on young adults and the problem of suboptimal glycaemic control in this group, a multi-disciplinary team from Sheffield Teaching Hospitals applied for funding from CLAHRC to develop and evaluate a programme sensitive to the needs of young adults with Type 1 DM in South Yorkshire. CLAHRC is an initiative of the National Institute for Health Research and stands for 'Collaboration for Leadership in Applied Health Research and Care'. CLAHRC is concerned with long term health conditions and as the name suggests applied research is central to the aims. A young adult programme was designed as part of the CLAHRC South Yorkshire (CLAHRC-SY) diabetes theme (http://clahrc-sy.nihr.ac.uk/theme-diabetes-introduction.html). The programme is divided into two phases. Phase one ran from October 2009 to October 2011. The aim for phase 1 was to apply a mixed methods approach to collect data to facilitate the development of informed interventions in phase 2. Figure P.1 illustrates the activities of CLAHRC at each phase.

Phase 1 involved firstly qualitative interviews with a sample of (i) young adults with Type 1 DM from the South Yorkshire clinics, (ii) their parents and (iii) members of the multidisciplinary healthcare team from Sheffield Teaching Hospital. The aims of the interview study were to understand the views of young adults regarding Type 1 DM, self-care and what they would like from Type 1 DM services. Secondly, systematic reviews and meta-analyses of previous literature were conducted to establish the degree of psychological co-morbidity and to understand what forms of intervention have been trialled in this group. Finally, a quantatative study of young adults with Type 1 DM in the Sheffield clinics was conducted to collect medical and psychological data to establish the prevalence and predictors of psychological problems and to be used as baseline data for evaluation of the interventions proposed in phase 2.

The aim for phase 2 was for a multi-disciplinary team of dieticians, consultants, psychologists and diabetes specialist nurses (DSN) to develop and evaluate an evidence-based intervention to improve glycaemic control in this group. To date, the multidisciplinary team have used data from phase 1 to inform and develop a complex health intervention. The intervention consists of enhanced standard care, an education programme (WICKED) and goal-setting. The intervention was first implemented in clinics in March 2012 and is currently ongoing. At the end of phase 2, the intervention will be evaluated against baseline data collected in phase 1. This thesis describes parts of both phases 1 and 2 of the overall CLAHRC project.

Figure P.1 Flow chart to illustrate activities of CLAHRC



Aims of thesis

i) To understand the views of young adults with Type 1 DM about self-care and services

ii) To review literature concerning prevalence of eating problems in young adults with Type 1 DM compared with peers and the association with glycaemic control.

iii) To investigate prevalence and predictors of eating problems in young adults with Type 1 DM.

Organisation of Thesis

This thesis includes seven chapters. Following this preface, chapter 1 is an overview of Type 1 DM and the specific problem as it applies to young adults. This information is not a comprehensive summary of the diagnosis and treatment of Type 1 DM but focuses on aspects that are essential for understanding the seriousness of the illness and the importance of good self-care.

Chapter 2 discusses provides theoretical context for the thesis. Specifically, it introduces the health belief model and evidence relating to the obstacles that must be overcome to perform health behaviour. Also discussed is the theory of impulse control from developmental neuroscience that might explain why overcoming distractions to health behaviour might be especially difficult for young adults than for adults. This is followed by a discussion of the competing demands to self-care that young adults might experience and the psychological difficulties that might be more common in this population.

Chapter 3 investigates self-care of Type 1 DM from a family perspective. Specifically it investigates how families manage the transfer from paediatric to young adult services and how self-care is affected after the young adult has transferred. Qualitative interviews were conducted with young adults (n = 26), their parents (n = 18) and staff (n = 13) from the multi-disciplinary team. The results suggest that the transfer from paediatric to young adult care is not problematic for young adults or parents but practical information about transfer would facilitate the process. Secondly, the results suggest that post-transfer, young adults want to be responsible for self-care and parents want them to be responsible for self-care. However parents have difficulty releasing control of care when they feel that young adults inadequately care for Type 1 DM. Young adults react by resisting any parental input and parents feel excluded.

Following from this, Chapter 4 focuses specifically on interviews with young adults, building on the themes of chapter 3 to identify the specific barriers and facilitators to self-care. We found that these were mostly oriented around social image and activities. Young adults neglected self-care if it conflicted with social activities or their social image. Young adults were willing to actively risk their health to maintain their social image. Facilitators to care were also oriented around social activities. Some young adults realised that if they cared for Type 1 DM they looked better and were well enough to take part in social activities.

As a next step we investigated the issue of eating problems in young adults with Type 1 DM. First, we conducted a meta-analysis (Chapter 5) of studies investigating eating problems. Specifically the meta-analysis aimed to determine the prevalence of eating problems, methodological considerations for measurement and the barriers to achieving good glycaemic control associated with eating problems. We distinguished between eating disorders (i.e. eating problems that met criteria for clinical eating disorders) and disordered eating behaviour (i.e. self-reported symptoms over a cut-off point on a continuous measure). We interpreted the findings to suggest that eating problems were relatively common (6.4% clinical eating disorders and 58.1% disordered eating behaviour) and consistently associated with suboptimal glycaemic control. The meta-analysis also provided evidence in support of previous arguments to suggest that generic measures of eating problems inflate indications of eating problems in young adults with Type 1 DM.

In Chapter 6 we therefore attempted to measure (in a sample of young adults with Type 1 DM, n = 99) the prevalence and predictors of eating problems and the role of eating problems in glycaemic control using a measure of disordered eating designed for and validated in a Type 1 DM population. We achieved a good response rate and found that eating problems were common in both males and females (36.1% in the overall sample, 50.0% in females and 15.4% in males) and were predicted by female gender, suboptimal glycaemic control, elevated BMI and (in the case of females) diabetes-related distress.

Chapter 7 summarises what we have learnt from the studies in this thesis. The results are discussed in relation to self-care and eating problems. For each, findings are discussed in the context of previous work and suggestions are given for how the findings further develop our understanding (clinical and theoretical implications).

Chapter 1 – Overview of Type 1 Diabetes

1.1 Chapter Summary

The purpose of this chapter is to give an overview of Type 1 DM and the problem of suboptimal glycaemic control in young adults with a view to emphasise the complexity and difficulty individuals face daily in managing this multifaceted illness. As a result it is hoped that the reader will understand the need for psychological intervention, and the difficulty researchers face in developing interventions that meet the needs of young adults with Type 1 DM.

The overview of Type 1 DM includes information about incidence; physiology; cause, symptoms and diagnosis; and treatment and complications. This is followed by a discussion of suboptimal glycaemic control in young adults and the need for psychological care.

1.2 Overview and incidence

Diabetes is a chronic disease characterised by higher than normal blood glucose levels (hyperglycaemia). The major defect in diabetes is an absence or relative deficiency of the hormone insulin, which governs the body's ability to metabolise glucose and use it for energy. The two main types of diabetes are type 1 diabetes (Type 1 DM), characterised by insufficient insulin production and type 2 diabetes (Type 2 DM) characterised by insulin resistance and impaired insulin secretion (WHO, 2011). This thesis is concerned with Type 1 DM.

Diabetes affects 2.8 million people in the UK, Type 1 DM is thought to account for 10% of all cases of diabetes (NHS, 2010). In children (0-14 years), incidence of Type 1 DM in the UK between 1990 and 1999 was between 15.3 and 26.4 per 100,000, per year and in the Yorkshire region 18.5 per 100,000 per year (The Diamond Project Group, 2006). The incidence of Type 1 DM in children (0-14 years) is increasing every year at an average rate of 4.1% in the UK (1998-2008) for reasons which are unclear (Imkampe & Gulliford, 2011; Patterson, Dahlquist, Gyürüs, Green, & Soltész, 2009) and 3% in Europe (0-15 years; Patterson et al., 2009). Incidence in young adults (15-34 years) between 2006 and 2008 was 15 per 100,000, per year and is increasing every year at an average rate of 2.8% (1991-2008; Imkampe & Gulliford, 2011).

1.3 The Pancreas, insulin and Type 1 DM

Insulin is an essential hormone that allows glucose to be metabolised and moved from the blood stream into the cells where it is used as energy. Insulin is secreted by the pancreas beta cells. A normally functioning pancreas constantly secretes low levels of insulin. The amount of insulin secreted is increased as glucose enters the blood stream from ingestion of carbohydrate or release of glucose from the liver. In Type 1 DM, the pancreas fails to produce insulin due to destruction of the beta cells which make insulin in the islets of Langerhans. Consequently glucose cannot be absorbed and abnormal concentrations remain in the blood stream, until it is eventually excreted in the urine (Norman, 2011b). Because the body cannot use glucose as energy, it breaks down fat instead. As fats are broken down, a by-product called ketones is produced and builds up in the body causing a condition known as ketoacidosis. Insulin treatment is essential to prevent immediate death (A.D.A.M., 2012).

1.4 Cause, symptoms and diagnosis of Type 1 DM

The cause of Type 1 DM is largely unknown, although an inherited susceptibility and viral infections are thought to be triggers. As the immune system attacks the virus it also inappropriately attacks insulin producing pancreatic beta cells. The destruction of these cells results in an insulin deficiency (Smith-Marsh & Walker, 2010a).

The abnormally high concentration of glucose in the blood (hyperglycaemia) is largely accountable for the symptoms of Type 1 DM. Symptoms typically occur suddenly and include excessive thirst, frequent urination, abdominal pain, nausea, vomiting, changes to menstruation, yeast infections, weight loss, blurred vision, confusion, fatigue and coma (Smith-Marsh & Walker, 2010c).

Type 1 DM is most commonly diagnosed when an individual presents with symptoms of hyperglycaemia. Typically a diagnosis is made by testing for raised blood glucose (Norman, 2011a). If diagnosis and treatment are delayed, a potentially fatal state of ketoacidosis may occur, clinical features of which include abdominal pain, nausea, vomiting, dehydration, over-breathing, and loss of consciousness. Ketoacidosis may be the first indication of Type 1 DM and requires hospital admission (Smith-Marsh & Walker, 2010b).

1.5 Treatment

Treatment of Type 1 DM is multi-faceted and largely self-managed. Most basically it involves insulin therapy, blood glucose monitoring, diet and exercise (National Institute for Health and Clinical Excellence, 2004). Current guidelines in the UK (National Institute for Health and Clinical Excellence, 2004) specify how care for young adults should be organised and are summarised in this section.

1.5.1 Insulin

Insulin regimens should be individualised, but generally young adults with Type 1 DM are offered one of three insulin therapy regimens. They can opt for: (i) *one, two or three insulin injections per day* (ii) *Multiple daily injections (basal bolus)* (iii) *Continuous subcutaneous insulin infusion (insulin pump therapy)*

One, two or three insulin injections per day involve individuals injecting a fixed dose mixture of short-acting and intermediate-acting insulin one, two or (in some cases) three times a day. *Multiple daily injections (basal bolus)* involves one or more injection a day of intermediate or long acting insulin (basal insulin) as well as doses of short acting insulin at meals (boluses) which are calculated based on blood glucose levels and the amount of carbohydrate consumed. The aim of a *multiple daily injections* regimen is to reproduce physiology (albeit imperfectly) by separating basal insulin and quick acting insulin. *Continuous subcutaneous insulin infusion (insulin pump therapy)* involves an individual wearing a programmable insulin pump that gives regular or continuous amounts of fast acting insulin via a subcutaneous needle or cannula. The aim of insulin pump therapy is that the constant infusion mimics basal insulin secretion. Patients can give additional insulin (boluses) with meals.

1.5.2 Blood glucose testing

Glycated haemoglobin (HbA_{1C}) is the amount of glucose attached to haemoglobins (red blood cells). HbA_{1C} is one of the most important clinical markers associated with Type 1 DM. Young adults should aim for an HbA_{1C} of 7.5 mmol/litre or lower without frequent disabling hypoglycaemia. HbA_{1C} should be monitored by clinicians 2-4 times a year and fed back to young adults immediately

Targets for short-term glycaemic control are 4–8 mmol/litre (pre-prandial) and 10 mmol/litre (post-prandial). Young adults are encouraged to use frequent short-term blood glucose monitoring and to record results in a diary. For individuals who are trying to improve their glycaemic control, blood glucose testing should be performed at least four times a day. Young adults on a multiple daily injection regimen are encouraged to adjust insulin dose dependent on blood glucose results. Young adults on a one, two or three insulin injections regimen are encouraged to adjust their insulin dose according to trends in blood glucose testing results.

1.5.3 Diet

Young adults with Type 1 DM should be offered dietetic support to help them manage weight and glycaemic control. As with any young adult, individuals with Type 1 DM should maintain a healthy and varied diet. However, it is especially important that young adults with Type 1 DM have a sound understanding of the nutritional properties of foods and especially of carbohydrates. Traditionally, individuals on one, two or three insulin injections a day would eat a very strict prescribed diet. However, the introduction of multiple daily injection regimens offers individuals increased flexibility in diet. However, individuals using a multiple daily injection regimen must adjust their insulin dose to reflect carbohydrate intake. This requires careful and accurate calculation of carbohydrate in all food consumed so that insulin can be calculated based on a prescribed insulin to carbohydrate ratio. Therefore these individuals should be offered education about insulin and dietary training.

1.5.4 Exercise

As with all young adults, those with Type 1 DM are encouraged to exercise on a regular basis. However, since exercise can affect blood glucose levels, young adults must understand how to manage insulin and diet when exercising to avoid exercise-induced hypoglycaemia. Specifically, young adults are encouraged to monitor blood glucose before and after exercise. This allows them to identify when changes in insulin or food intake are necessary to maintain target blood glucose. Often it is necessary to consume additional carbohydrate before exercise and carbohydrate rich foods should be kept nearby during exercise. Changes to daily exercise are likely to require adaptations to insulin dose or carbohydrate intake.

1.5.5 Managing care

Multi-faceted treatment provides a general model for care, but individual differences mean care must be individualised and adjusted accordingly. Often, establishing the best model of care for an individual involves trial and error. Young adults with Type 1 DM must take into consideration a number of other factors and how these will affect blood glucose. These include but are not limited to use of alcohol, tobacco and recreational drugs. Changes are also needed when feeling unwell or travelling.

1.6 Complications

Type 1 DM is associated with the risk of microvascular and macrovascular complications (The Diabetes Control and Complications Trial Research Group, 1993). Potentially fatal Type 1 DM related complications include cardiovascular disease (heart disease), nephropathy (kidney disease), retinopathy (eye disease), neuropathy (nerve damage) and complications in pregnancy (The Diabetes Control and Complications Trial Research Group, 1993). Cardiovascular disease accounts for 44% of deaths in Type 1 DM and nephropathy accounts for 21% of deaths (Morrish et al., 2001). Approximately 4,200 people in England are blind due to diabetes related retinopathy and this increases by 1,280 each year (Scanlon, 2008). Nearly all people with Type 1 DM are likely to have some degree of retinopathy within 20 years of diagnosis and although this does not affect eyesight, it may be a forerunner for proliferative changes which do (Scanlon, 2008). Neuropathy is estimated to effect up to 50% of individuals with diabetes (both Type 1 DM and Type 2 DM Boulton, Gries, & Jervell, 1998). Chronic painful neuropathy is estimated to affect 16.2% of people with diabetes (both Type 1 DM and Type 2 DM) compared to 4.9% of age and sex matched comparisons (Daousi et al., 2004).

The Diabetes Control and Complications Trial (DCCT; The Diabetes Control and Complications Trial Research Group, 1993) demonstrated that the risk of Type 1 DM related complications can be reduced by effectively controlling glycaemia through insulin therapy. Importantly for this thesis, this was also demonstrated in a subsample of adolescents (The Diabetes Control and Complications Trial Research Group, 1994) in which results persisted over 4 years (The Diabetes Control and Complications Trial Research Group, 2001).

1.7 Glycaemic control in young adults with Type 1 DM

The problem of suboptimal glycaemic control in young adults with Type 1 DM has long been recognised with only 17.1% (of young adults aged 16-24 years old) in the UK achieving recommended targets (The NHS Information Centre, 2007). Findings of the Epidemiology of Diabetes Interventions and Complications study (EDIC; The Diabetes Control and Complications Trial Research Group, 2001) and the recent National Diabetes Audit (NDA; The NHS Information Centre, 2011) demonstrate the urgency of the issue.

The EDIC study (The Diabetes Control and Complications Trial Research Group, 2001) followed up the young adult sub-sample from the DCCT trial (The Diabetes Control and Complications Trial Research Group, 1994) 3-4 years after the close of the trial. Findings indicated that suboptimal glycaemic control during the early years of Type 1 DM had a lasting detrimental effect on the development and progression of complications even after glycaemic control had improved. The NDA (The NHS Information Centre, 2011) indicated that young adults (15-34 years old) with Type 1 DM are nine times (females) and four times (males) more likely to die than the general population. Problems typically occur in mid-adolescence. The mean age of onset for suboptimal management is 14.8 years (Kovacs, Goldston, Obrosky, & Iyengar, 1992) and hospital re-admission for ketoacidosis, hypoglycaemia or poor control increases between 14 and 15 years (Glasgow et al.1991).

The advent of modern intensive insulin therapy (i.e. multiple daily injections) offers individuals increased flexibility in self-care (Devendra et al., 2004). Intensive insulin therapy can (when managed efficiently) be more effective in slowing the onset of complications compared to traditional regimens (The Diabetes Control and Complications Trial Research Group, 1993, 1994). Regardless, glycaemic control in young adults with Type 1 DM remains suboptimal to the extent that mortality is a real risk for many (The NHS Information Centre, 2011).

Rapid hormonal changes during this age period and poor absorption of insulin may in part explain suboptimal glycaemic control (Greene, 2001; Faulkner, 2003). However, other explanations suggest that suboptimal glycaemic control is a result of poor self-care (Skinner, Hampson, & Fife-Schaw, 2002; Skinner, 2009). Specifically it has been suggested that simultaneously managing an extremely complex chronic condition as well as the demanding tasks and transitions of young adulthood is difficult and self-care is impaired as a result (Weissberg-Benchell, Wolpert, & Anderson, 2007).

1.8 Summary and Conclusions

Type 1 DM is a complex chronic condition demanding equally complex self-care. The alarming situation of suboptimal glycaemic control in young adults with Type 1 DM is compounded by the findings of the recent NDA (The NHS Information Centre, 2011). Despite advances in Type 1 DM care, there has not been the corresponding improvement in glycaemic control that was hoped for in young adults. This implies that poor self-care is responsible for suboptimal glycaemic control. Managing a complex chronic condition in addition to the normal demands of adolescence has been held responsible for suboptimal glycaemic control. However it is unclear exactly how these interfere with self-care. Chapter 2 introduces theory and evidence that might help us understand the difficulties young adults face in managing self-care.

Chapter 2 Self-care in young adults with Type 1 DM

2.1 Chapter Summary

The purpose of this chapter is to provide a theoretical context for the empirical studies in this thesis. With the aim of understanding Type 1 DM self-care behaviour, this chapter utilises the health belief model and evidence relating to the performance of health behaviours. Theories from the field of developmental neuroscience are then used to understand why young adults have more difficulty performing health behaviour than adults might. In particular we discuss health behaviours in relation to impulse control. This is followed by a discussion of the competing demands to self-care that young adults might experience and the psychological difficulties that might be prevalent in young adults with Type 1 DM.

2.2 Introduction

Adolescence can be broadly defined as the second decade of life (Steinberg, 2007) and involves transition from childhood to adulthood (Allen & Gregory, 2009). Arnett (2000) describes the challenges of the transition period. Individuals must begin to take steps towards independence from parents and make decisions about their future. Normal challenges of the transition period include moving away from home, beginning work or new education, developing relationships, lifestyle, political and religious values, and making educational and vocational choices. According to Arnett, establishing independence from parents in modern society may be more prolonged than in previous generations. Individuals are staying in education for longer and leaving home later. As a result, young adults are financially dependent on parents for longer than they were in previous generations and the transitory period between childhood and adulthood is prolonged well into young adulthood.

Suboptimal glycaemic control in young adults with Type 1 DM is a serious concern given the associated risk of diabetes-related complications (The Diabetes Control and Complications Trial Research Group, 1994). This thesis is based on the widely acknowledged assumption that suboptimal self-care of Type 1 DM predicts suboptimal glycaemic control (Anderson & Wolpert, 2004; Skinner et al., 2002; Skinner, 2009). Young adults do not engage in self-care behaviour as effectively as adults contributing to suboptimal glycaemic control (Skinner et al., 2002; Skinner, 2009).

This chapter utilises evidence from the fields of health psychology and developmental neuroscience to understand why young adults might differ from adults in how they manage self-care. In particular this chapter discusses how individuals engage in health behaviour and the reasons that young adults have difficulty engaging in health behaviour. We also consider how both competing demands of young adulthood and psychological co-morbidity might affect self-care.

2.2.1 Predicting whether people engage in self-care behaviour

Self-care is an essential component of Type 1 DM management, and includes health behaviours such as blood glucose testing, calculating carbohydrate and insulin ratios, administering insulin, correcting blood glucose levels and testing for ketones (National Institute for Health and Clinical Excellence, 2004). Within the field of health psychology there exists a number of theoretical models that aim to predict whether people engage in health behaviours. In this thesis, the Health Belief Model (HBM; Rosenstock, 1966) is utilised as a framework for understanding whether people engage in self-care.

According to the health belief model (Rosenstock, 1966), intentions to perform any health behaviour are a function of an individual's beliefs about the health behaviour itself as well as the illness it is proposed to prevent. Specifically, these include perceived benefits and barriers of performing the health behaviour (tangible and psychological positive and negative aspects of an action), cues to action (events or strategies that activate 'readiness'), self-efficacy with respect to the behaviour (confidence in one's ability to take action), perceived susceptibility to the illness (perceived chance of getting a condition), and perceived severity of the illness (perceived seriousness and consequences of the condition).

Applied to self-care, an individual with Type 1 DM is typically aware of the risk of diabetes-related complications but considers their susceptibility to illness (i.e. perceived likelihood of developing diabetes-related complications) to be low because they have good glycaemic control. However, their glycaemic control deteriorates and consequently their doctor suggests that they use ratios and carbohydrate counting to inject appropriate doses of insulin before meals. The individual considers their *susceptibility to illness* to be increased and the *severity of illness* (i.e. diabetes-related complications) to be serious enough to warrant action. Therefore they consider the action suggested by their doctor (i.e. taking appropriate doses of insulin before meals) in terms of the *perceived benefits and barriers.* Although they perceive barriers to the prescribed course of action (e.g. embarrassment caused by injecting insulin in public), they perceive the benefits (e.g.

minimising the risk of diabetes-related complications) to outweigh the barriers. Progressive deterioration in glycaemic control and concern from the doctor serve as *cues to action.* Encouragement from the doctor installs a sense of *self-efficacy* (i.e. they believe they are capable of taking more insulin) in the individual and they make an intention to calculate and give appropriate doses of insulin before meals.

The HBM and other similar theoretical models (e.g. the theory of planned behaviour; Ajzen, 1991) have been criticised because, as demonstrated by a meta-analysis study (Webb & Sheeran, 2006)), intentions to perform behaviour do not necessarily result in the successful performance of behaviour. There appears to be another step involved in performing health behaviours. Empirical studies aiming to understand what prevents us from achieving our intended behaviour identified many obstacles that must be overcome to translate intentions into action (Gollwitzer & Sheeran, 2006). First, competing demands on situational attention and memory might mean that; an individual forgets to initiate behaviour (Milne, Orbell, & Sheeran, 2002), fails to seize an appropriate opportunity (Oettingen, Honig, & Gollwitzer, 2002) or is unwilling to act when an opportunity is identified (Gibbons, Gerrard, Ouelette, & Burzette, 1998; Shepperd, Hartwich, & Warshaw, 1988). Second, to sustain behaviour (e.g. inject insulin at meal times), we must suppress attentional responses and behavioural responses to more appealing distractions (e.g. eating and talking with friends). This can be made more difficult where more appealing behaviour has become automated (i.e. habitual) (Hodgkins & Orbell, 1998; Norman & Conner, 1993). For example an individual with Type 1 DM might habitually eat as soon as food is prepared. They are likely to have difficulty delaying this habitual behaviour so that they can first calculate the carbohydrate content of the meal and inject appropriate doses of insulin.

Thus self-care in Type 1 DM can be understood in terms of intentions and performance of intended behaviour. Consequently poor self-care is the result of either weak intentions or an inability to translate intentions into behaviour. Young adults differ from adults in their ability to regulate psychosocial influences on behaviour and this affects the performance of health behaviour.

2.2.2 Regulation of psychosocial influences on behaviour in young adulthood

The transition from childhood to adulthood is typically characterised as a turbulent time of life associated with higher prevalence of risk-taking behaviour compared with childhood and adulthood. For example, rates of drug and alcohol use, substance use, unemployment and delinquency are all more prevalent in adolescent compared with adult populations (Steinberg, 2007). However most risk-taking behaviour exhibited during this transitory period is also transitory and resolved before adulthood with few implications for the longer-term (Steinberg, 2004).

