

**A Social Media-Based Intervention to Support the
Management of Adolescents with Type 1 Diabetes Mellitus**

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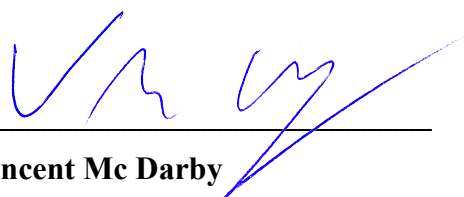
Declaration

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Summary

Chapter 1 described diabetes, its incidence rate and the difference between Type 1 Diabetes Mellitus (T1DM) and Type 2 Diabetes Mellitus (T2DM), with a focus on T1DM. Management of T1DM is very demanding process that places a significant burden on individuals. Failure to adhere to recommended diabetes management advice can lead to both acute and chronic health problems. Adherence difficulties are common in T1DM and are particularly common during adolescence. The awareness of the problem of poor adherence has led to research aimed at psychological correlates and predictors of adherence. Social cognitive theory, including self-efficacy, self-regulation and illness perceptions, has been used to frame the problem of adherence in T1DM.

Chapter 2 examined the impact of social support on the adherence of adolescents with T1DM. Positive parental social support has been found to be associated with better glycaemic control. The influence of peers has also been found to impact on the adherence of adolescents with T1DM and this can be positive or negative depending on the nature and context of the peer support. There is very little research on influence of social support from T1DM peers on adolescents with T1DM; however, research on support from peers with similar medical conditions suggests that it could be beneficial. Social support from the diabetes healthcare team (DHCT) is another source of support for individuals with T1DM that warrants further research. Research on patient-centred communication and autonomy support suggests that it could hold significant efficacy. Chapter 3 examined the potential of social network sites (SNS) in the management of T1DM. The role of SNS in healthcare is becoming ubiquitous and this has led to the proliferation of online patient expert groups. A number of research studies have suggested that SNS could be a useful tool in

supporting adolescents with T1DM, however; there has been very little research on the efficacy of SNS in adolescent diabetes management.

Chapter 4 outlines the rationale and aims of the present study. A social media based intervention (SMBI) was developed and administered via a SNS that targeted increasing the support adolescents receive from the DHCT and from T1DM peers with the aim of improving glycaemic control and quality of life. Chapter 5 described a pilot study that was undertaken where the SMBI was designed, implemented and evaluated. Chapter 6 outlines the methodology employed in the current study to investigate the efficacy of the SMBI and included both quantitative and qualitative analysis.

Chapter 7 looks at the results of the quantitative analysis of the SMBI. The SMBI was not found to have had any significant impact on glycaemic control or quality of life. The SMBI was found to result in an increase in diabetes specific knowledge. Chapter 8 examined that qualitative analysis of the SMBI. Participants found the SMBI to be a very positive experience and noted increased support from the DHCT and T1DM peers as a result of the SMBI. Chapter 10 integrated the findings of the thesis and discussed the implications for understanding interventions to improve adherence in adolescents with T1DM. Limitations of the research were discussed and directions for future research suggested. Finally the conclusions of the thesis are presented.

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Publications arising from this work

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List of Abbreviations

- ADKnowl – Audit of Diabetes Knowledge
- BIPQ – Brief Illness Perceptions Questionnaire
- CSII – Continuous Subcutaneous Insulin Infusion
- DCCT – Diabetes Complications and Control Trial
- DFRQ – Diabetes Family Responsibility Questionnaire
- DHCT – Diabetes Healthcare Team
- DKA – Diabetic Ketoacidosis
- HbA1c – Haemoglobin A1c
- HCCQ – Healthcare Climate Questionnaire
- IDF – International Diabetes Federation
- MDI – Multiple Daily Injections
- PCDS – Perceived Competence for Diabetes Scale
- PedsQL – Pediatric Quality of Life Inventory
- QOL – Quality of Life
- RCT – Randomised Controlled Trial
- SCI – Self-care Inventory
- SED – Self-efficacy for Diabetes Scale
- SMBG – Self-Monitoring of Blood Glucose
- SMBI – Social-Media Based Intervention
- SNS – Social Network Site
- T1DM – Type 1 Diabetes Mellitus
- T2DM – Type 2 Diabetes Mellitus
- WHO – World Health Organisation

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Chapter 1: Adherence in T1DM

1.1 Introduction

Diabetes management adherence is particularly difficult for many adolescents with Type 1 Diabetes (T1DM). This thesis aims to examine the issue of non-adherence from a psychological perspective with regard to behaviour theory change and to assess the impact of two specific support networks of the adolescent, their diabetes healthcare team (DHCT) and T1DM peers, to target non-adherence. These will be incorporated into a social media-based intervention (SMBI), which will be designed and implemented with the goal of providing a resource light and engaging intervention medium to support adolescents with T1DM and improve glycaemic control and quality of life.

1.2 Diabetes Mellitus

1.2.1 Definition. The term diabetes mellitus, often shortened to diabetes, is derived from the Greek word *diabetes*, meaning ‘siphon’ or ‘flowing through’, and the Latin word *mellitus*, meaning ‘sweet like honey’. This definition refers to both the excessive urination and sugar in the urine of individuals with the condition and characterises the understanding of the condition at the time the term originated. Historically diabetes was often diagnosed by tasting the urine of the individual to determine if it was sweet and descriptions of the symptoms of diabetes, namely excessive urination, have been found in ancient Egyptian manuscripts dating back as far as 1500BC.

In modern medicine diabetes denotes a group of metabolic diseases characterised by hyperglycaemia (i.e. high blood glucose levels) resulting from

defects in insulin secretion, insulin action, or both (American Diabetes Association, 2014). Insulin is a hormone produced in the pancreas that regulates the level of glucose in the blood by allowing the glucose in the blood stream to be transported into the cells of the body where it is converted to the energy needed by muscles and tissue to function. If there is insufficient insulin in the body, blood sugar levels start to rise and this can lead to diabetic ketoacidosis (DKA), which is potentially fatal if left untreated. In addition to the acute implications of abnormally high blood sugar, chronic high blood sugars can lead to life-threatening complications, such as retinopathy, neuropathy and nephropathy (The Diabetes Control and Complications Trial Research Group, 1993) and over the long term diabetes is associated with reduced life expectancy, significant morbidity due to specific diabetes related microvascular complications, increased risk of macrovascular complications, and diminished quality of life (World Health Organisation, 2006).

1.2.2 Types of Diabetes. Generally diabetes is classified into three broad conditions: Type 1 Diabetes Mellitus (T1DM), Type 2 Diabetes Mellitus (T2DM) and Gestational Diabetes. T1DM is characterised by an absolute deficiency of insulin secretion and is as a result of T-cell mediated autoimmune destruction of the insulin producing β -cells of the pancreas (American Diabetes Association, 2014). T2DM, in which autoimmune destruction of the β -cells does not occur, results from a combination of resistance to insulin action and an inadequate compensatory insulin secretory response (Craig et al., 2014). T2DM, which is by far the most common type, is associated with excessive body weight, poor diet and physical inactivity among individuals with a genetic predisposition and is usually diagnosed in adulthood, although the incidence and prevalence of T2DM in youths is increasing (Pinhas-

Hamiel & Zeitler, 2005). Gestational Diabetes is defined as impaired glucose tolerance with onset or first recognition during pregnancy (American Diabetes Association, 2014). It occurs where women develop a resistance to insulin during pregnancy, resulting in abnormally high blood sugar levels and, if left uncontrolled, can have serious consequences for both the mother and baby. The incidence of Gestational diabetes has been reported to be as high as 9.2% of pregnancies (DeSisto, Kim, & Sharma, 2014); however, Gestational Diabetes normally disappears shortly after birth.

1.2.3 Incidence and Prevalence. According to the International Diabetes Federation's (IDF) Diabetes Atlas Sixth Edition (International Diabetes Federation, 2013, 2014), an estimated 387 million adults (age 20 to 79) worldwide live with some form of diabetes, representing a prevalence rate of 8.3%. However, this is expected to increase by an additional 205 million people by 2035. The IDF Diabetes Atlas also estimates that 46.3% of individuals currently living with diabetes are undiagnosed and that diabetes accounted for 4.9 million deaths worldwide in 2014.

The prevalence of diabetes varies from region to region, with the highest prevalence rates in North America and the Caribbean (11.4%) and the lowest prevalence rates in Africa (5.1%). The prevalence rate in Europe is 7.9% and represents 52 million people living with diabetes. However, within Europe the prevalence rate varies significantly from country to country. Turkey, Montenegro and Macedonia have the highest comparative prevalence rates, with 14.84%, 9.82% and 9.76%, respectively. Whereas Moldova, Georgia and Azerbaijan have the lowest comparative prevalence rates, with 2.52%, 2.55% and 2.56%, respectively (International Diabetes Federation, 2014). In Ireland the comparative prevalence rate

of diabetes was estimated at 5.37% in 2014, with 1,528 diabetes related deaths in 20 to 79 year olds and a cost per person with diabetes of approximately €3,700 (International Diabetes Federation, 2014).

As T2DM is by far the most common type of diabetes, accounting for approximately 90% to 95% of those with diabetes (American Diabetes Association, 2014), the figures and trends for incidence and prevalence of diabetes overall, as reported above, are generally reflective of T2DM. T1DM, which accounts for approximately 5% to 10% of those with diabetes (American Diabetes Association, 2014), has a somewhat different profile. It has been estimated that 79,100 children under 15 years develop T1DM annually worldwide and of the 497,100 children living with T1DM, 26% live in the European region, where the most reliable and up-to-date estimates of incidence are available (International Diabetes Federation, 2013). Worldwide there is an increasing incidence of T1DM, with the trends estimated for continents showing statistically significant increases all over the world (4.0% in Asia, 3.2% in Europe and 5.3% in North America), except in Central America and the West Indies where the trend was a decrease of 3.6% (The DIAMOND Project Group, 2006). It is predicted that if present trends continue there will be a doubling of new cases of T1DM in European children younger than 5 years between 2005 and 2020, and prevalent cases younger than 15 years will rise by 70% (Patterson, Dahlquist, Gyürüs, Green, & Soltész, 2009).

In terms of incidence and prevalence rates of T1DM at a country level, the highest rates are among the Nordic countries, with Finland, Sweden and Norway having incidence rates of T1DM in 0 to 14 year olds per 100,000 population of 57.6, 43.2 and 32.8, respectively. Countries with the lowest rates of T1DM tend to be the ones with warmer climates, with Venezuela, Papa New Guinea, Peru and the

Dominican Republic having incidence rates of T1DM in 0 to 14 year olds per 100,000 population of 0.1, 0.1, 0.5 and 0.5, respectively (International Diabetes Federation, 2013). However, the incidence and prevalence rates of T1DM in many third world countries are unknown due to a lack of reliable data. In addition, it is likely that many cases of T1DM in third world countries go undocumented as children are dying before they can be diagnosed due to lack of access to appropriate medical services. In Ireland the standardised incidence rate in those aged under 15 years was estimated at 27.5 per 100,000 per year in 2008 and 26.0 per 100,000 per year in 2009, with the peak rate among adolescents aged 10-14 years (Roche et al., 2014).

1.3 Type 1 Diabetes (T1DM)

1.3.1 Management of T1DM. T1DM results from an autoimmune mediated destruction of the insulin producing beta cells in the pancreas, and is usually, but not always, diagnosed in children. In T1DM the body is unable to produce the insulin needed to control blood sugar levels. Insulin therapy, the only treatment for T1DM, is both lifelong and lifesaving. It involves the daily administration of insulin, either through injections or continuous subcutaneous insulin infusion (CSII), also known as the insulin pump, with the goal of maintaining blood sugar levels as close to the normal range (i.e. non-diabetic range) as possible. In addition to insulin administration, regular self-monitoring of blood glucose (SMBG) and intensive dietary management are necessary core components of insulin therapy. The goal of insulin therapy is to keep blood glucose levels as close to the range of individuals without diabetes (i.e. 3.9 to 10 mmol/L) as possible, while avoiding hypoglycaemia.

In insulin therapy, the dosage of insulin administered to the patient varies greatly between individuals and changes over time (Danne et al., 2014). Determining

the actual dosage of insulin to be administered at any given time is often complex and is dependent on numerous factors, including the person's age, weight, sensitivity to insulin, time of day, activity level and diet. There are also different types of insulin, with differing speeds of action, and many people use a combination of insulin types, for instance, using long-acting insulin overnight and short-acting insulin at meal times. Insulin regimens can vary from one injection per day to multiple daily injections (MDI), where an insulin injection is taken every time carbohydrates are consumed. Although non-MDI regimens require fewer daily injections, they require significant rigidity in timing and carbohydrate quantity of meals to ensure that carbohydrate consumption is matching insulin action. MDI offers flexibility around the timing and carbohydrate quantity of meals but at the cost of increased insulin injections. Historically, MDI was primarily used with adults, as insulin therapies in children focused on avoiding painful injections, leading to regimens with little flexibility and dietary restrictions. However, nowadays intensive regimens (i.e., MDI) are becoming the gold standard in in paediatric diabetes care (Danne et al., 2014).

The delivery device for insulin injections can be conventional syringes or an insulin pen. When using a conventional syringe as an insulin delivery device, a measured amount of insulin is drawn up from a vial of insulin and then injected subcutaneously. Insulin pens, which can be reusable or disposable, carry insulin in self-contained cartridges and disposable pen needles are attached to the pen prior to administration. Insulin pens have the advantage of being more portable and generally easier to use than syringes, however, they are not suitable for mixing different types of insulin and not all insulin types are available in an insulin pen.

The administration of insulin injections, be it by syringe or insulin pen, can be undertaken by the patient themselves or by a third party, such as a parent. It is

important that the person administering the injection uses the correct technique, as an incorrect technique can result in the incorrect dosage of insulin being delivered, significant discomfort or both, and as such the procedure can be a source of anxiety. One study that looked at 23 children and mother pairs found that 40.9% of children reported experiencing fear around injections at diagnosis and 9.5% continued to experience fear 6 to 9 months after diagnosis. In addition, 22.7% of children reported experiencing pain from injections at diagnosis and 9.5% continued to experience pain 6 to 9 months after diagnosis (Howe, Ratcliffe, Tuttle, Dougherty, & Lipman, 2011). The same study found that 13.6% of mothers continued to report high fear and distress with injections 6 to 9 months after diagnosis.

An alternative to insulin injections is CSII, which is an external medical device, often referred to as an insulin pump, that provides a constant supply of insulin to the body and extra doses as needed, and as such is the treatment regimen that most closely resembles the action of a functioning pancreas. The insulin pump itself, which contains an insulin reservoir, is generally carried in the pocket or in a pouch and delivers insulin subcutaneously via a cannula attached to an infusion set. A small background, or basal, dosage of insulin is administered continually, while a larger, or bolus, dosage is administered when carbohydrates are consumed. CSII is similar to MDI in that it is an intensive regimen that offers flexibility around the timing and carbohydrate quantity of meals. However, it also frees the patient from having to administer regular insulin injections, although the infusion set does have to be changed approximately every two days. Insulin pumps have evolved significantly since their initial introduction in the 1970's and are now smaller, more precise and more reliable (Heinemann et al., 2015), increasing their appeal. A review of studies comparing CSII to MDI in children and adolescents found that the majority of

patients and families chose to continue with CSII after the completion of the studies, even in studies where insulin pumps showed no objective benefit (Nahata, 2006). However, insulin pump treatment may be hazardous when education and adherence to therapy is inadequate, because of the smaller depot of subcutaneous insulin and the sudden rise in ketones when insulin supply is interrupted (Danne et al., 2014).

SMBG is the use of regular testing of blood glucose levels to understand diabetes control and inform changes to insulin therapy. This process involves piercing the skin with a lancet to draw a drop of blood, which is then applied to a disposable test strip and inserted into a portable glucometer, where the glucose level in the blood is determined. This immediate measure of glycaemic control allows for the identification and documentation of hypoglycaemia and hyperglycaemia, allowing for the implementation of strategies to prevent and treat such occurrences. Tracking of SMBG over longer periods can inform insulin dosage adjustment and is often an indicator of diabetes management compliance. SMBG is a core component of insulin therapy and increased frequency of SMBG has been found to be associated with better glycaemic control (Haller, Stalvey, & Silverstein, 2004). Ideally blood glucose levels should be checked before meals, before going to sleep and if hypoglycaemia or hyperglycaemia is suspected. The International Society for Pediatric and Adolescent Diabetes (ISPAD) in their 2014 Clinical Practice Consensus Guidelines recommend that SMBG should be prescribed at a frequency to optimize each child's diabetes control, usually four to six times a day, because frequency of SMBG correlates with glycaemic control (Rewers et al., 2014).

Along with insulin administration and SMBG, nutritional management is a core component of T1DM management. Intensive nutritional management is required to ensure that carbohydrate intake is balanced over the day and is consistent with the

amount of insulin administered. Carbohydrate counting plays a key role in this and involves calculating the total volume of carbohydrate in all food consumed. Generally, in less intensive insulin regimes (i.e., three or less injections per day) the quantity of carbohydrate in each meal and snack is predetermined so as to match the action of the insulin. In addition, meals and snacks need to be consumed at regular fixed intervals. In more intensive insulin regimes (i.e., MDI or CSII) the quantity and timing of carbohydrate consumption is variable, meaning that people can eat when they want and the amounts they want. However, the volume of carbohydrate consumed at each meal and snack has to be calculated in advance so that a corresponding bolus of insulin can be administered. In addition to monitoring carbohydrate consumption, dietary management for T1DM involves normal healthy eating with an avoidance of high sugar foods and drinks. According to ISPAD's 2014 Clinical Practice Consensus Guidelines, dietary recommendations in T1DM are based on healthy eating principles suitable for all children and families, with the aim of achieving a balance between food intake, metabolic requirements, energy expenditure, and insulin action profiles to attain optimum glycaemic control (Smart, Annan, Bruno, Higgins, & Acerini, 2014).

As well as the core diabetes management components of insulin administration, SMBG and nutritional management, there are many other secondary components of T1DM management that must also be assimilated into the person's daily life to avoid the acute and chronic complications of diabetes. These include, but are not limited to, managing activity level, particularly with regard to sports, attending regular diabetes clinics, ensuring treatments for a hypoglycaemic episode are always at hand, recording and reviewing blood glucose readings and maintaining stocks of diabetes management supplies. Overall, self-management in T1DM is a multi-

behavioural challenge that requires a relentless and burdensome combination of preventative and remedial behaviours that regularly interfere with the tasks of daily living.

1.3.2 Complications. Hypoglycaemia occurs when blood glucose levels drop below the target range and can be caused by taking too much insulin, not eating enough carbohydrate or increasing physical activity without adjusting insulin or carbohydrate consumption to compensate. The symptoms of hypoglycaemia differ from person to person but can include confusion, dizziness, shakiness, sweating and anxiety. Without treatment the symptoms of hypoglycaemia become worse and will eventually result in unconsciousness and diabetic coma. Hypoglycaemia can be a particular difficult issue for young children who are very often unable to identify or articulate the symptoms. Hypoglycaemia is treated by the administration of a quick-acting carbohydrate, such as a sugar-sweetened drink, to rapidly increase blood glucose levels, followed by a longer-acting carbohydrate, to prevent blood glucose levels dropping again after the quick-acting carbohydrate has been absorbed.

Hyperglycaemia occurs when blood glucose levels rise above the target range and can be caused by not taking enough insulin, eating too much carbohydrate or decreasing physical activity without adjusting insulin or carbohydrate consumption to compensate. Hyperglycaemia is often asymptomatic in the acute phase but symptoms can include irritability, fatigue, concentration difficulties, frequent urination and increased thirst. Chronic hyperglycaemia can lead to long-term health consequences such as neuropathy, nephropathy and retinopathy (The Diabetes Control and Complications Trial Research Group, 1994). Acute hyperglycaemia, if left untreated, can lead to diabetic ketoacidosis (DKA). DKA occurs when, unable to use glucose

for fuel, the body breaks down fats to use for energy, producing ketones as a waste product that build up in the blood. DKA is a life-threatening condition and requires immediate treatment by medical personnel. The treatment of hyperglycaemia depends on the blood glucose level and often requires adjustment to insulin regime or diet.

Glycated haemoglobin, often referred to as HbA1c, is used as a marker of blood glucose levels over a prolonged period of time. Haemoglobin is a protein found in red blood cells and HbA1c is a minor component of haemoglobin to which glucose is bound. Given that the half-life of a red blood cell is approximately 8 to 12 weeks, by measuring the level of HbA1c in the blood we can estimate how much glucose there has been in the blood over the previous 8 to 12 weeks. Higher HbA1c readings are indicative of higher blood glucose levels over the preceding 8 to 12 weeks, while lower HbA1c readings are indicative of lower blood glucose levels. The HbA1c measurement is given as a percentage figure or as mmol/mol and is essentially a measure of how much glucose is stuck to haemoglobin in the blood.

The Diabetes Control and Complications Trial (DCCT) was a landmark multicentre prospective study that investigated whether an intensive treatment regimen aimed at maintaining blood glucose levels as close to normal as possible impacts on the appearance or progression of early vascular complications and compared this approach to the conventional management approach. 1,441 patients from 13 to 39 years of age with T1DM were followed for a mean of 6.5 years and the appearance and progression of diabetes related complications were assessed regularly. Significant reductions in microvascular complications (retinopathy and nephropathy) were demonstrated in intensively managed patients versus the conventional group, with each reduction in HbA1c of 10% of total (e.g., from 10% to 9%) equating with a

50% reduction in microvascular risk (The Diabetes Control and Complications Trial Research Group, 1993). Furthermore, the reduction in microvasculopathy seen in the intensive group persisted for several years following the end of the study (White et al., 2001). Since the DCCT ended in 1994 researchers have continued to track the original DCCT cohort in an observational follow-up study called Epidemiology of Diabetes Interventions and Complications (EDIC). The most recent data from the EDIC study continues to demonstrate the effectiveness of intensive treatment regimens in T1DM in improving the prospects for a healthy life span (Nathan, 2014). Taken together, the results of the DCCT and the EDIC study demonstrate that interventions aimed at maintaining blood glucose levels as close to non-diabetic levels as safely possible reduces the risk of all of the microvascular and cardiovascular complications of T1DM.

