

# **The Relative Roles of Family and Peer Support in Metabolic Control and Quality of Life for Adolescents with Type 1 Diabetes**

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# Declaration

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## Abstract

**Background:** Metabolic control declines during adolescence, increasing the risk of severe medical complications. Numerous burdensome treatments including insulin management, blood glucose monitoring, diet and exercise are necessary to prevent such complications. Adolescence is characterised by the transition from reliance on the family to independence and increased peer affiliation. It is therefore important to examine the roles of family and peer support for diabetes management tasks within a developmental context. Previous research indicates that family may have a role in supporting practical diabetes management, whilst peers may provide emotional support. Currently there is no research that compares the impact of diabetes-specific family and peer support on both metabolic control and quality of life. The present study addresses these issues.

**Methods:** Ninety adolescents aged 13-18 with type 1 diabetes participated in this cross-sectional study. Data included youth report of diabetes-specific social support (DSSQ) from peers and family, quality of life (PedsQL) and metabolic control (HbA1c). The relationships between social support, quality of life and HbA1c were examined using *t*-tests and correlations. Fishers Z transformations and hierarchical multiple regression were used to investigate the social support measures as potential predictors of HbA1c and quality of life.

**Results:** Family provided significantly more support for practical diabetes management tasks than did peers. Peers provided significantly more support for exercise, but less emotional support, than did family. Better metabolic control was predicted by lower levels of peer support for insulin management, higher levels of peer support for blood glucose monitoring, increased mood and higher levels of family support for exercise. Quality of life was predicted by increased mood, higher levels of family emotional support, family support for diet, lower levels of peer support for insulin management and higher levels of peer support for exercise.

**Conclusion:** Whilst family support remains important throughout adolescence, peer support also has an important role in the metabolic control and quality of life of adolescents with diabetes. This has implications for clinical practice, the most significant of which being the education and inclusion of peers in diabetes care.



# 1 Introduction

## 1.1 *General introduction*

Diabetes mellitus (type 1) is a disease primarily diagnosed within childhood or young adulthood that is fatal if left untreated. However, with modern advances in treatment and management it is now considered to be a chronic illness requiring intensive and continuous monitoring. As monitoring is performed almost entirely by the patient, the disease differs from most other chronic illnesses. Even when the condition is under strict control, acute difficulties such as hypoglycaemic attacks are relatively common and require additional support. The unrelenting nature of the management and symptoms of diabetes can prove to be a psychological burden for all patients. Negotiating diabetes as well as the developmental tasks of adolescence can be an added burden. The transition for young people from parental control and dependence to independence and autonomy is of particular importance when considering diabetes-related management tasks. Disruptions caused by diabetes to the psychological, social or physical development of adolescents may therefore have a significant impact on both physical health and quality of life.

This introduction provides an overview of diabetes, its management and available treatments. The issues surrounding the support available to adolescents with diabetes, medical complications and quality of life for those with the condition are then discussed.

The literature for this review was initially obtained through numerous search-term strings on the following databases: Psychlit, Psycharticles, Medline, Ovid, Cochrane Library and PubMed. The following search terms were used: “adolesc\*, diabet\*, social support, quality of life, metabolic control, glyc\* control. Further articles were obtained through the exploration of citations in the original research papers.

## **1.2 What is diabetes?**

### **1.2.1 Historical context**

The term ‘diabetes’ is Greek in origin, meaning ‘passing through’ which highlights the two common symptoms of diabetes: polydipsia (excessive thirst) and polyuria (excessive urine volume). The term ‘mellitus’ also has Greek roots, meaning ‘honey or sweet’. The honey-sweet nature of the urine of patients with diabetes was first noticed by the ancient Hindus, when ants and flies would be attracted to the urine of those with the disease (Sanders, 2002). The first use of the term ‘diabetes’ is thought to have been by Aretaeus, a disciple of Hippocrates, who described the ailment as “... a wonderful affection, not very frequent among men, being a melting down of the flesh and limbs into urine...” (as cited in Owens, 1986 p.3).

Until 1921, diabetes was a fatal condition. Those affected would develop severe dehydration followed by widespread organ failure. The work of Joseph von Mering and Oskar Minkowski in 1889 began the life-saving discovery of the role of insulin in preventing diabetes-related deaths (Sanders, 2002). This work was more famously repeated and developed by Sir Frederick Gant Banting and his 22-year-old research assistant, Charles Herbert Best in 1921 (Sanders, 2002). For the first time, insulin was identified and used as a treatment for diabetes. It was not a cure, but appeared to give life to those with inevitable death sentences. That said, medical professionals later realised that there were severe complications associated with the condition including renal failure, loss of limb function and blindness.

Since 1921, the development of modern technologies and research has led to dramatic changes in diabetes care. In the last 20 years, patients have moved from using glass syringes with primitive porcine and bovine insulins, through to continuous subcutaneous insulin infusion (CSII) using electronic insulin pumps and synthetic insulins with

varying response times. The medical goals have significantly changed over the last century, from survival to 'normal life'. A 'normal life', however, implies both physical health and well-being: at present, this requires intensive daily management of the condition.

### **1.2.2 Types of diabetes**

The first internationally accepted classification of diabetes was drawn up by the World Health Organisation and modified in 1985 to include three distinct types of diabetes: (a) insulin dependent diabetes mellitus (IDDM, also known as type 1), (b) non-insulin dependent diabetes mellitus (NIDDM, also known as type 2) and (c) gestational diabetes. More recent research into the aetiology of the conditions resulted in a modification of the classification. In 1997, the American Diabetes Association suggested that the terms IDDM and NIDDM be removed from diabetes classifications, the definitions of type 1 and type 2 be expanded, and an 'others' group be included to give a better idea of the underlying causes (Turner & Wass, 2002).

Type 1 diabetes is the most common metabolic disease of the young (Struwe, 1991). It is an autoimmune disorder in which the destruction of pancreatic beta cells causes an absolute insulin deficiency and inability to produce any further insulin (Bach, 1994). This results in chronic hyperglycaemia (an accumulation of glucose in the blood) with disturbances in the metabolism of carbohydrates, protein and fat (Scottish Intercollegiate Guidelines Network; SIGN, 2001). There is no cure for this condition and it requires life-long management and treatment.

While not studied here, type 2 diabetes is the most prevalent of all the conditions, affecting approximately 5-7% of the UK population with a peak onset age of middle to late adulthood (Turner & Wass, 2002). It is classified by a reduction in insulin production and concurrent increase in insulin resistance, although is not autoimmune in

nature. It is often associated with poor diet, being overweight and co-morbid conditions including arthero-sclerotic vascular disease, coronary heart disease and stroke (SIGN, 2001). This condition can be effectively treated, with patients sometimes requiring reduced treatment or, occasionally, no further medical treatment when significant weight has been lost and a healthy diet and lifestyle maintained.

Gestational diabetes occurs primarily during pregnancy and can result in poorer foetal health than a non-diabetic pregnancy. It is managed through a strict diet and occasionally through insulin treatment or tablets. Regular blood glucose monitoring is required. It is usually temporary and remits postpartum.

Due to clinical and epidemiological distinctions between the different types of diabetes, it is important to treat them as distinct conditions with different management strategies required. This study and the following review will therefore focus only on the autoimmune condition of type 1 diabetes.

### ***1.3 Type 1 diabetes***

#### **Pathophysiology**

Insulin is a 51 amino acid peptide hormone that is secreted into the blood and facilitates the entry of glucose from the blood into the body's cells. Without insulin, this glucose will accumulate within the blood (hyperglycaemia) and cannot provide the body with the energy it requires. Cells are therefore forced to use the body's stored energy reserves (Seiffge-Krenke, 2001). This is initially glycogen, and then later the body relies on fat and protein stores to sustain itself. The burning of fat stores for energy leads to the production of highly acidic ketones that accumulate in the blood (diabetic ketoacidosis or DKA). This places an increased demand on the kidneys to work harder to clear the blood of both excess glucose and ketones resulting in frequent urination, dehydration

and the loss of essential minerals including sodium. Without treatment by subcutaneous injection of insulin, type 1 diabetes will result in death caused by the body's cells starving - despite the presence of sufficient foodstuffs.

## Prevalence

The UK charity, Diabetes UK, states that of a (2006) population of 5.2 million in Scotland, approximately 197,000 had confirmed diabetes mellitus and a further 90,000 were believed to have the disease but were as yet undiagnosed (Scottish Diabetes Survey Monitoring Group, 2008). The number of people with diabetes is doubling every decade and it has been reported that 10% of the total NHS budget (approximately £1 billion each year) is used to treat the disease and its complications (NHS Quality Improvement Scotland, 2008).

This study focuses on three health board areas: Tayside, Forth Valley and Fife. The prevalence of diabetes in each is representative of that in Scotland as a whole (Table 1).

**Table 1:**

*Prevalence of Diabetes within the Diabnet Health Boards*

Health Board	Number of people diagnosed with each sub-type of diabetes:				Total	Total prevalence within general population
	Type 1	Type 2	'Other'			
NHS Tayside	1,570	13,792	302	15,664	4.0%	
NHS Forth Valley	1,460	10,114	112	11,686	4.1%	
NHS Fife	1,782	12,563	227	14,572	4.1%	
<b>SCOTLAND</b>	<b>26,294</b>	<b>166,926</b>	<b>3,581</b>	<b>196,801</b>	<b>3.9%</b>	

There are nearly 2000 people with type 1 diabetes under the age of 16 in Scotland, with a 2% rise in prevalence per annum (Greene & Waugh, 2004). Therefore diabetes in adolescence has a potentially significant impact on NHS services, especially in the areas

of finance, staffing capacity and service development. As a result, this population warrants further study.

### **1.3.1 Management**

Although diabetes cannot be cured, it can now be treated very successfully with intensive management. The aim of diabetes management is to maintain stable levels of blood glucose within the range of 4-10 mmol/L. To achieve this, a number of treatment strategies are required. These include insulin management, blood glucose monitoring, diet (these will be collectively referred to as practical diabetes management tasks) and exercise (considered to be a form of ‘companionship’ in diabetes social support research and will subsequently be identified as such, Bearman & La Greca, 2002). Diabetes is considered to be one of the diseases most heavily reliant on self-management and self-care (Austin, 2005). The day-to-day management of the condition is undertaken almost entirely by the patient themselves, with additional support given from medical teams, and social supports that include family and peers. This support is vital to ensure that the patient maintains their health and is able to persevere with their life-long treatment, 24 hours a day. The treatment strategies required in diabetes management will now be discussed in turn.

#### **Insulin management**

As individuals with diabetes are unable to produce insulin themselves it must be provided artificially. Currently, insulin cannot be taken orally as the stomach’s digestive enzymes break down the hormone before it can take effect. It must therefore be delivered subcutaneously, usually in the form of individual injections, but increasingly using a continuous subcutaneous insulin infusion device or ‘insulin pump’. Recently, an inhaled insulin has become available for adults and is currently under clinical trials for children and adolescents (Skyler *et al.*, 2001).

### ***Types of insulin***

There are more than 30 types of insulin preparations available that vary in terms of onset of action, peak effect and duration of action. Long-acting insulins (e.g., human ultratard) are typically taken once (at night) or twice a day, as their effects can last up to 24 hours. This means that frequent injections are not required throughout the night. However, if used during the day, this form of insulin therapy is very restrictive for the individual as it cannot allow for any changes in routine. Long-acting insulins require the individual to eat specific types and amounts of food at the same time each day to fit with the insulin's pattern of onset. This insulin also needs to be refrigerated, therefore it is more difficult for adolescents to take part in spontaneous social plans such as sleepovers or meals out.

Short-acting insulins allow greater flexibility but must be taken 30 minutes prior to eating to be effective. This allows the individual to have greater choice over their menu, but is more likely to lead to hypoglycaemia (acute complication of diabetes due to lack of glucose in the blood) if meals are delayed or insufficient carbohydrate is consumed. The newer insulins available (e.g., lispro) can be taken at the same time as food is eaten, allowing much greater flexibility in terms of the choice and timing of their diet, with a reduced risk of hypoglycaemia. Both short-acting and the newer insulin analogues must be taken more frequently as they have shorter durations. This, therefore, requires the individual to carry the injection equipment and inject throughout the day, which can be intrusive to their daily routine.

### ***Insulin regimens***

The vast majority (94%) of young people in Scotland are required to take two or three injections daily (Greene & Waugh, 2004). This typically reduces the number of injections required whilst away from family support (e.g. at school). Each dose of insulin must be calculated based on current blood glucose levels, planned dietary input and future energy expenditure (e.g., exercise). Intensive insulin therapy (four injections

per day) is associated with significantly reduced risk of long-term complications (The Diabetes Control and Complications Trial research group; DCCT, 1994). However, it has a number of potential disadvantages: injections are required more frequently throughout the day, including at times when the young person is at school or away from family support (McMahon *et al.*, 2005; SIGN, 2001). The SIGN guidelines identify that an intensive insulin therapy should be delivered as part of a comprehensive support package, however it is acknowledged that at present there is “no evidence on the most effective form of support” (SIGN, 2001 p.4). The guidelines suggest that this might involve patients, their families and the local multidisciplinary team; however the specific roles are not identified.

### ***Insulin pump therapy***

Insulin pump use has been shown to improve metabolic control and reduce the frequency of hypoglycaemic attacks, particularly for young people (Battelino, 2006; McMahon *et al.*, 2005). Insulin pumps are external devices that consist of a programmable pump and insulin storage reservoir to which the patient is continuously connected through a cannula inserted under the skin. The pump delivers insulin continuously at a constant or variable basal rate (pre-programmed by the patient), with an additional dose delivered by the patient at meal times (National Institute for Health and Clinical Excellence; NICE, 2004). This allows a greater degree of flexibility in lifestyle (e.g. less rigid meal times and the ability to take part in social activities; NICE, 2004). Insulin pumps can contain up to 6 or 7 days' worth of insulin that does not need to be refrigerated. Therefore young people can be more flexible in terms of spontaneous social plans.

Pump therapy requires regular and intensive blood glucose monitoring to prevent the risk of acute complications such as DKA (discussed in detail later). Individuals on pump therapy are at an increased risk of DKA from potential pump failure, as the individual



has no ‘back up’ of long-acting insulin in their blood. Therefore those who use pump therapy must be committed and diligent in their approach to monitoring (NICE, 2004). This is often challenging and requires additional reminders from family or peers. Whilst insulin pump technology is currently unable to automatically adjust for food consumption or altered blood glucose levels, insulin is delivered by the touch of a button, rather than a (painful) injection. This is less physically intrusive than injections for the adolescent. However, the task might also be more easily forgotten without prompts from family or peers (McMahon *et al.*, 2005).

### ***Individual differences in insulin requirements***

Due to individual physiological differences such as insulin sensitivity and resistance, insulin requirements vary greatly between individuals. During puberty, there is a physiological rise in insulin resistance, which is particularly exaggerated in type 1 diabetes (Caprio *et al.*, 1994). Adolescence is typically a time that requires many dose adjustments and frequent additional monitoring to calculate the changing dose of insulin required.

### ***Summary***

Whilst long acting insulins reduce the frequency of injections needed, they are more rigid and restrictive in terms of routine and diet. Short-acting insulins are more flexible, but require more frequent administration. This has consequences for adolescents when with peers in social situations, when they may be more likely to forget or avoid their injections due to social pressures.

Adolescents using pump therapy who regularly monitor their own blood glucose are able to identify their insulin requirements throughout the day and night, adjust their pump to respond to these changes and create a more individualised and flexible approach to treatment. Pumps allow more flexibility for social activities, but pose a greater challenge

with an increased need for blood glucose monitoring; pump users may require additional support and reminders from others.

### **Blood glucose monitoring**

The constantly changing requirements for insulin within the body require close monitoring to maintain blood glucose levels. This is typically done using a home monitoring blood glucose meter. The adolescent with diabetes must use a ‘finger-prick’ device, which consists of a small needle inserted into the finger to produce a blood droplet. This blood is then placed on a testing strip inserted into the meter and the levels of glucose in the blood are displayed. International guidelines based on the DCCT (1994) suggest that all individuals with diabetes should test their blood glucose at least four times per day. The tests enable the person to react to changes in blood glucose level before they escalate into acute emergencies. However, it is widely acknowledged that blood glucose monitoring is often the most challenging aspect of diabetes care for young people (Bui *et al.*, 2005). Barriers to daily blood glucose monitoring include the inconvenience of obtaining the testing materials required, finding the time and opportunity to test and the pain associated with the ‘finger prick’ itself. Such testing can also attract unwanted attention from others (Bui *et al.*, 2005).

Close monitoring of blood glucose enables insulin doses and carbohydrate intake to be altered to maintain a stable blood glucose level, and is particularly vital when adolescents with diabetes are unwell, doing extra exercise or have a change in routine. However, blood glucose monitoring is often the aspect of diabetes management most readily forgotten or ignored due to its intrusive impact on daily functioning (Thomas *et al.*, 1997). Young people regularly estimate their own blood glucose based on internal physical sensations rather than using the specialist equipment to respond to nagging to test by family members. (Kyngas & Barlow, 1995; Meltzer *et al.*, 2003) Such errors lead to inappropriate self-treatment such as overeating or overdosing on insulin. Whilst blood

glucose monitoring often requires prompting to ensure that it is completed, it is clearly difficult to achieve a balance between maladaptive ‘nagging’ and adaptive support.

### ***Summary***

Blood glucose monitoring is painful and intrusive. However, it is vital to ensure blood glucose stability and prevent acute and chronic complications. Achieving the recommended four tests per day may require prompting from others.

### **Diet**

Nutritional recommendations for adolescents with type 1 diabetes are the same as for all healthy adolescents (Committee on Examination of the Evolving Science for Dietary Supplements, 2002). However there are a number of additional dietary concerns that must be taken into account with type 1 diabetes. The focus of a dietary approach to treatment is to achieve blood glucose goals without excessive hypoglycaemia (low blood glucose levels; Silverstein *et al.*, 2005). The diet has a direct effect on blood glucose levels, and the amount of insulin taken must correlate to the amount of carbohydrate consumed.

Whilst the long-acting insulin regimens require the individual to have a rigid and routine diet, the intensive insulin injection regimens allow more flexibility. The amount of carbohydrate in each meal or snack must be calculated and the insulin requirement is adjusted to suit the meal (DAFNE Study Group, 2002). However, individuals must not only take into account the amount of carbohydrate in a meal, but also its glycaemic index (Rendell, 2000). Carbohydrate-rich foods can take varying amounts of time to affect blood glucose levels, depending on their fat and fibre composition. High sugar, low fibre foods will raise blood glucose levels quickly and are therefore good for treating hypoglycaemia. However, slower-acting carbohydrates, such as those containing fibre or low glycaemic index are preferable for day-to-day consumption to avoid sharp

increases in blood glucose levels. These foods are therefore recommended to reduce the risk of postprandial hyperglycaemia (high blood glucose levels; Rendell, 2000). Adolescents must be acutely aware of the food they are consuming and its possible impact on their blood glucose. This may take a great deal of education and support from diabetes teams and family. If the adolescent were to miscalculate their food intake, it is likely to lead to acute complications (hypo- or hyperglycaemia).