Many researchers have attempted to explain the reasons for this change in behaviour during the transition period. Traditionally researchers thought that young adults were less able to reason logically and consequently made poorer decisions than adults (Piaget, 1972). However, modern evidence indicates that logical reasoning is in fact fully developed by age 15 years (Reyna & Farley, 2006). Young adults are able to assess the risks of potentially dangerous situations as well as adults are. As such they can competently make informed logical decisions (Millstein & Halpern-Felsher, 2002).

Unlike logical-reasoning abilities, psychosocial capacities that improve decision-making and regulate risk-taking (e.g. impulse control, emotion regulation, delay of gratification and resistance to peer influence) continue to develop well into young adulthood (Steinberg, 2004). As such, young adults may make adequate decisions through logical reasoning. However, decisions are undermined by an inability to control impulses to engage in a risky behaviour, regulate associated emotions, delay gratification or resist peer influence (Steinberg, 2007). Thus, psychosocial immaturity may undermine what would otherwise be competent decision-making. In short, decision-making is only comparable to that of adults under conditions where psychosocial factors are minimised.

2.2.3 Performance of self-care behaviour in the context of young adulthood

Because young adults have difficulty regulating psychosocial influences on behaviour, they may find it more difficult to overcome obstacles to performing health behaviour. The performance of health behaviour is dependent on being willing to act in situ (Gibbons et al., 1998; Shepperd et al., 1988), remembering to act (Milne et al., 2002) and being able to ignore more appealing distractions (Hodgkins & Orbell, 1998; Norman & Conner, 1993). Psychosocial immaturity may make young adults less able than adults to overcome these obstacles. Applied to Type 1 DM, self-care in young adults is poor in relation to adults (Skinner et al., 2002; Skinner, 2009) because they are limited in their decision-making by psychosocial immaturity

Adults are able to more often than not overcome feelings (emotions) of unwillingness to perform behaviour, attentional and behavioural responses to distractions (that might make them forget to perform behaviour or engage in more appealing behaviours) and impulses to engage in risky behaviour. Consequently, self-care behaviour is frequently and consistently performed. However, young adults are less able to overcome their emotions and therefore may be less willing to perform behaviour. They are also less able to ignore attentional distractions and delay the gratification of more desirable behavioural distractions. Therefore they may forget to perform self-care behaviour or engage in other more desirable behaviour. Consequently, young adults do not engage in consistent self-care behaviour.

In practice, an individual with Type 1 DM might intend to calculate and administer insulin before meals. This involves serving up a meal portion, assessing or weighing each component of the meal, calculating insulin dose and injecting insulin. All before food is consumed. An adult is likely to be able to delay the gratification of eating when the food is ready. However, a young adult is less able to control their urge to eat immediately (behavioural response) as this would delay gratification. The enjoyment of eating may be so distracting that the young adult does not even remember that they should calculate insulin before eating.

Similarly, an adult with Type 1 DM might wish to control blood glucose better when socialising. Therefore they intend to reduce their alcohol consumption on evenings out with friends. Because adults can more often than not control psychosocial influences on behaviour, they successfully resist the influence of peers to drink excessively. Whereas, despite prior intentions to drink only small amounts of alcohol, in situ a young adult might have difficulty controlling their impulses or peer influence to drink more alcohol. In short, young adults make competent logical decisions about self-care, but in situ are less able than adults to control their impulses to more appealing distractions.

There is strong evidence from prospective studies to indicate that being able to control one's impulses is indeed predictive of health behaviours (Friedman et al., 1995; Siegler, Feaganes, & Rimer, 1995). Furthermore, the association between ability to delay gratification and health behaviour may occur directly and indirectly by means of health beliefs (Vollrath, Knoch, & Cassano, 1999). In Type 1 DM specifically, evidence suggests that adults who are able to delay gratification form stronger health beliefs resulting in better self-care (Christensen & Smith, 1995).

Given the multi-faceted nature of Type 1 DM management, an inability to delay gratification of more appealing distractions could be a barrier to many self-care behaviours. For young adults, the context in which behaviour is performed is very important. If interventions to improve self-care in young adults are to be successful, we must first understand the experiences of young adults with regard to self-care, the context in which self-care must be performed and obstacles to self-care. However as highlighted by Davidson, Penney, Muller, and Grey (2004) there is very little qualitative evidence investigating the challenges to self-care that young adults experience. Furthermore, the work that does exist was predominantly conducted in the 1990's and is outdated by the advent of intensive insulin regimens around the same time.

2.2.4 Competing demands of the transition period

Transition from childhood to adult life is challenging for any young adults (Arnett, 2000). However, those with Type 1 DM face additional burden (compared with healthy young adults) as they gain independence from their parents. They must learn to manage essential self-care in the context of the normal challenges of the transition period. Unlike their peers, young adults with Type 1 DM must also develop competence in managing highly complex self-care. They must assume increasingly more responsibility for a condition that is extremely difficult to manage and was most likely managed earlier in life by parents (Harris et al., 2011).

In addition to accepting responsibility for self-care on a daily basis, young adults also must negotiate changes in clinic organisation, including the transfer from paediatric to adult services (Pai & Schwartz, 2011). Unlike healthy adolescents for whom turbulence during adolescence has few implications for the long-term, for adolescents with Type 1 DM, disturbances in adolescence can have serious and enduring implications for future health (Anderson & Wolpert, 2004; Dyer, Lloyd, Lancashire, Bain, & Barnett, 1998).

Simultaneously managing an extremely complex chronic condition as well as the demanding tasks and transitions of young adulthood is difficult and self-care is likely to be impaired as a result (Weissberg-Benchell et al., 2007). Qualitative evidence supports the proposal that young adults have difficulty managing self-care in conjunction with normal demands of their age group. Davidson et al. (2004) conducted a qualitative study of 6 young adults with Type 1 DM. Young adults reported that Type 1 DM was a pervasive intrusion on their lives. The way that Type 1 DM affected their self-concept, social opportunities and social relationships was unacceptable to young adults. Self-care interrupted normal routines and young adults found it difficult to care for Type 1 DM out of the home. All of these concerns that young adults reported relate to the tasks typically associated with adolescence and young adulthood suggesting that indeed young adults have competing demands that make self-care difficult.

The limited abilities of young adults to control emotions and impulses (described earlier in this chapter) may make it harder for young adults to choose self-care over competing demands. They have more distractions from self-care than adults do and less ability to resist distraction.

2.2.5 Psychological functioning in young adults with Type 1 DM

In addition to managing the daily demands of self-care, young adults may experience depression, anxiety, disordered eating, maladaptive coping strategies, problematic transfer from paediatric to adult care and cognitive and behavioural disorders (Anderson, 2009; Kipps et al., 2002). A seminal study conducted over a decade ago (Bryden et al., 2001) aimed to determine the psychological course of Type 1 DM through adolescence and the relationship with glycaemic control into young adulthood. Young adults (n=76) aged 11-16 years at baseline were assessed on a number of psychological measures (anxiety, depression, behavioural problems, self-esteem and eating attitudes) and re-interviewed as young adults (20-28 years of age). Results showed associations between psychological problems at baseline and mean glycaemic control over the follow up period.

Psychological issues in young adults with Type 1 DM pose a significant dilemma in that self-care, which is so crucial to effective management, might actually increase susceptibility to psychological illness. Depression, anxiety and eating problems are all thought to be more prevalent in young adults with Type 1 DM than in healthy young adults (Bryden et al., 1999; Bryden et al., 2001; Fairburn, Peveler, Davies, Mann, & Mayou, 1991; Kovacs, Mukerji, Drash, & Iyengar, 1995; Mayou, Peveler, Davies, Mann, & Fairburn, 1991; Rydall, Rodin, Olmsted, Devenyi, & Daneman, 1997). This suggests that the burden of managing self-care promotes psychological problems. In particular, some researchers have argued that although modern intensive insulin regimens potentially offer more flexibility in care, they can also place more stress on individuals (Davidson et al., 2004). This argument is supported by higher prevalence estimates in modern studies of psychological co-morbidities in young adults with Type 1 DM compared with older studies involving older insulin regimens (Hood et al., 2006).

Eating problems in particular pose an extremely complex problem in the care of young adults with Type 1 DM (Colton, Rodin, Bergenstal, & Parkin, 2009). A study published in the British Medical Journal (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000) found that clinical eating disorders and non-clinical disordered eating behaviour were more prevalent in adolescents with Type 1 DM compared with healthy adolescents. Furthermore, they were associated with poorer glycaemic control. Eating problems also are potentially triggered by body dissatisfaction and drive for thinness from weight gain as a result of insulin therapy (Nielsen & Mølbak, 1998). Unfortunately, the association between insulin and weight means that neglecting or sabotaging self-care (by taking less insulin than necessary) can in fact be used to control or lose weight at the expense of metabolic control (Jones et al 2000). One study described the transition period as a time of experimentation with eating habits and weight. Consequently, even those who do not express concerns about weight may engage in insulin manipulation (Logan et al., 2008).

The complexity of eating problems in this population poses many unanswered research questions. In particular, controversy surrounds claims that eating problems are more common in young adults with Type 1 DM compared with peers (Young-Hyman (Young-Hyman & Davis, 2011). The association between being overweight and eating problems is also not well established (Markowitz, Lowe, Volkening, & Laffel, 2009).

2.2.6 The current studies

The context in which young adults manage self-care and their experience of managing self-care are not well understood. The beliefs of young adults about self-care are important to understanding how young adults form intentions to self-care and the barriers and facilitators to care that they experience. Given the lack of qualitative work in this area, very little is known about the beliefs of young adults in relation to self-care. The qualitative work in this thesis (chapters 3 and 4) was designed with the aim of increasing knowledge in these areas.

In addition the studies in chapters 5 and 6 of this thesis were designed to increase knowledge about eating problems in young adults with Type 1 DM. In particular we aimed to increase knowledge about the prevalence of eating problems in young adults with Type 1 DM and variables associated with eating problems.

2.3 Summary and conclusions

Young adults are less able than adults to control their impulses. This immaturity is likely to make the performance of Type 1 DM self-care behaviours more difficult than it is for adults. Competing demands such as the normal demands of young adulthood are also likely to make self-care more difficult for young adults compared to adults. There is a lack of qualitative work investigating the context in which young adults manage self-care and the barriers and facilitators to care that they experience. The next chapter introduces a study that aims to increase knowledge in these areas through qualitative interviews with young adults, parents and members of a Type 1 DM MDT.

Chapter 3 - The Transition Period in Type 1 DM: Transfer, Self-care and Family Interactions

3.1 Chapter summary

The period between childhood and adult life (often referred to as the transition period) is particularly demanding for individuals with Type 1 DM. To avoid Type 1 DM-related complications later in life it is important that individuals engage with health services and maintain good self-care. However, little is known about the needs of young adults and their families during this transition period. Therefore health services for this age group may be less effective than they might be.

This study aimed to increase knowledge about the critical transition period in the context of the family.

Semi-structured interviews were conducted with young adults with Type 1 DM (aged 11-21 years, n = 26), their parents (n = 18) and healthcare professionals (n = 13) recruited from clinics in South Yorkshire. Interviews were analysed using thematic analysis. Findings were organised into two themes; *transfer from paediatric to transition services* and *managing self-care*.

Young adults looked forward to *transfer from paediatric to transition services*. Few experienced problems other than administrative issues (e.g. inefficient transfer of medical notes). Nevertheless young adults thought that to facilitate transfer, services should make available practical information (e.g. directions to the transition clinic and a guide to processes at the transition clinic). Like young adults, parents were not concerned about *transfer,* but they expressed concerns about the organisation of care post-transfer. Specifically, they worried about being excluded from clinic and from care. Staff placed little emphasis on the event of *transfer* itself and more on care afterwards. They viewed transfer as a point at which young adults should assume more responsibility for self-care.

Post-transfer, young adults mainly still wanted parental assistance in *managing self-care,* but also wanted to be in control of their own self-care. It was important that parental involvement did not intrude on this. Parents wanted their child to be responsible for their own self-care too. However, parents understood the reality of Type 1 DM-related complications. Therefore if they perceived that the quality of self-care was deteriorating as young adults took over, they had difficulty releasing control of care fully. Young adults were frustrated at being unable to control their own self-care. This caused family disagreements and in some cases young adults deliberately excluded parents from care.

Like parents, staff thought young adults should take responsibility for care. They empathised with both parents and young adults. They recognised that parents did not want to fully release control of care to young adults because the self-care skills of young adults were not good enough to maintain good glycaemic control. At the same time they realised that young adults wanted to be in control of their own self-care.

The results of this study suggest that transfer is not particularly troublesome for families. However self-care after transfer is a more complex issue. The quality of self-care demonstrated by young adults often does not meet expectations of parents and staff. Thus young adults may benefit from age-appropriate Type 1 DM education to improve their self-care skills. Better self-care in young adults may reassure parents so that they feel less need to intervene with care. This may subsequently reduce the frustration that young adults feel towards parents when they interfere. Motivational interviewing skills for parents may also be beneficial so that they can develop non-confrontational communication skills and support young adults in directing their own care.

3.2 Introduction

In chapter 2 we discussed the challenges young adults face in effectively managing Type 1 DM. During the transition period, young adults must manage the normal demands of young adulthood alongside complex self-care. Self-care might be compromised by psychosocial immaturity and further complicated by psychological co-morbidity. Given these challenges and the implications for suboptimal self-care (The Diabetes Control and Complications Trial Research Group, 1994, 2001), it is crucial that Type 1 DM services support young adults effectively.

To facilitate the transition period, young adults with a chronic condition should be given the opportunity to develop a transition plan with the assistance of their MDT (Allen & Gregory, 2009; Department of Health, 2006, 2008). The plan should be flexible and adaptable but should specify how care will be arranged and support organised. It should address how the impact of illness on future choices can be minimised and independence maximised. A procedure for transfer to adult services should also be specified in the plan. As the time for transfer approaches, the MDT in paediatric, transition and/or adult services should communicate to ensure efficiency and continuity in care. Guidelines for young adults with chronic conditions and corresponding services have been criticised. Allen & Gregory (2009) suggested that there is a lack of empirical evidence about the needs of transitioning young adults and as a result services are not grounded in evidence.

Likewise, Pai and Schwartz (2011) suggested that recommendations to guide transition are underdeveloped due to limited evidence.

In short, little is known about what makes a successful transition service. This is supported by a recent scoping review that aimed to identify formally evaluated, successful models of transition for young adults with complex health care needs (Watson, Parr, Joyce, May, & Le Couteur, 2011). For diabetes specifically, 14 models were identified (five UK-based) and included paediatric to adult transition clinics, residential camps and computer training. Results indicated that few service models provided information about service evaluation or formally evaluated the experience of users and providers against outcome measures. Research evaluating the success of transition services has also been criticised for a tendency to focus on easily accessible medical outcomes. Whilst these are important, developmental and psychosocial outcomes (e.g. adherence, resilience, quality of life, coping and self-efficacy) are often neglected (Amaria, Stinson, Cullen-Dean, Sappleton, & Kaufman, 2011).

One UK transition clinic reorganised services with the input of young adults and evaluated the service 3 years later (Logan et al., 2008). In focus groups, young adults aged 18-23 years olds were asked about current services and their needs for a new service. Important elements of a new service included evening clinic sessions run by a designated MDT (consultant diabetologist, DSN specialist registrar, specialist dietician and a clinical psychologist), choice in which member of the MDT young adults saw and four-monthly appointments. Young adults were unwilling to commit additional time to attend group educational sessions. The transition service in Newcastle was reorganised based on the results. In addition, young adults received a letter (copied to their GP) following each clinic visit summarizing the agreed plan for care and DSN communicated with young adults between clinic appointments and rescheduled missed and cancelled appointments. At 3 year follow-up improvements were seen in attendance and HbA1c (mean HbA1c: 9.7% at first appointment vs. 9.0% 8 months later, $p<0.05$). However there were no improvements in Median HbA1c and those achieving HbA1c <7.5%.

Logan et al. (2008) published one of the first studies that attempted to understand the clinical needs and preferences of young adults with Type 1 DM. The current study aims to extend this understanding so that we can understand not only the needs of young adults for services, but also the context in which they must manage care and the challenges they face. To deepen our knowledge in these areas, we thought it important to interview young adults individually as this would allow an in depth discussion. The transition period often involves the hand-over of self-care from parents to young adults. To fully understand the context in which young adults manage Type 1 DM, we considered it equally as important to interview parents of young adults with Type 1 DM. Parental perspectives on how their child cares for Type 1 DM and family interactions over Type 1 DM might provide valuable insight into how to improve self-care. We also considered it important to include members of the MDT to provide an objective, medical perspective on self-care amongst young adults.

The current study aims to further understand the transition period from the perspective of young adults, their families and the MDT with the assumption that this will provide (i) insight into the needs of young adults and parents during transition and (ii) evidence to inform the development of specialist Type 1 DM transition services.

3.3 Method

3.3.1 Sample

Currently in Sheffield, Type 1 DM care is organised in Paediatric departments for those under 16 years and there is an adult service for those over 21 years. Type 1 DM services are held across two sites (Royal Hallamshire and Northern General Hospitals). At each site, a specialist transition service is available for young adults between the ages of 16 and 21 years to prepare them for adult services. Young adults (*n* = 26, aged 11-21 years) were recruited from both the transition and paediatric services (to establish experience prior to, and after transfer) across both sites and from an additional transition service at Barnsley General Hospital. Inclusion criteria were diagnosis of Type 1 DM for more than one year, and current age 11-21 years. Exclusion criteria were diagnosed additional chronic illness, severe learning difficulties or lack of fluency in English that would jeopardise the interview process. To ensure the sample was broadly representative of the clinic population individuals were selected for interview ensuring variation in terms of gender, clinic site, insulin regimen and metabolic control.

Parents of young adults (*n* = 18) and staff members from the MDT (*n* = 14) were recruited from each of the clinics from which young adults were recruited.

3.3.2 Procedure

Ethics approval was gained from the York Research Ethics Committee (appendix 3.1). Recruitment took place between April and July 2010. DSN identified eligible young adults (and accompanying parents) from clinic lists and introduced them to the researchers. The researcher explained the aims of the study and answered questions.

Young adults who were interested left their contact details with researchers. An invitation letter (appendix 3.2) together with an information sheet for young adults (appendix 3.3) and for parents (appendix 3.4) was sent by post or email to those who expressed interest. For individuals under 16, an invitation letter (appendix 3.5) and information packs (including an information sheet for parents; appendix 3.6 and an age-appropriate information sheet for children; appendix 3.7) were sent to parents. Approximately one week after the information sheets were sent, researchers contacted young adults (or parents of those under 16) by telephone and asked if they and/or their parents would like to participate. If contact could not be made by telephone on the first attempt, a further three attempts were made by telephone, email or text message. If on the fourth attempt there had been no contact, it was presumed that the individual no longer wished to take part. In addition, DSN contacted young adults who missed clinic appointments by telephone to ask if they would like to receive information about the study. Information packs were sent to those who were interested, and researchers attempted to contact individuals in the same way as those who attended clinics. Interviews took place at the University of Sheffield Psychology department or in individual's homes. Attempts were made to rearrange interviews where appointments were missed. At interview young adults and parents gave informed consent to take part in the study (appendices 3.8 and 3.9 respectively). For children, parents gave informed consent for themselves and their child to take part (appendix 3.10) and the child gave assent (appendix 3.11).

The clinical lead for the transition clinic identified members of the MDT who worked in transition clinics. Staff were invited to participate via email and appointment times arranged. Staff interviews took place at the University of Sheffield, Department of Psychology or at the individual's place of work.

3.3.3 Interview/measures

A semi-structured interview schedule (appendix 3.12) was designed by researchers and comprised three main sections: i) Views of clinic and experience of transfer ii) Family, friends and life activities and (iii) Views about what services should provide. All interviews were audio recorded and subsequently transcribed for analysis.

3.3.4 Epistemological Approach

This study was undertaken from a pragmatic perspective. Therefore duality associated with traditional epistemological approaches (reality vs. the experience or knowledge of reality) was not a concern. Instead, focus was given to the research problem, the methodological approaches that could be applied to understanding the problem and the consequences of the research (Creswell, 2003). As such a qualitative approach was considered most appropriate to understanding in depth views of young adults with Type 1 DM about living with Type 1 DM.

3.3.5 Analysis

Thematic analysis (Benner, 1985) was selected as the most appropriate method of analysis for the current study. Thematic analysis involves the systematic grouping of units of text into categories (codes). Related codes are subsequently organised together into themes (Polit & Hungler, 1983). By assigning meaning to sections of interview data, data can be described whilst keeping the relations between codes intact so that the interviews can be understood as a whole (Miles & Huberman, 1994).

Thematic analysis was considered the most appropriate method to interpret the current data because, consistent with the pragmatic epistemological approach, it allowed us to answer specific research questions. In addition, compared to other techniques of qualitative analysis, thematic analysis is associated with less risk of interpretation bias.

Interviews were analysed separately for staff, parents and young adults/children using thematic analysis (Benner, 1985). We followed the six stages for analysis described by (Braun & Clarke, 2006) involving; familiarisation with the data, generation of initial codes, generation of themes, reviewing of themes, naming of themes, reporting results. Here each stage of the process is described. As with any thematic analysis, the procedure was not linear and involved moving between stages to ensure that the process was completed thoroughly.

3.3.5.1 Familiarisation with the data

Interview transcripts were each read through once. No data were coded, but emerging patterns in the data were noted (e.g. data that seemed related or similar).

3.3.5.2 Generation of initial codes

The notes that were made during the first reading of transcripts were developed as transcripts were read for a second time. As such a framework of related or reoccurring data items (codes) was constructed. To ensure meaning of the data was preserved, codes were generated using participant's own terminology. A memo specifying meaning accompanied each code added to the framework. Codes were assigned a numerical identifier. Each data item was assigned to one or more code using the numerical identifiers. As analysis progressed, codes were split and merged as necessary (e.g. codes were split if data items assigned the same code varied in meaning. Codes were merged if data items assigned to the same code represented the same idea). To ensure that all patterns and important concepts were identified all data items were given equal attention. Assigning a code to each data item even if it seemed irrelevant ensured this.

3.3.5.3 Generation of themes

The coding framework was reviewed and given more structure by identifying broader patterns in the data. Specifically, codes that were related, similar, or formed a pattern were grouped to form over-arching themes. This involved assessing which codes were feasible under themes and how themes related to each other. The new framework of proposed themes was taken forward to the next stage.

3.3.5.4 Reviewing of themes

A search of the data was conducted to find evidence that supported or refuted proposed themes. Specifically, a tabulation of potential themes was compiled with data extracts that supported and refuted themes. Themes were selected and rejected based on the data extracts. If during this process it became apparent that two themes were linked, they could be merged. If there was diversity within themes, subthemes could be created and if necessary additional themes added. Data extracts were compiled to assess new themes. Once the framework was considered adequate, returning to data for each theme and ensuring that themes represented data accurately checked the validity of themes.

3.3.5.5 Naming of themes

Themes were given names that reflected the content. Within the overarching themes, subthemes were developed to reflect diversity in data that were related (e.g. concepts with opposite positions/opinions) and to tell a story within each theme.

3.3.5.6 Reporting results

Themes that addressed the research questions were chosen for inclusion in the final report. Descriptions of each theme were written with the aim of conveying the complex story of the data. Results are reported in this thesis.

3.3.6 Reliability

Inter-rater reliability is the degree of consistency with which data are assigned to the same category by different coders. To ensure reliability of our analysis, a subsample of interviews (10.3% of the total sample; young adults n = 2, parents n = 2 and staff n = 2) were analysed by a second coder using steps 1 and 2 for thematic analysis (described in section 3.3.5). Coders categorised 89.2% of data (text from interview transcripts) into the same categories indicating a high level of shared understanding of the data. Discrepancies (10.8%) were resolved through discussion.

3.4 Results

3.4.1 Sample characteristics

In total, 89 families agreed to receive information about the study. All of these were subsequently contacted by telephone or email, 35 families (young adults n = 34, parents n = 1) refused participation and 54 families agreed to take part. Of the 54 families that agreed to take part a total of 31 families took part (parent and child n = 15, child only n =13, parent only n = 3). The remaining 23 families either missed interview appointments that could not be rearranged, decided not to take part or became un-contactable.

In total, 28 young adults, 18 parents and 14 members of staff were interviewed. Two interviews with children under 16 years were excluded from the sample because the child responded throughout the interview either positively or negatively, but did not elaborate on answers. Therefore the final sample consisted of 26 young adults, 7 of which were attending paediatric services and 19 attending transition services. As expected given our recruitment strategy, there was a wide range of metabolic control within the sample, (HbA_{1C} range = 40 – 114 mmol/mol (5.8 – 12.6%), mean = 72 mmol/mol (8.7%); paediatrics: HbA_{1C} range = 62 – 84 mmol/mol (7.8 - 9.8%), mean = 73 mmol/mol (8.8%); transition services: HbA_{1C} range = 40 – 114 mmol/mol (5.8 – 12.6%), mean = 72 mmol/mol (8.7%)) and there was a range of Type 1 DM regimens (including multiple daily injections, insulin infusion pump and one/two injections daily). Of the 18 parent interviews (16 mothers, 1 father and 1 interview involving both a mother and father), 11 were with parents who had children who attended a paediatric clinic (all mothers) and 7 were with parents who had children who attended transition clinic. All but two of the parents' children were also interviewed. The 14 members of staff (males = 8) interviewed included one clinical lead, four consultants, four DSN, three dieticians, one registrar and one clinical psychologist. Staff were recruited from the transition (*n* = 7) or paediatric care team (*n* = 3). Four members of staff worked across both teams.

