**Depression and Diabetes Related Distress in Young People with Type 1 Diabetes Mellitus**

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**Abstract**

Young people with Type 1 Diabetes are a group at special risk.  Demanding insulin regimes conflict with changes characteristic of this stage life. Consequently there can be a decrease in motivation to achieve the glycaemic control necessary to avoid the life-limiting complications associated with this chronic illness. This group is at risk of worse physical and mental health compared with the general population, yet little work has focused on improving outcomes in this group.

In a first study, we sought to clarify the prevalence of depressive symptoms, anxiety and diabetes-related distress in a sample of young people (16-21 years). Depression and anxiety were found to be comparable to the general population, with elevated depression and diabetes-related distress associated with worse glycaemic control. Diabetes-related distress was found to mediate the relationship between depressive symptoms and glycaemic control.

In light of these findings, we conducted a meta-analysis to determine interventions which improve both medical and psychological outcomes in young people with Type 1 Diabetes (study 2). Thirty-four trials were identified. Those interventions incorporating goal setting or focused on the individual were the most effective. These findings were used in order to design an action planning intervention for our target group.

The intervention was piloted in Sheffield to determine its feasibility (study 3) and achieved a moderate response rate (66%). The responses were explored qualitatively using content and thematic analysis. A range of goals related to self-management and social life were identified. Barriers to achieving goals and potential sources of support are highlighted.

Overall the results support previous work that young people with diabetes are at risk of mental health problems. We conclude that those who report greater diabetes-related distress have worse glycaemic control. Interventions need to be adapted to the specific concerns of young people and address some of the practical difficulties they face related to self-management. An individually based intervention, delivered by a research student appears to have potential to improve HbA1c. Improved success may occur when doctors provide greater back up support and adopt a similar approach to counselling in clinic.

For my dad,

Andrew Allan Brierley

**Acknowledgements**

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**Abbreviations**

|  |  |
| --- | --- |
| **Abbreviation** | **Meaning** |
| CAMHSCIDICESDCLAHRCCSIIDCCTDDSDMDSMHADSHBMHbA1cHLAIAPTMDINICENGHPAIDPCARHHSIGNTPBType 1 DMType 2 DM | Child and Adolescent Mental Health ServiceComposite International Diagnostic InterviewCentre for Epidemiological Studies Depression scaleCollaboration for Leadership in Applied Research and CareContinuous Subcutaneous Insulin InfusionDiabetes Control and Complications TrialDiabetes Related Distress ScaleDiabetes MellitusDiagnostic and Statistical Manual of mental disordersThe Hospital Anxiety and Depression ScaleThe Health Belief ModelGlycated HaemoglobinHuman Leucocyte AntigenIncreasing Access to Psychological TherapiesMultiple Daily InjectionsNational Institute of Clinical ExcellenceNorthern General HospitalProblem Areas In Diabetes scale Principle Components AnalysisRoyal Hallamshire HospitalScottish Intercollegiate Guidelines NetworkThe Theory of Planned BehaviourType 1 Diabetes MellitusType 2 Diabetes Mellitus |

**Preface**

**CLAHRC-SY Diabetes Theme**

Adolescence is a time when people with Type 1 Diabetes Mellitus (Type 1 DM) struggle to maintain optimal blood sugar levels. Prolonged periods of poor blood glucose control can increase the chance of complications in both the short and long term. This leads to increased mortality and creates a huge financial burden on the National Health Service (NHS) with estimates indicating 2-3% of people with diabetes consume around 10% of the total annual budget of the NHS (British Diabetes Association, 1997). Research into improving self-management skills and motivation to self-manage Type 1 DM in young people is important. Funded by the National Institute for Health Research (NIHR) our CLAHRC-SY project group aims to develop a new model of care for young people with Type 1 DM, engaging young people with their treatment plan, tailoring care to the individual and improving physiological and psychological outcomes. This work is being conducted in line with the Medical Research Council (MRC) recommendations for developing and evaluating complex health interventions (Craig et al., 2008).

**Developing a complex health intervention**

A complex intervention can be defined as any intervention built from a number of different components acting both independently and inter-dependently. Each component is essential to the proper functioning of the whole intervention (Craig et al., 2008). The many different components often create difficulties in intervention description leading to problems in replication. The MRC framework provides a sequence of objectives to meet in order to overcome this. The framework has four stages: *development, feasibility/piloting, evaluation,* and *implementation*, each including three stages(see Figure P.1). The authors advise that the sequential framework should not be used as an inflexible list but as guidance, each stage should be used to the extent to which it is relevant. For example, within the development phase the preliminary stage ‘identifying the evidence’ may be unnecessary if the preliminary evidence already exists. This thesis describes part of the work of the development and feasibility/piloting phases.

My role within the CLAHRC-SY project was to gather information which would help inform the design of a complex intervention targeted to this specific age group as well as administer questionnaires within a clinic setting, analyse data and assist in the piloting of all interventions developed. The roles I undertook reflected my particular interests. Firstly, I interviewed staff from the Sheffield transition clinics for young people with Type 1 DM focusing on their view towards their patients and analysed the resultant data. This work was carried out during my Masters year and as a result is not reported here. However, this work was published in Diabetic Medicine (Brierley, Eiser, Johnson, Young & Heller, 2012) and is included in the appendices section of this thesis (appendix 1.1). Further roles developed as a result of this work and included: 1) the analysis of psychometric data relating to depression, anxiety and diabetes related distress experienced by the young people in these clinics. 2) Carrying out a systematic review and meta-analysis of interventions which have previously been trialled in young people with Type 1 DM. 3) Developing and piloting an Action Planning intervention for this group in order to determine the feasibility of this within a clinic setting.

It should be noted that outside of my interactions with the young people within these transition clinics during this study I do not have any personal experience of Type 1 DM. However, I developed a keen interest in improving the outcomes in this group during my Masters year.

**Figure P.1 Guidelines for developing complex interventions from the MRC framework (Craig et al., 2008).**



1. **Identify the evidence base**

A detailed review of the current evidence forms chapters one to three of this thesis. In the light of the research aim it was necessary to review the complex treatment regimen and problems associated with Type 1 DM and its management in general (Chapter 1). Following the theoretical framework of Arnett (2000), Chapter 2 reviews the special difficulties that may arise during adolescence and how self-care might compromise normal development. Next, given the established links between Type 1 DM and depression among adults we wanted to review the various mental health issues faced by young people with Type 1 DM, this formed chapter 3. The aim of these chapters was to develop a picture of the issues faced by this group and how they affect the young people psychologically.

In order to examine whether the psychological issues arising from this review were of concern to young people attending our clinics and if these issues have an effect on medical outcomes study one of this thesis was conducted (Chapter 4). In this study the prevalence of depression, anxiety and diabetes-related distress is described, and analyses conducted to determine those most associated with poor glycaemic control.

On determining the prevalence rates of psychological symptoms and their relationship to glycaemic control it was necessary to conduct a detailed systematic literature search and meta-analysis of previous interventions. This formed study two (Chapter 5) of this thesis. The aim was to identify interventions previously trialled with young people with Type 1 DM which were the most effective at improving psychological and medical outcomes. This study also explores and identifies the behaviour change techniques associated with the greatest improvements in outcomes by using a behaviour change technique framework (Abraham & Michie, 2008; Michie, Ashford, et al., 2011)

1. **Identify/ develop theory**

The MRC suggests taking time to identify or develop theory before developing an intervention. This is due to evidence to suggest theoretically guided interventions are more effective than non-theoretically guided interventions (Michie et al., 2005). In Chapter 6 the theories associated with the most effective intervention technique identified in the meta-analysis (goal setting) are explored.

1. **Model process and outcomes**

The information from Chapter 5 and the literature review at the beginning of Chapter 6 was used to inform the design of an action planning intervention including goal setting and implementation intentions (Chapter 6). This intervention was piloted on a sample of young people in our clinics, and forms study three of this thesis. The aim was to ascertain how many young people would be willing to be involved in action planning, the most commonly adopted goals, barriers to goal attainment, sources of support identified and the rate of the goal attainment.

Chapter 7 discusses the findings of this thesis. This includes changes to be made to the intervention piloted in chapter six, potential problems and how these may be overcome and the limitations of the intervention. Finally, the direction of the next phase of the development of the complex intervention is discussed.

Figure P3 illustrates the activities of the CLAHRC-SY project group and highlights where the work of this thesis lies within the wider project.

Figure P.3 Flow Chart Illustrating the activities of CLAHRC-SY

**Qualitative interviews:**

Young adults

Parents

Staff

**Systematic Reviews:**

Behavioural interventions

Depression

Eating Problems

**Quantitative study:**

Medical & Psychological data.

**Analysis**

**Enhanced Standard Care**

Phase 1- Data Collection

Phase 2- Analysis

**Care-Planning**

**Action Planning**

Denotes where this thesis fits within the CLAHRC-SY overall project

It should be noted that given the complex nature of the CLAHRC-SY project and the pragmatic factors associated with conducting research within a clinical setting, the aims and focus of the overall project developed over time. As a result, my thesis also developed with this. Most notable were changes occurring as a result of the overlaps between this study and other developments taking place within the NHS. New equipment was introduced within the clinics for young people, which improved the overall running of the clinics and potentially the outcomes of the patients. As a result of this positive change it was difficult to identify whether improvements in outcome were due to the Action Planning intervention or the introduction of new equipment. In addition, it would have been unethical to deny those who would like to take part in one intervention access to another. Given time constraints, we were unable to measure outcomes from individual interventions.

**Aims of thesis**

The overall aims of this thesis are to:

1. Examine the psychological difficulties experienced by young people with Type 1 DM and their relationship to blood glucose control.
2. Explore the range of psychological interventions previously trailed.
3. Develop and pilot an intervention to improve outcomes in young people with Type 1 DM.

**Chapter 1**

 **Medical Background of Type 1 DM**

**1.1 Summary**

Type 1 Diabetes Mellitus (Type 1 DM) affects approximately 25,000 people below the age of 25 in the UK. Evidence shows this is increasing. The cause of Type 1 DM is unclear but it is likely to be due to a combination of environmental and genetic factors initiating immunological damage to the insulin producing beta cells of the pancreas. As a result, people with Type 1 DM must learn to balance their own blood glucose levels by injecting insulin subcutaneously and monitoring diet and exercise. Self-management is life-long and complex involving significant lifestyle changes in order to maintain the best possible blood glucose control. Failure to adhere to the strict diabetes treatment regimen can lead to a range of acute and long term complications such as hypoglycaemia, hyperglycaemia, retinopathy, neuropathy, nephropathy and cardiovascular disease. This chapter describes the medical background of Type 1 DM as well as the strict treatment regimen faced by people with this complex chronic illness and their families.

**1.2 Overview**

This thesis focuses purely on the impact of Type 1 DM in young people and interventions to improve psychological outcomes. However, diabetes in its various forms affects all age groups. This chapter explains what diabetes is and how it is treated more generally, before Chapter 2 explains the special difficulties faced by young people with Type 1 DM.

**1.3 Type 1 and Type 2 Diabetes Mellitus**

There are several chronic conditions that fall under the label of ‘Diabetes Mellitus’ (DM) the most common being Type 1 and Type 2 Diabetes Mellitus (Type 2 DM). DM describes a metabolic disorder characterised by persistent high blood sugar levels (hyperglycaemia) with disturbances in carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action or both (World Health Organization, 1999). Type 2 DM, previously known as ‘non-insulin dependent diabetes mellitus’ or ‘adult-onset diabetes mellitus’, occurs when the body is resistant to insulin. It is mainly prevalent in adults or over-weight people although prevalence rates are increasing in children and young people.

 Type 1 DM is also known as ‘insulin-dependent diabetes mellitus’ and has previously been referred to as ‘juvenile onset diabetes mellitus’. Given the increasing prevalence of Type 2 DM in children and young people this label is less frequently used. Type 1 DM results from the autoimmune destruction of the beta cells found in the islets of Langerhans in the pancreas. These beta cells are responsible for producing the hormone insulin. Insulin is essential for the metabolism and movement of glucose from the bloodstream into the cells of the body, where it is used as energy. A normally functioning pancreas constantly secretes low levels of insulin into the bloodstream, this insulin secretion is increased when a carbohydrate is ingested or when glucose is secreted from the liver. In the case of Type 1 DM, the beta cells are destroyed and the body is no longer able to produce insulin. This means the ability to transport glucose from the blood into the cells to be converted to energy is lost. As a result glucose remains in the blood and is excreted in the urine in large quantities (Norman, 2011b).

**1.4 Prevalence**

The prevalence of DM has been estimated at 360 million globally (International Diabetes Federation, 2011), and 2.9 million in the UK (Diabetes UK, 2012). However, over three-quarters have Type 2 DM. Approximately 20 million people worldwide and Type 1 DM affects 237,000 within the UK. It is estimated that a further 850,000 people within the UK remain undiagnosed (Type 1 and Type 2 DM; Diabetes UK, 2012). This is especially concerning when considering young people. Among those under 25 years old, approximately 25,000 have Type 1 DM; this equates to 15% of all young people with Type 1 and Type 2 DM (Diabetes UK, 2012). Although Type 1 DM can occur at any age, the peak age for diagnosis is between 10-14 years (Diabetes UK, 2012) with many patients diagnosed before the age of 30. Males have been reported to be at higher risk for Type 1 DM within all age groups (Ostman et al., 2008).

The incidence of Type 1 DM is increasing with an estimated annual rise in the past 30-40 years of 2.8% globally and 3.2% in Europe (The Diamond Project Group, 2006). Between 1990-1994 statistically significant increases were found all over the world except in Central America and the West Indies (The Diamond Project Group, 2006). Incidence of Type 1 DM has been shown to range from as low as 0.1 per 100,000/year in China and Venezuela to 40.9 per 100,000/year in Finland (The Diamond Project Group, 2006). In the UK for young adults (15-34 years) the incidence of Type 1 DM was estimated to be 15 per 100,000/year between 2006 and 2008, this was increasing by an average of 2.8% between 1991 and 2008 (Imkampe & Gulliford, 2011). As a result in general within the UK each NHS diabetes clinic cares for between 100-150 patients with Type 1 DM (Diabetes UK, 2009); this can vary from region to region.

Certain ethnicities seem to have a higher rate of Type 1 DM. In particular in the USA Caucasians are at higher risk than African-Americans and Hispanic Americans (Mokdad et al., 2000). Additionally, people of Asian origin seem to have a lower susceptibility to Type 1 DM (Harron, Feltbower, et al., 2011; Harron, McKinney, et al., 2011). The impact of socio-economic status on the incidence of Type 1 DM has previously been examined. However, social deprivation was not found to be a factor in the development of this complex chronic illness (Evans, Newton, Ruta, MacDonald, & Morris, 2000).

**1.5 Aetiology**

The precise reason for the increasing prevalence and for the existence of Type 1 DM remains unclear, but the possible explanations can be broadly categorised as genetic or environmental.

**1.5.1 Genetics**

The higher concordance rate between monozygotic in comparison to dizygotic twins indicates important genetic factors in the cause of Type 1 DM (Blasetti et al., 2012; Redondo, Jeffrey, Fain, Eisenbarth, & Orban, 2008). Dizygotic twin studies and familial studies have also shown there to be an increased risk if a close family member has diabetes (Van Belle, Coppieters, & Von Herrath, 2011), with the odds of inheriting the disease being 10% in first degree relatives and 33% in twins. Consequently, research has focused on finding a gene for Type 1 DM.

At least 18 interacting genetic locations for susceptibility to Type 1 DM, labelled IDDM1-18, have been related to the condition. The most important location is the IDDM1, which contains human leucocyte antigen (HLA) genes. HLA genes are responsible for assisting the immune system in distinguishing between the body’s own cells and exogenous cells by encoding proteins called the major histocompatibility complex, located on chromosome 6. In Type 1 DM the HLA genes attack chains of proteins from the body’s own healthy cells as a result of faulty alleles of the HLA gene, the inheritance of which can account for over 50% of the genetic risk for developing Type 1 DM (Todd, Bell, & McDevitt, 1987). Among Caucasians, 95% of those with Type 1 DM have been found to have at least one faulty allele. Those with more than one are particularly susceptible. HLA genes have also been shown to prevent Type 1 DM.

In many cases children need to inherit risk factors from both parents. It is therefore, unlikely that genetic factors alone can account for the rise in incidence of Type 1 DM. Furthermore, many who have the susceptibility genes do not develop the disease at all.

**1.5.2 Environment**

As many people who are at risk do not develop diabetes, and the concordance rate of Type 1 DM in monozygotic twins is far below the concordance rate for illness onset in other chronic conditions, environmental factors must play a role in the onset of Type 1 DM.

***Psychological***

Stress was found to be associated with onset of Type 1 DM in 9 out of the 10 studies included in a review by Sepa and Ludvigsson (2006). In a large epidemiological study, stress was related to diabetes-related autoimmunity at 1 and 2-3 years of age (Sepa & Ludvigsson, 2006). Sepa and Ludvigsson (2006) concluded that stress could both accelerate the onset of Type 1 DM and contribute to its induction and progression. Major life events (Dahlquist, 2006) particularly during the first two years of life (Sepa, Frodi, Wahlberg, Ludvigsson, & Vaarala, 2005), conflict (Harold & Conger, 1997a; Harold, Fincham, Osborne, & Conger, 1997b) and trauma (Zung et al., 2012) have all been found to increase stress and risk factors for Type 1 DM. Stress is directly linked to the nervous system and hormone release both of which have the ability to alter insulin sensitivity. Further, it has been hypothesised (‘the overload hypothesis’; Dahlquist, 2006) that beta cells could be overloaded by psychological or physical stress increasing the speed of onset of Type 1 DM.

***Viruses***

Research on viruses as a potential cause for Type 1 DM dates back as far as 1926 when a seasonal variation in the onset of diabetes was hypothesised to be a result of an increase in viruses in cooler temperatures (Adams, 1926). Such viruses may directly destroy the beta cells of the pancreas (Jenson, Rosenberg, & Notkins, 1980), or could cause inflammation of the pancreas, indirectly destroying beta cells (Horwitz et al., 1998). The search for evidence for this relationship has in recent years led to the focus on enteroviruses and more specifically Cocksackie viruses, which infect tissues in contact with the pancreas. Gamble and Taylor (1973) found 70% of Type 1 DM patients had Cocksackie antibodies compared to 58% of non-Type 1 DM controls. A subsequent study (Lee et al., 2013) has not found this to be the case adding to the argument that viral infections alone do not cause Type 1 DM but could be a trigger in the presence of a susceptibility gene.

***Diet***

It is possible that dietary aspects could lead to the onset of Type 1 DM or affect its progression. The mechanisms of this are not yet known. However, a number have been put forward, and the most popular is the ‘Cow’s milk hypothesis’ (Gerstein, 1994). This has arisen from animal studies, which show the elimination of milk proteins from birth to significantly reduce the risk of Type 1 DM. A review focusing on humans found evidence for a weak but positive effect for exposure to cow’s milk in the early diet (Gerstein, 1994). Subsequent evidence has largely been mixed. Relationships with other dietary factors have been observed. These include the early introduction of cereals, potatoes, fruits and increased calories (Stene & Joner, 2003; Ziegler, Schmid, Huber, Hummel, & Bonifacio, 2003). However, a difficulty in recording what each individual has eaten makes this difficult to test.

Although possible causes of Type 1 DM can be listed, the current view is that an interaction between genetics and the environment trigger the onset. Additionally there is currently no ‘cure’ and as a result focus for a person with Type 1 DM is purely on treatment.

**1.6 Treatment**

Although Type 1 DM cannot be cured it can be effectively treated with careful monitoring of diet, exercise, blood glucose levels and insulin therapy (National Institute for Health and Clinical Excellence, 2004). In a normal functioning pancreas the amount of insulin secreted is proportional to the amount of glucose secreted by the gut and liver as a result of the food eaten. The peripheral tissues of the body then absorb the glucose in order to produce energy. If the beta cells are damaged or destroyed, as in Type 1 DM, a person must learn to self-manage their diabetes. This involves administering regular subcutaneous insulin injections and monitoring blood glucose levels. At the same time they must be constantly aware of diet and activity levels and frequently attend diabetes clinics (National Institute for Health and Clinical Excellence, 2004). Current UK guidelines from the National Institute for Health and Clinical Excellence (2004) specify the organisation of care for young people with Type 1 DM these guidelines are summarised in the following sections.

In order to monitor blood glucose levels a patient must take frequent blood tests using a blood glucose monitor which provides a reading based on the amount of glucose in a small sample of blood provided by a finger prick. Within a clinic setting the ‘gold standard’ measure of how well a patient is managing their Type 1 DM is the levels of glycated haemoglobin (HbA1c) in the body. HbA1c is the amount of glucose attached to haemoglobins (red blood cells). The HbA1c reading gives an average of blood glucose level from the previous three months. Within a clinic consultation focus is largely placed on this marker. High and low levels of HbA1c are to be avoided. In the short term, patients are advised to aim for blood glucose levels between 4-8%, but as close as possible to 7.5% (The National Institute for Clinical Excellence, 2004) in order to avoid complications. Given that blood glucose levels fluctuate throughout the day and most notably after eating, it is recommended that post-prandial blood glucose be no higher than 10% within two hours of eating.

Blood glucose levels are also influenced by a number of other individual factors meaning treatment cannot follow a ‘one size fits all’ format. Treatment will vary for any given individual depending on their lifestyle, current situation, motivation, and ability to cope. For those aiming to improve their blood glucose control, testing blood glucose levels four times a day, with results recorded in a diary, is recommended.

**1.6.1 Insulin**

As insulin has to enter the bloodstream in order to be effective, it must be injected subcutaneously, most commonly in the arm, thigh, or abdomen. The different areas allow the insulin to enter the bloodstream at different rates. Insulin is most commonly administered via insulin pen, or auto-injector pump, this should be carried out before a meal so that glucose has not yet had time to enter the bloodstream. However, if hypoglycaemia is a risk some may be advised to administer insulin during or after a meal. The type of insulin regimen required varies from individual to individual and both regimen and insulin type is dependent on a number of factors: motivation to monitor blood sugar levels regularly; knowledge of the treatment regimen; activity levels; stability of blood sugar levels and diet.

A pancreas with normally functioning beta cells produces insulin, which is released at different rates according to the blood glucose stimulus. When food is ingested the delivery of increased substrate into the portal vein demands a rapid increase in insulin release from the beta cells, as a result, insulin is released. Mimicking this precise process is difficult and as a result there are five different types of insulin available, which have been produced to provide a similar effect. These types of insulin are divided into two categories. The first type is basal insulin (background insulin) and mimics the insulin, which is constantly secreted by a normally functioning pancreas. The second is bolus insulin, which is injected, in order to adjust for the rapid increase in glucose in the bloodstream following meals. All insulins vary in their duration of action, time of onset, peak of action and origin (see Table 1.1).

As discussed above, the insulin regimen prescribed depends on a number of factors. In recent years intensive insulin therapy has steadily taken over conventional insulin therapy as a means to treat Type 1 DM. This is due to the landmark Diabetes Care and Complications Trial (DCCT; The Diabetes Control and Complications Trial Research Group, 1993, 1994). This trial outlined the development and progression of the complications arising from Type 1 DM. The findings were that achieving sustained tight control of blood glucose levels through the use of intensive insulin therapy slows the onset and progression of retinopathy, neuropathy and nephropathy, even with a history of poor blood glucose control. Additionally the follow up study called the Epidemiology of Diabetes Interventions and Complications trial found a 42% decrease in risk of cardiovascular disease and a 57% decrease in risk of non-fatal heart attack, stroke or death from cardiovascular causes (The Diabetes Control and Complications Trial Research Group, 2005). In the following sections the regimens are split into conventional insulin therapy and the more flexible intensive insulin therapy (The Diabetes Control and Complications Trial Research Group, 1993, 1994).

**Table 1.1 Insulin used in management of Type 1 DM**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Insulin | Duration | Onset | Peak | Notes |
| Rapid-acting | 3-5 hrs. | 5 mins | 30 mins- 1.5hrs | Administered at the same time as meal, usually used with long acting.  |
| Short-acting | 6-8 hrs. | 30 mins | 2-4 hrs. | Can be taken in advance of a meal. |
| Intermediate-acting | 18-24 hrs. | 1-3 hrs. | 6-12 hrs. | Often used with rapid or short acting. |
| Long-acting  | 24 hrs. | 1 hr. | None | Basal insulin, taken in the morning |
| Pre-mixed | Differs | Differs | Differs  | Mixes short and intermediate taken twice a day before meals. |

***Conventional Insulin Therapy***

*2x daily injections*

This is the least flexible of the treatment regimens and works on the assumption that a person eats the same amount of carbohydrate at three specific meal times in the day. A mixture of short acting and intermediate acting insulin is injected twice a day; before breakfast and before the evening meal either by using pre-mixed insulin or mixing manually. The quantity and type of insulin is prescribed by the health care professional. If the insulin is to be manually mixed a syringe will be used with the shorter acting insulin drawn up before the intermediate acting insulin. Many people find this regimen restrictive as diet must be adjusted to suit the insulin administered and people must eat at set times even if they are not hungry. It is useful for children as insulin can be injected before and after school, and is often the regimen newly diagnosed patients are prescribed.

*3x daily injections*

This regimen is similar to the 2x daily regimen. It allows more flexibility at the evening meal and is therefore often used in preparation for the more flexible insulin regimen. Short and intermediate acting insulin is taken at breakfast time, fast acting at the evening meal, and a long acting at bedtime. The quantity of fast-acting insulin is not prescribed and must be calculated by the individual based on the amount of carbohydrate to be eaten at the evening meal, the amount already eaten throughout the day and the current blood glucose level (insulin dose adjustment). A technique called carbohydrate counting is advisable here, but many choose to guess their carbohydrate intake leaving their insulin regimen open to error. The long acting insulin quantity is prescribed by the health care professional.

***Intensive insulin therapy***

*Multiple daily injections (MDI)*

This regimen more closely mimics the basal-bolus process of a fully functioning pancreas. A basal insulin injection of either intermediate or long acting insulin is given during periods of fasting, usually before bedtime. This can be split and administered 12 hours apart, and a bolus injection of short or rapid acting insulin is given before meal times. This regimen relies on the ability of the patient to be able to use insulin dose adjustment, meaning frequent blood glucose tests and monitoring of carbohydrate intake. This gives the patient more flexibility in their meal choices, however it is difficult to master.

*Continuous subcutaneous insulin infusion (CSII)/ pump therapy*

This regimen is similar to that of the MDI. A pump device is fitted to the patient’s body, which continuously administers a steady stream of insulin to mimic the basal rate of the pancreas. The wearer then administers further short or rapid acting bolus doses of insulin prior to meal times using insulin dose adjustment and inputting the information into the insulin pump. This method does not require injections, but the device can cause distress in some as it is attached to the body at all times. CSII is recommended for those who fail to achieve adequate control on the MDI regimen and who are capable of and committed to using insulin therapy.

Despite the obvious benefit of subcutaneous insulin therapy, there are still limitations to this form of insulin delivery further complicating the management of Type 1 DM. The absorption of all types of insulin, including rapid acting insulin, is delayed, and there are difficulties in predicting basal insulin concentrations. This can lead to high insulin levels, high post-prandial glucose levels (Heller, 2009) and a high risk of hypoglycaemia, particularly at night.

**1.6.2 Diet**

Historically the dietary requirements attached to the insulin regimen were strict, requiring a person to eat at the same time every day, and to tailor foods to the insulin they were taking, much of the time avoiding sugar rich foods. This made food choices very limited. However, since the development of Insulin Training and Teaching Programme in Germany (Muhlhauser et al., 1983), the DCCT (1993; 1994), and the Dose Adjustment for Normal Eating course in the UK (McIntyre, 2006), requirements connected to Type 1 DM have become more flexible. The advice is always to eat a balanced diet including all the main food groups with roughly half of the nutrient intake deriving from carbohydrates. The main consideration is how sharply different foods impact blood glucose levels and how to balance this with the correct quantity of insulin.

**1.6.3 Exercise**

As with the general population, exercise is generally recommended. However, exercise in Type 1 DM has both benefits and shortfalls. The main risks of exercise include the possibility of hypoglycaemia and hyperglycaemia (Peirce, 1999). Blood glucose levels drop during exercise especially when insulin has been administered and hypoglycaemia can occur up to 24 hours after exercise (Peirce, 1999). Eating a source of carbohydrate 15-30 minutes prior to physical activity and carrying a source of carbohydrate whilst exercising can help prevent hypoglycaemia. Even though maintaining regular activity has not been consistently proven to improve glycaemic control in Type 1 DM, it has the ability to reduce the risk of cardiovascular disease, decrease weight and stress, increase sensitivity to insulin and improve muscle strength and flexibility. For these reasons, people with Type 1 DM are strongly advised to undertake regular physical activity.

In short, self-management is a 24-hour responsibility and a person with Type 1 DM must make significant lifestyle changes to maintain the delicate balance between insulin and glucose, in order to avoid the significant complications outlined below.

**1.7 Complications**

Complications arising from inadequate treatment of Type 1 DM are numerous and even a mildly raised blood glucose level can have damaging consequences in the long term (The Diabetes Control and Complications Trial Research Group, 1993, 1994). Here complications are divided into acute, micro and macrovascular complications (Fowler, 2008). Although it could be argued that micro and macro-vascular complications are not a current concern for young people with Type 1 DM, young people are made aware of the complications which can arise from prolonged suboptimal glycaemic control. This adds to the pressure faced by the patient.

**1.7.1 Acute complications**

***Hyperglycaemia and Diabetic Ketoacidosis***

Hyperglycaemia refers to high blood sugar levels which usually develop over a couple of days and can arise from eating too much food, stress, lack of exercise or neglecting to administer insulin. In the absence of insulin the body uses fat to produce energy, which, when broken down, produces poisonous acids called ketones. Diabetic ketoacidosis (DKA) occurs as ketones are built up in the blood, although they can also be detected in the urine. DKA can lead to coma and even death if left untreated and in many cases is the first sign a patient has Type 1 DM (Smith-Marsh, 2010). A quarter of children diagnosed with Type 1 DM present with DKA prior to diagnosis (Norman, 2011a). Symptoms of DKA include fruity smelling breath, rapid deep breathing, dry skin and mouth, nausea and vomiting and stomach pain. If caught early enough and blood glucose levels are corrected and fluid balance restored the patient should make a full recovery. Figures have shown that over 3,000 children in the UK were admitted to hospital with DKA in 2007 (Diabetes UK, 2012).

***Hypoglycaemia***

Hypoglycaemia usually occurs as a result of taking too much insulin, not eating enough, taking part in intense exercise, or drinking alcohol without eating adequate food. The extra insulin moves too much glucose out of the bloodstream; blood sugar levels become very low impairing brain function. This can lead to confusion and coma. The average person with Type 1 DM experiences mild hypoglycaemia at least twice a week. If not treated early, mild symptoms of hypoglycaemia can become moderate or severe even in those with previously well controlled blood glucose levels. Initial symptoms of hypoglycaemia can include confusion, dizziness, shakiness, and fatigue (Smith-Marsh, 2010) but their presence differs from individual to individual. Patients often become aware of their own symptoms and treat them using ‘fast acting carbohydrates’ such as a small amount of a glucose rich drink, or glucose tablets. Sugary chocolate or sweets should be avoided as the fat content slows down the uptake of glucose into the blood. If a severe hypoglycaemic episode is experienced assistance will be needed to administer an injection of glucagon. Emergency services should be called in this situation in order for the condition to be monitored.