Alcohol can have a significant effect on blood glucose levels. Initially leading to a sharp rise in blood glucose, alcohol has a hypoglycaemic effect and can subsequently lead to severe hypoglycaemia up to 24 hours after consumption. This is important within the adolescent context, when young people are more likely to experiment with alcohol within social settings. The signs of hypoglycaemic attacks are often identical to the signs of excessive alcohol consumption and therefore can result in serious and fatal consequences untreated. It is vital therefore, that peers are aware of the increased risks and complications for adolescents with diabetes and are available to support them, should they become hypoglycaemic.

Diet also has important long-term consequences for adolescents with diabetes. People with diabetes have a significantly greater risk of coronary heart disease, cerebro-vascular disease, and peripheral vascular disease than the general population (Turner & Wass, 2002). Most people with diabetes will die from one of these diseases (Cull *et al.*, 2007). During adolescence, the family is largely responsible for menu planning and therefore has a role to support the individual in informed diet choices. Increasingly, adolescents spend more time socialising with peers, and this also has clear implications for the dietary management of their diabetes away from the family home.

### ***Summary***

It is vital that diet is considered seriously as an important aspect of diabetes management to prevent acute and chronic complications. The type and amount of food consumed must be carefully considered when calculating the required insulin dose, and therefore requires support from others whilst adolescents take on the responsibility for themselves.

### **Exercise**

Whilst exercise offers a number of health-promoting benefits for all people, the benefits for those with diabetes are of particular importance. The American Diabetes Association technical review (Wasserman & Zinman, 1994) highlights a number of benefits, including an improved lipid profile, increased sense of well-being, weight control and improved cardiovascular fitness. In adolescence, exercise appears to have particular benefits on lipid and lipidprotein levels (Austin *et al.*, 1993)

Exercise also has a direct effect on blood glucose levels. Approximately 20% of all hypoglycaemic attacks in adolescence are associated with exercise, which is usually of unexpected intensity, duration or frequency (Silverstein *et al.*, 2005). When exercise is commenced with pre-existing hyperglycaemia, it can actually increase the level of blood glucose due to the release of glycogen from the liver. Less than six hours after exercise, however, hypoglycaemia can occur due to hepatic glycogen depletion (Macdonald, 1987; SIGN, 2001). It is vital that adolescents taking part in exercise frequently monitor their blood glucose and treat accordingly. During adolescence, exercise is often undertaken as a social activity with peers (Field *et al.*, 2001). Therefore, whomever the adolescent is exercising with should also be aware of the risks of hypoglycaemia and be able to provide support if required.

## ***Summary***

Exercise has a clear impact on long-term health and immediate effects on blood glucose, thus requiring more intensive blood glucose monitoring. Exercise is most often experienced within social settings with peers. Therefore additional support required for hypoglycaemia is more likely to be provided by peers than family.

### **1.3.2 Acute health difficulties associated with type 1 diabetes**

There are many factors which may disrupt an adolescent's ability to maintain stable blood glucose levels including exercise, unexpected changes to the diet, stress and illness. These result initially in acute health difficulties such as hypoglycaemia (lack of glucose in the blood) or alternatively can raise the blood glucose (hyperglycaemia), and in the absence of sufficient levels of insulin can lead to DKA. Both these difficulties can be effectively treated in their early stages, but require hospital admission if left untreated. Therefore it is important to consider these acute difficulties and the support that may be beneficial to the adolescent to prevent such difficulties escalating into serious medical emergencies.

## **Hypoglycaemia**

The wish to avoid hypoglycaemia is one of the major barriers to achieving good metabolic control (Cryer, 2002). Hypoglycaemia is defined by insufficient blood glucose levels as a result of diet, exercise, illness, or stress (Bennett Johnson *et al.*, 2000) and is classified by blood glucose levels below 3-4 mmol/L (Cryer *et al.*, 2003).

Initial symptoms usually include sweating, nausea, tremor, shivering and palpitations. These are followed by confusion, tiredness, headache, lack of concentration, dizziness, lack of coordination and aggression (Turner & Wass, 2002). If not treated, hypoglycaemia may lead to seizures, coma and even death. Unfortunately, severe hypoglycaemic attacks are relatively common for all young people with diabetes (Davis

*et al.*, 1997). The early signs of hypoglycaemia can be treated simply with a high sugar snack. However, if left untreated or unnoticed, the adolescent may require an intramuscular injection delivered by medical or paramedic staff.

At the developmental stage of adolescence, young people are often striving for autonomy. The need for additional support from peers or family is frequently required but might affect the adolescent's sense of independence. Hypoglycaemia is most likely to occur after social activities such as exercise; therefore peers are often in a better position to provide support for hypoglycaemia awareness and treatment. Many young people understandably fear the possibility of hypoglycaemia and will under-dose their insulin to prevent such attacks, but this is associated with serious and chronic complications such as blindness and renal failure (DCCT, 1993).

### **Diabetic Ketoacidosis (DKA)**

Acidic ketones are produced in the liver when there is an absolute lack of insulin in the blood, as attempts are made to source energy from the body's own stores. This leads to polyuria, polydypsia and weight loss. More immediately, young people develop muscle cramps, abdominal pain, shortness of breath, nausea, vomiting and severe dehydration (Turner & Wass, 2002). Coma is common and can lead to permanent cell death and mortality if untreated.

The most common cause for DKA is insulin omission and therefore highlights the importance of regular and sufficient insulin delivery (Smith *et al.*, 1998). If young people fail to take their insulin, it is likely that DKA will develop and hospitalisation will be required. Therefore the support available to take insulin regularly is important to consider.

## ***Summary***

Hypoglycaemia is a lack of sufficient blood glucose. It is relatively common and can be prevented by the under-dosing of insulin, but this has serious long-term health consequences. Young people with diabetes require the external support of family or peers who are aware of the signs and symptoms. Either peers or family may need to intervene when necessary to prevent serious consequences such as coma. DKA most commonly results from insulin omission and has serious and life threatening consequences. Family or peer support may therefore ensure that insulin injections are remembered and adhered to.

### **1.3.3 Chronic complications of type 1 diabetes**

A number of severe and chronic complications are implicated with diabetes. They are often referred to as macro-vascular (referring to damage to the large blood vessels in organs including the heart), or micro-vascular (damage of small blood vessels including those in the eyes, kidneys or nerves). These potential complications are often a focus of diabetes care and therefore are vital to consider when examining an adolescent's diabetes management.

Cardiovascular disease and peripheral vascular disease are leading causes of poor health and death in adults with type 1 diabetes and are present for some patients in adolescence (DCCT, 1994; Jarvisalo *et al.*, 2002).

Retinopathy (damage to the eyes) is the most common micro-vascular complication of diabetes and the most common cause of blindness in the working population of developed countries (Turner & Wass, 2002). The UK Prospective Diabetes Study indicated that most patients with type 1 diabetes develop evidence of retinopathy within 20 years of diagnosis (Cull *et al.*, 2007; Watkins, 2003). However, 34-42% of adolescents may already have background levels of retinopathy (DCCT, 1994).



Nephropathy (damage to kidneys) is a major cause of premature death in patients with all types of diabetes (Turner & Wass, 2002). It is identified by abnormal protein excretion from the kidneys. Whilst this can sometimes be reversible at very early stages, left untreated it can progress to total renal failure (Perkins *et al.*, 2003).

Neuropathy describes the injury to peripheral nerves from hyperglycaemia (Fowler, 2008). Typically patients experience burning, tingling and ‘electrical’ pain, or simple numbness. There is an increased risk of foot ulceration, which can lead to amputation if not treated. Neuropathies can also affect organ systems, leading to reduced food absorption, increased risk of hypo- and hyperglycaemia, and hypoglycaemia unawareness (Trotta *et al.*, 2004).

The Diabetes Control and Complications Trial clearly identified that all macro- and micro-vascular complications could be treated with improved metabolic control (as a result of frequent blood glucose monitoring and the maintenance of stable blood glucose levels), and attention to diet and exercise guidelines (DCCT, 1994; National Cholesterol Education Program, 1992). In some cases, the prevalence of complications were decreased by 38-59% following improvement in metabolic control (DCCT, 1994). Whilst improved metabolic control has a role in the treatment of complications, it is also vital in their prevention (DCCT, 1994; Trotta *et al.*, 2004). One of the main aims of diabetes management for adolescents is to prevent future complications through regular monitoring and adherence to diabetes management tasks. Maintaining stable blood glucose levels is not an easy task for adolescents and requires additional support from both family and peers. This might include reminding adolescents to take insulin or test blood glucose, and assisting in the prevention or treatment of acute complications previously discussed, such as hypoglycaemia or DKA.

### **1.3.4 Summary**

Type 1 diabetes is a chronic, irreversible disease, characterised by the autoimmune destruction of insulin-producing pancreatic cells. Chronic hyperglycaemia therefore results and can be fatal in the absence of subcutaneous insulin injection. The aim of diabetes treatment is to maintain blood glucose levels as close to the 'normal' range as a possible, avoiding hypo- or hyperglycaemia. To achieve this, patients must adhere to a complex and intensive treatment regimen including insulin injections or continuous insulin infusion, blood glucose monitoring, diet, and exercise. Almost constant monitoring is required to ensure that changes in blood glucose level are identified and treated appropriately. Serious complications can result if blood glucose levels are not maintained at the recommended level. It is therefore important that young people are supported by family and peers with all the required diabetes management tasks. This might include reminders for blood glucose testing, or practical support in terms of the provision of testing equipment or appropriate menu choices. As acute complications such as hypoglycaemia are common, peers are also likely to be involved in adolescents' treatment.

### **1.4 Metabolic control**

The aims of all diabetes treatments are to stabilise blood glucose levels to a 'near 'normal' level of 4-10 mmol/L. To obtain a picture of the longer-term level of diabetes control (metabolic control), a blood test can be taken at the diabetes clinic, which provides the glycated haemoglobin level, or HbA1c. The HbA1c provides an objective measure of the average blood glucose concentration over the last 120 days. When glucose molecules bond to haemoglobin within the red blood cells, glycated haemoglobin is formed. Therefore the greater the amount of glucose present in the red blood cells during their 120 day life span, the higher the HbA1c level (expressed as the percentage of the normal haemoglobin range). The reference range (that found in the general population) is approximately 4-5.9%. The DCCT recommended that for patients

with diabetes, HbA1c results should remain lower than 7.5% to prevent diabetes-related complications (DCCT, 1993).

Internationally, the current policy guidelines strongly recommend the use of the HbA1c as the ‘gold standard’ for the objective measurement of metabolic control (ADA Consensus Committee, 2007; DCCT, 1993). As a result it is the only measurement routinely used within Scottish diabetes teams.

Within Scotland, the average HbA1c result was found to be 8.9% for children and 9.4% for adolescents (Greene & Waugh, 2004), significantly above the recommended guidelines, and placing young people at an increased risk of complications. The National Paediatric Diabetes Audit (Diabetes UK, 2002) reported that the average HbA1c result for children in England was 8.6% and 9.2% for adolescents (9.0% in Northern Ireland). International studies report a mean HbA1c for adolescents of 9.1% in New Zealand (Scott *et al.*, 2006). Within the UK, the average HbA1c for adults was 7.9% (American Diabetes Association, 2002). These results support the known deterioration in HbA1c with age from childhood to adolescence (Greene & Waugh, 2004). The Scottish HbA1c data indicates that metabolic control is comparable in this population to other international groups. The HbA1c, however, remains at a level predictive of future complications and therefore it is important to study this population to identify any factors that may explain this deterioration in HbA1c, and thereby attempt to develop possible solutions.

### **1.4.1 Summary**

Metabolic control refers to the extent to which blood glucose levels are maintained within a recommended range. Metabolic control has been identified as the strongest predictor of future complications. It is highly likely that young people diagnosed with diabetes will at some point develop either acute or chronic complications due to their

diabetes, but these risks can be dramatically reduced through intensive monitoring and treatment adherence. It is also widely recognised that adolescents with type 1 diabetes have significantly poorer metabolic control than both children and adults.

## **1.5 Quality of life**

### **1.5.1 Quality of life and health related quality of life**

Despite the growing importance of quality of life within diabetes care (DCCT, 1993; Delamater, 2000) and other chronic medical conditions, it still remains a poorly defined concept. The World Health Organisation (World Health Organisation, 1995, p.1405) defined quality of life as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and relation to their goals, expectations, standards and concerns”. Even without a universally accepted definition, quality of life remains, within the western world, a familiar concept that encompasses components such as happiness and satisfaction with life (Fayers & Machin, 2007).

Within a health context, the term ‘health-related quality of life’ (HRQOL) is regularly used to describe a patient’s sense of his or her own health and well-being in the broad areas of physical, psychological and social functioning (Petersen *et al.*, 2006; Polonksy, 2000). There has been an increasingly strong interest in examining HRQOL as an outcome to medical intervention and research (Polonksy, 2000). This highlights the shift in focus upon which medical teams reflect, towards being led by the patients’ own experiences of how their health care is affecting their immediate and future well-being. As a result, medical teams are therefore being encouraged to consider their patient’s welfare in a broader context.

Whilst HRQOL is clearly a multidimensional construct, it has traditionally been evaluated using one-dimensional questionnaires that might take into account psychological distress such as depression, functional limitations in daily life or the

burden of physical symptoms (Polonksy, 2000). Measures such as the Medical Outcomes Study SF-36 and Child Health Questionnaire (CHQ) have typically been used due to their popularity in previous research. They allow for comparison between patients with and without disease and can take into account existing co-morbidities. However these measures are typically less sensitive to changes in disease and have been found to under-represent the impact of disease on young people (Cameron, 2003; Graue *et al.*, 2003).

### **1.5.2 Diabetes-specific quality of life**

Disease-specific quality of life is defined by the extent to which a patient's sense of their particular disease might compromise their general well-being in three areas of functioning: physical, psychological and social.

#### **The impact of diabetes on quality of life**

Physical functioning can be influenced by diabetes in three main ways. First, the development of chronic complications such as loss of sight and chronic pain are likely to lead to a drop in quality of life. These difficulties may lead to a reduced ability to attend school, or enjoy pleasurable activities, and reduce their sense of autonomy as a developing adolescent. Second, acute difficulties such as hypoglycaemia are likely to affect an adolescent's sense of well-being. Finally, the diabetes management regimen itself may force adolescents to limit their activities. This might include being unable to spontaneously eat at a restaurant, or attend sleepovers, thus reducing their quality of life.

Psychological functioning such as mood difficulties can be significantly affected by diabetes. The disease regimen can cause a sense of 'learned helplessness' as their best efforts to control their diabetes may be unsuccessful due to physiological changes associated with puberty (Kuttner *et al.*, 1990). Most young people with diabetes experience anxiety, low mood or social withdrawal, although psychological symptoms

*per se* are not detrimental to diabetes care (Gonder-Frederick *et al.*, 2002). Anxious patients are hypothesised to be more ‘diligent in monitoring’ their diabetes (Bryden *et al.*, 2001, p.1539). It is therefore important that the individual’s perceptions of quality of life are considered in addition to metabolic control as a clinical outcome.

Social functioning can be affected by diabetes through the quality and quantity of a patient’s relationships. Friends or peers may act as the “diabetes police” (Roszler, 2005, p.1), encouraging self-care changes even if the patient is unwilling to accept them. This may lead to conflict and a sense of loneliness for young people with diabetes. Social situations such as parties may become fraught with conflict as young people seek to gain acceptance in a peer group, and are subsequently pressured by peers to take part in behaviours that might be harmful to their diabetes management (Polonksy, 2000). Social functioning is therefore particularly important in the developmental context of adolescence when young people are striving for independence from family and a greater reliance on peers for support and intimacy.

## **Measures**

Disease-specific measures have been argued to be of greater value than generic HRQOL measures within research because they are more sensitive to change and lifestyle issues (Delamater, 2000; Garratt *et al.*, 2002; Polonksy, 2000). Diabetes-specific measures have also demonstrated greater accuracy than generic quality of life measures at discriminating between respondents with differing metabolic control. It is important to take this into account when designing research that investigates both quality of life and metabolic control (Huang *et al.*, 2007). The present study has used diabetes-specific measures for this reason.

The first diabetes-specific quality of life measure for young people was developed in response to the DCCT research group (Ingersoll & Marrero, 1991). There are a number

of empirically validated paediatric HRQOL instruments to include specific adolescent measures. The Disabkids was developed for use with young people aged between 4 and 16 and has specific diabetes modules (Baars, Atherton, Koopman, Bullinger & Power, 2005). The Kidscreen covers the age range of 8-18 years but does not include specific diabetes modules (Robitail *et al.*, 2006). Most recently, the Paediatric Quality of Life Inventory (PedsQL) was developed, including a diabetes-specific measure (Varni *et al.*, 2003), which has demonstrated both sensitivity and responsiveness. The PedsQL adolescent measure has a specific diabetes module and is developed for 13 to 18 year olds. For these reasons, the PedsQL diabetes module has been used in the present study.