3.4.2 Themes

Although a number of themes emerged from the interviews, many of these were specific to parents, young adults or staff. However all three groups discussed *transfer from paediatric to transition services* (example quotes available in table 2.1) and *managing self-care* (example quotes available in table 2.2).

3.4.3 Transfer from paediatric to transition services

The theme of *transfer from paediatric to transition services* emerged from three subthemes: *significance of transfer*, *facilitators to transfer* and *difficulties in transfer* (See table 2.1 for example quotes). Within the theme of *transfer from paediatric to transition services* there were no differences between those who had transferred and those who had not and so the data are presented for all young adults together, and then for parents and staff.

3.4.3.1 The significance of transfer

Young adults described transfer from paediatric to transition services as an inevitable, logical step that was an integral part of growing up. For most, it was not associated with any special anxiety, but was seen to be comparable with other situations, such as transfer from primary to secondary school or home to university. Even so, some were eager to make the move whilst others were more apprehensive. For all, transfer was a significant and positive event resulting in much sought after independence, progression towards adulthood or simply moving on from an environment that was considered noisy and childish.

Parents' views paralleled those of young adults, they saw transfer to be an integral part of the process of growing up and attaining independence. They saw the transfer to be one of a number of events that occurred during this stage of life. Transfer was not only about changing clinics but also about acquiring greater responsibility for care. Parents considered it to come at an entirely appropriate age (about 16 years old).

Staff also saw transfer to the transition clinic as part of the overall progression from childhood to adult life, but placed little significance on the event itself and more on the transition period that followed. They considered the start of this transition to be marked by transfer from paediatric to transition services but thought that self-care and responsibility developed more gradually into adulthood.

3.4.3.2 Facilitators to transfer

Young adults, parents and staff all thought that the presence of familiar paediatric staff in the transition service was invaluable. Apart from the familiar face, it negated the need for families to explain their history to staff over again. Even so, more information prior to transfer could facilitate the move. Specifically, parents and young adults suggested that practical information about the clinic location, transport and how the clinic functions would be helpful. A pre-transfer visit to the transition clinic was also suggested.

3.4.3.3 Difficulties in transfer

Young adults had very few worries about transfer and where difficulties did occur they were often a result of administrative errors, including inefficient or untimely transfer of medical records and inefficient booking of appointments. Parents were more likely than young adults to have difficulties and these were often related to uncertainties. Parents were worried about how their child would be affected after transfer and if they were prepared for what the change might involve. Parents were concerned the child would be affected by unfamiliar approaches to care, they were unsure about their own role and worried about being excluded from the clinic. Most concerns subsided post-transfer, with parents largely reporting no difficulties related to the new clinic for their child or themselves. Where there were difficulties, it was because parents felt they were excluded from care. They felt inadequately informed about appointment times and clinic discussions between their child and staff.

Staff realised that some young adults might experience difficulties in transfer. According to staff, a young adult's experience of transfer was unpredictable and dependent on differences between clinics. They described how some clinics were led by inexperienced registrars or might appear especially rushed and disorganised. The emphasis by staff was on the atmosphere in clinic after transfer and they were less likely to discuss anticipatory concerns. These staff also acknowledged that some young adults adjusted poorly after transfer. They attributed increased non-attendance at the transition clinic (compared with Paediatrics) to difficulties with the unfamiliar process of clinic and the level of responsibility expected.

Table 3.1 Example quotes from young adults, parents and staff regarding the significance of transfer.

Theme: The significance of transfer		
Young adults	**Parents**	**Staff**
Just like going into another episode of your life with diabetes (Y20) You expect it [transfer] really don't you? You have to get older. (Y12) In the Northern one you get treated better like more grown up. You	I think the transition needs to start earlier, they just sit there and you can see them looking at the little kids and thinking what am I doing here? (P10) I think the one at the Hallamshire's better for her now because she's not in	Some are relieved that they're actually going to get some meaningful adult advice because they've outgrown paediatrics. (S05) Some of them have outgrown the sort of environment at the

don't have like little kids running around. You've got people your own age. (Y09) I think I had a choice. I could have gone then or waited a bit longer till I was I think 16 to go. But I just decided I'd just go anyway (Y03)	with the little kiddies because that was a big thing (P06) At the end of the day Children's was alright for him cause he was young, small and now he's getting older its a lot better for him to go to the Northern (P04)	Children's Hospital (S02) It's just another phase of getting independence really so they've got to get on with it. (S04) Well it has to happen. So I think it's inevitable. I think we probably could do it better than we do. (S13)
Theme: Facilitators to transfer		
Young adults	**Parents**	**Staff**
Best thing was the fact that I kept the same doctors and that. Its just because you feel comfortable with them. (Y05) My nurse since I was 5 is still there but the rest of the staff had changed but they're all friendly and nice and they like know me when I go in now. (Y07)	It was no different because you were still seeing the ones you saw at the Children's, you know what I mean, so it weren't as though you had to go and explain it all over again. (P07)	By then they'd already built up some contact with us so it wasn't such a strange transition. (S11)
Theme: Difficulties in transfer		
Young adults	**Parents**	**Staff**
It was ok. I just went there by myself. I was dropped off. I went in and I found the place by myself so I suppose it was quite scary but it felt good to be able to do that by myself. (Y01) I hated it when they like put discharged on, I felt right upset cause I'd been there for like nearly 10 years and then you just get kicked off somewhere else but it's just part of life really isn't it? Just like school you've got to move	It is 16 isn't it yeah? That's a difficult time they don't need any more added complications. And then obviously they're treated a bit more like adults. But they're not actually. Not at 16. (P01) It worries me, its not just me personally its X. Its that change, she's been going there since she was 2 and I think she'll be frightened (P08) For the adolescent clinic it would be nice to know when the appointments are	Some of them hate coming because it's not the Children's 'cause the Children's is all like a little cocoon and this isn't. (S07) Sometimes they [young adult at first appointment in transition clinic] might hit a good day and they might end up meeting quite a lot of the team and feel like they've had quite a good introduction and sometimes you know if you've just got again registrars doing the clinic who maybe haven't really

up to secondary and college and whatever. (Y08)	because they let X know and X arranges and such like but then as her mother, I know its that transitional period and supporting her more than us, but we don't know when the appointments are. (P06) I am concerned about her moving to the adult clinic to be honest cause I don't know what sort of things you're going to see there. (P09)	thought that perhaps this is quite a big deal, it's their first appointment at young persons clinic. (S01)

N.B. S = staff participant number, P = parent participant number, Y = young adult participant number, X indicates an individual's name has been removed

3.4.4 Managing self-care

The theme of *managing self-care* emerged from three subthemes: *Managing care, developing responsibility for care* and *family interactions* (example quotes are available in table 2.2).

3.4.4.1 Managing self-care

Preliminary analyses of the data suggested that the way people talked about managing self-care differed depending on whether the young adult involved was cared for in paediatrics (and therefore in our sample of under 16s) or in the transition clinic (and therefore in our sample of 16-21 years olds). For that reason we report these data separately.

Children and young adults *attending paediatric services* and their parents described how they worked together as a family to manage care. However, parents thought that as guardians, they were ultimately responsible and oversaw all components of care, as they did for any other aspect of their child's welfare. They were responsible for ensuring their child was happy and healthy, so caring for Type 1 DM became a logical part of this. Parents' descriptions of the tasks were detailed and included subtle and complex tasks (e.g. calculating carbohydrate in snacks, anticipating the effects of exercise). In contrast, children and young adults *attending paediatric services* tended to report that they completed most care tasks themselves, albeit with some assistance from parents. However, their descriptions of the tasks were less detailed than those of parents perhaps indicating that they did not understand exactly what was involved. They described the more tangible tasks (e.g. injecting insulin and blood glucose testing). Few described the more subtle or complex tasks (e.g. ordering equipment, anticipating the effects of exercise, meal planning, carbohydrate counting, or calculating insulin dose).

Young adults *attending the transition clinic* and parents both reported that although parents assisted with care, young adults were responsible for their own care. Young adults generally liked a degree of continued parental involvement. Parents still helped with organisational tasks (e.g. collecting prescriptions), in an advisory role (e.g. a second opinion for carbohydrate counting) and/or when care did not go to plan (e.g. in the case of hypoglycaemia or illness). Young adults who refused parental assistance were in the minority and even these young adults wanted assistance at times.

Staff were keen to report that there was no concrete rule for how care is best managed within families, recognising individual differences in readiness for responsibility. However, an ideal situation might be where care is the responsibility of the young adult but parents are on hand for guidance, much as described by young adults and parents above.

3.4.4.2 Developing responsibility for care

According to young adults, responsibility for care increased naturally as they became more independent in life (e.g. going out independently with friends, moving from high school to sixth form, starting work or moving to Type 1 DM transition services). However, they often recognised that they did not manage responsibility for care well. They admitted that other priorities (e.g. wanting to spend time with friends, eat erratically and/or experiment with alcohol) interfered with, and took precedence over, self-care.

Parents recognised that it was important for young adults to become responsible for their own care and so largely encouraged it. However, some parents worried that increased responsibility could be overwhelming because of the complexity of self-care and subsequent intrusion on the other interests of young adults. They thought their child might be placed under an unnecessary burden. They wanted their child to be similar to their friends and to relieve some of the inconvenience of self-care. Parents also felt that they would be excluded from care as the young person became more responsible, and so some were reluctant to encourage it.

Other parents were keen for their child to take on more responsibility for self-care but found it difficult to make this happen without compromising the quality of care. Many reported that as they released control of care, the quality of care deteriorated because young adults were ineffective at self-caring. Parents' fears about their child developing complications were stronger than their wish for their child to take responsibility for care. Therefore they were unwilling to release control of care.

Staff views were mostly consistent with those of young adults and parents. Although they recognised the need for parental and staff support, they thought most young adults should increasingly be responsible for care. Some exceptions to this were young adults with learning difficulties or physical disabilities. Staff thought young adults were generally reluctant to develop responsibility and equally some parents were reluctant to relinquish control of care. Staff regarded it a mistake to exclude parents completely or give a young adult too much responsibility prematurely. They saw it as their role to encourage responsibility in young adults and persuade parents to surrender control of care and develop an advisory role instead.

3.4.4.3 Family interactions

Mostly young adults and parents reported little serious conflict regarding Type 1 DM. Parents often worried about how their child was managing Type 1 DM and the quality of self-care. Parents described a difficulty in striking a balance between allowing their child to have freedom and ensuring health. Although they wanted their child to be able to lead a normal life, they also wanted it to be a long life and they recognised the reality of consequences for suboptimal glycaemic control. As described under the theme of *developing responsibility for care*, this made parents reluctant to release control of care to young adults. Not being allowed to control self-care frustrated young adults and led to disagreements with parents. However, both young adults and parents tended to normalise Type 1 DM related disagreements in the context of general disagreements common during adolescence. They saw it as a typical, inevitable part of young adults assuming more responsibility for care.

Families who experienced more extreme conflict were in the minority. Nevertheless, some young adults responded to parents who would not allow them to be in control of their own self-care by resisting parental input completely. They felt unable to negotiate care with parents and so refused to involve them even though they knew this distressed their parents. In these cases, parental input was viewed as interfering, irritating and/or confrontational. They felt parents expected better management without understanding how difficult self-care was. Parents of these young adults realised their input was perceived by their child as confrontational and understood the anger it caused. They disliked interfering, but felt it was preferable to letting their child become ill or die.

Staff were aware that for some families interactions over Type 1 DM were difficult. They recognised a danger in ‘refereeing’ between parents and young adults. Parents asking staff at clinic to rebuke their child for neglecting care was common. Staff were to some extent unsure how to deal with difficult family interactions, but tried to acknowledge concerns of young adults and parents. They often agreed with the views of parents about the poor quality of self-care exhibited by young adults, but recognised that young adults wanted parents to let them control their own care. Some staff thought parents were let down by transition services. Inconsistent messages (e.g. advising them to withdraw from care in some instances and encouraging their involvement in others) made parents unclear about their role in transition.

Table 3.2 Example quotes from young adults, parents and staff regarding managing self-care

Theme: Managing care		
Young adults (attending paediatric services)	**Parents (of young adults attending paediatric services)**	**Staff**
My mum helps me a lot [with care tasks] (Y08). Yeah I have to wash my hands and everything before and test it [blood glucose] then I have to show like my mum…Yeah me and my mum do it [give insulin] (Y02)	I said you work it out and then we’ll decide together if that’s right. (P13) I think he just thinks ‘My mum will sort it. (P02) I seem to do all the ordering the repeat prescriptions and making sure there’s enough in stock. That’s my job. (P14)	There’s no hard and fast rule [for how self-care is managed between parents and children]. It is, in some young people, entirely appropriate that they do everything. In others it’s entirely appropriate that parents still do everything. And usually it’s somewhere in the middle.’ (S03)
Young adults (attending transition services)	**Parents (of young adults attending transition services)**	**Staff**
Sometimes I'll say to my parents 'How much insulin do you think I ought to have for that?' I mean I have a rough idea but just to check. (Y04) But even now if say like in the middle of the night if I'm in hypo I	He checks his blood and if he’s concerned he’ll mention it to us and we can always check it on his blood meter. (P05) Now and again I’ll help him. But he seems to manage it well himself to be honest with you. (P07) Don’t know when clinic	Ideally mum is there in a parental role but guiding as opposed to making decisions. (S06)

would still call my mum. (Y14) Well my parents do stuff like ordering my prescriptions and stuff like that and getting snacks and stuff so yeah (Y16) I suppose they've got to the stage where I've asked them to kind of leave me to it but they're still really worried about it so they do but they try not to get too involved in it I suppose. (Y01)	appointments are, she's very 'its mine'. (P06)	
Theme: Developing responsibility for care		
Young adults	**Parents**	**Staff**
As I've grown up they've kind of stepped back a little bit and I want to do it on my own. (Y04) I can be going out with my friends and I'll be drinking and drinking and drinking and not thinking anything of it, you know to have some food to stable it out so I don't go low. Then all of a sudden I'll go low and be like oops forgot about that, I need some food. (Y25)	Yeah. I think sometimes I hang back and you know like say no come on you can do it yourself but step back and you know make sure he was doing it? (P07) I have to be on top of him all time. I don't mind. But I'm just thinking ooh I hope he gets a grip for when he gets older. (P02)	With a young person they have to take responsibility and that's the hard bit and part of our job, part of the trick is getting them to take that responsibility and encouraging, enabling the parents to back off and let them do it. (S04) I don't think side lining the parent completely is necessarily a good idea.' (S13)
Theme: Family interactions		
Young adults	**Parents**	**Staff**

Yeah because like me and my mum, we can get into arguments all the time about my sugars and that and why my sugars are high but she doesn't see where I'm coming from with how frustrating and annoying it is (Y25) I'm very good at taking things on myself you know responsibility wise? My mum and dad help a lot just with little things…I'm pretty good [at controlling diabetes]. – (Y14).	We have had little tiffs. Because he knows what he's doing but then I think I know what he should be doing. (P04) We're just having a bit of a phase at the moment where he just won't, just can't be bothered to do it. (P13) But it becomes a big thing when she won't reason with you in any way, shape or form. She knows she's going hypo but she won't have anything to correct it. So you try and encourage her and then you get to the frustration part. You think that she's going end up being really poorly' (P06) I pick my moment and I confront her. She usually throws a strop and I shouldn't be checking up on her and stuff, yeah its quite upsetting [that diabetes is not being looked after]. (P08)	The parent thing is, I find it quite difficult. I had a parent who came in last week with a 17 year old. He just basically wanted me to tell this boy off. (S01)

N.B. S = staff participant number, P = parent participant number, Y = young adult participant number, X indicates an individual's name has been removed

3.5 Discussion

Transition services have been criticised for failing to meet the needs of young adults (Allen & Gregory, 2009; Pai & Schwartz, 2011). To improve self-care and ensure the future health of young adults with Type 1 DM we must increase awareness of their multi-faceted needs and implement this knowledge in services. This study aimed to go some way in increasing knowledge of the needs of young adults with Type 1 DM. Two broad themes were identified from interviews with young adults, their parents and staff from their MDT. These were *transfer from paediatric to transition* services and *managing self-care*.

3.5.1 Transfer from paediatric to transition services

Successful transfer from paediatric to transition/adult services is a crucial component of any service for young adults with Type 1 DM. Individuals who lose contact with services have poorer outcomes (Anderson & Wolpert, 2004; Dyer et al., 1998). However, clinic attendance during the transition period is problematic, with many young adults missing arranged appointments and losing contact with services (Kipps et al., 2002). Therefore it is critical that we understand the transfer needs of young adults and organise services accordingly. The results of this study go some way towards doing this.

The results indicate that although transfer is significant for young adults with Type 1 DM and their parents, most do not worry about it and their needs for transfer itself are in fact relatively simple. To facilitate transfer, it is important for both young adults and parents to see familiar staff from paediatrics at transition clinics. Staff believe that difficulties in transfer occur as a result of young adults seeing unfamiliar, inexperienced registrars at their first appointment in the transition clinic. Practical information prior to transfer is also important. Young adults and parents want to know about the clinic location, how they can get there and what the clinic process will involve.

Although the needs of young adults for transfer are minimal, it is perhaps the remainder of the transition period (post-transfer) that can be most difficult. For both young adults and parents, transfer from paediatric to transition services signals a change in self-care. Specifically, young adults take more responsibility for care and parents less. Young adults look forward to managing their own self-care and parents recognise it is necessary. However, some parents worry about how care will be organised post-transfer. Staff have few concerns about transfer beyond the administrative practicalities. Instead they stress the importance of how self-care is managed post-transfer. Managing self-care is discussed in the following section.

3.5.2 Managing self-care

Previous work indicates that good self-care is associated with better glycaemic control (Amaria et al., 2011). Continued parental involvement in self-care can be beneficial for young adults but the quality of family interactions impacts on the quality of self-care (Betz & Smith, 2011; Grey, Davidson, Boland, & Tamborlane, 2001; Murphy, Wadham, Rayman, & Skinner, 2007). Effective family interaction in self-care and a lack of conflict are associated with better health-related quality of life (Weissberg-Benchell et al., 2009) and glycaemic control (Anderson et al., 2002). In a study investigating parent/child responsibility for self-care (Betz & Smith, 2011), the authors suggest that we ought to understand exactly how families share responsibility. The results of the present study increase knowledge of how families interact and share self-care together.

Findings indicate, as might be expected, that organisation of care differs pre- and post- transfer from paediatric to transition services. Pre-transfer, young adults might complete certain self-care tasks themselves, but parents direct and manage care. Post-transfer, young adults start to direct self-care themselves (not necessarily successfully) and seek parental assistance when necessary. Young adults mostly still want a degree of parental support post-transfer for collecting prescriptions, checking calculations with and providing back-up when care does not go well. Nevertheless, it is important that young adults to not perceive parental input in care to be too controlling.

Although young adults perceive the hand-over of care to develop alongside general independence in life, parents are more conscious of the process and often experience difficulty in handing over care. Although they often very much would like to hand over responsibility for self-care to their child, they sometimes feel that their child will not successfully manage self-care. Parents are very aware of the complications associated with suboptimal glycaemic control. This makes them hesitant to fully surrender their control of care. Being unable to fully control their own self-care frustrates young adults and as a result family disagreements can occur. Families normalise disagreement over care viewing it in the context of general disagreement common of adolescence. Even so, some families experience more extreme conflict whereby young adults resent and resist parental input completely.

Staff empathise with both parents (being unable to release control of care) and young adults (wanting to fully control self-care), but are unsure how to ease the process. They are careful not to exclusively align with young adults or parents during consultation. They think families are let down by a system that fails to support parents or enable families to clearly define individual roles in self-care as they change. This is supported by previous work that found during the transition period families become confused about who is responsible for different elements of care (Butner et al., 2009).

The current study builds on results of previous work that found parents worry about their future participation and have difficulty surrendering control as young adults develop independence (Reiss, Gibson, & Walker, 2005). It describes the reasons *why* parents have difficulty releasing control of care to young adults (i.e. because they worry about complications associated with suboptimal management and do not believe their child is effectively self-caring).

Although previous work indicated that effective family interactions result in better self-care, it was unclear what difficulties within the family can interfere with better self-care. The findings of this study increase knowledge of the types of difficulties families experience in managing care and have implications for services. Specifically, services should aim to improve self-care skills of young adults. This may go some way to reassuring parents who doubt the ability of their child to self-care sufficiently and as a result are reluctant to release control of care. Young adults want to be in control of their own self-care with non-confrontational, supportive parental input. Therefore, it may be beneficial for services to also work with parents to improve communication skills and enable them to develop a supportive role in care.

3.5.3 **Implications**

The findings of this study have implications for improving the quality of the transfer from paediatric to adult/transition services and the way services support families in managing self-care post-transfer.

3.5.3.1 Implications for transfer from paediatric to transition services

Based on the results of this study, there are a number of practicalities that transition services might address to ensure efficient transfer.

Services should ensure that:

1. young adults and parents meet familiar staff from paediatric care at the new clinic.
2. practical information is provided to both young adults and parents about the location of the new clinic, how they can get there and what the procedure at the new clinic will involve.

3. transferral of medical notes and referrals to the new clinic is organised by one designated person for each young adult to ensure efficiency.

3.5.3.2 Implications for managing self-care

Based on the results of this study, there are a number of self-care management issues that transition services might consider to improve family interactions and self-care.

Services should:

1. consider introducing age-appropriate education for young adults to improve self-care skills

2. work with parents to enhance communication skills and enable them to develop a supporting (rather than directing) role in care (e.g. Diabetes oriented family intervention - DOLFIN; Ismail & Treasure, 2009).

3.5.4 Strengths and limitations

Together the results from the two themes discussed in this chapter go some way to broadly understanding the context in which young adults manage self-care and increasing knowledge to inform services. Previous quantitative work indicates that family difficulties are associated with poorer self-care. Through qualitative methods, this work provides a more detailed understanding of the sorts of family difficulties that may interfere with good self-care.

Limitations of this study include the possibility of a response bias whereby individuals presenting in clinic differ from those who do not attend. There is also a possibility of a response bias in our parent sample since young adults were often unwilling to allow their parents to participate. This is reflected by a smaller sample of parents from the young adult clinic (compared with paediatric clinic) and may explain why we found little extreme conflict between young adults and parents within the sample. The staff we interviewed work in a programme of care specifically for transitioning young adults. Therefore their views may not be representative of staff in other diabetes centres (although some staff also worked in paediatric services).

The strengths of this study include the use of a semi-structured interview schedule and structured analysis procedure. We followed standard recommendations for analysis of qualitative data and checked reliability across two independent coders. The interviews were conducted by skilled psychology postgraduates, in patients' homes or other sites away from the clinic setting where they were likely to feel confident. Furthermore, we recruited young adults and children with a broad range of HbA_{1C} and insulin regimens. Finally the staff sample also included a range of disciplines involved in Type 1 DM care and is likely to be representative of specialist transition services in the UK.

3.5.5 Generalisability of results

Given the sampling strategy of this study and the diversity in young adults that took part (e.g. age, site, glycaemic control) results of interviews with young adults are likely to be highly generalisable to young adults attending other specialist Type 1 DM transition services in the UK. However, because we were unable to recruit young adults who regularly did not attend clinic, the results might not be generalisable to individuals who are lost to follow-up or regularly miss clinic appointments.

The results of interviews with parents are likely to be generalisable to other parents of young adults with Type 1 DM given that the sample size was adequate to identify themes. However, results should be generalised with some caution given that 13 young adults were interviewed without parents and this was largely because young adults did not want their parents to be involved. As such the sample of parents might be biased including only those parents that were allowed by young adults to be involved .

Because, every member of the specialist transition clinic team took part in interviews, the staff sample is likely to be highly generalisable staff in other specialist transition services. However, in locations where services are organised differently, these results should be generalised with caution.