**1.7.2 Microvascular complications**

***Retinopathy***

Retinopathy is the name given to various disorders of the retina and is the most common cause of blindness among people of working age in the UK (Diabetes UK, 2012). Retinopathy increases at a rate of approximately 1,280 people per year (Scanlon, 2008), with approximately 4,200 people blind due to diabetes-related retinopathy. Nearly all of those diagnosed with Type 1 DM will develop some degree of retinopathy within 20 years of illness onset (Scanlon, 2008). Retinopathy is caused by persistently high blood glucose levels, which weaken and damage the blood vessels of the retina. Retinopathy is generally classified as either background or proliferative. The former refers to small haemorrhages in the middle layer of the retina and appears as ‘dots’ during eye screening, this can in some cases lead to visual deterioration (Scanlon, 2008). However, visual deterioration is more likely to arise from ‘proliferative retinopathy’. Here new blood vessels form on the surface of the retina, without intervention loss of vision may occur. Eye screening is crucial in people with diabetes given that retinopathy can remain undetected by the patient until damage has already occurred (Diabetes UK, 2012).

***Nephropathy***

Nephropathy is the general name given to the deterioration of function of the kidneys in diabetes. Approximately 20-30% of those with DM will develop nephropathy during the course of their lives (Diabetes UK, 2012) and it is the leading cause of renal failure in the USA (Fowler, 2008), accounting for 21% of deaths (Morrish, Wang, Stevens, Fuller, Keen & Grp, 2001). Nephropathy occurs when the small blood vessels of the kidney are damaged by high blood sugar levels and is divided into five stages of deterioration. It takes approximately 20 years to reach end stage renal disease (Melendez-Ramirez, Richards, & Cefalu, 2010). Patients reaching this stage require kidney dialysis or a kidney transplant. Symptoms are only apparent once nephropathy reaches the fourth stage. However, if it is caught early, nephropathy may be contained by maintaining optimal glycaemic control (Diabetes UK, 2012).

***Neuropathy***

Neuropathy is a nerve disorder which may affect up to 50% of people with diabetes and is more common in those who have had the disease for longer (Boulton, Gries, & Jervell, 1998). Neuropathy causes damage to the nerves. There is no conclusive evidence for the cause of neuropathy although persistently high blood glucose levels do lead to an increased risk of this complication. There are two types of neuropathy: peripheral, affecting the toes, feet, legs and arms; and autonomic, affecting the bowel, bladder, digestion, perspiration and sexual response (Melendez-Ramirez et al., 2010). Peripheral neuropathy is easier to diagnose than autonomic neuropathy given its more obvious symptoms, which may lead to ulcers and amputations. Autonomic neuropathy is more dangerous as the body becomes unaware of hypoglycaemia. There is no specific treatment but drugs are available to treat the symptoms.

**1.7.3 Macrovascular complications**

The risk of macrovascular complications later on in the progression of Type 1 DM is high and arises in part from persistently suboptimal glycaemic control. Such complications include cardiovascular disease and stroke. The main mechanism in macrovascular complications is atherosclerosis in which the walls of the arteries narrow and harden as a result of injury to the arterial walls; this process is accelerated in people with prolonged suboptimal glycaemic control (Melendez-Ramirez et al., 2010). Middle aged men with Type 1 DM are over five times more likely to develop heart disease or stroke than the general population, and women more than 8 times as likely (Béjot & Giroud, 2010). Coronary heart disease is recognised to be the cause of death in 44% of people with Type 1 DM (Morrish et al., 2001), however, many of these deaths are preventable. Again symptoms can go undetected for years.

**1.8 Conclusion**

Type 1 DM is a chronic illness with serious complications if not managed effectively. Effective self-management is difficult to master requiring significant lifestyle modifications to allow for 24 hour attention to blood glucose monitoring, diet and activity levels. In order to mimic the function of a normal pancreas a person with Type 1 DM must take on a large amount of information, undertake complex tasks of estimating food intake and calculating insulin dose and cannot neglect their treatment for even a day. The implications of this are that care is especially challenging for young people. Given the extensive complications that we know to be associated with Type 1 DM there is pressure to achieve and maintain optimal glycaemic control. Young people often avoid treatment, believing that if they do not feel unwell, they will not experience any complications. In the next chapter the special difficulties experienced by young people with Type 1 DM during adolescence are reviewed.

**Chapter 2**

 **Type 1 DM During Adolescence**

**2.1 Summary**

The purpose of this chapter is to provide a background of the special difficulties faced by young people and their families in managing Type 1 DM. The transition from childhood into adulthood is a difficult period in general. The need to carry out complex self-care behaviours further complicates this important developmental period. Young people generally neglect their self-care behaviours in order to fit in with their peers and to avoid feeling different. This often leads to conflict within families. Given the complex treatment regimen, Type 1 DM is given priority over other activities and the diagnosis becomes central to the family. The challenges related to the nature of the condition are discussed here followed by the personal challenges of adolescent development. Challenges related to the management of care are then introduced before the difficulties in forming and maintaining healthy relationships. Finally situational issues arising from transitions and behaviours adopted to cope with these stressors are discussed.

**2.2 Introduction**

The diagnosis of Type 1 DM can be traumatic for the child and the family (Anderson, 2009) as they struggle to cope with diagnosis, the complex treatment regimen, self-care behaviours and the possibility of significant long-term complications. A “new normal” must be established, daily routines changed, increased levels of organisation achieved and self-care behaviours mastered rapidly. During adolescence treatment is complicated by the developmental and life changes unique to this period, as the young person attempts to maintain optimal glycaemic control whilst appearing “normal”. Self-care conflicts with goals of adolescence, particularly independence as in reality the young person must still be reliant on the parent.

Mortality among those with Type 1 DM is increased four (men) and nine times (women) in the 15-34 year old age group (The NHS Information Centre, 2011) with acute complications being the major cause. From the age of 30, cardiovascular disease is the predominant cause of death for people with Type 1 DM. The worsening glycaemic control during adolescence (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Insabella, Grey, Knafl, & Tamborlane, 2007) has been attributed to the increased risk of premature morbidity and mortality in this age group. Adherence to the diabetes regimen remains poor despite evidence that strict glycaemic control significantly decreases long term-complications and mortality (The Diabetes Control and Complications Trial Research Group, 1993).

This chapter aims to describe normal adolescent development, why adherence to the diabetes regimen is low during this stage, the challenges faced by young people with Type 1 DM, barriers to adhering to the treatment regimen and the implications this has on the young person and their family.

**2.3 Adolescent Development**

**2.3.1 Adolescence**

Early thinking characterised adolescence as a period of “storm and stress”, a time of rebellion and questioning of social norms (Hall, 1904), where mood swings, impulsive behaviour and conflict are common. During adolescence many face a number of physical, social, emotional and cognitive challenges in moving from childhood to adolescence. It is said that at this stage a young person experiences a second dramatic period of physical growth and experiences increased desire for independence from parents (Weissberg-Benchell, Wolpert, & Anderson, 2007). Major developmental goals include the formation of identity (Eriksson, 1968), increased ability to reason logically and systematically (Piaget, 1977), and geographic, emotional and economic transitions (Arnett, 2000). Social context expands to include peers, and work colleagues as well as the family. These changes can give rise to stereotypical adolescent characteristics such as rebellion, risk taking, conflict with parents and conformity to peer pressure.

Traditionally the period from the age of 10 years to 25 years has been described as “adolescence”. However, contemporary thinking suggests that this period is too broad, and young adulthood does not immediately follow on from adolescence, rather, there is a stage in between. From the ages of 10 through to 17 years adolescents are going through puberty, in many cases attending schools and living at home, this is less true from the age of 18 years old (Arnett, 2006). At this point most adolescents are sexually mature, and may no longer live with their parents but may still be financially or emotionally reliant on them.

**2.3.2 Emerging adulthood**

The differential needs of the developing young adult have been recognised by Arnett (2000), who proposed the post high school period through to the late twenties actually forms “Emerging adulthood” which is distinct from “adolescence”. The needs of the emerging adult are potentially different to any other age group as the young person develops and learns the skills needed to progress into adulthood. It is possible therefore, that specialised care in this age group would be beneficial.

In 2012 a National survey in the USA called the Clark University Poll of Emerging adulthood sought to identify the developmental characteristics of those aged between 18-29. There were 1009 respondents and the survey identified five features of this period, these five features will be discussed below.

*Identity exploration*

Traditionally, identity exploration was associated with earlier in adolescence (Erikson, 1950). However, this survey would suggest that this may be more prominent during emerging adulthood, and in fact, although this may begin earlier in adolescence, identity issues reach their peak during emerging adulthood. This has been attributed to later transitions toward making life choices and is evidenced by the Clark Poll in which 77% of the respondents agreed “somewhat” or “strongly” that “This is a time in my life for finding out who I am”. For young people with chronic illnesses delayed identity formation can be related to suboptimal coping mechanisms, this is discussed later in this chapter.

*Instability*

Feelings of instability may occur later for modern young people, this has been related to delayed identity formation and due to the journey into adulthood being “long and winding” (Arnett, 2014). The instability has been described as feeling inbetween adolescence and adulthood and relates to jobs, relationships, and finances. Arnett (2014) proposes this will be resolved once identity is fully formed.

*Self focus*

Arnett (2014) describes emerging adulthood as a self-focused age. The young person has relatively few obligations to others compared to other stages. Although obligations to family, friends, educational authorities and employers are present, these are lower than in other stages. This opportunity is unlikely to return at other life stages.

*Feeling “in between”*

Emerging adulthood has been described as a stage-in between adolescence and adulthood (Nelson & Luster, 2014). This is attributed to the fact that many emerging adults continue to rely on parents in some way.

*Possibilities/optimism*

Emerging adulthood has been described as a period of struggle for many (Arnett, 2014). However, the Clark Poll revealed many are optimistic about future prospects. This has been attributed to the increased level of education many young people obtain over and above their parents.

The theory of emerging adulthood is not without criticism. It could be argued that this is not a new developmental phase, but rather is just an induced social condition and that only those in western society go through this stage. Côte and Bynner (2008) have previously argued that if some young people do not experience this stage yet in adulthood still function at the same level as those who have experienced that stage, this cannot be deemed a developmental stage, “a developmental stage must add something to development beyond simple change” (Lerner, 2002).

Despite this criticism, the challenges described above still remain. Given the many developmental changes and challenges described above coupled with the regular blood glucose testing, carbohydrate counting, and insulin injections, these factors lead to a decline in glycaemic control in this period. Particularly as responsibility for diabetes care is shifted from parent to young person, a task that many are unprepared for.

**2.4 Challenges Faced by YP with Type 1 DM**

Although there is evidence (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986; Bloch, Clemons, & Sperling, 1987; Hannon, Janosky, & Arslanian, 2006; Tamborlane et al., 1989) that decreased sensitivity to insulin during adolescence complicates the management of Type 1 DM and accounts for some of the decline in adherence in this age group, psychosocial factors also play a role. Davidson, Penney, Muller, and Grey (2004) conducted a qualitative study in order to determine potential stressors and self-care challenges related to Type 1 DM in young people. Within this study transcripts of six participants from a coping skills training course were analysed using a content analysis. The participants mean age was 14.7 and mean HbA1c was 9.7. This study provides a detailed account of the stressors faced by these six participants. However, it is acknowledged that only one of the participants was male meaning there may have been a bias towards this gender. All participants were attending a coping skills training course which may have biased perceptions and response to stressors, and given the small sample, these results are unlikely to be representative of the general population of young people. As a result the findings are to be interpreted with caution.

Despite this the stressors identified provide a useful structure for possible challenges faced by this group. The authors identified many daily challenges, which can be categorised as: the nature of the condition, the individual (personal), care management, relationships, situation, coping behaviours and dilemmas. Here possible challenges faced by young people with Type 1 DM are reviewed following these categories.

**2.4.1 Nature of the condition**

Young people with Type 1 DM face a huge challenge. The regimen that many are prescribed is the more flexible multiple daily injection regimen with basal insulin providing a background rate and bolus insulin adjusting for the carbohydrates ingested. This more flexible regimen is prescribed as a result of the lifestyles of the young people. However, the cost of the flexibility this regimen provides is that diabetes management is complex and demanding and the young people can become demotivated, realising that care-management is “never ending” (Davidson et al., 2004).

The self-management behaviours associated with Type 1 DM are very observable. Injecting needles to administer insulin can be distressing to the patient (Howe, Ratcliffe, Tuttle, Dougherty, & Lipman, 2011) and can be difficult to carry out independently. A study by Nir, Paz, Sabo, and Potasman (2003) on attitudes to injections in travel clinics in a sample of young adults without chronic illness showed that among young adults in general, needle anxiety is widespread. Of the 400 adults surveyed, 21.7% indicated fear with 8.2% displaying “unreasonable and intense fear”. Such anxieties can create a barrier to the treatment of Type 1 DM (Howe et al., 2011), although it is possible that it is the perception of pain rather than actual discomfort which results in these fears.

Family and peers can also find insulin injections distressing (Howe et al., 2011). Early studies in both Type 1 and Type 2 DM provided evidence that individuals avoid injecting insulin in public due to the fear of being seen to be ill (Brod, Kongso, Lessard, & Christensen, 2009), dependent or an illicit drug user (Broom & Whittaker, 2004; Shiu, Kwan, & Wong, 2003). This is likely to be exacerbated in young adulthood due to growing self-consciousness. As a result, young people often avoid administering insulin in public or at school, where areas in which to carry out self-care behaviours privately are sparse.

Achievement of good control also leads to weight gain, and the young person quickly learns that withholding insulin leads to significant weight loss through hypoglycaemia as a result of caloric purging (Colton & Rodin, 2009). Further, correct insulin dosage puts the young person at risk of hypoglycaemia, the symptoms of which are perceived to be embarrassing, and so there is a tendency to purposefully keep blood glucose at levels higher than recommended.

 Added to this is evidence that changes in hormone levels, in particular alterations in the growth hormone and cortisol can create insulin insensitivity in the adolescent population (Amiel et al., 1986; Bryden et al., 2001). This leads to higher levels of HbA1c than previously experienced in the paediatric clinic, and potentially ketosis (elevated levels of ketones in the body). This usually coincides with transfer to the adult or adolescent clinic where emphasis is placed on maintaining or reducing levels of HbA1c. The young person may be self-managing their diabetes to the best of their ability, but achieving higher HbA1c than previously experienced. As a result they quickly experience the feeling that they “can’t win”. This is a classic example of the learned helplessness paradigm, the feeling that nothing they do improves their HbA1c (Miller & Seligman, 1975). The young person may then avoid self-care behaviours such as blood glucose testing in order to avoid bad news.

These feelings are exacerbated by pressure from the health care professionals and parents (Wikblad, 1991), which can lead to increased guilt and shame and further avoidance (Weissberg-Benchell et al., 2007). Young people and health-care professionals have different views about what is important at this stage (Weissberg-Benchell et al., 2007). The former experience the need to appear “normal” and enjoy the activities and sports their peers are able to take part in. As a result they may only engage in self-care behaviours when appearance is not likely to be compromised, or where there is serious risk of microvascular complications. The latter believe motivation should arise from optimal glycaemic control and the reduced risk of future complications this brings. Different developmental levels of the young people can lead to variations in these motivators (Weissberg-Benchell et al., 2007).

**2.4.2 Personal challenges**

Young people are at different stages developmentally, emotionally, cognitively and physically. During this period the young person develops the ability to engage in analytical and metaphorical reasoning (Piaget, 1977) and is able to think logically and systematically. However, the age at which this reasoning is developed varies. Some young people are more able to make mature decisions enabling them to optimally manage their diabetes, while others of the same age make decisions which may endanger their health and safety.

Those who do not make decisions which lead to optimal management may experience an increased desire for taking risks. Elkind (1967) provides an explanation for this in his theory of adolescent egocentrism. Elkind reported adolescents to be preoccupied with their appearance and their behaviour, and believe they are of central interest to others around them. A consequence of this is “personal fable”, the belief that their thoughts are unique, and have never been experienced before. This belief transforms the outlook of the developing adolescent and leads to greater risk taking behaviour. More recently this behaviour can be said to relate to self- focus. As identified by Arnett (2014), a young person has relatively few obligations to others at this point and therefore may act “selfishly” (Twenge, 2013).

Risk taking behaviour is dangerous particularly for young people with a chronic illness. The young person may not accept they have a potentially life-threatening illness or may believe the negative long-term consequences will never happen to them. As a result self-care behaviours may be neglected in favour of what is believed to be a more normal life. This is convenient for the young person as they are better able to fit in with their peers, but conflicts with advice from parents and health care professionals. This conflict comes at a time where responsibility for care management is transitioning, with the young people taking a more active role in their care (Vesco et al., 2010).

**2.4.3 Care management**

One of the greatest challenges faced by young people with Type 1 DM is that of increased responsibility. A major goal of adolescence is independence and autonomy. The desire for independence begins in early adolescence (Eriksson., 1968) and continues through to emerging adulthood (Arnett, 2000). The young person strives for independence from parents but also must maintain strong bonds with the family in order to progress normally into young adulthood (Eiser et al., 1993). The importance of maintaining family bonds cannot be overstated as alienation from the family can lead to negative consequences, from increased disruptive behaviour and risk taking to increased rates of suicide (Dahlquist & Kallen, 2005). The responsibility that increased independence and autonomy brings is often intimidating to the young person (Arnett, 2000). With responsibility arises important decisions which often require knowledge and abilities to reason that the young person has not yet gained.

These challenges are likely to be exaggerated among young people with Type 1 DM, particularly as parents are often relied on for assistance with the complex diabetes regimen. In childhood it is the responsibility of the parent to manage the child’s Type 1 DM. The child is not routinely taught the skills necessary to manage their Type 1 DM independently. This dependence continues into adolescence as the young person struggles to gain independence but is still heavily reliant on the parent (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997; LaGreca et al., 1995),

The degree to which the young people take responsibility for the care of Type 1 DM varies. It would be irresponsible to impose an exact age at which the young person should assume full responsibility given the differing developmental stages and different levels of knowledge. This is a problem as premature responsibility for self-management has been associated with poorer self-care quality and outcomes (Wysocki et al., 1996). Even those who are able to self-manage must rely on the parent for transport to clinic appointments, assistance in communication with health care professionals and further assistance in times of ill health (Eiser et al., 1993). This dependence is unavoidable.

Gillibrand and Stevenson (2006) found a high level of family support in Type 1 DM was the strongest predictor of adherence to the diabetes regimen. Evidence has also shown better outcomes where the young person perceives help from their caregiver, (Vesco et al., 2010) as some fear the responsibility of self-care (Weissberg-Benchell et al., 2007). These differences in responsibility can also be attributed to the young person’s readiness to change and incorporate the diagnosis of Type 1 DM into their identity by integrating the illness into everyday life (Kralik, Koch, Price, & Howard, 2004). This has been linked to compliance to a medical regime (Dalton & Gottlieb, 2003). However, often even when the young person is capable of self-managing autonomously, parents criticise. This is due to parental anxieties related to the negative outcomes associated with Type 1 DM. At this time relationships can become strained.

**2.4.4 Relationships**

 ***Family relationships***

Managing Type 1 DM has major implications not only for the child but the whole family. Relationships between parents, siblings and the extended family are altered (Hanna, Juarez, Lenss, & Guthrie, 2003) as the diagnosis takes priority over other family issues. The potential for stress within the family is high (Burroughs & Rindfleisch, 1997; Jacobson & Rowe, 1999) and conflict may be a regular occurrence.

Family functioning within families where at least one child has Type 1 DM has been extensively studied, and family plays an important role in the success or failure of the treatment regimen (Leonard, Jang, Savik, & Plumbo, 2005). Links between dysfunctional family units and suboptimal HbA1c (Forsander, Sundelin, & Persson, 2000; Leonard et al., 2005) have been reported with HbA1c among adolescents within a dysfunctional family reported to be greater than 9% (Leonard et al., 2005). In their study Leonard et al. (2005) also found perceived family function to be related to glycaemic control. Those who perceived a positive cohesive family relationship achieved better control in comparison to those with a less cohesive family relationship. The authors concluded the healthier and more supportive a family unit the greater the ability for optimal glycaemic control. This provided support for a previous study (Burroughs & Rindfleisch, 1997) which reported a more supportive and cohesive family to be related to better adherence and glycaemic control. Links between psychological outcomes and family functioning have also been found (Anderson, Brackett, Ho, & Laffel, 1999; Hanna et al., 2003).

As a result of the importance of being normal and being seen to be normal self-management is neglected, metabolic control worsens with age and communication becomes more emotionally charged (Burroughs & Rindfleisch, 1997). As mentioned earlier, normal adolescent development has been characterised by emotional upheavals and extensive stress (Hall, 1904) as the young person rebels against the parent and questions social norms in the search for identity. This can be damaging particularly when combined with a chronic illness.

Conflict within the family has been associated with lower self-efficacy (Sander, Odell, & Hood, 2010). Those with lowered self-efficacy may disengage from all aspects of self-management due to the belief they are incapable of achieving adequate control (Sander et al., 2010). Parent-child conflict has many forms in Type 1 DM. The young person may rebel against the reminders of the parent to carry out management tasks. The parent may worry the young person is not carrying out self-management to the best of their ability, or the young person may simply rebel against the diagnosis of Type 1 DM. Whatever the reason, lower levels of conflict and greater parent-child communication has been associated with better outcomes (Anderson et al., 2002; Mellin, Neumark-Sztainer, & Patterson, 2004).

 ***Peer relationships***

On entering adolescence, peer influence increases at the expense of parental influence. Such relationships are often viewed negatively by parents and are associated with stereotypical peer activities from drinking alcohol to taking drugs, taking increased risks and other antisocial behaviours. Young people often feel pressure to “fit in” with their peers. This can be especially problematic when combined with the observable treatment behaviours associated with Type 1 DM. Studies have made a direct link between peer relations and treatment adherence (Bearman & LaGreca, 2002; LaGreca, Bearman, & Moore, 2002).

Young people with Type 1 DM often neglect to tell their friends about their illness through fear of being perceived as different. Jacobson et al. (1986) found that in a sample of young people, 55% of those newly diagnosed did not discuss the diagnosis with their peers, and 35% believed their peers would like them better if they did not have Type 1 DM. Such anxieties may not be imagined as evidence has shown greater relational victimization in this group (Storch et al., 2004). Fewer pro-social behaviours and elevated levels of bullying directed towards young people with Type 1 DM have been found in comparison to an age matched control without Type 1 DM (Storch et al., 2004). Additionally, Cole, Roberts, & McNeal (1996) found that peers perceive those with a chronic illness to be “different”.

Negative attitudes have also been observed from teachers who may view a person with a chronic illness to have “special needs” (Cole et al., 1996; Olson, Seidler, Goodman, Gaelic & Nordgren, 2004). A possible explanation for this is the high levels of attention some medically ill children expect from others, which leads to the view that they are too demanding (Miller & Wood, 1991). For those who do not display this trait, it is possible that diagnosis is withheld, and the very observable self-management behaviours not conducted as a result of an “imagined audience” (Elkind, 1967).

Elkind’s theory of adolescent “egocentrism” (Elkind, 1967) could provide an explanation for those who conceal their diagnosis and self-care behaviours from peers. As discussed earlier, Elkind proposed that young people believe themselves to be of central interest to others around them. A consequence of this is an “imagined audience”, the belief that everyone is always looking at them, resulting in increased self-consciousness. In the case of Type 1 DM, this relates to the need to keep diagnosis and self-management behaviours private.

In situations where peers are made aware of a diagnosis they can be helpful and provide support with the treatment regimen. However, peers can also be obstructive as they may fail to understand the complex treatment regimen and the long-term consequences associated with suboptimal glycaemic control. The peers may even encourage rebellion away from the regimen. Desperate to “fit in” and avoid the stigma associated with Type 1 DM the young people may give in to peer pressure and conform. Additionally peers who also have Type 1 DM may share bad habits. For example, girls may learn that insulin omission leads to weight loss and subsequently omit insulin.

**2.4.5 Situational**

An additional problem for young people is that of increased transitions. The period following high school has been referred to as “demographically dense” (Rindfuss, 1991). Many transitions from changing schools, starting employment, moving away from the parental home to perhaps attending a university are experienced. At this time young people do not yet see themselves as adults but equally do not wish to be referred to as children. These transitions are the first step to gaining independence for many.

For those with a chronic illness, a further transition complicates development, the transition from paediatric to adult care.

Transition in health care has been referred to as:

*"the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems" (Blum et al., 1993).*

Although diabetes clinics have the potential to help improve or maintain optimal diabetes control, many young people opt out of attending clinics in adolescence. A potential reason for this is the necessary transfer from the comfort of the paediatric clinic to the more independence focused adult clinics.

Within the UK, transfer from paediatric to adult clinics occurs at the age of 16 but some may transition earlier or, in exceptional circumstances, later. Children and parents are made aware of the eventual progression from paediatric to adult clinics, but for some this change is not welcome and can be distressing. Many have attended paediatric diabetes clinics for most of their childhood and the thought of change can seem daunting for both the young person and the parent. The healthcare team have become a source of constant support and may feel part of the family. In many cases transfer is delayed for as long as possible. Evidence has shown many young people are “lost” and rates of clinic non-attendance are high with as little as 61% attending clinics post-transfer (Kipps et al., 2002). These rates of clinic non-attendance have been associated with poor adherence to the diabetes regimen (Kaufman, Halvorson, & Carpenter, 1999). Possible reasons for this drop in attendance rates are discussed below.

Many young people express anxieties about transitioning due to being unaware of the location of their new clinic, how to access the clinic and what to do on arrival. Currently little is done to ensure the young people have all the information they need to decrease such anxieties (NHS Diabetes, 2012). On arrival at the new clinic the difference between the appearance of the paediatric and the more adult clinics (Eiser et al., 1993) may also pose a problem. The young person may come into contact with older patients who are experiencing the serious medical complications associated with Type 1 DM which have previously been sheltered from them. This may create further anxieties and possible reasons for clinic avoidance.

Another consideration on arrival at the new clinic is the lack of familiar faces. Although often at least one familiar health care professional may be present at clinics post-transfer, many new and unfamiliar care staff will be in attendance. The young person may feel uncomfortable discussing sensitive issues with new staff, particularly as the parent has previously communicated with the health care professional on their behalf (Weissberg-Benchell et al., 2007).

Additionally perceived differences between the paediatric and adult clinics have been recorded (Eiser et al., 1993). While paediatric clinics are perceived to be family-centred and informal, focusing on social issues, adult clinics are perceived to be more formal with emphasis placed on complications, risks and management (Eiser et al., 1993). Evidence has also shown adult clinics often assume young people have the skills necessary to self-manage their diabetes (Peters, Laffel, & Group, 2011), require a much greater degree of independence and encourage communication without the presence of the parent. This can cause anxieties for many who still rely on the parent for some aspects of self-management, may not yet have the required knowledge to self-manage autonomously and may not be confident in communication with health care professionals. Conversely, the paediatric clinic may not recognise the growing need for independence of the young person.

For these reasons it has been argued that the paediatric and adult clinics fall outside the needs of the young person (Wolpert & Anderson, 2001) and neither model of care serves the developing young adult well (Viner, 1999). Young people have indicated a preference for care which is sensitive to their specific needs (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005). Although not currently a government requirement some hospitals do hold special clinics for young people in an attempt to bridge the gap. These clinics address some of the issues highlighted above, by providing care specific to the needs of this group. Here health care professionals from the paediatric clinic may be present, and parents are welcome. Although findings suggest transfer to a young adult clinic is preferable to an adult only clinic (Kipps et al., 2002), clinic non-attendance remains high.

Further possible reasons for non-attendance relate to more personal issues. First it is likely that as there is no immediate positive consequence of attendance in clinic. According to the Theory of Planned Behaviour (Ajzen, 1991) this would influence motivation and, in turn attendance behaviours. Second, expectations that clinic attendance may bring unwelcome news or punishment may lead to avoidance. The perception of the costs and benefits to clinic attendance the young person has are important determinants of behaviour and may account for the poor attendance at specific clinics for young people (Gillibrand & Stevenson, 2006).

**2.4.6 Coping behaviours**

As discussed above, adaptation to the diagnosis and treatment regimen associated with Type 1 DM is complex during adolescence. Many struggle to adapt or accept their diagnosis so in order to cope various strategies are implemented. Coping has been referred to as:

 *“typical habitual preferences for ways of approaching problems and might be regarded as strategies that people generally use to cope across a wide range of stressors”* (Carver, Scheier, & Weintraub, 1989).

Or, more recently:

*“conscious and volitional efforts to regulate emotion, cognition, behaviour, physiology and the environment in response to stressful events or circumstances”* (Compas et al. 2001; p.89).

Evidence has shown the use of coping strategies to contribute to adherence and responsibility for self-management (Reid, Dubow, Carey, & Dura, 1994), and to be associated with glycaemic control (Graue, Wentzel-Larsen, Bru, Hanestad, & Sovik, 2004).Various styles of coping have been associated with adaptation to Type 1 DM and its treatment regimen, and current perspectives place an emphasis on the difference between automatic and controlled responses. Automatic responses to stress are those behaviours that are habitual, automatic and conditioned. In contrast, controlled coping responses are controlled and volitional. Recent focus has been placed more firmly on control-based models of coping, and the distinction between primary and secondary control coping strategies.

 Primary control coping refers to attempts to change the objective environmental condition (e.g. altering the stressor) and encompasses problem solving, emotional regulation, denial and avoidance. Secondary control coping refers to attempts to change oneself in response to a stressor (e.g. altering beliefs) and encompasses cognitive restructuring, distraction and positive thinking. Primary coping is utilised in the presence of a controllable stressor, and secondary in the presence of an uncontrollable stressor. Controlled coping responses emerge later in development than automatic responses and have been linked to identity development later in childhood and during adolescence (Compas, Jaser, Dunn & Rodriguez, 2012). It is a failure to accomplish strong sense of identity that has been associated with maladaptive illness specific coping strategies and poor illness integration. It is suggested that this may lead to increased disease related issues (Luyckx et al., 2008)

Further schools of thought related to coping styles focus on a distinction between problem and emotion-focused coping. Here, problem-focused coping refers to managing a problem by changing the situation causing distress. In Type 1 DM this would involve adopting optimal self-care behaviours and is associated with optimal glycaemic control (Graue et al., 2004). Emotion focused-coping (Folkman, Lazarus, Gruen, & Delongis, 1986), in particular avoidance coping, refers to reducing emotional distress by avoiding the stressor. In Type 1 DM this involves rejecting the diagnosis and avoiding self-care behaviours in order to avoid bad news. Although this style of coping has been previously associated with suboptimal glycaemic control (Graue et al., 2004; Reid et al., 1994), evidence is largely mixed (Compas et al., 2012). Whatever the school of thought adopted, evidence suggests those adopting maladaptive coping strategies may not only develop physical difficulties but psychological difficulties as well (Graue et al., 2004).