1.4 Adherence in T1DM

1.4.1 Definition. According to the World Health Organisation (WHO) adherence in the context of chronic illness is the extent to which a person's behaviour (i.e., taking medication, following a diet, and/or executing lifestyle changes) corresponds with agreed recommendations from a health care provider (Burkhart & Sabate, 2003). Often within this context the term adherence is used interchangeably with the term compliance, with an underlying assumption that both terms refer to the same thing. However, the WHO specifically differentiates adherence from compliance on the grounds that adherence requires the patient's agreement to the recommendations and reflects the belief that patients should be active partners with health professionals in their own care. To this same end, arguments have also been made for the use of the term concordance over compliance to better reflect the patient

as being the equal of the healthcare provider and as having a right to make informed decisions (Chatterjee, 2006). Within the context of the present study, the term adherence, as defined by the WHO, will be used.

1.4.2 Measurement. Accurate measurement of adherence in chronic illness is important for effective treatment planning and to ensure that changes in health status can be attributed to changes in treatment. Inaccurate estimates of adherence can mask the effect of poor patient compliance on health status and confuse the cause of treatment failure, resulting in effective treatments being incorrectly identified as ineffective. In addition, dose-response treatment adjustments are contingent on treatment adherence and as such require accurate estimations of treatment adherence. However, measuring adherence in chronic illness can be a complex and resource heavy process that requires careful consideration of the relationship between measurable behaviours and the illness management goals.

Although healthcare professionals often refer to patients as being adherent or non-adherent, in reality adherence is very seldom such a dichotomous variable, and most adherence behaviours are best seen as a continuous variable along which patients can be more or less adherent. Even viewing adherence as a continuous variable, the determination of whether a particular level of adherence is determined as ‘good’ or ‘bad’ is often arbitrary, as such categorical descriptors are usually based on subjective cut-off points on the continuous measurement scale. In addition, adherence for a particular chronic illness is not necessarily the measurement of one variable. As management of a chronic illness often requires a multi-behavioural approach, patients can exhibit differing levels of adherence on the different management behaviours of a particular chronic illness. For example, a patient may exhibit ‘good’ adherence to one

aspect of their chronic illness management, yet ‘poor’ adherence to another. In such cases a global measure of adherence may not be particularly useful, as it doesn’t reflect the variation among adherence behaviours within the chronic illness. Understandably, given these issues, there is no universally accepted measure of adherence, instead measures of adherence are best defined in the context of the specifics of the management behaviour being measured.

Very often when attempting to measure adherence in chronic illness, a number of different adherence measures are available. The determination of which adherence measure to select should be based on knowledge of the validity and reliability of the measures in relation to the specific adherence behaviour of interest. As with any measurement instrument, measures of adherence must demonstrate appropriate reliability and validity. The validity of a measure is the degree to which it measures what it’s supposed to measure, whereas the reliability of a measure refers to the consistency of the measure across time, items, settings, assessor or condition. As validity and reliability are independent constructs, it can sometimes be difficult to identify a measure for a particular adherence behaviour that has both adequate reliability and validity. For example, more objective measures of adherence, such as biological markers, could have good reliability but poor validity, whereas more subjective measures of adherence, such as self-reports, could have good validity but poor reliability. In situations where the identification of a measure of adherence that demonstrates appropriate validity and reliability proves difficult, the utilisation of more than one measure of adherence for a given behaviour can be beneficial.

In T1DM, as in other chronic illnesses, there are no widely accepted, reliable measures of adherence, nor is there a common approach to quantifying levels of adherence. HbA1c is one of the most commonly cited outcome measure in studies of

T1DM, as it is the only measure of glycaemic control for which robust outcome data are available (Rewers et al., 2014), and is often used as a proxy measure of adherence due to its direct association with blood glucose levels. As outlined earlier, the goal of diabetes management is to maintain blood glucose levels at as close to the normal range as possible. Therefore individuals who better adhere to their diabetes management recommendations are more likely to have blood glucose levels in the normal range. Given that HbA1c can be used to give an estimate of blood glucose levels over an 8 to 12 week period, it can be used as a biometric surrogate measure of adherence over the same period. However, using HbA1c as a measure of adherence is subject to a number of limitations with regard its reliability and validity and, as such, warrants caution.

Estimating average blood glucose levels from HbA1c assumes that there is little individual variation in the relationship between HbA1c and average blood glucose levels; however, this is not necessarily the case. One study that looked at the variability between blood glucose and HbA1c followed 252 patients (aged 8 to 74 years) over three months, the majority of whom had stable HbA1c values. The researchers collected near continuous glucose sensor data for the three months and compared it with laboratory measured HbA1c. They found substantial individual variability between the measured versus the calculated mean glucose concentrations. Consequently, the authors urged caution when estimating average glucose concentrations calculated from measured HbA1c values (Wilson et al., 2011).

Poor adherence is often associated not just with high blood glucose levels, but with erratic blood glucose levels, that include hypoglycaemic episodes, as well as hyperglycaemic episodes. Given that HbA1c is directly related to blood glucose levels over an 8 to 12 week period, in essence giving a measure of average blood

glucose levels over this period, frequent severe hypoglycaemic episodes over this period have the effect of lowering HbA1c (The Diabetes Control and Complications Trial Research Group, 1994). An HbA1c reading that might be interpreted as reflecting good or reasonable glycaemic control and consequently good adherence to diabetes management recommendations, may in fact be a reflection of poor adherence resulting in poor glycaemic control that includes frequent severe hypoglycaemic episodes. Therefore the validity of HbA1c as a measure of adherence is critically compromised without reference to the individual variation in glycaemic control over the same period.

Despite the fact that HbA1c is at best a somewhat removed proxy measure of adherence, its robust association with long-term health complications of poor adherence (The Diabetes Control and Complications Trial Research Group, 1993, 1994) renders it an important adherence outcome measure in T1DM research and clinical practice. However, where reasonable, the inclusion of others measures of adherence can give a more comprehensive understanding of the nuances of adherence in T1DM.

Patient or parent self-reports, via self-report measures or structured interview, are commonly used measures of adherence in chronic illness. Self-report measures usually involve a respondent completing a standardised questionnaire that asks about the frequency of particular adherence behaviours over a specified time interval. These measures have the advantage of being inexpensive, easy to administer and allow for the same measure, or parallel forms of it, to be administered to different respondent types (e.g., patients, parents, healthcare providers, etc.). However, these measures are limited by problems with accurate recall, particularly respondents' tendency to overestimate adherence. Structured interviews usually involve a trained

interviewer interviewing a respondent about their adherence behaviours. This approach allows for follow-up questions, which can lead to more comprehensive adherence behaviour information, particularly with regard to patient specific barriers to adherence. As well as the problems of accurate recall, structured interviews, because of their need for trained interviewers, can be costly and time consuming to undertake.

The Diabetes Self-Management Profile (DSMP) (Harris et al., 2000) is a structured interview that has been designed for measuring adherence in T1DM. The measure was validated specifically to capture the nuances of current therapy for T1DM, including self-regulation of insulin dosing in response to blood glucose data and carbohydrate intake. The DSMP has demonstrated adequate psychometric properties across a number of studies and its correlation with HbA1c across these studies has ranged from 0.27 to 0.60, with a mean correlation of 0.41 (Wysocki, Buckloh, Antal, Lochrie, & Taylor, 2012). However, given the semi-structured nature of the DSMP, interviewers must possess a comprehensive knowledge of the diabetes regimen to accurately and reliably administer the measure. Lewin et al. (2009) estimated that clinicians required five to fifteen hours of training in order to be able to score the DSMP reliably. As such, the utility of the DSMP as a measure of adherence is limited in situations where the availability of trained interviewers is scarce.

In a review by Quittner, Modi, Lemanek, Ievers-Landis, and Rapoff (2008) of evidence-based assessments of adherence to medical treatments in paediatric psychology, only eleven self-report questionnaires and structured interviews were identified for all paediatric medical conditions. Of the eleven, three focused on T1DM; the Self-Care Adherence Interview (SCAI) (Hanson et al., 1989), the Self-Care Inventory (SCI) (La Greca, 2004) and the Diabetes Regimen Adherence

Questionnaire (DRAQ) (Brownlee-Duffeck et al., 1987). They noted that all three measures reported good psychometric properties in terms of either internal consistency or stability coefficients, and most had validity data that demonstrated a significant association between adherence and better glycaemic control. They also categorised the SCI and DRAQ measures as “well-established”. Lewin et al. (2009) evaluated the psychometric properties of the SCI specifically with adolescents. They examined the reliability of the SCI through internal consistency, test-retest data and parent-child agreement, and the validity of the SCI through comparisons with a previously established adherence measure (i.e., the DSMP), frequency of SMBG and glycaemic control (i.e., HbA1c). The SCI was found to have strong psychometric properties, including adequate internal consistency, parent-youth agreement, and test-retest agreement. In addition, relations between the SCI and the DSMP and HbA1c were strong. The authors concluded that the SCI was an empirically supported measure of regimen adherence and its brevity, ease of implementation, and robustness for multiple regimens makes it an ideal tool for clinicians and researchers.

1.4.3 Rates of Adherence. Non-adherence to medication recommendations is an issue across all chronic illnesses. In 2003 the World Health Organisation (WHO) reported that adherence to long-term therapy for chronic illnesses in developed countries averages 50%, and is even lower in developing countries. This highlights the undeniable implication that many patients have difficulty following treatment regimens and as the burden of chronic illness grows, so too will the consequences of poor adherence. In T1DM treatment non-adherence has been associated with increased all-cause mortality in patients (Currie et al., 2013).

Given the complex and invasive nature of the diabetes regimen, patients with diabetes, and in particular T1DM, are particularly prone to issues of non-adherence. One study found that 60% of adults with T1DM reported to checking blood sugars less frequently than the American Diabetes Association recommendation of three to four times daily (Karter, Ferrara, Darbinian, Ackerson, & Selby, 2000). An international study that surveyed 1,250 physicians who treat patients with diabetes and 1,510 insulin-treated patients (180 with T1DM, 1,350 with T2DM) found that one third of patients reported insulin omission or non-adherence at least one day in the previous month, with an average of 3.3 days. Three quarters of physicians reported that their typical patient does not take their insulin as prescribed (Peyrot, Barnett, Meneghini, & Schumm-Draeger, 2012). The results of a large cross-national study, entitled Diabetes Attitudes, Wishes, and Needs (DAWN) that examined the experiences of patients and healthcare professionals in dealing with diabetes indicated that only 46% of T1DM patients achieved complete success in at least two-thirds of their diabetes self-care domains. In addition, patient-reported success was significantly higher for insulin administration (83%), blood glucose testing (70%), and appointment keeping (71%) than for diet (39%) and exercise (37%) (Peyrot et al., 2005).

1.4.4 Adherence during Adolescence. Adolescence is the transitional stage of human development between childhood and adulthood and is characterised, in part, by the uptake of more adult roles and responsibilities. In the context of T1DM, adolescence is the period when the responsibility for diabetes management begins to shift away from parents and onto the young person themselves. This increased responsibility places increased demand on the resources of the adolescent and, when

combined with the demands of becoming an independent adult, poses its own unique challenges and adaptations that impact on diabetes management adherence. Adolescence is also associated with inconsistent behaviour, exploration, boundary testing and a degree of emotional upheaval, all of which can be difficult to reconcile with the rigors of diabetes management responsibility (Cox & Hunt, 2015). Given these changes, both within the adolescents themselves and within their environments, it is understandable that adolescence would be associated with its own particular adherence issues. However, the actual rate of non-adherence among adolescents with T1DM is unclear with studies estimating the extent of non-adherence as ranging from 20% to 93% (Lewin et al., 2009).

As part of the DCCT, researchers compared the HbA1c levels of adults (n = 1,226) and adolescents aged 13 to 17 years (n = 215) and found HbA1c to be significantly higher in adolescents, despite similar and extensive support from healthcare professionals (The Diabetes Control and Complications Trial Research Group, 1993). However, the DCCT was unable to recruit significant numbers of adolescents capable of engaging in an intensive insulin management regimen, which limits the generalizability of this comparison. A more recent survey of 2,837 children and adolescents with T1DM from 22 centres world-wide found that 41% of children under 11 years old had an HbA1c below 8.0 %, while only 29% of the adolescent age group (12–18 years) had an HbA1c in the same range (Mortensen et al., 1998). The researchers noted that although the better glycaemic control among the younger children may have been due to improved insulin sensitivity in these early years, partly caused by reduced growth hormone secretion during the day, increased compliance was a more likely cause.

Using HbA1c as an indicator of treatment adherence, in the United Kingdom the National Paediatric Diabetes Audit revealed that for the year 2013 – 2014 only 12.1% of females aged 15 to 19 had an HbA1c level in the target range of less than 7.5%. Whereas for ages 10 to 14, 5 to 9 and 0 to 4 the percentage of females with HbA1c levels in the target range were 15.6%, 20.3% and 20.9, respectively. For males, 16.7% aged 15 to 19 had HbA1c in the target range. For ages 10 to 14, 5 to 9 and 0 to 4 the percentage of males with HbA1c in the target range were 16.5%, 22.1% and 25.4, respectively. They also found that 40% of males aged 20 to 24 had HbA1c levels in the target range (a figure was not available for females in this age group due to small numbers) indicating that adherence improved again as young people moved from adolescence into early adulthood (National Paediatric Diabetes Project Board, 2015).

1.5 Psychological Factors Related to Adherence

The awareness of the problem of poor adherence in T1DM, particularly in relation to adolescents, has stimulated a great deal of research aimed at identifying psychological correlates or predictors of adherence (Griva, Myers, & Newman, 2000). When looking at non-adherence it is important to distinguish between non-adherence that is non-intentional (e.g., forgetting to SMBG) or inadvertent (e.g., not being aware that SMBG was necessary) and non-adherence that is intentional. Intentional non-adherence is where a person chooses to deviate from recommended medical advice in order to suit their lifestyle and this is where research on the psychological factors related to adherence has focused. Research in this area emphasises the patient's perspective and studies have looked at both emotional variables, such as anxiety and depression, and cognitive variables, such as self-efficacy, self-regulation and illness

perceptions. A recent systematic review of psychological factors associated with diabetes self-management adherence among adolescents with T1DM undertaken by Martinez et al. (2016) looked at both emotional and cognitive variables. They concluded that there was a greater quantity of evidence for cognitive variables impacting adherence, with emotional variables demonstrating conflicting findings, particularly for anxiety and stress.

1.5.1 Self-efficacy. Social cognitive theory (Bandura, 1986) explains how people acquire and maintain certain behavioural patterns, while also providing the basis for intervention strategies. According to social cognitive theory, behaviour is learnt through observing others and the consequences of their actions, and determining if the behaviour is successful in obtaining a favourable outcome. Central to social cognitive theory is the concept of self-efficacy, an individual's belief in their capacity to execute behaviours necessary to produce specific performance attainments (Bandura, 1977). According to Bandura (2004) unless people believe they can produce desired effects by their actions, they have little incentive to act or to persevere in the face of difficulties. Whatever other factors may serve as guides and motivators, they are rooted in the core belief that one has the power to produce desired changes by one's actions.

When applied to chronic illness, self-efficacy is the person's belief that they have the ability to manage their chronic illness as advised by their health professional, including the ability to overcome any internal and external obstacles to this. The importance of self-efficacy in influencing self-management behaviours in chronic illness has been demonstrated empirically and it is a core component in the design of many effective intervention programmes aimed at enhancing self-management

behaviours (Connolly, Aitken, & Tower, 2014; Jackson, Wang, Wang, & Fan, 2014; Magklara, Burton, & Morrison, 2014).

Within the area of diabetes, self-efficacy beliefs have been found to be strongly associated with diabetes regimen adherence. Gherman et al. (2011) undertook a meta-analysis to investigate the association between beliefs related to diabetes and adherence to diabetes regimens. Their research looked at studies of adults with any type of diabetes, reaching a final sample of 48 studies. The meta-analysis focused on identifying the degree of influence that cognitive factors have on diabetes self care behaviours. In particular, it focused on beliefs about illness, treatment, benefits, barriers, self-efficacy related to diabetes, perceived quality of relationship with health care providers and coping strategies. The analyses revealed that self-efficacy beliefs, perceiving a positive relationship with the healthcare provider, and beliefs about the personal consequences have the highest association with adherence to diabetes regimen. The authors concluded that patients who believe in themselves and their ability to manage their own diabetes are more likely to have good management practices and they recommended that healthcare professionals should develop interventions that increase self-efficacy and learn the best ways to give patients the confidence they need.

Looking specifically at T1DM, self-efficacy has also been found to be associated with diabetes regimen adherence. Iannotti et al. (2006) assessed self-efficacy for diabetes management, expected outcomes of adherence, adherence to the diabetes regimen, and glycaemic control in 168 adolescents with T1DM. In regression analyses, self-efficacy and the interaction of self-efficacy with expectations of positive outcomes were significantly associated with diabetes self-management adherence and glycaemic control. The effect of self-efficacy was greatest when

adolescents had stronger beliefs in the beneficial outcomes of adherence. They suggested that interventions targeting self-efficacy may lead to improved diabetes self-management.

1.5.2 Self-regulation. Self-regulation has been defined as the ability to control one's behaviours, together with emotions and cognitions to accomplish important goals (Tangney, Baumeister, & Boone, 2004). It refers to the person as an active agent and decision-maker, and is a vital aspect of human adaptation to life without which the individual would be a helpless spectator of events (Baumeister, 2005). People are able to resist their own impulses, adapt their behaviour to a range of standards, and change their current behaviours in the service of attaining distal goals (Baumeister, 1999). As such, effective self-regulation results in the completion of a desired behaviour and the avoidance of undesired but competing behaviours.

Self-regulation theory is informed by social cognitive theory in that self-efficacy beliefs affect standards of performance, such as goal setting (Ridder & Wit, 2006). According to social cognitive theory, individuals engage in behaviour because of the outcomes they hope to achieve, and these expectations reflect the motivational function of reinforcement (Bandura, 1986). Self-regulation begins from having a valued personal standard on certain actions or behaviours, which then generate heightened motivation in realising the action or behaviour (Chew, Shariff-Ghazali, & Fernandez, 2014).

Chronic illness self-management involves a self-regulatory process of competing adherence behaviours in the context of competing emotions, cognitions, and behaviours (Lansing & Berg, 2014). Self-regulation is driven by executive functioning, which refers to higher-order cognitive skills that enable a person to self-

regulate or maintain behaviour on a goal and calibrate behaviour to context (Pennington & Ozonoff, 1996). As such, within the context of chronic illness self-management, self-regulation theory suggests that management adherence is associated with executive functioning. McNally, Rohan, Pendley, Delamater, and Drotar (2010) investigated the relationship between executive functioning, diabetes treatment adherence, and glycaemic control in 235 children with T1DM. Their results indicated that executive functioning skills were related to adherence, which was related to diabetes control. A review by Duke and Harris (2014) examined the associations between executive functioning, adherence and glycaemic control in adolescents with T1DM. They reported that the major conclusions of the review supported the presence of an association between executive functioning, adherence, and glycaemic control.

Research has also looked at the association between emotional processing (i.e., understanding emotions) and self-regulation in T1DM. Hughes, Berg, and Wiebe (2012) examined whether emotional processing, self-control (regulation of thoughts, emotions, and behaviour), and their interaction predicted HbA1c for adolescents with T1DM over and above diabetes-specific constructs. They had 137 adolescents with T1DM complete self-report measures of self-control, emotional processing, self-efficacy for diabetes management, diabetes-specific negative affect, and adherence. Results indicated that emotional processing interacted with self-control to predict HbA1c, such that when adolescents had both low emotional processing and low self-control, HbA1c was poorest. Also, both high emotional processing and self-control buffered negative effects of low capacity in the other in relation to HbA1c. The interaction of emotional processing with self-control predicted HbA1c over diabetes-specific self-efficacy, negative affect, and adherence. The authors concluded that the

findings suggest the importance of emotional processing and self-control for health outcomes in adolescents with T1DM.

1.5.3 Illness Perceptions. Illness perceptions involve beliefs, cognitive and emotional representations or understandings that patients have about their illness (Leventhal H & Linda P-M, 1997). Just as people construct representations of the external world to explain and predict events, patients develop similar cognitive models of the bodily changes that reflect either transient symptoms or more long-term illness (Weinman & Petrie, 1997). Illness perceptions constitute beliefs on the chronicity of the illness, locus of control of the illness and efficacy of treatments; it includes an assessment on the perception of understanding the patient has of the illness; illness perception evaluates the emotional impact of the illness directly and indirectly from the aspects of symptoms experience and concern for the illness's consequences (Chew et al., 2014). Patients' perceptions of their illness have been found to be associated with health behaviours and clinical outcomes, such as treatment adherence and functional recovery (Weinman & Petrie, 1997).

Illness perceptions act as a framework to guide and evaluate health related behaviours and coping responses and behaviours (Griva et al., 2000). According to self-regulation theory, illness perceptions should influence adherence behaviours, since treatment adherence can be conceptualised as a coping behaviour or a set of coping behaviours (Leventhal, Diefenbach, & Leventhal, 1992). A review by Kucukarslan (2012) looked at research that evaluated the impact of illness representations with medication adherence. Eleven published studies that compared illness perceptions and medication adherence were identified and from these it was found that each illness perception factor, with the exception of illness coherence,

directly or indirectly impacted medication adherence. She concluded that further research is needed to elucidate the relationships between illness perceptions and patient medication adherence, which can help practitioners to better engage and communicate with patients.