3.6 Conclusion

This chapter presented results of an interview study, which aimed to broadly understand the context in which young adults with Type 1 DM must manage self-care. Two themes of *transfer from paediatric to transition services* and *managing self-care* emerged and had implications for how services i) organise transfer from paediatric to transition services and ii) address management issues in self-care. In the next chapter young adult interviews are analysed in further depth

Chapter 4 - Self-care in Young Adults with Type 1 DM: Barriers and Facilitators to self-care

4.1 Chapter summary

In chapter 3, we described a qualitative interview study of 26 young adults with Type 1 DM, parents and staff. Results indicated that managing self-care was an important theme warranting further investigation. Therefore we conducted a thematic analysis of interviews with young adults to identify barriers and facilitators to self-care. Findings were organised into four themes; *Burden of self-care, barriers to self-care, facilitators to self-care* and *requirements from services.*

Young adults felt overwhelmed by the *burden of self-care* because they knew that it would be life-long. They understood that they would never be able to have a break from the time-consuming tasks that tainted every day life. Burdensome self-care made them different from their friends at a time when being socially accepted was imperative. Unlike their friends they were unable to be spontaneous. Every time they left the house they had to consider what they would eat and what equipment they would carry.

Because young adults were very socially oriented, *barriers to self-care* were also oriented around social issues. Specifically, self-care tasks that interfered with social activities or threatened social image were avoided. This could mean not wearing insulin pumps at times when they could not be concealed, avoiding injecting insulin in public and prioritising time with friends over spending time on self-care. Moreover, when they were out with friends, young adults were willing to deliberately raise blood glucose (to dangerously high levels) to avoid embarrassing themselves as a result of hypoglycaemia.

Facilitators to self-care were also socially oriented. Friends who were supportive of self-care could be motivational. Young adults wanted to gain the approval of friends and were conscious of letting them down by being unwell and unable to participate in social activities as a result of poor self-care.

With regards to *requirements from services,* young adults wanted specialist transition services to consider their individual needs and lifestyles rather than prescribing care. This mostly (but not always) specifically meant the social priorities that most young adults had. Young adults thought that it was impossible to manage self-care to the standard expected (by staff and parents) as well as doing all the things they wanted to do. They wanted self-care to be organised around their lifestyle and not to organise their life around self-care.

The results of this study suggest that social activities and image are so important to young adults that they will prioritise them over self-care regardless of the risk to health. Services currently fail to enable young adults to organise their self-care around these priorities. This could in part explain why young adults do not self-care appropriately.

If self-care conflicts with the priorities of young adults, it will simply be avoided regardless of the potentially devastating consequences. Clinicians organising specialist transition services and Type 1 DM education ought to consider how self-care can be organised around individual lifestyles and priorities rather than prescribing an incongruous plan for self-care.

4.2 Introduction

Chapter 3 described a qualitative interview study and reported two themes common across interviews with young adults, parents and staff; *transfer from paediatric to transition services* and *managing self-care.* Although the actual transfer from paediatric to transition services was relatively uncomplicated for young adults, managing self-care post-transfer was complex. In this chapter we explore some of the challenges that might explain difficulties with self-care post-transfer.

Good self-care is associated with lower glycaemic control (Amaria et al., 2011). However, young adults with Type 1 DM do not manage self-care as well as adults do (Skinner et al., 2002; Skinner, 2009). As discussed in chapter 2, this might be explained by theories of psychosocial development, which argue that impulse control is not fully developed until well into adulthood (Steinberg, 2007). As such young adults with Type 1 DM are heavily influenced by distractions to self-care and their peers. Furthermore, the competing demands of young adulthood (Weissberg-Benchell et al., 2007) mean that young adults have more distractions to self-care than adults do. Current services are thought to be inadequate in supporting young adults with self-care (Allen & Gregory, 2009).

There is little qualitative evidence that investigates the experience of young adults in managing self-care of Type 1 DM. The evidence that does exist is limited by small samples or the use of focus groups, which do not allow in depth individual perspectives to be recorded (Davidson et al., 2004; Diabetes Federation of Ireland, 2009; Logan et al., 2008). However the results of these studies indicate that young adults feel that Type 1 DM impacts on their family and school life. They feel abnormal as a result of their condition, compromising the strong desire to be aligned with peers. Young adults are limited with regard to the activities in which they can participate in (e.g. staying over at friend's houses). Not carrying equipment necessary for self-care (e.g. blood glucose monitors) in social outings is commonplace even though such activities often involved eating.

It is arguable that the results of previous qualitative work indeed suggest that self-care is a secondary priority to young adults in the context of social interactions and that current services do not support them well. Further to the themes from our qualitative work reported in chapter 3, we found other themes relating to self-care that support and extend the findings of previous qualitative work.

The aim of this chapter is to report results from our qualitative interview study that relate specifically to self-care of Type 1 DM in young adults. In particular this chapter describes from young adults' perspective, the burden of self-care, barriers and facilitators to self-care and requirements from services.

4.3 Method

Interviews were organised and conducted as described in chapter 3. In total 26 young adults were interviewed. Themes were developed in the same way as described in the methods section of chapter 3. Inter-rater reliability for the themes reported in this chapter was calculated for 3 (11.1%) interviews. Agreement between coders was 87% and discrepancies (13%) were resolved through discussion.

4.4 Results

From the data, four themes were identified. These were *burden of self-care, barriers to self-care, facilitators to self-care,* and *requirements for services.*

4.4.1 Burden of self-care

The theme of *burden of self-care* emerged from two sub-themes; *life-long self-care* where young adults were troubled by the knowledge that self-care was a life-long task and *feeling different from friends* where young adults resented the ways self-care made them dissimilar to their friends.

4.4.1.1 Life-long self-care

Young adults were troubled that self-care would be necessary for their entire life. Type 1 DM was a life-long condition and it was impossible to have a break from self-care. This knowledge was at times upsetting to young adults since self-care was a time-consuming burden that complicated everyday routine tasks and tainted enjoyable experiences. Although young adults recognised that parents and staff tried to empathise with them, only someone who had Type 1 DM could understand the endless reality of self-care. Therefore, young adults thought parents and staff did not wholly understand their frustration at having to self-care every day for their entire life.

4.4.1.2 Feeling different from friends

Friends and social activities were extremely important to young adults. They wanted to be socially accepted, but Type 1 DM made them feel different from friends. They disliked the attention that it brought to them and some felt isolated by this. Like their friends, they wanted to be sociable and spontaneous. However, they had to be more organised than their friends. Every time they left the house, they needed to consider what and when they would eat and what medical equipment and food to carry. They were unable to be impulsive and carefree like their friends. Some young adults were also conscious of inconveniencing friends or drawing attention to themselves by having to eat at certain times or complete self-care tasks. Young adults thought such a level of structure and organisation was unrealistic for their age and were frustrated that their parents thought it was appropriate.

4.4.2 Barriers to self-care

Wanting to be like friends was so important for young adults that it actually posed significant barriers to effective self-care. The theme *barriers to self-care* emerged from two subthemes; s*ocial barriers* where self-care compromised social image and activities and *time-perspectives* where competing demands for time meant that self-care was compromised.

4.4.2.1 Social barriers

Young adults often neglected self-care when it threatened to compromise social image or activities. Social image and/or activities were so important that young adults always prioritised them over self-care tasks even when it meant risking their health. This manifested in a number of ways. Firstly, they disliked carrying or wearing self-care equipment (e.g. insulin pumps) when it might compromise social image. For example when they wanted to carry a small handbag or wear tight clothing. The need to wear insulin pumps compromised fashion to such an extent that young adults chose not to wear them. Secondly young adults were reluctant to perform certain self-care behaviours when it might compromise social image. In particular, for some young adults who disliked people watching them inject insulin it was preferable to let their blood glucose get dangerously high instead of injecting insulin in public. Thirdly, some young adults intentionally raised their blood glucose levels (to dangerously high levels) by omitting insulin to avoid embarrassing themselves in public as a result of hypoglycaemia. This was especially common when consuming alcohol. Young adults were aware that alcohol could cause blood glucose to lower suddenly and thought it preferable to induce a state of high blood glucose than become hypoglycaemic and out of control.

4.4.2.2 Time perspectives

Young adults purposely minimised the time they spent on self-care so that they could maximise the time they spent with friends, working or studying. This was especially true when life was busy. Self-care was ignored in favour of more important activities. Blood glucose monitoring in particular was neglected. Young adults did not want to acknowledge high readings because they knew they were indicative of poor health and they found this upsetting. They felt that blood glucose testing was the most time-consuming of all tasks. Too high or low readings meant they should complete additional care tasks (e.g. giving insulin or eating carbohydrates and re-testing) and this was too demanding for young adults.

Longer-term time perspectives also created barriers to self-care. Specifically young adults felt justified in delaying care in the short-term so long as they intended to improve in the future. They thought that so long as they controlled Type 1 DM later in life, it was acceptable to ignore it in the short-term. Young adults often set a time-scale in which they would improve care and this nearly always related to a significant event (e.g. after exams, going travelling, starting work or going to university). They admitted that in the interim they intended to self-care as little as possible. They acknowledged that they were risking their health and were aware that other people with Type 1 DM developed complications. However, the possibility of experiencing complications themselves was not tangible enough to motivate them to engage in better self-care.

4.4.3 Facilitators to self-care

Although social priorities often hindered self-care, the importance that young adults placed on social activities and image could also be a facilitator to self-care. The theme facilitators to self-care emerged from two sub-themes; *Social facilitators* were ways in which friends encouraged self-care. *Minimising burden* was when young adults realised that Type 1 DM would be less disruptive to social image and activities if it were well managed.

4.4.3.1 Social facilitators

For some young adults having supportive friends could motivate them to engage in self-care. They sought the approval of friends and disliked letting them down. Friends reminded young adults to complete specific self-care tasks (e.g. blood glucose testing and insulin). However, young adults did not report that friends helped them with or reminded them about the more complex tasks of self-care (e.g. ratio calculations). Wanting to participate in social activities could also motivate young adults. They worried about missing out on what their friends were doing and wanted to be well enough to join in. They also disliked letting their friends down if they could not participate. Consequently consideration for the emotions of friends and partners and fear or missing out on social activities could become a motivation for good self-care.

4.4.3.2 Minimising burden

Although all described how self-care interfered with social image and activities, some young adults realised that good self-care resulted in less interruptions to these important priorities. Specifically they thought they would look better, feel healthier and be less lethargic if they managed self-care properly. This was important to them, they wanted to look good, feel well and have the energy required to enjoy day-to-day life. Young adults who had neglected self-care and subsequently experienced complications or ketoacidosis sometimes gained insight from their experience. They realised that good self-care resulted in fewer Type 1 DM-related complications and became motivated to self-care so that they could avoid further complications.

4.4.4 Requirements from services

The theme of requirements from services emerged from three sub-themes. Young adults wanted transition services to provide *consistency in consultations* with regards to seeing the same consultants and getting consistent advice. They also wanted staff and parents to have *appropriate expectations for self-care*, and most importantly they wanted *individualised care*.

4.4.4.1 Consistency in consultations

Young adults rarely saw the same doctor each time they visited clinic. The inconsistency was frustrating because different doctors involved in their care knew little about their interests and lifestyle. Therefore doctors could not appropriately advise them about self-care. Doctors had to search through notes, which wasted time in clinic, and decisions made at previous consultations were not remembered or followed up. Young adults thought that consistency in consultations should be a fundamental element of service.

4.4.4.2 Appropriate expectations

Some young adults thought that the expectation for self-care was too much at their clinic. Self-care was so complex, involving many different components and it was impossible to manage all of these at the same time. They thought that clinic staff were experts in Type 1 DM from a medical point of view but did not understand the reality of fitting self-care into every day life. This in part was due to seeing different doctors at each clinic so that doctors did not understand their every day life. They thought staff focused too heavily on medical outcomes (e.g. HbA_{1C}) and had unrealistic expectations that could only be met if they did nothing else in life but take care of Type 1 DM. Conversely, other young adults thought that staff expectations for self-care were low. They felt that staff went through a repetitive process in clinic and did not really try to help young adults improve their self-care. They wanted to be challenged more by working towards specific goals for each clinic visit that were followed up proactively by staff.

4.4.4.3 Individualised care

The overarching requirement that young adults had for transition services was *individualised care.* Young adults needed a service that enabled them to tailor and organise self-care around their own lifestyle and priorities. They were frustrated by generic or prescriptive advice from staff that they could not realistically apply to their lives. Again young adults felt that this was largely a result of seeing different members of staff at each consultation. Doctors were unable to give them advice suited to their priorities because they did not understand their lifestyle. The need for individualised care was also reflected in what young adults wanted from Type 1 DM education. They thought it important that Type 1 DM education covered lifestyle topics. They wanted to learn how they could tailor self-care to their specific situation (e.g. what to do when drinking alcohol, managing Type 1 DM in social situations). They also wanted to know what would happen in the future (e.g. during pregnancy or if Type 1 DM-related complications occurred.

Table 4.1 Example quotes from young adults regarding self-care

Theme: Burden of self-care	
Life-long self-care	It's hard at times and like its quite, it can get upsetting from time to time. It's like you always know its there. (Y08) Diabetes is a pain yeah. Even though people say it doesn't, it's you know, it's just, cause its there all the time I think. (Y05) Yeah they [staff and parents] seem to understand to a degree but I guess you only understand to a degree unless it's your life. (Y24)
Feeling different from friends	Its made life more stressful I think and it's also made me feel a bit different to everyone else, compared to before when I was just an equal I suppose you could say. (Y01) I think it makes you stick out. I hate it, I like to blend in with the

	crowd. (Y14) I used to get bullied about it cause I was the only person in the school that had it and I used to think I was special, one time the other kids turned on me and started picking on me just calling me names and stuff. (Y13) It's just in your mind before I'd go out or something, am I going to eat while I'm out? Should I take my insulin pen with me? (Y17)
Theme: Barriers to self-care	
Social barriers	I was going out all the time and I used to take my insulin pump off because when you're wearing short dresses and stuff. (Y07) It's like I don't like people watching me do it. They're just sort of staring and talking about it. I don't like it, I don't like people looking. It's a bit awkward. (Y13) I think when I just got older then my priority became making it possible for me to just do everything that I wanted to do so in other words not having hypos was more important to me than not having high blood sugar because if I had hypos I'd start to feel ill and might keel, so as I started going out drinking and just having a more active lifestyle my priority shifted. (Y23).
Time perspectives	When I'm busy and I've got things on my mind I definitely don't test my blood glucose. (Y03) Just injecting like it's very quick and easy and simple whereas if you test your blood sugar you have to get it out on the and do it all and stuff. (Y11) If you do have a high sugar level or a low sugar level you're supposed to test a few times after that and you don't necessarily want to over and over again until it goes down or goes up again. It's just wasting time. (Y01)
Theme: Facilitators to self-care	
Social facilitators	My friends are a big help. Yeah make me do it; they do remind me to do it .(Y05)
Minimising burden	There's nothing really that I've thought I can't do that because I've got diabetes. (Y11) If you're just managing it well then it's just like it's easier. It's much less of a burden if you're taking care of it. (Y23) Yeah I can notice it in my appearance as well like I'll look drained or I just don't look as healthy as I would do if I'm controlling it well on a good day. My skin gets drier, dark circles round my eyes things like that. Which kind of make me snap back into doing it properly to try and make myself feel healthier. (Y01)

Theme: Requirements from services	
Consistency in consultations	See the same one [consultant] all the time cause if you see different ones you've got to get used to the new person and get to know them again. (Y09)
	Like maybe it would be better to see the same consultant every time just because then they kind of know your history instead of sit there like reading the notes. (Y11)
Appropriate expectations	I suppose the doctors do look at it from the emotional side but they're looking at it more from the results and it's harder than maybe they think it is. (Y01)
	I think one of the main things I thought about like the expectation is quite low, if you just sort of went along and said your things then you'd just be left alone. I think if I was running it then I would try and make it a bit more fierce maybe in some ways. (Y24)
	Even though that is their job, they want to keep you safe and everything I just think yeah, I can't always be the best diabetic all the time. (Y05)
	I think you need to think about each person's different aren't they? You've all got different lifestyle and it can be difficult to fit their advice into. It can be difficult to do blood tests with the hours I work and stuff and so yeah I think you need to think about each person's different and they've got a different like routine. (Y07)
	It's like sometimes when I was younger they were like talking to me as though I didn't know what I was talking but I've had it for well probably about 16, 17 when they were saying it. (Y11)
	She [mother] doesn't see where I'm coming from with how frustrating and annoying it is and that its, I don't know, it doesn't rule my life but it's always there in the background. (Y25)
Individualised care	More how to handle everyday situations like school. What to do when you're in school and when you're out with your friends because that's more relevant to you. (Y01)
	What happens if you were to just get pregnant. (Y03)
	Yeah. I'd have liked to have known what would happen if it all went wrong because at least you're prepared for it. (Y05)

N.B. Y = young adult participant number, X indicates an individual's name has been removed

4.5 Discussion

Good quality self-care of Type 1 DM is important for achieving optimal glycaemic control (Amaria et al., 2011). Results reported in chapter 3 suggest that managing self-care is an important theme amongst young adults with Type 1 DM, parents and staff. We were interested in further exploring self-care and in this chapter conducted a second analysis of interviews with young adults. In particular we were interested in the specific barriers and facilitators to self-care as well as what requirements young adults have for specialist transition services.

Our results indicate that self-care poses an arduous burden for young adults. It interferes with social activities and makes them dissimilar to friends at a time when being socially accepted is crucial. It is therefore unsurprising that the main barriers to self-care occur when social activities or image are threatened. Social priorities are so important that young adults are willing to neglect self-care to protect them. This means that time-consuming self-care tasks (e.g. blood glucose testing) are not completed in favour of spending time with friends. Furthermore, to avoid social embarrassment and preserve social image, other self-care behaviours are neglected at times when they cannot be managed discretely (e.g. injecting insulin when others can see or wearing an insulin pump when clothing will not conceal it).

Given the complications that are associated with high blood glucose, the willingness of young adults to risk high blood glucose by neglecting self-care is extremely concerning. Even more concerning is the fact that young adults are also willing to risk raised blood glucose to minimise the risk of social embarrassment. Because young adults fear hypoglycaemia in public they may intentionally omit insulin to raise blood glucose. This is especially common when young adults are drinking alcohol because they understand that alcohol can cause blood glucose to drop suddenly. This provides support for, and extends findings of previous work in young adult males (13-18 years) suggesting that individuals who fear hypoglycaemia and are socially aware (e.g. fear negative peer evaluation) adhere less to the Type 1 DM regimen (Di Battista et al, 2009). Our results suggest that fear of hypoglycaemia and being socially oriented are also likely to be associated with less adherence to the Type 1 DM regimen in females. Furthermore, our results describe the ways in which young adults do not adhere to treatment (e.g. by not wearing pumps and omitting insulin) and in which contexts (e.g. when they cannot disguise pumps, when out drinking, when they fear being embarrassed).

Although there were significant barriers to self-care, our results also suggest facilitators that might encourage young adults to engage in self-care. Like barriers to self-care, facilitators are also oriented around social priorities. Young adults may want to avoid becoming ill in the short-term in case they disappoint their friends (e.g. by being unable to participate in activities). Young adults also may have particular friends from whom they seek approval. If these friends are supportive of self-care behaviours, young adults are encouraged to perform behaviours to ensure approval. Nevertheless the support of friends to facilitate self-care may be limited given that friends only help with the more tangible tasks of self-care (e.g. blood glucose testing) and not the more complex tasks (e.g. calculating ratios). These results support previous work indicating that although supportive friends have no effect on HbA_{1C} (Helgeson et al. 2009; Bearman and La Greca, 2009), they can improve specific self-care behaviours (e.g. blood glucose monitoring) (Bearman and La Greca, 2009).

A second facilitator to self-care is the realisation that although it is a burden, better self-care may in fact *reduce* the overall burden of Type 1 DM. Young adults may be motivated to self-care if they think it will make them look and feel healthier and have sufficient energy to enjoy social activities. These findings extend those of previous work indicating that young adults are motivated by the possibility of controlling Type 1 DM in the short-term as opposed to preventing future complications (Department of Health, 2006; Harris et al., 2011; Skinner, John, & Hampson, 2000). Our findings give specific details of *what sorts* of short-term gain young adults are motivated by.

Our findings suggest that young adults with Type 1 DM have a number of needs that are inadequately addressed by specialist transition services. This supports previous suggestions that transition services are failing to meet the needs of young adults (Allen & Gregory, 2009). The overarching reason for dissatisfaction amongst young adults is a lack of individualised care. Earlier results clearly demonstrate that young adults prioritise their individual interests and lifestyle over self-care. If self-care is prescribed and not individualised to fit around the interests and lifestyle of young adults, it will be avoided. Currently young adults do not feel that care is individualised. They believe that staff focus heavily on clinical outcomes and neglect discussion about how self-care can fit in around lifestyle demands. Seeing different doctors at each clinic compounds the issue since doctors may not know the individual interests and lifestyles of young adults. Whilst young adults appreciate the importance of clinical outcomes they want staff to understand the reality of achieving good glycaemic control in the context of other lifestyle demands. Many young adults believe that staff do not acknowledge this and therefore have unrealistic expectations for self-care. As a result young adults dismiss advice they are given by staff as redundant in the context of their lifestyle. Our results support previous work indicating that patients believe healthcare professionals overestimate the importance of clinical outcomes and underestimate the importance of quality of life (Puder, Endrass, Moriconi, & Keller, 2006).

4.5.1 Strengths and limitations

The results in this chapter emerged from the same sample as in chapter 3. Thus, the strengths and limitations outlined in chapter 3 also largely apply to the results in this chapter. The most important limitation for both chapters is arguably that young adults who were interviewed were probably relatively well functioning given that they were prepared to be interviewed. Thus the findings provide evidence for the barriers and facilitators to self-care experienced by relatively well functioning young adults.

4.5.2 Implications

The results of the second analysis of young adult interviews further the family focused results of the first analysis of interviews (reported in chapter 3) and have implications for theory and clinical practice .

Specifically results imply that young adults are motivated to self-care not by the possibility of *long-term* complications but by *short-term* improvements in wellbeing (e.g. feeling and looking better). They require an individualised approach to care that enables them to fit self-care around their own lifestyle. This often means managing self-care so that it does not compromise social image or activities. Young adults will always prioritise these and therefore we must acknowledge and consider these concerns. To better meet the needs of young adults with Type 1 DM specialist transition services should:

1. consider care planning to incorporate the lifestyle choices and concerns of each young adult and working practically to enable them to manage self-care around these.
2. ensure consistency in consultations (i.e. young adults see the same doctor at clinic each time)

4.6 Conclusion

Chapters 3 and 4 of this thesis investigated the special needs of young adults with Type 1 DM and their families. Some important theoretical and clinical implications were discussed. As discussed in limitations, it may be that for some young adults with Type 1 DM, their needs are more complex. For example some young adults with Type 1 DM may experience psychological problems, including eating problems. There are indications that eating problems are common in young adults and have adverse consequences for glycaemic control (Jones et al., 2000) In the next chapter, (chapter 5) I will consider the topic of eating problems with the goal to extend these findings for relevance to young adults with Type 1 DM with more problems than those who took part in this study.

Chapter 5 - Eating Problems in Young Adults with Type 1 Diabetes: A systematic review with meta-analysis

5.1 Chapter Summary

This chapter reports a systematic review to determine in young adults with type 1 diabetes (1) prevalence of eating problems compared with peers and (2) the association between eating problems and glycaemic control. This study is also reported in a paper published in Diabetic Medicine (Young et al., 2012) which can be found in appendix 5.1.

We conducted a systematic literature search via electronic databases and meta-analysis. Cohen's *d* (the mean difference score between Type 1 DM and comparison groups) was calculated for 13 studies that met inclusion criteria.

We found that eating problems [both disordered eating behaviour (39.3% and 32.5%; *d* = .52, *CI* =.10 to .94) and eating disorders (7.0% and 2.8%; *d* = .46, *CI* = .10 to .81)] were more common in young adults with Type 1 DM compared with peers and both were associated with poorer glycaemic control (*d* = .40, *CI* = .17 to .64).

In restricted analyses involving measures adapted for diabetes, associations between eating problems and poorer glycaemic control remained (*d* =.54, *CI* = .32 to .76). Disordered eating behaviour (51.8% and 48.1%; *d* = .06, *CI* = -.05 - .21) and eating disorders (6.4% and 3.0%; *d* = .43, CI = -.06 to .91) were more common in young adults with Type 1 DM compared with peers but differences were non-significant.

Our findings indicate that eating problems are common among this age group. Research focus should shift from comparing eating problems in young adults with Type 1 DM and peers and towards establishing predictors of eating problems in those with Type 1 DM. Generic measures should be used with caution and diabetes-specific measures developed.

5.2 Introduction

Eating disorders are complex psychological conditions characterised by disordered eating behaviour, unhealthy weight loss and heightened concern about body weight and shape (Polivy & Herman, 2003). They are associated with an increased incidence of medical complications (e.g. osteoporosis and heart conditions) (Grinspoon et al., 2000), psychological distress (Derenne, Baker, Delinsky, & Becker, 2010; Grinspoon et al., 2000) and a high mortality rate (Zipfel, Lowe, Reas, Deter, & Herzog, 2000). Eating disorders often develop during adolescence and young adulthood (Striegel-Moore & Bulik, 2007), and a third of those affected continue to meet the diagnostic criteria five years after diagnosis (Fairburn, Cooper, Doll, Norman, & O'Connor, 2000; Keel, Mitchell, Miller, Davis, & Crow, 1999). Milder eating problems may develop into clinically significant eating disorders (Shisslak, Crago, & Estes, 1995; Taylor et al., 2006) making them a legitimate cause for concern.