**2.5 Dilemmas Impacting Self-Care Decisions and Coping Responses**

Young people face many dilemmas arising from the challenges discussed above. This can include decisions surrounding: 1) illness acceptance, 2) risk taking, 3) level of responsibility for care, 4) whether to tell the truth about self-care deviations or to lie, 5) if or when to tell friends about their diagnosis, 7) whether to give in to peer pressure, 8) transitions, and 9) whether to ask for help or to cope alone.

**2.6 Conclusion**

This chapter presented a number of stressors faced by young people with Type 1 DM. During this period the young people face significant developmental challenges associated with this stage of life as well as further challenges associated with Type 1 DM and its management. Without psychosocial support young people with Type 1 DM are not able to overcome these challenges and develop physically, emotionally or cognitively, (Anderson et al., 2009). The mental health issues arising from the diagnosis and self-management of this complex chronic illness are numerous and will be discussed in Chapter 3.

**Chapter 3**

**Mental Health in Type 1 DM**

# 3.1 Summary

In chapter 2 the special difficulties faced by young people with Type 1 DM and their families were highlighted, it was concluded that the impact on both the patient and those around them is profound. This chapter presents the psychological issues faced from a diagnosis of a chronic illness and discusses the impact a co-morbid psychological condition has on the patient. First, a general history of mental health policy within the UK is presented followed by a consideration as to how psychological issues are related to Type 1 DM. Next, detailed descriptions of the psychological issues faced by young people with Type 1 DM are presented along with current estimates of their prevalence. This is followed by reasons co-morbid psychological conditions pose a problem in Type 1 DM. Finally a description of current NHS guidelines regarding emotional and psychological support and care in diabetes in the UK is presented.

**3.2 Introduction**

*"One in four of us will have a mental illness at some point in our lifetime. It is the biggest unaddressed health challenge of our age...Too often governments have been stuck in a mind-set that thought that physical health should always take priority..."* (Ed Miliband, cited in BBC News, 2012)

In 2012, Ed Miliband, leader of the British Labour party, criticised celebrities for insulting and demeaning those with a mental illness. This was in response to comments such as “depression is the latest must have accessory” (Janet Street Porter, 2010) and references to “Johnny suicides” (Jeremy Clarkson, cited in The Guardian, 2011). Miliband claimed the government had created “a taboo running across our society which infects both our culture and our politics” through silence on the issues. He made a call for the same treatment for “mentally ill” patients as “physically ill” patients.

This is not a new concept, over half a century ago a similar call was made by the Percy Commsion (1957) in response to growing concerns over the state of psychological care in the UK in the first half of the twentieth century.

*“…the law should be changed so that whenever possible suitable care may be provided for mentally disordered patients with no more restriction of liberty or legal formality than is applied to people who need care because of other types of illness, disability or social difficulty”* (Percy Commsion, 1957).

Prior to 1948 psychological care involved the involuntary institutionalisation of those viewed as “mentally ill”, into one of over 100 asylums in the UK. The “mentally ill” ranged from those displaying symptoms of anxiety and depression to alcoholism or women who had committed social transgressions. Each asylum had its own rules and treatment practices from “padded cells” and electroconvulsive therapy to sports and relaxation. The chief aim of the Percy Commission was to drive mental health care from the institutions into the community. The report called for mental illness to be considered in the same way as physical illness or disability (Percy Commsion, 1957), and for those who could comfortably live in the community to be released from the asylums. Following this the first Mental Health Act was developed which sought to incorporate the recommendations of the Percy Commission. This was ill fated, as concerns over abuses of power increased due to the ambiguity over whether the ability for a hospital to detain a mentally ill person also empowered the hospital to commence treatment procedures without consent.

The decades following saw a further shift towards patient-centred care (Rankin, 2004). Grounds (2001) argued that the 1950s, 1970s and 1990s saw major mental health reforms, yet there was still a long way to go with regards balancing the rights of the individual with the funds of the public. Today, the Mental Health Act (Dow, 2008) has once again undergone major revisions to include strict criteria for mental disorder and for detaining patients, along with the redefinition of professional roles. However, as highlighted by Miliband (BBC News, 2012), progress is far from over.

There has been some promising developments in the past decade. In particular, the recognition that children and young people need care for mental health problems which is separate to care for adults. A key development in this is the production of two documents ‘A Handbook on Child and Adolescent Mental Health’ (NHS, 1995) and ‘Together We Stand’ (NHS, 1995). These documents paved the way for the Child and Adolescent Mental Health Services (CAMHS). The CAMHS service aims to promote well-being in children and adolescents, prevent relapse, and provide a range of family, group and individual therapeutic approaches. Following these developments a series of further documents were published to further develop and improve this service.

More recently, it was recognised that provision for children and young people was still lacking, a response to this was the development of ‘Child and Young Persons Increasing Access to Psychological Therapies’ (CYP IAPT). This is a service delivered by NHS England working alongside and aiming to improve existing CAMHS services working to ultimately increase access to physical therapies for all. The psychological therapies selected are all NICE approved, but the more comprehensive CAMHS may offer further interventions in cases where this is required.

In 2013 the Joint Commissioning Panel for Mental Health published their “Guidance for commissioners of Child and Adolescent Mental Health Services” document. Within this document a need for improved care for those with comorbid chronic illnesses given the psychological effects of living with such illnesses was highlighted. This was in response to figures suggesting those with chronic illness and comorbid mental health problems are two times more likely to suffer emotional distress than those without.

More specifically, related to young people with Type 1 DM. A document published in 2007 by the Department of Health entitled ‘Making Every Young Person Matter’ outlined the best quality practice markers which should be adhered to by all NHS services in the provision of mental health care for young people with Type 1 DM. However, a survey carried out in the Yorkshire and Humber in 2009 to determine the availability of psychological support and care for young people with Type 1 DM (Diabetes UK, 2008) revealed improvements must be made. Twenty centres were included in this survey which was developed in line with the National Service Framework (NHS, 2010) for children and young people with Type 1 DM with the findings that many of the services lacked provision of screening for mental health issues, access to structured behavioural intervention strategies and specific support strategies for young people.

It is clear, that even in 2015, there remains an increasing need to improve mental health services within the UK and there is a disparity between annual NHS expenditure on mental health services and the burden of mental health problems on the NHS. Reports indicate (Department of Health, 2007) regional variation in provision for psychological care with Clinical Commisionning Groups spending from as little as 5% up to 18% of their budget in this area. Those spending lower often experience the highest number of people suffering from mental health problems, thus making the need for increased support clear.

 It is difficult to determine the exact annual NHS expenditure related to psychological care for those with Type 1 Diabetes given the complexity of the condition and the need for multidisciplinary input. What is clear is that for all who have a co-morbid chronic illness, psychological care is often neglected in favour of illness management.

**3.3 Chronic Illness and Co-morbid Psychological Problems**

### *“The psychological side effects may represent a greater threat than the chronic illness itself”* Sigmund Freud (1895).

The conflict and interaction between demands of Type 1 DM self-management and the demands of everyday life may ultimately lead to problems in psychological functioning. As a result people with Type 1 DM are at an increased risk of psychological difficulties. The co-morbidity of mental and physical disorders is becoming a major problem (Sartorius, 2013). As a result, in recent years there has been heightened interest in the psychological well-being of people with Type 1 DM.

Diagnosis of Type 1 DM is often a stressful time. Northam (1997) describes the case of a hypothetical child who believes himself only to be ill when he is in hospital. The child is taken to hospital in a state of diabetic ketoacidosis. Once there, the child accepts he is ill, and accepts treatment in the form of insulin injections, even though he may not like them. On leaving the hospital and arriving at home the child becomes distressed to learn the injections continue. Given the egocentrism present at that stage in the child’s development, he believes he is receiving injections as a punishment and is confused as he has done nothing wrong. This situation is stressful not only for the child, but for the parent too.

For those diagnosed in adolescence this concept of only being ill when in hospital is often replaced by denial of illness. The young person may be able to understand the diagnosis and its future implications cognitively, but may be unwilling to accept either diagnosis or the complications which may arise due to incorrect self-management. As a result avoidant coping strategies as discussed in chapter 2 may be taken on. This denial causes significant distress to the parent (Whittemore, Jaser, Chao, Jang, & Grey, 2012) and the potential conflict may also lead to problems in psychological functioning for the young person (Anderson et al., 2002). Eventually the young person will accept and attempt to adapt to the diagnosis. This may be accompanied by denial, grief at the loss of good physical health, stress and further problems coping (Northam, 1997).

Adding to the initial stress caused on diagnosis and acceptance is the challenges discussed in chapter 2. These significant challenges theoretically put young people with Type 1 DM at significantly higher risk for mental health problems. However, in some cases psychological difficulties may also predate a diagnosis of Type 1 DM.

# The Pyramid of Psychological Problems

The Pyramid of Psychological Problems (Trigwell et al., 2008) can be used to conceptualise the variation of psychological needs which may be experienced by people with diabetes (Figure 3.1). The-five level pyramid was created initially for a patient survey (Trigwell et al., 2008) in order to enable the participants to assess their level of need. As the levels increase the psychological problems become more severe yet less prevalent, with the top level requiring specialist psychiatric intervention. The levels may overlap and the boundaries are not fixed. During the lifespan it is likely that a patient will travel through different levels as different life and disease specific challenges are faced (Trigwell et al., 2008). Here the psychological problems experienced by young people with Type 1 DM are presented within the framework of this this five level pyramid model.

**3.4.1 Level 1**

The general stressors discussed both earlier in this chapter and in chapter 2 means almost all young people with Type 1 DM will fall into Level 1 at some time from diagnosis through illness progression. Level 1 forms the broadest level of the pyramid and relates to the general difficulties coping with diagnosis, treatment, peers, families, school or work, and complications associated with Type 1 DM (Trigwell et al., 2008).

In comparison to people of the same age, young people with Type 1 DM have reduced quality of life (Graue et al., 2004; Sawyer, Drew, Yeo, & Britto, 2007), increased stress, and increased family conflict (Cameron et al., 2008) as a result of the complex treatment regimen (Drotar et al., 2000) all of which have negative implications for medical outcomes (Cameron et al., 2008; Forsander et al., 2000; Kovacs, Mukerji, Iyengar, & Drash, 1996; Leonard et al., 2005; Rewers et al., 2002). Additionally, mild disease specific concerns such as problems with adjusting to diagnosis and treatment (Northam, Matthews, Anderson, Cameron, & Werther, 2005) fear of hypoglycaemia (Barnard, Thomas, Royle, Noyes, & Waugh, 2010), and fear of needles (Howe et al., 2011) are often experienced. Those in level 1 do not require specialist attention. Exact prevalence rates are lacking in young people but it is estimated approximately 60% of adults report one concern related to Type 1 DM at any one time (Polonsky et al., 1995; Polonsky et al., 2005). Given additional concerns related to adolescence, this is likely to be elevated in young people.

**3.4.2 Level 2**

Level 2 includes those who are unable to cope with the problems related to Type 1 DM. Mood is impaired and worries are present which lead to problems with self-management. Those experiencing sub-clinical symptoms of anxiety and depression (discussed in further detail in level 3) which may hinder their abilities to carry out everyday tasks fit into this level. A further problem within this level is Diabetes Related Distress.

***Diabetes Related Distress***

Diabetes related distress is distinct from general psychological distress as it relates only to distress arising from a diagnosis of DM or self-management. However, the two are similar in symptoms. Psychological distress forms due to the inability to cope with everyday stressors (Snoek & Skinner, 2006). Symptoms include: feeling anxious, feeling nervous, sadness, low mood, restlessness, agitation, fatigue and difficulties concentrating.

Psychological distress in chronic illness is a relatively new concept, but is gaining growing recognition in medicine (Bultz & Carlson, 2006; Hodges, Humphris, & Macfarlane, 2005). Discussions currently surround how distress relates to clinical depression or anxiety given the similarity in symptomatology. Three theories are central to these discussions. First, psychological distress is a symptom of clinical depression or anxiety; second, psychological distress is a risk factor for clinical depression or anxiety; and third, psychological distress arises as a consequence of clinical depression or anxiety (Snoek, 2013). A conclusion as to the exact mechanism is yet to be drawn.

It has been argued (Fisher et al., 2007; Fisher et al., 2008b; Fisher et al., 2009; Fisher et al., 2010a; Fisher, Glasgow, & Strycker, 2010b; Fisher, Hessler, Polonsky, & Mullan, 2012; VanBastelaar et al., 2010) that, at least in Type 2 DM, diabetes-related distress (e.g. concerns about living with a chronic illness and managing appropriate self-care) rather than clinical depression contributes to suboptimal glycaemic control.

**Figure 3.1 Pyramid of Psychological Problems**

**Level 5**

Severe and complex mental illness requiring specialist psychiatric intervention (s).

 **Level 4**

More severe psychological problems which are diagnosable and require biological treatments, medication and specialist psychological interventions.

**Level 3**

Psychological problems which are diagnosable/classifiable but can be treated through psychological intervention alone e.g. mild and some moderate cases of depression, anxiety states, and obsessive compulsive disorders

**Level 2**

More severe difficulties with coping, causing significant anxiety or lowered mood, with impaired ability to care for self as a result.

**Level 1**

General difficulties coping with diabetes and the perceived consequences of this for the person’s lifestyle etc. Problems at a level common to many or most people receiving the diagnosis.

**3.4.3 Level 3**

Level 3 includes mild psychological conditions diagnosable by the Diagnostic and Statistical Manual of Mental Disorders volume 5 (DSM-5; American Psychiatric Association, 2013). The DSM is a manual produced by the American Psychiatric Association (APA) which provides a common framework for the diagnosis of mental disorders. With regards to Type 1 DM, these include mild depression, anxiety (including obsessive compulsive disorders, acute stress disorder, needle phobia, and generalized anxiety disorder) and eating disorders.

Problems surrounding eating are complex in Type 1 DM (Colton & Rodin, 2009). In general those with Type 1 DM are heavier than the general population due to the inability of self-administered insulin and self-management to fully imitate a correctly functioning pancreas. In fact, by not administering insulin weight can significantly decrease; as a result many may withhold injections. This perhaps provides and explanation for the increased prevalence of eating disorders among young people with Type 1 DM relative to an age-matched control (Jones, Lawson, Daneman, Olmsted, & Rodin, 2000). Although depression, anxiety, and eating disorders have all previously been shown to be elevated in people with Type 1 diabetes, only depression and anxiety will be discussed in detail here and throughout this thesis.

***Depression***

Rates of depression are rising worldwide in the general population (Moussavi et al., 2007). Currently the most commonly diagnosed mood disorder, rates of depression among those with Type 1 DM are said to be increasing faster than can be explained by the individual prevalence estimates of each (Sartorius, 2013). This could be as a result of i) the greater flexibility of self-management afforded in the past decade and therefore a need for greater knowledge, ii) the greater awareness of the symptoms of depression by the general public, iii) greater diagnoses arising from more rigid criteria for clinical depression and reduced focus on personal context.

For a diagnosis of clinical depression, the DSM-5 requires at least one of the first two items of the diagnostic criteria (see Table 3.1) to be present as well as additional symptoms from the remaining criteria to total five symptoms or more. The greater the number of symptoms the more severe the depression with a range from mild to severe. The five symptoms must be present during the same two week period and must represent a change from normal functioning.

**Table 3.1 DSM-5 Diagnostic criteria for depression**

|  |  |
| --- | --- |
| Item number | Description |
| I. | Depressed mood |
| II. | Loss of interest or pleasure |
| III. | Fatigue or loss of energy |
| IV. | Decrease or increase in appetite or significant weight loss or weight gain |
| V. | Insomnia or hypersomnia |
| VI. | Psychomotor agitation or retardation |
| VII. | Poor concentration or indecisiveness |
| VIII. | Suicidal thoughts or acts |
| IX. | Guilt or self-blame |

Much of the recent research surrounding depression among young people with Type 1 DM has focused on depressive symptoms as opposed to clinical depression. That is, sub-threshold levels of MDD, which may still interfere with everyday functioning. This can be seen as a response to work in the adult population suggesting sub-threshold depression as opposed to MDD is associated with medical outcomes (Fisher et al., 2010b; Fisher et al., 2010a; Fisher et al., 2009; Fisher et al., 2007).

Evidence for the prevalence of MDD and sub-threshold depression in young people with Type 1 DM is mixed (Johnson, Eiser, Young, Brierley, & Heller, 2013). One study found that out of a sample of 145 patients aged 10-17 years, 22 scored above the clinical cut-off for elevated depressive symptoms on the Children’s Depression Inventory (Hood et al., 2006). This was over double the highest estimate of depressive symptoms in an age-matched control. Additionally this study highlighted an increase in prevalence of psychological co-morbidities in comparison to older studies (Hood et al., 2006). This research provides support for the concerns of those who believe the more flexible intensive treatment regimen causes greater stress (Davidson et al., 2004).

#### Anxiety

*“An unpleasant state of inner turmoil, often accompanied by nervous behaviour, such as pacing back and forth,*[*somatic complaints*](http://en.wikipedia.org/wiki/Somatic)*and* [*rumination*](http://en.wikipedia.org/wiki/Rumination_%28psychology%29)*.”* (Seligman, Walker, & Rosenhan, 2000)

Anxiety as an emotion has strong survival benefits. In its absence dangerous risk taking behaviour is likely to increase (Zuckerman & Kuhlman, 2000). In the case of Type 1 DM, this may mean the complete avoidance of self-management behaviours. However, when anxiety is raised to levels disproportionate to the stimulus, symptoms of anxiety become problematic.

Ten different anxiety disorders are recognised by the DSM-5. Within Type 1 DM there is evidence at least three of these are elevated or are linked to problems with self-management. First, symptoms of acute stress disorder are elevated in children and young people (up to 17 years) following diagnosis of Type 1 DM (Cline, Schwartz, Axelrad, & Anderson, 2011). Second, the need to frequently self-administer via insulin injections can cause problems for those with a pre-existing fear of needles or even expose a fear of needles in others resulting in high levels of avoidance behaviours (Hanas & Ludvigsson, 1997; Howe et al., 2011). Detection of fear of needles can be problematic in young people with Type 1 DM with many feeling embarrassed by the fear. Detection of needle phobia is often only likely to occur through the realisation insulin has not been administered (Christie & Barnard, 2012).

Third, more general anxieties arise from the many stressors associated with Type 1 DM and challenges of adolescence. In some, these anxieties and worries may be difficult to control, cause functional impairment and be pervasive, excessive and on-going over a period of six months. In these cases General Anxiety Disorder may be diagnosed in accordance with the DSM-5. Evidence has shown the prevalence of Generalised Anxiety Disorder to be elevated in this group (Kovacs, Goldston, Obrosky, & Bonar, 1997). Finally, it is possible that some may develop obsessive-compulsive behaviours such as obsessive testing of blood glucose levels in an attempt to ensure optimal glycaemic control. However, evidence in this area is lacking.

Whilst a wealth of literature has focused on depression and depressive symptoms, much less has focused on anxiety. The little research that has been conducted has focused on symptoms of anxiety at sub-threshold for clinical diagnosis. In particular most research has been conducted in adult or child populations and has proved inconclusive. Trait anxiety related to diabetes, that is, general and on-going worries which are related to personality have been associated with reduced self-management practices and worsened HbA1c (Herzer & Hood, 2010; Mortensen, 2002; Naar-King et al., 2006). Conversely, researchers argue for a protective effect of moderate levels of anxiety, in that as discussed earlier, high risk behaviours such as withholding insulin or neglect of blood glucose tests is likely to decrease in the presence of anxiety (Herzer & Hood, 2010).

**3.4.4 Level 4**

This level is characterised by more severe cases of the diagnosable psychological disorders discussed in level three. Disorders in this level cannot be treated solely through psychological intervention and require specialist psychological intervention, psychiatric referral and perhaps medication. The most predominant psychological disorder at this level is Major Depressive Disorder (MDD), which is detected only through a diagnostic interview using the same criteria used to diagnose mild and moderate depression. Research into the prevalence of MDD in young people with Type 1 DM is scarce. Anderson, Freedland, Clouse and Lustman (2001) conducted a survey of the prevalence of psychiatric conditions in adults with Type 1 DM and found rates of MDD two times higher than in the general population. Severe anxiety was also found to be elevated. More severe eating disorders also fit into this category and, within the adolescent population, are twice as common among females with Type 1 diabetes in comparison to an age-matched control (Nielsen, Emborg, & Molbak, 2002).

**3.4.5 Level 5**

Level 5 represents the smallest group, with the most severe symptoms. Those in this category require specialist psychiatric intervention, and potentially even hospitalisation. The disorder is complex and examples include severe depression, eating disorders requiring hospitalisation, and schizophrenia.

# 3.5 Why are Co-morbid Psychological Conditions a Problem?

There are a number of important problems associated with co-morbid psychological conditions or elevated distress symptoms in young people with Type 1 DM. First, co-morbidities are associated with worsening medical outcomes. In a systematic review Johnson et al. (2013) found prevalence rates of depression in young people with Type 1 DM from study to study were inconsistent. However, 14 of the 15 included studies found associations between higher depressive symptoms and suboptimal HbA1c. The same relationship has also been found between elevated symptoms of anxiety, and diabetes related distress and HbA1c (Herzer & Hood, 2010; Hislop, Fegan, Schlaeppi, Duck, & Yeap, 2008). Further, higher depressive symptoms have also been related to increased hospitalisations (Stewart, Rao, Emslie, Klein, & White, 2005) and low frequency of blood glucose monitoring (McGrady, Laffel, Drotar, Repaske, & Hood, 2009). Acute stress symptoms have been shown to predict attendance at clinic appointments (Cline et al., 2011).

The relationship between elevated psychological symptoms and poorer outcomes seems clear, yet research has been unable to attribute causality. That is, it is possible the lack of motivation associated with a decrease in mental wellbeing causes a lack of motivation to self-manage. Consequently blood glucose monitoring decreases and suboptimal glycaemic control is prevalent. Conversely the presence of suboptimal glycaemic control and neglect of self-management, or the need to carry out complex self-management activities leads to increased depressive symptoms, anxieties and distress.

Second, an important problem with co-morbidity is the similarity between negative symptoms related to psychological health and symptoms related to diabetes. For example, a young person may not be diagnosed with a psychological problem when presenting with feelings of fatigue, loss of concentration, and weight gain as these are all major characteristics of Type 1 DM. For this reason it is hypothesised that estimates of psychiatric problems in a population with Type 1 DM are conservative, and there may be significantly more cases of psychiatric disorder than are diagnosed (Esbitt, Tanenbaum, & Gonzalez, 2013). Finally, there is evidence to suggest young people are less likely to seek help for a mental health issue due to shame, embarrassment and the stigma associated with visiting a psychologist or psychiatrist (Gulliver, Griffiths, & Christensen, 2010).

**3.6 Psychological Care and Support in Diabetes**

In 2000 the International Society of Pediatric and Adolescent Diabetes consensus guidelines stated that:

*“Psychological factors are the most important influences affecting the care and management of diabetes”*

They recommended psychologists and social workers should be part of the diabetes multidisciplinary care team. Psychological support should be available for all, and non- psychology staff should be trained in detecting symptoms of psychosocial problems. Additionally the NICE guidelines (2008), the Scottish Intercollegiate Guidelines Network (SIGN, 2010) guidelines and the diabetes National Service Framework (NHS, 2010) provide a clear statement of what level of care quality patients with diabetes should receive.

The NICE guidelines (2008) state that care teams working with young people with Type 1 DM should be made aware of the elevated risk of emotional and behavioural problems, including depression and anxiety in particular. With attention paid to the possibility that these symptoms may further increase with persistently poor HbA1c. Those with persistently poor HbA1c should be screened for depression and anxiety, with those with suspected mental health concerns referred promptly to mental health professionals. With regards to psychosocial support, the guidelines state that professionals should be made aware of the negative impact poor support can have. Individuals and families should be offered specific support strategies and offered “timely and ongoing access to mental health professionals”.

Similar guidelines are offered by SIGN (2010) which states that regular assessment of a broad range of psychological and behavioural problems should take place. Also, both children and adults shoule be offered psychological interventions to improve glycaemic control in the short and medium term.

However, the Mind the Gap report (Trigwell et al., 2008) revealed significant gaps in the provision of psychological care and support, with 85% of the population in the UK lacking defined access. Furthermore, of the six NICE guidelines relevant to psychological health and diabetes, less than 3% of NHS services within the UK met all six, whilst 26% did not meet any of the guidelines at all (Trigwell et al., 2008). In 2008 Diabetes UK in conjunction with the NHS formed the Psychological and Emotional Support Working Group to develop guidelines and best practices for the psychological and emotional support of people with diabetes in the UK to increase access to psychological support for all.

**3.7 Summary**

Young people with Type 1 DM face two different types of stressor: physical and psychological (Northam, 1997). Outcomes have been shown to be poorer for those with co-morbid psychological issues. Although steps are being taken to improve access and decrease the stigma surrounding psychological support and care, there is still a long way to go and there lies a need for interventions to improve outcomes in this group. In the next chapter the prevalence of depression, anxiety and diabetes related distress within a clinic population will be measured. In addition, given research in adults surrounding the relationship between depression, diabetes related distress and HbA1c, this relationship will be examined in this population. The results from this study will inform the development of an intervention sensitive to the needs of this vulnerable group.

**Chapter 4**

**Prevalence of Mental Health Symptoms in Young People with Type 1 DM**

**4.1 Summary**

Reports of prevalence rates for psychological problems in young people with Type 1 DM have been inconsistent, with some reporting higher prevalence rates than the general population, and others, no significant difference. Possible explanations for this include differences in health care provision between countries, different measures used to estimate prevalence rates and differences depending on gender. There are also arguments that people with diabetes are not clinically depressed but have mental health issues associated with the distress of managing chronic conditions. This is supported by recent work in adults with diabetes which has focused on the relationship between depression and diabetes related distress with the overall finding that diabetes related distress mediates the relationship between depression and HbA1c. This has implications for care delivery.

Following from these findings, we aimed to clarify the relationship between depression, anxiety and diabetes related distress in young people. Specifically, this study aimed to determine: i) the prevalence of depression, anxiety and diabetes-related distress among young people with Type 1 DM, ii) gender differences in depression, anxiety and diabetes related distress, iii) the relationship of depression, anxiety and diabetes related distress to HbA1c. Finally, we explored whether the relationship between depressive symptoms and HbA1c is mediated by diabetes-related distress as reported for adults, taking account of demographic and medical variables.

Ninety-six young people (79.3% response rate, mean age 17.61±1.29 years) consented to complete standardised psychological measures of depression, anxiety and diabetes-related distress and demographic data. Medical information was obtained from NHS records. Multiple regression analyses were used to explore the relative contribution of these scales to glycaemic control.

Depression and anxiety rates were comparable to the general adolescent population, and rates of diabetes related distress were comparable to an adult population. Symptoms of anxiety were significantly higher for females

(6.78±2.63) compared to males (4.13±2.63, t(94) = 4.14, p<0.01). Diabetes related distress scores were significantly higher for females (2.27 ± 0.91) than males (1.64 ± 0.59, t(94) = -4.47, p<0.01). This was not true for depressive symptoms. Depressive symptoms and diabetes-related distress were significantly positively associated with HbA1c, but there was no relationship between anxiety and HbA1c. Diabetes-related distress was found to be a significant mediator of the relationship between depression and HbA1c.

 The results of this study provide support for screening programmes to assess depressive symptoms and diabetes related distress measured as separate conditions, as well as the introduction of interventions to reduce symptoms of diabetes related distress in young people with Type 1 DM.

**4.2 Introduction**

Chapter 3 highlighted the psychological problems experienced by young people with Type 1 DM including depression, anxiety and diabetes related distress. Given the burden of the demands of the diabetes treatment regimen, it might be hypothesised that these rates would be higher when combined with a diagnosis of Type 1 DM. Indeed, in young people, depressive symptoms have been found to be more prevalent in the two years following diagnosis (Grey, Cameron, Lipman, & Thurber, 1995), after the initial “honeymoon” period (Abdul-Rasoul, Habib, & Al-Khouly, 2006) and ten years post diagnosis (Grey, Whittemore, & Tamborlane, 2002), with rates of anxiety higher than those for depression (Axelson & Birmaher, 2001; Dierker et al., 2001). Yet, prevalence estimates in the adolescent population vary, with some reporting rates significantly higher than the general population (Abdul-Rasoul et al., 2006; Moussa et al., 2005), and others reporting no significant difference between adolescents with Type 1 DM and those without (Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007).

**4.2.1 Determining prevalence rates**

A lack of consistency in prevalence estimates in the adolescent population could be due to a number of reasons. First, previous studies in young people with Type 1 DM have been conducted in a number of different countries. Cultural differences and socio-economic inequalities in prevalence estimates are evidenced in both the general adult population (Lorant et al., 2003) and the general adolescent population (Steptoe, Tsuda, Tanaka, & Wardle, 2007). In their meta-analysis of 50 studies measuring depressive symptoms in 25 different countries, Lorant et al. (2003) found depressive symptoms to be inversely associated with socio-economic status (measured by income and highest educational attainment). This study showed those with a lower income and lower educational attainment to have significantly higher depressive symptoms. It is likely that cultural differences may have an effect on mental health outcomes through differences between health care provisions from country to country (Belfer, 2008a, 2008b).

In the adolescent population, Steptoe et al. (2007) conducted a large international study into the prevalence of depressive symptoms as measured by the Beck Depression Inventory (Beck, Ward, & Mendelson, 1961) including 17,348 students of university age from 23 countries of low, medium or high income. A wide variation in depressive symptoms was reported between countries with lower levels in Western and Southern Europe and North and South America, intermediate levels in Central and Eastern Europe and high levels in Taiwan, Korea, Japan and South Africa. Lower socio-economic status was associated with higher depressive symptoms. Given the differences between cultures shown in these studies it is clearly important to obtain specific prevalence rates for different countries. To date, very few studies into the prevalence of mental health issues among young people with Type 1 DM have been conducted in the United Kingdom.

Second, a wide range of measures have been used to detect sub-clinical levels of depressive symptoms and anxiety. These measures tend to differ based on the definition of depression or anxiety held in measure development leading to huge variations and misleading outcomes. Additionally, these measures can differ in meaning when translated into different languages. This causes issues in comparison between studies using different measures.

Third, more specifically to diabetes, some items from validated measures used to measure depressive symptoms are somatic in nature (Lloyd & Roy, 2013). For example somatic items (e.g. I feel full of energy) included in the Child Depression Inventory (CDI; Kovacs, 1985) and the Centre for Epidemiological Studies Depression Scale (e.g. I slept more; CESD; Radloff, 1977) have been used frequently, and can overlap with the physical symptoms associated with Type 1 DM. This can lead to inflated estimates of the prevalence of depression. Bias in the interpretation of data when using measures including somatic items have been documented when considering the prevalence of behaviour problems in children with chronic health conditions (Perrin, Stein, & Drotar, 1991).