Within the context of T1DM Fortenberry et al. (2014) looked at longitudinal trajectories of illness perceptions among adolescents and its relationships with intelligence, diabetes responsibility, and diabetes outcomes. They had 213 adolescents complete the Illness Perceptions Questionnaire three times over twelve months. In addition, they also examined adolescents' intelligence, perceived responsibility for diabetes, adherence, quality of life (QOL), and HbA1c. The researchers found significant increases in perceptions of diabetes coherence, chronicity, consequences, personal and treatment control, and decreases in diabetes cyclicalness and parental control across time. More favourable illness perceptions were generally associated with adolescent intelligence at baseline, more adolescent responsibility for management, better adherence and QOL, and lower HbA1c at each time point. They concluded that adolescents develop complex illness perceptions, which are associated with better diabetes management.

The relationship between illness perceptions and self-efficacy is unclear. However, Leventhal and Cameron (1987) suggested that different concepts such as self-efficacy could be integrated into self-regulatory framework. Given that self-efficacy is essentially a person's perceptions of their ability to accomplish a task, within the context of management of a chronic illness like T1DM where the nature of the task is dependent on the features of the illness, it would be expected that self-efficacy would therefore be associated with the person's perceptions of their illness. Griva et al. (2000) examined the role of illness perceptions and self-efficacy in

adherence and metabolic control in adolescents with T1DM. They had 64 adolescents complete measures of illness perceptions, generalised and diabetes specific anxiety, and self-report measure of adherence, in addition to assessing HbA1c. Control, identity and consequences components of illness perceptions were significantly correlated with self-efficacy expectations. Control beliefs were consistently associated with self-reported adherence across all treatment aspects and accounted for 39% of the predicted variance in total adherence. Multiple regression analysis showed that 30.8% of the variance in HbA1c was explained by patients' diabetes specific self-efficacy, consequences and identity. The authors concluded that patients' beliefs are useful predictors of physiological and behavioural outcomes in diabetes self-management and should be the focus of routine clinical assessments and intervention.

1.6 Interventions to Improve Adherence

Given the association between glycaemic control and adherence it is not surprising that there has been a lot of interest in interventions that improve adherence in adolescents with T1DM. Hood, Rohan, Peterson, and Drotar (2010) reviewed interventions for adolescents with T1DM with adherence-promoting components and documented their impact on glycaemic control via meta-analysis. The 15 studies that met their criteria for inclusion in their review involved 997 adolescents with T1DM. They found that the mean effect size for pre to post treatment change for the intervention versus control group comparison was 0.11 (95% CI - 0.01 to 0.23). This is a small effect, demonstrating very modest improvements in glycaemic control. However, analysis for the pre to post treatment effects for the intervention group alone did show significant variability. Multicomponent interventions, those that

targeted emotional, social, or family processes that facilitate diabetes management, were more potent than interventions just targeting a direct, behavioural process (e.g., increase in blood glucose monitoring frequency). The authors concluded that interventions that focus on direct, behavioural processes and neglect emotional, social, and family processes are unlikely to have an impact on glycaemic control and that multicomponent interventions show more robust effects on HbA1c.

A systematic review by Hampson et al. (2001) looked at the effects of educational and psychosocial interventions for adolescents with T1DM designed to improve their adherence. They looked specifically at whether the interventions had any beneficial effects on biological and psychosocial outcomes, if certain features of interventions are more effective than others and what evidence there is for cost-effectiveness of interventions. 64 reports describing 62 studies were identified as empirical papers evaluating educational or psychosocial interventions. Of these, 25 studies were RCTs and effect sizes could be calculated for 14 of them. The mean effect size for psychosocial outcomes was 0.37 and 0.33 for HbA1c, indicating again that these interventions have small to medium beneficial effects on diabetes management outcomes. Few studies addressed economic considerations associated with interventions, and the lack of information on costs and the diversity of outcomes included by investigators impeded cost effectiveness comparisons.

A more recent systematic review and meta-analysis by Viana, Gomes, Zajdenverg, Pavin, and Azevedo (2016) looking at interventions to improve adherence compared the efficacy of psychological, telecare and educational interventions. Using HbA1c as an indirect measure of compliance and the principal outcome measure, 19 articles met the inclusion criteria providing data from 1,782 patients. The randomised control trials (RCTs) were divided into four groups

according to type of intervention: psychology (seven studies; 818 patients), telecare (six studies; 494 patients); education (five studies; 349 patients), and psychoeducation (one study; 153 patients). They found that a decrease in HbA1c was observed after psychological interventions (MD -0.310 ; 95% CI, -0.599 to -0.0210 , $P = 0.035$) but not after telecare or educational interventions.

A systematic review and meta-analysis by Ayling, Brierley, Johnson, Heller, and Eiser (2015) looked at the efficacy of theory-based interventions for young people with T1DM. They examined the nature and extent of explicit theory use in published interventions involving adolescents with T1DM and the relationship between how theory is used and intervention outcomes. From the 34 articles comprising 27 RCTs, 8 did not use theory in any of the ways assessed. Where present, the most common use of theory was providing evidence that a targeted theoretical construct predicted behaviour. Trials that used theory to some extent had marginally larger pooled effect sizes for both medical and psychological outcomes than those that did not. However, in meta-regression models, use of theory did not significantly predict intervention outcomes. The authors concluded that theory is under utilised in intervention development for adolescents with T1DM and that when employed, theory appears to be advantageous, but not necessarily predictive of intervention success.

1.7 Summary

T1DM is a chronic illness that places significant demands on young people and their families. Management of T1DM involves a complex process of daily insulin administration, dietary adjustment and SMBG, with the goal of keeping blood glucose levels at close to the normal range. This can be burdensome and regularly

interferes with the tasks of daily living. In addition, failure to maintain blood glucose levels within the normal ranges can lead to serious chronic and acute complications.

Adherence to medical recommendations for diabetes management is important to ensure optimal wellbeing. However, accurate measurement of adherence can be difficult. HbA1c is very often used as a proxy measure of adherence but its efficacy as such is somewhat limited. Of all chronic illnesses, individuals with T1DM are acutely prone to issues of non-adherence, particularly during adolescence.

Research has aimed to identify the psychological correlates or predictors of adherence. Self-efficacy has been demonstrated empirically to influence self-management behaviours in T1DM. Self-regulation is driven by executive functioning, which has been found to be associated with adherence and glycaemic control. Illness perceptions act as a framework to guide health related behaviours and coping responses and have been found to be associated with self-efficacy. Adolescents develop complex illness perceptions that are associated with diabetes management behaviours.

Research on interventions to improve adherence has found that their impact is modest at best and more likely to be successful if multicomponent rather than just target a direct behaviour. In general theory is in under utilised in intervention development and is not necessarily predictive of intervention success. Future research on interventions to improve adherence needs to look at having more robust designs, in particular the inclusion of RCTs.

1.8 Conclusions

A great deal of research has explored adherence in adolescents with T1DM. The rates and consequences of non-adherence in this population are very well

documented. However, the causes and effective treatment of non-adherence remains somewhat unclear. Psychological theory has postulated a number of mechanisms through which an individual's cognitions, emotions and behaviours interact to influence their adherence and this has been used to inform interventions. However, on the whole, interventions to improve adherence among adolescents with T1DM have been modest at best. There remains wide scope for the development of an effective, cost efficient intervention to increase management adherence among this population.

Chapter 2: Social Support and T1DM

2.1 Introduction

Self-management of T1DM, as with other chronic illnesses, is informed by social cognitive theory, which emphasises self-efficacy, an individual's belief in their capacity to execute behaviours necessary to produce specific performance attainments (Bandura, 1977), as a central component. However, self-efficacy does not occur in a vacuum, instead it occurs in a context that includes the patient, their wider social network, including family, friends and healthcare professionals, and their environment. To this end social cognitive theory emphasises that personal factors, such as beliefs and cognitions, and environmental factors, both physical and social, interact to influence behaviour (Gallant, 2003). One such environmental factor that has been the focus of a significant amount of research over the years is social support.

Cobb (1976) defined social support as information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations. Since then the term social support has been applied to a broad range of conceptualisations of supportive social networks and there is no consensus among researchers as to a definite definition (Cohen, 1988). However, common to all conceptualisations and definitions of social support is a basic acknowledgement of some combination of the perceptions, availability and utilisation of social networks and their interaction with the individual. The actual range of behaviours and situations that could be regarded as socially supportive is quite broad and somewhat subjective, and as such social support is better conceptualised in terms of the type of supportive interactions. Hogan, Linden, and Najarian (2002) identified three main types of supportive social interactions: emotional, informational and instrumental.

Emotional support involves verbal and nonverbal communication of caring and concern and is believed to reduce distress by restoring self-esteem and permitting the expression of feelings. Informational support, which involves the provision of information used to guide or advise, is believed to enhance perceptions of control by reducing confusion and providing patients with strategies to cope with their difficulties. Instrumental support involves the provision of material goods and may also help decrease feelings of loss of control. In order for social support to have a positive impact on physiological and psychological wellbeing, both the type and the amount of support available must be in line with the individual's needs (Peters, Nawijn, & van Kesteren, 2014).

In 1976 two formative reviews on the role of social support in the aetiology of physical wellbeing were published. Cobb (1976) reviewed the evidence that supportive interactions among people are protective against the health consequences of life stress and concluded that social support can safeguard people from a variety of physiological and psychological ailments, including arthritis, depression and alcoholism as well as facilitating compliance with prescribed medical regimens. Cassel (1976) also highlighted the importance of social relationships in ameliorating the impact of stressors but emphasised the role of psychosocial processes in enhancing susceptibility to disease. These two papers generated a lot of interest in the relationship between social support and physiological wellbeing, particularly with regard to chronic illness management, and a significant amount of subsequent research has demonstrated a strong positive relationship between social support and positive chronic illness outcome measures (Ireys, Chernoff, DeVet, & Kim, 2001; Uchino, Cacioppo, & Kiecolt-Glaser, 1996; Vassilev et al., 2011).

A review by Gallant (2003) on the influence of social support on chronic illness self-management found evidence for a modest positive relationship between social support and chronic illness self-management, especially for diabetes. Although most of the quantitative studies identified in this review (13 of 22) involved diabetes management, only one focused on T1DM. As such it is difficult to generalise this finding to T1DM. Indeed much of the research on the impact of social support in diabetes management has focused on T2DM. Some of these studies also include participants with T1DM; however, given the significantly higher incidence rate of T2DM, the participants with T1DM tend to be far outnumbered by participants with T2DM.

Although there are some commonalities across T1DM and T2DM, they are still very separate and different medical conditions with different etiologies and management regimens. Grouping patients with T1DM and T2DM together for the purpose of investigating the impact of social support assumes that social support mediates both conditions similarly. One of the few, if only, studies that looked specifically at the differences between people with T1DM and T2DM in relation to social support was undertaken by Hempler, Joensen, and Willaing (2016). In order to look at the differences between people with T1DM and T2DM with regard to social relations and health behaviours they conducted cross sectional surveys of people with T1DM (N=2419) and T2DM (N=1081) attending a specialist diabetes clinic. They found significant associations between diabetes type and social network, social support and health behaviour. People with T2DM had less contact with the social network, less certainty about support in case of severe illness and fewer healthy behaviours than people with T1DM. Given these results, it is important when looking

at the impact of social support in T1DM that studies are selected that only include participants with T1DM rather than ones that group T1DM and T2DM together.

The first, and to date only, critical review to look at social support in T1DM was undertaken by Burroughs, Harris, Pontious, and Santiago (1997). They reviewed thirty-two studies that examined the relationship between social support and adherence in adolescents with T1DM. They found that supportive cohesive families were more likely to have adolescents with strong adherence and metabolic control than families without such cohesion. In relation to the influence of specific family support behaviours, they found the results of the studies to be inconsistent. For instance, both positive and negative support behaviours were associated with adherence. However, they found that adolescents with good adherence had interactions with their parents that were characterised as open and empathetic, whereas adolescents with poor adherence had interactions characterised as emotionally charged and confrontational. They also found that interventions aimed at increasing adolescents' social support, such as helping adolescents better develop their social skills so that they would be better equipped to handle situations in which adherence would be difficult or helping families understand what it's like to live with diabetes and develop effective diabetes problem-solving skills and support mechanisms, led to significant improvements in adherence or metabolic control.

2.2 Parental Support

The first and most significant source of social support for very young children with T1DM comes from parents. Very young children do not have the skills and cognitive capacity to undertake the very significant demands of diabetes management responsibility and so the onus falls on parents to undertake this role. However, as

children mature they begin to take on more and more responsibility for certain aspects of their diabetes management. In fact, management of T1DM over the course of childhood and into adolescence and early adulthood is characterised by an evolving process whereby diabetes management responsibility gradually passes from parents to the young person. From parents initially having total responsibility for diabetes management, to children gradually acquiring the skills required for management and taking on some of the responsibility, to young adults taking over complete responsibility for their diabetes management. In between the start and end points of this process, children acquire and trial the skills of independent management, usually under the direction and guidance of parents. During this phase, diabetes is somewhat co-managed by both the parent and the child, with the responsibility for management gradually shifting to the child as the skills of independent management are acquired.

The rate and timing of the transfer of diabetes management responsibility from parents to children differs from family to family. Obviously the goal for parents is to support the child or adolescent to become autonomous in their diabetes management. In order for this to occur the parent has to begin to withdraw at least some of the direct diabetes management support they provide to the young person. A key question for parents is, what level of support to provide at what stage of the child's development and is there a point at which they should completely withdraw their involvement in their child's diabetes management. Wysocki and Greco (2006), in reviewing the empirical research literature on the role of social support in children and adolescents with T1DM, concluded that premature withdrawal of parental involvement is associated with poor diabetes outcomes, whereas continued parental support and monitoring is associated with better outcomes among adolescents. They conclude that there is a consistent body of evidence supporting the argument that

maintenance of parental involvement in diabetes management should be encouraged, rather than discouraged, and that adolescents who enjoy continued parental support tend to achieve and maintain healthier adaptation to diabetes than do those who don't enjoy the same level of parental support.

However while continued parental support in adolescent diabetes management may, in the whole, lead to better outcomes for adolescents, over-involvement by parents may have the opposite effect. The Hvidøre Study Group on Childhood Diabetes had 2,062 adolescents with T1DM complete a questionnaire that asked, among other things, whether they thought their parents were over-involved in their diabetes management, specifically whether their parents were too protective, worried too much, or acted as if diabetes was their own disease. They found that 26% of respondents felt that their parents were too protective, 36% felt that they worried too much, and 22% felt that they frequently or always acted as if diabetes was their own disease. The researchers also found that parent over-involvement was significantly correlated with poorer metabolic control, and was a stronger predictor of metabolic control than age, gender, or insulin treatment regimen (Cameron et al., 2008).

A review by Young, Lord, Patel, Gruhn, and Jaser (2014) into the quality of parental support suggested that inconsistent findings for the effects of parental involvement on adolescent adjustment may be explained by how involvement is executed by the parent and perceived by the adolescent. They identified two broad categories of parental involvement in adolescents' diabetes management, good cop and bad cop. Good cop is high-quality parental involvement that enables collaboration and is characterised by open communication, emotional support, and independence encouragement. This approach to parental diabetes support is associated with better quality of life, adherence, glycaemic control, and self-efficacy

as well as lower frequency of diabetic ketoacidosis and lower levels of externalising behaviour. Bad cop is low-quality parental involvement that is often referred to as intrusive support and is characterised by controlling, critical and restrictive parenting behaviours that can create family conflict and reduce adolescent's self-efficacy. This approach to parental diabetes support is associated with lower adherence, suboptimal glycaemic control, poorer health-related quality of life and greater family conflict. They concluded that parental involvement can serve as a risk or protective factor for children with T1DM and identified factors that may compromise parental involvement, including marital status, income, parental stress and distress, and child behaviour. They also concluded that parental monitoring should not decrease during adolescence and may in fact need to increase depending on the child's self-efficacy and current abilities.

2.3 Peer Support

As we have seen, research has consistently demonstrated the relationship between appropriate parental support and better outcomes for children and adolescents with T1DM. Although parental support may be one of the most significant sources of support impacting on the diabetes management of children with T1DM (Wysocki & Greco, 2006), it is not the only source of social support. As children mature into adolescence, they strive for independence from their parents, often turning instead to peers for support. This increasing influence of peer relationships can mediate the influence of parental support on diabetes management. In a study by Drew, Berg, and Wiebe (2010) 252 adolescents completed assessments of extreme peer orientation (i.e., tendency to ignore parental advice and diabetes care in order to fit in with friends), adolescent-parental relationship and adherence. The

researchers found that adolescents' high quality relationships with their parents were associated with better treatment adherence and metabolic control through less peer orientation. In other words, the positive benefits of parental support were mediated by peer influence. The researchers suggested that high quality adolescent-parent relationships may be beneficial to adolescent diabetes management through a healthy balance between peer and parental influences (Drew et al., 2010).

As well as having a mediating effect on parental support, peer influence can itself be a source of social support for adolescents with T1DM and may in some cases be a more significant source of support for the young person than family support. One study that evaluated the support provided by family members and friends for adolescent diabetes care interviewed 74 adolescents with T1DM about the ways that family members and friends provided support for diabetes management and helping them to feel good about diabetes. The researchers found that friends provided more emotional support than families and recommended involving peers as supportive companions for meals and exercise (La Greca et al., 1995).

Despite evidence of the influence of peers on adolescents with T1DM, relatively little research has studied the effect of peer relationships on diabetes management (Palladino & Helgeson, 2012). The review by Wysocki and Greco (2006) on the influence of parents and friends on diabetes management in childhood and adolescence, concluded that social support from friends can be a unique source of support that complements parents' involvement and improves adolescents' diabetes management. The review noted that friends provide social support which is unique from parents' contribution and provide an important source of emotional support, especially for girls, and as such disclosure to friends is important and is related to successful diabetes self-care. The authors concluded that interventions aimed at

involving friends in a positive, helpful manner appear to increase support from friends and to improve adolescents' self-management of diabetes. However, a review by Palladino and Helgeson (2012) of peer influence on self-care and glycaemic control in adolescents with T1DM that included both qualitative and quantitative studies concluded that the literature linking peer relations to diabetes outcomes is mixed. Although the qualitative studies revealed that adolescents believe peers have an impact on diabetes behaviour, the quantitative findings were inconclusive. The authors recommended that future research should consider moderator variables, expand the conceptualisation of peer relationships, and consider interactions between person and social context.

The conceptualisation of peer relationships is somewhat subjective and the type and level of social support that adolescents with T1DM receive from peers can vary greatly according to the nature of their interactions. In one study, 51 adolescents with T1DM completed questionnaires and were interviewed concerning their compliance with their diabetes management regimen. The adolescents described their interactions with friends in terms of silent support, domination or no influence. When friends dominated the adolescents they adopted the friends' lifestyle. In these situations the demands of diabetes management were incongruent with this lifestyle, and the friends tempted the adolescents to depart from required diabetes management regimens. Silent support was typically expressed as friends reminding adolescents about their self-care and friends changing their own behaviour to fit with the lifestyle of the adolescent with T1DM. Adolescents whose relationships with friends had no influence on compliance viewed diabetes care as a natural part of their lives. They felt that nothing could disrupt their self-care and as such friends actions were irrelevant. The researchers found that adolescents who were dominated by their

friends reported poor compliance, whereas those adolescents whose friends provided silent support or who were perceived to have no influence, reported good compliance (Kyngas, Hentinen, & Barlow, 1998).

There is some evidence that the impact of peer support can be specific to certain diabetes management behaviours rather than treatment adherence as a whole. One study of 74 adolescents found that friend support was not related to overall treatment adherence but was related to adherence for blood glucose testing. The researchers found that friends provided the most frequent support for exercise, emotions, and blood glucose testing and friends' behaviours in these areas were perceived as most supportive. However, adolescents reported less frequent friend support for insulin injections, as adolescents typically manage this on their own (Bearman & La Greca, 2002).

The influence of peer social support on diabetes management behaviours is also likely to be disproportionately weighted towards management behaviours that occur in peer environments. For adolescents with T1DM, the influence of peers may be particularly salient for self-care behaviours that occur at school or during other social events where peers are present. Often adolescents with T1DM can find themselves in social situations where they perceive the behaviours of diabetes regimen adherence to be in direct conflict with the behaviours of peer impression management. In such situations, the adolescent perceives the two behaviours to be mutually exclusive and must prioritise diabetes management over peer impression, or vice versa. For example, when dining with peers, the choice is between consuming the same high sugar food as peers or looking for a lower sugar alternative that is more consistent with good diabetes management. One study that looked at problem-solving ability and reported regimen adherence among children and adolescents with T1DM

in response to hypothetical social situations where a choice between diabetes regimen adherence and peer desires must be made, found that adolescents had better problem solving abilities than children, probably reflecting greater cognitive maturity. However, adolescents were more likely than children to choose behaviours that were less regimen adherent and results indicated an age-related trend of decreasing adherence in social situations despite increasing problem-solving abilities (Thomas, Peterson, & Goldstein, 1997).