Three main types of diagnosable clinical eating disorders are recognised (American Psychiatric Association, 2000). These include anorexia nervosa, bulimia nervosa and eating disorder not otherwise specified (Colton et al., 2009). Milder eating problems (i.e. those that do not meet the criteria for a clinical eating disorder) may be classified as sub-threshold disorders, but sometimes are termed simply disordered eating behaviour. In this chapter we are concerned with both eating disorders and disordered eating behaviour, collectively referred to as eating problems.

Awareness of complications associated with suboptimal control of Type 1 DM (The Diabetes Control and Complications Trial Research Group, 2001) may discourage some individuals from engaging in disordered eating behaviour (Peveler & Turner, 2005), but individuals with Type 1 DM may be a population at risk of eating problems for a number of reasons. The main risk factors associated with the development of eating problems in the general population include a history of dieting or dietary restraint (Graber, Brooks-Gun, Paikoff, & Warren, 1994), increased BMI and/or body dissatisfaction (Polivy and Herman 1985) and female gender (Kessler, Chiu, Demler, Merikangas, & Walters, 2005). Individuals with Type 1 DM may be more susceptible than the general population to develop an eating problem given focus on diet and carbohydrate intake, risk of insulin-related weight gain and associated body dissatisfaction (Striegel-Moore & Bulik, 2007; The Diabetes Control and Complications Trial Research Group, 2001). Additionally, insulin manipulation (omitting or giving less insulin than required) offers individuals with Type 1 DM a means of potentially rapid weight loss through intentional hyperglycaemia resulting in caloric purging (Colton et al., 2009), but may be associated with suboptimal glycaemic control (Jones et al., 2000). Given that eating problems are more common in girls and women than boys and men in the general population, it is likely that young women with Type 1 DM are also more at risk of eating problems than young men.

The prevalence of eating problems in young adults with Type 1 DM compared to non-Type 1 DM peers is unclear. Some studies suggest that eating problems are more common in young adults with Type 1 DM compared with non-Type 1 DM peers (Colton, Olmsted, Daneman, Rydall, & Rodin, 2004; Jones et al., 2000; Pinar, 2005; Smith, Latchford, Hall, & Dickson, 2008) while others indicate no differences (Ackard et al., 2008; Engstrom et al., 1999; Hsu, Chen, Huang, Lin, & Lin, 2009; Svensson, Engstrøm, & Aman, 2003).

One explanation for the inconsistencies in findings may relate to the method of measurement of eating problems (Young-Hyman & Davis, 2011). Commonly used generic measures of eating problems validated in a general population might inflate the prevalence of eating problems in those with Type 1 DM, because they assess the extent to which individuals worry about their diet, reduce the intake of certain food groups and eat when they are not hungry. As a consequence of low blood glucose, or their insulin regimen individuals with Type 1 DM may score highly on such items as they may restrict foods with high carbohydrate content or eat when they are not hungry (often because of the need to treat hypoglycaemia). Furthermore, generic measures are not designed to acknowledge insulin omission as either weight loss behaviour or general non-adherence to treatment. Many previous studies have used generic measures validated in the general population, and this may contribute to higher or biased prevalence estimates. Thus methodological considerations, including differences in measurement of eating problems, may in part explain the contradictory data in this area.

Eating problems in young adults with Type 1 DM are of major clinical importance, not least the implications for glycaemic control. A previous meta-analysis (Nielsen & Mølbak, 1998) investigated the prevalence of eating problems in adults (including young adults) with Type 1 DM compared with similar aged comparison groups. Eating problems were found to be more common in Type 1 DM. However as discussed in previous chapters of this thesis, young adults are a unique population already at risk for Type 1 DM related complications and increased mortality associated with suboptimal glycaemic control (Insabella, Grey, Knafl, & Tamborlane, 2007; Kovacs et al., 1990; The Diabetes Control and Complications Trial Research Group, 2001; The NHS Information Centre, 2011). The presence of eating problems may increase this risk (Peveler et al., 2005).

It is inevitable that small sample sizes characterise much work in this area and limit understanding of the prevalence and implications of eating problems in Type 1 DM. We therefore conducted a meta-analysis to determine in young adults with Type 1 DM:

1. prevalence of eating problems compared with peers, measured by generic or diabetes-adapted measures

2. association between eating problems (both disordered eating behaviour and eating disorders) and glycaemic control, taking into account use of generic or diabetes-adapted measures.

5.3 Method

5.3.1 Search strategy

Empirical studies were located primarily via a search of electronic databases (i.e. Journals@Ovid full text, PsycARTICLES full text, Ovid MEDLINE, psycINFO, Web of Knowledge) using text word and thesaurus terms. The following key words were used with Boolean logic: (i) adoles*, young adult*, child* (ii) disordered eat*, eating disorder* weight control, eating behav* (iii) diabet* (iv) outcome*, glyc?mic control, (e.g. , 'adoles* AND diabet* AND outcome*'). Retrieved articles were hand searched for additional references.

5.3.2 Inclusion and exclusion criteria

Inclusion criteria:

- primary focus on eating problems in Type 1 DM
- sample of young adults or children and young adults who were diagnosed with Type 1 DM at least 6 months previously
- publication in a peer reviewed journal between 1999 and 2011 (given that a previous meta-analysis was conducted in 1998)
- in English language
- standardised measure of eating disorders with established validity for making clinical diagnoses and/or a standardised continuous measure of disordered eating behaviour with a cut off point
- classification of eating disorders based on the Diagnostic and Statistical Manual (DSM) version IV (American Psychiatric Association, 1994) or version IV-TR (American Psychiatric Association, 2000)
- comparison group similar in age to the experimental group (for aim 1 only)
- measure of HbA_{1C} from medical records (for aim 2 only).

Exclusion criteria:

- case studies
- review articles.

5.3.3 Data extraction

Duplicates were removed, titles and abstracts screened, full texts read and exclusions made in an unblinded systematic manner by two reviewers. Differences between reviewers' judgements were resolved initially by discussion and if necessary by a third reviewer.

The following data were extracted: author; publication; year; sample size (by gender if appropriate); mean age and age range of sample; measure of eating behaviours, criteria used for diagnosis of eating disorders or disordered eating behaviour; and mean HbA_{1C} for groups or correlation between HbA_{1C} and eating problem scores.

To assess differences depending on measures, studies were categorised to one of three groups depending on type of measure: (i) diabetes adapted (validated in a Type 1 DM population or adapted for consideration of both insulin misuse and Type 1 DM restricted diet), (ii) partially diabetes adapted (adapted for consideration of either insulin misuse or Type 1 DM restricted diet) and (iii) generic measures (not adapted in any way for Type 1 DM). If a study involved more than one measure, both were coded independently.

5.3.4 Data synthesis

5.3.4.1 Effect size derivation

For aim 1, eating disorder effect size (for each relevant study) was calculated from the cell frequencies of four groups (i.e. Type 1 DM (eating disorder x no eating disorder) and peers (eating disorder x no eating disorder)). Disordered eating behaviour effect size (for each relevant study) was calculated in the same way. For aim 2, glycaemic control effect size was calculated (for each relevant study) from mean HbA_{1C} scores of two groups (e.g. Type 1 DM (eating disorder x no eating disorder) or from correlations between scores on disordered eating behaviour scales and HbA_{1C}.

Effect sizes were calculated from the data provided in the studies using means, standard deviations and sample sizes. Using the revised metan command in STATA Version 11 (StataCorp, 2009) random effects meta analysis was conducted, weighted by sample size, to calculate overall effect sizes, 95% Confidence Intervals (*CI*), significance of heterogeneity (Q) and the extent of heterogeneity (I^2) for outcome variables.

5.3.4.2 Meta-analytical strategy

Effect size computations were conducted using meta-analysis software (Comprehensive Meta-Analysis Version 2, (Borenstein, Hedges, Higgins, & Rothstein, 2007), META program). The effect size metric employed in the current analysis was Cohen's *d*, which represents the mean difference score between two groups.

$$d = \frac{x^1 - x^2}{(SD_1 + SD_2)/2}$$

Following recommendations, Cohen's $d < 0.3$ was considered small, >0.3 and <0.8 medium and > 0.8 large (Cohen, 1988). For outcome variables with significant heterogeneity the influence of moderator variables was explored using the revised metareg command. Random effects meta-regression with restricted maximum likelihood estimation and the improved variance estimator of Knapp & Hartung (Knapp & Hartung, 2003) were used to regress outcome variables onto the potential moderator. The regression coefficients (β) indicate the estimated increase in the effect size per unit increase in the covariate and adjusted R^2 is the percentage of heterogeneity explained by the covariate.

5.3.4.3 Interpretation of prevalence estimates

Homogeneity of eating disorder prevalence estimates according to (generic vs. diabetes adapted measures) was assessed by first calculating 95% confidence intervals for each estimate and second interpreting confidence intervals according to guidelines. The method used to calculate and interpret confidence intervals for prevalence estimates was the Newcombe-Wilson method without continuity correction (Newcombe, 1998).

5.4 Results

5.4.1 Review procedure

A flowchart to illustrate the inclusion and exclusion of studies is shown in Figure 4.1. Database searches identified 87 publications, 41 were duplicates or did not meet inclusion criteria (e.g. review articles) and were excluded, 25 were excluded after title screening. Full text versions of the remaining 21 were examined in detail and 11 met the inclusion criteria. Another 2 of 6 studies identified by hand searches met the inclusion criteria making a total of 13 studies.

Figure 5.1 Review procedure

Eleven of the final studies included children and young adults (11-22 years), one included those aged 9-14 years (Colton et al., 2004) and one included those aged 9-18 years (Olmsted, Colton, Daneman, Rydall, & Rodin, 2008). Three studies were from Canada (Colton et al., 2004; Jones et al., 2000; Olmsted et al., 2008), three from the USA (Meltzer et al., 2001; Neumark-Sztainer et al., 2002; Schwartz, Weissberg-Benchell, & Perlmuter, 2002), two from Sweden (Engstrom et al., 1999; Svensson et al., 2003), one from Spain (Garcia-Reyna et al., 2004), one from Austria (Grylli, Hafferl-Gattermayer, Schober, & Karwautz, 2004), one from Taiwan (Hsu et al., 2009), one from Turkey (Pinar, 2005) and one from the UK (Smith et al., 2008). Study characteristics are shown in table 4.1.

Table 5.1 Sample characteristics

Study author **Country** **Design**	**Type 1 DM n (% male)** **Mean HbA_{1c} (SD)** **Mean duration of diabetes (SD)**	**Non-Type 1 DM n (% male)**	**Age range (years)** **Mean age (SD)**	**Eating disorder measure (type of measure)**	**Disordered eating measure and criteria** **(type of measure)**
Colton Canada Age-matched case control	101 (0%) 66mmol/mol - 8.2 (1.0)% 7.1 (3.0) years	303 (0%)	9-14 Type 1 DM: 11.8 (1.5) Non-Type 1 DM: 11.8 (1.5)	cEDE (DA)	-
Engstrom Sweden Age-matched case control	89 (0%) 68mmol/mol - 8.4 (2.0)% 7.7 (3.8) years	89 (0%)	14-18 Type 1 DM: 16.3 (1.4) Non-Type 1 DM: 16.4 (1.4)	BAB-T (DA)	EDI drive for thinness subscale >14 (G)
Garcia-Reyna Spain Case-control	98 (61.2%) NR 1.5 (3.4) years	565 (56.8%)	12-16 Type 1 DM: 13.8 (1.1) Non-Type 1 DM 13.7 (0.6)	EDE (G)	EAT40 >30 (G)
Grylli Austria Cross-sectional	199 (51.8%) NR NR	-	NR Type 1 DM : 14.1 (2.6)	-	EAT-26 and EDI-2 (PDA)
Hsu Taiwan Age-matched case control	71 (40.8%) 76mmol/mol - 9.1 (2.0)% 6.0 (3.7) years	71 (40.8%)	10-22 Type 1 DM: 15.9 (3.1) Non-Type 1 DM: 15.9 (3.1)	-	EAT - 26>20 (G)

Jones Canada Age-matched case control	358 (0%) 73mmol/mol - 8.8 (1.7)% 6.7 (3.6) years	1098 (0%)	12-16 Type 1 DM: 14.9 (2.0) Non-Type 1 DM: 14.8 (1.9)	EDE (DA)	Predefined criteria on EDI, EAT and DSED (DA)
Meltzer USA Cross-sectional	99 (46%) 75mmol/mol - 9.0 (1.7)% 6.1 (3.5) years	-	11-19 Type 1 DM: 14.5 (2.0)	-	EDI (PDA)
Neumark-Sztainer USA Cross-sectional	143 (51%) 73mmol/mol 8.8 (1.6)% NR	-	12-21 Type 1 DM: 15.3 (2.3)	-	DEPS (DA)
Olmsted Canada Prospective cohort	98 (0%) 73mmol/mol - 8.3 (1.1)% 4.3 (3.1) years	-	9-13 Type 1 DM: 11.9 (1.4)	cEDE (DA)	-
Pinar Turkey Case control	45 (approx. 50%) 69mmol/mol - 8.5 (2.7)% 4.7 (2.8) years	55 (approx. 50%)	12-18 Total sample: 15.5 (1.4)	-	EAT40 >30 (G)
Schwartz USA Cross-sectional	53 (0%) 81mmol/mol - 9.6 (1.8)% NR	-	12-18 Type 1 DM: 14.4 (1.72)	-	EDE-Q scale (G)
Smith UK Case control	40 (0%) NR NR	76 (0%)	11-19 Type 1 DM: 15.2 (1.8) Non-Type 1 DM: 15.8 (1.2)	EDE-Q (G)	-

Svensson Sweden Age-matched case control	141 (100%) 60mmol/mol - 7.6 (1.5)% 7.2 (4.0) years	141 (100%)	14-18 Type 1 DM: 16.6 (1.1) Non-Type1 DM: 16.4 (1.1)	RAB-T (DA)	-

cEDE = Children's Eating Disorder , DA = diabetes adapted measure, Examination, DEPS = diabetes eating problems survey, EAT = eating attitudes test, EDE = Eating Disorder Examination, EDI = eating disorders inventory, project EAT = eating among teens G = generic measure, NR = not reported PDA = partially diabetes adapted (insulin manipulation acknowledged or restrictive diet acknowledged, but not both), SD = Standard deviation.

5.4.1.1 Aim 1: Prevalence of eating problems compared with peers, measured by generic or diabetes adapted measure

Eight studies addressed the prevalence of eating problems (Colton et al., 2004; Engstrom et al., 1999; Garcia-Reyna et al., 2004; Hsu et al., 2009; Jones et al., 2000; Pinar, 2005; Smith et al., 2008; Svensson et al., 2003). Five of these measured disordered eating behaviour (Engstrom et al., 1999; Garcia-Reyna et al., 2004; Hsu et al., 2009; Jones et al., 2000; Pinar, 2005) and in total included 664 individuals with Type 1 DM and 1894 non-Type 1 DM peers. Of these, 261 (39.3%) individuals with Type 1 DM were classified as having disordered eating behaviour compared with 615 (32.5%) peers. Prevalence estimates are shown in table 4.2.

Six studies measured eating disorders either subsequently to measuring disordered eating behaviour (Engstrom et al., 1999; Garcia-Reyna et al., 2004; Jones et al., 2000) or independently (Colton et al., 2004; Smith et al., 2008; Svensson et al., 2003). In total these included 825 individuals with Type 1 DM and 2282 non-Type 1 DM peers. Of these, 58 (7.0%) individuals with Type 1 DM had eating disorders compared with 64 (2.8%) of peers. Prevalence estimates are shown in table 4.2.

Table 5.2 Prevalence estimates

Outcome	**Type 1 DM prevalence %**	**Non-Type 1 DM prevalence %**	***K***	***N***
Disordered eating behaviour				
Both generic and diabetes adapted measures	39.3	32.5	5	2558
Diabetes adapted measures	51.8	48.1	1	1475
Generic measures	24.4	10.1	4	1083
Eating disorders				
Both generic and diabetes adapted measures	7.0	2.8	6	3107
Diabetes adapted measures	6.4	3.0	4	2318
Generic measures	10.1	2.3	2	789
Glycaemic control				
Both generic and diabetes adapted measures	-	-	11	1363
Eating disorders	-	-	2	457
Disordered eating behaviour	-	-	9	906
Diabetes adapted measures (disordered eating behaviour and eating disorders)	-	-	4	664
Generic measures (disordered eating behaviour and eating disorders)	-	-	5	348
Partially adapted measures	-	-	2	351

(disordered eating behaviour and eating disorders)

N = number of participants, K = number of tests of outcome

Effect sizes for disordered eating behaviour and eating disorders are shown in figures 4.2 and 4.3. There were medium effect sizes for both disordered eating behaviour (d = .52, *CI* = .10 to .94) and eating disorders (d = .46, *CI* = .10 to .81) showing that prevalence of disordered eating behaviour and eating disorders was higher in children and young adults with Type 1 DM compared with peers. Age moderated the effect for eating disorders (as age increased, eating disorders decreased) but not for disordered eating behaviour (table 4.3). The number of studies with null results that would be needed to negate these effects (i.e. the fail safe N) suggest that these results are robust both for eating disorders and disordered eating behaviour (fail safe N = 483 and 113 respectively).

Table 5.3 Moderation effect of age

Outcome	β	***SE***	***CI***	I^2	***Adj*** R^2
Disordered eating behaviour	.27	.19	-.56 to 1.09	66.22	8.42
Eating disorders	-.26	.09	-.53 to -.00*	17.94	100
Glycaemic control	-.02	.09	-.24 to .19	55.80	-24.93

*indicates significant confidence interval

For disordered eating behaviour and eating disorders, separate analyses based on generic measures (figures 4.2 and 4.3) resulted in significant effects (disordered eating behaviour: n = 4; d = .68, *CI* = .15 to 1.20 and eating disorders: n = 2, d =.60, *CI* = .15 to 1.05) showing that prevalence of disordered eating behaviour and eating disorders was higher in children and young adults with Type 1 DM compared with peers. These results were not replicated for separate analyses based on diabetes adapted measures (disordered eating behaviour: n = 1; d =.08, *CI* = -.05 to .21 and eating disorders: n = 4; d = .43, *CI* = -.06 to .91). Prevalence of eating disorders in the Type 1 DM group was higher when measured with generic measures compared to diabetes adapted measures. Confidence intervals around prevalence estimates did not overlap indicating that this difference was significant (diabetes adapted measures: 6.4%, *CI* = 5.5% to 7.5% and generic measures: 10.1% *CI* = 8.2% to 12.4%).

Figure 5.2 Effect sizes for disordered eating behaviour

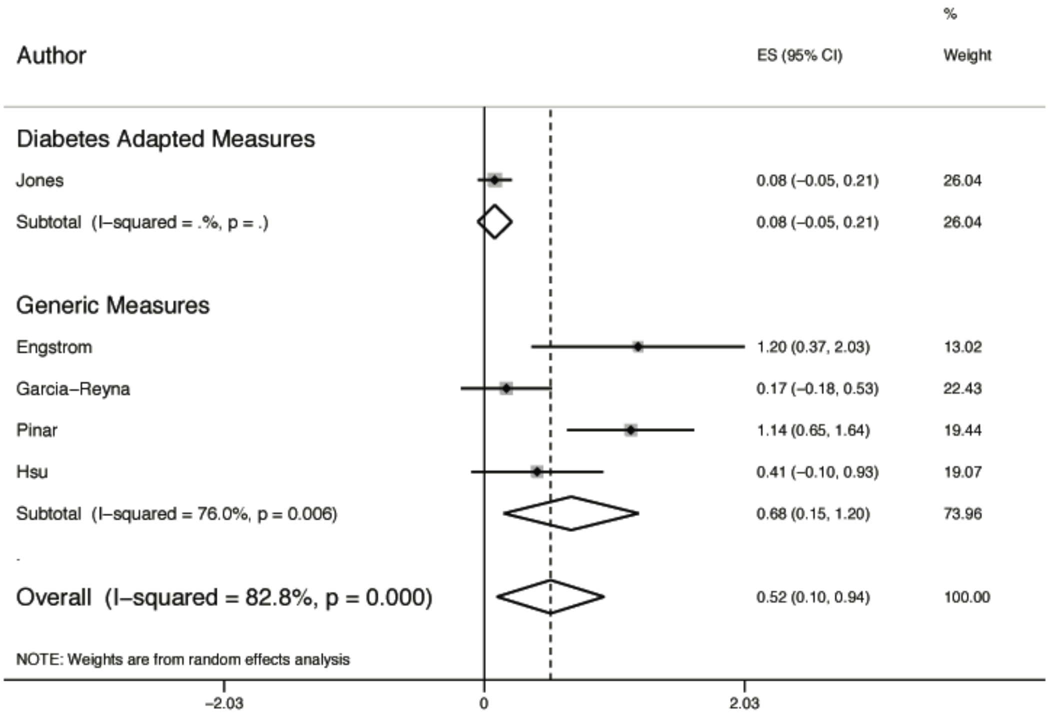
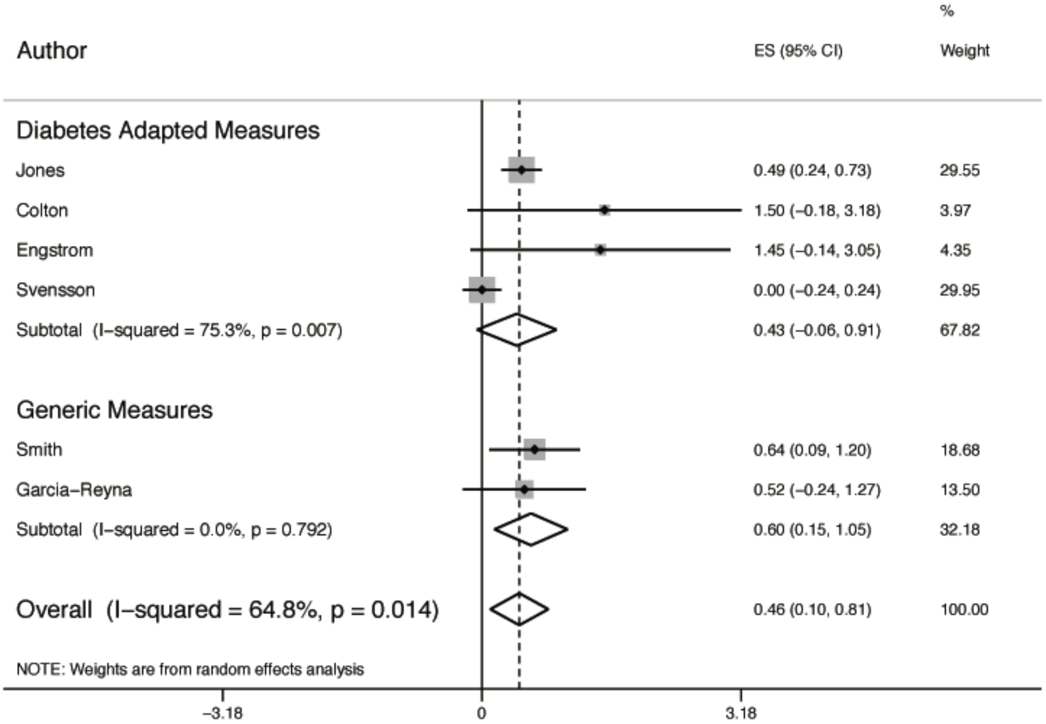


Figure 5.3 Effect sizes for eating disorders

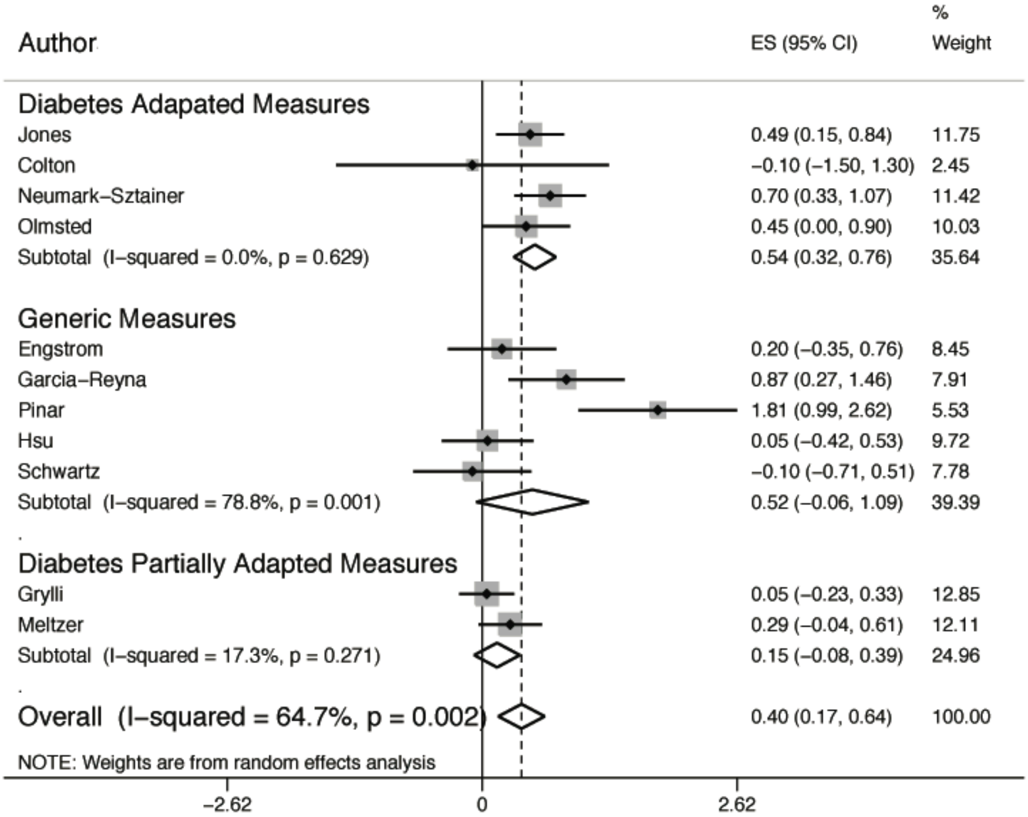


5.4.1.2 Aim 2: Association between eating problems and glycaemic control taking into account use of generic or diabetes adapted measures

Eleven studies measured the association between eating problems and glycaemic control (Colton et al., 2004; Engstrom et al., 1999; Garcia-Reyna et al., 2004; Grylli et al., 2004; Hsu et al., 2009; Jones et al., 2000; Meltzer et al., 2001; Neumark-Sztainer et al., 2002; Olmsted et al., 2008; Pinar, 2005; Schwartz et al., 2002) and in total included 1363 individuals. Of these, two studies measured the association between glycaemic control and eating disorders (Colton et al., 2004; Jones et al., 2000) and nine measured the association between glycaemic control and disordered eating behaviour (Engstrom et al., 1999; Garcia-Reyna et al., 2004; Grylli et al., 2004; Hsu et al., 2009; Meltzer et al., 2001; Neumark-Sztainer et al., 2002; Olmsted et al., 2008; Pinar, 2005; Schwartz et al., 2002). Sample characteristics are shown in table 4.2 and effect sizes for glycaemic control are shown in figure 4.4. Overall (for disordered eating behaviour and eating disorders) there was a significant medium effect for glycaemic control (*d* = .40, *CI* = .17 to .64).