Finally, gender differences in mental health outcomes exist in the general population. Greater rates of depression and anxiety disorders have been reported in women compared to men across all age groups (Seedat et al., 2009). However, Seedat et al. (2009) also identified a closing of the gender gap for depressive symptoms in recent years. This was attributed to changes in traditional gender roles leading to greater equality. It is possible that gender may also have played a role in the variation of prevalence rates. For these reasons there is need to determine, using non-somatic measures, the prevalence of mental health issues in a specific sample population when considering introducing new interventions

**4.2.2 Depression and diabetes related distress**

As discussed in chapter 3, a correlate of depressive symptoms is HbA1c. It might be expected that alleviating these symptoms would improve HbA1c, or the improvement of HbA1c would lead to their reduction. However, in the past decade the general view is that the symptoms shown by those with Type 1 DM that are linked to HbA1c are more accurately described as diabetes related distress (Gask, Macdonald, & Bower, 2011). Understanding the role of distress arising from diabetes has been facilitated by the development of the diabetes related distress scale (DDS; Fisher, Glasgow, Mullan, Skaff, & Polonsky, 2008a; Polonsky et al., 2005). Polonsky et al. (2005) described a 28-item scale which was subsequently reduced to 17-items including two screening items which could be quickly administered to participants (Fisher et al., 2008a). Fisher et al. (2008a) also consulted diabetes care staff and conducted a factor analysis in order to split the 17-items into four subscales including: regimen related distress, emotional distress, physician related distress and interpersonal distress.

Fisher et al. (2007, 2008b, 2009, 2010a, 2010b, 2012) conducted a series of studies examining the relationship between clinical depression, depressive symptoms and diabetes related distress in adults with Type 2 DM. In their cross sectional study, 506 participants were assessed for clinical depression using the Composite International Diagnostic Interview (CIDI; Kovacs, 1985), depressive symptoms using the Centre for Epidemiological Studies Depression scale (CESD; Radloff, 1977), and diabetes related distress using the Diabetes Related Distress Scale (DDS; Fisher et al., 2008a; Polonsky et al., 2005). The findings revealed 22% of the participants reached the cut-off for ‘likely depression’, and of these 70% were not diagnosed with clinical depression. Of those diagnosed with clinical depression (9.9% of whole sample), 34% did not reach the cut-off point for ‘likely depression’ on the CESD. Diabetes related distress was found to be related to CESD scores, the authors concluded those diagnosed with ‘likely depressed’ were better described as distressed.

These findings were found to be persistent over time (Fisher et al., 2009) and so at least in Type 2 DM, diabetes-related distress rather than clinical depression contributes to suboptimal glycaemic control. In later work (Fisher et al., 2010a) with the same population, diabetes related distress was found to have both a concurrent and time-concordant relationship with HbA1c. Clinical depression and depressive symptoms did not show the same relationships. The authors conclude that measures of depression may include two conditions: major depressive disorder and diabetes-related distress, with only the latter showing significant associations with HbA1c.

Van Bastelaar et al. (2010) found similar results using a different measure of diabetes related distress, the Problem Areas in Diabetes Scale (PAID; Welch, Jacobson, & Polonsky, 1997). They examined the mediating effect of diabetes specific distress, on the relationship between depressive symptoms, measured by the CESD (Radloff, 1977), and glycaemic control. Participants (n= 627) had either Type 1 or Type 2 DM. Both depressive symptoms and diabetes related distress were associated with HbA1c with higher scores on the measures related to higher HbA1c. Diabetes related distress was found to be a significant mediator in the relationship between depressive symptoms and HbA1c, for both Type 1 and Type 2 DM.

Compared with the adult literature, the research in young people with Type 1 DM is less extensive. Hislop et al. (2008) have attempted to examine the relationship between HbA1c and general distress in young people (18-28 years) using the CESD as a measure of depressive symptoms and the Adult Self Report scale (Kessler et al., 2005) as a measure of general distress. Of the 96 young people included, 35.2% scored above the threshold for ‘likely depression’ on the CESD and 35.5% scored above the threshold for distress. Depressive symptoms were found to be related to HbA1c. Unlike in the adult literature; distress was not associated with HbA1c but was associated with the use of an insulin infusion pump and hypoglycaemic episodes. Here a general measure of distress was used, making it difficult to determine whether the distress experienced was associated with diabetes or with non-illness related triggers.

One way to clarify the issues with distress is using qualitative methodology. Balfe et al. (2013) conducted semi-structured interviews with 30 young people (23 – 30 years) and, utilising thematic analysis found some aspects of distress present in the sample population. The most common distress arose from self-consciousness or stigma, management difficulties, fighting with the health care system, future concerns, and concerns surrounding pregnancy. Isolating the type of distress experienced could provide invaluable for alleviating these symptoms and has not been previously examined quantitatively. Disentangling the constructs of depression and diabetes related distress, replicating the work conducted in the adult population in young people, and isolating specific types of distress could prove invaluable both in clinic consultations and in the design of future interventions.

**4.2.3 Study rationale, aims and hypotheses**

As discussed in this, and the previous chapter, psychological problems are prevalent in the general population and, in the case of diabetes, have been associated with suboptimal medical outcomes. Based on the review of prevalence estimates of psychological problems in young people with Type 1 DM, the aims of this study were to determine:

1. the prevalence of depression, anxiety and diabetes related distress among young people with Type 1 DM,
2. gender differences in depression, anxiety and diabetes related distress,
3. the relationship of depression, anxiety and diabetes related distress to HbA1c,
4. if the relationship between depressive symptoms and HbA1c is mediated by diabetes-related distress as reported for adults, taking account of demographic and medical variables.

Specifically, it was hypothesised that:

1. Depression and anxiety will be more prevalent in the diabetes population than the general population.
2. Prevalence of depression, anxiety and diabetes related distress will be more common in females than in males.
3. In univariate analyses; depression, anxiety and diabetes related distress will be associated with HbA1c.
4. In multivariate analyses; relationship between depression and HbA1c will be mediated by diabetes related distress.

**4.3 Method**

**4.3.1 Sample**

Participants were recruited from two specialist diabetes clinics for young people in the Sheffield Teaching Hospitals. These clinics run once a month at two different sites, the Northern General (NGH) and the Royal Hallamshire Hospitals (RHH). All patients with Type 1 DM (16-21 years) attending specialist diabetes clinics for young people in Sheffield were eligible to take part. Exclusion criteria included those with English language difficulties, special educational needs, co-morbid life-limiting conditions, or those diagnosed less than 6 months prior to consent.

**4.3.2 Procedure**

Ethics approval and research governance was obtained from the NHS National Research Ethics Service in York prior to study commencement (REC: 10/H1310/67; appendix 4.1). Data were collected between November 2010 and September 2011. Eligible patients were identified by the research team from clinic lists provided by the Sheffield Teaching Hospitals. These patients were then sent an invitation letter (appendix 4.2) and an information sheet (appendix 4.3) by mail with the routine reminder that precedes clinic appointments, explaining the purpose of the study and inviting them to take part. Parents were sent a separate information sheet to inform them about the study (appendix 4.4). Young people who attended clinic were approached by a Diabetes Specialist Nurse (DSN). The DSN’s were recruited for the purpose of the CLAHRC funded project, and provided further information about the study, answered any questions and obtained signed consent (appendix 4.5) to take part and to have medical records accessed. All participants were given a questionnaire pack (appendix 4.6) which was either completed in clinic or taken home and returned by mail. DSNs also answered any questions related to completing the questionnaire and assisted with questionnaire completion where necessary. Additionally, to reduce the possible bias that may arise from differences between frequent clinic attendees versus frequent non-attendees, young people who did not attend clinic during the study period were sent questionnaires by post. Non-attendees were also reminded to complete questionnaires when they were visited at home by a DSN. Medical information was extracted from medical records by a trained member of the CLAHRC administration team.

**4.3.3 Measures**

Questionnaire packs consisted of standardised psychological measures including the DDS (Fisher et al., 2008a; Polonsky et al., 1995), the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the Diabetes Eating Problem Scale (Markowitz et al., 2010). Relevant demographic questions were also included. For the purposes of this study, only results for the DDS, and the HADS are reported this is due to the fact that the Diabetes Eating Problem Scale is part of another PhD thesis and concerns regarding overlap between these two theses were raised.

***The Hospital Anxiety and Depression Scale (HADS)***

Symptoms of anxiety and depression were assessed using the HADS (Zigmond & Snaith, 1983). The HADS is a 14 item self-report scale frequently used to determine the prevalence of anxiety and depression in individuals with chronic conditions and is also one of the screening tools recommended by the Department of Health in primary care (Lloyd & Roy, 2013). This scale does not include any somatic items (e.g. I feel I lack energy) meaning there is no overlap with symptoms associated with Type 1 DM. The HADS has also been found to be sensitive to change during the course of illness and in response to intervention (Herrmann, 1997). The HADS has good reliability and validity when used with 12-16 year olds (White, Leach, Sims, Atkinson, & Cottrell, 1999). The measure is divided into two subscales: anxiety and depressive symptoms, each including seven items and with good reliability. Example items from the depressive symptom scale include: ‘I can still enjoy the things I used to enjoy’ and ‘I feel cheerful’. Example items from the anxiety subscale include: ‘I feel tense or wound up’ and ‘worrying thoughts go through my mind’. Items are scored from 0 to 3, with higher scores indicating greater depression or anxiety. Total scores range from 0-21.

***The Diabetes Distress Scale (DDS)***

The DDS (Fisher et al., 2008a; Polonsky et al., 1995) is a 17-item measure assessing diabetes-related distress. Responses are typically made on six- point Likert scales (‘not a problem’ to ‘a very serious problem’ 0-5). In order to simplify questionnaire completion for young people, for the purposes of this study the 6 point scale was changed to a 5-point scale. This enabled comparability with other scales used. In the adult population the 17 items are organised around four subscales, includingi) regimen-related distress (n=5, e.g. feeling that I am not sticking closely enough to a good meal plan) ii) physician-related distress (n=4, e.g. feeling that my doctor doesn’t take my concerns seriously enough) iii) interpersonal distress (n=3, e.g. feeling that my friends and family don’t appreciate how difficult living with diabetes is) iv) and emotional distress (n=5, e.g. feeling overwhelmed by the demands of living with diabetes). The DDS has established reliability and validity and has been associated with problems with meal planning, exercise, and total cholesterol as well as HbA1c (Polonsky et al., 1995). In previous studies (Fisher et al., 2007, 2008b, 2009, 2010a, 2010b, 2012) a cut-off point of 3.0 indicated diabetes related worthy of clinical attention. For the purpose of this study a cut-off of 2.5 was used given our shortened Likert scale. The DDS includes two screening questions (feeling overwhelmed by the demands of my diabetes regimen; I feel I am often failing with my diabetes treatment). In an adult population, those scoring above cut-off on the screening questions can then be asked to complete the full screening measure.

***Demographic items***

Patients completed demographic questions including gender, employment status, educational level, living situation, ethnicity, and any disability.

***Medical data***

Data included date of birth, age at diagnosis, duration since diagnosis, insulin treatment regimen, body mass index (weight(kg)/height(m)2), and most recent HbA1c.

**4.3.4 Treatment of data**

Data were entered independently by two staff (V.Y, S.B), checked for accuracy and analysed using IBM SPSS Statistics version 20 (IBM Statistics, Chicago, IL, USA). Patient participation and questionnaire completion was also recorded.

All categorical demographic variables were dummy coded into dichotomous variables according to published guidelines (Field, 2009), allowing analyses using multiple regression to be performed. Employment status was re-coded as ‘in employment’ (including participants working full time or part time) or ‘not in employment’ (participant is a student, unemployed or on leave). Educational level was re-coded as ‘in education’ (participant working towards GCSEs, A Levels, Vocational Qualification or University Degree) or ‘not in education’ (participant not working towards GCSEs, A Levels, Vocational Qualification or University Degree’). Living situation was re-coded as ‘living with parents’ or not living with parents (participant lives alone, with friends or with a partner). Ethnicity was re-coded as ‘White ethnicity’ or ‘minority ethnicity’ (participant is of Mixed race, Asian, Asian British, Black, Black British, Chinese or Chinese British). Insulin regimen was re-coded as ‘multiple daily injections’ or ‘not multiple daily injections’, ‘twice a day’ (participant takes insulin twice a day) or not ‘twice a day’, ‘pump’ (participant is on an insulin infusion pump regimen) or ‘not on pump’. For multivariate analyses continuous variables were transformed into standardised Z scores (i.e HbA1c, DDS score, HADS score and BMI).

**4.3.5 Data analysis**

A-priori power analyses were not conducted given that this study was a pilot phase of the CLAHRC-SY overall study. It was anticipated that sample sizes would be small given that data collection was carried out in two hospitals which had a total of only 150 young people meeting our criteria. However, as this study was intended to determine feasibility and function as a pilot for the larger study, analyses were necessary. Internal reliabilities were calculated for all scales and subscales. Distribution of data was checked for normality and presented as means and standard deviations; descriptive statistics were computed for all variables. Correlations between continuous variables were calculated using Pearson’s correlation coefficient (r).

We conducted a Principal Components Analysis (PCA) using orthogonal rotation on the DDS to assess the factor structure of this scale in this age group. The Kaiser-Meyer-Olkin (KMO) measure was used to verify sampling adequacy. Values between 0.5 and 0.7 are deemed mediocre, between 0.7 and 0.8 good, between 0.8 and 0.9 great and values of 0.9 and above are deemed superb (Hutcheson & Sofroniou, 1999). Bartlett’s test of sphericity was used to measure correlations between the included variables. A significant *p*-value is taken to be <0.05 and indicates correlations are sufficiently large enough for PCA. Kaiser’s criterion of eigenvalues >1 was used to extract component factors.

In order to determine the prevalence of depression and anxiety among young people with Type 1 DM and any gender differences, scores for the HADS-D and HADS-A were summed separately to yield a total score for each scale. We used scores ≥ 7 as indicative of possible cases of depression and ≥9 for anxiety (White et al., 1999). For the DDS, mean scale scores were calculated for each participant and a cut-off score based on the scale mid-point (≥2.5) was assumed to indicate distress worthy of clinical attention. Continuous scores for the HADS and DDS were used in analyses.

In the absence of data for a comparable age group with Type 1 DM, the prevalence of depression and anxiety was compared against data for a sample without chronic illness described previously (White et al., 1999; Jorngarden, Wettergen & von Essen, 2006). Mean item DDS scores were compared with those for adults with Type 1 or 2 DM (Fisher et al., 2008b). Chi-square analyses and independent samples T-tests were conducted to assess gender differences within the psychological variables and demographic data.

Linear multiple regression analyses were used to determine if DDS scores mediate the relationship between depressive symptoms and HbA1c, with HbA1c as the outcome variable, using published guidelines (Baron & Kenny, 1986; Field, 2009). In order to check if the data met the necessary assumptions for these analyses scatterplots were plotted to test for normality, linearity, and homoscedasticity as defined by Tabachnick and Fidell (2000). Collinearity between variables was tested by conducting correlation analyses of continuous variables using Pearson’s correlation coefficient (*r*) in the first instance, and collinearity statistics and collinearity diagnostics were calculated for all regression analyses in the second instance. Using the mediator model (Baron & Kenny, 1986) the following hypotheses were tested i) depressive symptoms significantly predict HbA1c, ii) depressive symptoms significantly predict DDS scores iii) DDS scores are significant predictors of HbA1c iv) the relationship between HbA1c and depressive symptoms is significantly decreased when controlling for DDS scores. A mediation effect was deemed present if the effect of depressive symptoms on HbA1c became non-significant after controlling for DDS score. A Sobel test was used to determine significance of the mediation and post-hoc probing was used to determine the percentage of the relationship accounted for by DDS score (Holmbeck, 2002). Subsequent regression analyses were conducted to determine contributions of subscales of the DDS to the prediction of HbA1c.

**4.4 Results**

**4.4.1 Response rate**

Of the 118 patients registered and eligible to participate in the study in the specialist clinics for young people a total of 96 questionnaires were completed (81.4% response rate). Ethical approval for accessing medical records was not obtained for those who did not respond and therefore it was not possible to compare differences between responders and non-responders.

**4.4.2 Baseline Characteristics**

For the 96 participants, baseline characteristics for the total sample and by gender are presented in tables 4.1 and 4.2. Participants were 91.6% Caucasians from the UK, 75% were still in education, 75% were on intensive insulin regimes (13% 2-3x daily injections, 12% insulin infusion pump). Mean age was 17.61 ± 1.3 years, mean diabetes duration was 7.60 ± 4.8 years, and the mean HbA1c was 9.98% ± 2.1, which was comparable to previous work (9.40% ± 2.0) with young people in the UK (Wills, Scott, Davies, Mackie & Mansell., 2003).

**Table 4.1** **Categorical demographic data and completion rates**

|  |  |  |  |
| --- | --- | --- | --- |
| Variable (total response) | Sub-category |  Frequency | Percentage |
| Gender(n=96) | MaleFemale | 3957 | 40.659.4 |
| Employment(n=95) | Working full timeWorking part timeStudentStudent working part- timeUnemployedOther | 114 51 2081 | 11.64.253.721.18.41.1 |
| Currently in education (n=94) | YesNo | 7024 | 74.525.5 |
| Living status (n=95) | Living with parentsLiving with friendsLiving with partnerLiving aloneOther | 8722 13 | 91.62.12.1 1.13.2 |
| Ethnicity (n=95) | White ethnicityMinority ethnicity | 878 | 91.68.4 |
| Insulin regimen (n=96) | Multiple daily injections2x daily injectionsInsulin infusion pump | 721311 | 7513.511.5 |
| Disability (n=88) | YesNo | 583 | 5.794.3 |

**Table 4.2 Continuous medical and demographic variables for the total sample and by gender**

|  |  |  |  |
| --- | --- | --- | --- |
| Characteristic (total responses) | Total Sample (n=96) | Male (n=39) | Female (n=57) |
| Age (years) (n= 96) | 17.61 ± 1.3 | 17.69 ± 1.3 | 17.56 ± 1.3 |
| Age at diagnosis(years) (n= 96) | 9.54 ± 4.7 | 9.72 ± 4.8 | 9.42 ± 4.6 |
| Diabetes duration (years) (n = 96) | 7.60 ± 4.8 | 7.60 ± 5.1  | 7.61 ± 4.5 |
| HbA1c (%) (n = 96)  | 9.98 ± 2.1 | 9.45 ± 1.8 | 10.34 ± 2.2 |
| BMI (kg/m2) (n = 94) | 23.60 ± 3.2 | 23.10 ± 3.1 | 23.81 ± 3.5 |

Data are mean ± SD.

**4.4.3 Factor analysis of the DDS**

A PCA with orthogonal (varimax) rotation was conducted on the 17 items of the diabetes related distress scale. The Kaiser-Meyer-Olkin measure confirmed the sample size to be adequate for the analysis KMO= 0.88 (‘great’; Field, 2009), all individual KMO values were above the acceptable limit (>0.5; Field, 2009) for analyses. Bartlett’s test of sphericity indicated correlations between variables to be large enough to conduct principal components analysis (Х2 (136) = 1068.70, p<0.001). The scree plot was ambiguous, but three components had eigenvalues over Kaisers criterion of >1, and these three factors explained 68% of the variance. Three components were therefore retained in the final analysis (see table 4.3) these were labelled regimen/emotional related distress, physician related distress and interpersonal distress. These are similar to the subscales proposed by Fisher et al. (2008), but the regimen and emotional subscale are combined to form one subscale.

**Table 4.3 Factor loadings for the DDS scale**

|  |  |
| --- | --- |
| DDS Item | Component |
| Regimen/ emotional related distress | Interpersonal distress | Physician related distress |
| Not feeling motivated to keep up my diabetes self-management | .86 |  |  |
| I am often failing with my diabetes treatment | .80 |  |  |
| Feeling that I will end up with serious long-term complications no matter what I do | .75 |  |  |
| I do not feel confident in my day to day ability to manage diabetes | .74 |  |  |
| Feeling that I am not sticking closely enough to a good meal plan | .73 |  |  |
| I am not testing my blood sugars frequently enough | .70 |  |  |
| Feeling overwhelmed by the demands of living with diabetes | .69 |  |  |
| Diabetes is taking up too much of my mental and physical energy | .68 |  |  |
| I feel angry, scared and/or depressed when I think about living with my diabetes | .64 |  |  |
| Feeling that friends or family don't give me the emotional support that I would like |  | .82 |  |
| Friends or family are not supportive enough of my self-care efforts |  | .73 |  |
| Feeling that friends or family don't appreciate how difficult living with diabetes can be |  | .66 |  |
| Diabetes controls my life |  | .55 |  |
| My doctor doesn't know enough about diabetes and diabetes care |  |  | .86 |
| My doctor doesn't give me clear enough directions on how to manage my diabetes |  |  | .73 |
| My doctor doesn't take my concerns seriously enough |  |  | .66 |
| Feeling that I don't have a doctor who I can see regularly about my diabetes |  |  | .65 |

**4.4.4 Treatment of Scales**

All scales showed good internal consistency. Internal reliability was good for total DDS (α = 0.93) and subscales (regimen/emotional related distress (α = 0.93), physician related distress (α = 0.79), interpersonal distress (α = 0.79), the HADS-D scale (α = 0.83) and the HADS-A scale (α=0.79)). The two DDS screening questions correlated highly with the total DDS scale (r = 0.91, p<0.01). Given the quality of results of this factor analysis and high alphas obtained for the three subscales, we used these three scores in subsequent analyses.

**4.4.5 Aim i: determine the prevalence of depression, anxiety and diabetes-related distress among young people with Type 1 DM**

Twenty-seven (28%) patients reported symptoms indicative of clinical anxiety and ten (11%) reported depressive symptoms indicative of depression. This is comparable to previous work with a healthy age matched sample (White et al., 1999). There was no significant difference between mean HADS-D scores for our sample (2.93 ± 3.39) and an age-matched sample without Type 1-DM (3.34 ± 3.2; t(200)=0.82, p>0.05 (Jorngarden, Wettergen, & von Essen, 2006). There was no significant difference between mean HADS-A scores for our sample (5.74 ± 3.5) and a sample of young people without Type 1 DM (6.14 ± 4.1; t(200)=0.74, p>0.05; Jorngarden et al., 2006). There were no significant associations between any demographic or medical variables with HADS-D or HADS-A, except longer duration of diabetes, which was associated with lower depression scores (*r*=-0.27, p<0.01) but not anxiety scores (*r*= -0.17, r>0.05).

For DDS, thirty two patients scored over the threshold for distress, mean item score (2.02 ± 0.9) was comparable to a previous study with adults with diabetes (2.1±1.0; t(198)=0.73, p>0.05, Fisher et al., 2010). Diabetes-related distress was not related to any demographic variables or insulin regimen.

**4.4.6 Aim ii: Determine gender differences in depression, anxiety and diabetes related distress**

Females reported significantly higher anxiety (4.13 ± 2.6) than males (6.78 ± 2.6, t(94) = 4.14, p<0.01) and reported significantly higher DDS score (2.30 ± 0.9) than males (1.62 ± 0.6, t(94) = -4.47, p<0.01) on the whole scale, and on each subscale (table 4.4). There were no significant gender differences within our sample for depression scores or any of the demographic variables. Females (10.34% ± 2.2) had a significantly higher HbA1c than males (9.45% ± 1.8, t(94) = 2.10, p<0.05).

**4.4.7 Aim iii: determine the relationship of depression, anxiety and diabetes related distress to HbA1c**

HbA1c was not related to anxiety (*r*=0.12, p >0.05), age (*r*=0.02, p >0.05), duration of diabetes (*r*=-0.90, p >0.05), and age at diagnosis (*r*= 0.09, p >0.05). Depressive symptoms (*r*=0.27, p<0.05), and DDS scores (*r*=0.43, p<0.01) were related to higher HbA1c. Given the associations between DDS scores, depressive symptoms and suboptimal HbA1c, we examined the mediating effect of DDS scores on HbA1c.

**4.4.8 Aim iv: determine if the relationship between depressive symptoms and HbA1c is mediated by diabetes-related distress**

In testing the mediating effect of DDS score on the relationship between HbA1c (see table 4.5) and depressive symptoms we found that i) HADS-D scores were associated with HbA1c, ii) HADS-D scores were significantly associated with DDS scores, iii) DDS score was related to suboptimal HbA1c, and iv) in the full regression model predicting HbA1c, HADS-D was no longer significant whilst DDS score remained significant, indicating a mediation effect. The Sobel test showed a statistically significant mediation effect of DDS score on the relationship between HADS-D and HbA1c (Z=4.05, p<0.01). Post-hoc probing (Holmbeck, 2002), showed a high percentage of the relationship between depression and HbA1c to be accounted for by DDS score (62.4%, p<0.05). This model explained 18% of the variance in HbA1c. Gender was not a significant covariate in the final regression model and was therefore removed from the analyses. Depression was not found to mediate the relationship between diabetes related distress and HbA1c.

**Table 4.4 Comparisons between psychological variables and gender**

|  |  |  |  |
| --- | --- | --- | --- |
| Measure | Males | Females | P-value |
| HADS-A n=94 | 4.13 ± 2.6  | 6.78 ± 2.6  | <0.01 |
| HADS-D n = 94 | 2.18 ± 2.3 | 3.43 ± 3.9 | NS |
| DDS n = 96 | 1.62 ± 0.6 | 2.30 ± 0.9 | <0.01 |
| Regimen/ emotional distressn = 96 | 1.90 ± 0.7 | 2.70 ± 1.2 | <0.01 |
| Interpersonal distressn = 96 | 1.50 ± 0.7 | 2.09 ± 0.9 | <0.05 |
| Physician distressn = 96 | 1.19 ± 0.4 | 1.49 ± 0.8 | <0.01 |

*Note*. Data are mean ± sd. *Abbreviations.* NS, not significant

**Table 4.5 Results of regression analyses following the hypotheses of the mediation model**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Hypothesis | Coefficient (β) | CI | *R*2 | P |
| i) depressive symptoms predicting HbA1c | .29 | 0.05 to 0.30 | 0.08 | <0.01 |
| ii) depressive symptoms predicting DDS scores | .51 | 0.08 to 0.18 | 0.26 | <0.01 |
| iii) DDS scores predicting HbA1c | .40 | 0.52 to 1.44 | 0.16 | <0.01 |
| iv) depressive symptoms predicting HbA1c correcting for DDS scoreDDS score predicting HbA1c correcting for depressive symptoms | .11.35 | -0.07 to 0.200.30 to 1.37 | 0.17 | *p=*0.074<0.01 |

*Notes:* i), ii), iii) univariate analyses; iv) multiple-regression analyses

***DDS screening questions***

Given the high correlation between the DDS screening questions and DDS scores, the above analyses were repeated using the mean score for the screening questions, and similar results were observed. The screening questions correlated with HbA1c (*r*=0.33, p<0.01) and HADS-D (*r*=0.39, p< 0.01). When using screening questions rather than total score in the regression model, results were as above and confirmed that in the final step HADS-D loses significance (B= 0.18, p>0.05) whilst the DDS screening score remains significant (B=0.26, *R*2= 0.14, p<0.01). This final model explained 14% of the variance in HbA1c.

***Which type of distress best predicts HbA1c***

Given that diabetes related distress was a significant predictor of HbA1c we conducted further analyses to determine the contribution of each DDS subscale to HbA1c. HADS-D score was added to the analyses to control for the proportion of the variance accounted for by depression. All subscales were significantly correlated with HbA1c (*r* between 0.30 and 0.38; p <0.01). In stepwise regression analyses HADS-D, regimen/emotional related distress, physician related distress, interpersonal distress were entered together. Regimen/emotional related distress was shown to be the only variable associated with HbA1c (B= 0.59, CI= 0.07-1.11, *R*2=0.16, P<0.01) accounting for 16% of the variance. This would suggest that higher regimen/ emotional related distress was significantly related to higher HbA1c.

**4.5 Discussion**

This study was prompted by the previous work of Fisher and colleagues (Fisher et al., 2007, 2008b, 2010a, 2010b, 2012) and (Van Bastelaar et al., 2010), who argued that diabetes related distress rather than depression is related to HbA1c in diabetes. These findings would have important implications if they could be replicated with young people with Type 1 DM because it would suggest that interventions should target diabetes related distress. In addition to investigating the relations between these variables the prevalence of depression, anxiety and diabetes related distress in this cohort and any differences between genders on these variables were reported.

PCA was conducted on the DDS (Fisher et al., 2008a; Polonsky et al., 1995) to confirm the subscales previously described (Fisher et al., 2008a). The reliability analysis confirmed that the scale is suitable for use with this sample given the high Cronbach alphas obtained. The PCA revealed three components which together explained 68% of the variance in the responses. The three components were identified as regimen/emotional related distress, physician related distress and interpersonal distress. This is a similar factor structure to that suggested by Fisher et al. (2008a). However, two subscales have been collapsed into one subscale, regimen/emotional related distress. The young people do not seem to discriminate between the regimen and emotional distress found in the previous study (Fisher, 2008a).

The prevalence of symptoms of depression and anxiety were comparable to age related comparison data (White et al., 1999). In contrast to previous evidence suggesting adolescent females in the general population have significantly higher depressive symptoms than males (Lewinsohn, Striegel-Moore, & Seeley, 2000), we found that depressive symptoms were comparable between males and females in our sample. This is in line with more recent work by Seedat et al. (2009) which suggested the gender gap in depression rates is closing.

The results suggest the females in our sample are more anxious than the males in our population. Additionally, in univariate analyses, both depressive symptoms and diabetes-related distress were associated with glycaemic control, anxiety was not. As previously reported (Fisher et al., 2010a; Van Bastelaar et al., 2010), in multivariate analysis, diabetes related distress, and not depressive symptoms was associated with HbA1c. This suggests diabetes related distress is a mediator of the relationship between depressive symptoms and glycaemic control. Previous evidence suggests this may be a result of diabetes related distress adversely affecting self-management and adherence to treatment regimens with negative implications for glycaemic control (Gonzalez, Delahanty, Safren, Meigs, & Grant, 2008).

These results extend previous findings from adult populations (Fisher et al., 2007, 2008b, 2010a, 2010b, 2012; Van Bastelaar et al., 2010) that diabetes related distress is related to glycaemic control. To conclude, in this sample at least, diabetes related distress is a predictor of suboptimal HbA1c in this age group and mediates the relationship between depressive symptoms and HbA1c. Additionally, specific distress associated with emotions and the diabetes regimen was found to be more important in determining glycaemic control than physician related or interpersonal distress. Specifically we found higher regimen/emotional related distress was related to higher HbA1c, indicating the young people are distressed at the treatment regimen associated with Type 1 DM.