### **1.5.3 Summary**

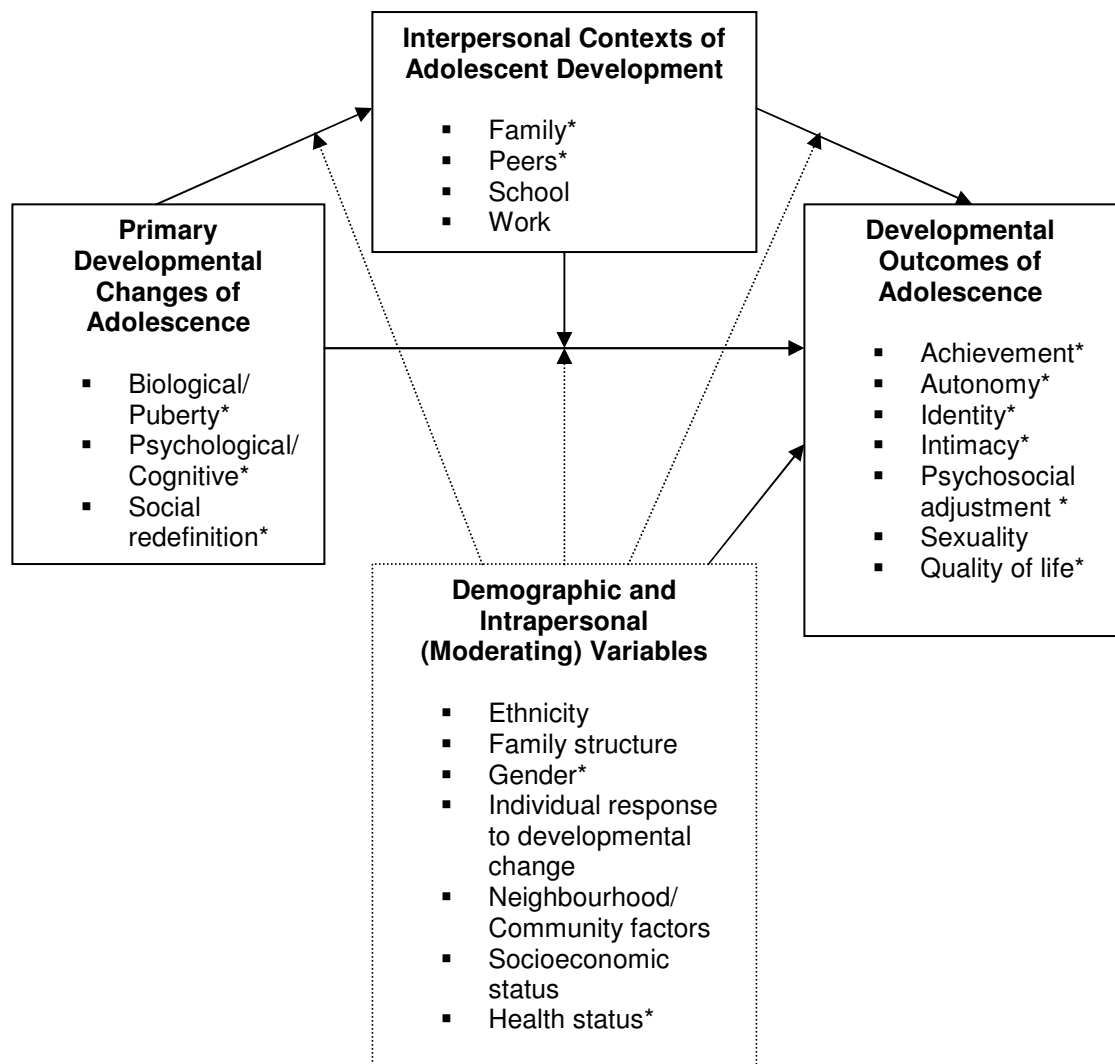
HRQOL is an important tool in the measurement of clinical outcome within diabetes populations. Increasingly diabetes teams are placing more emphasis on the impact of diabetes and its treatments on the individual's sense of well-being as well as attempting to prevent chronic complications and maintain good metabolic control. Within the context of adolescent development, three areas of quality of life are of particular importance. Physical functioning takes into account the consequences of the chronic condition and the need for intensive monitoring. Psychological functioning however, can be affected greatly by the demands of the medical regimen, which can lead to a sense of learned helplessness and lowered mood. Finally, social functioning is vital to adolescents' sense of autonomy, identity and belonging. As metabolic control is strongly associated with quality of life, it is therefore important to evaluate both within the clinical and research setting. Diabetes-specific measures appear to hold greater sensitivity and validity for the adolescent population and are therefore recommended for research and clinical use.

## ***1.6 The developmental context of adolescence***

Change is often seen as a defining feature of adolescence, as many physical, psychological and social changes affect the young person's experience of life and their development and transition to adulthood (Holmbeck, 2002). Any research with adolescents must take into account the unique developmental changes associated with this life stage. Investigating the health and well-being of adolescents is important due to the magnitude and number of physical, psychological and social changes, second only to those found in infancy (Feldman & Elliott, 1993).

It is important, therefore to consider any health and well-being evaluations within the context of normal adolescent development. A biopsychosocial framework has been proposed (Figure 1) for understanding adolescent development and adjustment, as well as the possible implications for diabetes within this framework (Holmbeck, 2002).





Items marked with \* indicate factors relevant to the present study

**Figure 1: Framework for understanding adolescent development and adjustment (adapted from Holmbeck, 2002).**

Diabetes may influence the impact of developmental changes on adolescents' experiences of well-being and health. According to this model, the behaviours of significant others (i.e., family and peer support) may mediate relationships between developmental changes such as puberty or cognitive development, and the adolescent's development of autonomy, independence and identity (Holmbeck, 2002). For example, family or peer support may impact on an adolescent's cognitive ability to prioritise

personal health over social acceptance, thereby influencing their adherence to diabetes management tasks and consequently affecting their quality of life. Demographic and intrapersonal variables, such as diabetes health status, may also act as moderating factors, influencing the strength and direction of relationships between family and peer support and the development of autonomy, independence and identity.

### **1.6.1 Summary**

Many physical, psychological and social changes associated with normal adolescent development may be relevant to the investigation of the impact of family and peer support on both quality of life and health status. When considering diabetes in a developmental framework, it is important to take into account the role of interpersonal factors such as family and peer support on the developmental outcomes of adolescence. Should these developmental outcomes be limited by social support factors or diabetes health status, it has significant implications for adolescent development, and quality of life.

### **1.7 Family support**

At present there is no specific guidance as to how families can be involved in their adolescent's diabetes care. The SIGN guidelines state that "parental support and family communication should be encouraged", however specific forms of support are not identified or suggested (SIGN, 2001, p.5). The NICE guidelines also identify that families should be offered access to mental health professionals because they may experience family conflict that can impact on the management of diabetes and well-being (NICE, 2004). It is important therefore to identify sources of support and potential difficulties for the family that can impact on an adolescent's metabolic control and quality of life.

### 1.7.1 Family support and adolescence

Adolescence is defined as the transition between childhood and adulthood, where the young person ultimately aims to develop a sense of autonomy, identity, achievement and intimacy (Figure 1; Holmbeck, 2002). To develop a sense of identity, adolescents strive to achieve independence from their family and redefine themselves as autonomous, rather than dependent. However, as the term ‘transition’ implies, this is not a clear cut or easy process and requires adaptation from both the young person and their family. Until adolescence, families are almost entirely responsible for the safety, development and care of the young person. Therefore a shift from parental control to a more mutual and collaborative decision-making process is required (Youniss & Smollar, 1985). This shifting of control, along with the biological, psychological and social changes associated with adolescence, inevitably involves a renegotiation of roles and reorganisation of family relationships (Allison & Schultz, 2004). As a result, adolescence can be fraught with conflict as both the family and adolescent test the boundaries of safety and autonomy (Leonard *et al.*, 2005). These conflicts often centre around mundane recurring events (Montemayor & Hanson, 1985) but are important for negotiation and boundary setting within the family.

Whilst the family context can be fraught with conflict, it is important to highlight the positive and protective aspects of family life for the adolescent. Parental warmth has been shown to be a vital component of an adaptive parent-adolescent relationship. This refers to the emotional nurturance and affection given by the parent to the adolescent (MacDonald, 1992) and research has indicated that parental warmth is associated with reduced psychological distress and less anti-social behaviour in adolescents (Pettit *et al.*, 1997). During the transition towards relinquishing control over the adolescent, parental monitoring has been found to be important for reducing risk behaviours and increasing adolescents’ sense of safety and well-being (Li *et al.*, 2000). The balance between

maintaining safe boundaries in a warm and caring environment and allowing the adolescent to explore these limits for themselves is an inevitable challenge.

### **1.7.2 Family support and diabetes**

Adolescents with diabetes face the same developmental tasks and family conflicts as any other adolescent. Studies have shown that the quantity, intensity and frequency of conflicts are similar in families with and without diabetes (Viikinsalo *et al.*, 2005). However, research into the family context of adolescent diabetes has typically focused on conflict and its impact on the adolescent's sense of autonomy. Studies indicate that poor family cohesion, high family conflict and critical or negative parenting leads to poorer treatment adherence for adolescents with diabetes (Dashiff *et al.*, 2008; Duke *et al.*, 2008; Kyngas, 1999; Lewandowski & Drotar, 2007; Lewin *et al.*, 2006) This indicates that the family emotional environment is important for adaptive diabetes care.

The addition of a chronic illness at this life stage also brings its own challenges. The transition from dependence on family to independence and responsibility for self-care is just as salient in terms of diabetes management. In childhood and early adolescence, diabetes treatment is mainly the responsibility of the family and parents, ensuring stable blood glucose levels and providing an adequate diet and exercise (Leonard *et al.*, 2005). Ultimately, the individual must be responsible for their own diabetes management. This shift in responsibility is a difficult one for both adolescent and family, particularly as this may come of necessity as adolescents spend more time with peers. Ideally, the renegotiation of roles and responsibility within adolescence should be developmentally appropriate and timely for each individual (Aanstoot *et al.*, 2007; Wiebe *et al.*, 2005). However, these changes occur much earlier for adolescents with diabetes than their peers due to the requirement for adolescents to continue diabetes-specific care tasks in social situations away from the family (Leonard *et al.*, 2005). Therefore, a developmentally premature shift to autonomy and responsibility for adolescents'

diabetes care is likely to lead to poorer metabolic control (Wiebe *et al.*, 2005). Conversely, continued parental assistance when adolescents are attempting to become independent can lead to a sense of incompetence for the young person (Helgeson, Reynolds, Siminerio, *et al.*, 2007). Achieving this balance is difficult and often leads to conflict when adolescents do not achieve the recommended diabetes targets.

### **1.7.3 Family support and metabolic control**

Despite the shift away from family responsibility for diabetes care during adolescence, a number of family factors have been associated with metabolic control. Conflict related to diabetes management tasks strongly predicts poor metabolic control (Dashiff *et al.*, 2008; Kyngas, 1999; Lewandowski & Drotar, 2007). Research investigating the role of family factors such as marital status of parents has indicated that adolescents of single parent families are more likely to have poor metabolic control. This was mediated, however by the number of diabetes management tasks (blood glucose monitoring) completed each day (Urbach *et al.*, 2005). Lower parental intelligence and knowledge have also been associated with poor metabolic control (Ross *et al.*, 2001; Stallwood, 2006). Adolescents who are classified as having good metabolic control have higher parental involvement in their care (Gowers *et al.*, 1995). It appears that the parent's ability and opportunity to provide diabetes-related care has a significant impact on the metabolic control of the young person.

Upon further examination of family involvement in diabetes care, the evidence overwhelmingly states that increased supervision and practical support of diabetes care tasks predict better metabolic control for adolescents (Ellis, Yopp *et al.*, 2007; Lewin *et al.*, 2006). More specifically, family involvement in adherence to treatment such as blood glucose monitoring appears to be a strong predictor of metabolic control even if the adolescent has been diagnosed for many years (Anderson *et al.*, 1997; Ellis, Podolski *et al.*, 2007; Wiebe *et al.*, 2005). However, studies indicate that if the family are

perceived to be ‘nagging’, this can lead to poorer metabolic control (Leonard *et al.*, 2005).

#### **1.7.4 Family support and quality of life**

While family support for diabetes care tasks is clearly linked to metabolic control, it is important to consider the effects of such continued family control on the adolescent’s well-being and developmental outcomes. Holmbeck’s (2002) model (Figure 1) highlights the importance of the development of autonomy and psychosocial adjustment. Parents of adolescents with diabetes have been found to be more involved in the young person’s free time and activities than parents of adolescents with other illnesses such as arthritis (Graue *et al.*, 2005). There are two main components to family support for diabetes: (a) the practical and instrumental monitoring and support for diabetes related tasks (such as ensuring blood glucose monitoring takes place) and (b) the emotional support for coping with a chronic illness.

Continued practical involvement in diabetes-specific tasks by family during adolescence has not been shown to affect quality of life for these young people *per se*. Conflict associated with such involvement, however, is associated with poorer quality of life (Laffel *et al.*, 2003).

Adolescents report that practical support for diabetes care, such as checking blood glucose with the family before a meal, can bring the family closer together, reduce conflict and make the tasks easier to remember and complete (Leonard *et al.*, 2005). However, adolescents attributed frequent conflict and arguments with parents to difficulties managing their diabetes (Leonard *et al.*, 2005). When parental involvement is perceived to be ‘controlling’ rather than ‘collaborating’, there is a greater likelihood for conflict and poorer quality of life (Leonard *et al.*, 2005; Pomerantz & Eaton, 2000).

Family support for diabetes has typically focused upon practical diabetes-related tasks. As a result, the impact of emotional support by the family has been understudied. The existing literature proposes that emotional support may be predictive of enhanced quality of life (Delamater, 2000; Grey *et al.*, 1998; La Greca & Bearman, 2002) but there is need for further research. When examining the experience of diabetes for a young person within the family context it is therefore important to be aware of the emotional, as well as the practical, support given.

### **1.7.5 Measures**

There are a number of existing measures that identify the diabetes-specific support given by families. These include both the Diabetes Family Behaviour Checklist (DFBC) and the Diabetes Family Behaviour Scale (DFBS), which examine the frequency of practical support for meals, blood glucose monitoring, insulin management and exercise. However, these measures do not include emotional support, which might be important in terms of quality of life for young people (McKelvey *et al.*, 1989; Schafer *et al.*, 1983). La Greca & Bearman (2002) developed and evaluated the Diabetes Social Support Questionnaire – Family Version (DSSQ-Family) for adolescents with diabetes. This measure is directly comparable with a version for peers, and includes items that identify both practical and emotional support and will therefore be used within the present study.

### **1.7.6 Summary**

The transition between childhood and adulthood for all adolescents within the family context is often conflictual and fraught due to the shift from parental control to autonomy and independence. However, when a young person has diabetes, it appears that such conflict is qualitatively different and may have severe consequences for diabetes-related health and quality of life. There appears to be a difficult balance that must be sought between continued family involvement in diabetes care (associated with better metabolic control) and the young person's independence and psychosocial adjustment (that might improve quality of life).

## **1.8 Peer support**

### **1.8.1 Peer support in adolescence**

Normal adolescent development includes the formation of a social network that leads to more intimate relationships (Seiffge-Krenke, 2001). One of the many changes within adolescence includes the separation of young people from families, and seeking and maintaining close relationships away from the family home. Experiences within a peer group are important for developing autonomy and a sense of identity (Youniss & Smollar, 1985). However, having a high status in a peer group has not been found to be as important for psychological well-being as having a best friend (Parker & Asher, 1987). Having a close friendship becomes increasingly important through adolescence. Peer group acceptance is clearly important to adolescent development, but as young people develop, the quality of relationships are more important for psychological adjustment than the number of friends within a network (Frankel, 1990). A friend's ability to be emotionally supportive is thought to be important in the confrontation of developmental tasks and role transitions for general psychological well-being (Seiffge-Krenke, 2001). Both close friends and the wider peer group will be considered and subsequently referred to as 'peers' in this study.

### **1.8.2 Peer support and diabetes**

When discussing adolescent development in the context of chronic illness, surprisingly little attention has been paid to the role of peer relationships (Patterson & Garwick, 1998). Additionally, no clinical guidance is available concerning the involvement of peers in adolescent diabetes care. One study, however, examined the friendships of adolescents with and without diabetes and followed them for four years (Seiffge-Krenke, 2000). Both groups of adolescents reported similar numbers of close friends. A more recent study reported that adolescents with diabetes were equally likely to have a best



friend and boyfriend/girlfriend and that similar levels of support were reported for adolescents with and without diabetes (Helgeson, Reynolds, Escobar *et al.*, 2007).

Friendships do not appear to be fundamentally different for adolescents with or without diabetes. However, within a diabetes population, higher rates of victimisation and lower levels of pro-social support have been found (Storch *et al.*, 2004). This is reported by adolescents as due to “being different [than non-diabetics]” (Kyngas & Barlow, 1995 p.943). As peer group affiliation and social acceptance are a central aspect of adolescent development, being ‘different’ can be detrimental to an adolescent’s sense of identity (Kyngas & Barlow, 1995). Health-risk behaviours are strongly associated with the close friendships and peer groups with which a young person is affiliated. For example, in a study based in the USA, those identifying themselves as ‘Jocks’ were more likely to engage in risky sexual behaviour, whereas ‘Brains’ were least likely to engage in any health-risk behaviours (La Greca *et al.*, 2001). More recently, peer affiliation has also been found to have a strong influence on eating behaviours and exercise, two major components of diabetes management (Mackey & La Greca, 2007). These studies highlight the role of peer influence over adolescents’ health behaviours. As has been illustrated, this is of particular importance in diabetes management. Thus, the role of the peer group, including friendships, is key to examining support for diabetes-related tasks.

### **1.8.3 Peer support and metabolic control**

Adolescence brings cognitive changes that are potentially both positive and detrimental to diabetes management. Cognitive changes in later adolescence include the ability to problem solve and be aware of future consequences of behaviours that might increase the likelihood of better diabetes management and better metabolic control. However, these cognitive changes also enable the adolescent to choose their own personal priorities. This can include the prioritisation of peer affiliation over diabetes management tasks and their future health (Holmbeck, 2002). The degree to which an

adolescent's peers are supportive of the completion of diabetes management tasks appears to buffer an adolescent's cognitive ability to make adaptive decisions about their diabetes care (Holmbeck, 2002).

Diabetes management tasks such as blood glucose monitoring and insulin management are likely to differentiate adolescents with diabetes from their peers in social settings. It is not surprising therefore, that adherence to these tasks is more difficult in such contexts (Hains *et al.*, 2007). Poorer adherence in social settings is dependent on negative attributions made about the peer's reactions rather than the peer's presence *per se* (Hains *et al.*, 2006). Therefore, if peers are supportive of the adolescent's diabetes management, diabetes tasks (e.g., blood glucose monitoring and insulin management) may interfere less with peer relationships or social acceptance. As adherence to blood glucose monitoring and insulin management strongly predicts metabolic control, it is important to consider the adolescent's perceptions of their social support.

Peers have been reported to provide more emotional support (e.g., when adolescents with diabetes are asked questions such as "How often do your peers understand when you sometimes make mistakes in taking care of your diabetes") than practical support (e.g., when adolescents with diabetes are asked questions such as "How often do your peers remind you to take your insulin") (DSSQ- Friends questionnaire; Bearman & La Greca, 2002, p.421; Helgeson *et al.*, 2006; La Greca *et al.*, 1995). The lower frequency of practical support given by peers was investigated using a peer group intervention (Greco *et al.*, 2001). It was found that even when peer knowledge about diabetes and diabetes-related tasks was increased, the amount of practical support did not increase, nor did adherence.