Therefore further analyses of glycaemic control were conducted considering eating disorders and disordered eating behaviour together. Age did not moderate the effect for glycaemic control (table 4.3). Separate analyses for diabetes adapted measures and generic measures suggested a significant association between eating problems and glycaemic control for diabetes adapted measures (*d* = .54, *CI* = .32 to .76) but not for generic measures (*d* =.52, *CI* = -.06 to 1.09, figure 4). Partially adapted measures (n = 2) were included in an additional separate analysis but suggested no significant association between eating problems and glycaemic control (*d* = .15, *CI* = -.08 to .39).

Figure 5.4 Effect sizes for glycaemic control



5.5 Discussion

We aimed to determine the prevalence of eating problems in young adults with Type 1 DM compared with peers, and the association between eating problems and glycaemic control. We also aimed to determine how use of generic or diabetes specific measures affected the results.

Considering all studies (using diabetes adapted or generic measures), the results indicate that eating problems are more common in young adults with Type 1 DM compared with non-Type 1 DM peers (disordered eating behaviour: 39.3% Type 1 DM and 32.5% peers, eating disorders: 7.0% Type 1 DM and 2.8% peers). In addition there was an association between self-reported eating problems and poorer glycaemic control (*d* = .40, CI = .17 to .64). However, our results indicate that prevalence estimates are critically dependent on the type of measure used. For non-Type 1 DM peers prevalence of eating disorders remained relatively stable across studies. However for the Type 1 DM groups, prevalence varied depending on the type of measure used; restricted analyses involving generic measures (10.1%), compared with diabetes adapted measures (6.4%), and both (7.0%), suggesting that generic measures result in inflated prevalence estimates.

Considering only diabetes adapted measures, prevalence estimates indicate that eating disorders are more common in young adults with Type 1 DM compared with non-Type 1 DM peers but confidence intervals indicate this difference is not significant (Type 1 DM: 6.4%, peers: 3.0%, *d* = .43, CI = -.06 to .91). Importantly there is an association between eating problems (including both disordered eating behaviour and eating disorders) and poorer glycaemic control (*d* =.54, CI = .32 to .76).

5.5.1 Methodological implications

Measuring eating problems in Type 1 DM poses one of the most difficult challenges in this work. Two recent papers (Colton et al., 2009; Young-Hyman & Davis, 2011) propose that generic measures of eating problems intended for the general population may inflate estimates of eating problems in a population with Type 1 DM. Our results support this, in that restricted analyses involving generic measures suggested increased estimates of eating disorders in the Type 1 DM group, and no association between eating problems and glycaemic control. It is less clear how prevalence of disordered eating is affected because only one study used a diabetes adapted measure.

A small number of diabetes specific measures of disordered eating behaviour (but not eating disorders) have been developed (Antisdel, Laffel, & Anderson, 2001; Markowitz et al., 2010; Young-Hyman & Davis, 2011) and show good validity. However neither diabetes specific nor diabetes adapted measures are appropriate for use with non-Type 1 DM comparison groups. Given that generic measures might not be valid in a Type 1 DM population, true like for like comparisons between Type 1 DM populations and non-Type 1 DM populations are not possible. Consequently, we propose that the focus of research should shift from investigating differences between Type 1 DM and non-Type 1 DM populations to concentrate on more clinically relevant issues, such as how best to identify and treat eating problems in patients with Type 1 DM.

5.5.2 Strengths and limitations

As with any systematic review, the strength of our conclusions is based on the structured search and analysis procedure. Quality of studies was ensured by predefined inclusion and exclusion criteria. The addition of meta-analytical synthesis increases certainty in conclusions. However, a number of limitations are acknowledged. The use of cross-sectional data for meta-analyses means we cannot confirm a causal direction for results. The lack of studies including diabetes adapted measures of disordered eating behaviour limits the conclusions related to disordered eating behaviour.

5.5.3 Clinical implications

The observed association between eating problems and poorer glycaemic control suggests an argument for routine screening for eating problems in young adults with Type 1 DM. There is also a strong case for developing measures of eating problems validated in a population of young adults with Type 1 DM. Previous evidence suggests that clinicians treating patients with Type 1 DM may lack confidence to identify, discuss and refer individuals with Type 1 DM and eating problems appropriately (Tierney, Deaton, & Whitehead, 2008). Future work should also focus on identification of predictors of eating problems in young adults with Type 1 DM. This would be useful so that clinicians can identify and address problematic eating in this population before it develops or progresses.

5.6 Conclusions

The findings of this chapter indicate that based on both diabetes adapted and generic measures of eating problems, prevalence of disordered eating behaviour and eating disorders are higher in young adults with Type 1 DM compared with peers. However, we conclude that prevalence of eating disorders in adolescents with Type 1 DM is dependent on the type of measure used (generic or diabetes adapted). Based on diabetes adapted measures, prevalence of eating disorders remained similar to analyses based on both types of measures, although differences between the Type 1 DM group and peers were not significant using diabetes adapted measures. Generic measures appear to inflate prevalence of eating disorders given that restricting analyses to generic measures increased prevalence of eating disorders in the Type 1 DM group. For disordered eating behaviour, conclusions are limited by a lack of studies using diabetes adapted measures.

Of clinical importance, young adults with Type 1 DM and eating problems (both disordered eating behaviour and eating disorders) have poorer glycaemic control than those who do not have eating problems. Clinicians need to be alert to the risks of eating problems among young adults with Type 1 DM and particularly amongst those with suboptimal glycaemic control. Future work should focus on developing Type 1 DM sensitive measures of eating problems, establishing predictors of eating problems in a Type 1 DM population and developing specific interventions for this population. In the next chapter we attempt to establish the predictors of eating problems in a sample of young adults with Type 1 DM.

Chapter 6 - Demographic and Clinical Predictors of Eating Problems in Young Adults with Type 1 Diabetes

6.1 Chapter summary

Results of the meta-analysis in chapter 5 indicate that eating problems in young adults with Type 1 DM are prevalent and pose a problem for achieving optimal glycaemic control. Nevertheless, accurately measuring eating problems is challenging in this group. Generic measures (intended for the general population) may not be appropriate for those with Type 1 DM. To overcome this many researchers adapt generic measures to make them more appropriate for Type 1 DM groups. However there is a lack of studies investigating the prevalence of eating problems using a measure validated specifically in a Type 1 DM population. Furthermore, little is understood about how we can identify eating problems in these young adults (i.e. what variables predict eating problems). This chapter aimed to investigate the prevalence and predictors of eating problems in these young adults using a measure designed specifically for a Type 1 DM population.

Young adults (n = 99) from two specialist transition clinics in Sheffield completed questionnaires and medical data were collected from records. Results indicated that just over a third of the sample experienced eating problems. Predictors of eating problems were female gender, elevated HbA_{1C}, elevated BMI and particularly in females, diabetes-specific distress. Results also indicated that diabetes-specific distress and eating problems predicted suboptimal glycaemic control.

The results have a number of clinical implications. Most importantly this study indicates that clinicians should be alert to the risk of eating problems. The association between eating problems and glycaemic control indicates the importance of timely recognition and treatment. Clinicians should be especially alert to the possibility of eating problems in young adults who are female, have elevated HbA_{1C}, elevated BMI or for females, have high diabetes-specific distress.

6.2 Introduction

In chapter 5, I reported a systematic review and meta-analysis of studies investigating prevalence of eating problems (eating disorders and disordered eating behaviour) in young adults with Type 1 DM and the association with glycaemic control. Results indicated that eating problems are prevalent in young adults with Type 1 DM and associated with suboptimal glycaemic control. However, results were limited by methodological problems, especially use of generic measures that may not be appropriate for individuals with Type 1 DM.

It was concluded that eating problems in young adults with Type 1 DM warrant concern. Although the increased prevalence in individuals with Type 1 DM compared with peers was not *statistically* significant, it is likely to be *clinically* significant given the association with suboptimal glycaemic control. That is, eating problems may not be especially prevalent in individuals with Type 1 DM (compared with peers) but they have adverse clinical consequences for those affected. In that suboptimal glycaemic control carries the risk of Type 1 DM complications and mortality (The Diabetes Control and Complications Trial Research Group, 2001), eating problems are of particular significance when managing Type 1 DM in young adults.

6.2.1 Variables associated with disordered eating in the general population

In the general population predictors of eating problems include *overvaluation of appearance* (Stice, Presnell, & Spangler, 2002), *dieting* (Graber et al., 1994), *elevated BMI* (Striegel-Moore & Bulik, 2007), *body dissatisfaction* (Wertheim, Koerner, & Paxton, 2001) and *female gender* (Woodside, 1995).

Perhaps the most well established predictors of eating problems in the general population are demographic. In 2007, a review published in the American Psychologist (Striegel-Moore & Bulik, 2007) drew together evidence relating to predictors of eating problems. Presented evidence consistently showed *female gender* to be associated with eating problems. Females with eating problems outnumbered males and lifetime prevalence rates were greater in females compared to males (Kessler et al., 2005). Gender differences were less pronounced in eating problems characterized by binge-eating without purging (Hudson, Hiripi, Pope, & Kessler, 2007; Woodside et al., 2001). *Age* also predicted eating problems and adolescents were shown to be particularly susceptible (Garfinkel et al., 1995; Kendler et al., 1991; Striegel-Moore et al., 2005; Woodside et al., 2001). However, eating problems characterized by binge-eating without purging did not follow this pattern since onset typically occurred in adulthood. (Garfinkel et al., 1996; Striegel-Moore & Cachelin, 2001; Woodside et al., 2001).

The review (Striegel-Moore & Bulik, 2007) also presented evidence relating to psychosocial and medical predictors. Evidence from longitudinal studies consistently showed that idealising being thin, body dissatisfaction, elevated BMI and dieting predicted onset of eating problems in women (Polivy & Herman, 1985; Striegel-Moore, Silberstein, & Rodin, 1986). However, these predictors of eating problems were rarely independent of each other. For example, a disordered eating behaviour such as binge-eating (characteristic of bulimic and binge-eating disorders) frequently is preceded by a period of *dieting* or calorie restriction (Stice, 2001; Telch & Agras, 1996; Wertheim et al., 2001). This period of *dieting* may be motivated by other variables such as *overvaluation of appearance* (i.e. placing disproportionate importance on appearance), *elevated BMI* and *body dissatisfaction*. These variables may interact to initiate disordered eating behaviour. That is, an individual who values appearance highly, has elevated BMI and experiences body dissatisfaction is motivated to diet to reduce BMI and body dissatisfaction. BMI, in combination with overvaluation of appearance was highly predictive of eating problems (appearance overvaluation does not independently predict eating problems) and this risk is further increased by the presence of dieting (Stice et al., 2002).

Thus, a number of demographic, psychosocial and medical variables appear to predict eating problems in the general population. However, individuals with Type 1 DM differ from their peers in a number of ways. Specifically, they are often i) heavier ii) required as part of their treatment regimen to closely monitor their diet and iii) able to manipulate their weight through insulin omission. These differences between individuals with Type 1 DM and their peers make it highly plausible that the eating problems experienced by individuals with Type 1 DM also differ from those of their peers.

6.2.2 Variables associated with eating problems in a Type 1 DM population

In the Type 1 DM population less is known about the predictors of disordered eating behaviour. However some variables have been found to be associated with disordered eating in Type 1 DM groups and are discussed in this section.

6.2.2.1 BMI

Children and young adults with Type 1 DM are typically heavier than their peers (Stice, Maxfield, & Wells, 2003; Taylor et al., 2003). Since increased BMI predicts eating problems in the general population, it is critical that we understand how BMI and eating problems are related in young adults with Type 1 DM who are likely to have elevated BMI.

In a prospective study (Bryden et al., 1999), a cohort of males and females with Type 1 DM (11-18 years at baseline) were followed over 9 years. Results indicated that BMI increased from adolescence to adulthood and was associated with increases in dietary restraint (measured on a subscale of the EDE scale; Fairburn & Cooper, 1993). Work in Canada also indicated a relationship between BMI and eating problems in adolescent females with Type 1 DM (Colton, Olmsted, Daneman, Rydall, & Rodin, 2007; Olmsted et al., 2008).

A more recent related study (Markowitz et al., 2009) involved adolescent females with Type 1 DM (aged 12-19 years, n = 90) self-reporting height, weight, and weight history. Results indicated that 20% of the sample scored in the clinically significant range for eating problems on at least one subscale of the EDE-Q (Fairburn & Cooper, 1993; Luce & Crowther, 1999). Adolescents who reported ever being overweight were eight times more likely to score within the clinical range on at least one subscale of the EDE-Q compared with those who reported never being overweight. The question 'have you ever been overweight?' was found to be more sensitive as a screening tool for eating problems than self-reported BMI (83% sensitivity and 67% respectively).

Together the results of these studies suggest that elevated BMI is associated with eating problems in young adults with Type 1 DM. However conclusions are limited by the use of generic measures of eating problems and reliance on self-reported BMI. Further work is necessary and ought to use diabetes specific measures of eating problems as well as BMI obtained from medical records.

6.2.2.2 Diet

In chapter 5, I briefly described how management of Type 1 DM requires greater attention and vigilance to eating than is normal for the general population. Depending on regimen, individuals with Type 1 DM may be required to avoid foods with very high carbohydrate content (e.g. sugary foods). They may avoid foods containing any carbohydrate at certain times or in particular circumstances (e.g. when it is not convenient to give insulin). They may at times be expected to eat when they are not hungry (e.g. to use excess insulin or to treat hypoglycaemia) and may have to calculate the exact carbohydrate content of everything they consume (The Diabetes Control and Complications Trial Research Group, 2001). The unusual eating practices involved in management of Type 1 DM and the disproportionate attention to diet necessary to manage care means that young adults with Type 1 DM differ from their peers (Colton et al., 2009). Since dieting is a predictor of eating problems in the general population (Graber et al., 1994), it may be particularly significant in individuals with Type 1 DM for whom exercising dietary restraint and awareness of diet is a much larger part of life (Young-Hyman & Davis, 2011).

6.2.2.3 Insulin manipulation

In chapter 5, I briefly described insulin manipulation whereby individuals with Type 1 DM have available a unique method of weight control. Insulin manipulation is likely to be more efficient than either healthy weight control behaviours (e.g. reducing calorie intake or regular exercise) or unhealthy weight control behaviour often used to compensate for excessive calorie intake (e.g. vomiting or using laxatives). Unlike other weight control behaviour, giving less insulin than required is painless in the short-term. In fact, it actively evades the pain and inconvenience of injecting insulin. Unhealthy weight control behaviours (e.g. vomiting or using laxatives) are uncomfortable and effortful. Similarly, maintaining a calorie-restricted diet is difficult and (as self-control lessens) likely to be short-lived or worse, lapse into binge eating. By manipulating insulin, individuals with Type 1 DM may efficiently and painlessly lose weight or avoid weight gain from overeating. Insulin manipulation for weight loss is thought to be used by approximately 30% of individuals with Type 1 DM (Markowitz et al., 2009). The seriousness of insulin manipulation is demonstrated by a study that found self-reported insulin manipulation at baseline resulted in a 3.2 times increased risk of death during the 11 year follow-up compared to individuals who did not report insulin manipulation (Goebel-Fabbri, 2009). The ease with which individuals can manipulate insulin may create a type of eating problem that differs from eating problems characterised by uncomfortable weight loss behaviours. Individuals, who in the absence of Type 1 DM would need to engage in effortful or uncomfortable behaviours to lose weight, may lose weight easily by manipulating insulin.

6.2.2.4 Demographic and psychosocial variables

Evidence indicates that demographic predictors of eating problems in Type 1 DM mirror those in the general population. Studies have shown that gender differences are similar, with eating problems being more common in females (Garcia-Reyna et al., 2004; Hsu et al., 2009; Pinar, 2005). However age may not follow this pattern. A prospective longitudinal study of 38 girls with Type 1 DM who were in adolescence at baseline (and were followed up 5 years later) indicated that age was not predictive of eating problems (Olmsted et al., 2008).

6.2.3 Study rationale

Previous work has indicated that individuals with Type 1 DM and eating problems have poorer glycaemic control (Jones et al., 2000). The conclusions from the meta-analysis reported in chapter 5 support this association. There is also indication that eating problems combined with elevated BMI in Type 1 DM are associated with poorer outcomes (Agras & Telch, 1998; Nielsen, 2002). A longitudinal study that followed young adults with Type 1 DM over 8-12 years found that eating problems were associated with microvascular complications (Peveler et al., 2005).

This chapter has outlined a number of ways that young adults with Type 1 DM differ from their peers. Given these reasons, it is highly plausible that eating problems may also differ and predictors may not mirror those of the general population. To date, studies in young adults with Type 1 DM have shown that clinical variables (e.g. BMI and HbA_{1C}) are likely to be important indicators of eating problems. However previous work may be limited by reliance on self-reported estimates of BMI and generic measures of eating problems (that are likely to inflate indications of eating problems as shown in chapter 5 of this thesis). Even generic measures that have been adapted for Type 1 DM may be inaccurate. It is imperative that diabetes specific measures of eating problems are used in work involving young adults with Type 1 DM. Another limitation of previous work is the lack of evidence relating to males. Studies predominantly have focused on female samples. To overcome these methodological limitations, this study uses a diabetes-validated measure to investigate clinical and demographic predictors of eating problems in a mixed gender cohort of young adults with Type 1 DM.

6.2.4 Aims

Based on this review, this study aims to determine in a cohort of young adults (aged 16-21 years old) with Type 1 DM:

(i) The prevalence of eating problems and insulin manipulation using a measure previously validated in a Type 1 DM population

(ii) The role of gender, BMI and history of being overweight in predicting eating problems

(iii) The role of eating problems and BMI in glycaemic control.

6.2.5 Hypotheses

(i) Eating problems will be present within the sample and more common in females than males.

(ii) Insulin manipulation will be more common in females than males.

(iii) Eating problems will be predicted by female gender, elevated BMI, history of being overweight and diabetes specific distress.

(iv) Eating problems and BMI will be significant predictors of glycaemic control.

6.3 Method

6.3.1 Sample

The sample included young adults (16-21 years old) registered at specialist transition clinics at Sheffield Teaching Hospitals. Data were collected across two sites (NGH: Northern General Hospital and RHH: Royal Hallamshire Hospital). Inclusion criteria were individuals: aged 16 -21 years old who had sufficient fluency in English to be able to read questionnaires and were able to provide informed consent.

6.3.2 Procedure

Ethics approval for this study was obtained from the NHS National Research Ethics Service (Appendices 6.1). Data were collected between November 2010 and September 2011. We contacted eligible participants by letter (signed by the lead clinic consultant) explaining the reason for the study and inviting them to take part. This letter (appendix 6.2) was sent together with an information sheet (appendix 6.3) and the routine reminder that precedes clinic appointments. DSN (especially appointed and trained as part of the CLAHRC team) approached young adults in clinic, introduced the research and answered questions. Signed consent (appendix 6.4) to take part in the study and for research staff to access medical records was obtained by the DSN. All participants who consented to take part were given a questionnaire pack (appendix 6.5), which they completed in the waiting room of the clinic. DSN were available to answer questions or assist with completion of the questionnaire where necessary. A trained CLAHRC research administrator extracted additional data (detailed in the next section) from patient medical records.

6.3.3 Measures

The questionnaire (appendix 6.5) comprised a package of standardised measures and demographic questions relevant to the wider study but I report only those relevant to the aims of this study. These were the Diabetes Eating Problems Scale - revised (DEPS-r; Markowitz et al., 2010), the Diabetes Distress Scale (DDS; Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008; Polonsky et al., 2005) and demographic questions.

6.3.3.1 Disordered eating behaviour: Diabetes eating problem survey- revised (DEPS-r; Markowitz et al., 2010)

The DEPS-r is a short, 16-item diabetes-specific measure of disordered eating behaviour that has been validated in young adults with Type 1 DM. Each item on the DEPS-r refers to weight, eating habits, weight loss behaviours (e.g. intentional vomiting or insulin manipulation) or general diabetes management (e.g. 'other people tell me to take better care of my diabetes). Response options for each item range from 0 to 5, with 0 indicating that in the past month an item was 'never' true and 5 indicating that an item was 'always' true. A higher score is indicative of more eating problems. Based on personal communication with the authors, a mean score of >1.25 was considered indicative of eating problems. The DEPS-r has excellent internal consistency (Cronbach's alpha = 0.86) and construct validity (significant correlations with BMI, HbA_{1C}, diabetes-specific conflict, youth negative affect around blood glucose monitoring and quality of life). For the purposes of this study, item 10 'I try to eat to the point of spilling ketones in my urine' was removed as the MDT deemed 'spilling ketones' as a term not well understood by young adults in the UK.

6.3.3.2 Diabetes distress: Diabetes distress scale (DDS; Fisher et al., 2008; Polonsky et al., 2005)

The DDS is a 17 item scale organised around four subscales, including regimen related distress (*n* = 5, e.g. 'feeling that I am often failing with my diabetes regimen'), physician related distress (*n* = 4, e.g. 'feeling that my doctor doesn't give me clear enough direction on how to manage my diabetes'), interpersonal distress (*n* = 3, e.g. 'feeling that friends and family don't appreciate how difficult living with diabetes can be'.) and emotional distress (*n* = 5, e.g. 'feeling that diabetes controls my life'). We used a 5-point rating scale with responses ranging from 'not a problem' to 'a very serious problem'.

6.3.3.3 Demographic questions

Participants were asked to report their gender, qualifications, employment status, living situation, ethnicity and any disability. Additional data were collected from medical records and included HbA_{1C} at the time of recruitment, BMI (weight – kg/height^{2} – metres), previous BMI where recorded (up to 5 years prior to recruitment), insulin regimen, time since diagnosis, age and age at diagnosis.

6.3.4 Treatment of data

Patient participation was recorded using Microsoft Excel. Data were analysed using SPSS version 19.

6.3.4.1 Categorical variables

Categorical demographic variables (living situation, ethnicity, education, employment status and insulin regimen) were dummy coded into dichotomous variables according to guidelines (Field, 2000) to allow multiple regression analyses to be performed. Living situation was recoded as 'living with parents' (e.g. individual lives with parents) or 'not living with parents' (e.g. individual lives alone, with a partner, or with friends). Ethnicity was recoded as 'White ethnicity' (e.g. individual is White) or 'minority ethnicity' (e.g. individual is Mixed, Asian, or Asian British, Black or Black British, Chinese or Chinese British). Education was recoded as 'not in education' (e.g. individual is not working towards GCSEs, A levels, vocational qualification or university degree) and 'in education' (e.g. individual is working towards GCSEs, A levels, vocational qualification or university degree). Employment status was recoded as 'working for pay' (e.g. individual works full-time or part-time for pay) or 'not working for pay' (e.g. individual is a student, unemployed or on sick leave) and finally insulin regimen was recoded as 'multiple daily injections' (e.g. individual is on multiple daily injections regimen) or 'not multiple daily injections' (e.g. individual is not on multiple daily injections regimen), 'twice a day' (e.g. individual is on a twice a day regimen) or 'not twice a day' (e.g. individuals is not on twice a day), 'pump' (e.g. individual is on an insulin infusion pump regimen) or 'not pump' (e.g. individuals in not on an insulin infusion pump regimen).