**4.5.1 Strengths and limitations**

The findings from this study should be considered within the context of the limitations of the measures used, the sample studied and the cross-sectional nature of the data. It was difficult to identify measures of depression and diabetes related distress appropriate for the target age group. Although the HADS is a well-validated measure of depression and anxiety it was originally developed for adults, but has been previously used with younger samples (White et al., 1999). Additionally, the DDS was developed for an older sample that included both Type 1 DM and Type 2 DM (Fisher et al., 2008a; Polonsky et al., 1995) and has only been validated for use in adult samples. This could cause issues given the developmental differences between adults and young people causing potential differences in item comprehension and the way responses to items are made.

The lack of age sensitive measures is especially important when comparing scores with population norms since there was no directly comparable data. Consequently, in the absence of appropriate norms, diabetes related distress in young people with Type 1 DM was compared to an older sample with Type 2 DM (Fisher et al., 2008b). Further, given that in this study a five point Likert scale was used where previous studies (Fisher et al., 2008b) had used 6-point Likert scales a different cut-off point for distress worthy of clinical attention was used, making direct comparability difficult.

This study did not use a measure of social deprivation. This is may have affected the results and interpretation. Those of lower socio-economic status may find it more difficult to attend the specialist diabetes clinics and access resources, leading to suboptimal glycaemic control. In not measuring results we could not detect whether rates of depression, anxiety and diabetes related distress were related to socio-economic status. In summary, this affects the ability of this study to be applied to the population as a whole as it may be the case that only those of higher socio-economic status were captured.

Finally, given the small sample size, it is possible that although there is enough power to conduct a factor analysis, and there may not have been enough power to identify all the significant relationships in the main analyses. This increases the possibility that Type II errors may have been made. Further data collection will be carried out during Phase 2 of the overall CLAHRC study, this will involve a greater number of hospitals from different NHS Trusts thus yielding a greater sample size, and providing a stronger analysis.

 Additionally given the cross-sectional nature of the data, causality in the relationship between diabetes related distress and glycaemic control cannot be inferred. Suboptimal glycaemic control may lead to neglect of self-care behaviours, leading to greater distress, or conversely higher distress may lead to neglect of self-care behaviours and consequent suboptimal glycaemic control. Further, criticisms of the use of meditational analysis on cross-sectional data have been made (Maxwell & Cole, 2007), with evidence of bias found in previous cross-sectional mediation analyses. For these reasons this study requires replication, especially given the low numbers above cut-off for each psychological variable.

A strength of this study was in the use of a specific measure of the distress arising from diabetes care and treatment. General measures of distress do not allow us to distinguish whether diabetes or other everyday stressors are the cause of poor glycaemic control. For this reason, a specific measure of diabetes related distress that enabled the comparison of findings with those conducted in adult populations (Fisher et al., 2008b) was used. Despite the lack of appropriate norms, the DDS was well accepted by this age group and appeared to have adequate face validity. It was relatively quick to complete and there were few missing data. Fisher et al., (2008b) reported the reading age of the DDS to be within recommended levels for this population, but a larger sample is needed to confirm the factor structure in this age group.

Although the mean HbA1c for our sample (9.98 ± 2.1), was considerably higher than the recommended level of ≤7.5%, it was comparable to a previous study in young people with Type 1 DM (Wills et al., 2003). A good response rate (79.3%) was obtained and included young people from a wide range of backgrounds, including those who do not regularly attend clinic appointments. In this respect, we believe this to be a representative sample and is not biased due to the inclusion of young people with a wide range of glycaemic control (range= 6.45 - 15.40).

**4.5.2 Clinical implications**

This study provides support for the significance of distress in the treatment of Type 1 DM. In particular, for the acknowledgement of the possible presence of distress arising from the treatment regimen in the design and implementation of interventions. Interventions with this age group should focus on reducing diabetes-related distress, especially those areas indicated by the regimen/emotion related distress scale (e.g. ‘feeling that I am often failing with my diabetes regimen’).

Support is also obtained for the separate screening of depression and diabetes related distress. Although there is evidence for the improvement in screening for mental health symptoms in those with diabetes in the UK (Lloyd, Gill, & Stone, 2013), diabetes related distress is not currently screened for separately. The two DDS screening items correlate highly with the total DDS scale and provide a quick and efficient assessment of diabetes related distress which could be easily implemented within a clinic setting. For those scoring above cut-off on the screening questions, the full scale could then be administered to diagnose the type of distress the young person is experiencing. The availability of this brief screening tool meets some of the criteria set by the (National Screening Committee, 2003) that the *“benefit of the screening programme should outweigh the physical and psychological harm [caused by the measure]”.* Clearly, beyond the short measures it is also essential to make appropriate interventions for this age group available.

**4.6 Conclusion**

The results of this study indicate that at least in this sample the relationship between depressive symptoms and HbA1c is mediated by diabetes related distress. This has now been established for both Type 1 and Type 2 DM and across a wide age-range and appears robust even when different measures of diabetes distress are used. However, the amount of variance was relatively small (18%) suggesting other variables make a significant contribution to predicting HbA1c. Several barriers to adherence specifically in this age group including family conflict, psychological issues, and carbohydrate counting (Lancaster et al., 2010) should be investigated in future work. Interventions need to address the specific problems associated with managing diabetes as well as clinical depression.

**Chapter 5**

**Behaviour Change Interventions for Young People with Type 1 DM: A Systematic Review and Meta-Analysis**

**5.1 Summary**

This chapter reports a systematic review and meta-analysis with the aim to identify i) the efficacy of behaviour change interventions to improve glycaemic control and psychological outcomes in the short and longer term, and ii) behaviour change techniques and iii) delivery characteristics (mode of delivery: individual, family, group; setting; facilitator; duration of intervention) associated with the most effective interventions.

A systematic search of nine databases was conducted to identify randomised controlled trials, conducted between 1999 and 2013, of behaviour change interventions for young people (8-21 years) with Type 1 DM. Behaviour change techniques were coded using a systematic taxonomy.

Twenty-seven trials were identified. There was a small but significant improvement in glycaemic control in the short term (d+=0.26, CI= 0.09 to 0.43), which was maintained in the longer term (d+=0.29, CI= 0.08-0.50). The most effective behaviour change technique was ‘goal setting’ (d+=0.38, CI= 0.17 to 0.60). Meta-regression showed mode of delivery to be a significant predictor of glycaemic control (B=0.24, t=1.72 p<0.05). There was a small improvement in psychological outcomes (d+=0.28, CI= 0.13 to 0.43).

This is the first time a systematic taxonomy has been used to code behaviour change techniques in order to evaluate interventions for young people with Type 1 DM. The results show behaviour change interventions can contribute to improved glycaemic control and psychological outcomes. Interventions directed at the individual rather than group and incorporating goal setting appear to have the most potential for success.

**5.2 Introduction**

In the field of health psychology, behaviour change interventions can be defined as:

 “*coordinated sets of activities designed to change specific behaviour patterns”* (Michie, Ashford, et al., 2011).

Behaviour change interventions have been used to change or improve a wide range of health behaviours from increasing fruit and vegetable consumption (Pomerleau, Lock, Knai, & McKee, 2005) to improving self-management behaviours in chronic conditions (Newman, Steed, & Mulligan, 2004). In terms of Type 1 DM these interventions fall under two broad categories, psychosocial and educational interventions. Psychosocial interventions address the psychological aspects of either the individual or the group and usually provide social support, counselling, problem-solving skills, coping skills, skills of communication or a combination of all. Educational interventions aim to increase the knowledge of the participants about a range of topics related to the individual’s life. In the case of Type 1 DM this usually includes increasing knowledge of self-management skills, future complications and “sick-day rules” (what to do when feeling ill).

Behaviour change interventions have been reported to have the potential to improve medical and psychological outcomes in children and young people with Type 1 DM (Hampson et al., 2001; Murphy, Rayman, & Skinner, 2006; Winkley, Landau, Eisler, & Ismail, 2006). An early review (Hampson et al., 2001) reported interventions which had been trialled up until 1998. This review identified 25 randomised controlled trials of behavioural interventions for young people (9-21 years). Fourteen of the included studies had enough data to allow for the calculation of effect sizes. The mean pooled effect size for the 14 studies was 0.37 for psychosocial outcomes and 0.33 for HbA1c. This is deemed a small to medium effect and for HbA1c equated to an overall reduction of 0.60%.

A later review focusing on diabetes-education programmes found a smaller effect on HbA1c (Murphy et al., 2006). Twenty-four interventions were identified with effect sizes calculated for nine. Pooled mean effect of intervention on HbA1c was 0.11 and on psychosocial outcome was 0.35. A further meta-analysis included a search for interventions targeting adults or young people. Of the 10 trials identified with young people as a target group that had enough data to calculate effect sizes, a small effect size for medical and psychological outcomes (Winkley et al., 2006) was observed. One limitation common to the previous reviews is a lack of studies which were eligible for inclusion. This reflects the relative lack of research in this population in general in comparison to adults and children with Type 1 or Type 2 DM. However, the evidence there is available needs to be utilised effectively.

Attempts have been made to identify the characteristics of effective interventions in this age group. Family based interventions have shown greater improvements in medical outcomes than individual or group interventions (Winkley et al., 2006). Additionally, a study in adolescents without diabetes from low-income families (Michie, Jochelson, Markham, & Bridle, 2009) concluded that at least in this sample, those interventions using fewer techniques were the most effective. Two further studies (Murphy et al., 2006; Winkley et al., 2006) were also unable to draw conclusions on the characteristics of effective interventions and so there remains a lack of clarity and consistency in reporting intervention content.

Keen, (2010) highlighted the need for clear reporting of intervention content, stating many psychological interventions are broad approaches (e.g. cognitive behavioural therapy) which often encompass different behavioural techniques. Additionally, different names may be used to describe a group of related techniques (Keen, 2010), complicating synthesis of intervention research. These issues can hinder synthesis of intervention research and may prevent the identification of beneficial techniques that could be employed usefully in future interventions. Indeed, it is currently difficult to identify which techniques have been investigated to date, let alone establish which are the most effective.

Similar criticisms have been made of health behaviour change interventions in general (Keen, 2010). Considerable recent attention has been given to developing a universal taxonomy to describe discrete active components of behaviour change interventions (Abraham & Michie, 2008; Michie, Hyder, Walia, & West, 2011). This approach allows researchers to compare across interventions in order to select the most appropriate behaviour change techniques. To date there are no published articles applying a taxonomy to existing interventions for young people with Type 1 DM.

Following guidelines for the development of complex interventions (Craig et al., 2008) and as a preliminary to developing an intervention specifically for young people aged 16-21 years (see chapter 6); this chapter reports a meta-analysis to extend previous reviews. The rationale for conducting this meta-analysis is based on the following points. First, in previous reviews, intervention content was frequently unclear (Keen, 2010) making it difficult to identify which behaviour change techniques had been used, or were more effective. Second, intervention delivery characteristics such as increased contact time, or differences between intervention facilitators may affect outcomes (Keen, 2010) and have not previously been explored. Third, previous reviews have generally failed to analyse results according to length of follow-up. Thus it is not known if interventions that do work are effective only in the immediate period afterwards, or remain effective for months or even years.

**5.2.1 Study aims**

1. Assess the efficacy of interventions to improve glycaemic control and psychological outcomes in the short and longer term,
2. identify effective behaviour change techniques,
3. identify characteristics of intervention delivery associated with effectiveness in young people with Type 1 DM.

**5.3 Methods**

This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009), with the exception that a formal protocol was not published.

**5.3.1Search strategy**

The following databases were searched: Science Citation Index; Social Science Citation Index; MEDLINE; PsycINFO; ProQuest; CINAHL; Embase; Cochrane database of systematic reviews; and Conference proceedings citation index. The following search terms were used with Boolean logic and Medical subject headings (MeSH) where possible: i) Type 1 diabet\*, diabet\*, insulin dependent diabet\*, IDDM, juvenile diabet\*; ii) psychological intervention\*, psychosocial intervention\*, educational intervention\*; iii) young people, teen\*, adol\*, young person, young adult\*; iv) randomised controlled trial\*, clinical trial\*, controlled clinical trial\*, random allocation. Reference lists of relevant articles and citations from included studies and previous reviews were hand searched. Searches were limited to papers published between 1999 and March 2013 for this systematic review and meta-analysis. This start date was chosen due to concerns that developments in research of Type 1 DM over the last two decades have led to a large increase in flexibility in treatment. Any interventions before this point may therefore be less useful in improving the outcomes of our target group due to the difference in treatment approach.

**5.3.2 Inclusion and exclusion criteria**

 Inclusion criteria were English language articles of randomised controlled trials in young people with Type 1 DM diagnosed at least 6 months prior to the study and aged between 8 and 21 years on study entry. Only studies with a control group and including outcome measures of glycaemic control (HbA1c) or a validated psychological measure were included. Exclusions were samples with co-morbid chronic conditions for example asthma or cystic fibrosis, and those studies which did not provide enough information to calculate an effect size.

**5.3.3 Study selection**

SB independently performed literature searches and SB and KA assessed the eligibility of abstracts for inclusion in the review. Where differences between reviewers occurred or ambiguity was present, full papers were retrieved and disagreements resolved through discussion.

**5.3.4 Data extraction**

Data were extracted from each study using a data extraction form developed using the CONSORT guidelines (Moher et al., 2010) and piloted with the wider CLAHRC-SY Health Psychology team. A second member of the team was trained to use the data extraction form and second coded the studies in order to ensure accuracy. Information on the following variables was extracted: a) study population, b) study characteristics, c) intervention characteristics, d) control group characteristics, e) behaviour change technique f) outcome variable. Where these details were not available or unclear within the articles obtained, authors were contacted for further clarification by email.

With regards the study population the following information was extracted: sample size at baseline and follow up, age (years), gender (% male), and duration of diabetes (years). For study characteristics the following information was extracted: author, year of publication, country. For intervention and control group characteristics information was extracted under the same categories: type of intervention (what was the intervention), mode of delivery (group, family, individual), setting (clinic, community, home), facilitator (health care professional, research assistant, intervention specialist, psychologist, technology, peer), duration of intervention (both months over which the intervention was carried out and minutes of contact time), and duration of follow-up (months).

Data on behaviour change techniques were extracted using the 40-item Behaviour Change Technique Taxonomy (Michie et al., 2011). Each item was scored as 0 (not present) or 1 (present), and summed to yield a total score with possible range between 0 and 40. For the outcome variable HbA1c, the mean and standard deviations of HbA1c at baseline and at all follow-up time points were extracted. For psychological outcome, the type of variable (diabetes-related distress, depression, anxiety), measure used, and mean and standard deviation score at follow up were collected.

If any information was not present or unclear the principal author was contacted. Inter-rater reliability was calculated using Cohen’s Kappa (*κ*) for categorical variables and Intra-class correlations (ICC) for continuous variables.

**5.3.5 Quality assessment**

Study quality and risk of within study bias was assessed using the Jadad checklist (Jadad et al., 1996) for randomised controlled trials. The checklist includes three main quality criteria (selection, attrition, and detection biases). Studies were categorised as follows: A (all quality criteria met), B (one or more of the quality criteria met-moderate risk of bias), C (more than one criteria not met- high risk of bias).

**5.3.6 Statistical analyses**

Data were entered into SPSS 20 (IBM Statistics, Chicago, IL, USA). For all studies effect sizes (*d*+) were calculated for all outcomes for which the necessary data were available. Intervention effect was assessed by the interaction between group (intervention versus control) and time (baseline versus follow-up). The formula used to calculate these effect sizes was as follows:

(Difference between group means

 at follow-up) – (Difference between

 group means at baseline)

Pooled SD at baseline

 This eliminated the possibility of unreliable results arising from baseline differences, the higher the value the greater the effect. A positive effect reflects an improvement in the outcome in the intervention group relative to the control group (an effect in the expected direction). A negative effect reflects an improvement in the control group relative to the intervention group (an effect in the opposite direction to that expected). The majority of effect sizes tend to fall between the values -1 and +1 although it is possible for an effect size to fall outside this range. Published guidelines (Cohen, 1992) were used to interpret effect sizes (*d+* ≤0.2 = small effect size, *d+* ≤0.5 = medium effect size and *d+* ≤0.8 = large effect size). The standard error of each effect size was estimated according to the formula provided by Cooper, Hedges, and Valentine (2009) using the estimated effect size and sample sizes.

For HbA1c, short-term follow-up was defined in terms of the effect size calculated up to 6 months after the intervention. In some cases the data also allowed for the calculation of long-term follow-up, this was based on effect sizes at the time point longest from delivery of the intervention (but over 6 months). This included data published in subsequent papers.Due to the more limited information available for psychological variables, a single follow-up based on effect sizes at the furthest time point since the intervention was calculated.

Meta-analyses were conducted on HbA1c and psychological variables using the revised *metan* command in STATA 11.2 (Statacorp, 2009). Following a previous review (Winkley et al., 2006), where multiple psychological outcomes were measured within a single trial a mean effect size was calculated to estimate overall impact on psychological variables. Standardised effect sizes were weighted by sample size and pooled in a random effects model as the variation between trials was expected to be high.

Heterogeneity between trials was assessed using Cochran’s Q and its associated *p*-value and the I2 statistic. Statistical heterogeneity refers to differences between the results of studies which cannot be attributed to chance alone (Sterne et al., 2011). These differences could arise due to moderators such as different methodologies used or different study characteristics (e.g. different age groups, different interventions, different settings). Where Cochran’s Qstatistic was non-significant, heterogeneity between studies was assumed and possible moderators explored.

Where heterogeneity between trials was present, effect sizes were regressed onto the potential moderators which were coded during data extraction using random effects meta-regression with restricted maximum likelihood estimation and the improved variance estimator (Knapp, Biggerstaff, & Hartung, 2006). The revised *metareg* command in STATA 11.2 was used for this. Here regression coefficients (B) show the estimated increase in effect size for one unit increase in the moderator variable. Additionally adjusted R2 indicates the percentage of heterogeneity explained by the moderator.

Publication bias for the effect of intervention on HbA1c was estimated with a funnel plot using the *meta funnel* command. In the absence of publication bias the funnel plot should be roughly symmetrical and resemble an inverted funnel shape, (Stern et al., 2011). Given disputes surrounding the statistical validity of this test (Stern et al., 2011), publication bias was also assessed more formally using the Begg and Mazumdar (1994) adjusted rank correlation test in the *meta bias* command in STATA. This is the statistical analogue of the funnel plot.

**5.4 Results**

**5.4.1 Study characteristics**

A total of 3,964 articles were extracted. Once duplicates were removed (n= 3,412) a total of 552 abstracts were screened, from which 48 full texts were extracted for further review. Fourteen of these did not meet the inclusion criteria and were excluded. There was substantial agreement between reviewers for categorical (*k*= 0.85) and continuous variables (ICC= 0.95). Twenty-seven trials reported across 33 articles were deemed appropriate for inclusion in the review. Figure 5.1 shows the flow of studies considered for review. Analysis of study quality revealed five trials scored in category A (low risk of bias), 20 in category B (moderate risk of bias) and two in category C (high risk of bias). Given the relatively small number of studies deemed suitable for inclusion in this review, we included all categories in analyses.

Study characteristics are reported in table 5.1, and are synthesised descriptively here. Fifteen of the trials were conducted in the USA (Ambrosino et al., 2008; Charron-Prochownik, Ferons-Hannan, Sereika, & Becker, 2008; Cook, Herold, Edidin, & Briars, 2002; Ellis et al., 2005b; Grey et al., 2009; Hains, Davies, Parton, Totka, & Amoroso-Camarata, 2000; Laffel et al., 2003; Lehmkuhl et al., 2010; Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010; Nansel et al., 2007; Wang et al., 2010; Whittemore, Jaser, Jeon, et al., 2012; Wysocki et al., 2000), three in the UK (Channon et al., 2007; Franklin, Waller, Pagliari, & Greene, 2006; Murphy, Wadham, Hassler‐Hurst, Rayman, & Skinner, 2012), three in Canada (Lawson, Cohen, Richardson, Orrbine, & Pham, 2005; Olmsted, Daneman, Rydall, Lawson, & Rodin, 2002; Panagiotopoulos, Preston, Stewart, Metzger, & Chanoine, 2003), and one from each of Austria (Rami, Popow, Horn, Waldhoer, & Schober, 2006), Australia (Couper, Taylor, Fotheringham, & Sawyer, 1999), France(Gay et al., 2006), Norway (Graue, Wentzel-Larsen, Hanestad, & Sovik, 2005), Sweden (Viklund, Örtqvist, & Wikblad, 2007), and the Netherlands (de Wit et al., 2008). Initial sample sizes ranged from 15 to 320 (mean=87.07, SD=71.01) yielding a total sample size of 2,259.

Nine interventions were delivered at home (see table 5.1), eight in hospital, and two in the community. Eight trials did not include this information. Interventions were directed at the individual (n=12), groups (n=10), or family (n=5). Interventions were delivered by health care professionals (n=12), technology (n= 5), psychologists (n=4), research assistants (n= 4), or intervention specialists (n=2). None were delivered by peers. Thirteen of the interventions lasted between one and five months, thirteen between six and 12 months, and one over 12 months. The mean duration of follow-up was 5.33 months (SD 5.8, range = 0-24 months).

**5.4.2 Sample characteristics**

The mean age of participants across all trials was 13.98 years (SD 1.7) and ranged from 9.91 to 17.40 years. Mean duration of diabetes was 6.28 years (SD 1.3). Mean HbA1c was high at study commencement (9.9%, ± 2.1). Eight of the included trials specifically selected participants with sub-optimal control, with cut-offs between 8.0% and 10.0%.

**Figure 5.1 Study selection process**

Records identified through database searching
(n = 3,964 ), duplicates removed (n=3,412)

## Screening

## Included

## Eligibility

## Identification

Additional records identified through other sources
(n = 138 )

Records screened
(n = 552 )

Records excluded
(n = 404 )

Full-text articles assessed for eligibility
(n = 48 )

Full-text articles not meeting inclusion criteria.
(n=14)

Reasons for exclusion:

Sample too young (n=7)

Non-RCT (n=4)

Type 2 DM (n=3)

Studies included in qualitative synthesis
(n = 34 )

Studies included in quantitative synthesis (meta-analysis)
(n = 27)

Studies excluded from meta-analysis due to missing data.

(n=7)

**Table 5.1: Characteristics of included trials**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Author, country, year | Number randomised/ at follow up | Intervention | Mode of delivery | Facilitator | Setting | Duration of intervention | Control | Duration of follow up | Quality rating |
| Ambrosino, USA, 2008  | 111/79 | Coping skills training | Group | Health care professional | \*Not specified | 6 weeks | Group education | 3 months | B |
| Channon, UK, 2007  | 80/60 | Motivational interviewing | Individual | Health care professional | Home | 6 months | Non-directive support visits | 12 months | A |
| Charron-Prochownick, USA, 2008  | 37/37 | Educational/supportive CD | Individual | Technology | Clinic | 1 hour | Standard care | 3 months | B |
| Cook, USA, 2002  | 53/48 | Problem solving diabetes education | Group | Research assistant | Clinic | 6 weeks | Standard care | \*4 months | B |
| Couper, Australia, 1999  | 69/51 | Support  | Individual | Health care professional | Home | \*6 months | Standard care | 12 months | C |
| deWit, Netherlands, 2008  | 91/81 | Monitoring and discussing health related quality of life | \*Individual | Health care professional  | Clinic | 12 months | Standard care | Immediate | B |
| Ellis, USA, 2004  | 25/25 | Multisystemic therapy  | Family | Intervention specialist | Community | 6 months | Standard care | Immediate | B |
| Ellis, USA, 2005a, 2005b, 2007  | 127/127 | Multisystemic therapy | Family | Intervention specialist | Community | 6 months | Standard care | \*7 months | B |
| Franklin, UK, 2006 | 61/59 | Sweet talk text messaging | \*Group | Technology | Home | \*12 months | Standard care | Immediate | A |
| Gay, France, 2006  | 100/71 | Reinforced follow up | Individual | Health care professional | Home | 6 months | Standard care | Immediate | B |
| Graue, Norway,2005  | 101/83 | Education | Group | Health care professional  | \*Not specified | 15 months | Standard care | 9 months | B |
| Grey, USA, 2000 | 75/75 | Coping skills training | Group | Health care professional | \*Not specified | 6 weeks | Standard care | 12 months  | B |
| Grey, USA, 2009  | 111/82 | Coping skills training | Group | Health care professional | \*Not specified | 6 weeks | Group education | 12 months  | B |
| Hains, USA, 2000  | 15/14 | Cognitive behavioural stress management training | Group | Psychologist | Clinic | 6 weeks | Waiting list | \*1 month | C |
| Laffel, USA, 2003  | 100/100 | Teamwork intervention | Individual | Research assistant | \*Not specified | 12 months | Standard care | Immediate | B |
| Lawson, Canada, 2005  | 46/23 | Telephone support | Individual | Health care professional | Home | 6 months | Standard care | 6 months | B |
| Lehmkuhl, USA, 2010  | 32/22 | Telehealth behaviour therapy | Family | Psychologist | \*Not specified | 12 months | Waiting list | Immediate | B |
| Mulvaney, USA, 2010  | 52/52 | Internet based self-management | Individual | Technology | Home | 11 weeks | Standard care | Immediate | B |
| Murphy, UK, 2012  | 305/295 | Family team work | Family | Health care professional | \*Not specified | 6 months | Standard care | 12 months | A |
| Nansel, USA, 2007, 2009  | 81/73 | Personal trainer intervention | Individual | \*Research assistant | Clinic | 2 months | Standard care | 24 months | B |
| Olmstead, Canada, 2002  | 85/81 | Psycho-education | Group | Psychologist | Clinic | 6 weeks | Standard care | 6 months | B |
| Panagiotopoulos, Canada, 2003  | 50/50 | Telephone support | Individual | Health care professional | Home | 6 months | Standard care | 6 months | B |
| Rami, Austria, 2006  | 36/36 | Telemedical support | Individual | Technology | Home | 3 months | Standard care | Immediate | C |
| Viklund, Sweden, 2007  | 55/32 | Empowerment education programme | Group | Research assistant | \*Not specified | 6 months | Waiting list | Immediate | B |
| Wang, USA, 2010  | 54/44 | Motivational interviewing education | Group | Health care professional  | Clinic | 4 months | Diabetes education | 6 months | B |
| Whittemore, USA, 2012  | 320/272 | Coping skills training | Individual | Technology | Home | 5 weeks | Internet education | 6 months | B |
| Wysocki, USA, 1996, 1999, 2000, 2001  | 79/76 | Behavioural familysystems therapy | Family | Psychologist | Clinic | 12 weeks | Standard care | 3 months | A |

\*Denotes where authors were contacted for further clarification.

**5.4.3 Aim i: Assess the efficacy of interventions to improve glycaemic control and psychological outcomes in the short and longer term,**

As shown in Figure 5.2, 22 studies included short-term follow-up data appropriate for meta-analysis. Using random effects analyses and pooling data across all 22 trials the overall effect size was small (*d+*= 0.16, CI= 0.01 to 0.30). Examination of Cochran’s Q suggested heterogeneity (Q= 43.41, p<0.05, I2=51.6), indicating variability in effect size across all trials. To give an indication of clinical relevance, this effect size was converted to HbA1c using the mean and standard deviation reported by Mortenson and Hougaard (1997). Results indicate average reductions in HbA1c of 0.3%.

**Figure 5.2 Effect of intervention on HbA1c**



0.16 (0.01, 0.30) 100.00

d+

Eight trials included short and long-term follow up data (Ambrosino et al., 2008; Charron-Prochownik et al., 2008; Couper et al., 1999; Ellis et al., 2005; Ellis et al., 2007; Grey et al., 2000; Nansel et al., 2009; Murphy et al. 2012; Panagiotopoulos et al., 2003). Pooling short-term data for these eight trials only, effect size was small (*d+*=0.26, CI= 0.09 to 0.43), indicating reductions in HbA1c of 0.4%. Examination of Cochran’s Q and I2 (Q=8.84, p>0.05, I2= 20.8) suggested little variation between effect sizes. A small but reliable effect was maintained in the long-term (*d+*=0.29, CI= 0.08 to 0.50) with a reduction in HbA1c of 0.5% (Q=11.74, p>0.05, I2=40.0).

***Publication bias***

A funnel plot based on all 22 included trials with HbA1c data was inconclusive (Figure 5.3). However, the Begg’s adjusted rank correlation test did not indicate the presence of bias (p>0.05).

**Figure 5.3 Funnel plot to assess publication bias**

***Effect of intervention on Psychological variables***

Although 21 studies included some measure of psychological outcome, 10 different psychological variables were included and measured using 22 different measures: quality of life (n=6 measures), social support (n=3), coping (n=3), distress (n=1), depression, (n=2), self-efficacy (n=2), conflict (n=2), anxiety (n=1), beliefs (n=1), and responsibility (n=1). Given this variation it would be inappropriate to pool all studies into meta-analyses. However, there were not enough studies measuring diabetes related distress to allow for analyses of intervention effects on this variable alone. As a result depression was included in the analyses. Five different scales were used to measure these three outcomes (Table 5.2).

**Table 5.2 Psychological variables and measures**

|  |  |
| --- | --- |
| Psychological Variable | Measure |
| Diabetes-related distress | Diabetes Stress Questionnaire (Boardway, Delamater, Tomakowsky & Gutai, 1993) |
| Depression | Centre for Epidemiologic Studies Depression Scale (Radloff, 1977); Children’s Depression Inventory (Kovacs, 1985); Well-being questionnaire (Bradley, 1994) |

Ten studies included data sufficient to calculate effect sizes, for those studies including more than one psychological outcome we calculated a mean effect size (Figure 5.4). With random effects meta-analyses the pooled estimate effect of intervention on psychological outcome was small but reliable (*d+*=0.22, CI= 0.05 to 0.40), with little variation between trials (Q= 14.91 p>0.05; I2= 39.6). Given the homogeneity within the data, further analyses of moderator variables was not possible.

**Figure 5.4 Effect of intervention on psychological outcomes**



d+

**5.4.4. Aim ii: Identify behaviour change techniques associated with improved HbA1c**

In order to identify the most effective behaviour change techniques the 40-item Behaviour Change Technique Taxonomy (Michie et al., 2011) was used. Where we were unable to distinguish between two similar behaviour change techniques, they were combined to form single items. ‘Goal setting (behaviour)’ and ‘goal setting (outcome)’ became ‘goal setting’; ‘prompt review of behavioural goals’ and ‘prompt review of outcome goals’ became ‘prompt review of goals’, and ‘prompt self-monitoring of behaviour’ and ‘prompt self-monitoring of behaviour outcome’ became ‘prompt self-monitoring of behaviour’. Twelve of the behaviour change techniques were not used in any intervention. As a result, a total of 25 different behaviour change techniques (Figure 5.5) were employed across all interventions. The number of techniques used in each intervention ranged from 1-9, mean number of behaviour change techniques used was 4.05 (SD 1.8). The most commonly used behaviour change techniques were prompt barrier identification/problem solving (n=17) and general communication skills training (n=12).