### 1.8.4 Peer support and quality of life

In a qualitative study by Kyngas and Barlow (1995), adolescents were asked to describe their experiences with a chronic illness. Diabetes was described as “hell”, “a nightmare” and “prison” (p.943). This highlights the negative psychological and social implications of diabetes (Kyngas & Barlow, 1995). Adolescents with diabetes also reported increased “stress and concern for the future” (Kyngas & Barlow, 1995, p.943). Psychological distress associated with diabetes therefore has an important impact on quality of life for the individual. However, peer emotional support has been found to serve a protective function for psychological health and well-being when faced with the demanding and chronic nature of diabetes (Hains *et al.*, 2007; Helgeson, Reynolds, Escobar *et al.*, 2007).

Adolescents with diabetes miss twice as much school as their peers without diabetes (Ryan *et al.*, 1985), therefore missing out on opportunities for peer group activities, socialisation and acceptance. This consequently may limit the individual’s ability to make and maintain supportive relationships with peers and restrict their quality of life.

Peers have an important role in providing emotional support for adolescents (Skinner *et al.*, 2000). However, negative peer relationships can have serious and detrimental effects on both psychological and physical health for the adolescents with diabetes (Helgeson, Reynolds, Escobar *et al.*, 2007). If adolescents make negative attributions of their peer’s reactions to diabetes, it is more likely to lead to increased diabetes-related stress (Hains *et al.*, 2006). These negative attributions (e.g., “I’d think my friends wouldn’t like me anymore”; Hains *et al.*, 2006, p.820) are more likely if the adolescent has experienced similar peer reactions in the past and is subsequently apprehensive about being singled out by others (Hains *et al.*, 2006). Such attributions could lead to psychological distress and poorer quality of life.

Paradoxically, high levels of perceived peer support have been associated with poor health outcomes such as metabolic control, whilst indicating higher levels of quality of life (Greco *et al.*, 2001). This can be partly explained by the nature of the support given. To fit in with a peer group, adolescents may want their peer group to “treat [them] like anyone else” in terms of social functioning, acceptance and identity (Shroff Pendley *et al.*, 2002 p.435). However this may mean that diabetes tasks are neglected, leading to poorer health outcomes. It is important, therefore, to identify the nature of support given by peers when considering metabolic control and quality of life.

### **1.8.5 Measures**

Measures have been developed to examine general peer support in adolescence (Procidano & Heller, 1983), but there is limited research that attempts to examine the role of diabetes-specific peer support in metabolic control and diabetes-related quality of life. The Diabetes Social Support Interview-Peers (DSSI-P) was developed to identify the specific aspects of support given by peers for diabetes (La Greca *et al.*, 1995). To study the specific ways that adolescents’ peers provide support, the Diabetes Social Support Questionnaire (DSSQ-Friends) was developed from the DSSI. Advantages to using a questionnaire format rather than interview includes the shortened time taken to administer and score the measure. The DSSI requires the adolescent to recall specific support behaviours. However, adolescents typically find recall more difficult than recognition, and therefore may be more likely to miss important support behaviours during an interview (Bearman & La Greca, 2002). The DSSQ-Friends will be used in the present study for these reasons.

### **1.8.6 Summary**

Peer support has been found to be both helpful and detrimental to adolescents’ experiences of diabetes, depending on the nature of the support given and its context. Adolescents with diabetes must balance normal adolescent development aims such as group affiliation and acceptance with intrusive and intensive diabetes management tasks.

It appears that peers are more likely to offer emotional support, which is beneficial in terms of buffering psychological difficulties and enhancing quality of life. However, in doing this, peers might also encourage fewer diabetes-adherent behaviours and promote detrimental health outcomes. It is important, therefore, to identify the nature of support given by peers before examining its relationship to quality of life and metabolic control.

### **1.9 Family and peer support**

Family support appears to be more practical in nature than emotional (La Greca *et al.*, 1995; Shroff Pendley *et al.*, 2002), which is predictive of better adherence and metabolic control. Peer support, however, appears to be more companionship-related or emotional in nature (La Greca *et al.*, 1995; Shroff Pendley *et al.*, 2002) and has been proposed to have an impact on quality of life. Few comparative studies have been completed in the field of diabetes, and to date, none has examined the role of specific forms of diabetes-specific family and peer support on metabolic control and quality of life. La Greca *et al.* (1995) and Shroff Pendley *et al.*, (2002, p.435) conducted interview-based studies to identify whether “total [diabetes-specific] perceived family support” or “total [diabetes-specific] perceived peer support” had a greater role on adherence or metabolic control. These studies highlight the need for further investigation into the specific ways in which family and peers provide support for adolescents and the impact of support types on both metabolic control and quality of life. The existing literature (Bearman & La Greca, 2002; Delamater, 2000; La Greca *et al.*, 1995; La Greca & Bearman, 2002) also highlights the need for further study using both objective (metabolic control) and subjective (questionnaires of social support and quality of life) measures.

The development of the comparable DSSQ-(Family and Friends versions) has enabled the study of diabetes-specific support given by those who most greatly influence the adolescent’s diabetes experience. The relative role of the specific areas of support given by peers and family for both metabolic control and quality of life can therefore be

investigated. As a result, it is hoped that a clearer picture of the specific impact of different types and sources of support can be identified.

## **1.10 Mood**

The prevalence of depression or depressive symptoms in type 1 diabetes ranges from two to three times that of peers without diabetes (Blanz *et al.*, 1993; Kokkonen & Kokkonen, 1995). The prevalence of depression in adolescent diabetes ranges significantly within the literature from 11% (Grey *et al.*, 1998) to 47% (Kovacs *et al.*, 1997), depending on the research method employed. Kovacs *et al.* (1997) highlight that the prevalence of depressive symptoms shortly after diagnosis is very high, however this falls significantly after 6-12 months. Diabetes appears to be a significant risk factor for psychiatric disorders, particularly those characterised by internalising symptoms, such as depression (Blanz *et al.*, 1993). Both family factors and peer factors are associated with depression in adolescence. Poor family functioning, lack of cohesion and conflict have been identified as risk factors (Blanz *et al.*, 1993). Peer group pressure and negative peer relations are also significant predictors of low mood (Helgeson, Reynolds, Escobar *et al.*, 2007).

### **1.10.1 Mood and metabolic control**

It is widely reported and acknowledged that lower mood is associated with poorer metabolic control (Delamater *et al.*, 2001; Hood *et al.*, 2006; Lawrence *et al.*, 2006). It is suggested that the relationship between mood and metabolic control may be bidirectional (Cox & Gonder-Frederick, 1992). Psychological stress can directly affect blood glucose through the release of stress hormones, or indirectly by decreasing motivation and adherence to diabetes management tasks (Cox & Gonder-Frederick, 1992). The neuropsychological impact of depression may also impact memory, and therefore the ability to remember daily blood glucose monitoring and insulin management (de Groot *et al.*, 1999). The physical symptoms associated with hyper- and

hypoglycaemia may also induce negative mood states (Gonder-Frederick *et al.*, 2002). Whilst most studies have used clinical cut-offs such as the DSM-IV diagnostic criteria (American Psychiatric Association, 2000), significant associations with poor metabolic control have also been found with sub-clinical levels of low mood (Gonder-Frederick *et al.*, 2002).

### **1.10.2 Mood and quality of life**

Quality of life is known to be reduced in the presence of depression, independent of physical complications (Grey *et al.*, 1998; Jacobson *et al.*, 1997). This is still true of sub-clinical symptoms in the adolescent diabetes population (Jacobson *et al.*, 1997). Depression is more likely for adolescents who struggle to manage the demands of diabetes with developmental tasks of adapting to puberty, peer group affiliation, independence from parents and identity formation (Delamater, 2007).

### **1.10.3 Measures**

Within chronic illness settings, physical aspects of the health condition can be mistaken for depressive symptoms. For example, the fatigue and loss of motivation associated with hyperglycaemia might be falsely identified as a symptom of depression using standard questionnaires such as the Beck Depression Inventory (Beck *et al.*, 1996). Questionnaires such as the Hospital Anxiety and Depression Scale (HADS) have been developed and validated for adolescent hospital and illness settings and are less likely to identify false positives (White *et al.*, 1999; Zigmond & Snaith, 1983).

### **1.10.4 Summary**

Depression is a common co-morbidity of diabetes in the young and is associated with both family and peer factors. Depression significantly impacts on both metabolic control and quality of life, even at sub-clinical levels. When investigating quality of life and metabolic control, it is therefore important to consider the potential role of low mood using measures that are valid and reliable for the diabetes population.

## **1.11 Aims and hypotheses**

### **1.11.1 Aims**

The clinical importance of both metabolic control and quality of life in adolescent diabetes are apparent. It is also clear that adolescence is defined by the transition from childhood and dependence on family to independence and increased importance of peers. However, the role of specific forms of support given by both family and peers on both metabolic control and quality of life are unclear. The present study aims to investigate the nature and impact of support for adolescents (aged 13-18) with type 1 diabetes in the Tayside, Forth Valley and Fife clinical populations.

Metabolic control remains at unsatisfactory levels for adolescents in Scotland (Greene & Waugh, 2004), so it is important to attempt to identify factors that may predict better metabolic control in this age group. This study aims to consider the potential impact of factors specific to type 1 diabetes (mood, age and insulin management) when examining the role of social support in metabolic control and quality of life. It also aims to determine the specific source and type of social support given to adolescents, and their relationships with both metabolic control and quality of life.

The following questions guide the study:

- To what extent does diabetes-specific social support provided by family and peers predict metabolic control for adolescents with diabetes?
- To what extent does diabetes-specific social support provided by family and peers predict quality of life for adolescents with diabetes?



### **1.11.2 Hypotheses**

Based on previous findings and research, the following hypotheses are presented:

#### ***Hypothesis 1:***

Support for practical diabetes management tasks (insulin management, blood glucose monitoring and diet) will be provided more frequently by family than by peers.

##### *Hypothesis 1a*

Support for insulin management will be provided more frequently by family than peers.

##### *Hypothesis 1b*

Support for blood glucose monitoring will be provided more frequently by family than peers.

##### *Hypothesis 1c*

Support for diet will be provided more frequently by family than peers.

#### ***Hypothesis 2:***

‘Companionship’- related support (emotional support and support for exercise) will be provided more frequently by peers than family.

##### *Hypothesis 2a*

Emotional support will be provided more frequently by peers than family.

##### *Hypothesis 2b*

Support for exercise will be provided more frequently by peers than family.

***Hypothesis 3:***

Family support for management tasks (blood glucose monitoring, insulin management and diet) will be more predictive of metabolic control than (a) peer support for management tasks (blood glucose monitoring, insulin management and diet), (b) family emotional support and support for exercise, or (c) peer emotional support and support for exercise.

***Hypothesis 4:***

Peer emotional support and support for exercise will be more predictive of diabetes-related quality of life than (a) family emotional and exercise support, and (b) support for management tasks (blood glucose monitoring, insulin management and diet) by both family and peers.

## **2 Method**

### ***2.1 Design***

This study examines the relative role of family and peer support on diabetes-related quality of life and metabolic control in adolescent type 1 diabetes. The study is cross-sectional in design, examining the links between two predictor variables (family and peer diabetes-specific support) and two criterion variables (quality of life and metabolic control). The data were taken at one point in time, from three health board areas, NHS Tayside, Forth Valley and Fife (members of the diabetes managed clinical network, Diabnet).

The study was approved by NHS Forth Valley and Fife Joint Research Ethics Committee (Appendix 1), and then by the Multi-centre Research and Development Committee (MRAD; Appendix 2). Caldicott Guardian approval was also granted for each of the three health boards (Appendix 3a, b & c).

### ***2.2 Participants***

#### **2.2.1 Selection criteria**

Following ethical and research and development approval, patients diagnosed with type 1 diabetes within the three paediatric diabetes teams were identified as potential participants (ethical considerations are outlined later in the section). The local diabetes specialist nurses identified all potential participants, namely adolescents who attend their local diabetes team for regular and routine reviews regarding their diabetes care. All adolescents who had been diagnosed with type 1 diabetes mellitus for more than 24 months from NHS Tayside, Forth Valley and Fife were invited to participate in the research. A letter informing the adolescents of the research was sent to each patient prior to their routine appointment, including information regarding the study and contact

information for the chief investigator in case of query or discussion regarding the research (Appendix 4a).

All participants were between 13 and 18 years of age. In all cases, informed consent to participate in the study was obtained from the participants. Parental approval for their child's participation was obtained, but was not a necessity as per Section 2(4) of the Age of Legal Capacity (Scotland) Act 1991 which states that "A person under the age of 16 years shall have legal capacity to consent on his own behalf....where, in the opinion of a qualified medical practitioner attending him, he is capable of understanding the nature and possible consequences of the procedure or treatment." The Children (Scotland) Act 1995 also states that parental consent is required for children aged under 16 only if research involves a clinical trial of a medicinal product. Therefore the present study did not require parental consent if the young person had capacity to consent. Capacity to consent was assessed by both the diabetes specialist nurses and the chief investigator prior to participation.

Diabnet covers a large geographical area encompassing the three health board areas of Tayside, Forth Valley and Fife. These are large rural areas with varied geography and several centres of population. They have populations of approximately 390,000, 286,000 and 350,000, respectively. Within all three areas, patients with either type 1 or type 2 diabetes are seen by the diabetes services. The Scottish Diabetes Survey 2006 reports the statistics of diabetes prevalence by health board in Scotland (Table 1; Scottish Diabetes Survey Monitoring Group, 2008). The 2006 report indicated that across Tayside, Forth Valley and Fife, approximately 500 adolescents with diabetes are seen collectively within the routine clinics.

### 2.2.2 Inclusion criteria

- Adolescents (aged 13-18 years inclusively) who have been diagnosed for longer than 24 months with type 1 insulin dependent diabetes mellitus.

Individuals with diabetes typically experience a 'honeymoon' phase during the first 12 months following diagnosis as the pancreas is still producing small amounts of insulin. Metabolic control at this time is dependent on the amount of residual pancreatic activity and is often under close scrutiny from the diabetes team. It is therefore recommended that a 12 month grace period after diagnosis is kept when researching metabolic control in this cohort (Shroff Pendley *et al.*, 2002).

### 2.2.3 Exclusion criteria

- Individuals deemed unable to consent as per the Age of Legal Capacity (Scotland) Act, 1991 including (a) individuals with an intellectual disability and (b) individuals with global impairment due to head injury.
- Current hypo- or hyperglycaemia (blood glucose below 4 mmol/L or above 20 mmol/L) at the time of assessment.
- Individuals with a psychotic illness.

Capacity to consent was required to ensure that the research project was ethically sound and all participants were aware of the consequences of their participation. The present study required young people to complete a number of self-report questionnaires independently, without parental or external assistance. The questionnaires were validated only for an adolescent population and no alternative versions of the questionnaires were available for those with intellectual impairments.

As cognitive functioning rapidly declines when individuals' blood glucose levels become too high or too low (Gold *et al.*, 1995; Gschwend *et al.*, 1995; Strudwick *et al.*, 2005),

adolescents who were currently in a hypoglycaemic (as defined blood glucose below 4mmol/L (Cryer, 2002)) or hyperglycaemic (above 20 mmol/L) state were temporarily excluded from the study, but permitted to rejoin once their blood glucose levels had stabilised. All adolescents test their blood glucose as a matter of routine practice within clinic when hypo- or hyperglycaemia is suspected.

Acute mental health difficulties such as psychosis have been found to be strongly associated with decreased metabolic control (Lawrence *et al.*, 2006; Nakazato *et al.*, 2000). Therefore, this group was excluded to reduce confounding variables.

Participation was completely voluntary and participants did not receive any payment for their participation. All responses were guaranteed to be anonymous and confidential.

#### **2.2.4 A priori sample size**

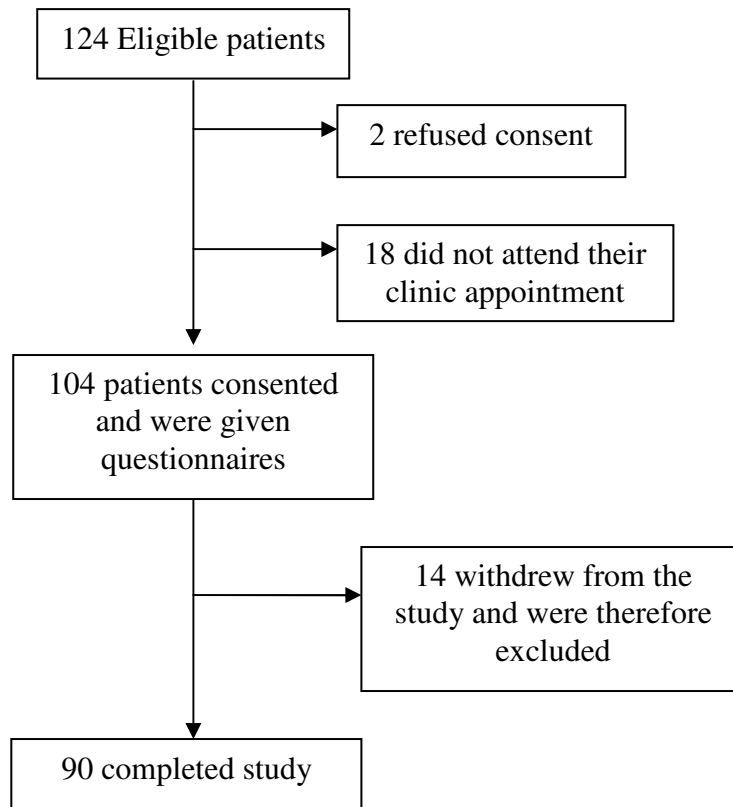
Using a-priori sample size calculation for multiple regression, at the significance alpha level of 0.05, a medium anticipated effect size (0.15), a desired statistical power level of 0.8, for the 11 assessment scales and subscales to be statistically analysed as predictors, a sample size of 123 was indicated.

#### **2.2.5 Sample description**

The present sample included 90 participants (51% male, 49% female), aged 13-18 ( $M = 15.8$ ,  $SD = 1.61$ ) derived from paediatric diabetes clinics across Tayside, Forth Valley and Fife health boards. The participant flow through the study is described in Figure 2.

During the data collection period, 124 patients were identified as eligible by the diabetes specialist nurses using the exclusion/inclusion criteria. Two patients did not consent to participation, both stating time constraints as the reason. Eighteen (15%) of the eligible patients did not attend their routine clinic appointment and were therefore not present to

give consent or participate in the study. Fourteen (11%) gave consent and started the study, but withdrew from the study when they were unable to complete the questionnaires during the clinic due to time constraints. These patients were not followed up as this would have contravened the protocol agreed by the Ethical committee. In total, 90 participants consented to the study and completed the questionnaires.