This trend of decreasing adherence in social situations among adolescents is likely influenced by a fear of negative appraisal from peers. One study that examined the relationship between negative attributions of peer reactions to diabetes management in social situations and metabolic control had 102 adolescents complete questionnaires measuring attribution of peer reactions, anticipated adherence, friend support and diabetes stress. The researchers found that adolescents who make negative attributions about reactions of peers are likely to find adherence difficult in social situations and have increased stress (Hains et al., 2007). Even in social situations where positive peer support is available, fear of negative appraisal from peers can be a barrier to adolescents' utilisation of potentially beneficial peer support. In a qualitative analysis of adolescents' experience of social support from friends, the authors concluded that fear of coming across as needy or different are major reasons for adolescents with T1DM for not being more open or not seeking more support (Peters et al., 2014).

Although the research clearly demonstrates that peer support influences aspects of adolescents' diabetes management, most studies have focused on peer support from friends without T1DM. Research on the influence of peers who also have T1DM is significantly lacking. However, research on the positive impact of

support from others with similar medical conditions has been demonstrated with adolescents with other chronic illnesses (Mackner, Ruff, & Vannatta, 2014; Zelikovsky & Petrongolo, 2013) and in adults with Type 2 diabetes (Joseph, Griffin, Hall, & Sullivan, 2001; Rogers et al., 2014).

The lack of research on the influence of peers with T1DM is due largely to the fact that for the most part this is not a naturally occurring source of peer support. Most adolescents with T1DM are unlikely to have an adolescent with diabetes among their immediate peer group (i.e., the peers with which they have regular contact). Consequently research into the impact of support from peers with T1DM would have to create the conditions that provide this kind of peer support. Some studies have looked at interventions where adolescents with T1DM have interacted, such as through group education or training, and found a positive impact on diabetes management (Anderson, Wolf, Burkhart, Cornell, & Bacon, 1989; Grey, Boland, Davidson, Li, & Tamborlane, 2000), however, these studies have not specifically looked at the impact of the support of the peer with diabetes.

Peer mentoring, whereby individuals are linked with a slightly more experienced peer with a similar condition, has been found to be beneficial in parents of children with T1DM (Sullivan-Bolyai & Lee, 2011) and provides a potential useful source of peer support for adolescents with T1DM. Lu et al. (2015) looked at the perceptions of 54 adolescents with T1DM (ages 13-18) as prospective mentees and 46 young adults with T1DM (ages 19-25) as prospective mentors through means of a self-administered survey. They found that the majority of adolescents and young adults were interested in a peer mentoring programme. Having supportive friends and living in a large household positively predicted adolescent interest in having a peer mentor. In addition, both adolescents and young adults were open to multiple communication

modes, including in-person meetings, phone, text messaging and social media. Although this study does highlight the interest among adolescents with T1DM to receive support from a peer with T1DM, it does not address the potential effectiveness of such support.

As mentioned previously, adolescents are at particular risk of decreasing adherence in social situations because of a fear of negative appraisal from peers. Peer mentoring in particular may be useful in overcoming these social barriers to diabetes control. In the study by Lu et al. (2015), non-adherence due to embarrassment in social settings was significantly more prevalent among adolescents than young adults (50% versus 15%) and the authors suggest that young adults who have overcome social embarrassment may be able to share this experience with adolescents.

One of the major barriers to peer mentoring programmes has been geography, particularly outside urban centres. For some individuals with T1DM there may not be someone who would be a suitable peer mentor within the vicinity of where they reside. However, the advancement of telecommunication technologies has helped to overcome this obstacle. Suh et al. (2014) developed an Internet-based mentoring programme to improve glycaemic control in adults with T1DM. They randomly assigned 57 adults with T1DM to mentored (glucometer transmission to a website with feedback from mentors) or control (glucometer transmission to a website without feedback) groups. Although the mentored group monitored their blood glucose and logged onto the website more frequently than the control group, they failed to show significant improvements in HbA1c levels or including quality of life.

2.4 Diabetes Healthcare Team Support

As well as social support from family and peers, the diabetes healthcare team (DHCT) can also be a significant source of social support for young people with T1DM and their families. The DHCT provides instrumental and informational support for adolescents with T1DM by providing access to the healthcare equipment and supplying the necessary medical information required to effectively manage T1DM. However, like any healthcare team, the DHCT can also be a significant source of emotional support through verbal and nonverbal communication of caring and concern.

Central to the emotional support provided by healthcare teams is the quality of the communication between the healthcare provider and the patient. Patient-centred communication, which is communication characterised by partnership building, empathy, interpersonal sensitivity, and information giving (Erickson, Gerstle, & Feldstein, 2005), encourages the discussion of psychosocial issues and leads to a broader understanding. A review by Stewart (1995) looked at whether the quality of physician-patient communication makes a significant difference to patient health outcomes. She found that most of the studies reviewed demonstrated a correlation between effective physician-patient communication and improved health outcomes. A review by Dimatteo (2004) concluded that research evidence supports the important role of effective communication in fostering adherence to preventive and chronic disease treatment regimens in the care of children and adolescents.

In the context of adolescents with T1DM, Croom et al. (2011) examined whether adolescents' and parents' perceptions of patient-centred communication with doctors was associated with aspects of patient empowerment and diabetes management. 190 adolescents with T1DM and their parents completed measures of

competence, illness perceptions, and adherence in the weeks following their clinic visit and again six months later. Results demonstrated that higher levels of patient-centred communication were associated cross-sectionally and longitudinally with greater perceptions of control and competence for both adolescents and their parents. The authors concluded that patient-centred communication with healthcare providers may empower adolescents and parents in their diabetes management.

If better patient-centred communication empowers patients, then engaging adolescents in patient-centred communication may help support their growing autonomy. This autonomy support is another form of social support that can be provided by healthcare teams. Autonomy support originates from self-determination theory, which is built around the distinction between motivations that are autonomous versus controlled. Central to self-determination theory is the concept of autonomous self-regulation comprising both intrinsic motivation and well-internalised extrinsic motivation (Deci & Ryan, 2012). According to self-determination theory being autonomous refers to acting with a sense of volition and the experience of willingness. This is in contrast to behaviour that is controlled to the extent that individuals feel pressured by interpersonal forces. For example, adolescents with T1DM would be autonomous if they adhered to diabetes management advice from healthcare providers because they believed the advice was correct and were personally committed to achieving optimal health. However, their behaviour would be controlled if they adhered to diabetes management advice because they felt pressure from their parents or healthcare professionals. It must be noted that being autonomous is different to acting independently. Patients can be autonomous but still decide to rely on others for advice and guidance, in essence being autonomously dependent. Alternatively,

patients can be autonomous but decide not to rely on others, becoming autonomously independent.

Communication from healthcare teams that is perceived as autonomy supportive has been found to impact on patients' health behaviour. Williams, Freedman, and Deci (1998) examined whether T2DM patients' perceptions of autonomy supportiveness from their DHCT related to improved glycaemic control. A total of 128 patients with T2DM completed the Health Care Climate Questionnaire (HCCQ), a scale that assesses participants' perceptions of the degree of autonomy supportiveness of their healthcare provider, the Perceived Competence for Diabetes Scale (PCDS) and the Treatment Self-Regulation Questionnaire (TSEQ), a questionnaire that measures autonomous versus controlled motivation, and had their HbA1c measured over a twelve-month period. The results indicated that patients' perceptions of autonomy support from a healthcare provider related to a change in HbA1c at twelve months. In addition, perceived autonomy support related to significant increases in patient autonomous motivation, increases in autonomous motivation related to significant increase in perceived competence, and that increases in perceived competence related to significant reductions in HbA1c. The authors concluded that patients with diabetes whose healthcare providers are autonomy supportive will become more motivated to regulate their glucose levels, feel more able to regulate their glucose, and show improvements in HbA1c.

Autonomy supportive communications from healthcare teams has also been found to have a positive impact on the health behaviour of adolescents. Williams, Cox, Kouides, and Deci (1999) examined whether the degree to which adolescents experience an appeal to not smoke as autonomously supportive would affect their autonomous motivation for not smoking and, in turn, their behaviour of either

refraining from smoking or smoking less. Physicians presented information about not smoking to 400 adolescents using two different message styles, one of which was designed to be more autonomously supportive. The authors found that perceived autonomy supportiveness of the presentation was positively correlated with autonomous reasons for not smoking. In addition, change in autonomous reasons for not smoking significantly predicted reduction in smoking.

Mohn et al. (2015) investigated the association of perceived competence in diabetes management and autonomy support from healthcare providers with diabetes distress in adults with poorly controlled T1DM: 178 adults with T1DM completed the HCCQ, the PCDS and the Problem Areas in Diabetes Scale (PAID), a scale that measures negative emotions related to living with diabetes, as well as recording HbA1c levels. A significant negative association was found between autonomy support and diabetes distress, indicating that lower autonomy support was associated with greater diabetes distress. When perceived competence was controlled, it mediated the association of autonomy support with diabetes distress, reducing it to non-significance. There was a significant negative association between perceived competence and the diabetes distress, indicating that lower perceived competence was associated with greater perceived distress. The authors concluded that there was a fully mediated indirect relationship between autonomy support and diabetes distress; autonomy support was associated with increased perceived competence, which, in turn, was associated with reduced distress. They suggested that healthcare providers' communications styles enhancing perceived competence through autonomy support may contribute to better outcomes for people with T1DM.

These studies suggest that increased perceptions of autonomy support from healthcare providers are associated with increased perceptions of competence, lower

distress and improved health behavior. Therefore enhancing autonomy support from the DHCT through better patient-centred communication may lead to improvements in physiological and psychological outcome measures for adolescents with T1DM. In addition, adoption of a patient-centred interaction style encourages the discussion of psychosocial issues, offering increased opportunity for the DHCT to provide emotional support to the adolescent with T1DM.

2.5 Summary

Social support is a broad term that refers to a range of conceptualisations of supportive networks available to individuals. A significant amount of research has demonstrated a strong positive relationship between social support and positive outcome measures in chronic illness, including T1DM. Although T1DM and T2DM are often grouped together in studies of the impact of social support, research suggests that the mediating role of social support differs between the two conditions.

The most significant source of social support for young children with T1DM comes from parents. As children mature into adolescence they begin to take on more of the responsibility for managing their diabetes, requiring a phased handover of responsibility from parents to adolescents. Premature withdrawal of parental support at this point is associated with poorer diabetes outcomes. However, over-involvement has also been found to be associated with poorer diabetes outcomes. The quality of parental support may account for some of the inconsistent findings on the impact of parental involvement. High quality parental involvement that enables collaboration and is characterised by open communication, emotional support, and independence encouragement, is associated with better diabetes outcomes. In contrast, low quality

parental involvement is characterised by controlling, critical and restrictive parenting behaviours and is associated with poorer diabetes outcomes.

Peers are another significant source of support for adolescents with T1DM and, as well as mediating the influence of parental support, can also impact directly on diabetes management. Peers provide social support unique from parents' contribution and can be an important source of emotional support. However, research on the influence of peers on glycaemic control is mixed. Qualitative studies indicate that adolescents believe that peers have an impact on diabetes behaviour, whereas quantitative findings are inconclusive. There is some evidence that the impact of peer support is dependent on the nature of the interactions with peers and may be specific to certain diabetes management behaviours. The influence of peers may be particularly salient for management behaviours that occur during social events where peers are present. This can lead to poorer adherence in social situations with peers because of fear of negative peer appraisal.

There is very little research on the impact of the support of other peers with T1DM. However, research has found positive impacts of the support of other adolescents with similar medical conditions and other adults with T2DM. Peer mentoring is a potential useful source of peer support for adolescents with T1DM, particularly with regard to addressing the risk of decreasing adherence in social situations due to fear of negative appraisal from peers. The Internet also provides a potentially useful medium for providing peer support from peers with T1DM.

The DHCT can also be a significant source of social support for adolescents with T1DM. Central to this is patient-centred communication, which has been found to be associated with greater perceptions of control and competence for adolescents with T1DM. Patient-centred communication can also foster autonomy support from

the DHCT. Research suggests that increased perceptions of autonomy support are associated with increased perceptions of competence, lower distress and improved health behaviour.

2.5 Conclusions

The three main sources of social support for adolescents with T1DM are parents, peers and the DHCT. Positive social support from parents and peers without T1DM has received the most attention in the research and has been found to be associated with better physiological and psychological outcomes measures. Social support provided by the DHCT and peers with T1DM has received considerably less research attention. However, the limited research that has been undertaken, and research in similar chronic illnesses, suggests that both these sources of social support hold significant potential for increasing the physiological and psychological wellbeing of adolescents with T1DM. Further research is warranted to explore the impact of enhancing support from the DHCT and peers with T1DM on adolescents with T1DM.

Chapter 3: Social Network Sites in the Management of T1DM

3.1 Introduction

The initial stages of the Internet, known loosely as Web 1.0, were characterised by relatively static websites accessed by users in order to obtain information. However, the way in which we use the Internet today has evolved into a much more interactive user experience that blends technology and social interaction. This phase in the evolution of the Internet, known loosely as Web 2.0, is based around social media and driven by the creation and exchange of user-generated content. Given how pervasive social media has become to our everyday lives, Facebook has over 1 billion users worldwide (Facebook, 2013), it is not surprising that its impact on healthcare has grown rapidly (Randeree, 2009).

The advent of the Internet was associated with a significant increase in access to health-related information by non-health professionals; for example five per cent of all searches on Google were found to be health related (Eysenbach G, 2004). As the Internet evolved to encompass social media it changed from a medium where patients could simply search for and find health information to a place where patients can interact and provide information for one another.

3.2 The Increasing role of Social Network Sites in Healthcare

The platforms for social media are varied and include social network sites (SNS), Internet forums, podcasts, blogs and wikis, with the only common thread among them being the blending of technology and social interaction. However, of all the different social media platforms, SNS have evidenced the fastest and broadest uptake. A SNS is an internet-based platform that facilitates the building of social networks or social relations among people. Typically users create profiles, make connections with other users, and communicate and

share content together. Although there are many different SNS, generally differentiated by the different audiences or content they target, by far the most popular are the ones that target broad ranges of audiences and content, and include Facebook and Twitter.

The features that define contemporary SNS were first popularised by Friendster in 2002. Although a few SNS predated it, it was the first SNS to attain a million members. It was launched as a dating site but users quickly began to see its potential for a variety of social activities. By 2003 bands began to use Friendster to connect to fans and promote concerts, however, Friendster forbid this practice and began removing bands' profiles. When MySpace launched in 2003 it welcomed bands and, given the role of music in the lives of a lot of young people, it became a popular spot for them to be able to interact around different musical interests. As people interested in music began to migrate to MySpace so too did their friends, who may have been less musically inclined, in order to avail of this increasing popular online community.

By 2005 MySpace had become the most visited SNS in the world and retained this position until 2008, when it was overtaken by Facebook. Throughout this period other SNS came online and achieved varying degrees of traction in different markets, however, none have reached the number of users or experienced such a rapid expansion as Facebook. Facebook was established in 2004 as an online social network for Harvard students, later being expanded to other universities and schools and eventually to anyone aged thirteen or over. By 2008 Facebook had obtained one hundred million users, by 2010 it had obtained five hundred million users, and as of the first quarter of 2016 it has 1.65 billion monthly active users (Statista, 2016).

The widespread use of SNS is changing the way in which patients request and access health information, with a blurring of the lines between health information seekers and providers. SNS enable individuals to exchange information on behalf of themselves or of

others on different medical conditions, treatments and experiences with different healthcare providers (Griffiths et al., 2012). The consequences of such unabridged exchange of health information include the appearance of online patient expert groups and the development of online communities around particular illnesses or conditions. The role and extent to which health information gathered by patients on SNS substitutes conventional sources of health information or merely complements it is being increasingly debated (Griffiths et al., 2012; Powell, Inglis, Ronnie, & Large, 2011).

Being able to share personal health information on SNS has led to the creation of geographically dispersed online communities around particular illnesses. The benefits of real world (i.e., non-virtual) support from individuals with similar medical conditions have been often demonstrated and include improvements in disease specific knowledge, better psychosocial functioning, better quality of life and more appropriate health behaviour (van Dam et al., 2005). There is evidence that online disease specific support groups may also provide benefits to patients. For example, “PatientsLikeMe” is an online community providing customised disease-specific outcome and visualization tools to help patients understand and share information about their condition (Frost & Massagli, 2008). In one study users reported a range of benefits of using the site, including increasing levels of comfort in sharing personal health information, reduction in risky behaviours and less inpatient care (Wicks et al., 2010). In addition, patients who used more features of the site perceived greater benefit. Frost and Massagli (2008) suggested that patients who choose to explicitly share health data within a community may benefit from the process, helping them engage in dialogues that may inform disease self-management.

3.3 Social Network Sites and Adolescent Diabetes Care

The role of SNS specifically in relation to diabetes management is coming under increasing scrutiny, with a 2009 systematic review of technology-based approaches to patient education for young people living with diabetes identifying SNS as an important area for further investigation (Cooper, Cooper, & Milton, 2009). While there are currently few empirical studies evaluating the effectiveness of SNS in diabetes management, there is some evidence that SNS may be an appropriate way to reach people to deliver diabetes education and support (Shaw & Johnson, 2011), with the potential for better glycaemic control (Toma, Athanasiou, Harling, Darzi, & Ashrafian, 2014).

Prior to the widespread use of contemporary SNS, online forums were a resource where people could exchange information on particular topics. A 2004 analysis of online forum messages posted by adolescents with diabetes suggested that they visit online forums for social support, information, advice, and shared experience (Ravert, Hancock, & Ingersoll, 2004). Contemporary SNS provide all of the supports of earlier online forums but are much more accessible, easier to use and serve much wider populations. As a result, many traditional websites aimed at creating online forums for children with T1DM and their families have either migrated to SNS or established a parallel SNS presence. For example, two popular Facebook groups focused on creating an online community for children with T1DM and their families, Children with Diabetes and Type One Teens, originated as traditional websites. The Children with Diabetes website was launched in 1995 as an online support for families living with T1DM, while the Type One Teens website was created by an adolescent with T1DM in 2011 as an online social group for teenagers with T1DM. Both websites continue to operate but they also have parallel Facebook group pages that provide the additional functionality and reach of SNS. Although anecdotally such SNS groups would appear to be popular among children with T1DM and their families, there is very little

empirical evidence of their actual utility. A qualitative analysis of communication on the fifteen largest diabetes management Facebook groups found that patients with diabetes, family members, and their friends use Facebook to share personal clinical information, to request disease specific guidance and feedback, and to receive emotional support (Greene, Choudhry, Kilabuk, & Shrank, 2011).

Social support has been shown to be an important factor in diabetes management for people with diabetes (van Dam et al., 2005), with peer support particularly beneficial for adolescents with diabetes (Joseph, Griffin, Hall, & Sullivan, 2001). On-site bespoke adolescent peer support groups can utilise the benefits of such support, however, these can be costly to run, time consuming and difficult to organise. SNS can provide a level of peer support without these financial, organisational and geographical constraints and, given the extent to which adolescents have embraced this technology (with one study reporting that 95% of adolescents identified themselves as Facebook users), may be particularly useful for this age group (Machold et al., 2012). Nordfeldt, Hanberger, and Bertero (2010) created a SNS for adolescents and their parents containing both specific diabetes related information and social networking functions such as message boards and blogs. They found on analysis of feedback from adolescents and their parents that features of the SNS such as message boards, chat rooms and being able to find reliable information were regarded as beneficial.

When attempting to utilise SNS to support adolescents' diabetes self-management it would appear logical that any intervention be integrated into the SNS they use frequently. However, a number of studies have examined the experience of using custom built SNS. Nordfeldt, Angarne-Lindberg, and Bertero (2012) in their study created an Internet portal that contained specific diabetes-related information and social networking functions, such as boards and blogs, for use by invited patients and parents, as well as their relevant healthcare practitioners. Feedback about the experience of using the site indicated that patients and

parents found benefit in being able to find reliable information on the site and that it enhanced the peer-to-peer sharing of information. However, restrictions with accessing the portal, such as having to login, caused users to drop the portal. A study in the UK evaluated usage of an adolescent designed website that provided information and support on diabetes through interactive models, quizzes, an online forum and a blog. Using website usage statistics they were able to identify the frequency that adolescents logged into the website and then used this information with semi-structured phone interviews to identify facilitators and barriers to website use. This indicated that while the adolescents found the online information and support useful, they did not use the website as intended, preferring instead mainstream websites used in their everyday life (McPherson, 2012).

Using a mainstream SNS, rather than a custom built one, may be a better platform for engaging adolescents for the purpose of supporting their diabetes management. In this regard, in 2011 Facebook had over five hundred existing diabetes related groups (Shaw & Johnson, 2011). However, using a pre-existing established SNS (e.g., Facebook or Twitter) rather than constructing a SNS specifically for the purpose of a diabetes specific intervention has implications for the privacy and security of the SNS. Of thirty-four intervention studies identified in a recent review of SNS (defined very broadly) in the management of patients with diabetes, none used any of the larger established SNS, and the authors speculated that this might have been down to issues of privacy and security on these SNS (Toma et al., 2014).

Evidence suggests that patient interest in communicating with health professionals through electronic means, such as SNS, is increasing. A survey of more than 7,000 citizens from seven European countries found that an increasing number of people reported using the Internet to request/renew prescriptions, schedule an appointment or ask a particular health question. Among those using the Internet for health-related purposes, more than 40% considered the provision of these eHealth services to be important when choosing a new

doctor (Santana et al., 2010). In a further study, a group of adolescents uploaded the data from their insulin pumps to their clinic from home and were then provided with interventions by their healthcare team via Skype and Facebook, while another group downloaded the data from their pump at regular clinic visits, during which interventions were given in person by their healthcare team. The researchers concluded that where new technologies can examine diabetes management similar to regular clinic visits, adolescents reported preferring to communicate with their healthcare providers using SNS (Petrovski et al., 2012).