Pre-recruitment BMI data were compared with BMI-for-age growth charts (Centers for Disease Control and Prevention, 2011) and recoded as 'ever overweight' (e.g. individual has been overweight) or 'never overweight' (e.g. individual has never been overweight).

For the purposes of this chapter, one item on the DDS relating to eating ('feeling that I am not sticking closely enough to a meal plan') that might have correlated highly with the DEPS-r scale was not included in analyses. The remaining 16-items were assessed for reliability using Cronbach's alpha internal consistency analyses.

The DEPS-r scale was also assessed for reliability using Cronbach's alpha internal consistency analyses. For categorical analyses, DEPS-r mean scores were recoded (based on the cut-off point described in the Measures section of this chapter) as 'disordered eating; (e.g. the individual had a mean score on the DEPS-r of >1.25) or 'no disordered eating (e.g. the individual had a mean score on the DEPS-r of < 1.25).

To calculate insulin manipulation, three questions on the DEPS-r scale were used as screening questions. These were items 4 ('When I overeat, I don't take enough insulin to cover my food'), 9 ('I try to keep my blood sugar high so that I will lose weight') and 12 ('After I overeat, I skip my next insulin dose'). The internal consistency of these items was tested using Cronbach's alpha. Two new variables were created to categorise insulin manipulation. The first was coded as 'ever manipulated insulin' (e.g. the individual answered 1 or above on any of the items) and 'never manipulated insulin' (e.g. the individual answered 0 to all of the items). The second variable was coded as 'regularly manipulated insulin' (e.g. the individual answered 3 or above on any of the items) or 'did not regularly manipulate insulin' (e.g. the individual answered 2 or below to all of the items).

6.3.4.2 *Continuous variables*

Standardised Z scores were used in all multivariate analyses for continuous variables (i.e. DEPS-r scores, DDS scores, BMI and HbA_{1C}). For BMI, extreme outliers were identified as those 3 or more standard deviations from the mean and were removed (*n* = 5) for multivariate analysis (as recommended by Tabachnick & Fidell, 2000). To investigate interactions between risk factors interaction terms were added to regression analyses. Interaction terms were created by multiplying predictors together. In predicting DEPS-r scores the effects of the following interactions were assessed: gender and DDS; gender and BMI; gender and HbA_{1C}; HbA_{1C} and BMI; HbA_{1C} and DDS scores; and DDS scores and BMI. To predict HbA_{1C} scores an interaction variable for DDS scores and DEP-r scores was created:

6.3.5 Analyses

6.3.5.1 *Reliability*

In this study, the DEPS-r showed excellent internal consistency as a 15- item scale (Cronbach's alpha = 0.87) and the insulin manipulation sub-scale showed adequate reliability (Cronbach's alpha = 0.62). The DDS showed excellent internal consistency as a 16-item scale (Cronbach's alpha = 0.93).

6.3.5.2 *Response bias and descriptive statistics*

Independent samples t-tests were conducted to assess for response bias in DEPS-r scores and HbA_{1C}. For biases in DEPS-r scores, we compared individuals for whom BMI was available with individuals for whom BMI was not available, individuals for whom HbA_{1C} was available with those for whom HbA_{1C} was not available. For biases in HbA_{1C} we compared individuals for whom DEPS-r scores were available with those for whom DEPS-r scores were not available and individuals for whom DDS scores were available with those for whom DDS scores were not available. Descriptive statistics were computed for all variables.

6.3.5.3 *Prevalence of eating problems and insulin manipulation*

Prevalence of eating problems was computed from the percentage of individuals who scored >1.25 on the DEPS-r. Chi-square analysis was conducted to assess gender differences.

Prevalence of insulin manipulation was computed from the percentage of individuals who had a total score of >1 on DEPS-r items (4, 9 and 12) assessing insulin manipulation. Prevalence of frequent insulin manipulation was computed from the percentage of individuals who had a total score of >3 on items assessing insulin manipulation. Chi-square analyses were conducted to assess gender differences in insulin manipulation.

6.3.5.4 History of being overweight

Independent samples t-tests were conducted to assess differences in 1) BMI at recruitment and 2) HbA_{1C} between individuals who had been overweight in the past and individuals who had not been overweight in the past.

6.3.5.5 Correlations and multiple regression analyses

Prior to conducting multiple regression analyses, Pearson's correlations matrices were computed to identify relationships between dependent variables and potential predictor variables. Multicollinearity among the independent variables was tested in two ways. First, correlations between the independent variables were examined. Second, collinearity statistics (i.e., tolerance, variance inflation factors) and collinearity diagnostics (i.e., condition index, variance proportions) were computed for all regression analyses. Scatterplots were plotted to test for linearity, homoscedasticity and normality as defined by Tabachnick and Fidell (2000).

Hierarchical multiple regression analyses were conducted to assess predictors of 1) DEPS-r scores and 2) HbA_{1C}. Those predictor variables which were significantly correlated with outcome variables were included in regression analyses. Simple slopes analyses were conducted to establish the direction of any interaction effect.

6.4 Results

6.4.1 Response rate and bias

Out of the 121 patients registered at Sheffield Teaching Hospital's young adult clinics, 99 questionnaires were completed (response rate = 81.8%). Since we did not have ethical approval to access medical records for non-responders, it was not possible to test for differences between responders and non-responders.

There were no differences between individuals for whom BMI data were available and those for whom BMI data were not available in terms of DEPS-r scores ($t(95) = -.24$, $p>.05$) and HbA_{1C} ($t(89) = 1.24$, $p>.05$). Individuals for whom HbA_{1C} data were available did not differ from individuals for whom HbA_{1C} data were not available in terms of DEPS-r scores

($t(95) = -.95$, $p>.05$). Individuals for whom DEPS-r scores were available did not differ significantly from individuals for whom DEPS-r scores were not available in terms of HbA_{1C} ($t(89) = -1.86$, $p>.05$) . Individuals for whom DDS scores were available did not differ significantly from individuals for whom DDS scores were not available in terms of HbA_{1C} ($t(89) = .58$, $p>.05$).

6.4.2 Participant demographic and clinical data

Demographic and clinical data for the 99 responders are shown in tables 5.1 (categorical variables) and 5.2 (continuous variables).

Table 6.1 Participant demographic and clinical data - categorical variables

Demographic variable (total responses)		**Frequency**	**Percentage**
Gender (n = 99)	Male	40	40.4
	Female	59	59.6
Ethnic group (n = 95)	White ethnicity	87	91.6
	Minority ethnicity	8	8.4
Currently in education (n = 90)	Yes	70	74.5
	No	24	25.5
Living status (n = 95)	Alone	1	1.1
	Living with parents	87	91.6
	Living with friends	2	2.1
	Living with partner	2	2.1
	Other	3	3.2

Work status (n = 95)	Student	51	53.7
	Student working part time	20	21.1
	Working part time	4	4.2
	Working full time	11	11.6
	On sick leave	0	0
	Unemployed	8	8.4
	Other	1	1.1
Disability (n = 88)	Yes	5	5.7
	No	83	94.3
Previous BMI (n = 98)	Ever been overweight	29	29.6
	Never been overweight	69	70.4
Insulin regimen (n = 99)	Multiple daily injections	75	75.8
	2x a day	13	13.1
	Insulin infusion pump	11	11.1

Table 6.2 Participant demographic and clinical data – continuous variables

	Range	Mean	Standard deviation
Age at recruitment (years)	16-21	17.61	1.28
(n = 99)			
Age at diagnosis (years)	0-19	9.80	4.87

(n = 89)			
Years since diagnosis (n = 99)	0-19	7.37	4.84
BMI at recruitment (n = 94)	18.1-33.6	23.30	3.16
DDS mean score (n = 98)	0-3.33	1.02	.83

6.4.3 Disordered eating behaviour, insulin manipulation and HbA_{1C}

The full range of scores was used for the DEPS-r scale. Mean scores and range for the DEPS-r by gender and HbA_{1C} at recruitment are shown in table 5.3. Prevalence of disordered eating behaviour was 36.1%. There was a significant difference in prevalence of eating problems between females (50.0%) and males (15.4%: c2(1, N = 97) = 0.89, *p* <.01).

Table 6.3 Descriptive statistics for DEPS-r scores and HbA_{1C}

Outcome variables		**Range**	**Mean**	**Standard deviation**
DEPS-r scores	Male (n = 39)	0.00 – 1.73	.63	.47
	Female (n = 58)	0.00 – 4.07	1.36	.93
	Total (n = 97)	0.00 – 4.07	1.06	.85
HbA_{1C} at recruitment	Male (n = 37)	6.90 – 13.10	9.47	1.68
	Female (n = 54)	6.10 – 15.40	10.34	2.28
	Total (n = 91)	6.10 – 15.40	9.98	2.09

In total, 66.7% of the sample reported that they had manipulated insulin and 21.6% reported that they frequently manipulated their insulin. Females reported frequent insulin manipulation more commonly than males (25.9% and 15.4% respectively) but gender differences were not significant (c2(1, N = 97) = 1.51, *p*>0.05).

HbA_{1C} in the sample ranged from 6.1% to 15.4%, mean HbA_{1C} was 9.9% (SD = 2.11%). There were no gender differences in HbA_{1C} (*t*(89)=-1.97, *p*=.05). There were no significant differences in HbA_{1C} between those who had ever been overweight and those who had not (*t*(88)=1.12, *p*=.27).

6.4.4 Predicting disordered eating behaviour

Pearson's correlations indicated that most relationships between predictor variables and DEPS-r scores were small to moderate and most were non-significant (table 5.4). Correlations between predictor variables were not large enough to warrant concern over multicollinearity (i.e. >.80). Independent predictor variables found to be significantly correlated with DEPS-r scores included gender (*r* = .42, *p*<.01), BMI at recruitment (*r* = .22, *p*<.05), HbA_{1C} at recruitment (*r* = .40, *p*<.01) and DDS mean scores (*r* = .69, *p*<.01).

Table 6.4 Correlations between predictors and outcome variables

	DEPS-r mean	**HbA1C at recruitment**
Gender	.42**	.21
Age	-.16	-.02
Age at diagnosis	.03	.06
Years since diagnosis	-.09	-.08
BMI at recruitment	.22*	-.02
History of overweight	.16	-.12
Living with parents	.13	-.12
Working for pay	-.14	-.01
In education	-.09	-.10
White ethnicity	-.08	.08
Disability	.05	.13
Insulin – intensive	-.03	-.13
Insulin – 2x a day	.05	.17
Insulin – pump	-.03	-.09

DDS mean	.69**	.40**
DEPS-r mean	1	.40**
HbA1C at recruitment	.40**	1

Note. ** Correlation is significant at the 0.01 level (2-tailed).

* Correlation is significant at the 0.05 level (2-tailed).

The regression model predicting DEPS-r scores is shown below (table 5.5)

Table 6.5 Hierarchical multiple regression predicting scores on the DEPS-r.

	R2	β (95% CI)
Step 1	.17***	
Gender		.41*** (.22 – .65)
Step 2	.30***	
Gender		.35** (.16 - .57)
HbA$_{1C}$		.36*** (.17 - .58)
Step 3	.36**	
Gender		.30** (.12 -.52)
HbA$_{1C}$		.38*** (.20 - .59)
BMI		.26** (.09 - .56)
Step 4	.58***	
Gender		.12 (-.04 - .30)
HbA$_{1C}$		.17*

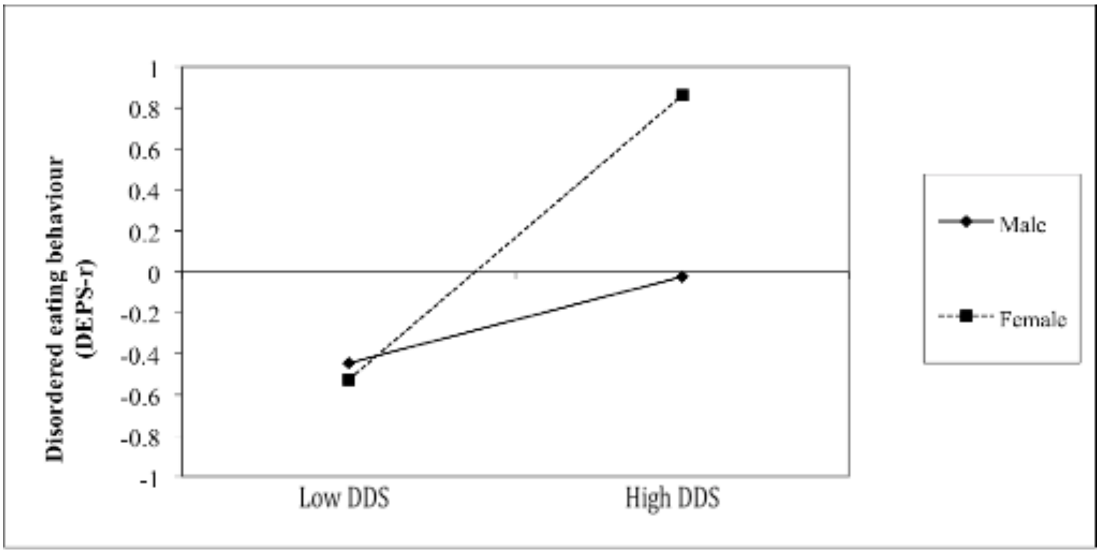
		(.00 - .35)
BMI		.24**
		(.11 - .49)
DDS		.56***
		(.38 - .74)
Step 5	.61*	
Gender		.18*
		(.02 - .36)
HbA_{1C}		.16*
		(.00 - .34)
BMI		.22**
		(.09 - .46)
DDS		.20
		(-.13 - .54)
DDS x Gender		.39*
		(.09 - .84)

*p<.05. **p<.01. ***p<.001

In step 1 gender was predictive of DEP-r scores and explained 17.0% of variance. In step 2 the inclusion of HbA_{1C} explained an additional 13.0% of variance, including BMI in step 3 explained an additional 6.0% of variance, and including DDS mean scores in step 4, explained 22.0% more variance (gender was no longer a significant predictor). The addition of an interaction term between DDS mean scores and gender in step 5 explained an additional 3.0% variance in DEPS-r scores. The addition of interaction variables for gender and BMI (β = .12, p = .14); gender and HbA_{1C} (β = -.40, p = .35); HbA_{1C} and BMI (β = -.12, p = .74); HbA_{1C} and DDS mean scores (β =.44, p = .27); and DDS mean scores and BMI (β = .03, p = .84) did not explain any more variance in DEPS-r scores and so were not included in the final model.

Simple slopes analysis was conducted to visualise the predictive effect of DDS scores at each level of the moderator (i.e. males vs females). Figure 5.1 illustrates how gender moderated the predictive effect of DDS mean scores on DEPS-r scores. Those who had high scores on the DDS scale also had high scores on the DEPS-r scale. This relationship was significant for females (β = .67, p<.001) but not for males (β = .20, p =.23).

Figure 6.1 Moderating effect of gender



N.B. DEPS-r and DDS scores shown are standardised.

6.4.5 Disordered eating behaviour as a predictor of HbA_{1C}

Pearson's correlations indicated that most relationships between predictor variables and HbA_{1C} scores were small to moderate and most were non-significant (table 5.4). Independent predictor variables found to be significantly correlated with HbA_{1C} scores included DEPS-r scores (r= .40, p<.001) and DDS scores (r= .40, p<.001). Since DEPS-r scores and DDS score were significantly correlated with each other (r =.69, p<.01) multicollinearity among independent variables was tested according to guidelines (Tabachnick & Fidell, 2000). Multicollinearity statistics (i.e. tolerance, variance inflation factors) and collinearity diagnostics (i.e. condition index, variance proportions) were computed. None of these tests indicated that multicollinearity was a cause for concern. The model predicting DEPS-r scores is shown below (table 5.6).

Table 6.6 Hierarchical multiple regression predicting HbA_{1C}.

	R2	β (95% CI)
Step 1	.20***	
DDS		.24 (-.03 - .50)
DEPS-r		.24

	(-.03 – 50)

*$p<.05$. **$p<.01$. ***$p<.001$

Predictors of higher HbA$_{1C}$ were DEPS-r mean scores and DDS scores. The addition of an interaction term between DEPS-r scores and DDS scores did not explain any more variance in HbA$_{1C}$ and so was excluded from the final model (β = -.16, p=.11).

6.5 Discussion

6.5.1 Aim 1: To establish the prevalence of eating problems and insulin manipulation using a measure validated in a Type 1 DM population

We expected that eating problems would be more common in females than males. These predictions were supported. Based on the DEPS-r scale, eating problems (over the predetermined cut-off point) were present in 36.1% of the sample. Eating problems were significantly more common in females (50.0%) than males (15.4%). This result is of particular interest and is likely to have clinical importance given that eating problems have typically been associated with female gender in the general population (Woodside, 1995).

It was hypothesised that insulin manipulation would be present in the sample and more common in females than males. These predictions were partially supported. Based on DEPS-r items relating to insulin manipulation, prevalence of frequent insulin manipulation within the sample was 21.6%. Insulin manipulation was more common in females (25.9%) than males (15.4%) but gender differences were not significant. It should be acknowledged that the items relating to insulin manipulation in this study together showed a Cronbach's Alpha of .62. Therefore the results relating to insulin manipulation should be interpreted with caution. Nevertheless, insulin manipulation is associated with increased risk of death (Goebel-Fabbri, 2009) and the prevalence rates recorded in the current study indicate cause for concern for both male and female young adults.

6.5.2 Aim 2: To establish predictors of eating problems

It was hypothesised that eating problems would be predicted by female gender, elevated BMI and history of being overweight. These predictions were partially supported. Independent predictors of eating problems were gender, HbA$_{1C}$, and BMI at recruitment. History of being overweight was not a predictor of disordered eating behaviour. Diabetes distress was predictive of disordered eating but it was moderated by gender. That is, higher diabetes distress was predictive of eating problems, but this effect was only significant in females and not males. The non-significant effect in males may be the result of an underpowered sample of males. Therefore results should be interpreted with caution. Further research is necessary to establish whether diabetes distress may predict disordered eating in young adult males with Type 1 DM.

Since history of being overweight predicted eating problems in previous work involving young adults with Type 1 DM (Markowitz et al., 2009), it was expected to also predict eating problems in this cohort. However, the current study differed from Markowitz's study in two ways that may account for the discrepancies in findings. Firstly, they used self-reported history of being overweight but in the current study, BMI was extracted from medical records. By relying on self-reported history of overweight Markowitz may have inadvertently measured young adults' perception of body size and not actual history of being overweight. This may have predicted eating problems irrespective of whether individuals were medically overweight. Alternatively BMI obtained from medical records (used in our study) may not accurately identify individuals who have been overweight in the past. Previous work has found that BMI is poor at identifying individuals who have been classified as overweight based on body fat percentage (Piers, Soares, Frandsen, & O'Dea, 2000). Perhaps a more important difference between this study and the study conducted by Markowitz et al. is the measures used to assess disordered eating behaviour. Markowitz et al. used generic measures of eating problems (likely to inflate indications of eating problems) whereas the current study used a disease-specific measure intended for the Type 1 DM population.

6.5.3 Aim 3: To establish the role of eating problems and BMI in glycaemic control

It was expected that eating problems and elevated BMI would predict glycaemic control. This was only partially supported. The best model predicting glycaemic control included both eating problems and diabetes distress. Elevated BMI was not a significant predictor and there were no interaction effects. These results support the findings of the meta-analysis reported in chapter 5. Both this study and the meta-analysis indicate that eating problems are associated with suboptimal glycaemic control.

6.5.4 Strengths and limitations

As discussed in the introduction to this chapter, studies investigating predictors of eating problems typically used generic measures of eating problems. The greatest strength of the current study is that it used a disease-specific measure of eating problems. Disease-specific measures are likely to be more accurate than generic measures designed for the general population. The measure used in this study (the DEPS-r Markowitz et al., 2010) was designed specifically for young adults with Type 1 DM and previously demonstrated excellent internal consistency, construct validity, and external reliability.

Further strengths of the current study include the high response rate (81.8%) and inclusion of males where many other studies focus on females. Since less is known about eating problems in males than females in both the general population and Type 1 DM populations, the findings of the current study relating to males are particularly important.

Limitations of the study include the cross-sectional design. A prospective study is necessary to document the development of eating problems in young adults with Type 1 DM. However, the current study provides baseline data for a follow-up planned by CLAHRC in 2013. The follow up data will increase knowledge regarding the association between BMI and eating problems in young adults with Type 1 DM. Specifically, it will be possible to identify young adults who were overweight at baseline but that had no indication of disordered eating. If these young adults report disordered eating at follow-up it would suggest that elevated BMI precedes eating problems and may cause disordered eating. Finally, the cut-off point for the DEPS-r scale is not well-established and in this study was based on a personal communication with the author. More work is needed to establish a cut off point on the DEPS-r indicative of eating problems and more generally to develop additional diabetes-specific measures of eating problems.

6.5.5 Implications

The findings of the current study have important clinical and research implications. The results indicate that eating problems are common in young adults with Type 1 DM (both males and females) and predictive of suboptimal glycaemic control. Therefore, eating problems should be identified and addressed as quickly as possible. Early detection of eating problems results in more successful intervention (Bulik, Berkman, Brownley, Sedway, & Lohr, 2007; Eisler, Simic, Russell, & Dare, 2007). The results of the current study indicate that clinicians should be alert to the possibility of eating problems in individuals who have elevated BMI or HbA_{1C} (regardless of gender) or who are female (especially females who present with high diabetes distress). Similarly, interventions should be targeted at these individuals since interventions for eating problems aimed at high risk groups are more successful than universal ones (Shaw, Stice, & Becker, 2009). Given that the results of this study indicated that eating problems are present in males as well as females, it is important that future work includes males with Type 1 DM for whom eating problems are just as relevant as females.

6.6 Conclusion

This chapter investigated prevalence and predictors of eating problems in young adults with Type 1 DM. Results indicated that eating problems are problematic in these young adults with regard to glycaemic control and therefore warrant clinical attention. Clinicians working with this age group should be alert to the possibility of eating problems especially in young women, those with elevated BMI or glycaemic control or young women reporting diabetes related distress. The next chapter attempts to bring together the results of the entire thesis and draw conclusions.

Chapter 7 - Final Discussion

7.1 Chapter Summary

This chapter summarises findings of this thesis, bringing together the results of the qualitative interviews, meta-analysis and cross-sectional studies. Methodological considerations are then presented including some reflection on the method and measures used and the research design and analyses. Theoretical considerations are then outlined followed by clinical implications of the findings. This is followed by a discussion of the limitations and strengths of the research. Ideas for future research are then presented followed by final conclusions.

7.2 Summary of research questions and study design

This thesis aimed to address questions about the special difficulties of young adults with Type 1 DM in self-caring and achieving optimal glycaemic control. We wanted to understand firstly how young adults and their families manage and negotiate self-care and secondly how eating problems impact on self-care. To achieve this we conducted three studies. First, we conducted qualitative interviews of young adults with Type 1 DM, their parents and healthcare staff from their clinics. The interviews were analysed using thematic analysis and reported over two chapters. Chapter 3 reported common themes relating to self-care as reported by young adults, parents and staff. Chapter 4 reported themes reported specifically by young adults. We found a number of barriers and facilitators to self-care that have service level implications for specialist transition clinics.

We were also interested in investigating how psychological problems affected young adults with Type 1 DM, in particular eating problems. Therefore two quantitative studies were also conducted. First a meta-analysis was conducted to investigate how young adults and their glycaemic control are affected by eating problems. These results are reported in chapter 5 and raise important methodological considerations for measuring eating problems in young adults with Type 1 DM. Based on these results we thought it important to establish predictors of eating problems in a sample of young adults with Type 1 DM using a measure designed for and validated in a Type 1 DM population. Therefore we conducted a cross-sectional study to address these issues. The results are reported in chapter 6 and the results have important implications for identifying eating problems in young adults with Type 1 DM.

The key findings of this thesis will be discussed in relation to 1) self-care of Type 1 DM in young adults and 2) eating problems. These results have important theoretical and clinical implications which are discussed in sections 7.5 and 7.6 respectively.