**Figure 2: Patient's progress through the study from identification of eligibility to participation.**

### **2.3 Procedure**

All eligible participants and their parents/guardians were sent a letter of invitation (Appendix 4a), a young person's information sheet (Appendix 4b), a parent's information sheet (Appendix 4c) and a consent form (Appendix 4d) at least one week prior to their routine diabetes review appointment. All participants were asked to

undergo the same assessment procedure, consisting of a number of questionnaires and agreement for the chief investigator to obtain the results of a routine blood test (HbA1c). The chief investigator was present at the clinics to describe and explain the research and to answer any queries or questions. A thorough briefing was available to all participants before and after participation if required.

The diabetes teams involved in this study review their adolescent population within clinic every 3-4 months, therefore data collection took place over a 4-month period to reduce the chance of participants being approached more than once and increase the efficiency of data collection.

The completed consent form was placed in the participant's medical file and two copies were made (one for the patient and one for the chief investigator). To reduce inconvenience to participants, the study was held during routine diabetes clinics where patients must often wait between consultations with the nurses, consultants and dieticians.

The questionnaires were completed in the waiting areas of each diabetes clinic. Some participants attended this appointment on their own, although the majority were accompanied by parents/guardians or significant others. It was emphasised to those accompanying the individual that they should not, at any time, assist the participant during the assessment. The participants were encouraged to sit away from their carers if it was less distracting.

The participants were asked to complete four questionnaires. These explored family and peer diabetes-specific support, (DSSQ- Family and Friends Versions; Bearman & La Greca, 2002; La Greca & Bearman, 2002), mood (Hospital Anxiety and Depression Scale: (Zigmond & Snaith, 1983)) and diabetes-related quality of life (Peds-QL Diabetes



Module; Varni *et al.*, 2003). In addition, demographic data was collected including age, length of diagnosis, method of insulin delivery (injection or pump), gender and location of diabetes clinic (Appendix 5). The assessment took approximately 25 minutes to complete.

## 2.4 Measures

All measures used within the study were standardised, reliable, valid and widely used (Bjelland *et al.*, 2002; Hanna, 2006; Varni *et al.*, 2003). The measures administered fell into three basic categories: (a) diabetes-specific social support, (b) quality of life and (c) mood, and are summarised in Table 2:

**Table 2:**  
*Summary of Assessment Measures*

Area Assessed	Assessment Used	Source
Diabetes-specific family support	DSSQ – Family Version	(La Greca & Bearman, 2002)
Diabetes-specific peer support	DSSQ – Friend Version	(Bearman & La Greca, 2002)
Quality of life	PedsQL – Diabetes Module 3.0	(Varni <i>et al.</i> , 2003)
Mood	Hospital Anxiety and Depression Scale	(Zigmond & Snaith, 1983)

A description of each assessment and information regarding reliability and validity is provided below.

### 2.4.1 Diabetes-specific social support

The Diabetes Social Support Questionnaire – Family Version (Appendix 6; La Greca & Bearman, 2002) is a specific 58-item Likert scale questionnaire that identifies adolescents’ perceived and enacted support from family, including insulin management,

blood glucose monitoring, diet, exercise and emotional support. The scale was developed for 11–18 year olds and has been used and found to be reliable and valid within the adolescent diabetes population (Hanna, 2006; La Greca & Bearman, 2002). The internal consistency reliabilities ranged from .75 to .95 (Hanna, 2006). Both face and content validity are evident within the scale upon inspection of the items. The DSSQ-Family was developed from the DSSI (Hanna, 2006; La Greca *et al.*, 1995), which also has strong predictive and construct validity (La Greca *et al.*, 1995). The questionnaire is reported to be more advantageous than the structured interview for paediatric research due to its simplified scoring and reduced time required for administration (La Greca & Bearman, 2002).

The measure was scored in accordance with the test manual. The frequency of supportive behaviours (e.g. “how often does your family...”) were summed, with each item ranging from a score of 0 to 5 (high scores indicate greater frequency of the reported behaviour). A total for each of the subscales can therefore be calculated:

- insulin management (ranging from 0 - 50)
- blood glucose monitoring (0 - 70)
- diet (0 - 100)
- exercise (0 - 45)
- emotional support (0 - 25)

Developed in parallel with the DSSQ-Family, the DSSQ–Friends Version (Bearman & La Greca, 2002) is a specific 27-item Likert scale questionnaire that also identifies the frequency of support behaviours in terms of insulin management, blood glucose monitoring, diet, exercise and emotional support for adolescents with diabetes (Appendix 7; Hanna, 2006). The items of the questionnaire are based upon the DSSQ-Family. Item selection for the DSSQ-Friends was based on data collected from a cohort of 74 adolescents with type 1 diabetes in the United States (Bearman & La Greca, 2002).

Following data analysis, the DSSQ-Friends was developed with 31 of the original 58 items eliminated as they were found to be irrelevant for peer support of diabetes care. These items were generally perceived as neutral or negative in support, and were rated as very low in frequency (Bearman & La Greca, 2002).

The measure was scored as per the test manual, using identical methodology to that used for the DSSQ-Family (see above). This enabled a score for each subscale to be calculated:

- insulin management (ranging from 0 - 10)
- blood glucose monitoring (0 - 30)
- diet (0 - 65)
- exercise (0 - 20)
- emotional support (0 - 15)

#### **2.4.2 Quality of life**

Quality of life has been increasingly recognised as an important factor in outcome assessment of individuals with diabetes since the Diabetes Control and Complications Trial (1994). From the DCCT, the first diabetes-specific quality of life measure for adolescents was developed, which has since been revised and reviewed (Ingersoll & Marrero, 1991). To date, there are several scales available and validated to measure quality of life in diabetes populations. Research has indicated that diabetes-specific scales are more sensitive to change in this population than general scales (Jacobson *et al.*, 1994; Polonksy, 2000) therefore the current study uses the PedsQL-3.0 Diabetes module, using both adolescent and diabetes-specific items to assess quality of life.

The PedsQL- 3.0 diabetes module (Appendix 8; Varni *et al.*, 2003) is a specific 27-item Likert scale questionnaire for 13-18 year olds with type 1 diabetes that identifies five scales: diabetes symptoms (11 items), treatment barriers (4 items), treatment adherence

(6 items), worry (3 items) and communication (3 items). Each item is scored depending on how frequently the item has been a problem over the last month. The scores for each subscale range from 0 (never) to 4 (almost always), leading to a total score between 0 and 108.

This is a reliable and valid measure of quality of life for adolescents with type 1 diabetes based upon a sample size of 147 adolescents (Varni *et al.*, 2003; Varni *et al.*, 2005). Adolescent self-report of the diabetes module exceeded the reliability standard of .70, with Cronbach alpha's ranging from .81 to .77 (Nunnally & Bernstein, 1994; Varni *et al.*, 2003).

### **2.4.3 Mood**

The Hospital Anxiety and Depression Scale (Appendix 9; Zigmond & Snaith, 1983) is a widely used measure to assess depressive symptomology in health care settings and has been shown to be reliable and valid in both adult ( $\alpha = .76$ ) and adolescent ( $\alpha = .74$ ) populations (Mykletun *et al.*, 2001; White *et al.*, 1999). The HADS has been used widely in studies with several aspects of disease and quality of life. A main characteristic of HADS is that items covering somatic symptoms of depression have been eliminated to avoid false-positive results when used with diabetes populations (Engum *et al.*, 2005). It is also sensitive to change during the course of disease (Shaban, 2003) and has therefore been shown to be an appropriate measure of mood disturbance for use in a diabetes clinic setting (Lloyd *et al.*, 2000). The total possible score for the depression subscale is 21.

White and colleagues (1999) validated the HADS for an adolescent population and recommend that a score of 0-6 should be considered 'normal', 7-9 should indicate 'possible depression' and 10+ should indicate 'probable depression' to minimise the risk of false positives.

#### **2.4.4 Metabolic control**

Metabolic control is also referred to within research literature as ‘diabetes control’, ‘glucose control’, and ‘glycaemic control’ (Goldstein *et al.*, 2004). This study will follow the terminologies used within the DCCT, which uses language widely accepted and replicated in international diabetes research. The DCCT established specific diabetes treatment goals using the HbA1c blood test. It is therefore used as the ‘gold standard’ of metabolic control and is routinely used throughout all diabetes clinics in the UK and USA (Goldstein *et al.*, 2004; DCCT, 1993; DCCT, 1994).

The HbA1c provides a value (reported as a percentage value) indicating the average blood glucose levels over the previous three months. The NICE Guidelines (Clinical Guideline 15) and SIGN (Guideline 55) (NICE, 2004; Scottish Intercollegiate Guidelines Network, 2001) have supported the DCCT guidelines for a target HbA1c value of less than 7.5% to prevent future complications. HbA1c values of over 9% are considered to indicate ‘poor metabolic control’.

### **2.5 Ethical considerations**

The Joint Research Committee of NHS Fife and Forth Valley passed this study for multi-site inclusion (all three health boards) in January 2008. The Multi-centre research and development committee passed the study in March 2008. Some of the key ethical issues considered in this research are outlined below.

#### **2.5.1 Participant confidentiality**

To ensure response anonymity and confidentiality, each consenting participant was assigned a number used to identify their completed questionnaires and HbA1c results thereafter. These data were collected from March 2008 until the end of June 2008. The completed questionnaires were stored securely by the chief investigator in a locked

filing cabinet on NHS property. The list of identification numbers and participation consent forms will be kept for five years in a locked cabinet within NHS property.

Data were entered into a statistical package on a password-protected NHS computer. No patient details (e.g. CHI, name) were collected. The computer data will be held for a minimum period of five years in line with the research guidelines (Singleton & Wadsworth, 2006) and will be the responsibility of the chief investigator.

### **2.5.2 Distress during assessment**

It was not anticipated that this study would cause any distress to participants. The questionnaires are routinely used in clinical practice and in research and there are no findings to suggest that completion leads to an elevation in negative mood or distress. All the questionnaires have been administered to adolescents with diabetes previously with no noted adverse effects (Hains *et al.*, 2007; Laffel *et al.*, 2003; Lewandowski & Drotar, 2007; Miller & Drotar, 2007; Sudhir *et al.*, 2003). Opportunities to discuss psychological support issues may be beneficial to the young person, allowing time for reflection (Surkan *et al.*, 2008). The measures selected are standardised and are routinely used in clinical practice and research. Shortened versions of the questionnaires were used where possible, to avoid prolonged completion time.

Completion of the questionnaires in a setting with clinician and health professional support ensured that, in the unlikely event of distress occurring, such distress could be promptly addressed. The chief investigator was also available throughout if further support was required. All participants were already under the care of the diabetes teams, which each have Clinical Psychology support and a referral would have been made should any further input have been required. Participants were informed that they were under no obligation to participate and could withdraw at any point, without their care being affected in any way.

### **2.5.3 Capacity issues**

It was foreseen that there may be issues relating to an individual's capacity to consent to participate in this research. It was therefore agreed that if there were any doubt (by the chief investigator) regarding an individual's ability to consent, they would be excluded as per Section 2(4) of the Age of Legal Capacity (Scotland) Act 1991 and Adults with Incapacity (Scotland) Act 2000.

### **2.5.4 Other ethical issues**

It was possible that the assessment might reveal previously undetected psychological dysfunction, for example clinically significant levels of depression. If any participant scored within the 'probable depression' range, it was agreed that the chief investigator would discuss with the adolescent about sharing this information with the diabetes team, considering both duty of care and the participant's right to confidentiality.

## **2.6 Data analysis**

The data were entered onto a spreadsheet and all statistical analyses were run using the Statistical Package for the Social Sciences (SPSS) for Windows, Version 12.0. The data were examined for normality, homoscedasticity and linearity. Questionnaires with more than 5% of missing data were excluded from the analysis following the test scoring guidelines: (Bearman & La Greca, 2002; La Greca & Bearman, 2002; Varni *et al.*, 2003; Zigmond & Snaith, 1983). When less than 5% of data were missing from the questionnaires, means were calculated from the available data and used to estimate the missing values prior to analysis (using the 'means substitution' function of SPSS). This is the most conservative method of estimating missing values, as the means for the distribution as a whole do not change. Demographic and clinical characteristics of the participants including age, mood and insulin management regimen (pump use or injections) were further examined to identify how far these variables might explain any variance in the outcome variables.

Pearson correlation coefficients were calculated to examine the links between the participant's scores from the social support measures (DSSQ), metabolic control (HbA1c) and diabetes-related quality of life (PedsQL) scores. The differences between the frequency of support given by family and peers were examined using *t*-tests. Standard multiple regression analysis was then carried out to examine the relationship between social support and metabolic control, and between social support and diabetes-related quality of life. All post hoc analyses and effect size calculations were performed using G\*Power Version 3.0.



## 3 Results

### 3.1 Participant characteristics

#### 3.1.1 Demographic characteristics

Demographic and clinical data are summarised in Table 3. The participants' average age was 15 years, with an average length of diagnosis of 6 years. In the total sample, 46 participants were male (51%) and 44 were female (49%).

**Table 3:**

*Demographic Characteristics: The Age and Length of Diagnosis of Participants*

	Mean (SD)	Range
Age in years	15.87 (1.59)	13.0-18.8
Length of diagnosis in years	6.45 (4.25)	2.0-17.5

*N* = 90

Table 4 provides a summary of the frequency of participants recruited from each of the diabetes clinics involved in the study. Most participants were seen at the city clinics (Dundee, Stirling, Kirkcaldy and Perth). The remaining participants were seen at the satellite clinics in Arbroath and Montrose.

**Table 4:*****Demographic Characteristics: The Distribution of Clinics Attended by Participants***

		Frequency	Percentage of total sample
Clinic Attended	Fife: Kirkcaldy	17	18.9
	Forth Valley: Stirling	17	18.9
	Tayside: Dundee	32	35.6
	Tayside: Perth	12	13.3
	Tayside: Arbroath	8	8.9
	Tayside: Montrose	4	4.4
<i>N</i> = 90			

**3.1.2 Clinical characteristics**

Within the current sample, 11 of the 90 participants (12%) used an insulin pump to deliver their insulin treatment; the remaining 79 used injections. The average HbA1c for the sample was 9.73% (SD = 1.73). This is classified as ‘poor’ metabolic control and is significantly higher than the international recommendation of 7.5% ( $t(89) = 12.21$ ,  $p < 0.001$ ).

Within an adolescent population, a HADS Depression score of 7 - 9 is indicative of ‘possible depression’ (White *et al.*, 1999). Seven of the 90 participants (8%) scored within this range. None of the participants scored 10 or more (indicative of ‘probable depression’) on the subscale. The mean HADS depression score was 2.47 (SD = 2.30).

**3.2 Preliminary analysis**

All data were analysed to identify whether the assumptions of normality, linearity and homoscedasticity had been violated.

### 3.2.1 HADS: Depression data

The kurtosis values, and visual inspection of the data indicated that the HADS: Depression subscale data did not violate assumptions of homoscedasticity or linearity. However, the data was positively skewed. Following visual inspection of the data, the Kolmogorov-Smirnov ( $p < .001$ ) and Shapiro-Wilk ( $p < .001$ ) statistics were performed, and these revealed that the HADS Depression data were not normally distributed. Therefore, a square root transformation was used and the transformed skewness and kurtosis data are shown in Table 5. Following transformation, parametric statistics were used for data analysis.

**Table 5:**

*Preliminary Data Analysis of HADS: Depression Data including Skewness and Kurtosis values prior to and post-transformation*

Variable	Subscale	Mean (SD)	Range	Skewness (Standard Error)	Kurtosis (Standard Error)	Cronbach's $\alpha$
Hospital Anxiety and Depression Scale	Depression	2.47 (2.30)	0-9	0.94 (0.25)	0.29 (0.50)	.56
	Depression (transformed using SQRT)	1.30 (0.87)	0-3	-.18 (0.25)	-0.97 (0.50)	
<i>N</i> = 90						

According to previous research, the HADS Depression subscale has good internal consistency, with Cronbach alpha coefficients reported to be .76 (Mykletun *et al.*, 2001). In the current study, the alpha coefficient was found to be .56.

### 3.2.2 HbA1c data

The skewness and kurtosis values, and visual inspection of the data indicated that the HbA1c data did not notably violate assumptions of homoscedasticity, linearity or

normality (Table 6) and therefore parametric statistics could be performed without the need for transformation of the data.

**Table 6:**

*Preliminary Data Analysis of HbA1c Data including Skewness and Kurtosis values*

Variable	Mean (SD)	Range	Skewness (Standard Error)	Kurtosis (Standard Error)
HbA1c	9.73 (1.73)	6.50-13.73	0.52 (0.25)	-0.36 (0.50)
<i>N</i> = 90				

### **3.2.3 Psychometric information for the self report measures**

Psychometric information for the social support and diabetes related quality of life self-report measures is summarised in Table 7. Distributions of all subscales (with the exception of DSSQ-Friends Insulin management and diet, and DSSQ-Family Emotion subscales) were positively skewed, however, visual inspection of the data indicated that the distributions fell within acceptable ranges for both skewness and kurtosis (Tabachnick & Fidell, 2007). Therefore the data did not seriously deviate from normality and parametric statistics were used without the need for data transformation. Visual inspection of the data revealed that there were no outliers for any of the variables.

According to Bearman & La Greca (2002), the DSSQ-Friends subscales have good to excellent internal consistency, with Cronbach alpha coefficients reported between .58 (insulin management) to .89 (meals). In the current study, the alpha coefficient was ranged from .47 (insulin management) to .92 (diet). The smaller alpha reported for insulin management subscales may be partly explained by the small number of items within the subscale (two). However the internal consistency reported within the current study suggests that the individual subscales may be used reliably within the analysis.

Likewise, La Greca & Bearman (2002) found the internal consistency of DSSQ-Family subscales to be good to excellent with Cronbach alphas reported between .75 (insulin management) and .93 (diet). In the current study, the Cronbach alphas were found to range between .84 (insulin management) and .94 (diet). Therefore the subscales may be used individually within the present study.

Finally, the PedsQL scale was also found to have good internal consistency with a Cronbach alpha coefficient of .82. A previous study reported alpha values ranging from .63 to .81 (Varni *et al.*, 2003).