3.4 Utilising Smartphone Technology

The widespread adoption of smartphone technology has allowed SNS to move away from the confines of the desktop computer and become truly mobile. However, even prior to smartphones and the evolution of SNS, mobile phones were being highlighted as a valuable tool in healthcare communication technologies for people with T1DM (Gimenez-Perez et al., 2002). In one study, a web-based comprehensive information system, consisting of Internet and cellular phone use, improved HbA1c readings in patients with T2DM at six months post initiation (Noh et al., 2010). However, a more recent systematic review of text message interventions for children and adolescents with T1DM concluded that they are feasible and enjoyable, but that their clinical significance for long-term daily T1D management behaviors and glycemic control is unclear (Herbert, Owen, Pascarella, & Streisand, 2013)

Smartphone technology opens a new avenue for mobile phones as a tool in diabetes management, as smartphones act as an interface for most SNS, thus further extending the reach of SNS into everyday life. Although there is very little research on using smartphones in adolescent diabetes management, a study of adults with T2DM diabetes using cellular technology to mediate interactions between patients and supporters (i.e., family members or friends) to motivate regular self-monitoring of blood glucose found that patients reported

improved attention to self-monitoring (Roblin, 2011). However, the effects of the intervention on actual behaviour and health outcomes were not examined.

Smartphone apps have further expanded the functionality of social media. In particular, smartphone apps that support diabetes management have proliferated. In July 2009 the iTunes store, which hosts apps for the iPhone, hosted sixty diabetes apps. However, by February 2011 this had increased by more than four hundred per cent to two hundred and sixty apps and other mobile platforms reflected similar trends (Lyles, Chomutare, Fernandez-Luque, Arsand, & Hartvigsen, 2011). A more recent study yielded approximately six hundred apps from a search for the term “diabetes”, with only 14% not being related to diabetes (Eng & Lee, 2013). These apps were categorised into apps for medical management of diabetes, apps for tracking and displaying health information, apps for teaching/training, food reference databases, social forums/blogs and physician-directed apps. However, despite the rapid increase of diabetes related apps, there has been little research into their efficacy. A systematic review by Deacon and Edirippulige (2015) that looked at the research on using mobile technology to motivate adolescents with T1DM concluded that the evidence base supporting the use of apps in T1DM management for adolescents was weak, with most studies adopting text messaging as the intervention tool.

3.5 Potential Risks

The use of SNS in diabetes management raises numerous questions with regard to potential risks, particularly when dealing with adolescents. Specific issues with regard to confidentiality and the quality of information posted on the SNS are a concern and the potential safety risks of diabetes-related SNS are not yet fully appreciated. One study found the quality and safety of diabetes related SNS policies and practices to be variable (Weitzman, Cole, Kaci, & Mandl, 2011). Some of the issues of concern included misinformation,

transparency of advertisements on sites, insecure data storage and transmission, and lack of control over personal information.

As most health information on SNS is posted by non-healthcare professionals, the increasing influence of SNS in healthcare has the potential to challenge the quality of health-related information. One analysis of the communication (i.e., wall posts and discussion topics) on the fifteen largest diabetes-management Facebook groups (both T1DM and T2DM) however, found that clinically inaccurate recommendations were infrequent, with only 3% of all posts containing inappropriate or unsupported therapeutic claims. 36% of those were found to be related to advertisements for non-FDA approved products (Greene et al., 2011).

3.6 Lack of Empirical Research

There remains a notable lack of empirical studies on the efficacy of SNS in adolescent diabetes management, despite evidence of their increased role. A 2011 systematic review of communication technologies to promote access and engagement of young people with T1DM into healthcare only identified one study using web-based discussion boards that met their criteria for inclusion (Sutcliffe et al., 2011). However, they did suggest that SNS represent a novel opportunity to improve and engage young people in their healthcare delivery, and to be potentially guided by young people themselves.

Furthermore, the diversity of study designs and the range of SNS technologies used makes comparison very difficult. One study that included social networking via a peer forum as part of an intervention found that the mean HbA1c for the treatment group remained constant while it increased for the control group. In addition, the treatment group showed statistically significant improvements in self-management (Mulvaney, Rothman, Wallston, Lybarger, & Dietrich, 2010). However, as the overall intervention included many facets of

social media, including online multimedia presentations, e-mail support and online problem solving, as well as SNS, it is not possible to extrapolate the specific impact of SNS or indeed any specific social media modality utilised.

The lack of a clear taxonomy in relation to social media in general has also led to confusion over what exactly is being evaluated. “Health 2.0” and “Medicine 2.0” are broad terms used to classify how social media technologies, such as SNS, are being adapted to healthcare; however there is still no general consensus as to their definition (Van De Belt, Engelen, Berben, & Schoonhoven, 2010). Indeed, research into the use of social media in healthcare covers such varied technologies as text messaging (Napolitano, Hayes, Bennett, Ives, & Foster, 2013), e-mail (Lapp & White, 2012), SNS (Jones, Sinclair, Holt, & Barnard, 2013), smartphone apps (Lyles et al., 2011) and automated web-based communication (Choi, Berry-Caban, & Nance, 2013), among others. For example, one study that looked at peer support in adolescents with type 1 diabetes via, what the authors referred to as social media, concluded that it provided little benefit (Lapp & White, 2012); however, the social media in question was individual anonymous e-mail access to a peer with diabetes, and this is not reflective of the scope of contemporary social media. A recent meta-analysis of SNS in the management of patients with diabetes found that SNS interventions beneficially reduced HbA1c when compared to controls (Toma et al., 2014). However, this review used a very broad definition of SNS and consequently it includes interventions that do not meet the definition of SNS as presented here.

3.7 Future Research

Future research into SNS in adolescent diabetes care needs to employ designs that are more methodologically robust. In particular, they need to include standardized quantitative measures, including health outcomes, behavioural outcomes and quality of life measures.

Furthermore, the relationships between these standardized quantitative measures and levels of engagement with the SNS and the patterns of interaction on the site need to be examined. Study designs also need to be employed that use comparison groups to directly investigate the use of SNS as an adjunct to standard clinical care against standard clinical care on its own. In addition, the cost-effectiveness of such approaches needs to be determined.

The very rapid and broad uptake of SNS that we have witnessed in recent times may well be followed by an equally rapid and broad shift away from SNS towards a different form of social media. In addition, there is also the potential for a shift between SNS, particularly among adolescents, whose habits are very often dictated by peer conformity. Both of these issues have implications for future research, as the potential redundancy of a specific SNS, or SNS in general, may result in reluctance from researchers to formally investigate the efficacy of SNS in the treatment of adolescent diabetes. However, understanding such processes may inform how future technologies can optimally enhance health outcomes and therefore potential redundancy shouldn't deter researchers from investigating them.

3.8 Evolution of the Internet

The next stage in the evolution of the Internet, known loosely as Web 3.0, is likely to be characterised by the 'semantic web' (the sharing and reusing of data across applications), personalisation of websites and intelligent searches. This will result in a portable personal Internet where content is more connected and user experiences are unique and tailored. In terms of healthcare, the move towards Web 3.0 should lead to enhanced interactions between healthcare providers and patients, improved access to health related information, and an expansion in the role and function of online disease specific communities. Web 3.0 is likely to see a greater role for SNS in the treatment and management of adolescent diabetes, particularly as a conduit for education, support and interaction between adolescents and

healthcare providers. Although the timescale for this transition is largely unclear, the recent increase in interest in SNS and diabetes suggests that it may be approaching sooner than expected.

3.9 Conclusions

The increasing presence of SNS in everyday life is paralleled by their presence and utility in healthcare, including diabetes management. This rapid uptake and integration of SNS into diabetes management is often occurring independent of healthcare professional involvement and therefore without an evidence-based assessment of its actual efficacy or accuracy as an adjunct treatment modality.

There are few published studies on the use of SNS in adolescent diabetes management, and many of those that have been published have tended to focus on the process and experience of integrating SNS into diabetes management rather than their impact on specific objective physiological or psychosocial outcome variables. Although this preliminary research suggests SNS to be a promising new intervention in the treatment of adolescents with T1DM, its actual efficacy, and the mechanisms through which any treatment benefits may occur, remains largely unknown. As such, there is a pressing need for research to evaluate the impact of SNS on standard objective outcome measures such as HbA1c, treatment compliance, knowledge and quality of life. In particular, future research studies need to employ designs that allow for the direct comparison of SNS to conventional approaches in the treatment of adolescent diabetes.

Chapter 4: Aims

4.1 Introduction

As has been outlined in the introductory chapters, considerable research exists documenting the difficulties of adherence in T1DM, particularly among adolescents. In addition, there is also significant evidence of the negative consequences, both acute and chronic, of non-adherence to the physiological and psychological wellbeing of adolescents. To date, research on interventions to increase adherence in adolescents have found, at best, only modest improvements in glycaemic control and quality of life.

Positive social support from parents and family has demonstrated a positive impact on the adherence behaviours of adolescents with T1DM and consequently on their wellbeing. Positive peer social support has also been found to impact positively on the adherence behaviours of adolescents with T1DM and can often extoll a larger influence on adolescents' adherence behaviours than parents. However, the influence of peers can also have a negative effect on adherence behaviours, particularly in situations where the adherence behaviours occur in the presence of peers. The influence of peer support from other adolescents with T1DM is unclear due to a lack of research in this area. Research in other chronic illnesses suggests that support from others with similar medical conditions can have a positive impact on adherence. However, this is generally not a naturally occurring form of social support due to the geographic dispersion of adolescents with T1DM, in that the majority of adolescents with T1DM will not know or be acquainted with another adolescent with T1DM in their everyday lives.

The diabetes healthcare team (DHCT) are another source of social support for adolescents with T1DM that impact on adherence behaviours. However, this is also an area that has been somewhat neglected in the research literature. Although primarily seen as a source of informational and instrumental support, the role of the DHCT also has the potential to be a significant source of emotional support that is often overlooked. Research on patient-centred communication in adolescents with T1DM, although sparse, has demonstrated that it has the potential to lead to better adherence behaviours.

The advent of social media has led to an increase in patients receiving and providing support around their medical conditions online. Of all forms of social media, SNS have seen the largest and fastest uptake and the widespread use of smartphones has extended the support that individuals can receive from SNS to a wide range of environments. Although more and more people are turning to SNS for support around their medical conditions, this is occurring largely without the involvement of healthcare professionals. Although there has been a significant lack of research on the effect of SNS on adolescents with T1DM, it has been suggested to represent a novel opportunity to better engage adolescents in their diabetes management.

4.2 Overview of the Intervention

This thesis aims to assess the potential of SNS as a medium to better engage adolescents with T1DM, and to examine the potential role of increased social support from the DHCT and peers with T1DM to increase glycaemic control and quality of life among the same population. A social media based intervention (SMBI) will be developed that will create supportive online relationships between participants and the

DHCT and between participants and T1DM peers, as an adjunct to standard clinical care. This SMBI will be designed so as to facilitate online patient-centred communication between participants and the DHCT and positive interaction between peers with T1DM. It will also be designed in such a way as to minimise the resource implications on the DHCT of engaging with the SMBI.

Providing participants with online access to the DHCT via the SMBI as an adjunct to clinical care will increase the amount of communication they have with the DHCT. As this communication will not be directed specifically at obtaining clinical information (this will occur at the standard clinic appointments), the opportunity for patient centred-communication will be increased leading to more positive relationships with the DHCT and increased self-efficacy and more positive illness perceptions. The increased patient centred-communication will also increase the autonomy support participants receive from the DHCT.

Providing adolescents with online access with T1DM peers via the SMBI will lead to increased perceptions of support from T1DM peers. It will also create a forum where they can discuss the experience of living with T1DM within a non-critical and supportive environment leading to increased self-efficacy and more positive illness perceptions. It is also envisioned that this contact will allow participants to become both support seekers and support providers around the emotional, cognitive and behaviour challenges of living with T1DM. Access to this type of social support, and being able to provide this kind of social support to others, will increase participants' self-efficacy and lead to more positive illness perceptions.

4.3 Intervention Model

It is envisioned that the SMBI, though targeting increasing the availability and utilisation of social support from the DHCT and T1DM, will increase three separate but related factors: perceptions of support from the DHCT and T1DM peers, diabetes self-efficacy and diabetes illness perceptions. It is hypothesised that positive shifts in each of these factors will lead to increased diabetes management responsibility and diabetes management adherence, resulting in improved glycaemic control and quality of life. Figure 4.1 highlights a graphical model of how the SMBI is hypothesised to lead to improved glycaemic control and quality of life.

4.4 Hypothesis

4.4.1 Primary Hypothesis

- The SMBI will lead to an improvement in glycaemic control.
- The SMBI will lead to an increase in quality of life for participants.

4.4.2 Secondary Hypothesis

- The SMBI will result in an increase in participants' perceptions of the social support they receive from the DHCT.
- The SMBI will result in an increase in participants' perceptions of the social support they receive from T1DM peers.
- The SMBI will result in participants having more positive illness perceptions.
- The SMBI will result in an increase in participants' diabetes self-efficacy.
- The SMBI will result in an increase in participants' diabetes responsibility.
- The SMBI will result in an increase in participants' diabetes management adherence.

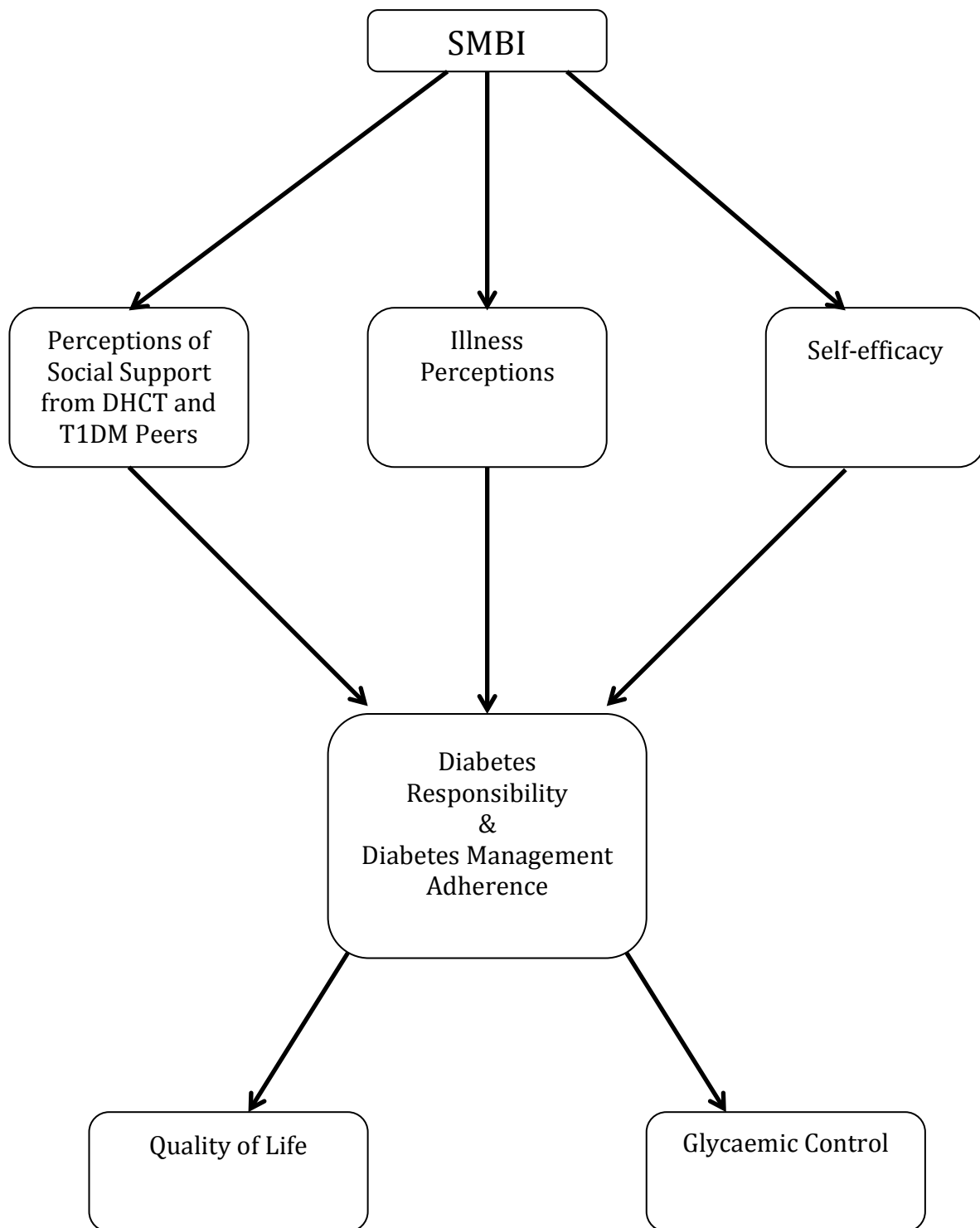


Figure 4.1 Model of the SMBI

Chapter 5: Pilot Study

5.1 Introduction

A pilot study was undertaken in order to explore the practicalities of using a SNS as a SMBI to support adolescents with T1DM. As the literature search did not identify any previous studies that had used a SNS as an intervention medium to support the management of adolescents with T1DM, there were no pre-existing interventions on which to base the intervention. This necessitated that the SMBI be designed from the ground up. As such, a pilot study was required to design the intervention and to evaluate its implementation and the experiences of adolescents using it. The pilot study was also an opportunity to explore the logistics of administration of the outcomes measures (i.e., HbA1c and questionnaire battery) that would be used in the main study, particularly with regard to administration duration, acceptability to participants and the practicalities of the continuity of repeated administration.

5.1.1 Aims. The aims of the pilot study were to:

1. Create a SMBI to support the management of adolescents with T1DM.
2. Evaluate the implementation of the SMBI. The specific aspects of the intervention that were evaluated were:
 - a. The DHCT's ability to use the SMBI.
 - b. Participants' engagement with the SMBI.
 - c. The usability of the SMBI for communication.
 - d. The confidentiality and security of using the SMBI.
 - e. The potential negative consequences on adolescents of using the SMBI.

3. Assess the usability of the outcome measures to be used in the main study.
4. Evaluate the participants' experiences of using the SMBI.

5.2 Method

5.2.1 Creation of the SMBI.

5.2.1.1 Choice of SNS. In order to create the SMBI a decision had to be made with regard to which SNS to utilise as the intervention medium and particularly, whether to utilise an existing generic SNS, such as Facebook, Twitter or Instagram, or to create a purpose-built SNS. Creating a specific purpose-built SNS would have had the advantage of allowing the functionality to be tailored to the specific needs of the intervention. It would also have allowed for the added security of being able to manage and store the information that is posted to the SNS. However, creation of a purpose built SNS would have been costly to setup and maintain, require a significant degree of technical expertise and, more importantly, may result in a significantly reduced uptake and level of activity, compared to more generic pre-existing SNS, as it would require participants to access an additional SNS to the one they commonly use. Also, as this SNS would be focused on diabetes related content, participants were likely to spend less time on it than one of the established generic SNS that have a broader user base and variety of content.

Using a generic SNS has the advantage of being easy to setup and maintain and require minimal to no technical expertise. More importantly, certain generic SNS's are likely to be already used by some of the participants. It was assumed that the likelihood of the participants engaging with the intervention would increase if they are already familiar with, and regularly use, the intervention medium. For our intervention, it was felt that engagement with the intervention was a primary concern

in deciding which SNS to utilise. For this reason, it was decided to use a generic SNS rather than custom build one. In terms of choice of generic SNS, popularity of the SNS was the key determinant in the decision-making process, as it was felt that a more popular SNS would facilitate better engagement.

At the time of creation of the SMBI, of the existing SNS, Facebook was the largest (94% of SNS users worldwide use Facebook) and one of the most visited websites on the Internet, and the most popular among the target demographic, adolescents aged 13 to 16 (Facebook, 2013; Socialbakers, 2013). Although use of an existing generic SNS (i.e., Facebook) meant that it was not possible to custom design features of the SNS to meet the needs of our intervention, the features already present in Facebook were deemed to suitable to the needs of the intervention (namely, the ability to create a readily accessible private online space where participants and the DHCT could interact in real-time).

5.2.1.2 Data Protection. A significant limitation of using a generic SNS over a purpose built one is the storage and security of the data contained in the SNS. Any communication between a patient and their healthcare provider in a professional capacity constitutes private medical information and as such is subject to data protection laws. Although such laws differ from territory to territory, they have at their core the protection of private medical information from being disseminated to unauthorised individuals and generally govern the storage and communication of such information. Historically such laws referred to physical files; however, the evolution of the Internet has changed the way in which information is disseminated, particularly with regard to its speed and reach, and the mass proliferation of social media has left

data protection legislation struggling to keep up with the pace at which new mediums of data communication and storage are emerging.

By using a SNS to communicate with a patient, even in private, a healthcare provider is essentially depositing private medical information on the SNS. This has significant implications for data protection legislation as the information posted to the SNS is stored on the servers of the SNS, which is beyond the control of the healthcare provider and therefore not subject to its data protection policies and procedures. In addition, the SNS may be based in a completely different jurisdiction and not subject to the laws of the jurisdiction in which the healthcare provider is located. Therefore, if using a SNS to communicate with a patient, the patient must be made completely aware that the information posted and stored on the SNS is not subject to the same rigours of data protection legislation as the rest of their private medical information. However, within some jurisdictions, certain aspects of data protection with regards to private medical information may be a statutory right that cannot be overridden by informed consent and it may not be possible to utilise SNS within such clinical settings and also be compliant with specific aspects of data protection legislation.

In the initial stages of creating the SMBI, management of the hospital were consulted with and the issues in relation to data protection were highlighted to them. Management agreed for the study to be undertaken provided that parents of the participants were informed of the issues in relation to data protection from the outset. To ensure parents were completely aware of the issues in relation to data protection, they were provided with a disclaimer that explained the issues to them (see Appendix 2). If after reading the disclaimer they were still happy for their son or daughter to engage in the SMBI they signed the disclaimer and returned it to the researcher.