7.3 Key findings

7.3.1 Self-care

Findings of chapter 3 indicate that as young adults with Type 1 DM transition from childhood to adulthood they also assume increasingly more responsibility for their own self-care. Young adults welcome increasing responsibility for care. They look forward to transfer from paediatric to transition services because of the independence it represents. However, young adults directly contradict this by reporting that self-care is too hard and that they are frustrated by the high expectations of staff and parents. Young adults still like a degree of parental input. This is because parents are a source of useful advice especially in relation to the more complex elements of care (e.g. calculating insulin ratios). Nevertheless, being allowed to direct and make their own decisions about self-care is important to young adults.

Parents acknowledge that young adults want to organise their own self-care and so long as this is done well parents are mostly happy to allow this. However, parents are reluctant to allow young adults complete responsibility when they believe self-care is ineffective or neglected. This creates a dilemma for parents. They desperately want young adults to take control of care but only if the quality of self-care is good. The views of parents regarding what constitutes good self-care differ from those of young adults. Consequently parents often believe their child is caring for Type 1 DM inadequately. Where self-care is inadequate parents' fears about Type 1 DM-related complications make it difficult for them to release control of care. This disparity between parent and young adult views of acceptable self-care can create family difficulties. Young adults become frustrated that parents will not allow them to control care. They interpret parental concern as interfering and consequently resist any input at all. Young adults often consider that both parents and staff have unattainable expectations for self-care, which are unrealistic in the context of real life. Staff are empathetic towards both young adults and parents. Nevertheless, they often agree that the quality of self-care demonstrated by young adults is inadequate. Furthermore, staff suggest that parents have difficulty negotiating their role as young adults increasingly develop independence. They also acknowledge that services do not integrate parents well so often they are uninformed about self-care decisions and confused about their role.

The results reported in chapter 3 support those of previous research. Previous work established that parents experience difficulty relinquishing control of care as young adults become more independent (Reiss et al., 2005). However it was not clear from previous work that parents are motivated to retain control of care because they fear for their child's health. Neither was it understood from previous work that young adults resist parental input completely when parents attempt to retain control of care. Other work found parental involvement to be beneficial, but the quality of self-care depended on the quality of family interactions (Betz & Smith, 2011; Grey et al., 2001; Murphy et al., 2007). Our study indicates that this is likely to be true. Given that young adults want a degree of parental involvement they will resist if parents will not release control of care. Furthermore our study adds to understanding of how families organise responsibility for self-care. This has previously been identified as a gap in the literature (Betz & Smith, 2011).

Effective self-care is known to be associated with better glycaemic control (Amaria et al., 2011). Based on both this assumption and on the results presented in chapter 3 (i.e. the emergence of self-care as an important theme in the qualitative interviews) the results of young adults interviews that relate to self-care (reported in chapter 4) have important implications. These results indicate that for young adults self-care of Type 1 DM poses a cumbersome interference on life. In particular, self-care is problematic for social activities (e.g. spending time with friends) and maintenance of social image (e.g. feeling normal and similar to friends). Young adults often minimise self-care as much as possible to reduce this burden. They are extremely reluctant to self-care if it encroaches on social activities or image. If self-care conflicts with these it is likely to be compromised. Social activities and image are such high priorities for young adults that they are willing to significantly risk their health to maintain them. Young adults are prepared to not wear insulin pumps and/or deliberately cause dangerously high blood sugar levels to maintain social image and avoid disruption to social activities.

Young adulthood is known to be a time when individuals are particularly socially orientated (Harris et al., 2011). However, these results provide important evidence to suggest that this can present a significant barrier to successful self-care of Type 1 DM. The strong sense of social priorities that young adults have may explain why they consider parent and staff expectations for self-care to be unrealistic (reported in chapter 3). That is social activities and image present such a strong competing demand that young adults do not have the capacity to self-care to the standard that parents and staff expect. This finding could be key to future interventions.

Young adults' time perspectives also raise significant barriers to effective self-care. That is, young adults feel they can justify insufficient self-care in the short-term because they intend to engage in better self-care later in their life when their priorities change (e.g. after exams or when social priorities are less important). This is consistent with evidence suggesting that young adults with Type 1 DM are not motivated to self-care to prevent future complications (Department of Health, 2006; Harris et al., 2011; Skinner et al., 2000).

Conversely, the need for young adults to maintain social image and activities can in some cases facilitate self-care. The need for approval from friends is strong enough to motivate some young adults to maintain self-care so as not to become ill and let friends down. Furthermore, friends who remind young adults to complete self-care tasks and disapprove when they neglect self-care also encourage young adults. This is in line with a study that found supportive friends could facilitate specific self-care behaviour in young adults with Type 1 DM (Bearman and La Greca, 2009).

Our findings also indicate that young adults may be motivated to engage in self-care if they realise that better management results in looking and feeling better and being well enough to participate in social activities. Again this parallels previous quantitative work that suggests young adults are motivated by the possibility of controlling the short-term implications of Type 1 DM rather than preventing future complications (Department of Health, 2006; Harris et al., 2011; Skinner et al., 2000).

Importantly, our results also suggest that current care does not adequately cater to the individual needs of young adults. It is clear from our results that young adults always prioritise their individual interests and lifestyle. Self-care ought to fit around the chosen lifestyle of each individual. For many this is socially oriented but it is critically important that in planning self-care individual differences are considered. Young adults currently perceive clinic to be heavily focused around medical outcomes with little discussion about lifestyle. This is consistent with previous work indicating that healthcare professionals are not confident discussing psychosocial issues even though they acknowledge their importance (Gregory et al., 2011).

Together the findings of chapters 3 and 4 of this thesis suggest that essential self-care is dependent on a number of variables. Family play an important role but the negotiation of responsibility can be difficult for parents and young adults. Parents often object to the quality of self-care demonstrated by young adults. Young adults place great importance on social image and activities. These priorities take precedence over self-care and may be so demanding that young adults are unable to understand how parents and staff also expect them to fit in self-care to the extent that they deem acceptable. Currently services do not facilitate young adults in arranging their self-care around their individual lifestyle. Young adults are unwilling to sacrifice social priorities for the sake of self-care. Therefore self-care is simply neglected.

The findings reported in chapters 3 and 4 are likely to be applicable to many young adults with Type 1 DM. Given the association of self-care and glycaemic control it is important that any intervention in young adults aiming to improve glycaemic control addresses issues in self-care. However in order to improve glycaemic control in this age group there are likely to be a number of other issues that ought to be addressed. In particular, some young adults may have the additional burden of psychological issues such as depression, anxiety and eating problems. Given that I was particularly interested in how eating problems effect individuals with Type 1 DM, the second part of this thesis (chapters 5 and 6) specifically investigate eating problems in young adults with Type 1 DM.

7.3.2 Eating problems

Results of a meta-analysis are reported in chapter 5 and in a recent paper (Young et al., 2012). Findings primarily indicate that the prevalence of eating problems in young adults with Type 1 DM (measured using diabetes adapted measures) is around 6.4% (clinical eating disorders) and 58.1% (disordered eating behaviour). Findings also indicate that eating problems and suboptimal glycaemic control are associated. Therefore eating problems are a significant concern in this group and should be considered in any work that aims to improve glycaemic control in young adults with Type 1 DM. Furthermore prevalence of eating problems in Type 1 DM may be dependent on the type of measure used to determine prevalence.

Given that generic measures may not be appropriate in a Type 1 DM population and diabetes adapted measures would be inappropriate in the general population, it is not possible to use the same measure and make like for like comparison between Type 1 DM and non-Type 1 DM groups. Thus, research efforts ought to instead move towards using measures specifically designed for and validated in Type 1 DM populations to determine the prevalence of eating problems in young adults with Type 1 DM. While this has not yet been attempted, it would have value in terms of understanding the extent of eating problems in young adults with Type 1 DM. In addition diabetes-specific measures should be used to investigate predictors of eating problems in young adults with Type 1 DM. This is also an area that has not yet, to my knowledge been attempted but would be clinically valuable in terms of screening for eating problems.

Results from our cross-sectional study (reported in chapter 6) indicate that disordered eating is common in young adults with Type 1 DM (36.1% of the sample) for both males and females (15.4% and 50.0% respectively). Given that we used a diabetes-specific measure, the findings represent an important development over most previous work that has reported prevalence based on generic measures or generic measures that have been adapted for Type 1 DM. Our results also indicate that many young adults with Type 1 DM manipulate their insulin with the intention of losing weight (15.4% males, 25.9% females). This supports previous suggestions that individuals with Type 1 DM make use of this unique weight loss method available to them (Colton et al., 2009; Young-Hyman & Davis, 2011).

Further findings reported in chapter 6 indicate that female gender, suboptimal glycaemic control and elevated BMI predict eating problems in young adults with Type 1 DM. Diabetes specific distress clearly predicts eating problems in females (although the relationship is less clear in males). These findings are consistent with previous work which indicates that eating problems (measured using a diabetes specific measure) are associated with glycaemic control (Markowitz et al., 2010). However, they do not support previous work suggesting that a history of being overweight also predicts disordered eating behaviour (Markowitz et al., 2009).

Our findings also indicate that eating problems (alongside diabetes specific distress) significantly predict glycaemic control. This is consistent with a number of studies that suggest an association between eating problems and glycaemic control (Garcia-Reyna et al., 2004; Jones et al., 2000; Neumark-Sztainer et al., 2002; Olmsted et al., 2008; Pinar, 2005).

Together the findings of chapter 5 and 6 indicate that eating problems are an important issue in young adults with Type 1 DM, not least because of their association with suboptimal glycaemic control. Insulin manipulation is of particular concern since it is very easy but could be potentially devastating to glycaemic control. The findings also raise methodological considerations that are discussed in the next section.

7.4 Methodological considerations

The important methodological considerations for this thesis are firstly whether eating problems and BMI have been adequately measured and secondly whether the studies were designed and analysed appropriately to answer the research questions.

7.4.1 Measurement of variables

7.4.1.1 Measuring eating problems

Measuring eating problems poses one of the most difficult obstacles in research involving young adults with Type 1 DM. Very few diabetes specific measures (i.e measures designed for and validated in Type 1 DM populations) are available for use. The lack of diabetes specific measures of eating problems is reflected in the meta-analysis study in chapter 5. Most included studies measured eating problems using generic measures or adapted versions of generic measures (to account for Type 1 DM diet and insulin manipulation). These latter measures are likely to be more sensitive for a Type 1 DM population. Nevertheless, given that adapted measures were not intended for or validated in a Type 1 DM population they are likely to also be limited. Therefore it is arguable that the outcomes of the meta-analysis lack validity. For this reason the main conclusions of the meta-analysis have been drawn from the most robust results. That is, conclusions regarding eating disorders were drawn not from data measured using generic measures but from data measured using diabetes adapted measures. These measures were considered more robust than most as they tended to be clinical interviews rather than self-report questionnaires. Interviews are likely to be more robust than self-report measures since highly trained researchers conduct them and can assess motivation for behaviours (i.e. as a function of Type 1 DM care or eating disorders).

We were particularly cautious in interpreting results that could be less robust. Because prevalence of disordered eating behaviour was measured using generic self-report measures or generic self-report measures that had been adapted we were cautious in interpreting results for disordered eating behaviour. Similarly, conclusions relating to the association between eating problems and glycaemic control were based only on eating disorders measured using diabetes-adapted clinical interview measures.

Results of the meta-analysis informed our decisions about measuring eating problems in our own sample. Careful consideration was given to how best to measure eating problems in the cross sectional study reported in chapter 6. We did not aim to make comparisons between young adults with Type 1 DM and a non-Type 1 DM group, but we did aim to accurately measure prevalence of eating problems. For these reasons it seemed most appropriate to use a measure of eating problems that had been designed for and validated in a Type 1 DM population (i.e. a diabetes specific measure). The DEPS-r measure of disordered eating behaviour (Markowitz et al., 2010) was chosen giving consideration in the first instance to *validity* and *reliability*. The DEPS-r is the only available measure of disordered eating designed for and validated in a Type 1 DM population. Therefore we considered it to be the most appropriate of the choices available. Furthermore the DEPS-r has shown excellent internal and external reliability (see page 95 of this thesis). Consideration was also given to reducing burden for respondents since they were asked to complete a pack of measures. For this reason the revised version (i.e. DEPS-r; Markowitz et al., 2010) was considered more appropriate than the full length scale (Antisdel et al., 2001). Consideration was also given to *interpretability, feasibility* and *acceptability* to respondents. Although the authors of the scale had already assessed these we also did so. Clinical leads and DSN from transition clinics were asked to comment on the *interpretability, feasibility* and *acceptability* of the scale. All but one item on the DEPS-r scale was deemed to be interpretable, feasible and acceptable. This item was removed (as described in chapter 6) on the grounds that young adults in the UK would not understand it. To ensure that removing this item did not affect the overall reliability of the scale Cronbach's alphas were calculated for our sample and indicated excellent reliability.

7.4.1.2 Measuring BMI

Measuring BMI (both historical BMI and current BMI) as accurately as possible was important to the aims of the cross-sectional study. Therefore it was considered appropriate to obtain these data from medical records of young adults. As with any data obtained from medical records the BMI data were subject to recording errors. Nevertheless this method of data collection is likely to be more reliable than asking young adults to self-report BMI. Some historical BMI data were difficult to obtain because records had been held in paediatric services and not transferred over when young adults moved to the transition clinic. Therefore some historical BMI data were missing. We acknowledge this as a limitation of the cross-sectional study. Missing data may explain the non-significant effect of historical BMI in predicting disordered eating behaviour. Nevertheless, it is arguable that despite missing data our cross-sectional study is more reliable than previous work that depended on self-reported history of being overweight.

7.4.2 Research design and analyses

With regard to designs of the studies, the first study was a qualitative interview design, the second study a meta-analysis design and the third study a cross-sectional design.

The qualitative interview study is of course subject to the inherent limitations of any qualitative work, although special consideration was given to addressing validity and reliability. Specifically we assessed validity using the principles of (Yardley, 2000). To ensure *sensitivity to context* we familiarised ourselves with the transition clinics by sitting in on clinics in the months before interviews commenced. We also familiarised ourselves with existing literature. We also considered *commitment, rigour, transparency and coherence.* Conducting interviews over the course of four months ensured *commitment.* Furthermore, selecting the sample on the basis of HbA_{1C} and insulin regimen ensured r*igour*. Throughout the write-up of the work *transparency* was given careful consideration. We outlined the research process as clearly as possible in chapters 3 and 4 with reference to how the sample was selected, how the interview schedule was constructed and how the interviews were conducted. We also acknowledged areas of weakness and potential bias. To ensure *coherence* a sub-sample of interviews were second-coded by another researcher, the level of agreement was calculated and differences were resolved through discussion. *Impact and importance* are subject to the reader, but we are confident that the work has useful and important implications with regards to understanding and improving self-care in young adults with Type 1 DM. Despite taking into account these principles throughout the research process we acknowledge that the interview study may be subject to sampling bias, interviewer bias or bias in analysis. With regards to the analysis, guidelines for thematic analysis were carefully followed throughout.

With regard to the meta-analysis study, recommendations regarding protocol development, literature searching, data extraction and data analysis (Centre for Reviews and Dissemination, 2009) were closely adhered to. We acknowledge that since studies were predominantly of cross-sectional design, causality cannot be established from the data. However, the strength of the conclusions is based on the structured search and analysis procedure. Quality of studies was ensured by predefined inclusion and exclusion criteria. The addition of meta-analytical synthesis of data increases certainty in conclusions.

Of course the cross-sectional design of the third study carried with it inherent limitations of all cross-sectional research. Most notably, only a small snapshot of disordered eating in young adults with Type 1 DM was gained and therefore causality cannot be inferred. However this limitation is arguably offset since this was the one of the first studies to use a diabetes-specific measure to investigate prevalence and predictors of eating problems in a population of young adults with Type 1 DM. In addition, a follow-up study is planned by CLAHRC to begin early in 2013 to assess how young adults with Type 1 DM experience eating problems over the short- and longer-term.

7.5 Theoretical implications

7.5.1 Self-care

This research has contributed to our theoretical understanding of how young adults with Type 1 DM manage self-care and how services therefore could be organised to optimise care. Specifically the findings relating to self-care contribute to our understanding of the challenges families face in caring for Type 1 DM and in particular the barriers and facilitators to self-care experienced by young adults. Perhaps one of the most important contributions to theory comes from the finding that young adults are willing to put their short- and longer-term health at risk for these priorities. Although previous theories of young adulthood stress the importance of social activities and image for young adults (Anderson, 2009), the extent to which young adults will go to preserve these was perhaps underestimated.

This is in line with theories discussed in chapter 2 (Steinberg, 2004; Steinberg, 2007) that suggest young adults are less able than adults to control their impulses. That is, they are less able to delay gratification and are more influenced by their emotions and peers. As such, young adults are likely to have more difficulty than adults in performing health behaviours, which require impulse control over attentional and behavioural distractions (Hodgkins & Orbell, 1998; Norman & Conner, 1993). The results of chapters 3 and 4 of this thesis are consistent with this theory. Young adults reported that they were unable to overcome the desire to engage in more appealing distractions to self-care (e.g. social distractions and peer influence). This was especially true for self-care tasks that they perceived to be particularly arduous. They also reported difficulties overcoming attentional distractions to self-care and consequently forgot to self-care.

This work also suggests that intentions to perform self-care behaviour may be formed in the way described by the HBM (Rosenstock, 1966) discussed in chapter 2. In line with the HBM, young adults perceived clear barriers and facilitators to self-care consistent with the ‘costs and benefits’ of the HBM. Specifically, the main cost of performing self-care behaviour was having to invest time which could be spent in more desirable ways. Conversely benefits of performing self-care behaviour were feeling well and maximising time with friends. As such, our findings suggest that young adults are motivated to self-care by short-term (and not longer-term) gain. Also consistent with the HBM is the finding that some young adults who had experienced Type 1 DM complications were more motivated to perform self-care behaviour than those who had not. They perceived their susceptibility to complications to be high and the consequences of complications to be serious enough to warrant action.

These findings go some way to addressing recent criticism suggesting that there is a lack of evidence about the needs of transitioning young adults and their families (Allen & Gregory, 2009). This research may offer a theoretical grounding to inform transition services that have previously been criticised for lacking a theoretical grounding (Pai and Schwartz, 2010). Specifically we found that contrary to previous assumptions, families (especially parents) are still important in self-care for Type 1 DM. However, families have difficulty negotiating the responsibility for self-care. We also found that young adults experience specific barriers and facilitators to care which must be acknowledged and respected when making decisions about the organisation of self-care.

7.5.2 Eating problems

This research contributes to our theoretical understanding of eating problems in young adults with Type 1 DM. The research contributes to (previously sparse) theory regarding the extent and characteristics of eating problems in young adults with Type 1 DM. The association with glycaemic control demonstrates the seriousness of eating problems in this population. This research was one of the first to implement a diabetes specific measure of eating problems to investigate (i) prevalence of eating problems and (ii) predictors of eating problems in a UK population of young adults with Type 1 DM.

7.6 Clinical implications

7.6.1 Self-care

This research suggests that there are a number of barriers and facilitators that hinder or encourage self-care in young adults with Type 1 DM. These are mostly grounded in the need for young adults to maintain social image and activities. Young adults may perceive a cost of performing self-care behaviour to be that it compromises time with friends. Conversely young adults may consider a benefit of performing self-care behaviour to be feeling well and maximising time with friends. Our findings suggest that young adults are motivated to self-care by short-term (and not longer-term) gain. Because this parallels constructs of the health belief model, application of the model may be useful in the development of interventions. In particular, strengthening perceived benefits of self-care behaviour and health motivation may strengthen the intentions of young adults to improve self-care behaviour.

Young adults stress the importance of looking at individual lifestyles. Therefore to overcome barriers to self-care it is important that each individual is consulted and is assisted in organising self-care around their personal priorities and individual lifestyle. Young adults' own priorities are so important that failure to fit care into these will almost certainly result in self-care being neglected.

This research suggests that parents of young adults are important to self-care, but families can find it hard to negotiate responsibility, as young adults get older. Parents may have difficulty releasing control of care if self-care is being neglected. Being unable to direct their own care frustrates young adults and may cause them to resist parental input completely.

Any intervention ought to be acutely aware that young adults are willing to risk their short- and long-term health for the sake of their short-term priorities. This is demonstrated by insulin manipulation with the intention of maintaining high blood sugars to avoid hypoglycaemia and the intention of losing weight.

Together these findings suggest that services should work with young adults to (i) enable them to tailor self-care to their priorities and (ii) improve the quality of young adults' self-care. This could be achieved through an age-appropriate educational intervention, which enables young adults to work intensively alongside health care professionals to restructure their self-care according to their lifestyle and priorities. This intensive time could also be used to strengthen perceived benefits of self-care behaviour and health motivations (Rosenstock, 1966) and form and practice habitual self-care behaviours (Gollwitzer, 1999) A similar adult education course is already available and offers flexibility in care (DAFNE Study Group, 2002). A version for children has also been piloted (Knowles et al., 2006). A course for young adults may be beneficial in two ways; first, if self-care is organised around individual lifestyles, young adults may perceive self-care to be less intrusive (minimising perceived costs of self-care behaviour; Rosenstock, 1966). This is supported by findings from the qualitative interview study indicating that some young adults are willing to self-care if they believe it will reduce the interference of Type 1 DM on social image and activities (e.g. if they look better and are well enough to see friends). Second, it may reassure parents who are struggling to release control of care because they doubt the quality of self-care. In turn this may minimise family tensions.

It may also be beneficial to offer young adults care-planning style consultations in clinic. This could be an additional way of tailoring care to lifestyle and is consistent with department of health recommendations (Department of Health, 2006).

Families may also benefit from a service that better includes parents. This could involve an educational intervention for parents that runs concurrently with young adult education and offers parents skills for non-confrontational communication (e.g. motivational interviewing) and educates parents in the techniques their child is learning on the young adult education course.

7.6.2 Eating problems

This research suggests that eating problems are prevalent in young adults with Type 1 DM and critically, associated with suboptimal glycaemic control. Therefore screening in clinics with the aim of identifying and addressing eating problems as early as possible is justified.

This research also goes some way to informing services about indicators of eating problems. The findings suggest that females are more likely than males to have eating problems and especially those experiencing diabetes specific distress. Further, any individual who has suboptimal glycaemic control or an elevated BMI may also have eating problems. Individuals with these indicators for eating problems should be screened using a diabetes specific measure.

7.7 Strengths and limitations

Limitations in this research programme must be acknowledged and those relating to methodology have been discussed in detail in the chapter discussion sections and the methodological considerations section of this chapter (section 7.4).

There are some limitations that are applicable to several parts of the research programme. In particular data were mainly cross-sectional. For the meta-analysis study discussed in chapter 5 we had to rely predominantly on cross-sectional studies and our own data relating to the prevalence and predictors of eating problems (reported in chapter 6) were cross-sectional. Therefore we only have a narrow understanding of eating problems at a given time and cannot suggest causal relationships.

Second it is important to acknowledge that in the qualitative interview study (chapters 3 and 4), meta-analysis and cross-sectional study some data were self-reported. As with any self-reported data this opens up the research to bias as a result of demand characteristics. However, every effort was made to minimise this. In the qualitative interview study it was emphasised to interviewees that the interviewers were independent of their clinic, that their answers would not effect their care and that all data would be anonymised. Although in the meta-analysis study it was not possible to minimise demand characteristics, studies were assessed for quality. In the cross-sectional studies self-report measures were conducted with privacy and anonymity as primary concerns (e.g. young adults were assured that data were anonymous and were given space in clinic to fill in questionnaires privately).

There were several strengths to this programme. First data were collected from a UK specialist transition clinic. As a result data are likely to be highly representative of other transition clinics in the UK. Work in this age group has in the past been very limited. Much work focuses on paediatric and adult services but little is understood about the need of transitioning young adults. Therefore the findings have important implications at a service level. Second, a mixed methods approach was taken to measuring the variables of interest. That is the research programme used qualitative methods to understand issues that required an in-depth approach, a meta-analytical approach to quantify large amounts of secondary data and quantitative, cross-sectional methods to record data at a given point in time. This triangulation is likely to have given a holistic insight into the research questions at service level, family level and individual level.

7.8 Future research

Suggestions for future research are based on the limitations as well as the results of the current research. First the qualitative study has implications for interventions (outlined in section 7.6). Interventions ought to be trialled and evaluated on a small scale to test potential efficacy. Specifically future research ought to pilot care-planning interventions and educational interventions for young adults and parents.

In relation to eating problems, future research should focus on developing diabetes specific measures since those currently available cannot be used to assess clinical eating disorders and lack established cut-off points indicative of disorder eating behaviour. Future work relating to eating problems also ought to focus on developing the findings of this research to establish predictors of eating problems in young adults with Type 1 DM. Specifically prospective longitudinal research would be beneficial to understand how eating problems develop over time.

7.9 Conclusions

Young adults with Type 1 DM are an extremely vulnerable group at serious risk of premature death (The NHS Information Centre, 2011). To successfully reduce the devastating impact of Type 1 DM on young adults and their families, it is critical that health services meet the unique needs for this age group. This work is one of the first attempts to truly address the concerns of young adults with Type 1 DM.

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* indicates studies included in meta-analyses (chapter 5)

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