**Table 7:**

*Psychometric Description of Self-reported Social Support and Quality of Life measures*

Measure	Subscale	Mean (SD)	Range	Skewness*	Kurtosis**	Cronbach $\alpha$
DSSQ-Friends	Insulin management	3.28 (2.82)	0-10	0.61	-0.60	.47
	Blood glucose monitoring	11.89 (8.68)	0-30	0.49	-0.84	.85
	Diet	24.02 (17.20)	0-65	0.56	-0.67	.92
	Exercise	8.77 (5.54)	0-20	0.10	-0.96	.75
	Emotion	7.49 (5.18)	0-15	-0.02	-1.28	.85
DSSQ-Family	Insulin management	23.75 (12.38)	0-50	0.14	-0.61	.84
	Blood glucose monitoring	33.02 (15.26)	6-70	0.39	-0.18	.89
	Diet	60.70 (24.38)	8-99	-0.39	-0.78	.94
	Exercise	15.69 (12.51)	0-45	0.57	-0.63	.91
	Emotion	16.30 (7.07)	0-25	-0.55	-0.57	.86
PedsQL-Diabetes Module		37.05 (18.31)	10-80	0.45	-0.59	.82
<i>N</i> = 90				*Standard Error = .26	**Standard Error = .51	

### **3.3 Correlations**

To examine the relationships between the variables, Pearson's correlation coefficients were calculated (Table 8). HbA1c was found to be negatively correlated with the frequency of support given by peers for blood glucose monitoring ( $r = -.22$ ). Higher levels of support given for blood glucose monitoring were associated with lower HbA1c (better metabolic control).

PedsQL scores were found to be negatively correlated with the frequency of emotional support given by their family ( $r = -.26$ ). Higher levels of emotional support were associated with lower PedsQL scores (better diabetes-specific quality of life).

Finally, the subscales of the DSSQ Friends and Family measures were all highly correlated, indicating that high levels of support given by family were associated with high levels of support given by peers. The only exception was that the association between levels of support given by family for exercise and levels of emotional support provided by peers was marginally non significant ( $r = .21$ ).

**Table 8: Pearson Correlations (r) for Measures of Social Support, Mood (HADS), Metabolic Control (HbA1c) and Diabetes-Related Quality of Life (PedsQL)**

		Age	DSSQ-Friends Insulin Management	Blood Glucose Monitoring	Diet	Exercise	Emotion	DSSQ-Family Insulin Management	Blood Glucose Monitoring	Diet	Exercise	Emotion	HADS- Depression (transfrmd)	PedsQL	HbA1c
<b>Age</b>	<i>Pearsons'(r)</i>	1													
	<i>Sig (p)</i>														
<b>DSSQ-Friends Insulin Management</b>	<i>N</i>	90													
	<i>r</i>	-.035	1												
	<i>p</i>	.744													
<b>Blood Glucose Monitoring</b>	<i>N</i>	89	89												
	<i>r</i>	.012	.665**	1											
	<i>p</i>	.910	<.001												
<b>Diet</b>	<i>N</i>	89	89	89											
	<i>r</i>	.092	.577**	.679**	1										
	<i>p</i>	.396	<.001	<.001											
<b>Exercise</b>	<i>N</i>	88	88	88	88										
	<i>r</i>	-.179	.387**	.438**	.496**	1									
	<i>p</i>	.096	<.001	<.001	<.001										
<b>Emotion</b>	<i>N</i>	87	87	87	87	87									
	<i>r</i>	.132	.571**	.617**	.544**	.227*	1								
	<i>p</i>	.224	<.001	<.001	<.001	.035									
	<i>N</i>	87	87	87	87	87	87								
<b>DSSQ Friends Insulin Management</b>	<i>r</i>	-.228*	.353**	.358**	.384**	.444**	.343**	1							
	<i>p</i>	.032	.001	.001	<.001	<.001	.001								
<b>Blood Glucose Management</b>	<i>N</i>	88	87	87	86	85	85	88							
	<i>r</i>	-.221*	.360**	.378**	.408**	.399**	.244*	.799**	1						
	<i>p</i>	.039	.001	<.001	<.001	<.001	.024	<.001							
<b>Diet</b>	<i>N</i>	88	87	87	86	86	86	87	88						
	<i>r</i>	-.153	.361**	.390**	.480**	.480**	.334**	.644**	.668**	1					
	<i>p</i>	.150	.001	<.001	<.001	<.001	.002	<.001	<.001						
<b>Exercise</b>	<i>N</i>	90	89	89	88	87	87	88	88	90					
	<i>r</i>	-.255*	.294**	.253*	.356**	.467**	.208	.473**	.473**	.604**	1				
	<i>p</i>	.016	.005	.017	.001	<.001	.054	<.001	<.001	<.001					
<b>Emotion</b>	<i>N</i>	89	88	88	87	86	86	87	87	89	89				
	<i>r</i>	-.157	.379**	.440**	.358**	.289**	.437**	.472**	.525**	.643**	.664**	1			
	<i>p</i>	.144	<.001	<.001	.001	.007	<.001	<.001	<.001	<.001	<.001				
<b>HADS- Depression (transformed)</b>	<i>N</i>	88	87	87	86	85	85	87	86	88	88	88			
	<i>r</i>	-.039	-.128	-.109	-.091	-.218*	-.119	.207	.155	.008	.054	-.056	1		
	<i>p</i>	.718	.233	.309	.398	.042	.272	.053	.149	.938	.617	.601			
<b>PedsQL</b>	<i>N</i>	90	89	89	88	87	87	88	88	90	89	88	90		
	<i>r</i>	-.016	.061	-.086	-.033	-.206	-.074	.212	.148	.026	-.080	-.255*	.610**	1	
	<i>p</i>	.880	.576	.434	.764	.062	.509	.053	.179	.811	.466	.019	<.001		
<b>HbA1c</b>	<i>N</i>	86	85	85	84	83	83	84	84	86	85	84	86	86	
	<i>r</i>	.025	.022	-.217*	-.059	-.106	-.072	.115	.083	-.019	-.179	-.110	.312**	.301**	1
	<i>p</i>	.812	.841	.041	.587	.328	.505	.288	.442	.862	.092	.307	.003	.005	
	<i>N</i>	90	89	89	88	87	87	88	88	90	89	88	90	86	90

\*p < 0.05, \*\*p < .001

### 3.4 Missing data

The distribution of missing data is indicated in Table 9. There was no consistent pattern to the missing data.

**Table 9:**

*Distribution and Quantity of Missing Data*

Variable	Quantity of missing data
<b>HADS- Depression subscale</b>	0
<b>DSSQ- Friends</b>	
Insulin management	1
Blood Glucose monitoring	1
Diet	2
Exercise	3
Emotions	3
<b>DSSQ-Family</b>	
Insulin management	2
Blood Glucose monitoring	2
Diet	0
Exercise	1
Emotions	2
<b>PedsQL Diabetes module</b>	3
<b>HbA1c</b>	0

### 3.5 Potential confounding variables

Previous research has highlighted the potential impact of age, mood and insulin pump use when considering relationships between social support, metabolic control and diabetes-related quality of life. For this reason, the data were further examined to assess how far the outcome variables (metabolic control and diabetes-related quality of life) could be explained by age, mood and pump use. Only relationships found to be significant by the Pearson's correlations calculations were further examined to identify if age or mood were mediating factors.



### 3.5.1 The potential impact of age

#### Age and metabolic control

Only the frequency of support for blood glucose monitoring by peers was found to be significantly correlated to metabolic control.

Partial correlation was used to explore the relationships between peers' support for blood glucose monitoring and metabolic control, whilst controlling for age. When age had been controlled for, the correlation between peers' support for blood glucose monitoring and metabolic control (HbA1c) remained significant ( $r = -.22$ ,  $N = 90$ ,  $p = .04$ ). An inspection of the zero order correlation ( $r = -.22$ ) suggested that controlling for age had a negligible effect on the strength of the relationship between these two variables.

#### Age and diabetes-specific quality of life

Family emotional support was the only independent variable to be significantly correlated with diabetes-related quality of life (PedsQL). Partial correlation was used to further explore the relationship between family emotional support and diabetes-related quality of life, whilst controlling for age. When age had been controlled for, the correlation between family emotional support and diabetes-related quality of life remained significant ( $r = -.26$ ,  $N = 90$ ,  $p = .02$ ). An inspection of the zero order correlation ( $r = -.26$ ) suggested that controlling for age had a negligible effect on the strength of the relationship between these two variables.

### **3.5.2 The potential impact of mood**

#### **Mood and metabolic control**

The relationship between mood (as measured by the HADS depression subscale) and metabolic control (as measured by the HbA1c), was investigated using Pearson product-moment correlation coefficient. The transformed HADS depression data were used to ensure no violation of the assumptions of normality, linearity and homoscedasticity.

Partial correlation was used to explore the relationship between peers' support for blood glucose monitoring and metabolic control whilst controlling for low mood. When mood had been controlled for, the relationship between peers' support for blood glucose monitoring and metabolic control was no longer significant ( $r = -.19$ ,  $N = 90$ ,  $p = .08$ ). An inspection of the zero order correlation ( $r = -.22$ ) suggested that controlling for mood had a small effect on the strength of the relationship between these two variables.

#### **Mood and diabetes-related quality of life**

Partial correlation was used to identify the extent to which the relationship between social support and diabetes-related quality of life scores might be explained by mood. When mood was controlled for, the relationship between family emotional support and diabetes-related quality of life remained significant ( $r = -.28$ ,  $N = 90$ ,  $p = .01$ ). An inspection of the zero order correlation ( $r = -.26$ ) suggested that controlling for mood had a small effect on the strength of the relationship between these two variables.

#### **Implications for data analysis**

As age appeared to have a negligible effect on the relationships between the independent variables (social support) and dependent variables (HbA1c values and PedsQL scores), it is unlikely that age will account for significant variance in the dependent variables.

Therefore, age was not included as an independent variable within the subsequent regression analyses.

However, mood had a small but significant effect on the relationship between the independent variables (social support) and dependent variables (HbA1c and PedsQL) so was included within subsequent regression analyses as a potential predictor.

### **3.5.3 Examining the effect of insulin management regimens**

The data were split according to those participants who used an insulin pump compared with those who injected insulin.

#### **Metabolic control and insulin management regimens**

An independent samples *t*-test was conducted to compare the HbA1c values for two different forms of insulin management regimens, namely pump use and injections. There was no significant difference in HbA1c values for pump users ( $M = 9.53$ ,  $SD = 1.43$ ), and participants who injected their insulin ( $M = 9.75$ ,  $SD = 1.77$ )  $t(88) = .40$ ,  $p = .69$ .

The magnitude of the differences in the means (effect size) was extremely small ( $d = -.09$ ).

#### **Diabetes-related quality of life and insulin management regimens**

An independent samples *t*-test was also used to compare the PedsQL scores for participants using an insulin pump and those who use injections. There was no significant difference in PedsQL scores for pump users ( $M = 30.60$ ,  $SD = 10.91$ ), and those using injections ( $M = 37.89$ ,  $SD = 18.96$ ),  $t(17.26) = 1.79$ ,  $p = .09$ .

The magnitude of the differences in the means (effect size) was large ( $d = 0.86$ ).

## Implications for data analysis

As pump use appeared to have very little effect on the dependent variables (HbA1c values and PedsQL scores), it is unlikely that this clinical characteristic will account for significant variance in the dependent variables.

### 3.6 Hypothesis 1

- Support for ‘practical diabetes management tasks’ (insulin injections, blood glucose monitoring and diet) will be provided more frequently by family than by peers.

The DSSQ Friends and Family questionnaires are reported to be comparable in research and clinic settings (Bearman & La Greca, 2002). The friends version has fewer items than the family version that were removed during the scale’s development to ensure reliability and validity (Bearman & La Greca, 2002). Support for insulin management, blood glucose monitoring and diet are rated as individual subscales of the questionnaire. As each subscale has a different number of items, to compare the frequency of support given by both family and peers, it was necessary to calculate a scaled or ‘percentage’ score of the total possible frequency of each subscale. Therefore, for each subscale, the score that identifies the frequency of support reported by each participant was divided by the total possible frequency score. This provided a scaled score that could be compared within the analysis.

A paired samples *t*-test was conducted to examine the differences between the total frequency of support for all ‘practical diabetes management tasks’ (insulin management, blood glucose monitoring and diet) by family and peers. Family ( $M = 52.41$ ,  $SD = 20.83$ ) provided significantly more support for ‘practical diabetes management

tasks' than peers ( $M = 37.26$ ,  $SD = 24.72$ ),  $t(84) = 6.34$ ,  $p < .001$ . The magnitude of the differences in the means revealed a large effect size ( $d = 0.98$ ).

### 3.6.1 Hypothesis 1a

- Support for insulin injections will be provided more frequently by family than peers.

A paired samples  $t$ -test was conducted to examine the differences between the frequency of support for insulin management by family and peers. Family ( $M = 46.92$ ,  $SD = 24.29$ ) provided significantly more support for insulin management than peers ( $M = 31.72$ ,  $SD = 27.54$ ),  $t(86) = 4.79$ ,  $p < .001$ . The magnitude of the differences in the means revealed a moderate effect size ( $d = 0.73$ ).

### 3.6.2 Hypothesis 1b

- Support for blood glucose monitoring will be provided more frequently by family than peers.

The difference between the amount of support given by family and peers for blood glucose monitoring was examined using a paired-samples  $t$ -test. A significant difference was found between the relative frequency of support given by family ( $M = 46.91$ ,  $SD = 21.51$ ) and peers ( $M = 40.50$ ,  $SD = 29.15$ ),  $t(79) = 2.01$ ,  $p = .048$ . Family therefore provided more support for blood glucose monitoring than peers. The magnitude of the differences in the means ( $d = -0.32$ ) indicated a small effect size.

### 3.6.3 Hypothesis 1c

- Support for diet will be provided more frequently by family than peers.

Following analysis using a paired-samples *t*-test, a significant difference was found between the frequency of support provided for diet by family ( $M = 46.57$ ,  $SD = 21.17$ ) and peers ( $M = 39.89$ ,  $SD = 29.08$ ;  $t(86) = 2.17$ ,  $p = .03$ ). Family therefore provided more support for diet than peers. The magnitude of the difference in the means ( $d = 0.37$ ) indicated a small effect size.

### 3.7 Hypothesis 2

- ‘Companionship’-related support (emotional support and support for exercise) will be provided more frequently by peers than family.

A paired samples *t*-test was conducted to examine the differences between the total frequency of ‘companionship’-related support (emotional support and support for exercise) given by family and peers. There was no significant difference between the frequency of ‘companionship’-related support (exercise and emotional support) given by family ( $M = 45.44$ ,  $SD = 25.33$ ) or peers ( $M = 46.44$ ,  $SD = 24.29$ ),  $t(82) = 0.36$ ,  $p = .72$ ). The magnitude of the differences in the means ( $d = -0.06$ ) indicated a very small effect size.

#### 3.7.1 Hypothesis 2a

- Emotional support will be provided more frequently by peers than family.

The data were split to analyse the difference between the frequency of support given by family and peers for emotional support alone.

A paired-samples *t*-test was used to identify any significant differences between the mean frequency of emotional support (as measured by the emotions subscale of the DSSQ) given by family and peers to adolescents with diabetes. Family ( $M = 65.25$ ,  $SD = 28.24$ ) provided significantly more emotional support than peers ( $M = 49.24$ ,  $SD = 34.72$ ),  $t(82) = 4.29$ ,  $p = <.001$ ). The magnitude of the differences in the means ( $d = 0.67$ ) indicated a moderate effect size.

### 3.7.2 Hypothesis 2b

- Support for exercise will be provided more frequently by peers than family.

Likewise, the frequency of support for exercise was analysed separately. A paired-samples *t*-test was also used to identify any significant differences between the mean frequency of support for exercise given by family and peers. In this study, peers ( $M = 44.41$ ,  $SD = 27.99$ ) provided significantly more support for exercise than family ( $M = 34.50$ ,  $SD = 27.04$ ;  $t(83) = 3.17$ ,  $p = .002$ ). The magnitude of the differences in the means ( $d = 0.49$ ) indicated a small to moderate effect size.

### 3.8 Hypothesis 3

- Family support for practical diabetes management tasks (blood glucose monitoring, insulin management and diet) will be more predictive of metabolic control than (a) peer support for practical diabetes management tasks (blood glucose monitoring, insulin management and diet), (b) family compassionate support (emotional support and support for exercise), or (c) peer compassionate support (support for emotions and exercise).

Pearson *r* correlations were calculated (Table 10) between the diabetes social support variables, HbA1c (metabolic control) and PedsQL (quality of life).

**Table 10:**

*Pearson r correlations between diabetes related social support (DSSQ), metabolic control (HbA1c) and quality of life (PedsQL)*

		HbA1c	PedsQL	Peer DMT Support	Family DMT Support	Peer Comp Support	Family Comp Support
<b>HbA1c</b>	Pearson <i>r</i>	1					
	Sig						
	N	90					
<b>PedsQL</b>	<i>r</i>	.301**	1				
	Sig	.005					
	N	86	86				
<b>Peer Diabetes Management</b>							
<b>Tasks support</b> (Insulin, blood glucose monitoring and diet)	<i>r</i>	-.111	-.044	1			
	Sig	.305	.689				
	N	88	84	88			
<b>Family Diabetes</b>							
<b>Management Tasks support</b> (Insulin, blood glucose monitoring and diet)	<i>r</i>	.041	.118	.543**	1		
	Sig	.704	.288	<.001			
	N	87	83	85	87		
<b>Peers' Compassionate</b>							
<b>support</b> (exercise and emotions)	<i>r</i>	-.115	-.180	.731**	.549**	1	
	Sig	.291	.103	<.001	<.001		
	N	87	83	87	85	87	
<b>Family Compassionate</b>							
<b>Support</b> (exercise and emotions)	<i>r</i>	-.169	-.156	.415**	.656**	.484**	1
	Sig	.116	.156	<.001	<.001	<.001	
	N	88	84	86	86	85	88

\*\* significant at the 0.01 level (2-tailed).

DMT = Diabetes Management Tasks

Comp = Compassionate

Fishers *Z* transformations were used to compare the correlation coefficients identified within Table 10 using the techniques of Meng *et al.*, (1992). The *Z* scores and significance values of the differences calculated between the correlations are reported in Table 11.



**Table 11:**

*Correlation coefficient comparisons of the relationships between Diabetes related social support and HbA1c*

<b>Diabetes related social supports compared in analysis with HbA1c</b>	<b>N</b>	<b>Z</b>	<b>p (one tailed)</b>
Family Diabetes Management Task support and Peer Diabetes Management Task support	85	.674	.250
Family Diabetes Management Task support and Peer compassionate support	85	.717	.237
Family Diabetes Management Task support and Family compassionate support	86	1.437	.075
Peer Diabetes Management Task support and Peer compassionate support	87	.050	.480
Peer Diabetes Management Task support and Family compassionate support	86	.504	.307
Peer compassionate support and Family compassionate support	85	.498	.309

\* significant at the 0.05 level

None of the correlation coefficients between types of diabetes related support were found to be statistically significantly different. Additionally, using the test for contrast among multiple correlated correlation coefficients (Meng *et al.*, 1992), family support for diabetes management tasks did not have a significantly higher correlation coefficient with HbA1c as predicted ( $Z = 1.07, p > .05$ ).