5.2.1.3 Privacy and Confidentiality. In creating the SMBI significant attention was given to the privacy and confidentiality of the information posted by participants. SNS are based around sharing personal content, and the intervention is based around participants sharing personal diabetes related information. However, participants may be uncomfortable with their peers or other third parties being aware of certain aspects of their diabetes management. As such, the possibility of engaging in the intervention exposing aspects of their diabetes management may limit their uptake or engagement with the intervention. To address this it was necessary to ensure that the online space created for the intervention (i.e., the Facebook group page) was not going to be accessible, or even visible, to anyone other than participants and members of the DHCT.

To ensure the privacy and confidentiality of the SNS, it was decided to create “secret” Facebook groups for the intervention, as opposed to “open” or “closed” Facebook groups. In an “open” Facebook group all Facebook users have complete access to the group. In other words, any Facebook user can easily find the group page through a search for its name or on the personal profile page of group members, they can see the membership of the group, they can post content to the group page and they can see content posted to the group page. In a “closed” Facebook group any Facebook users can easily find the group and see its membership but only members of the group can post content to the group page or see content posted to the group page. A “secret” Facebook group is similar to a “closed” group in that only group members can post content to the group page and see content posted to the group page, but differs in that the group and its membership is only visible to the members of that group (i.e., it will not show up in a search or the personal profile pages of group members). In other words, in a “secret” group, existence, membership and content of

the group are only visible to other group members. Such a privacy setup ensures that membership of the group and the personal content shared by the group members is not visible to non-members of the group, such as participants' Facebook friends.

Obviously for such privacy controls to be effective their needs to oversight over group membership. Group membership in a Facebook group is controlled by the group administrator. By default, the administrator is the person who initially creates the group and as they populate the group with additional members, they can create additional administrators. Only a group administrator can add new members to a group or adjust the privacy settings of a group. To ensure control over membership and the privacy settings of the Facebook groups it was decided that the researcher would undertake the role of group administrator for all the Facebook groups created. During the initial *in vivo* group session, the importance of ensuring that third parties did not get access to their personal Facebook accounts was highlighted.

As the SMBI required the DHCT members' presence on the Facebook group page in addition to participants, attention was also given to issues of privacy that might arise as a result of participants and members of the DHCT sharing the same social media space. "Friending" is a term that refers to the process of linking one's personal Facebook account to the personal account of another Facebook user and is a core component in the proliferation of Facebook. It is done by mutual acceptance, usually, but not always, by acquaintances, and allows individuals to view the content of each other's Facebook accounts (e.g., photos, conversations, etc.). Linking a DHCT member's Facebook account to a participant's Facebook account is potentially problematic, as neither may be comfortable with the content of their personal Facebook accounts being accessible to the other. In addition, having access to the content of a participant's Facebook account may put the DHCT member in position

where they become aware that the participant is engaged in certain risk-taking behaviours (e.g., they view pictures of the participant engaged in alcohol use), potentially obliging the DHCT member to bring this to the attention of the participant's parents. To avoid the possibility of participants or members of the DHCT feeling that their privacy is being compromised in this manner, it was decided that participants would be informed during the first *in vivo* group session that it would not be possible to 'Friend' members of the DHCT and any such requests would not be accepted.

5.2.1.4 Using a Facebook Group Page. In order to access or use Facebook an individual must create a Facebook account/profile by signing up to Facebook. Once signed up, the individual's account/profile, which is essentially a dynamic webpage, becomes visible to other Facebook users. The amount of detail from an individual's profile that is visible to other Facebook users is controlled by the individual through the privacy settings of their Facebook account. Once an individual has a Facebook account/profile they are free to join or create Facebook groups.

A Facebook group is dynamic webpage similar to Facebook profile page that has been created by a user around a particular theme or interest and allows members of the group to interact and share content around the particular theme or interest. It was decided that a Facebook group would be used as the online space in which the intervention would be undertaken. The members of the DHCT and the participants undergoing the intervention would populate this Facebook group and it would provide the forum for communication between them.

5.2.1.5 DHCT Training. One week prior to the commencement of the pilot study, the DHCT attended a once off, hour-long, group-based education session facilitated by the researcher that aimed at familiarising the DHCT with Facebook in general and how to use it specifically for the intervention. The topics covered in this education session were:

- An overview of Facebook.
- Privacy and security on Facebook.
- Facebook personal profiles.
- Facebook groups.
- Types of communication on Facebook.
- Conversation threads.
- Posting content on Facebook.

It was explained to the DHCT that the intervention was based around supporting participants' diabetes management and as such the content and communication topics that they would be engaging participants with on the group page would be diabetes related. However, the researcher directed that in order to allow participants to become comfortable using the group page, the DHCT would refrain from initiating diabetes related communications or content until after participants' second *in vivo* session.

All members of the multidisciplinary DHCT attended this training session. It was explained that participants would be encouraged to communicate with the DHCT and each other via the Facebook group page. The role of the DHCT on the Facebook group page was to:

- Respond to any communications from the participants.

- Encourage communication with and between participants on the group page by engaging them in conversation.
- Correct any diabetes misinformation that was posted to the group page by participants.
- Comment on posts to the group page made by participants.
- Post content to the group page that thought think might be of interest to the participants, both diabetes related, and non-diabetes related.

After the DHCT training session, a test “secret” Facebook group was created that was populated only by the members of the DHCT. The DHCT were encouraged to use this test page to practice what was learned in the DHCT training session and to become familiar with the general navigation of Facebook. Following this the researcher met with each member of the DHCT separately to ensure that they were comfortable using Facebook and to answer any questions they had.

Members of the DHCT who already had Facebook accounts were given the choice of either using their pre-existing accounts or else having a new account created specifically for the intervention. If they choose to use a pre-existing Facebook account they were instructed on how to adjust the privacy settings of their account to ensure that participants did not have access to any information from their personal profiles (except their name and profile picture which is always viewable to all users of Facebook). For any member of the DHCT that required a new Facebook account to be created, this was undertaken by the researcher in conjunction with the DHCT member during the DHCT training session. The privacy settings of these newly created accounts were adjusted from the outset to ensure participants did not have access to any information from the personal profiles of MDT members.

As well as access to the Facebook group page from laptop computers in their offices, DHCT members were also free to check the Facebook group page from their own personal Internet enabled devices (e.g., smartphones, home computers, etc.) whenever they wished. It was explained to the DHCT that as the intervention was intended not to place significant demand on their resources, it was up to each member of the DHCT to decide how much time they spent on the Facebook group page and that the only expectation was that they replied to any communications from the participants that were directed specifically towards them.

5.2.1.6 In Vivo Group Sessions. Five *in vivo* group-based sessions were created to be delivered over a three-month period. The time interval between *in vivo* sessions increased from two weeks between the first and second session, to three weeks between the second and third sessions and the third and fourth sessions, to four weeks between the fourth and fifth sessions. It was decided to gradually increase the interval between *in vivo* sessions as a way of phasing them out and encouraging communication to move exclusively to the Facebook group.

The purpose of initial *in vivo* group-based session was to introduce and explain the Facebook group to participants and then and to populate the group with the participants' Facebook profiles. The primary purpose of the four subsequent *in vivo* group-based sessions was to augment the online relations that were developing between the participants by allowing them to interact with one another. These four subsequent sessions also allowed participants to give feedback about the intervention to the researcher. All *in vivo* sessions were facilitated by the researcher and run according to a pre-structured format that set out what was to be covered in each session (see Appendix 3).

All *in vivo* sessions lasted one hour and occurred in the training room in the Diabetes Centre. Attendance at the first *in vivo* sessions was mandatory and participants that did not attend for this session were excluded from the study. Attendance at the four subsequent *in vivo* group sessions was not mandatory but was encouraged.

5.2.2 Participants

5.2.2.1 Ethics. Ethical approval for the study was obtained from Our Lady's Children's Hospital, Crumlin's Research Ethics Committee (Appendix 1) and Trinity College Dublin's School of Psychology Research Ethics Committee. As well as separate information leaflets being given to participants and their parents (Appendix 2), information evenings were held for parents of participants where the study was explained to them in more detail and they were given the opportunity to ask questions of the researcher. All participants and their parents provided written informed assent (adolescents) and consent (parents) prior to study inclusion (Appendix 2).

5.2.2.2 Participant Eligibility. All adolescents aged 16 or older on the 6th February 2013 who were attending the diabetes clinic at the hospital and resided within easy commuting distance to the hospital (i.e., counties Dublin, Wicklow, Kildare and Meath) were eligible to take part in the pilot study. Even though the intervention was being designed for a wider age (i.e., ages 13 to 16), it was decided to only select 16-year-old participants for the pilot study, as these participants were likely to be ineligible for the main study by the time it commenced, having turned 17, and therefore this would not reduce the potential population pool for the main study. Selecting only 16-year-old participants for the pilot study also ensured that the pilot

group was age-matched. Adolescents were excluded from the study if they had been diagnosed with Type 1 Diabetes Mellitus within twelve months of recruitment or if they had a significant comorbid medical condition that required intensive management (e.g., cystic fibrosis). For the purposes of selecting suitable participants, potential participants electronic patient records were analysed to determine their age, duration of diabetes, geographic area in which they resided and presence of a significant co-morbid medical condition.

5.2.2.3 Participant Selection and Recruitment. Parent and adolescent information leaflets (Appendix 2) that explained what would be involved in taking part in the study were posted to the parents of all eligible participants (n = 38). The parent information leaflet also informed parents that they would be receiving a follow-up telephone call from the researcher to answer any questions they had and to ascertain if their son/daughter wanted to take part in the study. These follow-up telephone calls were undertaken by the researcher within two weeks of the information leaflets being posted.

Of the 38 parents of eligible participants who were contacted about the study, 20 agreed for their son/daughter to take part. These parents were then informed that the intervention would be commencing the following month and that they would be contacted again by telephone in the week preceding the commencement of the intervention and informed if their son/daughter had been allocated to the treatment or comparison group. It was explained that if their son/daughter was allocated to the comparison group, they would be asked to continue to attend the regular diabetes clinics as per normal. However, during their regular diabetes clinics they would be

met by the researcher and asked to complete separate adolescent and parent questionnaire batteries.

If their son/daughter was allocated to the treatment group, they were given the dates and times for the five hour-long *in vivo* group-based sessions that would be occurring over a twelve-week period and formed part of the intervention. Although it was hoped their son/daughter would be able to attend all five *in vivo* sessions, the researcher understood that this might not be possible due to other commitments. However, if their son/daughter did not attend their first *in vivo* session they would have to drop out of the study, as it would be during this initial *in vivo* session that the SNS group page for their son/daughter's intervention group would be created, populated by the participants in their intervention group and then group membership locked out, preventing any further participants joining that intervention group.

Parents were asked if they had a preference for a particular day of the week or time of day for the *in vivo* sessions to occur should their son/daughter be allocated to the treatment group, and the researcher noted this. It was explained that the determination of the day of the week and time of day for the *in vivo* sessions to occur would be based on a collation of parents' preferences.

5.2.2.4 Assignment to Treatment and Comparison Groups. During the week before the first *in vivo* session, the names of the 20 participants were listed in alphabetical order by surname. Starting with the first name on the list, the parents of each eligible participant were contacted in turn by telephone and informed of the date and time of the first *in vivo* session (all *in vivo* sessions were held on Wednesdays at 3:30pm, as this was the most common time and date preference among parents). If the participant was able to attend the first *in vivo* session they were allocated to the

treatment group; however, if the participant was unable to attend the first *in vivo* session (e.g., if it clashed with an extra-curricular activity or holiday) they were allocated to the comparison group. This procedure was repeated until 10 participants had been placed into the treatment group, with the remaining participants being placed in the comparison group, leaving 10 participants each in the treatment and comparison groups. Four participants in the treatment group did not show for the first *in vivo* session and were excluded from the study, leaving six participants in the treatment group at the commencement of the pilot study.

5.2.3 Materials. Although each member of the DHCT had access to a computer terminal at their desk, it was not possible to access Facebook from these terminals as the hospital computer network blocked the Facebook webpage over concerns that access to it could compromise the security of the network. To overcome this, each member of the DHCT was provided with an additional computer terminal at their desk that was independent of the hospital computer network and was able to access the Internet, and the Facebook webpage, via a Wi-Fi Internet dongle. DHCT members were able to use these terminals at their desks to check the pilot group Facebook page whenever they wished.

All *in vivo* Group-based sessions occurred in the training room in the diabetes unit at the hospital, which is where participants also attended their regular diabetes clinic. This room was equipped with an overhead projector connected to a computer terminal that had Internet access via the Wi-Fi dongle. This was used to project the Facebook group page to a screen during the *in vivo* sessions. Two laptop computers, that also had Internet access via the Wi-Fi dongle, were made available to participants

during the initial *in vivo* session to enable them to log into their personal Facebook accounts and join the Facebook group.

5.2.4 Measures

5.2.4.1 Glycaemic Control. The primary outcome measure for the study was glycated haemoglobin (HbA1c), which was measured by means of a finger-prick blood sample obtained by the Diabetes Clinical Nurse Specialist who used a Siemens/Bayer DCA 2000+ Analyzer. Participants used their own lancets to extract a finger prick blood sample. If they did not have their own lancet they were provided with a disposable lancet. Finger prick blood samples were placed onto Siemens/Bayer DCA 2000+ Analyzer reagent cartridges, which were then inserted into the Siemens/Bayer DCA 2000+ Analyzer for analysis.

5.2.4.2 Quality of Life. Both general quality of life and diabetes specific quality of life were measured for all participants using the PedsQL – Generic Core – Version 4.0 (Varni, Seid, & Kurtin, 2001) and the PedsQL – Diabetes Module – Version 3.0 (Varni et al., 2003) respectively. Equivalent forms of both of these questionnaires were also completed by participants’ parents. The PedsQL – Generic Core is a twenty-three item questionnaire that yields four dimension scores (physical functioning, 8 items; emotional functioning, 5 items; social functioning, 5 items; and school functioning, 5 items), a psychosocial health summary score (15 items), a physical health summary score (8 items) and a total score. High scores on the PedsQL – Generic Core indicate better health related quality of life. The PedsQL – Diabetes Module is a twenty-eight item questionnaire that yields five dimension scores (diabetes, 11 items; treatment I, 4 items; treatment II, 7 items; worry, 3 items

and communication, 3 items) and a total score. High scores on the PedsQL – Diabetes Module indicate lower problems in this area. Only the total scores of the PedsQL scales were included in the analysis.

The PedsQL – Generic Core has been shown in the literature to have good construct validity and reliability, and as such to be a valid and reliable measure for assessing adolescent’s health-related quality of life (Kaartina et al., 2015). Another study reviewed nine validated generic and diabetes specific health-related quality of life questionnaires suitable for use in adolescents with Type 1 diabetes. The authors reported the PedsQL to be one of the most suitable measures in this population, with the PedsQL – Diabetes Module reported to correlate strongly with the PedsQL – Generic Core, thus demonstrating good construct validity (de Wit, Delemarre-van de Waal, Pouwer, Gemke, & Snoek, 2007).

5.2.4.3 DHCT Support. Participants’ perceptions of the degree of autonomy support they received from the DHCT were assessed using the Healthcare Climate Questionnaire (HCCQ) (Williams, Freedman, & Deci, 1998). An equivalent form of this questionnaire was also administered to participants’ parents to assess their perceptions of autonomy support from the DHCT. This questionnaire contains fifteen items on a seven point Likert scale and yields an overall total score, where higher scores represent a higher level of perceived autonomy support.

The HCCQ was developed and validated in an adult population attempting improved glucose control and weight-loss and has been found to be a reliable measure, with a Cronbach’s alpha of .8 and .96, respectively (Williams, Grow, Freedman, Ryan, & Deci, 1996). Cronbach’s α values of .70 and greater are considered acceptable (Streiner, 2003).

5.2.4.4 Diabetes Peer Support. T1DM peer support was measured by a set of seventeen questions that asked participants to rate on a seven-point Likert scale the degree to which they agreed with statements about the support provided by T1DM peers (see Appendix 4). An average of the seventeen Likert responses (after two items were reversed scored) was then obtained to get an overall measure of participants' perceptions of the level of support they receive from peers with T1DM. In the present sample, Cronbach's alpha was .986 at baseline for the T1DM peer support questionnaire.

5.2.4.5 Illness Perceptions. Participants' illness perceptions were measured using the Brief Illness Perceptions Questionnaire (BIPQ). The BIPQ is a questionnaire that assesses the cognitive and emotional representations of illness (Broadbent, Petrie, Main, & Weinman, 2006). This questionnaire contains eight items on an eleven point Likert scale. Each item assesses a different domain of illness perceptions (Consequences, Timeline, Personal Control, Treatment Control, Identity, Concern, Understanding and Emotional response). Only the Personal Control, Identity, Coherence and Emotional Representation subscales were included in the analysis, as the other subscales were not relevant to the theoretical model. A systematic review and meta-analysis of the BIPQ in 2015 that included 188 papers noted that it had good test-retest reliability and concluded that each subscale demonstrated sensitivity to change after interventions in randomised controlled trials (Broadbent et al., 2015).

5.2.4.6 Self-efficacy. Participants' self-efficacy regarding diabetes management was measured using the Self-Efficacy for Diabetes Scale (SED)

(Grossman, Brink, & Hauser, 1987). This questionnaire contains thirty-two items on a seven-point Likert scale. It yields a total self-efficacy score as well as scores for diabetes specific self-efficacy (e.g., “Change the amount of time I get insulin when I get a lot of extra exercise”, 22 items), medical situations self-efficacy (e.g., “Argue with my doctor if I felt he/she were not being fair”, 4 items) and general situations self-efficacy (e.g., “Take responsibility for getting my homework and chores done”, 6 items). Higher scores on the SED reflect greater self-efficacy or more self-confidence. Only the total self-efficacy score was included in the analysis. Research reviewing self-efficacy measurement instruments in youth with T1DM stated most studies using the SED to report Cronbach’s α values ranging from .84 to .94, indicating a high internal consistency (Rasbach, Jenkins, & Laffel, 2015).

5.2.4.7 Diabetes Management Responsibility. The Diabetes Family Responsibility Questionnaire (DFRQ) (Anderson, Auslander, Jung, Miller, & Santiago, 1990) measured who takes responsibility for different diabetes management tasks (e.g., insulin adjustment, making clinic appointments, etc.). An equivalent form of this questionnaire was also administered to participants’ parents. This questionnaire contains seventeen items (e.g., “Deciding what to eat at meals or snacks”) relating to different diabetes management tasks. For each item the responder indicates whether responsibility for the task is with the child (score of 1), the parent (score of 3) or equally shared (score of 2). It yields one overall score that indicates where the majority of responsibility lies. Scores range from 17 (child has complete responsibility) to 51 (Parent has complete responsibility), with a score of 34 indicating equal sharing of responsibilities. Acceptable internal consistency and test-

retest reliability have been previously reported for this measure (Anderson et al., 1990).

5.2.4.8 Diabetes Management Adherence. Participants' perceptions of the degree to which they adhere to recommendations for diabetes care were measured using the Self-Care Inventory (SCI) (La Greca, 2004). This questionnaire contains fourteen items on a five point Likert scale. It yields an overall adherence score as well as four dimension scores (blood glucose regulation, 3 items; insulin and food regulation, 3 items; exercise, 2 items; and emergency precautions, 2 items). Higher scores represent higher patient perceptions of the degree to which they adhere to recommendations for diabetes care. Only the overall adherence score was included in the analysis. The measure has demonstrated internal consistency in the literature ($\alpha = .80$ or higher) (La Greca, 2004; Lewin et al., 2009).

5.2.5 Procedure

5.2.5.1 Assessment Protocol. For participants in the treatment group, baseline measures were recorded at the start of the initial *in vivo* session. After all participants had arrived in the education room in which the *in vivo* session was taking place, the diabetes clinical nurse specialist obtained from each participant a finger prick blood sample that was placed onto a Siemens/Bayer DCA 2000+ Analyzer reagent cartridge. This cartridge was taken to a separate clinic room, inserted into the Siemens/Bayer DCA 2000+ Analyzer and an HbA1c reading obtained. Participants were not informed of their HbA1c readings. After the clinical nurse specialist had left the room, the researcher handed each participant a copy of the adolescent questionnaire battery and a pen. Participants were asked to complete the questionnaire battery

For parents of participants in the treatment group, the parent questionnaire battery was administered during the parent information session that occurred the day before the initial *in vivo* session. Parents were handed the parent questionnaire battery and a pen at the start of the session and asked to complete it. If both parents were present at the parent information session, the researcher asked that the parent who usually accompanies the participant to their regular diabetes clinic complete the parent questionnaire battery.

For participants in the comparison group, both adolescent and parent questionnaire batteries were administered during the participant's normal diabetes clinic visit. Upon arrival in the waiting room of the diabetes clinic, the researcher approached the participant and their parent and explained that they were hoping to administer the questionnaire batteries they had discussed previously on the telephone with the parent. The participant and their parent were then handed the adolescent and parent questionnaire batteries, respectively, along with pens, and asked to complete them separately, informing the researcher when they were complete. The researcher collected the test batteries once they were complete and thanked the participant and their parent for completing them. After completion of the questionnaire batteries, the diabetes clinical nurse specialist brought the participant into a clinic room and obtained a HbA1c reading by means of a finger prick blood sample using a Siemens/Bayer DCA 2000+ Analyzer and a Siemens/Bayer DCA 2000+ Analyzer reagent cartridge, as was normal clinical practice in the diabetes clinic.