HbA1c effect sizes for each behaviour change technique were entered into separate meta-analyses (Table 5.3). Techniques supported by less than 3 interventions were not examined to ensure reliable evaluations. Eleven behaviour change techniques were examined, the largest effects on HbA1c were observed for interventions that provided goal setting (*d+*=0.39, CI= 0.17 to 0.60), information on the consequences of a behaviour (*d+*=0.33, CI=0.12 to 0.54) or relapse prevention/coping planning (*d+*=0.17, CI=0.03 to 0.32). The other eight behaviour change techniques showed no reliable effects. Overall, meta-regression analyses indicated that the total number of intervention techniques used does not have an impact on HbA1c (B=0.03, p>0.05).



Figure 5.5 Frequency of use of Behaviour Change Technique

**Behavour Change Technique**

**Table 5.3 Weighted average HbA1c effect sizes by behaviour change technique.**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Behaviour change technique | k | *d+* | 95% CI | Q |
| Goal setting (behaviour and outcome) | 9 | 0.39 | 0.17 to 0.60 | 4.32 |
| Provide information on the consequences of the behaviour to the individual | 5 | 0.33 | 0.12 to 0.54 | 5.27 |
| Relapse prevention/coping planning | 7 | 0.17 | 0.03 to 0.32 | 6.88 |
| Prompt barrier identification/problem solving  | 17 | 0.11 | -0.11 to 0.23 | 8.16 |
| General communication skills training | 12 | 0.13 | -0.01 to 0.28 | 6.88 |
| Stress management/ emotional control training | 4 | 0.13 | -0.02 to 0.32 | 1.19 |
| Provide feedback on performance | 8 | 0.12 | -0.06 to 0.32 | 9.92 |
| Plan social support/social change | 4 | 0.11 | -0.13 to 0.36 | 1.98 |
| Prompt self-monitoring of behaviour/outcome | 10 | 0.09 | -0.07 to 0.25 | 3.25 |
| Prompt practice | 4 | 0.07 | -0.20 to 0.35 | 2.62 |
| Motivational interviewing | 3 | 0.02 | -0.74 to 0.78 | 16.88 |

Note: k= number of studies using technique, d=weighted average effect size, Q= homogeneity across the subgroup of interventions,

**5.4.5 Aim iii: Identify characteristics of intervention delivery associated with improved HbA1c in young people with Type 1 DM**

Meta-regression was used to assess the impact of five moderator variables of intervention effects on HbA1c. These included a) age (years), b) mode of delivery (individual, group, family), c) facilitator (health care professional, research assistant, intervention specialist, psychologist), d) setting (clinic, community, home), and e) duration of follow up (months). Few associations were found. One feature of mode of delivery (individual) was shown to be associated with greater intervention effects on HbA1c (B=0.24, p<0.05, R2 =3.25). Pooled effect sizes for individual interventions had a reliable positive effect on HbA1c (d+=0.27, CI= 0.10 to 0.45), group and family interventions had no reliable effects.

***Description of the most effective intervention***

Given that it was inappropriate to conduct moderator analyses on the psychological variables due to homogeneity between the studies, here the intervention that was the most successful at improving psychological outcomes (Channon et al., 2007) will be discussed.

Channon et al., (2007) conducted a randomised controlled trial of a motivational interviewing intervention. The trial was conducted in the UK and aimed to improve the medical and psychological outcomes of participants (n=66) aged 14 to 17. The participants met individually with one of two intervention facilitators with a nursing background. In order to control for the effects that increased contact with a health care professional may have, the control group had non-directive support from a health care professional. The contact time between patient and health care professional was similar between groups. The authors described using goal setting, problem solving and motivational interviewing techniques. Relative to the control results showed the intervention group experienced reductions in depressive symptoms (F=4.33, p<0.05), and HbA1c at 12 months (F=4.28, p<0.05). The intervention effect on HbA1c was maintained at 24 month follow-up (F=9.71, p<0.05). Showing the intervention effects to be robust.

**5.5 Discussion**

This systematic review and meta-analysis aimed to extend previous reviews (Hampson et al., 2001; Murphy et al., 2006; Winkley et al., 2006) regarding the effects of behaviour change interventions for young people with Type 1 DM. This review extends previous findings in a number of ways. First, previous reviews have made attempts to identify techniques within interventions which lead to the greatest success. However, standardised definitions of these techniques have not been used making it difficult to replicate such techniques in further interventions. This review utilised a standardised taxonomy to code behaviour change techniques so that effective techniques are well defined. Second, this review not only identifies behaviour change techniques associated with effectiveness but also identifies intervention characteristics associated with effectiveness. Finally, unlike previous reviews the impact of the intervention in both the short and longer term is assessed.

In the 22 trials that included HbA1c as a primary outcome, small but reliable improvements were found in the short term (up to 6 months post-intervention) with a pooled overall reduction in HbA1c of 0.30%. This is lower than a previous review that reported a reduction of 0.48% (Winkley et al., 2006). However, in the nine studies with longer follow-up data (6 months to a year post intervention) a higher reduction in HbA1c of 0.40% was found, these short-term effects improved over time. The 15 interventions that assessed psychological outcomes also indicated small but reliable improvements. However, it was not possible to investigate the difference in effect over time given a lack of data available.

The small effect sizes found reflect the huge task those designing interventions to improve self-management face. Self-management in Type 1 DM involves a collection of inter-related behaviours. Interventions seeking to improve self-management in this chronic condition therefore have ambitions much greater than those interventions which target only a single behaviour (e.g. smoking cessation, alcohol intake). Those developing interventions for Type 1 DM may be better advised to target only a single intervention (e.g. increase frequency of blood glucose monitoring) rather than general self-management. This would also enable authors to describe their intervention more clearly.

The analysis in this study indicates that delivering a greater number of behaviour change techniques does not increase the impact on HbA1c, suggesting that, in interventions for young people with Type 1 DM, it is not the number but the type of techniques used that determines trial efficacy. Goal setting appeared to be the most effective behaviour change technique of the eleven included in analyses. The apparent effectiveness of providing goal setting to improve outcomes has been highlighted previously (Michie et al., 2009). However, the analysis in this study goes further than previous reviews and indicates that delivering information on the consequences of behaviour and relapse prevention/coping planning are also effective methods of decreasing HbA1c. These approaches have the benefit that they can be delivered by non-medical staff and therefore may be administered with considerable cost-effectiveness (Nansel et al., 2007). This is supported by the finding that the type of intervention facilitator does not have an effect the intervention efficacy.

This review also established that the mode of intervention delivery was associated with improved HbA1c. More specifically, interventions delivered to the individual were more effective than family or group based interventions. This contrasts with a previous review including children and adolescents (Murphy et al., 2006) which was unable to conclude about the effectiveness of mode of delivery (e.g. individual, group, family) on medical outcomes in young people (9-21 years). Finally, the type of intervention facilitator delivering the intervention did not appear to have an effect on the effectiveness of the intervention. However, analyses were based on a limited number of facilitators and none explicitly used peers as an intervention facilitator, despite evidence that peers can facilitate treatment adherence (Greco, Pendley, McDonell, & Reeves, 2001; LaGreca et al., 1995). The strongest support for the use of goal setting, and interventions delivered on an individual basis was further gained from Channon et al. (2009). This study had the largest effect on psychological outcomes and reduced HbA1c.

Although direct comparison of the quality of studies included in previous reviews is difficult, we found some evidence that study quality had improved. Based on the Jadad scoring system (Jadad et al., 1996) the 27 included trials were largely of moderate quality. Winkley et al., (2006) rated only one of 29 trials to be in category A compared with five of 27 in the current review. However, there remains need for improved trial design and detailed reporting of methods and results. In particular, information on participants and baseline data should be included as highlighted in recent CONSORT guidelines (Moher et al., 2010).

**5.5.1 Strengths and limitations**

This review was reported according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). This ensured the search and analysis was structured and accurately reported. The predefined inclusion and exclusion criteria minimised selection bias. The use of meta-analytical synthesis decreased uncertainty in results and allowed a detailed analysis of effects. Overall sample size was considerably larger than previous reviews (Hampson et al., 2001; Winkley et al., 2006) providing this information. Further, a standardised taxonomy of behaviour change techniques was used (Michie et al., 2011) and provides evidence for the potential value of specific techniques for future interventions.

A number of limitations must be acknowledged. Few trials targeted the age group (16-21 years) of specific interest to the overall CLAHRC project. As a result search criteria were extended to include children and young people aged 8-21 years. The huge developmental changes which take place at this time makes it unlikely that any single intervention will be fully appropriate across this broad age range. Interventions suitable for paediatric populations necessarily require family involvement, whilst those for young people must take into account individual developmental needs as well as account for growing responsibility. However, when adding age as a moderator this did not appear to have an impact on intervention efficacy. Furthermore, most of the included trials were conducted in the USA, which limits the generalisability of these findings. Additionally, despite a previous call for increased sample sizes in intervention research (Murphy et al., 2004) the sample sizes of the included studies remains relatively small, with implications for limited power. A table of sample sizes necessary for adequate power was proposed by Murphy et al., (2006) and is a useful guide to ensure studies are sufficiently powered.

There was a variation in baseline HbA1c for the participants in each study which may have had an effect on intervention effects. Those with high baseline HbA1c have a greater scope for improvement in comparison to those with near optimal HbA1c. It would be useful to control for this in future meta-analyses researching interventions in Type 1 DM. It may be the case that there is a difference between the interventions proving useful for those with near optimal HbA1c and those with suboptimal HbA1c. Additionally, it would be useful to control for socio-economic status, for example, in the study by Whittemore et al., (2012), all participants were required to have high-speed internet access. This may not be possible for those who are socially deprived and therefore participants are likely to have had a higher socio-economic status. This may have been the reason a lower baseline HbA1c seen in this study in comparison to others.

Word count restrictions imposed by different journals often means that authors find it difficult to adequately describe all aspects of the intervention and trial. As a result the possibility that some behaviour change techniques used within interventions were not reported in the papers cannot be discounted. Indeed the detail of interventions included within the articles varied, and, in some cases further detail was sought from the author in order to provide clarification of intervention delivery or content. The usage of a Behaviour Change Technique framework in intervention reporting should therefore become common practice in order to provide a simple way of describing interventions and thus ensure replicability.

Finally, very few studies examined the effect of intervention on diabetes-related distress. As a result depression was also examined, but the number of studies that could be included in these analyses remained small (k=10).

**5.6 Conclusion**

These results provide evidence that behaviour change interventions can improve medical and psychological outcomes in young people with Type 1 DM. Interventions providing goal setting, information on the consequences of behaviour, or relapse prevention/ coping planning were found to have the largest effect on HbA1c*.* Future work should focus on utilising these techniques and directing interventions towards the individual, rather than groups. It was not possible to reach similar conclusions regarding psychological outcomes, in part given the wide range of outcome measures identified. The previous call for a core set of common psychological outcome measures (Keen, 2010; Murphy et al., 2006) to facilitate interpretation of future trials is also supported. The findings of this study were used in order to develop an intervention that is sensitive to the specific needs of our sample of young people with Type 1 DM. Given evidence that theoretically guided interventions are more effective than non-theoretically guided (Michie et al., 2005), theory was considered. As a result an action planning intervention was developed and piloted. The results of this study are reported in the following chapter.

**Chapter 6**

 **An Empirical Study to Determine the Potential of Action Planning in Routine Clinic Appointments**

**6.1 Summary**

The purpose of this chapter is to report a pilot study of an action planning intervention in our target sample of young people with Type 1 DM. This intervention was developed in light of the findings of Studies 1 and 2 of this thesis. An introduction to the theory behind goal setting and implementation intentions is provided, followed by examples of the use of such techniques in chronic conditions. The main aims were to determine the feasibility of this intervention, the range of goals set, the barriers to goal attainment, the type of support identified, and the rate of goal attainment.

Young people aged 16-21 (n=47) from one of two specialist diabetes clinics in Sheffield took part in the action planning intervention, 35 young people completed follow-up action plans. The results were analysed using content and thematic analysis.

The range of different goals set was broad and coded across two categories: self-management and social lives. The majority of those who took part set self-management related goals (n=33). This was attributed to the medical focus of the clinic. Further goals set reflected problems that might be expected for the age group for example coping with alcohol.

There was a large variation of barriers to goal attainment identified. These ranged from laziness to embarrassment*.* The main source of support identified was parents, although eight participants did not highlight any source of support. Twenty-six young people felt they had gone some way towards achieving their goals.

The overall uptake to the intervention was deemed moderate (66%) and reasons for non-participation varied. Many felt unable to think of a goal at the time or were too tired. Some felt they were coping well with their treatment and did not need help; others were moving up to the adult clinic and as a result could not take part in follow-up action plans.

The feasibility of the study is discussed along with potential ways to improve the intervention for a future trial.

**6.2 Introduction**

Given the lack of studies which directly measured diabetes related distress, the results from the meta-analysis were unable to provide conclusive evidence for an intervention which may be the most efficacious at improving this specific outcome. However, when considering depression and diabetes-related distress and HbA1c an intervention involving goal setting appears to have the greatest effect, therefore it was decided that this intervention would be piloted on our sample.

 As discussed earlier, self-care for Type 1 DM is multifaceted and complicated, involving a number of simple behaviours. So as not to overwhelm the young people, it was decided that it would be appropriate to target these individual behaviours. This is also in line with theories of goal setting which suggest small goals are more effective at engendering behaviour change. This is due to the fact that these small changes are easier to achieve and successful goal attainment leads to greater motivation. This concept is discussed further later in this chapter.

Everyone has to adopt health behaviours in everyday life in order to maintain optimal health. As discussed in previous chapters, the management of Type 1 DM involves individuals engaging in a number of self-care health behaviours, from testing blood sugar levels to counting carbohydrates and administering insulin. In order to provide a background for an action planning intervention involving goal setting and implementation intentions, the concept of health behaviours will be discussed here followed by the theories used to assist in the development of this intervention.

Health behaviours have been defined by (Matarazzo, 1984) in terms of ‘behavioural pathogens’, behaviours that may have a negative effect (e.g. smoking, drinking alcohol) or ‘behavioural immunogens’, behaviours that may have a positive effect (e.g. clinic attendance, eating a balanced diet). A positive change in health behaviour may improve health, manage illness or prevent health deteriorating. In the case of Type 1 DM, a positive change in self-management health behaviours might be carrying out more blood glucose tests or taking insulin. Making health-behaviour changes can be seen as conscious or effortful (Ogden, 2012, p. 182) and most psychological approaches to behaviour change focus on changes requiring effort through targeted interventions. As seen from the results of the meta-analysis reported in chapter 5, such interventions have targeted groups, families or individuals. The most successful, at least in Type 1 DM, seem to be those aimed at the individual and utilising goal setting.

**6.2.1 Theory and health behaviour**

A person may change behaviour as a result of increased motivation to achieve a goal. Goal setting research or intentions to bring about behaviour change has arisen from a broad category of theories called social cognitive models in which predictors and precursors to health behaviour change form a continuum. These models are based upon ‘social cognitive theory’ (Bandura, 1991), which suggests behaviour is directed, by expectancies (including situation outcome expectancies, outcome expectancies, and self-efficacy expectancies), incentives, goals and social cognitions. The models are placed within the context of the people involved, the behavioural consequences and personal representations of their social world. Two early models surrounding goal setting include the Health Belief Model (HBM; Rosenstock, 1966; Rosenstock, Strecher, & Becker, 1988) and Theory of Planned Behaviour (TPB; Ajzen, 1991; Ajzen & Madden, 1986). In order to provide a background to these models, the HBM will be discussed first followed by the TPB. Finally goal setting as a theory in its own right will be discussed.

**6.2.2 The Health-Belief Model (HBM)**

The HBM (Rosenstock, 1966; Rosenstock et al., 1988) was developed to predict health behaviours and response to treatment in chronically ill patients (Figure 6.1). According to this model, intentions to engage in behaviour are a product of demographic factors as well as an individual’s beliefs surrounding their susceptibility to illness, the severity of their illness, the costs and benefits involved in carrying out the behaviour and cues to action (Becker & Maiman, 1975). More recently, health motivation and self-efficacy have been added (Rosenstock et al., 1988). In the case of Type 1 DM the following example to illustrates how the components fit together:

* Perception of threat
	+ *Perceived severity* “I believe Type 1 DM to be a serious illness which is made worse by suboptimal self-care practices”
	+ *Perceived susceptibility* “I believe that I do not carry out adequate self-care practices to protect me from future complications”
* Behavioural evaluation
	+ *Perceived benefits “*If I improve my self-care behaviours my glycaemic control will improve”
	+ *Perceived barriers* “Improving my self-care behaviours takes up too much of my time”
* Cues to action
	+ *External cues* “My consultant told me if my glycaemic control does not improve my eyesight will deteriorate”
	+ *Internal cues* “ I have not been feeling well”
* Health motivation
	+ “It is important to me that I improve my health”
* Perceived control (self-efficacy)
	+ “I have the ability to improve my glycaemic control through increasing my self-care practices”

The HBM suggests that behaviour change results from changes in social-cognitive determinants of behaviour. In order to engender behaviour change, interventions should target these. In addition, external cues can also impact behaviour and so can be an additional target for intervention (Webb, Sniehotta, & Michie, 2010). The HBM has been used to develop a range of behaviour change interventions and has achieved success for a variety of health promoting behaviours (Webb et al., 2010).

**Figure 6.1 The Health Belief Model (Rosenstock et al., 1988)** 

**6.2.3 The Theory of Planned Behaviour (TPB)**

The TPB (Ajzen, 1981; Ajzen and Madden, 1986) emphasises the importance of intentions as a precursor to behaviour (Figure 6.2). The theory suggests behavioural intentions should be conceptualised as ‘plans of action in pursuit of behavioural goals’ and are an outcome of several beliefs including attitudes toward behaviours (positive or negative), subjective norms (belief about social norms and social pressures to perform behaviour), and perceived behavioural control (belief that the individual is able to carry out the behaviour). These three beliefs predict behavioural intentions which in turn are linked to behaviour. Applied to young people with Type 1 DM the TPB would predict the following: if the individual believed taking more insulin would be better for their health, believed that this was what family and friends would like and believed that increasing insulin intake was a possibility based on previous behaviour and evaluation of barriers then they would increase their insulin intake.

Both theories predict that as a result of attitudes and beliefs intentions to perform a behaviour are formed, leading to actual behaviour. This is sometimes the case. However, often creating behaviour change is not this simple, and there is a great deal of criticism surrounding both models.

**Figure 6.2 The Theory of Planned Behaviour**



**6.2.4 Goal setting**

Goals within social cognition models have been mentioned above. However, goal setting is a theory in its own right. This theory was developed in response to evidence of a relationship between performance goals set and performance (Locke & Latham, 2006). It was observed that goal difficulty, specificity and value to the individual all influence goal performance through encouraging greater and more persistent effort. With regards to goal difficulty, those goals which are perceived to be too easy may provide a barrier to performance by reducing motivation. Locke and Latham (2006) found support for a linear relationship between goal difficulty and performance, with greater effort exerted where goals are more challenging, until goals are perceived to be too hard. At this point people give up, reducing motivation for future goals (Erez & Zidon, 1984). Additionally, goals providing a specific reference point, as opposed to very general goals have been proven to be more effective, as well as those which have a greater meaning to the individual (Locke & Latham, 2002). These relationships have been incorporated into many models of behaviour change and interventions.

***Goal setting within a health care setting***

Attempts have been made to routinely introduce goals into a health care setting. The chronic care model was introduced as a means to improve care delivery (Wagner et al., 2001). There are six components to this model including; self-management support, assessment, goal setting, action planning, problem solving, and follow-up. Goal setting was to be collaborative, involving patient-centred communication. It was hoped that as individuals increased their self-management skills and became more active participants in their care, self-efficacy would increase as well as knowledge.

Descriptions of goal setting emphasise the need for patient-centred communication so that the process becomes collaborative involving two-way counselling and communication between patients and health care providers (Langford, Sawyer, Gioimo, Brownson, & O'Toole, 2007). Patient centred communication has been defined as a style of communication that includes partnership building, empathy, interpersonal sensitivity, and a mutual exchange of information (Erickson, Gerstle, & Feldstein, 2005). Approaches which may have the potential to facilitate success in goal setting, have been described by Langford et al. (2007). The process involved:

* Background: find out about the patient, how they view their disease, what is concerning them, what support they have at home, how well they are managing.
* Barriers: explore what has not worked well in the past for the patient and what makes it difficult to make lifestyle changes such as healthy food choices and physical activity.
* Successes: focus on what a patient has done well, and celebrate their accomplishments no matter how small they seem.
* Willingness to change: once you know the patients background and have explored barriers and celebrated successes find a behaviour he or she is willing to change.
* Action plan: coach the patient to set a specific and detailed goal that is important to him or her. Write down the goal and give the patient a copy.
* Reinforce and remember: conduct telephone follow-up to provide encouragement and motivation. Refine, redefine or stretch the goal at the next planned visit. It is vital for the health care team to remember patient goals and incorporate them into conversations at each visit.

Further to this DeWalt et al. (2009) used Social Cognitive Theory including modelling, problem solving, and goal setting skills in order to provide practical advice regarding the use of goal setting to improve self-management in diabetes. They describe five stages:

1. Action plan is patient and not provider generated. The provider can give general advice but the specific plan has to be decided by the patient.
2. Action plans are behaviours not results.
3. The plan should be specific about what behaviour, how, when and where it will be done.
4. Patient needs to have confidence they will succeed. If confidence is rated lower than 7 (on a 10 point scale), patient is encouraged to fine-tune behaviour to make it more achievable.
5. An action plan is short-term (e.g. 1 week) and should be followed by a decision to continue the same behaviour or perform additional behaviour. Short-term achievable goals are referred to as ‘baby-steps’.

**6.2.5 Criticisms of social cognition models and goal setting**

Although goal setting and interventions using social cognition theory have experienced some success, these early models face criticism. The main criticism centres on their inability to predict intentions and subsequent behaviour (Sutton, 1998). Although a previous meta-analysis of correlational data showed intentions to have an impact on behaviour (Sheeran, Trafimow, Finlay, & Norman, 2002) there may be a missing variable that better explains this link (Webb & Sheeran, 2006). In their meta-analysis using experimental data from 47 studies, Webb and Sheeran (2006) found manipulating intentions did change subsequent behaviour, but this effect was lower than previously predicted. A medium to large change in intention only led to a small to medium effect on behaviour. The authors concluded there was a gap between an individual’s intention and behaviour. Translated to goal setting research, an intention to achieve a goal did not consistently lead to the achievement of a goal.

In order to understand why this gap exists, Gollwitzer and Sheeran (2006) described a number of barriers to overcome in order to achieve behavioural goals and translate intention into behaviour. As a result of competing demands on attention and memory, an individual may forget to initiate behaviour (Milne, Orbell, & Sheeran, 2002), may fail to seize the appropriate opportunity to carry out a behaviour (Oettingen, Hönig, & Gollwitzer, 2000) or be unwilling to act when an opportunity arises (Gibbons, Gerrard, Ouellette, & Burzette, 1998). Additionally in the pursuit of health goals, positive health behaviours need to be maintained over a period of time. Often, a number of more appealing stimuli compete for our attention, for example an unhealthy fast food restaurant may compete for our attention over a healthy salad bar. In order to continue practising the positive health behaviours, attentional and behavioural responses to the appealing stimuli must be suppressed. This is complicated by habitual behaviour, and self-control must be exercised in order to overcome these habits. Previous research has highlighted a number of ways to overcome these barriers and thus close the intention-behaviour gap, the most widely used being implementation intentions (Gollwitzer, 1993)

**6.2.6 Implementation intentions**

As opposed to goals or intentions in which only the outcome is specified (e.g. I will carry out a blood sugar test), implementation intentions (Gollwitzer, 1993) involve the formation of simple yet specific plans of what an individual will do in a specific environment or situation (e.g. If this situation occurs I will perform the specified behaviour). Gollwitzer (1999) proposed that this creates an automatic association between the context and the behaviour. After adequate repetition, the behaviour will then be performed once the cue is recognised. This becomes habitual, and has helped overcome barriers to goal attainment (Gollwitzer and Sheeran, 2006).

Experimental research on implementation intention interventions has shown that encouraging individuals to make implementation intentions can improve the uptake of a number of positive health behaviours and decrease a number of negative health behaviours. This includes behaviours such as decreasing smoking (Armitage, 2007), reducing alcohol intake (Armitage, 2009) and increasing fruit and vegetable consumption (Gratton, Povey, & Clark-Carter, 2007). Gollwitzer & Sheeran (2006) conducted a meta-analysis of 94 studies of the impact of implementation intentions on a range of behavioural goals. Implementation intentions were found to have a medium to large effect on goal attainment on goals overall. More specifically there was a medium effect of implementations on the attainment of health-related goals. They concluded implementation intentions provide a simple way to promote and change health related behaviours.

***Implementation intentions in DM and other chronic conditions***

Previous work in chronic conditions other than Type 1 DM has found implementation intentions to be effective in improving outcomes. In a randomised controlled trial of 180 adult patients with Type 2 DM, Thoolen, de Ridder, Bensing, Gorter, & Rutten (2008) found that in comparison to a control group those completing an implementation intention intervention improved significantly in goal attainment, coping and self-efficacy. In a study on epilepsy patients Brown, Sheeran, and Reuber (2009) found those who specified a context in which they would take their medication were more likely to adhere to their treatment regimen compared to a control group of patients completing a questionnaire about their treatment regimen.

In chapter 5 interventions involving goal setting techniques were found to be an effective means of improving HbA1c and have the potential to improve psychological outcomes in young people with Type 1 DM. Three studies (Channon et al., 2007; Cook et al., 2002; Nansel et al, 2007, 2009) used goal settings as a main behaviour change technique in their intervention with the findings that HbA1c was improved in the intervention groups relative to the control. However, the results of these studies may have been improved with the addition of implementation intentions.

In summary, intentions or goals alone are not enough to engender behaviour change. A number of barriers must be overcome in order to achieve and maintain behavioural goals. Previous work has found implementation intentions to be effective at improving the attainment of behavioural goals by creating an automatic association between a contextual cue and a behaviour. It is possible that these implementation intentions overcome the barriers associated with goal attainment. Goal setting has been used in a number of studies in young people with Type 1 DM and has been found to be more effective when compared with a control group and compared with other interventions as found in chapter 5. Yet these results could be improved with the addition of implementation intentions as shown in other chronic conditions. Overall implementation intentions may offer a cost-effective (Thoolen et al., 2008) and easy intervention for improving outcomes in young people with Type 1 DM.

This chapter explores the acceptability of an action planning intervention for young people with Type 1 DM designed in the light of the findings from studies 1 and 2 of this thesis, considering the guidelines proposed by Langford et al. (2007) and DeWalt et al. (2009) and paying special attention to theory. The findings were analysed using content and thematic analysis. The use of qualitative methodology here was considered the most appropriate given the ability it has to assist in the informing and development of interventions which are acceptable to patients and fit into clinical practice.

**6.2.7 Study Aims**

The aim of this study was to determine:

1. the feasibility of delivering an action planning intervention in a clinic setting,
2. the type of goals set,
3. the barriers the young people identify,
4. the sources of support the young people identify,
5. the rate of goal attainment.

**6.3 Methods**

**6.3.1 Sample**

Seventy one young people were approached in one of the two specialist diabetes clinics for young people in the NGH and the RHH. Inclusion criteria were i) aged 16-21 years, ii) diagnosed with Type 1 DM, iii) be motivated to make a positive change. Exclusion criteria included those with i) English language difficulties, ii) special educational needs, iii) life-limiting conditions, iv) those diagnosed less than 6 months prior to consent, v) those identified by the Diabetes Specialist Nurses present in clinic as having safeguarding or mental health issues.

**6.3.2 Procedure**

This intervention is part of phase two of the CLAHRC-SY project. This phase involved administering questionnaires to assess fear of hypoglycaemia, parental responsibility, and measures of cost effectiveness as well as an educational intervention and action planning intervention which will be described in this chapter. All young people had participated in phase one of the research (see chapter 4). Given the large battery of tests, three research assistants were needed in order to collect all data. SB had special responsibility for delivering the action planning intervention. However, if there were more than one participant at any one time, a research assistant who was trained in the use of the action planning intervention also consented participants and delivered the intervention. Ethics approval and research governance was obtained from the NHS National Research Ethics Service in Leeds (REC: 11/YH1/0441) prior to the commencement of phase two (appendix 6.1). Data were collected between January 2012 and July 2013. Young people included on the diabetes clinic list were contacted by mail to invite them to participate in the study (appendix 6.2), to inform them of changes made within clinic as part of phase two of the research and about the action planning intervention (appendix 6.3). At their next appointment staff from the diabetes care team indicated eligible participants to the research assistants who then approached young people and asked if they had received the information letter. Any questions were answered, and the action plan explained in detail. Those willing to participate were consented (appendix 6.4) and approached again at their next clinic appointment in order to complete their action plan. Participants completed follow up action plans and set further goals at subsequent clinics. Young people mostly worked through the action plans with a research assistant, unless the young person understood the measure fully and requested to complete the plan alone. A consultation room was available for those who did not feel comfortable completing their action plans and discussing their goals with a research assistant in the waiting room.

**6.3.3 Measure**

The action planning measure was based on a previous action-planning sheet used in the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) study in adults with Type 2 DM (DESMOND Collaborative, 2011), which was designed based on the considerations of Langford et al. (2007) and DeWalt et al. (2009). However, given previous research indicating theory use to be important in the development of interventions (Michie, Johnston, Abraham, Lawton, Parker & Walker, 2005) this action-planning sheet was adapted in consideration of the theories discussed above and to reflect the variation in developmental and self-management stages of our sample. We also removed specific goal ‘choices’ from the DESMOND sheet and allowed for the participants to choose any goal which was meaningful to them.

***Time 1***

The action planning sheet took approximately 15 minutes to complete. The measure included 8-items and an implementation intention. The full measure can be seen in appendix 6.5. Those agreeing to participate filled in an action plan sheet which included the following items: i) what is your overall goal? ii) how could I do this? iii) what am I going to do? iv) who will help me? v) how confident am I? vi) how could I feel more confident? vii) what might stop me? viii) how can I overcome this? Finally, the young people were asked to form an implementation intention based on the information they provided in the action plan.

 All questions were open- ended apart from ‘how confident am I?’ This was scored on a 5-point Likert scale (1= not at all confident, 5= very confident). Those scoring below 3 on this scale were encouraged to think of a new goal given theories that a lack of motivation will hinder behaviour change (Locke & Latham, 2004). The action plan was printed on carbon paper with three copies, so that one copy could be kept by the young person to act as a reminder, one could be kept by the research team and one could be handed to the consultant for discussion in clinic consultations. Discussions with consultants regarding the action plans also ensured the research assistants were providing the young people with the correct advice and that the young people had highlighted appropriate goals. Two young people adapted their action plans as a result of this discussion and set goals which were viewed to be more appropriate for their personal situations. In both cases the confidence in succeeding was re-measured and rated greater than three.

***Time 2***

Follow-up action plans were completed at the next clinic between one and three months after time 1. The action plan sheet was similar to that of time 1, but had an extra section in order to measure the level of goal attainment (appendix 6.6). This extra section included one question as to how well the young person felt they had done in achieving their goal, answered on a 5 point Likert scale (0 = not well at all, 5 = I have achieved my goal), an open ended question about what happened, and a question about what the young people would like to do next. The answer to the final question included the following possibilities: a) carry on with this goal, b) carry on with this goal but change my action plan, c) try a new goal plan. During the course of the study the young people completed as many action plan sheets as they wished. However, this study reports two time points.