A forced entry hierarchical multiple regression was performed between metabolic control (HbA1c; the criterion variable) and the frequency of diabetes-specific social support provided by both family and peers (the DSSQ; the predictor variables). As mood was found to have a small effect on the relationship between some of the independent variables and HbA1c, this was included as a potential predictor. Analysis was performed using SPSS Regression and SPSS Explore for evaluation of assumptions. Family diabetes management task support variables were entered using the ‘enter’ method into

the first block of the regression analysis. All other variables were added to the second block using the stepwise method as described by Field (2000).

Preliminary analyses were performed to ensure no violations of the assumptions of normality, linearity and homoscedasticity (see Appendix 10). With the use of  $p < .001$  criterion for Mahalanobis distance, no outliers among the cases were found. Missing data were replaced using SPSS 'mean substitution', which is considered to be a conservative method (Tabachnick & Fidell, 2007).

Table 12 displays the unstandardised regression coefficients ( $B$ ), constant (intercept), the standard regression coefficients ( $\beta$ ),  $R^2$ , adjusted  $R^2$ .and  $R^2$  change for each step of the regression model

Table 12:

*Hierarchical Multiple Regression of Social Support given by Family and Peers on Metabolic Control (HbA1c)*

Variables entered	Unstandardised <i>B</i>	Standard Error <i>B</i>	Standardised $\beta$	$R^2$	Adjusted $R^2$	$\Delta R^2$
<b>STEP 1: Constant</b>	9.63	.52		.029	-.007	.029
<b>DSSQ Family</b>	.03	.03	.18			
Insulin Management						
Blood glucose monitoring	.006	.02	.05			
Diet	-.012	.01	-.17			
<b>STEP 2: Constant</b>	8.99	.56		.107	.061	.078
<b>DSSQ Family</b>	.02	.03	.11			
Insulin Management						
Blood glucose monitoring	.001	.02	.01			
Diet	-.007	.01	-.09			
<b>HADS</b>	.56	.22	.29*			
<b>STEP 3: Constant</b>	9.18	.55		.158	.104	.052
<b>DSSQ Family</b>	.03	.03	.17			
Insulin Management						
Blood glucose monitoring	.004	.02	.04			
Diet	-.003	.01	-.04			
<b>HADS – Depres (trnsf)</b>	.48	.21	.25*			
<b>DSSQ Friends</b>	-.05	.023	-.26*			
Blood Glucose Monitoring						
<b>STEP 4: Constant</b>	9.00	.55		.207	.145	.049
<b>DSSQ Family</b>	.03	.03	.19			
Insulin Management						
Blood glucose monitoring	.01	.02	.08			
Diet	.007	.01	.09			
<b>HADS – Depres (trnsf)</b>	.47	.21	.24*			
<b>DSSQ Friends</b>	-.05	.02	-.26*			
Blood Glucose Monitoring						
<b>DSSQ Family</b>	-.04	.019	-.29*			
Exercise						
<b>STEP 5: Constant</b>	8.91	.53		.261	.193	.054
<b>DSSQ-Family</b>						
Insulin management	.026	.024	.181			
Blood glucose monitoring	.005	.020	.042			
Meals	.008	.011	.114			
Exercise	-.045	.018	.319*			
<b>DSSQ-Friends</b>						
Insulin management	.205	.087	.330*			
Blood glucose monitoring	-.091	.028	.462**			
<b>HADS- Depres (trnsf)</b>	.546	.205	.280**			

\* $p < .05$ , \*\* $p < .01$ ,  $N = 84$

All ten social support variables were added as predictor variables in the regression. Mood (HADS Depression transformed scale) was added to explore if it was a significant predictor of metabolic control. Addition of the following variables added no further prediction and were excluded from the final regression model using the methods outlined as per stepwise regression analysis: peers' support for diet, peers' support for exercise, peers' emotional support, family emotional support.

The  $R$  coefficient for regression was significantly different from zero at the end of each step with the exception of steps 1 and 2. For the final model,  $R^2$  was .26,  $F(7,76) = 3.82$ ,  $p = .001$ . The adjusted  $R^2$  value was .19 which indicates that approximately 19% of the variability in HbA1c was predicted by all social support and mood variables added to the regression.

After step 1, with the three family diabetes management task support variables in the equation,  $R^2$  was .029,  $F(3,80) = .798$ ,  $p = .498$ . After step 2, with the square root of HADS-Depression added to the three family diabetes management task support variables,  $R^2$  was .107,  $F(4,79) = 2.357$ ,  $p = .061$ . Mood accounted for an additional 7.8% of the variance in HbA1c. After step 3, with Peer support for blood glucose monitoring added to the equation,  $R^2$  was .158,  $F(5,78) = 2.932$ ,  $p = .018$ , accounting for an additional 5.2% of the variance in HbA1c. After the addition of the variable Family support for exercise,  $R^2$  was .207,  $F(6,77) = 3.352$ ,  $p = .005$ , accounting for an additional 4.9% of variance in HbA1c. Finally after the addition of the Peers' support for insulin management variable,  $R^2$  was .261,  $F(7,76) = 3.82$ ,  $p = .001$ , accounting for an additional 4.9% of variance in HbA1c.

A number of significant predictors were identified from the variables entered, namely family support for exercise ( $\beta = .319$ ,  $p = .016$ ), peers' support for insulin management

( $\beta = .33$ ,  $p = .022$ ), peers' support for blood glucose monitoring ( $\beta = .462$ ,  $p < .01$ ) and low mood ( $\beta = .28$ ,  $p < .01$ ).

In order to obtain a final regression model which contained only significant predictors, the significant predictors identified in the final model (step 5) were re-analysed using forced entry method of multiple regression. The unstandardised regression coefficients ( $B$ ), constant (intercept), the standard regression coefficients ( $\beta$ ),  $R^2$ , and adjusted  $R^2$  for this model are shown in Table 13.

**Table 13:**

*Forced Entry Multiple Regression of only significant predictors identified on Metabolic Control (HbA1c)*

Variables entered	Unstandardised $B$	Standard Error $B$	Standardised $\beta$	$R^2$	Adjusted $R^2$
<b>Constant</b>	9.494	.418		.230	.193
<b>DSSQ-Friends</b>					
Insulin management	.232	.081	.376**		
Blood glucose monitoring	-.075	.026	-.374**		
<b>DSSQ-Family</b>					
Exercise	-.030	.014	-.213*		
<b>HADS- Depression (trnsf)</b>	.645	.190	.332**		

\* $p < .05$ , \*\* $p < .01$ ,  $N = 84$

The regression solution is extremely sensitive to the combination of variables that is included in it (Tabachnick & Fidell, 2007), therefore whether a predictor appears particularly important in a solution depends on the other potential predictors in the set. It is not unusual therefore that the standardised  $\beta$  reported in Table 13 for each variable is different to those reported in the final step of the hierarchical regression model.

The  $R$  coefficient for the regression was significantly different from zero  $F(4,83) = 6.193, p < .001$ .  $R^2$  was .23. The adjusted  $R^2$  was .193 indicating approximately 19.3% of the variability in HbA1c could be accounted for by levels of social support and mood.

In the final model, the criterion variable (HbA1c) was most strongly impacted by peers' support for insulin management ( $\beta = .376, p < .01$ ) followed by peer support for blood glucose monitoring ( $\beta = -.374, p < .01$ ), mood ( $\beta = .332, p < .01$ ) and finally family support for exercise ( $\beta = -.213, p = .04$ ).

The size and direction of the relationships suggest participants with lower levels of peer support for insulin management, higher levels of peer support for blood glucose monitoring, increased mood and higher levels of support from family concerning exercise will have better metabolic control (lower HbA1c values). The three variables for family diabetes management tasks support did not appear to have a significant impact on HbA1c as predicted.

Effect size calculations (Cohen's  $f^2$ ) revealed a large effect size of 0.35 and power ( $1 - \beta$ ) of .96, which indicates that the analysis was sufficiently powered. Very few studies in this field have reported effect size, the effect size of the current study is consistent with the work of La Greca *et al.*, (1995), who used similar methodology and populations.

### **3.9 Hypothesis 4**

- Peer emotional support and support for exercise will be more predictive of diabetes-related quality of life than (a) family emotional support and support for exercise, and (b) support for practical diabetes management tasks (blood glucose monitoring, insulin management and diet) by both family and peers.

Pearson  $r$  correlations were calculated (Table 10) between the diabetes social support variables, HbA1c (metabolic control) and PedsQL (quality of life). Fishers  $Z$  transformations were then used to compare the correlation coefficients identified within Table 10 using the techniques outline by Meng *et al.*, (1992). The  $Z$  scores and significance values of the differences calculated between the correlations are reported in Table 14.

**Table 14:**

*Correlation coefficient comparisons of the relationships between Diabetes related social support and quality of life (PedsQL)*

<b>Diabetes related social supports compared in analysis with PedsQL</b>	<b><math>N</math></b>	<b><math>Z</math></b>	<b><math>p</math> (one tailed)</b>
Family Diabetes Management Task support and Peer Diabetes Management Task support	85	.746	.228
Family Diabetes Management Task support and Peer compassionate support	85	-.595	.276
Family Diabetes Management Task support and Family compassionate support	86	-.425	.335
Peer Diabetes Management Task support and Peer compassionate support	87	-1.761	.039*
Peer Diabetes Management Task support and Family compassionate support	86	-.989	.161
Peer compassionate support and Family compassionate support	85	.832	.416

\* significant at the 0.05 level

Only in comparison with peers' support for diabetes management tasks was peers' compassionate support was significantly more highly correlated with quality of life. Additionally, using the test for contrast among multiple correlated correlation coefficients (Meng *et al.*, 1992), peers' compassionate support was not significantly higher correlated with quality of life ( $Z = .38, p > .05$ ).

Preliminary analyses were performed to ensure no violations of the assumptions of normality, linearity and homoscedasticity (see Appendix 11). With the use of  $p < .001$  criterion for Mahalanobis distance, no outliers among the cases were found. Missing data was replaced using SPSS 'mean substitution'. Peer compassionate support variables were entered using the 'enter' method into the first block of the regression analysis. All other variables were added to the second block using the stepwise method as described by Field (2000).



Table 15:

*Hierarchical Multiple Regression of Social Support given by Family and Peers on Diabetes-Related Quality of Life*

Variables entered	Unstandardised <i>B</i>	Standard Error <i>B</i>	Standardised $\beta$	R <sup>2</sup>	Adjusted R <sup>2</sup>	$\Delta$ R <sup>2</sup>
<b>STEP 1: Constant</b>	41.785	4.442		.040	.015	.040
<b>DSSQ Friends</b> Exercise	-.655	.373	-.202			
Emotion	.019	.407	.005			
<b>STEP 2: Constant</b>	23.368	4.670		.367	.342	.327
<b>DSSQ Friends</b> Exercise	-.300	.310	-.092			
Emotion	.057	.333	.016			
<b>HADS Depress (trsnf)</b>	11.978	1.910	.583**			
<b>STEP 3: Constant</b>	29.761	5.098		.422	.391	.054
<b>DSSQ Friends</b> Exercise	-.114	.307	-.035			
Emotion	.417	.348	.118			
<b>HADS Depress (trsnf)</b>	12.052	1.839	.587**			
<b>DSSQ Family</b> Emotion	-.671	.253	-.266*			
<b>STEP 4: Constant</b>	29.867	4.859		.482	.447	.060
<b>DSSQ Friends</b> Exercise	-.560	.330	-.172			
Emotion	.268	.335	.076			
<b>HADS Depress (trsnf)</b>	10.099	1.875	.492**			
<b>DSSQ Family</b> Emotion	-.933	.257	-.370**			
<b>DSSQ Family</b> Insulin Management	.498	.170	.330**			
<b>STEP 5: Constant</b>	30.669	4.769		.511	.471	.029
<b>DSSQ Friends</b> Exercise	-.687	.328	-.211*			
Emotion	-.166	.389	-.047			
<b>HADS Depress (trsnf)</b>	10.485	1.844	.510**			
<b>DSSQ Family</b> Emotion	-.971	.252	-.385**			
<b>DSSQ Family</b> Insulin Management	.451	.168	.299**			
<b>DSSQ Friends</b> Insulin management	1.549	.746	.236*			
<b>STEP 6: Constant</b>	28.401	4.808		.537	.492	.026
<b>DSSQ Friends</b> Exercise	-.858	.333	-.264*			
Emotion	-.187	.381	-.053			
<b>HADS Depress (trsnf)</b>	10.521	1.807	.512**			
<b>DSSQ Family</b> Emotion	-1.266	.287	-.502**			
<b>DSSQ Family</b> Insulin Management	.323	.176	.214			
<b>DSSQ Friends</b> Insulin management	1.627	.732	.248*			
<b>DSSQ Family</b> Diet	.191	.095	.257*			

\* $p < .05$ , \*\* $p < .01$ ,  $N = 80$

Table 15 displays the unstandardised regression coefficients ( $B$ ), constant (intercept), the standard regression coefficients ( $\beta$ ),  $R^2$ , adjusted  $R^2$  and  $R^2$  change for each step of the regression model

All ten social support variables were added as predictor variables in the regression. Mood (HADS Depression transformed scale) was added to explore if it was a significant predictor of diabetes specific quality of life. Addition of the following variables added no further prediction and were excluded from the final regression model using the methods outlined as per stepwise regression analysis: peers' support for blood glucose monitoring, peers' support for diet, family support for exercise and family support for blood glucose monitoring.

The  $R$  coefficient for regression was significantly different from zero at the end of each step with the exception of step 1. For the final model,  $R^2$  was 0.537,  $F(7,72) = 11.91$ ,  $p < .001$ . The adjusted  $R^2$  was 0.49 indicating that approximately 49% of the variability in PedsQL scores could be accounted for by levels of social support and mood.

After step 1, with peer emotional and exercise support variables in the equation,  $R^2$  was 0.04,  $F(2,77) = 1.612$ ,  $p < .206$ . After step 2, with the square root of HADS-Depression added to the peer exercise and emotional support variables,  $R^2$  was 0.367,  $F(3,76) = 14.715$ ,  $p < .001$ . Mood therefore accounted for an additional 32.7% of the variance in PedsQL (quality of life). After step 3, with family emotional support added to the equation,  $R^2$  was 0.422,  $F(4,75) = 13.680$ ,  $p < .001$  accounting for an additional 5.4% of the variance in PedsQL scores. After the addition of the family support for insulin management variable (step 4),  $R^2$  was 0.482,  $F(5,74) = 13.763$ ,  $p < .001$  accounting for an additional 6.0% in the variance of PedsQL scores. With the addition of peers' support for insulin management in step 5,  $R^2$  was 0.511,  $F(6,73) = 12.703$ ,

$p < .001$ , this variable accounted for an additional 2.9% of the variance in quality of life. Finally, the addition of family support for diet accounted for a further 2.6% of variance,  $R^2$  was 0.537,  $F(7,72) = 11.91$ ,  $p < .001$ .

A number of significant predictors were identified, namely levels of support for exercise by peers ( $\beta = .264$ ,  $p = 0.012$ ), levels of peers' support for insulin management ( $\beta = .25$ ,  $p = 0.03$ ), levels of family emotional support ( $\beta = 0.50$ ,  $p < 0.001$ ), levels of family support for diet ( $\beta = 0.257$ ,  $p = 0.049$ ) and finally mood ( $\beta = 0.51$ ,  $p < 0.01$ ).

In order to obtain a final regression model which contained only significant predictors, the significant predictors identified in the final model (step 6) were re-analysed using backward removal method of multiple regression. The unstandardised regression coefficients ( $B$ ), constant (intercept), the standard regression coefficients ( $\beta$ ),  $R^2$ , and adjusted  $R^2$  for this model are shown in Table 16.

**Table 16:**

*Forced Entry Multiple Regression of only significant predictors identified on Quality of Life (PedsQL)*

Variables entered	Unstandardised $B$	Standard Error $B$	Standardised $\beta$	$R^2$	Adjusted $R^2$
<b>Constant</b>	27.357	4.741		.534	.503
<b>HADS – Depression (transf)</b>	11.645	1.666	.568**		
<b>DSSQ-Friends –</b>					
Exercise	-.671	.318	-.203*		
Insulin Management	1.650	.592	.249**		
<b>DSSQ- Family</b>					
Emotion	-1.243	.280	-.483**		
Diet	.252	.089	.332**		

\* $p < .05$ , \*\* $p < .01$ ,  $N = 81$

The  $R$  coefficient for the regression was significantly different from zero  $F(5,75) = 17.17$ ,  $p < .001$ .  $R^2$  was .53. The adjusted  $R^2$  was .50 indicating approximately

50 % of the variability in PedsQL scores could be accounted for by levels of social support and mood.

In the final model, the criterion variable (PedsQL scores) was most strongly predicted by mood ( $\beta = .568, p < .01$ ), followed by family emotional support ( $\beta = -.483, p < .01$ ), levels of support for diet given by family ( $\beta = .332, p < .01$ ), peer support for insulin management ( $\beta = .249, p < .01$ ) and finally support given by peers for exercise ( $\beta = -.203, p < .01$ ).

The size and direction of the relationships suggest that participants with increased mood, higher levels of emotional support from family, higher levels of support for diet given by family, lower levels of support for insulin management given by peers and finally higher levels of support for exercise given by peers will have better diabetes-related quality of life (lower PedsQL scores).

Effect size calculations (Cohen's  $f^2$ ) revealed a very large effect size of 1.16 and power ( $1 - \beta$ ) of 1.00, which indicates that the analysis was sufficiently powered. This effect size is larger than previous studies, which typically report Cohen's  $f^2$  values of 0.3 to 0.45 (La Greca et al., 1995; Skinner et al., 2000).

## **4 Discussion**

### **4.1 Summary of results**

The present study examines the nature and impact of diabetes-specific social support for adolescents with type 1 diabetes in Tayside, Forth Valley and Fife. This aim was met. The findings suggest that peers and family were perceived to provide different forms of diabetes-specific social support. The source and nature of the support also had a significant impact on metabolic control and quality of life.

This section summarises the results of the study, considers to what extent the aims were met and the hypotheses confirmed, and discusses implications, methodological issues and suggestions for future research.

#### **4.1.1 Hypothesis 1**

The first hypothesis was confirmed: family was perceived to provide more support for practical diabetes management tasks (insulin management, blood glucose monitoring and diet) than peers. The current study is the only one to compare the relative and specific forms of support provided by peers and family in terms of their impact on metabolic control and quality of life. It also supports the findings of previous research that examined the separate roles of family and peer support on adherence (La Greca *et al.*, 1995; Shroff Pendley *et al.*, 2002).