5.2.5.2 Timing of Assessments. Baseline outcomes measures for participants in the treatment group were obtained over the course of two consecutive days (i.e., day one for the parent questionnaire battery and day two for the HbA1c reading and

the adolescent questionnaire battery) at the commencement of the intervention. These measures were repeated again three to four months later during participants' standard diabetes clinic.

Baseline outcomes measures for participants in the comparison condition were obtained at their first clinic visit to occur after commencement of the intervention. As clinic visits occurred every three to four months, this created a three to four month window during which the baseline measures for the comparison group were obtained. These measures were repeated once more at their subsequent clinic visit, three to four months later.

5.2.5.3 Parent Group Information Session. The day before the first *in vivo* group-based session with participants a group-based information session was held with the parents of participants in the intervention group. The purpose of this session was to explain to the parents:

- What was involved in the intervention
- The goals of the intervention
- Issues around privacy, confidentiality and security of data storage for participants engaging in the intervention.
- Potential risks for participants of using Facebook (i.e., cyberbullying, inappropriate exposures and inappropriate disclosures)

It was explained that the Facebook group was a tool to facilitate communication between the participants and the DHCT, as well as each other, and should be not be used by parents to communicate with the DHCT. Parents were instructed that standard clinical care would continue as per normal for their son/daughter and that contacting the DHCT for diabetes related emergencies was not

to be done via the Facebook group. It was also explained that each participant would need a Facebook account to take part in the intervention and that if their son/daughter didn't have a Facebook account they would have to set one up prior to the first *in vivo* session.

5.2.5.4 Creating the Facebook Group Page. For the pilot study intervention, the researcher created a Facebook group an hour before the initial *in vivo* session and gave it an arbitrary name. When first created, this Facebook group's privacy was set to "closed group" rather than "secret group", as the only users that can be added to a "secret group" are users whose profiles are already linked to the administrator's profile via "Friending", which would not be the case for the participants' profiles. Once the group was created the researcher populated the group with the members of the DHCT (i.e., three diabetes clinical nurse specialists, the paediatric diabetologist, the senior dietitian and the senior clinic psychologist) by sending a link to each one of their Facebook profiles inviting them to join the group, which they had already been primed to accept.

5.2.5.5 Adolescent In Vivo Group Sessions. Although ten participants had agreed to attend the first *in vivo* group session, only six attended on the day. The four who didn't attend all contacted the researcher prior to the session to explain that they would not be attending because, since agreeing to attend, they had become otherwise engaged.

At the start of the first *in vivo* group session participants were introduced to each other, with each adolescent stating their name, what year of school they were in, how long they had diabetes and the insulin regime they were on. Following this the

researcher explained to participants that the purpose of the intervention was to create a secret group on Facebook where participants could communicate with one another and the DHCT around diabetes or any other topic of their interest. The ground rules for using the Facebook group were then discussed with participants.

The purpose of the ground rules was to maintain the confidentiality of the group and to prevent cyberbullying, inappropriate exposures and inappropriate disclosures.

These ground rules were:

- Participants were to respect the privacy of other group members posts to the group page.
- Participants were not to allow third parties (e.g., friends) access to the group page.
- Participants were not to engage in any negative comment towards another group member.
- Participants were not were not to post content to the page that might be deemed as offensive or inappropriate (e.g., racist remarks, pornography, etc.).
- Participants were not to post personal information to the page that is highly sensitive or inappropriate within the group context (e.g., disclosures of parental marital difficulties).

It was explained to participants that the researcher would act as the moderator of the page. If content that was deemed unsuitable by the moderator were posted to the page, it would be removed and, if necessary, participants' parents would be informed. If the moderator felt that any participant was engaging in negative comments towards another participant they would be removed from the Facebook group page and the parents of both participants informed. Any participant that felt that they were being exposed to negative comment from another participant was encouraged to report this

to the moderator. Any participant who knowingly allowed access to the group page to third parties or disclosed private content from the group page to third parties would be removed from the group. It was also explained to participants that the group page was not to be used for emergency communications with the diabetes team and that in the case of emergencies they were to contact the diabetes team by phone as per normal.

Following an explanation of the ground rules, the researcher outlined to participants how the Facebook group page would work, while the Facebook group page, which had been created an hour before the group started and populated with the DHCT, was shown on the overhead projector. Participants were then given an opportunity to log into their personal Facebook accounts (via their own personal smartphones or else via laptop computers available in the training room) and join the group. After all participants had requested to join the group page, the researcher accepted all the requests and changed the privacy settings of the group page from a “closed group” to a “secret group”.

After all participants had joined the Facebook group and the researcher had changed the group’s privacy settings from “closed group” to “secret group”, the researcher highlighted to participants the membership of the group (i.e., the members of the DHCT and the participants themselves) and the fact that the existence of the group, its membership and the content posted to the group was only visible to the group members. The researcher then demonstrated four key operations that could be undertaken by participants on the group page:

- How to post information to the group page
- How to ask a question to the entire group
- How to direct a question to specific members of the group

- How to join a conversation on the group page

After demonstrating the four key operations, the researcher explained to participants that they were free to post whatever they liked to the group page so long as it didn't violate the ground rules set out at the start of the session. Participants were directed to become comfortable with posting to, and communicating via, the group page over the subsequent two-week interval and that their thoughts on the page would be discussed at the second *in vivo* session in two weeks. Participants were then thanked for attending the session and the session ended.

Each of the four subsequent *in vivo* sessions was based around developing the relationships among participants by facilitating them to communicate with one another in a non-virtual environment. All four sessions were loosely structured to encourage participants to talk about diabetes. The researcher facilitated discussion around what had been posted on the group page over the interval since the previous *in vivo* session. Participants were encouraged to talk about their views about the content that had been posted by the DHCT (e.g., online articles about novel developments in diabetes management) and to give suggestions as to the sort of content they would like to see posted by the DHCT. Conversations often deviated into non-diabetes or non-intervention based topics (e.g., participants' views on school, pop stars, etc.) and this was facilitated by the researcher, as it was felt to support the development of relationships between participants.

At the end of the final *in vivo* session, the researcher explained to participants that although there would be no further *in vivo* sessions, the Facebook group page would be maintained and that they could continue to communicate with the DHCT and each other via the group page. The ground rules that had been outlined during the

first *in vivo* session were reiterated and it was explained that the researcher would be continuing to moderate the page.

5.2.5.6 Qualitative Interviews with Participants. After the collection of follow-up outcome measures, all six participants in the treatment group were asked if they would meet with the researcher to discuss their experiences of using the Facebook group and all six agreed that they would. Although it was initially intended to interview all the participants together, it was not possible to schedule a time for interview when all six participants were available. Two participants were able to come at the same time and were interviewed together, two other participants came in at separate times to be interviewed and the other two participants were unable to make themselves available for interview. The interviews were conducted with the researcher and used a semi-structured interview format (see Appendix 6).

5.2.6 Analysis

5.2.6.1 Approach to Implementation and Process Analysis. The implementation of the SMBI and its process of delivery were analysed by observing the use of the intervention by participants and the DHCT over a six-month period. During this period the researcher observed all communications that occurred on the Facebook group page. The researcher also made himself available to the DHCT, participants and participants' parents over the same period for on-going feedback in relation to the implementation of the intervention.

The DHCT's ability to use the SMBI was analysed through observations of their engagement with the Facebook group page. In particular, attention was paid to their adherence to the process of the intervention, as set out in the DHCT training

session, and their responsiveness to online engagements from the participants. The participants' engagement with the SMBI was analysed through observations of their use of the Facebook group page, with attention being paid to the types of information they posted to the page and their frequency of posting.

The usability of the SMBI for communication was analysed by observing the types of communication posted to the Facebook group page by both participants and the DHCT. Observation was focused on whether participants were able to use the page to seek support around their diabetes management from the DHCT and from the other participants. Observation was also focused on the ability of the DHCT to effectively communicate support to participants.

The confidentiality and security of the SMBI was analysed by monitoring the number of security and confidentiality breaches, suspected breaches or potential breaches that occurred over the course of the six-month observation period. The frequency of these were gathered from direct observations of the Facebook group page, as well as reports from the DHCT, participants and participants' parents.

The potential harmful effects on adolescents of engaging in the SMBI were analysed by monitoring the incidents of cyberbullying, inappropriate exposure and inappropriate disclosures that occurred over the six-month observation period. Participants and their parents were informed at the outset to alert the researcher if they suspected that any incidents of cyberbullying, inappropriate exposure and inappropriate disclosures had occurred on the Facebook group page, or as a result of use of the page. The researcher also monitored all communications on the Facebook page for any signs that engagement with the intervention was having a potential harmful effect on any of the participants.

5.2.6.2 Approach to Qualitative Analysis. Qualitative analysis of interviews with participants was used to evaluate participants' experience of the intervention. The focus of the qualitative analysis was to explore if participants found the intervention to be a positive experience and if they found it to be beneficial to their diabetes management. A thematic approach, which is a method for identifying, analysing, and reporting patterns (themes) within qualitative data, was used for the qualitative analysis. Although, there is no universally accepted approach to thematic analysis, the structured approach outlined by Braun and Clarke (2006) was utilised in the present analysis. This approach was selected because it emphasises the active selection of themes, as opposed to passively discovering emerging themes residing in the data, which was felt to better meet the needs of the research question.

The audio recordings of the interviews with the participants were transcribed verbatim by the researcher and then rechecked against the original audio recordings for accuracy. Following this, repeated active reading of the interview transcripts was undertaken, with any emerging patterns or themes noted. From these emerging patterns and themes, a list of ideas about what was in the data was generated. The entire raw data set (i.e., the interview transcripts) was then manually coded by copying individual extracts from the data onto a separate document and then collating the individual extracts into non-mutually exclusive codes (i.e., the most basic meaningful groupings of data extracts). These codes were then sorted into potential themes in a separate document, collating all the relevant coded data extracts within the identified themes. From here the potential relationships between different codes and themes were explored, allowing for the development of different levels of themes (i.e., main themes and sub-themes).

The collated extracts for each theme and sub-theme were reread to consider if they appeared to form a coherent pattern for that theme and if not some extracts were discarded or the theme reworked. These themes and sub-themes were then further refined through, if necessary, collapsing themes into each other, breaking themes into separate themes and discarding themes. From this an overall thematic map was constructed. At this point the transcripts were reread to determine if the identified themes accurately reflected the data set and to code any additional themes that were missed during the earlier coding stages. The overall thematic map was then appraised and the coding further reviewed and refined if necessary until a satisfactory overall thematic map was constructed. Once a satisfactory overall thematic map was created the themes and sub-themes were defined and described in more detail. From here an overall narrative of the data to address the research question was created.

5.3 Results

5.3.1 Implementation and Process of Delivery

5.3.1.1 DHCT's Ability to use the SMBI. The DHCT's first experience of using the SMBI was in the week prior to participants' first *in vivo* session, after they had undertaken the DHCT training on using the SMBI. During this test week the researcher observed all members of the DHCT to use the page appropriately and as intended without difficulty. Of the six members of the DHCT who took part in the intervention and engaged with the SMBI, only two, the psychologist and the dietitian, already had a personal Facebook account/profile or had previously used Facebook.

When the intervention Facebook group commenced, the DHCT members responded appropriately to the communications from participants. Participants directed communications to members of the DHCT in private messages, which were

not visible to the other members of the Facebook group, or openly on the group page, and therefore visible to all members of the group. The DHCT were observed to respond appropriately to all communications from participants. Although DHCT members responded promptly (i.e., within one working day) to most communications from participants, occasionally the researcher had to alert DHCT members to communications from participants that had not been responded to. These included communications directed specifically at particular members of the DHCT and communications directed at the DHCT in general (e.g. “Can I put my insulin in the x-ray machine at the airport”).

Some members of the DHCT communicated with participants outside of work hours on the Facebook page via home computers or personal smartphone devices on which they had logged into their Facebook accounts. Although the DHCT had been informed during the DHCT training session that they were not expected to engage with participants online outside of work hours, some DHCT members reported feeling pressured to do so, as participants were waiting on responses to questions they had asked of them. They further explained that they did not always get to respond to participants during working hours and so ended up doing it outside of work hours.

During the pilot study an incident occurred where a participant communicated privately to DHCT member outside of work hours via the Facebook group that they were witnessing their parents having an argument and were upset by this. Had such a communication occurred via email or telephone conversation, which are only available to DHCT members during working hours, the DHCT member would have discussed the communication with a colleague and contacted social services if necessary, as is the standard procedure with any communications of this nature. However, because the communication was received outside of work hours, the DHCT

member did not have access to their work colleagues in responding to the communication, and as such reported feeling very vulnerable in their decision-making. The DHCT member reported that as a result of this incident they felt pressure to check the group page outside of work hours in case participants were communicating distress to them and expecting an immediate answer.

During the DHCT training sessions, members of the DHCT were encouraged to post content, such as diabetes related articles, videos and website links, to the Facebook group page as a means of facilitating interaction and generating discussion among participants. During the intervention all members of the DHCT were observed to spontaneously post content to the Facebook group page. However, the frequency of their postings of content decreased significantly after the first week. In discussion with the researcher, DHCT members identified the sourcing of appropriate content as the biggest barrier to them regularly posting content to the Facebook group page. They explained that they were not readily aware of appropriate content that could be posted to the Facebook group page and did not have the time to search the Internet for such content. They suggested that having appropriate content provided to them would be much more practical and increase the frequency with which they posted content to the page.

DHCT members reported that having to access Facebook through a computer terminal at their desk also impeded their use of the intervention as it prevented them for accessing it in other areas of the diabetes clinic. Also, as access was through a different computer terminal to the one they used for all other computer based work tasks, each time they wanted to check the Facebook group they had to log into this other computer, which they found prohibitively time-consuming. DHCT members who accessed the Facebook group page through their smartphones reported that as

their access was more straight forward (i.e. their Facebook account was always logged in on their smartphone), they didn't have these difficulties and as such were more likely to check the Facebook group page, particularly during work hours.

5.3.1.2 Participants' Engagement with the SMBI. After the first *in vivo* group-based session participants were encouraged to post whatever they wanted to the group page and to communicate with one another and the DHCT via the group page. The DHCT had been instructed not to initiate diabetes related communication or content posting until after the second *in vivo* session in order to allow participants to become comfortable using the group page. As such, during the time between the first and second *in vivo* sessions the DHCT posted generic content, such as popular music videos, and attempted to engage with participants around their areas of interest, such as asking them questions about sports their interests.

In the interval between the first and second *in vivo* sessions, participants made very few spontaneous posts to the group page and some participants made no spontaneous posts at all. They also did not initiate communication with the DHCT or one another. Participants did respond to questions that were directed specifically at them by the DHCT (e.g., "Adrian, what sports do you play in school?") but tended to give minimalist answers and generally didn't attempt to engage with the conversation. In general, the level of engagement with the SMBI form participants during the interval between the first and second *in vivo* sessions was poor.

During the second *in vivo* session the researcher spoke with participants about their experience of using the group page for the first two weeks and their apparent lack of engagement with it. Participants explained that as they had not previously met any of the other participants in the group, they were not comfortable engaging with them on the group page. Although they did know the DHCT and were more

comfortable in their interactions with them, they were not comfortable interacting with the DHCT online in front of the other participants whom they did not know.

As a result of the feedback from participants, the researcher decided to facilitate participants to get to know one another better by giving them all an “ice-breaker” task to complete during the second *in vivo* session. The task involved each participant contacting each other participant via the group page over the subsequent two days and finding out his or her interests (e.g., music they listen to, sports they play, television programmes they watch, etc.). Each participant was then to post to the group page a list of interests they shared with other participants. Although all participants agreed to undertake the task and agreed that it would be beneficial in helping them to better get to know one another, none of the participants had completed the task one week after the second *in vivo* session (i.e., no participant had posted a list of shared interests to the group page).

During the first week after the second *in vivo* session, participants’ engagement with the group page continued to be minimal, despite efforts from the DHCT to engage them. Up to this point the DHCT had not initiated any diabetes related conversations or content with the participants. However, one week after the second *in vivo* session the researcher posted a diabetes-related humorous cartoon to the group page. Participants were observed to comment on this cartoon and engage with each other on the fact that the humour of the cartoon was lost on individuals who did not have T1DM. Following this the researcher instructed the DHCT that they could initiate diabetes related conversations and content on the group page. Participants immediately began to respond to the diabetes related content and appeared to use this as a springboard to initiate diabetes related conversations with the DHCT and each other.

From this point, and over the subsequent four months of the pilot study, the participants engaged well with the group page and used it appropriately to interact with each other and the DHCT. The kinds of interactions observed were:

- Engaging in spontaneous conversations with each other and the DHCT
- Directing questions about diabetes management to each other and the DHCT
- Responding to other participants questions about diabetes management
- Commenting on their own personal challenges in diabetes
- Posting links to diabetes related articles for the DHCT to comment on their veracity
- Posting humorous diabetes related cartoons and videos

It was also noted that over the course of the pilot study, participants posted minimal non-diabetes related content to the group page, leading to the assumption that participants saw the group page as primarily being diabetes related.

5.3.1.3 Usability of the SMBI for Communication. Over the course of the pilot study the group page was observed to be an effective medium of communication for participants and the DHCT. As well as the open communication outlined in the previous section, participants also used the SMBI to communicate privately with members of the DHCT about more personal issues (e.g., asking the dietitian questions about weight loss). As participants became more comfortable using the group page, they began to use it to request information from the DHCT that was normally the responsibility of their parents (e.g., times of clinic appointments, letters for taking insulin through airport security, etc.).

5.3.1.4 Confidentiality and Security of using the SMBI. There were no indicators that either the confidentiality or the security of the group page were compromised at any point during the pilot study. The moderator maintained sole administrator rights of the group throughout the pilot study, ensuring that no one else could adjust the privacy settings of the group page.

5.3.1.5 Potential Harmful Effects on Adolescents. There were no indicators of cyberbullying, inappropriate exposures or inappropriate disclosures on the group page, nor were there any reports of such incidents from participants or their parents. The moderator monitored all content and open conversations that were posted to the group page and did not find any that were inappropriate. As such, at no point did any participant or participant's parent have to be contacted in relation to inappropriate content or behaviour on the group page.

5.3.2 Usability of the Outcome Measures. For participants in the comparison group the outcome measures were recorded at their regular clinic visits every four months as per normal. Given that diabetes clinics were run every week and different participants in the comparison group attended diabetes clinics on different dates, the collection of baseline and follow-up (i.e., four months later) outcome measures occurred on different weeks for different participants. For participants in the treatment group, their regular diabetes clinics were rescheduled so that one occurred between 12 and 16 weeks after the first *in vivo* session (where baseline outcomes measures were collected). This rescheduling of clinic appointments was undertaken to ensure that the time interval between the collection of baseline outcome measures (collected during first *in vivo* session) and follow-up

outcome measures (collected during the first clinic visit to occur after the first *in vivo* session) was between 12 and 16 weeks. Although this rescheduling of participants' clinic appointments was achieved, it was very disruptive to the functioning of diabetes clinics, as it led to a number of clinics that were over populated and put pressure on the DHCT. As a result of this, the DHCT requested that in future participants' clinic appointments not be rescheduled.

Three participants in the treatment group and two participants in the comparison group did not attend for their scheduled diabetes clinic visit, preventing the second set of outcome measures for these participants to be collected as planned. Normal practice of the DHCT in situations where patients do not attend their scheduled diabetes clinic was to reschedule them for the next clinic rotation (i.e., four months later). However, the DHCT agreed that for participants in the pilot study who missed their scheduled diabetes clinic, they would contact their parents and reschedule them for the next clinic date that they were able to attend. Despite this arrangement, two participants in the comparison group failed to attend for the rescheduled clinic visit, resulting in no outcome measures being collected for the second time point for these two participants.

The choice of which parent completed the parent questionnaire battery at baseline was determined by which parent was present at the point that the battery was due to be initially administered. For participants in the treatment group, this was the parent who was present during the parent information session the day before the first *in vivo* session. For participants in the comparison group, this was the parent who accompanied the participant to their scheduled diabetes clinic on the day that the baseline measures were being collected. If both parents were present at either of these times, the researcher asked that the parent who normally accompanies the participant

to their diabetes clinic to complete the parent questionnaire battery. However, two participants in the comparison group attended their scheduled clinic at which the follow-up outcome measures were due to be collected, accompanied by the parent who had not completed the baseline parent questionnaire battery, or by a guardian other than a parent (i.e., a grandparent). In these situations, the parent questionnaire battery was given to the parent or guardian accompanying the participant and they were asked to have the parent who completed the battery at baseline to complete the battery a second time and post it back to the researcher in a stamped addressed envelope that was included with the questionnaire battery. However, neither of these completed questionnaire batteries were received back by the researcher.

When completing the questionnaire batteries, both participants and their parents were instructed by the researcher to make sure to complete all questionnaires and to answer all items in each questionnaire. However, analysis of the completed questionnaire batteries found that two of the parent questionnaire batteries and one of the adolescent questionnaire batteries for the comparison group, and one of the parent questionnaire batteries for the treatment group had not been completed to the end, with either most or all of the final questionnaire (the self-efficacy for diabetes scale) omitted, preventing this scale from being scored.

5.3.3 Participants' Experience of Using the SMBI. This section outlines the main findings selected from analysis of the interviews with the four participants who underwent the pilot SMBI. Pseudonyms have been used in order to maintain the anonymity of the participants. Table 5.1 lists the pseudonym, age, age at diagnosis and current insulin regimen for each of the four participants.