The research assistants also recorded those who took part, those who had been approached but declined to participate along with reasons why, and finally any extra notes of interest arising from discussions during action plan completion.

 **6.3.4 Analysis**

Given the specific research questions of this study and the data gathered, thematic content analysis was selected as the most appropriate method to use.

Using SPSS version 20 (IBM Statistics, Chicago, IL, USA) to facilitate data-management, first a content analysis was conducted. Content analysis is “a research technique for making replicable and valid inferences from data to their context” (Krippendorff, 2012, p. 24). The assumption of this technique is that words and phrases mentioned most frequently in text or speech reflect the most important concerns of the individual or target group. At its most basic, this technique is more quantitative in nature, with the frequency of particular word use recorded.

Analysis procedure of the open-ended questions involved section by section scrutiny in order to sort and code data. Each action plan was read a number of times in order to sort the data for each question into meaningful categories which reflect the research question (Krippendorff, 2012). Once a separate framework had been established for each open-ended question the coding framework was expanded, refined and applied to all previously coded data in order to provide frequency data. This data was supplemented by notes taken by the research assistants during discussions with the participants in order to clarify understanding, assist in the interpretation of the action plans and add greater depth to the data.

# 6.4 Results

**6.4.1 Aim i: the feasibility of action planning in a clinic setting**

Seventy-one young people were approached by a research assistant in the two clinics, 47 (66%) agreed to take part and filled in action plans at time 1. Thirty-five young people filled in follow up action plans at time 2, ten of these filled in subsequent action plans. Demographic variables are shown in Table 6.1

**Table 6.1 Demographic variables for those taking part in the intervention**

|  |  |  |
| --- | --- | --- |
| Demographic variable | Time 1  | Time 2  |
| Gender (n (%) :male) | 22 (47%) | 15 (43%)  |
| Age (years) | 17.21 (SD 1.2) | 17.88 (SD 1.5) |
| Age at diagnosis (years) | 9.62 (SD 3.7) | 9.54 (SD 3.4) |
| HbA1c (%) | 9.84 (SD 2.4) | 9.64 (SD 2.6) |

***Reasons for non-participation***

Four reasons were given for not participating in the intervention. Of the 24 young people who were approached but did not take part, a main barrier was being *unable to think of a goal* at the time.

*I don’t know what I want to work on, I can’t think of anything now, I will think of one for next time* [p50]

Eight people gave this reason and all indicated they would think of a goal for their next clinic appointment.

A further reason for not taking part was the belief they were *coping well* with both their treatment regimen and in their daily lives (n=7).

*I’m fine, I don’t need any help* [p78]

Four young people did not participate as they were *moving up* to the adult clinic and believed it would not be a good use of their time as their goals would not be followed up. Five young people did not want to take part due to questionnaire *fatigue*.

*I can’t be bothered, I’ve already completed a questionnaire* [p65]

**6.4.2 Aim ii: determine the type of goals set**

Of those who did take part, thinking of an appropriate goal was an issue. Although the research assistants encouraged both goals related to the diabetes treatment regimen and goals related to life in general, many spent a significant amount of their clinic waiting time considering appropriate goals. At time 1 thirty-three of the overall goals were related to self-management, and fourteen to social life (see table 6.2).

**Table 6.2 Analysis framework for goals**

|  |  |  |
| --- | --- | --- |
| Theme | Code |  Participants (n) |
| Self-management | Blood glucose testInsulin injectionsDietExerciseMedical equipment | 157443 |
| Social life | Informing peersAlcohol | 104 |

***Self-management***

Of the 33 goals related to self-management, 15 related to *blood glucose testing*. It became clear this was a major concern and many felt increasing the number of tests would be an achievable way of improving outcomes. Ten of the *blood glucose testing* goals arose from the lack of tests currently undertaken by the young people. In the majority of cases the implementation intention related to the overall goal included the time of day the young person was to test their blood sugar levels.

 **Goal**  **Implementation intention**

*If it is breakfast time I will test my blood sugar levels* [p21]

*Test my blood sugar levels more* [p21]

*I have to test more frequently* [p16]

*If my alarm goes off I will test my blood sugar levels* [p16]

One young person feared the possible complications related to Type 1 DM and as a result tested very frequently. Her overall goal was to reduce blood glucose testing frequency throughout the day. Feelings of anxiety arising from not testing were discussed. These feelings had not previously been discussed with a health care professional. As a result, an implementation intention was created to reduce test frequency and to discuss this with a nurse.

*If I feel the need to test I will tell myself it’s not always necessary and call a nurse if I’m unsure* [p25]

*I do too much testing, I need to do less* [p25]

Further goals related to blood glucose testing resulted from a lack of response to the blood glucose test. Four young people recognised the need to respond to results and were aware of the complications which could arise from not correcting blood glucose levels based on these results but were unsure of the correct response. Implementation intentions to record test results and check the appropriate response with a nurse were set. An education course was also recommended, and further information of this provided.

*If I test I’ll write the results down and act on them, I’ll contact the nurse if I’m not sure* [p8]

*I test, but ignore results, I can’t be bothered to respond* [p8]

Another self-management goal related to *insulin injections*. Goals related to this involved injecting the appropriate insulin doses at the appropriate times. This was an area five young people wished to improve on. Ways to remember to inject insulin were discussed.

*I need to inject more insulin* [p42]

*If I have done a blood glucose test I will correct with my insulin* [p42]

A further goal related to insulin administration was injection sites. Two young people indicated a lack of knowledge about other areas of the body where insulin could be injected. Pain and bruising had been experienced from using the same site on a number of occasions. Information on other injection sites was provided by a nurse and an implementation intention to rotate sites based on this information was set.

*If I have used an injection site more than twice I will try another* [p36]

*I get bruises from injecting in the same place too much, I want this to stop.* [p36]

Specific concerns related to weight loss and healthy eating were expressed by eight young people. *Diet* and *exercise* related plans were discussed with each of these participants and led to four goals related to *diet* and four related to *exercise*. The implementation intentions formed as a result of these goals related to alternative, healthier food choices or the day or time at which exercise would be carried out.

*If it is a Sunday I will play tennis* [p1]

*I need to lose weight* [p1]

*If I crave an unhealthy snack I will have an apple* [p12]

*I need to eat healthier* [p12]

Three goals were related to medical equipment, more specifically changing equipment (n=2) which was currently on offer to them or remembering equipment when leaving home (n=1). Two participants set goals related to the discussion of conversion to a CSII pump with health care professionals. This was seen as a goal due to the fear the young people had of discussing their diabetes treatment with consultants.

*If I see a consultant I am comfortable with then I will discuss conversion to a pump* [p7]

*I want to go on a pump* [p7]

*To remember my kit* [p9]

*If it is night time then I will make sure my equipment is ready for morning* [p9]

***Social life***

Peers and social lives were very important. Ten participants indicated they had not told peers about their diabetes. Participants discussed finding it difficult to discussdiabetes with employers, colleagues and school friends fearing the stigma surrounding the illness. As a result goals to be more open about their diabetes and inform those who need to know of their diagnosis were set. It was hoped *informing peers* or work colleagues about their diagnosis would lead to greater support in their self-management regimen.

*If I am with my friends I will tell them about my diagnosis* [p31]

*I need to be more open about my diagnosis* [p31]

*If I am at work I will tell my boss about my diabetes* [p18]

*My boss doesn’t know about my diabetes so it’s hard when I’m feeling unwell* [p18]

Worries related to *alcohol* were expressed by eight young people but only four felt this was a large enough problem to create a goal. One of these participants feared the effects alcohol had on her, these fears were in response to a recent education course she had attended. This was a great cause of anxiety. As a result a decision to rotate alcoholic drinks with soft drinks was made.

*Reduce the amount I drink with friends* [p4]

*If I am drinking with friends then I will rotate alcoholic drinks with soft drinks* [p4]

Although the motivations for choosing goals did not form part of the research questions, notes taken by research assistants during discussions with the young person revealed a range of motivations. Motivation for self-management goals included fear of negative discussions during consultation (n=4), “hassle” from loved ones (n=6), wanting to avoid hypoglycaemia (n=8), wanting to fit in with friends (n=9) and, most commonly, appearance (n=12).

**6.4.3 Aim iii: Determine the barriers the young people identify.**

The young people identified both perceived barriers (at time 1) and actual barriers (at time 2) to goal attainment. The barriers identified at both time points were similar and therefore were combined in analyses. From this analysis five themes emerged from the data. These included *adolescent traits, appearance, illness denial, stigma and shame,* and *life events.*

***Adolescent traits***

The participants discussed feeling *too lazy* or *forgetting* to act on their action plan, and very few young people were able to determine a way to overcome this. As a result ten decided to set an alarm as a reminder that diabetes is important.

*I’ll set an alarm to remind me to take my insulin, it might remind me my diabetes is important, if I feel a change then I’ll want to carry on.* [p44]

This barrier was echoed at time 2, even though an implementation intention specific to their needs was created, this was forgotten once at home.

*I put my action plan in my bag and totally forgot about it by the time I’d got home.* [p18]

***Appearance***

For 12 young people appearance was a barrier to achieving goals. Keeping blood sugar levels high in order to avoid the embarrassment associated with hypoglycaemia was common. The risk of experiencing a hypoglycaemic episode acted as a deterrent to administering the correct insulin dosage for both males and females.

*I sometimes avoid controlling so I have high bloods, I won’t have a hypo then* [p33]

*I don’t want a hypo at school* [p21]

Concern about weight gain from taking the correct amount of insulin was present (n=4 females). Even though there was a general awareness of long-term complications, an over-riding belief that these complications would not happen to them meant the young people considered withholding insulin to lose weight. One participant indicated that she had long standing concerns about the relationship between insulin and weight gain that had not been previously discussed with a consultant.

*I get fat when I take my insulin* [p11]

Although the consultants had tried to discuss why she had been failing to administer insulin the young person described feeling reluctant to explain the reasons in her consultation. A further young person indicated avoidance of injecting, but realised the consequences and wanted to increase frequency of insulin administration, but also lose weight. In both cases the young person was referred to a psychologist and a dietician.

***Ignoring diagnosis***

Ignoring their diagnosis was an issue prevalent among the responses (n=14). Some young people indicated that a lot of the time they *felt fine*, and as a result did not feel the need to carry out self-management tasks, ignoring their diagnosis. To overcome this barrier one participant described how he could imagine feeling ill as a result of ignoring self-management tasks.

*I sometimes feel horrible when I haven’t been looking after myself, I’ll think of these times and how I don’t want to hypo in front of my friends!* [p63]

 *Not feeling better* even when engaging in optimal self-care behaviours, or adhering to their implementation intention also created a barrier (n=9). Those experiencing this did not see any reason to continue with their implementation intention.

*I tried it for two weeks and was doing really well at remembering, but I didn’t feel any better to when I wasn’t injecting, so what’s the point?* [p34]

***Stigmatisation***

This was a common theme for the young people who often described feeling *guilty* if they had not self-managed adequately as this would be detected in clinic (n=22). For many, this was a barrier to clinic attendance as well as a barrier to allowing support from families. The guilt motivated the young people to self-manage to an extent, but this was often short-lived and over shadowed by a feeling of *disappointment* that arose from high blood glucose readings.

*If I have done everything I can I sometimes still get a high reading, i‘m scared of getting a high reading, so I don’t test.* [p30]

Here a young person describes the disappointment felt from a high blood glucose reading, and illustrates how this can often stop the young people from testing at all in order to avoid this feeling.

Participants discussed the *embarrassment r*elated to self-care behaviours and the stigma they perceive surrounding this (n=5).

*I don’t want anyone to know I have diabetes, they’ll laugh* [p22]

*It’s embarrassing leaving class if I feel unwell, everyone stares* [p33]

As a result of these feelings and perceptions many felt uncomfortable discussing their diabetes with peers, and did not feel able to carry out self-care behaviours in public, at school or at work. Therefore, a lack of self-care behaviours as a result of *concealing diagnosis* became a common barrier to achieving optimal glycaemic control. Related to this was *fear,* more specifically the fearof experiencing hypoglycaemia in public.

*I don’t want anyone to see me hypo* [p44]

*Hypos feel horrible* [p42]

Participants indicated worrying how unpleasant it must appear to witness a hypoglycaemic episode (n=3). Some admitted withholding taking insulin in order to make sure they would not experience hypoglycaemia whilst with friends or at work (n=3). Withholding insulin was commonplace as a result of the symptoms experienced during a hypoglycaemic episode.

***Life events***

Life events were a problem for some young people. *Studying* and the stress this brings meant that in some cases good intentions disappeared (n=6).

*I was doing well, but then it was exam period so I concentrated on them and forgot about my plan.* [p26]

Additionally experiencing *life changes* posed a problem which meant goal attainment was difficult given the need to adjust to a new lifestyle (n=3).

*I was testing more but then I moved house, my routine fell apart and life just got in the way!* [p17]

Along with these barriers were *social activities* that often do not allow for adequate self-management tasks (n=11). These life events often paved the way for *time pressures*, the participants voiced the feeling there was not enough time during the day to carry out self-care behaviours (n=6). Particularly when working or at school. For those who found it difficult discussing their diagnosis with teachers or employers, asking for extra breaks was perceived to be impossible.

**6.4.4 Aim iv: determine the sources of support the young people identify**

The young people varied in their chosen source of support. A number of the participants identified more than one person who might help them to follow their action plan. In these cases only the primary source of support was recorded. Eight of the young people preferred not to identify anyone to help support them in achieving their goal. Twenty-two young people identified a parent as a source of support, eleven identified friends, and six identified their partner. The rates of goal attainment for each source of support are presented in the next section.

**6.4.5 Aim v: Determine the rate of goal attainment**

Of the 47 action plans completed, 35 young people (15 males) completed at least one follow up action plan allowing for the measurement of the rate of goal attainment (Table 6.2). Fifteen young people felt they had achieved their goal and as a result completed a new action plan with a new implementation intention. Eleven young people felt they had made significant progress but had not yet achieved their goals. For these young people action plans were modified to make the implementation intention more attainable and to suit current routines. A further nine young people felt they had not achieved their goal but would like to carry on with the same action plan. This equated to 74% of those completing action plans at time 2 either achieving or going some way towards achieving their goals. A greater proportion of females felt they had gone some way towards achieving their goals (75% of those completing at time 2) in comparison to the males (35%). Of the young people who preferred not to identify anyone who might help support them in achieving their goal (n=8), one felt they had achieved their goal. For those identifying parents as a source of support (n=22), five achieved their goals, for peers (n=11) seven achieved their goals and for partners (n=2), two achieved their goals. It would appear that peers were the most helpful in facilitating goal attainment.

**6.5 Discussion**

This study aimed to determine the acceptability of an action planning intervention for young people with Type 1 DM in a clinic setting. Additional aims were to record the types of goals made and if they were achieved, as well as the barriers and sources of support identified. Overall uptake to the intervention was moderate (66%). A variety of goals were set and the majority were focused on some element of self-management. Over half of the young people felt they had made some progress towards achieving their goal at follow up.

***Aim i: Determine the feasibility of action planning in a clinic setting***

Forty-seven young people took part in the action planning intervention. Overall the intervention was well received with 47 (66%) of the young people approached taking part. The majority of those who did not wish to take part could not think of a goal at the time. Although the young people received an information sheet explaining the intervention and had spoken to a research assistant many indicated they had forgotten about the intervention. As a result it is likely that they felt pressured to think of a goal at that particular time and found it difficult to respond without giving the matter a deeper level of thought. In future it would be helpful to contact the young people prior to clinic appointments in order to prompt and prepare the young people.

The variation in apparent willingness to take part could also be explained by variations in illness perceptions (Leventhal, Diefenbach, & Leventhal, 1992). It is possible that those who did not wish to take part perceived themselves to have low personal control over their illness, that is, they felt that their actions would not improve their illness. This has been shown in a study on skin cancer (Cameron, 2008b). In this study, those participants who scored lower for beliefs about personal control experienced lower intention to engage in preventative health behaviours. Additionally lower perceived personal control was associated with greater risk perception. Cameron (2008a) suggested this may be as a result of dispositional pessimism or anxiety.

***Aim ii: Determine the types of goal set***

There was a large range of goals set and these were arranged under two major themes including: self-management and social life.

The majority of young people focused on some element of self-management and many more specifically on increasing the number of blood glucose tests carried out each day. This was seen as a positive given many of the young people were encouraged to increase the frequency of their blood glucose tests within their clinic consultations. However, this may not have been a goal which was important to the individual. During action planning, patients were encouraged to set goals which were meaningful to them, and that would help them cope with their diabetes. The large number of those focusing on self-management could reflect the strong medical focus that is present in clinical consultations. A previous qualitative study (appendix 1.1; Brierley, 2012) of interviews with staff from this particular diabetes care team revealed a strong focus on medical outcomes as opposed to psychological outcomes within the care team. The young people may simply be focusing their goals towards what they believe their consultant would want them to focus on. Alternatively they may be reverting to a self-management goal as these are what have previously been discussed within clinic and are therefore more salient.

Social life was important to the young people. In particular they revealed difficulties in informing their friends, teachers or colleagues of their diagnosis for fear of the stigma attached to diabetes. This again reflects the need of young people to appear normal and be part of a social group. The belief that peers may react negatively to their diagnosis is something that is potentially damaging. A study into the moderating role of peer support in young people with Type 1 DM revealed adolescents who made negative attributions of the reactions of their peers about their illness were less likely to practice self-management behaviours and experienced greater stress. The increased stress was also related to suboptimal glycaemic control (Hains et al., 2007). It is important that these negative beliefs are addressed and peers informed about diagnoses. The young people overcame this problem by setting implementation intentions to inform peers of their diagnosis when the opportunity arose. Therefore this should be encouraged in clinic settings.

***Aim iii: Determine the barriers the young people identify***

A number of barriers to goal attainment were identified in the analysis and provided support for the various stressors highlighted in chapter 2.

At this stage in development appearance becomes important to the developing adult. Looking attractive to the opposite sex or just the same as their peer group is imperative. Therefore it could be expected that the young people would be fearful of experiencing symptoms of hypoglycaemia (confusion, trembling, feeling dizzy and sweaty) which can be confused with looking intoxicated, or would want to avoid significant weight gain.

Fear of hypoglycaemia is not a new concept. Early work identified hypoglycaemia as a complication which can lead to ‘various aversive symptomatic, affective, cognitive, physiological, and social consequences, which in turn can lead to the development of possible phobic avoidance behaviours’ (Cox, Irvine, Gonderfrederick, Nowacek, & Butterfield, 1987, p. 617). These behaviours can include taking too much insulin as well as ignoring hypoglycaemic symptoms. The finding that fear of hypoglycaemia creates a barrier to care provides support for previous work in young adult males (13-18 years) which suggested fear of hypoglycaemia to be related to reduced adherence to the Type 1 DM regimen. Our results suggest this to be the case in both males and females.

The avoidance of insulin administration as a result of the weight gain associated with optimal control is a growing concern among young people with Type 1 DM and was found to be prevalent in this sample. The threat to both short and long term health that this poses is very real. Staff within diabetes clinics often find it difficult to diagnose insulin omission arising from weight concerns, making this barrier very concerning in this age group. Greater awareness of this relatively new form of eating disorder should be raised.

The lack of symptoms related to Type 1 DM often resulted in illness denial and a neglect of self-care behaviours. This can be seen as risk-taking behaviour (Elkind, 1967). However, in these cases a diagnosis may not yet have been accepted, and it is unlikely that the participants will have believed themselves to be at risk of complications. The implications for the young person with Type 1 DM are that they may not be ready to take full responsibility for their care. Similarly, some participants described a lack of improvement in symptoms once self-managing optimally and as a consequence expected future outcomes from self-management to be similar. This provides support for social-cognitive theories which suggest negative outcome expectancies are likely to have a demotivating effect and could lead to feelings of learned helplessness (Miller & Seligman, 1975).

In order to avoid feelings of disappointment, guilt and embarrassment the participants engaged in negative coping mechanisms such as avoidance behaviours. By avoiding tests the disappointment and guilt associated with an undesired result could be avoided. By avoiding self-management practices in public their diagnosis could be concealed. This supports previous studies which point to the damaging effect of avoidant coping on self-management behaviours and consequent glycaemic control (Graue et al., 2004). In order to improve outcomes, these behaviours should be discussed within clinic consultation.

The readiness of the young people to neglect self-care due to these barriers is concerning. Perhaps most concerning is the readiness to risk high-blood glucose levels and future complications in order to avoid social embarrassment. Although these are significant barriers to self-care, the results of this study also suggested a number of motivators which could facilitate the uptake of optimal self-care behaviours. These motivations appear to be related to proximal problems, that is, the motivations for many of the goals set by the young people are all short-term concerns. This is consistent with what we might expect at this age. Distal goals such as prevention of long-term consequences may not be as attractive given the end point is perhaps perceived to be too far away. However, one participant wished to avoid long-term complications. This is a more distal concern and in this case the participant was displaying health anxiety (Salkovskis, Rimes, Warwick, & Clark, 2002). In particular the very frequent blood glucose testing carried out as a result on this need to avoid future complications is consistent with hypochondriasis.

***Aim iv: Determine the sources of support the young people identify***

The main source of support identified was parents. Adolescent literature has pointed to the decreasing role for parents in the adolescent stage of development, in the light of this, this result is perhaps surprising. Explanations for this could include the complexity of the self-management regimen. In childhood parents assume the responsibility for diabetes care but during adolescence the young person becomes increasingly responsible (Weissberg-Benchell et al., 2007). The high level of parents being identified as a source of support could indicate this reliance is still present and transition of care is not yet complete. Additionally, this provides support for contemporary theory more generally which hypothesises that given many young people are remaining in education for longer, they are financially dependent for longer and therefore are reliant for longer (Arnett., 2000).

Although many identified their parent as a source of support in helping them to achieve their goals, this did not always lead to success in goal attainment. Although there are likely to have been other barriers, it is also possible that discussing the goal with family members led to frequent reminders from parents. This can often be seen as ‘nagging’, can demotivate and lead them to rebel (Keen, 2010), perhaps explaining the poor results relating to support from parents. The most important form of support appears to arise from peers. The majority of young people identifying peers as a source of support achieved their goals. Peer support has been found to be helpful in a number of chronic conditions (Forgeron et al., 2009; Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011; Janicke et al., 2009). Peers can help decrease stress (Hains et al., 2007) by supporting young people in their self-management, and therefore may help improve rate of goal attainment if encouraged in future trials.

***Aim v: Determine the rate of goal attainment***

A total of 35 young people completed action plans at their follow up session. This allowed us to decipher the self-reported rate of goal attainment. Over half (74%) indicated they had managed to carry out their implementation intentions and had therefore gone some way towards reaching their chosen goal. This is higher than anticipated and suggests the intervention to be successful for those who take part. Success rates could be explained by the thorough discussion of any barriers which were anticipated along with the identification of a supporter and discussion in clinic. A further explanation lies in the decision to encourage participants to create a new goal if confidence levels were too low, which meant the young people felt the goal was achievable.

A higher proportion of females went some way towards attaining their goals in comparison to males. This could be explained in terms of self-regulation. Previous studies of behaviour change in general have pointed to the increase in self-regulation in females relative to males (Renner et al., 2008; Hankonen, Absetz, Ghisletta, Renner & Uutela, 2010). Both cognitive regulation (thought control/modification) and emotional regulation (emotional control/modification) are both needed in order to execute goal directed behaviour (Morrison and Bennett, 2012). Therefore it is possible increased self-regulation in the females could have helped the females to achieve their goals more consistently than males.

**6.5.1 Strengths and limitations**

This intervention has a number of strengths for use within a clinic setting. Action planning interventions are a cost-effective method of improving outcomes in young people with chronic conditions. In this study, three research assistants were successful in engaging young people with Type 1 DM and assisted in focusing on making small improvements. The research assistants were well received within clinic and were able to work in the waiting room in order to increase contact time and decrease the long-waiting times often associated with these diabetes clinics. This is a large strength given the numerous difficulties within clinic that were faced. Most notable was the resistance to the intervention from staff. Diabetes clinics are very busy and staff expressed fears that the research assistants would hinder the running of the clinics and slow down the already long post clinic meetings by providing an extra discussion topic. Adding to this were issues with clinic organisation. It was initially very difficult to find a time at which participants could be approached, particularly as consultants were often unhappy if their patients were engaging in goal setting when they were called into their appointment. Further, the clinics run from the afternoon into the evening meaning patients were tired and often did not wish to engage in conversation. Given these challenges, the response rate gained was higher than anticipated.

Additionally, in this intervention goal setting facilitated shared decision-making (Locke et al., 1999), between the young person and the research assistant. This allowed the young person to focus on areas important to them making care more patient-centred, whilst providing support and guidance where necessary. Consequently it has the potential to improve communication within clinic.

Consideration should be paid to a number of limitations in the interpretation of these findings. First, the participants attended clinic regularly, meaning many were likely to already be engaged with their care. Second, clinic staff selected participants and research assistants were unable to discuss issues with those who were deemed to be currently experiencing mental health problems. As a result the participants were all likely to be coping well with their treatment and lifestyles. Third, time constraints within clinic meant that the research assistants were unable to collaborate with the consultants effectively, meaning it is unclear as to whether goals were always discussed within consultation. Future trials should ensure such discussions are undertaken, particularly given the potential to reinforce the implementation intentions, provide further advice on overcoming barriers and provide extra support where necessary. Finally, given the other CLAHRC interventions running in parallel to this study it was impossible to determine the effect of the intervention on medical or psychological outcomes. However, the main aim of this study was to determine feasibility and not outcomes. Further work is needed in order to determine the effect of this intervention on outcomes in young people with Type 1 DM.

This intervention was a pilot and in light on the limitations discussed above, improvements could and should be made before trialling on a larger sample of participants. First, on agreeing to participate in the action planning intervention, participants should be asked to complete the intervention within a private consultation room. This would enable greater depth of discussion of any problems and goals they may wish to achieve, although each participant was given this option many completed the action planning sheet within the waiting room. This may have reduced the likelihood of more sensitive issues being discussed and led to a reduction in the successful achievement of goals.

Second, many young people revealed they had forgotten to carry out their implementation intention once they had left the clinic setting. Sending out text message reminders or calling the participants by telephone may have acted as a reminder to the young people and led to an increase in the number of participants applying their implementation intentions. Finally, it should become routine within the post-clinic meetings for the consultants to inform the research assistants as to whether the goal was discussed with each participant within consultation.

**6.6 Conclusion**

To conclude, young people engaged with an action planning intervention within a clinic setting. The main goals were related to self-management, which could be due to the setting in which the intervention took place. Further, the results provided confirmation that at this age the developing adolescent focuses on proximal rather than distal goals. A number of barriers to goal attainment were highlighted and should be addressed in order to improve goal attainment in future interventions. Additionally we gained evidence of the importance of peers in facilitating self-management. These findings should be taken into consideration when designing and implementing future interventions.

**Chapter 7**

**General Discussion**

**7.1 Summary**

The aims of this research were to examine the psychological difficulties of young people with Type 1 DM and pilot an intervention to assist in alleviating the negative outcomes associated with this chronic illness. To do this we conducted a quantitative prevalence study and a systematic review and meta-analysis. The results of these studies were then used to develop a pilot intervention. The findings are discussed in terms of theoretical implications, clinical implications, and strengths and limitations. Suggestions for future work in this area include the validation of the DDS for use in adolescent populations as well as the use of the CIDI to determine levels of clinical depression, and a trial of the action planning intervention on a larger sample.

# 7.2 Summary of Research Questions and Study Design

It is easy to see why it might be difficult to adhere to a strict diabetes treatment regimen during this period. Adolescence is a busy period full of transitions, new peer groups, increasing workload, as well as physical changes. The self-care behaviours associated with Type 1 DM interfere with the day-to-day life that would otherwise be afforded to them without a chronic illness. They make the young people feel different to their peers at a time when fitting in, feeling ‘normal’ and being socially accepted is a priority (Greenberg, Siegel, & Leitch, 1983).

The overall aims of this thesis were to:

1. Examine the psychological difficulties experienced by young people with Type 1 DM and their relationship to blood glucose control.
2. Identify and explore the range of psychological interventions previously trialled.
3. Develop and pilot an intervention to improve outcomes in young people with Type 1 DM.

Chapter 1 outlined the prevalence and aetiology of Type 1 DM as a complex chronic illness. Self-care behaviours essential for successful glycaemic control were highlighted along with both long- and short-term complications that may arise from prolonged suboptimal glycaemic control. These complications can be life limiting or fatal. In chapter 2 the stressors faced during adolescence, both during normal development and for those with Type 1 DM were introduced. The challenges faced for those with a co-morbid chronic illness are numerous and often lead to neglect of self-care and self-management practices with negative implications for both future physical and psychological health. Chapter 3 outlined the psychological difficulties arising from having a co-morbid chronic illness such as Type 1 DM during adolescence and the impact this has on the developing adult. Depression, anxiety and diabetes related distress were all discussed, along with current prevalence estimates and current UK health policy related to psychological treatment for those with Type 1 DM. As a result, it was concluded there was a need for an age-appropriate intervention targeted towards young people in the 16-25 years age range. This intervention would need to be sensitive to the needs of the group, addressing their special and often very personal concerns, whilst fitting in with clinical practice.

In order to determine which intervention would be most appropriate for our sample it was necessary to conduct two studies. The first, presented in chapter 4, aimed to estimate the prevalence of depression, anxiety and diabetes-related distress in those attending specialist transition clinics for diabetes in Sheffield across two hospitals. This study determined, by use of mediation analyses whether it is depression or diabetes-related distress which is the most related to HbA1c. We concluded that diabetes-related distress, and more specifically, distress related to the treatment regimen which was the most greatly associated with HbA1c.

The second study, presented in chapter 5, aimed to build on the findings of chapter 4 by determining previous interventions which have been found to help reduce symptoms of diabetes-related distress and improve HbA1c levels in young people. In order to do so, a systematic-review and meta-analysis of interventions for those aged 8-21 years with Type 1 DM was conducted. The results showed goal setting, and interventions aimed at the individual to be the most efficacious for this age group.

In light of these results an action planning intervention utilising goal setting and implementation intentions tailored to the individual was piloted in the adolescent clinics of Sheffield Teaching Hospitals. The results of this intervention are reported in chapter 6. The intervention proved easy to implement within a clinic setting and had a moderate uptake, with those participating moving some way toward achieving their goals in 74% of cases.

**7.3 Key Findings**

**7.3.1. The prevalence of depression, anxiety and diabetes related distress**

In Chapter 4, patients (n=96) completed a questionnaire assessing depressive symptoms and anxiety (HADS; Zigmond & Snaith., 1983), diabetes-related distress (DDS; Polonsky, 2005), eating behaviours (Diabetes Eating Problems Scale; Markowitz et al., 2010), self-reported HbA1c and demographic variables. For the purpose of this study only data from the HADS (Zigmond & Snaith, 1983), DDS (Polonsky, 2005) and demographic data were used, in combination with data collected from medical records.