#### **Hypotheses 1a, 1b, 1c**

Further examination of the data revealed that the support given for each of the practical diabetes management tasks (insulin management, blood glucose monitoring and diet) was provided more frequently by family than by peers. Therefore hypotheses 1a, 1b and 1c were all confirmed.

Each of the hypotheses confirmed the findings of previous research (La Greca *et al.*, 1995; Shroff Pendley *et al.*, 2002). This is not surprising in that parents are often fundamentally involved in diabetes management from diagnosis. Alternative explanations for the present study's findings have also been considered. Existing studies measured the frequency of support using the interview form of the DSSQ (La Greca *et al.*, 1995; Shroff Pendley *et al.*, 2002). The number and percentage of family and peers reported to provide 'at least one supportive behaviour' was compared. The authors of the DSSI acknowledge the possibility of over-representation of support using this method and called for further development of the measure. However, the DSSQ (questionnaire) used in the current study provides a more sensitive measure of the frequency of support, including and acknowledging support behaviours that were present but infrequent. Despite a significant alteration to the way in which support is measured, the current findings continue to support the work of La Greca *et al.*, (1995) and confirm the different support roles played by family and peers.

#### **4.1.2 Hypothesis 2**

The second hypothesis was not confirmed: When the frequency of support for both emotions and exercise were combined to provide a measure of 'companionship-related support', there was no significant difference between the frequency of support given by family or peers.

Previous studies have indicated that support for emotions and exercise are both aligned with companionship and belonging (Bearman & La Greca, 2002; La Greca & Bearman, 2002). La Greca *et al.*, (1995) identified that peers provide significantly more support for companionship tasks. However, the current study does not reflect these findings. Analysis of exercise and emotional support as separate and distinct behaviours provided further explanation for the results of hypothesis 2.

## **Hypothesis 2a**

It was hypothesised that peers would provide more emotional support than family. However, this hypothesis was not confirmed: family was found to provide more emotional support than peers.

This is contrary to the existing comparative study by La Greca *et al.* (1995), however it supports the findings of La Greca & Thompson, (1998). The latter study compared the frequency of social support by family and peers from varied socioeconomic backgrounds (including the population used in La Greca and colleagues' 1995 study). They reported that participants from lower-income backgrounds reported that emotional support was provided more frequently (although non-significantly) by family than by peers. This indicated a potential influence of socioeconomic factors on the provision of social support. Whilst socioeconomic variables such as family income were not collected in the present study, it is possible that these factors might provide an alternative explanation for the current study's findings.

## **Hypothesis 2b**

Peers were found to provide more support for exercise than family, confirming this hypothesis. The current study included items such as "how often do peers invite [you] to join in exercising with them?". These items highlight the companionship aspect to exercise and therefore support the findings of La Greca *et al.* (1995).

### **4.1.3 Hypothesis 3**

The third hypothesis was not confirmed. Only three forms of diabetes-specific social support were found to be significant predictors of metabolic control. The strongest predictor was found to be support for insulin management given by peers, followed by blood glucose monitoring given by peers, low mood and finally family support for exercise. Better metabolic control was predicted by greater frequencies of support, with

the exception of peers support for insulin management. In this study, increased support for insulin management was associated with poorer metabolic control. Each of these predictors will now be discussed in turn.

The impact of specific forms of social support has not yet been studied in relation to metabolic control. Peer support for insulin management was the only variable that was negatively associated with HbA1c. Increased peer support for insulin management led to poorer metabolic control. This does not support existing research, which identified that peer support for insulin management had little effect on adherence (Bearman & La Greca, 2002). It is important to consider alternative explanations for these findings. First, there are only two items in the DSSQ-Friends that identify peer support for insulin management. Psychometric analysis revealed weaker internal consistency for this scale than other social support behaviours. There are potential limitations therefore in the present study's methodology. Second, peer support for blood glucose monitoring was associated with better metabolic control and therefore one must consider the factors that differentiate support for blood glucose monitoring from insulin management. Blood glucose monitoring is acknowledged as the most challenging aspect of diabetes management (Bui *et al.*, 2005) and includes reacting to hypoglycaemia at an early stage. Adolescents might therefore appreciate additional support to prevent acute difficulties such as hypoglycaemia worsening and requiring medical attention. Dependent on the management regimen of the adolescent, they may not be required to administer insulin during the day when in the presence of peers. It is therefore less likely that they would require peer support. It is possible that support for insulin management may also be interpreted as a parental role, and thus would not be appreciated as 'helpful' by the adolescent if peers were to take on this responsibility. Whilst 'perceived helpfulness' of social support is not reported in the current study, future research should include the relative importance of perceived helpfulness of social support in relation to HbA1c and quality of life to answer some of these questions.



Bearman & La Greca (2002) reported that peer support for blood glucose monitoring significantly predicted adherence to blood glucose monitoring tasks. It is of note that in the current study, support for blood glucose monitoring was provided with relatively little frequency, but when this support was available from peers, it was a significant predictor of metabolic control. Peer support for blood glucose monitoring was a more significant predictor than any of the family factors. Whilst similar support provided by family was reported more frequently, it did not appear to predict metabolic control. Consequently it would be interesting to consider the nature of the support provided and how 'supportive' the adolescents rated the behaviours. For example, if support for blood glucose monitoring was interpreted as 'nagging' from the family, but 'helpful' from peers, this might provide more information to explain our findings.

Previous research has indicated the importance of low mood as a confounding variable in diabetes research. Despite few participants scoring in the 'possible depression' range, and none scoring in the 'probable depression' range, sub-clinical levels of mood were significant predictors of metabolic control. This supports existing research (Cox & Gonder-Frederick, 1992; Hood *et al.*, 2006; Lawrence *et al.*, 2006), although the direction of causation remains unclear.

The final significant predictor (and the only family factor found to be a significant predictor) of metabolic control was family support for exercise. La Greca & Bearman (2002) identified that family support for exercise was not related to adherence. This study highlights that whilst family support for exercise is not frequent, it is important for metabolic control when provided. It is unclear how exercise support from the family affects metabolic control, and these findings might indicate an indirect relationship that has not currently been explored in the literature. It is possible that families who provide

more support for exercise may hold greater value for general health, including weight, body mass index (BMI) and/or fitness. Although not examined in the current study, higher adolescent weight and BMI have been associated with poorer metabolic control (Pietilainen *et al.*, 1995) and may therefore act as a mediating factor in the relationship. Beliefs about exercise and general health are formed within the family context prior to adolescence and peer influence (Field *et al.*, 2001). Parents are influential role models for maintaining general health and fitness. This might reflect on the adolescents' general perceptions about health and well-being, including the importance of adherence to diabetes management tasks.

#### **4.1.4 Hypothesis 4**

The final hypothesis was confirmed in part. Peers' compassionate support was more strongly associated with quality of life than peers' support for diabetes management tasks. In the present study, better quality of life was most strongly predicted by higher levels of mood, a greater frequency of family emotional support and a greater frequency of support for diet given by family, but also by a lower frequency of support by peers for insulin management and higher frequency of support for exercise given by peers,.

Low mood has been indicated as a significant predictor of poor quality of life in previous studies that have controlled for physical health status and complications (Grey *et al.*, 1998; Guttman-Bauman *et al.*, 1998; Jacobson *et al.*, 1997). The current study supports these findings despite a small number of participants reporting depressive symptoms. Previous research indicates that sub-clinical levels of psychological distress appear to influence self care, although the precise nature of these effects remains unclear (Gonder-Frederick *et al.*, 2002).

The frequency of family emotional support was a significant predictor of quality of life. This has not yet been studied and therefore there is no existing research with which to compare the present study's findings. Whilst adolescents spend increasingly more time away from the family home, family support remains important for diabetes-related well-being. The number and nature of peer relationships can change throughout adolescence (Hardy *et al.*, 2002), and the family can be the only stable source of emotional support concerning diabetes. The requirements and difficulties associated with diabetes management may be more apparent to family members. Therefore, adolescents may choose to discuss their diabetes concerns with family, so as not to appear 'different' or 'needy' to their social group. Emotional support for diabetes care may promote self-efficacy and enhance psychosocial adjustment, thereby leading to greater quality of life.

A higher frequency of family support for diet was associated with better quality of life. Whilst there is limited available research which has examined the role of support for diet in relation to quality of life for adolescents with type 1 diabetes, some research has been undertaken for adults with type 2 diabetes. Sato, Miyashita, Suzukamo & Kazuma (2004) suggested that the burden of adhering to diet restrictions had a significant impact on quality of life. It is possible that if family were to provide support such as 'joining you in eating the same foods' (DSSQ-Family; La Greca & Bearman, 2002) this might reduce the impact of 'being different', reduce the sense of isolation and normalise the dietary requirements of the individual with diabetes.

Increased support for insulin management by peers was associated with poorer quality of life. Alternative explanations for the present study's findings are described above when considering metabolic control. Future implications of this research include the need to identify how 'helpful' the young person perceived the support to be. If it were perceived to be 'nagging', this might explain the association with poorer quality of life. 'Nagging'

might increase conflict, limit peer acceptance and integration, and therefore prevent successful transition to independence and autonomy.

It was hypothesised that peer support for exercise would have a significant impact on quality of life and this was confirmed. Whilst there does not appear to be existing research with which to compare these findings, an explanation for the present study's results is presented. Exercise is an important aspect of social integration, acceptance and 'normalisation' for the adolescent. Support for exercise does not necessitate discussions about diabetes or diabetes care, therefore the young person is able to develop a sense of identity that is not focused on diabetes. The establishment of a sense of identity is vital to successful adolescent development and quality of life (Holmbeck, 2002).

#### **4.2 Limitations and suggestions for future research**

The limitations of the present study must be noted. First, despite achieving sufficient power in all statistical analyses, the number of participants was relatively small. Analysis of the final hypothesis revealed a larger effect size than would be predicted in general psychological research (Barker *et al.*, 2002). Previous studies that have included an adolescent diabetes population typically report medium effect sizes (Bennett Johnson & Meltzer, 2002; La Greca *et al.*, 1995). However, research that has included measures of social support and quality of life have consistently reported medium to large effect sizes (Lewandowski & Drotar, 2007; Skinner *et al.*, 2000). It is plausible therefore that a greater variability within quality of life data might contribute to the increased effect size.

The number of participants who failed to attend their appointment and were subsequently unable to consent to participate in the current study was similar to rates reported by Kaufman and colleagues (1999). Patients who do not attend their diabetes clinic have been reported to have higher HbA1c results and are more likely to struggle

with their diabetes care (Kaufman *et al.*, 1999). Information about patients who did not consent to participate was not available in the current study, but it is worth considering that an important cohort of patients may therefore be missing from the analysis. For those who did consent to participate, the drop-out rate was consistent with those reported in similar studies (Bearman & La Greca, 2002; Hains *et al.*, 2007; La Greca *et al.*, 1995).

Significantly more adolescents in the current study indicated that they used an insulin pump than national prevalence statistics suggest (Greene & Waugh, 2004). NHS Tayside is currently a leading UK centre for insulin pump therapy in young people with diabetes and therefore has access to additional funding for pump therapy. Unsurprisingly, the vast majority of pump users within the current study were patients within the Tayside clinics. Whilst previous research has indicated that pump use is associated with better quality of life, and better metabolic control (Battelino, 2006; McMahon *et al.*, 2005), these differences were not observed in the current study. The reasons remain unclear and would require further investigation.

The current study did not find any participants who scored within the 'probable depression' range using the HADS. Each clinic involved in the present study also had a Clinical Psychologist attached to the team, and therefore it is likely that patients exhibiting significant depressive symptoms may have been identified and offered treatment prior to the study commencing. It is possible that young people experiencing significant symptoms associated with depression would be less likely to attend their clinic appointment and therefore were not available to participate in the study.

The average HbA1c of the current sample was significantly higher than the recommended guidelines, but also higher than reported HbA1c values from previous UK

and international adolescent populations (Greene & Waugh, 2004; Scott *et al.*, 2006). The reasons for this are unclear and would require further investigation.

The current study used an average measure of metabolic control over the previous 12 months. However the HADS depression subscale identified mood within the last four weeks. Any impact of recent mood changes on metabolic control might have been masked through the use of the average HbA1c. Future research might also include a measure of the most recent HbA1c when considering measures which identify mood states, e.g., anxiety or low mood.

The measures used in the present study are not without some limitations. Although the DSSQ has many strengths, it is not ideal for adolescents using insulin pumps. A number of questions are less relevant to this population (e.g. “how often does your family/friends give you your injections?”). To date there are no available diabetes-specific social support measures developed to include pump use. As pumps become more widely used within diabetes clinics, it is clear that the development of such a measure would be important. Likewise, as dietary advice for diabetes changes with new research, traditional rigid meal plans are becoming less common for adolescents with diabetes. This should be reflected in future measures.

Family members were encouraged to leave the adolescent to complete the measures independently to minimise the possibility of socially-desirable responding. The majority of participants were accompanied by their family and it was not possible to isolate the adolescent completely due to the nature of clinics. As a result it is possible that the participants were subject to pressure to respond in a biased manner.

The current study did not include parent or peer reports of the adolescent’s social support and therefore the findings are based solely upon the adolescent’s perceptions.

Adolescents are generally viewed as the ‘best’ informants for social support (La Greca & Lemanek, 1996) although previous studies have indicated high levels of agreement between parent and adolescent reports (Laffel *et al.*, 2003). One study, however, indicated that parents often report their adolescent to have higher levels of distress and poorer health than the young person self-reports (Hesketh *et al.*, 2004). Should parents experience greater concern over their adolescent’s health status, this might impact on the nature and frequency of support provided. Therefore future research should consider social support from multiple perspectives.

### **4.3 Clinical relevance**

Diabetes teams are constantly searching for new ways to engage adolescents and improve their metabolic control. More recently, quality of life has become an important outcome of treatment and therefore the identification of factors that may impact on either metabolic control or quality of life is relevant to developing services. Low mood has consistently been found to impact on both metabolic control and quality of life, even at sub-clinical levels. Therefore a comprehensive assessment of the young person’s psychological status should be included in the adolescent’s routine care. This highlights the important role of Clinical Psychology within diabetes teams. There are potential training and supervision needs of the multidisciplinary team for understanding and working with psychological issues, and also the role of Clinical Psychology in treating more complex cases.

Traditionally, the family of young people with diabetes was the main target of intervention, taking lead roles within clinic settings. There was a presumption that families were the sole source of influence over the young person and their diabetes care. This has shifted considerably, and now young people are often seen on their own in the clinic to enhance self-efficacy and independence. The findings of the current study

support the continued involvement of families for adolescents, but also highlight the potential impact of peer support.

Peers are often neglected in terms of their role in diabetes care for a number of reasons. The adolescents themselves may prefer to exclude peers from their diabetes care so as not to appear different and to protect their peer group integration. It is also possible that peers are not aware of the demands of a diabetes regime and therefore are unsure or unwilling to support the adolescent. It is clear that when peers do provide support for blood glucose monitoring, this has a significant effect on the adolescent's metabolic control. One could suggest therefore, that diabetes teams provide peer education, and involve peers in the clinic process to increase knowledge and awareness. Greco and colleagues (2001) designed an intervention for peers focused on all aspects of diabetes care, including insulin management. Despite reporting an increase in knowledge and awareness of diabetes management tasks, this had little effect on adherence. The study was based on newly-diagnosed adolescents with diabetes who were still adjusting to their condition and focussed on all aspects of diabetes care including insulin management. The current study has found that increased support for insulin management by peers has a detrimental effect and therefore education programmes (such as that described by Greco *et al.*, 2001) that attempt to increase this form of support may be unsuccessful. The present study suggests that a peer education programme focusing on blood glucose monitoring and reacting to hypoglycaemia may be more effective and helpful to adolescents with diabetes, even many years after diagnosis.

It is important to acknowledge that peers have a distinct role from family, and that in line with adolescent development, diabetes care should aim to support the transition to independence for the adolescent rather than transfer dependence from family to peers. Peers have a clear role in terms of the development of identity and independence and therefore any intervention that aims for peers to 'take on' the responsibility of diabetes



care is unadvisable. It is important to ask the adolescent with diabetes about their experience of sources of helpful support, and use this information to collaborate with the young person thus supporting them to manage their diabetes as well as possible.

#### **4.4 Conclusion**

Family and peers provide important support for adolescents' diabetes health and well-being. The present study highlights the need to consider adolescents in both a social and family context when discussing influences on their diabetes care.

The family has an important support role in many aspects of diabetes care. Therefore the family should not be forgotten within the context of the diabetes clinic, regardless of the patient's age. This study has been the first to highlight the importance of family support for exercise and emotions. These have typically been understudied compared to support for practical diabetes management tasks, and yet are significantly associated with the adolescent's metabolic control and quality of life.

Peer support for blood glucose monitoring has a positive impact on metabolic control. However, similar support for insulin management appears to be detrimental. The mechanisms of these relationships therefore require further attention. It is suggested that peers provide support that facilitates normalisation and social integration. Peer support for exercise enables the adolescent to take part in 'normal' adolescent social activities, thereby allowing the young person to develop a sense of identity separate from their diabetes. This also has a potential effect on an adolescent's ability to define their identity as an independent, autonomous young person. Aspects of peer support were found to be stronger predictors of metabolic control than family support. This highlights the need to develop ways to include peers in diabetes care.

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## 6 Appendices

**Appendix 1:** NHS Fife and Forth Valley Research Ethics Committee: Confirmation of Favourable Ethical Opinion

**Appendix 2:** Scottish Multi-centre Research and Development Management review: Confirmation of Favourable Opinion

Appendix 2a: Research and Development Approval NHS Forth Valley

Appendix 2b: Research and Development Approval NHS Fife

Appendix 2c: Research and Development Approval NHS Tayside

**Appendix 3:** Caldicott Guardian Approval

Appendix 3a: Caldicott Guardian Approval NHS Forth Valley

Appendix 3b: Caldicott Guardian Approval NHS Fife

Appendix 3c: Caldicott Guardian Approval NHS Tayside

**Appendix 4:** Information and Consent

Appendix 4a: Letter of Invitation to Participate

Appendix 4b: Information sheet for Young People

Appendix 4c: Information sheet for Parents/Carers

Appendix 4d: Consent form

**Appendix 5:** Demographic Information Sheet

**Appendix 6:** Diabetes-Specific Social Support Questionnaire – Family Version

**Appendix 7:** Diabetes-Specific Social Support Questionnaire – Friends Version

**Appendix 8:** PedsQL – Diabetes Module

**Appendix 9:** Hospital Anxiety and Depression Scale

**Appendix 10:** Normal P-P Plots and Residual Scatter-plots of Hypothesis 3 Regression Analysis

**Appendix 11:** Normal P-P Plots and Residual Scatter-plots of Hypothesis 4 Regression Analysis