Given the DDS had only previously been used in adult populations a principal components factor analysis was conducted on the data in order to examine the acceptability of the measure for young people. The analyses revealed a three-factor structure within the data with each factor having high internal consistency. This is contrary to previous research with older people (Fisher et al., 2008) showing a four-factor structure within the scale. Two of the factors extracted in this study map exactly onto two of the previously established factors, and as a result were given the same labels (physician related distress and interpersonal distress). Regimen related distress and emotional distress were not distinguished between as previously reported in an adult sample by Fisher et al., (2008). We were able to demonstrate this measures utility with young people with Type 1 DM. As such this signifies a significant development and an important step towards the use of disease specific measures. This is potentially valuable given that previous work in this age group has relied on generic measures of distress (Hislop et al., 2008).

It was hypothesised that our sample would report higher psychological symptoms in comparison to the general population. Rates of depressive symptoms and anxiety were similar to those in a previous study of young people aged 12-17 years without a chronic illness (White, 1999; Jorngarden et al., 2006)*.* Although it could be hypothesised that rates among young people should be higher, this provides support for recent evidence that in fact, rates are no higher (Johnson et al., 2013). This previous review found largely mixed results regarding prevalence estimates in this age group (Johnson et al., 2013). Given the illness specific measure of distress it would be impossible to compare our data to population norms. In the absence of age-matched comparison data for the DDS we compared our data with a previous study in adults, the results were comparable (Fisher et al., 2010a, 2010b).

A further finding related to gender. Symptoms of anxiety and diabetes related distress were higher in females than in males as predicted, but there was no significant difference between males and females for depressive symptoms. This is contradictory to previous work suggesting depressive symptoms are higher in females in the general population (Seedat et al.,2009) due to differences in development and roles.

A critical finding of this study was the relationship between the psychological variables and HbA1c. It was hypothesised that all variables would be associated with HbA1c, with higher psychological symptoms associated with higher HbA1c. Anxiety was not found to be associated, this was assumed to be a result of the protective effect anxiety can have (Herzer et al., 2010). Depressive symptoms and diabetes related distress however, were associated. This is consistent with a number of studies which suggest these associations are present in the adult population (Fisher et al., 2010a, 2010b ; vanBastelaar., 2010). Perhaps more importantly, we found that diabetes related distress mediates the relationship between depressive symptoms and HbA1c. This provides support for previous studies which have suggested that diabetes related distress as opposed to depression is the main predictor of HbA1c (Fisher et al., 2010a, 2010b; VanBastelaar., 2010). The apparent overlap between some questionnaires creates the illusion of an association between depressive symptoms and HbA1c.

Analyses were taken further than previous studies by examining the subscales of the DDS which predict HbA1c. Previous studies (Fisher et al., 2007, 2008b, 2009, 2010a, 2010b, 2012) have failed to examine these subscales and their relationship to HbA1c in such detail. In this study regimen/emotional related distress was the subscale with the highest association, and also the most prevalent issue faced by the young people.

In the literature review in chapter 2 we examined the stressors faced by this group. One stressor was the punitive nature of parents and health-care professionals perceived by the young people and their demands to pay more attention to self-care and achieve optimal glycaemic control. This may lead to increased shame, guilt and avoidance behaviours (Weissberg-Benchall, 2007). This stressor was hypothesised to arise due to the differing views of the parents, health-care professionals and young people about priorities. Additionally there was evidence that a change in relationship with health care providers during transition periods results in stress for the young people and consequent clinic avoidance (Kipps., 2002). Further stressors arose from peers, and the need to appear normal and “fit in”, along with family conflict. As a result of these stressors it seems surprising that the subscales of interpersonal distress and physician related distress were not scored more highly. It is likely that stressors associated at this stage in life make coping with the diabetes regimen more difficult, which in turn leads to increased emotional difficulties.

The associations between HbA1c and regimen related/emotional distress, is perhaps unsurprising, in that distress may arise from the frequency of self-care behaviours associated with Type 1 DM. As discussed in chapter 1, Type 1 DM must be constantly managed and cannot be ignored. The realisation of the complexity of the treatment regimen could lead to the avoidant coping strategies discussed in chapter 2. This has important implications for intervention design and delivery. Interventions to improve outcomes in this group should target those self-care behaviours which lead to distress, for example, carrying out blood glucose testing when results are anticipated to be high.

The findings of this study are important for three reasons. First, this is the first study to use a disease-specific measure of diabetes related distress. Second, the findings from the adult population were replicated with a sample of young people. Third, this study went further than either child or adult literature by providing evidence that distress related to the diabetes regimen/emotion is the most highly associated with HbA1c and should be a target for interventions.

**7.3.2 Behaviour change interventions: A systematic review and meta-analysis**

In systematically reviewing the literature from January 2004 until September 2013, only 27 randomised controlled trials of behavioural interventions involving adolescents with Type 1 DM were found. A small but significant improvement in HbA1c was reported in the short-term post intervention, which was maintained in the longer term. The most effective behaviour change technique overall was goal setting. In addition, those delivered to the individual proved to be the most effective over those delivered to a group or families. A small but significant improvement was also seen in the prevalence of psychological outcomes. Further analyses could not be conducted on the psychological variables given the limited number of studies. However, the intervention which led to the greatest improvement in psychological outcomes utilised goal setting.

Major limitations were found in the studies included in this review. First, a total of 22 psychological measures were used overall. Given the inherent difficulties associated with comparison between different measures of the same psychological problem, it is important that a gold standard for the measurement of psychological outcomes is reached for use in intervention research, in order to reach more reliable and robust and interpretable conclusions. Second, very few interventions had been conducted within the UK, with the majority conducted within the USA. Third, the included studies often did not provide enough data to allow the calculation of effect sizes necessary for meta-analysis.

## 7.3.3 Action planning intervention

Forty seven young people consented to take part in the action planning intervention. Thirty-five of these filled in action plans at time 2 allowing for the examination of the rate of success of the participants in adhering to their implementation intention and achieving their chosen goal. There were five main findings of this study: the rate of uptake to the intervention, type of goal set, barriers to goal attainment, chosen supporter, and level of goal attainment.

The most common goals were related to self-management, and in the majority of cases, increasing frequency of blood glucose testing. This could be due to the focus of the clinic consultations. A previous study has pointed to the very medical focus of diabetes related consultations (Brierley et al., 2012). Medical outcomes often are discussed at the expense of psychological outcomes or topics important to the young person which may be a hindrance or help to self-management practices (Brierley et al., 2012). Many of the participants struggled to identify a personal goal that would be important to them, perhaps as a result of these self-management goals being the most salient to the young people.

The second goal theme was social life. The young people did not wish to appear different to their peers and as a result often concealed their diagnosis. As discussed in chapter 2, peers become important during adolescence where independence from parents is sought after. The desire to conceal their diagnosis experienced may not be unfounded given studies indicating that those with Type 1 DM experience greater relational victimisation relative to their peers (Storch, 2004). Added to this is the finding that this group are perceived differently by not only their peers, but teachers too who often view those with a chronic illness as having “special needs” (Cole et al., 1996; Olson, Seidler, Goodman, Gaelic, & Nordgren, 2004).

The second finding was the range of barriers the participants perceived to achieving their goals. Many of these barriers could be anticipated given the transitional and developmental changes experienced by the participants and reflect those raised in chapter 2. Major themes included adolescent traits, illness denial, stigma and shame, appearance and life events. Importantly, some young people reported “feeling fine”, “embarrassment”, “ disappointment and guilt” and “social activities” to be barriers. Neglecting their implementation intention due to “feeling fine” could be related to the immortality belief typical of this age group and reported in a previous qualitative study (Brierley et al., 2013). The disappointment, guilt and social pressures experienced arose from anxieties about test results or consultations and led the young people to engage in avoidant strategies, such as neglect of self-care behaviours or clinic non-attendance.

In chapter 2 the importance of appearance as puberty is reached was discussed. Adolescents discover the opposite sex and want to appear attractive. Unfortunately, for some of the young people this meant insulin manipulation as a means to lose weight as discussed in chapter 3. The use of this unique weight loss strategy has been reported previously (Colton & Rodin, 2009; Young et al., 2013). Interestingly, these issues had not previously been discussed during consultations. As a result the prevalence of such symptoms may be higher within this sample than is currently acknowledged.

Third, the majority of young people identified a parent as a source of support in helping them to achieve their goals. Given the age group of our sample, historically this may be expected. However, as discussed in chapter 2, one theory is that establishing independence in modern society is more prolonged than in previous generations (Arnett., 2001). Children are staying in education longer; they are leaving home later, and are remaining financially dependent for longer leading to later transitions and greater overall dependence on parents. Further, given the complexities related to the management of Type 1 DM some young people may be more reluctant to relinquish control and may be more satisfied with a parent remaining in charge. Indeed, better outcomes have been reported where help is perceived from a caregiver (Gillibrand., 2001). Eleven young people identified friends as a source of support, and eight identified partners, perhaps given the importance of peers and relationships in this age group (Bearman et al., 2002; LaGreca, 1995).

Finally, 26 out of the 35 young people who completed action plans at time 2 achieved their initial goal or felt they had gone some way towards achieving their goal. Additionally this success rate was related to peer support. Those young people who identified a peer as a source of support generally achieved their goal. This provides support to previous studies finding a positive relationship between peer support and treatment adherence (Bearman et al., 2002; LaGreca, 1995).

**7.4 Methodological Considerations**

There are some methodological limitations to discuss within this thesis. These will be discussed in terms of the measurement variables, cross-sectional nature of the data, meta-analyses and the action planning intervention.

**7.4.1. Measurement of variables**

There are issues when measuring psychological outcomes in this target group. A lack of diabetes specific measures can mean results are not sensitive to the population on which they are being used. For this reason care was taken to select those measures which have good reliability, validity, interpretability, feasibility, responsiveness and that have low patient burden for those with diabetes.

***Depression and anxiety***

Depression and anxiety were measured using the HADS (Zigmond and Snaith, 1983). This measure was chosen given that it has been widely used in a number of long-term physical conditions including diabetes (Lloyd, Dyer & Barnett, 2000; Engum, Mykletun, Midthjell, Holen & Dahl, 2005; Shaban, Fosbury, Kerr & Cavan, 2006). Although a number of previous studies in this population have used the Centre for Epidemiological Studies Depression scale (Radloff, 1977), we deemed this scale unacceptable for our sample given the inclusion of somatic items and the moderate positive predictive value (i.e. a high rate of false positives). The HADS has been found to have good validity and excellent internal and external reliability (see chapter 4), and therefore we found this to be the most appropriate measure to use in this sample.

Given the young people were asked to fill in a questionnaire pack containing four scales as well as demographic items, we felt it important that the chosen questionnaire accounted for as little burden as possible. The HADS measures both symptoms of depression and anxiety using only 14 items (7 for depressive symptoms and 7 for anxiety) and so was deemed fit for this purpose. Although the feasibility and acceptability have been demonstrated in diabetes in general (Lloyd et al., 2000) we deemed it necessary to determine the interpretability, feasibility and acceptability in our sample population. In order to do this members of the diabetes care team were asked to comment on each of these topics during a team meeting. No concerns were expressed over the length or items within the scale.

Additionally, the HADS is not a measure of clinical depression, and can only be used to identify symptom severity in a population. Previous work in adult populations (Fisher et al., 2007, 2008b, 2009, 2010a, 2010b, 2012), has been able to use clinical interviews such as the CIDI (Kovacs, 1985) in order to provide a diagnosis of clinical depression. Not only are clinical interviews more robust than self-report questionnaires, this allowed the authors to determine whether the sample were experiencing clinical depression or diabetes related distress, or if the two were experienced together. We were unable to use such measures in our study given time constraints in clinic, and as a result were unable to reach such conclusions.

***Diabetes Related Distress***

Given the age of our sample, there was likely to be a great deal of distress arising from stressors associated with this stage of life, for example, transitions, hormonal changes, and conflict. For this reason we felt it important to use a measure of distress specific to diabetes. There are a number of measures available with the most widely used being the Problem Areas in Diabetes scale (PAID; Welch., 1997) and the DDS (Polonsky., 2005). Careful consideration was given to selecting the optimal scale for our population. Ultimately given the confusion reported by respondents to the PAID scale (Welch., 1997) and the lack of breadth of coverage of the varying types of distress in other scales (Polonsky., 2005), the DDS was chosen.

As with the HADS, careful consideration was paid to the validity and reliability of the scale. The DDS has been validated in adults, but not in a sample of young people. As a result, we conducted a factor analysis which revealed good validity for use with our sample. This scale was found to have high internal and external reliability (see chapter 4). Again, the diabetes care team were asked to comment on the scale with regards to its interpretability, feasibility and acceptability. Although all agreed the items were appropriate on the whole, some wording was changed in order to reduce confusion for the young people.

**7.4.2 Cross-sectional data**

Study one was cross-sectional in nature. This carries with it the limitations which are inherent to all cross-sectional research. First, our data includes only a small picture at one time point meaning there can be no attribution of causality. For example, it is unclear as to whether diabetes related distress causes an increase in HbA1c or if an increase in HbA1c causes an increase in diabetes related distress. This causes particular problems in meditational analyses as we were unable to reach any accurate temporal conclusions (Maxwell & Cole, 2007), so that our results may be susceptible to bias. However, these problems are offset by the strength of the relationship revealed and the addition of important results regarding the type of distress experienced in our sample.

**7.4.3 Meta-analysis**

As highlighted in Chapter 2, we have chosen to work with this age group given the lack of previous research. This is surprising given the increase in HbA1c recorded during this stage of life (Bryden et al., 2001; Insabella et al., 2007) and the implications this has for poor health and complications later in life (Bryden et al., 2003; The Diabetes Control and Complications Trial Research Group, 1993, 1994). As a result this impeded our literature searches and very few studies which focused interventions toward our target age group were found. The age range was increased for the purpose of the review in order to increase our chances of robust findings. However, in order to ensure a high quality, reliable review without the presence of bias we followed strict recommendations regarding protocol design, literature searches, data extraction, quality control, and data analysis (PRISMA, 2009). Additionally, in order to allow the attribution of causality we ensured only randomised controlled trials with a follow up period were included. Any pilot studies were excluded. The use of the PRISMA guidelines (2009) allowed us to reach strong conclusions with regards the effect of behavioural interventions on young people with Type 1 DM. In order to add further strength to our conclusions we added meta-analytical techniques.

**7.4.4 Action planning intervention**

With regards to the action planning intervention, we were only able to conduct a pilot study. This carries inherent limitations associated with pilot studies, along with limitations specific to our study. In particular, given the lack of a control group, it is difficult to ascertain whether the results gained were a specific response to the intervention or due to the increased contact and greater opportunity to discuss problems. This considered we were able to determine the feasibility of recruitment, feasibility for use within a clinic, retention and acceptability of this novel intervention (Leon, Davis, & Kraemer, 2011). Although were not able to determine whether our intervention led to improvements in medical or psychological outcomes, we were able to measure the variety of goals recorded along with self-reported success in achieving goals and possible ways of improving goal attainment. However, we are unable to generalize these results to the wider population. The main strengths of this pilot study were in its contribution to our understanding of the challenges faced by this group and the factors that may facilitate or hinder treatment adherence as well as our ability to determine possible improvements which may contribute to the success of this intervention in future clinical trials.

The results of this study were assessed using qualitative techniques. With this arises limitations common to all qualitative studies. Every effort was taken to ensure these limitations were minimised by adhering to published guidelines for good, valid qualitative research (Yardley., 2000). These include being sensitive to context, commitment and rigour, transparency and coherence, and impact and importance. In the months leading up to study commencement, the researchers were present within the clinics in which the intervention would take place, collecting questionnaire data and ensuring the young people were familiar with the research. This ensured the researchers were able to be sensitive to context. Second, the action plans were set over a period of 12 months ensuring commitment.

Sampling bias may have been an issue here. Given that this study was conducted within the clinics, the participants already had to have some level of engagement with their treatment. It could be assumed that those who participated may already be motivated on some level. In order to minimise this, special efforts were made to ensure a range of HbA1c levels were represented, and the diabetes care team provided input as to who were not currently engaging optimally, ensuring rigour. Third, in order to ensure transparency, detailed information on the methods of data analysis was provided. This included providing an example of the action plan used, and details of how the framework was developed. Coherence was given by second-coding of the data, any disagreements in coding were resolved through discussion. We are confident that this study has an impact and is important in that it allows for crucial and timely information on how to further develop and strengthen this intervention.

It is also possible that there were pre-existing predjudices held by myself given the previous studies and research undertaken. This could have influences the responses of the participants. For example, as discussed I bring with me knowledge that this group is often vulnerable and often have poor blood glucose control. Although I made every attempt to remain objective throughout, the knowledge I have gained in the four years working on this project may have both influenced the responses of the participants, and guided my interpretation of results. Most notable, in some cases participants were unable to think of a goal, here, any prompts given by myself may have reflected pre-existing beliefs and the medical model of the clinic.

**7.5 Theoretical Implications**

The work in this thesis has contributed to our theoretical understanding of the psychological experience of young people with Type 1 DM. Most notably, our understanding of the type of distress experienced, the interventions, which can help, reduce negative psychological burden, the barriers to the adoption of self-care behaviours and the support networks preferred by the young people.

***7.5.1* Psychological burden**

Perhaps the most important contribution this thesis has made to theory is the distinction between depressive symptoms and diabetes related distress and the effect these variables have on HbA1c. It has been previously assumed that depressive symptoms will be higher in those with Type 1 DM in comparison to those without, and that elevated depressive symptoms will be related to suboptimal HbA1c (Johnson et al., 2013). Our findings indicate the importance of diabetes-related distress in the psychological experience of young people and an effect of this on HbA1c over and above depressive symptoms. It would appear that diabetes related distress is distinct from depressive symptoms as measured by the HADS and this is an important factor in glycaemic control. This is consistent with previous work within an adult population with Type 2 DM (Fisher et al., 2007, 2008b, 2009, 2010a, 2010b, 2012).

Additional to this is our finding that regimen related/emotional distress is associated with suboptimal HbA1c within our sample. This subscale includes items such as “feeling overwhelmed by the demands of living with diabetes”, “not feeling motivated to keep up my diabetes self-management” and “feeling angry, scared and/or depressed when I think about my diabetes”. As a result of these negative feelings it is likely that the young people are engaging in emotion focused coping strategies. This includes avoidance coping where the attempts are made to reduce distress by avoiding the perceived stressful situation. Previous studies have found this to be related to suboptimal glycaemic control (Graue et al., 2004; Reid et al., 1994) further support is provided for this by the results of our action planning intervention. Here young people indicated avoidance of self-care behaviours or clinic due to feelings of guilt and shame.

Added to this is our increased understanding of the relationship between gender and depressive symptoms. Within the general population it is widely understood (Seedat et al., 2009) that females score more highly on depression scales than males. Within our sample we found the prevalence to be comparable. This may reflect a trend to increasing similarity between males and females in work and family related stress in the population generally (Seedat et al., 2009), or that gender differences may be reduced in the diabetes population as a result of the demands of self-care. These results suggest that both males and females with Type 1 DM are similarly vulnerable to depressive symptoms.

**7.5.2 Interventions**

A further addition to our theoretical understanding in this area is the components that make a behavioural intervention effective. We built on previous findings that psychological interventions are effective at improving psychological and medical and psychological outcomes (Winkley et al., 2006). We found those interventions using goal setting, and those interventions delivered to the individual to be the most effective. Goal setting is likely to be effective due to the patient-centred focus and the shared decision making process between the participant and the researcher. Previous research has pointed to the need for patient-centred care for young people (Langford et al., 2007). In addition our findings indicate individual interventions appear to have greater utility in this age group compared to family or group focused interventions. This is perhaps due to the specific individual needs of this groups and a transition of care responsibility from the family to the young person.

**7.5.3 Support and barriers**

Chapter 2 discussed the various barriers to achieving optimal glycaemic control and psychological well being in our sample. Our findings from the action planning intervention are consistent with these barriers. Adding to this is the type of support the young people identified. Many identified a parent to help them with their goal attainment, this is consistent with theories that young people are now transitioning later due to being reliant on parents for longer (Arnett, 2001). However, we contribute to current theoretical understanding by identifying that it is those who identify peers as a source of support who achieve their goals most consistently. This is likely to be due to the reduced burden these young people have given that they are not concealing their diagnosis.

**7.6 Clinical Implications**

In terms of clinical implications we make a number of recommendations, which may help improve the clinical experience of Type 1 DM. The first relates to in-clinic screening of psychological outcomes, the second tailored care and third use of action planning interventions within clinic settings.

**7.6.1 Screening**

The current National Screening Committee guidelines within the UK are underpinned by 10 principles set out by the World Health Organisation (Wilson & Jungner, 1968). These 10 principles became used globally for assessing the validity of proposed screening strategies for disease detection (Lloyd & Roy, 2013). Although diabetes-related distress is not deemed a “disease”, this thesis has highlighted it has a negative effect on outcomes in young people with Type 1 DM and therefore we argue for within-clinic screening. Support within this thesis was gained for all of those principles that do not relate to disease. The 10 principles and the support gained for screening for diabetes related distress from this thesis are summarised in Table 7.1.

**Table 7.1. Principles of early disease detection: World Health Organisation criteria**.

|  |  |
| --- | --- |
| Principle | Response |
| Condition should be an important health problem. | In chapter 4 diabetes related distress was identified to have significant associations with suboptimal glycaemic control. Previous studies using different measures and in adults have also found this (Fisher et al., 2010, Hislop et al., 2008).  |
| There should be an accepted treatment for people with the disease. | Although diabetes-related distress is not a disease, psychological referral in some cases in necessary.  |
| Facilities for diagnosis and treatment should be available. | Facilities for diagnosis and treatment are available within a clinic setting and can be administered cost-effectively. |
| There should be a recognisable latent or early symptomatic stage. | Relates only to disease. |
| There should be a suitable test available. | There are many screening tools available for detection of diabetes related distress, but we found the DDS to be the most appropriate, covering the most areas of distress. Additionally, a two-item screening questionnaire was developed from the DDS (Fisher et al., 2008a), we found this short screening questionnaire to correlate highly with the overall scale in Chapter 4. |
| The test should be acceptable to the population. | In Chapter 4 we found the DDS to be a valid and reliable measure acceptable to our target age group. For the purpose of saving time within clinic the two-item screening tool should be provided in the first instance. Those scoring above threshold should then fill in the full scale to determine the type of distress experienced. |
| The natural history of the condition, including development from latent to declared disease, should be adequately understood. | Relates only to disease. |
| There should be an agreed policy on whom to treat as patients. | Although there is no current policy on who to treat for diabetes related distress it is hoped the importance of this psychological issue has been highlighted by this thesis, and work will continue until there are adequate policies in place.  |
| The cost of case finding should be economically balanced in relation to possible expenditure on medical care as a whole.  | Within this study, research assistants administered screening questionnaires to the young people, thus reducing costs. However, as the patients respond to the questionnaire independently handing out screening tools on arrival at clinic appointment could reduce costs further.  |
| Case-finding should be a continuous process and not a “once and for all” project.  | Given the short screening questionnaire, this could be administered at every clinic appointment in order to detect any changes, given the scales ability to be responsive to change over time.  |

Thus we propose screening would not only be a cost effective method of determining psychological issues within a clinic setting, but also meets eight out of ten of the criteria for screening accepted currently by the National Screening Committee. Although a specific treatment for elevated levels of distress has not yet been identified, screening could be an important tool for targeting DSN support. Given that DSN support is a limited resource within the clinics of the Sheffield Teaching Hospitals, this could prove an effective and valuable method to provide assistance to those most in need. This would also go some way towards decreasing the gaps in current psychological care for DM identified in the ‘Mind the Gap’ survey (Trigwell et al., 2008).

**7.6.2 Guidelines for care**

Our systematic review and meta-analysis revealed those interventions targeted to the individual to be the most beneficial. Patient-centred care is a concept that is gaining greater recognition within the NHS, and is now part of the recommended guidelines for clinic practices (National Institute for Health and Clinical Excellence, 2012). This type of care allows for the identification of issues deemed important to the patient as opposed to the health care professional and as a result helps decrease the psychological burden to the young person. In our previous qualitative study into the views of a diabetes care team towards young people with Type 1 DM (Brierley et al., 2012), staff expressed concerns that they were not being truly patient-centred. A number recognised the need to work collaboratively with patients but highlighted a general focus on medical issues within clinic due to time pressures.

It is clear then that although it is a recommendation, patient-centred care is not always carried out. Our action planning intervention provides a cheap (Nansel et al., 2007) way of enabling patients to consider what is important to them and can then provide a focus for clinic consultations. Also our intervention reduces the burden of clinic time pressures by being completed in waiting rooms.

 As an addition clinics may benefit from the encouragement of peers in the treatment process and providing support on an individual basis to those who feel unable to inform their peers of their diagnosis.

A final implication for care delivery is that of increased education. A number of participants in the action planning intervention found it difficult to carry out self-care practices due to a lack of knowledge. As part of the CLAHRC-SY complex intervention an educational intervention specific to the needs of our target group was developed and delivered to groups of a similar age, this should be routinely recommended in clinic to those with gaps in their current knowledge.

**7.7 Strengths and Limitations**

We acknowledge a number of limitations of this research; some of those regarding methodology have been discussed in the methodological considerations section of this chapter as well as the discussion sections of each study chapter. In addition to these limitations there were several strengths.

**7.7.1 Limitations**

The main difficulty with conducting this research was the challenge posed by conducting research within a clinical setting. The specialist diabetes clinics at the Royal Hallamshire Hospital are by their nature very busy. The staff are overstretched and as a result are not always able to assist with research studies. This issue is reflected in Study 1 at the Royal Hallamshire Hospital site. Staff were often unable to assist in the identification of potential participants which meant in some cases those who were eligible were not approached. In addition, in Study 3 action planning sheets were often not followed up during clinic consultation due to the pressures created by the high number of those attending these clinics.

Conversely, the specialist clinics at the Northern General Hospital were often poorly attended by the young people. Although it would be expected that this would mean more staff time for assistance with the research studies and a greater number of participants recruited, this was not the case. These clinics were shorter, and as a result, patients often went straight into consultation on arrival, making recruitment difficult. Those who consented to the study did in some cases get called into consultation part way through questionnaire completion. In these cases the participant often requested to complete the questionnaire at home, this is likely to have reduced the response rate in Study 1.

Additionally, across both sites, potential participants in Study 3 often requested to consider a goal for their next clinic appointment. However, once prompted at their next clinic, the potential participant often had often forgotten this, as a result this slowed down the process of recruitment and potentially lowered the amount of follow up plans completed. This problem may have been reduced by encouraging the young people to make use of the private room set aside in the clinic, where issues and potential goals could be explored with the assistance of the researcher. Despite these problems our response rate for Study 1 was relatively high (81.4%) overall, and moderate (66% of those approached) in Study 3.

A main issue with this research is the use of self-reported data. The prevalence study, the studies included in the meta-analysis and the action plan intervention all to some extent used this type of data. There are, of course, problems with collecting data in this way, in that there may be the presence of bias in the form of demand characteristics (Craig et al., 2008; Orne, 1962). Participants may have anticipated what the research team was estimating, or they may have feared that the true responses they give would impact them negatively in some way. In order to minimise the risk of bias, participants were assured their responses would remain anonymous in the prevalence study and if necessary were able to fill in the questionnaire in a separate room. It was impossible to ensure all studies had done the same in the meta-analysis, in order to minimise bias here quality checks were carried out. Finally in the action planning study, participants were assured their action plans would remain confidential between the researcher and consultants, and were encouraged to discuss anything they would like.

A final limitation was the use of a number of interventions running simultaneously to our action planning intervention. The main aim of CLAHRC-SY was to develop a new model of care for young people with Type 1 DM. The project is in the preliminary development stage of the MRC framework for the development of complex interventions (Craig et al., 2008). In response to a series of systematic reviews, the overall prevalence study and a series of interviews with patients, parents, and staff, a number of interventions were recommended to help improve the clinic experience overall. As a result an educational intervention was developed to address the lack of knowledge which was identified to be a problem, and a care planning proforma was developed to aid clinic organisation. These novel interventions ran in parallel to our action planning intervention and together formed the overall CLAHRC-SY complex intervention and so we were unable to measure whether any one intervention had a more positive effect. All that can be measured is the effect of the overall care package had on the medical and psychological outcomes of the young people.

**7.7.2 Strengths**

There are many strengths to this body of research. First, recommendations could be made for future clinics as well as a number of theoretical considerations which arose from the work. Second, the use of the MRC framework to inform the development of the action planning intervention ensured that development was robust and not subject to any bias. Third, three different data collection techniques were used here. Quantitative data collection was used to provide a “snapshot” of the medical and psychological issues faced within the clinic. Meta-analytical techniques were used to synthesise large amounts of pre-existing data in order to reach robust conclusions. Qualitative techniques were used in order to reach conclusions about our intervention and to provide an in-depth picture of the issues the young people face in achieving their goals. This triangulation of data has enabled a unique insight into the experience of young people with Type 1 DM, and provided possible solutions to improve outcomes. Finally, and perhaps most importantly, this work has provided evidence to an area overlooked by previous research. We have successfully engaged with a group who are deemed difficult to engage with, and achieved positive improvements.

**7.8 Future Directions**

Recommendations for future research have arisen from both the findings of the included studies as well as the limitations of this research discussed in this chapter and throughout the thesis. First, relates to depression and diabetes related distress. This research should be repeated in the same target group using the CIDI interviews (Kovacs, 1986) in order to determine whether clinical depression has an effect on HbA1c and if so if this relationship is mediated by HbA1c. If the relationship is mediated, or clinical depression is not found to be associated with HbA1c at all this would provide further strength to the argument for within-clinic screening of diabetes-related distress. Second, in relation to measurement, the DDS (Fisher et al., 2008) should be used with another sample in order to further validate this measure. Additionally, further variables which may contribute to variance in HbA1c should be explored, and all variables measured at various time points in order to enable the attribution of causality.

Finally, this work provides a case for the need for improvements in care for young people with Type 1 DM, and indicates that such improvements can be made. The overall CLAHRC-SY complex intervention along should be trialled on a larger scale in other clinics throughout the UK in longitudinal studies thus moving into another stage of the MRC guidelines (Craig et al., 2008). Psychological and medical variables should be measured prior to the intervention and then again afterwards in order to determine its utility in this population and its benefit over time.

**7.9 Conclusions**

Young people with Type 1 DM struggle to maintain optimal glycaemic control and experience a number of different psychological stressors over and above those experienced by “normal” adolescents, leading to increased distress. Very little research has previously focused on the special issues of this group and this work has attempted to address some of the many issues faced, thus beginning to bridge this gap. Engaging with this group has previously been deemed challenging, yet this research has shown that young people can, and will, engage if given the opportunity. In order to reduce the devastating impact this chronic illness has, it is necessary that further steps are taken to optimise care, taking into consideration the findings from this research.

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