Table 5.1 *Participants’ pseudonyms, age, age at diagnosis and current insulin regimen at commencement of SMBI pilot*

Pseudonym	Age (years)	Age at diagnosis (years)	Insulin regimen
Lisa	16	12	Multiple daily injections
Sam	16	3	Insulin pump
Martin	16	10	Multiple daily injections
Dean	16	12	Insulin pump

Two superordinate themes and three subordinate themes were selected from the interviews and are highlighted in Table 5.2. All quotes are attributable to either one of the four participants who undertook the interview or the interviewer. The participant to whom a quote is attributable is identified by their pseudonym preceding the quote. Quotes attributable to the interviewer are identifiable by “Interviewer” preceding the quote. Line numbers indicate the location of the quotes in the original transcripts (see Appendix 6).

Table 5.2 *Superordinate and subordinate themes selected from the interview*

Superordinate themes	Subordinate themes
<ul style="list-style-type: none"> Interaction with Peers 	<ul style="list-style-type: none"> Anxiety Normalisation Vicarious learning
<ul style="list-style-type: none"> Problem Solving with the DHCT 	

5.3.3.1 Interaction with Peers. In relation to the superordinate theme of Interaction with Peers, three subordinate themes emerged: Anxiety, Normalisation and Vicarious Learning. The subordinate theme of Anxiety refers to anxiety participants reported feeling about interacting with other young people with diabetes that they did not know in the *in vivo* sessions. This appeared to have been particularly salient at the start of the intervention.

Martin: The bit that I had was just not knowing people and I felt a bit awkward doing it. (26-27)

Dean: Probably nervous about meeting a lot of new people all at once. I am very awkward when it comes to that. So I don't think I will be the only one... When you are put into a room with strangers, you tend to go into your own little corner. (44-46)

Sam: I think it's hard to bring a big number of people together and get them talking to each other. (72-73)

However, this initial anxiety did appear to dissipate for subsequent sessions as participants became more comfortable with one another.

Sam: I suppose with anything if you're meeting new people you'd be a bit hesitant but I didn't think it wasn't too bad then after a few sessions when we got together. (18-20)

This anxiety about being around unfamiliar peers in the initial *in vivo* sessions appeared to have been common among participants. In contrast, the online interactions, even at the start, did not appear to generate similar feelings of anxiety.

Dean: I didn't really mind that. That was the weird thing. When you're put in the same room as a couple of strangers, you're kind of like who are these people but when you're put into a Facebook group, it's kind of like that barrier is like, taken down. Because like you're not stuck in a room where it's kind of like everybody's awkwardly looking around. It's more like... It's probably easier to communicate. (53-57)

Indeed, the reports from participants seemed to indicate that the unfamiliarity or 'stranger' element of peers in the *in vivo* sessions that elicited anxiety, did not elicit the same response in the online forum.

Martin: Yeah, I would definitely agree with that. It'd be easier on Facebook. I'd say that it is for most people but for some people it could be harder. (62-63)

This ease of communication with unfamiliar peers on Facebook as opposed to in real world contexts was also highlighted in situations outside of the present study by Sam.

Sam: I know when I went to Donegal a few years ago and I came back and in a few days later I added one or two lads on facebook and I got talking to them. (73-75)

Participants were able to identify previous familiarity with peers in the group and smaller numbers of individuals in the group as something that reduces the level of anxiety experienced and facilitates better interaction in the *in vivo* sessions.

Sam: Yeah, if they know each other coming in it would make things easier. (77-78)

Lisa: Yeah, because you probably feel more comfortable with a smaller group of people or people they get along with. (59-60)

The subordinate theme of Normalisation refers to positive experiences that participants got from being exposed to the issues that their T1DM peers were experiencing and realising the commonality of these issues for adolescents with T1DM. This was a very common theme for all participants interviewed.

Dean: I know a few people with diabetes, yeah.

Interviewer: What's your experience with that?

Dean: It does help, it helps a good bit, yeah. Like you're able to talk to them and all. You feel better in your own skin like, as in you're not completely

awkward about it in front of others. Like I was completely awkward about it in public. Since I know people, no. I got a lot better. (367-372)

Dean: Yeah, especially I think someone mentioned the book, and I thought I was the only one that like when I got the book, just like throw it in the corner. I don't want to see you again. And I'd fill it out the night before. Like I didn't think that was common, I thought that was just me. (167-170)

From this normalisation there appeared to emerge a sense of solidarity among participants in relation to the difficulties they experience living with T1DM.

Dean: Yeah, I'd say so. It kind of made me realise that literally there's a lot of us that has diabetes and all kind of stick together in a way we can. (189-190)

Interviewer: How did you find being able to see other people's conversations with the members of the diabetes team?

Dean: Didn't really mind to be honest. If anything like, interesting to look at because you could relate to them. I suppose because we all suffer the same things. If we get insulin we all feel the exact same way once we forget our insulin. (139-143)

This subordinate theme of Normalisation is closely associated with the third subordinate theme of the Interaction with Peers superordinate theme, Vicarious Learning. Just as being exposed to the issues that their peers were experiencing helped participants normalise their experience of living with T1DM, being exposed to the questions posed by peers online and the responses given by peers and the DHCT was perceived by participants as being beneficial to their learning.

Martin: No, there is a curiosity I'd say, yeah. Which is... Me personally, I find that benefits because I don't really think of many questions to ask. I can just have a look through and say, ah I never thought of that. (149-151)

Sam: It was good because a lot of what they were asking about were questions that I had myself. The problems they'd have, I'd have myself. As good as they'd ask it I'd benefit from it. (36-38)

Being able to see other participants' conversations with the diabetes team appeared to be particularly useful for participants and an indirect learning aid. Lisa described how she found it interesting being able to read other participants questions.

Interviewer: How did you find being able to see other people's conversations with members of the diabetes team?

Lisa: Brilliant.

Interviewer: Why?

Lisa: Because I didn't have to ask the questions.

Interviewer: So you liked being able to read other peoples conversations?

Lisa: It was much easier because I could just read over their conversations. It was interesting. (24-31)

Dean reported being acutely aware of the impact of his questions on the vicarious learning of others and made decisions on whether to pose questions in a private or public forum on the Facebook group page depending on whether it benefited the other participants.

Dean: If I feel the answer to the question will benefit everyone else I'll put it on the wall. But if I feel like this is a personal thing that it's really only to me and everyone else seems to have that under control, I'll probably private message. (136-138)

5.3.3.2 Problem Solving with the DHCT. The second superordinate theme selected from the interviews was Problem Solving with the DHCT. This theme relates to participants perceptions of them being better able to use the DHCT to help them problem solve issues around their diabetes management. Dean noted that there was an informality about communications through Facebook that he felt made it easier to seek support around problems.

Dean. I thought it was a good idea as well because even when I had a problem, I was like... I can't talk to anyone on the phone, that's a weird thing I have, so on Facebook it was a lot easier, to communicate with people, even though it is weird having something really formal on Facebook because it's a hospital... Even though it is, they encourage you to be informal... There's still kind of a formality about it. (13-17)

Martin reported that there was less pressure when asking a question on Facebook and this allowed him the time to think about his questions.

Martin: It's just,... You have time to think about it as well, you don't have to... You're not put on the spot. (69-70)

In particular, participants appeared to find it useful for support around less serious diabetes management problems.

Sam: I wouldn't have a problem giving them a call, but sometimes if it's not a serious question you might feel like you are annoying them or they might be busy... So if you leave it on Facebook they can get back to you whenever they can. It seems a better way. (10-13)

Participants also identified being able to link in directly with the DHCT member that had the specific expertise to address their particular problem as helpful.

Sam: I think we had a good number because I talked to... (name of the dietitian on the DHCT) about food... Or if I'd any question about sites or finger checks I could talk to... (name of the nurse on the DHCT), and... (name of the doctor on the DHCT) there as well. (64-67)

The SMBI also appeared to provide a more immediate forum for participants to address particular problems than their regular clinic visits.

Dean: Probably the same yeah. It's easier to put on Facebook than... And also like, if you come into the clinic and then you forget what your question was, which I've done plenty of times. I've a question I have to ask them, then I forget, and then I go home and be like, crap, I have to wait for another six months. (72-75)

Sam: Not really , just little questions that you might forget to ask. You'd be going along and say I meant to ask about that and you can just give them a message on facebook. (31-33)

5.3.3.3 Summary. Overall, qualitative analysis with the four participants indicated that they found engaging with the SMBI to be a positive experience. They found the experience of interacting with other young people with T1DM to be particularly beneficial. Participants found that the initial *in vivo* group sessions caused them some degree of anxiety due to their unfamiliarity with the other participants. However, the anxiety that was evident in the *in vivo* group sessions was not carried over into the online interactions, where participants reported being much more comfortable interacting with peers.

Participants reported a sense of normalisation about being able to interact with T1DM peers. This arose from their realisation of the commonality of the issues they

all experienced living with T1DM and created a sense of solidarity among them. They also found being able to observe the questions that their peers posed within the online forum and the answers they received to be a beneficial vicarious learning experience.

Participants found the increased access with the DHCT that the SMBI facilitated helped them to problem solve issues around their diabetes management. This was particularly so for less serious problems that they felt they would annoy the DHCT if they contacted them by phone about. Being able to direct problems to the particular DHCT member with expertise in that area was reported to be beneficial, as was the immediacy of being able to pose questions on Facebook rather than having to wait for the next clinic visit.

5.4 Discussion

The pilot study was undertaken to explore the practicalities of using a SNS as a SMBI to support adolescents with T1DM. This involved the design and implementation of a SMBI and an evaluation of its implementation. In the following sections the different aims of the pilot study are discussed and evaluated.

5.4.1. DHCT's Ability to use the SMBI. Observation and interview with the DHCT indicated that they used the SMBI appropriately and engaged well with the participants online. However, they found it time consuming to source appropriate content to post to the page to facilitate interaction with participants. This was a particular concern because the SMBI was envisioned not to overburden DHCT resources. In addition, the pilot study ran with a single Facebook group, whereas in the main study it was intended to run a number of Facebook groups simultaneously,

thereby putting additional pressure on the DHCT to source content for multiple groups. It became clear that expecting the members of the DHCT to engage in multiple online group conversations and to source content for these conversations would place too significant a demand on their resources. In order to address this and reduce the demands on the DHCT of engaging in the SMBI, it was decided to source the content for the DHCT and to semi-script their conversations. This is described in detail in section 5.5.4.

It became clear during the pilot study that the DHCT were accessing the SMBI in their personal time at home through their personal smartphone devices. Although the DHCT had been informed that they were not expected to engage in the SMBI outside of work hours, some members of the SMBI said they did so because they didn't get time to respond to participants during the day. In addition, the incident where a participant contacted a member of the DHCT outside of work hours via the SMBI about an upsetting incident she had witnessed highlighted a vulnerability of having DHCT members engage with participants via the SMBI outside of work hours. It was therefore decided that for the main study DHCT members would be directed to only engage with the SMBI during work hours. It was also decided that participants would be told that due DHCT members busy work schedules it may in some cases take them a number of days to respond to a question and so not to expect immediate responses to their questions.

As it was not possible to access Facebook through the normal hospital computers, the DHCT were provided with separate computers at their desks with which to access the SMBI. However, they reported that having to log into these separate devices was slow and cumbersome and they felt it reduced the frequency with which they accessed the SMBI. It was noticed that DHCT members who had

been using their own Smartphones to access the SMBI were doing it more frequently and they reported that this was because of the ease of access with these devices. It was therefore decided to provide members of the DHCT with tablet computers (i.e., iPads) for the main study in order to increase the ease at which they could access the SMBI.

5.4.2 Participants' Engagement with the SMBI. Initially participants were slow to engage in any online interactions, making very few spontaneous posts. It was only when the DHCT began to post diabetes related content to the page that they began initiating interactions, both with the DHCT and each other. It had initially been decided that the DHCT would not post any diabetes related content to the page for the first week. This was done to allow participants settle into using the page by interacting around non-diabetes related content. However, this was clearly the wrong approach. Participants already engage in non-diabetes related content with their friends on Facebook. For them to take an interest in the SMBI, it has to offer them something different to their normal Facebook interactions with peers, namely diabetes related content. Once the DHCT began posting diabetes related content to the page, participants immediately began to interact with it and used the content to instigate conversations with each other. They engaged in numerous and varied types of online interactions with the DHCT and each other. As a result of this it was decided that for the main study, the DHCT would post diabetes related content to the page from the outset.

5.4.3 Usability of the SMBI for Communication. Over the course of the pilot study, the SMBI was observed to be an effective communication medium for

both participants and the DHCT. As such, it was felt that the SMBI as designed for the pilot study was an effective communication tool for the main study.

5.4.5 Confidentiality and Security of the SMBI. Over the course of the pilot study, there were no indicators that either the confidentiality or the security of the group page were compromised at any point. As such, it was felt that the SMBI as designed for the pilot provided the confidentiality and security required for the main study.

5.4.6 Potential Harmful Effects on Adolescents. Over the course of the pilot study there were no indicators of cyberbullying, inappropriate exposures or inappropriate disclosures on the group page, nor were there any reports of such incidents from participants or their parents. As such, it was felt that the SMBI as designed for the pilot study did not have any harmful effects on participants and so was safe to be used for the main study.

5.4.7 Usability of the Outcome Measures. In the pilot study, in order to have all participants' outcomes measures collected at fixed intervals, participants in the treatments group's regular four monthly clinic visits were rescheduled. However, this was found to be very disruptive to the functioning of the DHCT and led to clinics that were over populated. As a result it was decided that for the main study participants clinic visits would not be rescheduled. Instead participant outcome measures would be collected within an interval range, rather than a fixed interval (see section 6.4.2).

In the pilot study the questionnaire batteries were administered via pen and paper. Analysis of the completed questionnaire batteries found that they contained a significant number of omitted items. In addition, when questionnaires had to be posted out to parents, they were not returned. In order to overcome these two problems it was decided to digitise the questionnaires onto surveymonkey.com and then administer them in the clinic via tablet computers. If a participant's parent that needed to complete a questionnaire battery didn't attend clinic with the participant, a link to the questionnaire battery could be emailed out to them. In this way the researcher could send the parent reminder emails if the questionnaire wasn't completed within a set time.

5.4.8 Participants' Experiences of using the SMBI. Qualitative interview with participants indicated that they found engaging in the SMBI to be a positive experience. As hoped, they enjoyed the increased contact with the DHCT and T1DM peers that the SMBI facilitated.

5.5 Further Development of the SMBI

The pilot study demonstrated that the social media intervention as implemented in the pilot study was able to achieve the basic functionality that was required to be able to use it as an intervention medium. Namely, participants engaged with it, the DHCT were able to use it effectively, it facilitated participants' communication, confidentiality and security were maintained and it did not appear to have a negative impact on participants' wellbeing. However, as a result of the pilot study experience, it was decided to change certain aspects of the intervention, with the goal of increasing its effectiveness as an intervention medium for adolescents with

T1DM. The sections below describe the further developments to the SMBI that occurred following the pilot study.

5.5.1 Assignment to Treatment and Comparison Groups. The pilot study demonstrated a 40% attrition rate at the point of collecting baseline outcome measures for the intervention group (i.e., participants had agreed to take part in the intervention group but did not attend for the first *in vivo* session, and therefore had to be excluded from the study). There was no attrition rate for participants in the comparison group at the same time point, as their baseline outcome measures were collected during their standard diabetes clinic visit. In order to try and balance the numbers of participants in the treatment and comparison groups at baseline, it was decided to initially overload the treatment groups relative to the comparison groups by a ratio of approximately 1.6:1, so as to counteract the high attrition rate among participants in the treatment group at baseline.

Given the feedback from the pilot study it was felt that the optimum number of participants in each Facebook group was between 6 and 10 individuals. As each treatment group would constitute a Facebook group, it was decided to try to aim for between 6 and 10 participants in each treatment group. For the Eastern region, where there were a larger number of participants relative to the other three regions, it was decided to allocate 10 participants to each treatment group. Using the aforementioned attrition ratio it was decided to allocate 6 participants to the comparison group for each treatment group of 10 participants.

As there were significantly fewer eligible participants in each of the other three regions, it was only possible to create one treatment group within each of these regions. Rather than allocating 10 participants to each treatment group, as had been

done in the Eastern region, it was necessary to adjust the allocation of participants to each group (i.e. treatment and comparison) based on the total available population in each region (i.e., North-western, 8 participants allocated to treatment; Western, 7 participants allocated to treatment group; South-western, 10 participants allocated to treatment group) in order to maintain the same treatment group to comparison group ratio (i.e., 1.6:1). For more information on this see section 6.2.4.

5.5.2 Using the SMBI Outside of Working Hours. Although the DHCT had been instructed for the pilot study that they were free to respond to participants outside of work hours if they wished, it was decided to specifically direct them not to use the Facebook group page outside of work hours for the main study so as to ensure that DHCT members engagement with the intervention did not impact on their personal lives. Limiting the DHCT's use of the group page to working hours also ensured that should a participant's communication indicate that they were distressed, the DHCT member would have the support of work colleagues in their decision-making around how to respond to the communication. Participants were also instructed that DHCT members would not have access to the group page outside of normal work hours and such communications made outside of work hours would not be seen until the next working day, or possibly longer if the communication was directed towards a member of the DHCT who was absent from work (e.g., sick leave, holidays, etc.).

5.5.3 Initiating Diabetes Related Content. For the pilot study the DHCT was advised against instigating diabetes related conversations and posting diabetes related content to the group page until directed to do so by the researcher, in order to

allow participants become comfortable using the group page. However, during the pilot study, it was observed that it was the diabetes related content and conversations that instigated and maintained participants' interaction on the group page. The DHCT were therefore instructed that for the main study they could initiate diabetes related conversations and post diabetes related content to the page immediately following the first *in vivo* session.

5.5.4 Semi-scripted Conversation Threads. The main study utilised numerous treatment groups, differentiated by geographic area and/or age, and so multiple Facebook groups were created (i.e., one for each treatment group). As each participant was assigned to only one treatment group, each participant was connected to only one of these Facebook groups (i.e., the one created for their treatment group). DHCT members, on the other hand, were involved in all treatment groups and so were connected to every Facebook group. This had the potential to place significant demands on the resources of DHCT members, as they conversed with numerous participants across multiple Facebook groups, and consequently, reduced their engagement with the intervention.

The issue of the demand on DHCT resources of conversing across multiple Facebook groups did not arise during the pilot study due to there being only one Facebook group. However, the DHCT did note during the pilot study that they did not have the resources to source content to post to the Facebook group and saw this as a barrier to their engagement with the intervention. In order to reduce the demand on DHCT members' resources, both in terms of sourcing content and conversing across multiple Facebook groups, it was decided to provide the DHCT with pre-sourced structured content to use in online conversations with participants. This allowed DHCT members to replicate the same conversations across each Facebook group and

negated them having to source the content themselves. Such an approach, as well as maximising the efficiency of DHCT members' engagement with the Facebook group, also provided a degree of standardisation to the conversations between DHCT members and participants across groups.

The pre-sourced structured content was provided in the form of pre-constructed chunks of conversation that DHCT members could post to the Facebook group to generate and maintain a conversation chain around a particular topic area. Within the context of Facebook, conversation chains of written online communications between individuals are known as conversation threads. Using pre-constructed chunks of conversation in a temporal order within conversation threads allowed for the creation of semi-scripted conversation threads. The initial conversation chunk introduced a topic area (e.g., diet) with a number of statements or comments about the topic (e.g. "Chocolate biscuits can really send blood sugars soaring") and finished with a question directed to participants (e.g., "What kind of foods have you found that make you blood sugars crazy"). By finishing with a question, the conversation was opened for the participants to join in. The DHCT members then let participants engage around the question posed. At any point the DHCT member could re-engage with the conversation by posting the next conversation chunk, which started by referring to the question at the end of the previous conversation chunk (e.g., "Yes, there are lots of different foods that can make blood sugars crazy"), continued with a further number of statements or comments about the topic (e.g., "Certain types of high sugar foods release sugars faster and as a result raise blood sugars quicker") and finished with another question (e.g., "Have you noticed any particular foods that have a quicker effect on blood sugars than others?"). This process continued like this until the DHCT member had

posted all the conversation chunks from the particular topic area. The extent to which the DHCT member engaged participants in additional “unscripted” conversation at any point during the conversation thread was at the discretion of the DHCT member and participants were unaware that any sections of the conversation thread were scripted.

As the pilot study demonstrated that participants become most engaged around diabetes related content and conversations, it was decided to develop the semi-scripted conversation threads around different diabetes related topics. In consultation with the DHCT, eight main diabetes topic areas were identified: What is Diabetes, Insulin, Hypoglycaemia, Hyperglycaemia, Blood-Sugar Testing, Insulin Adjustment, Diet and Exercise. Within each of the eight topic areas, the main points of knowledge required for good T1DM management were identified. These points of knowledge were then used as a scaffold around which each semi-scripted conversation thread was constructed, such that each complete conversation thread contained within its content all the main points of knowledge for that topic area.

The content for semi-scripted conversation threads were provided to the DHCT members in digital format so that they could “cut and paste” the constituent conversation chunks into the conversation threads on the Facebook group pages as necessary (see Appendix 5 for all eight semi-scripted conversation threads). Different DHCT members took responsibility for administering different semi-scripted conversation threads (e.g., the dietitian administered the conversation thread on “diet”, while one of the diabetes clinical nurse specialists administered the conversation thread on “hypoglycaemia”).

At the start of each new treatment group, the researcher prompted each DHCT member when they could begin administering each semi-structured conversation

thread. However, once a DHCT member commenced administering a semi-structured conversation thread on a particular topic area, it was up to the DHCT member themselves to decide the timeframe over which they administered the entire conversation thread, providing it did not exceed eight weeks. DHCT members were also free to decide the extent to which they engaged participants in unscripted dialogue within each semi-scripted conversation thread.

5.5.5 Inclusion of Diabetes Knowledge to the SMBI Model. The semi-structured conversation threads that were included in the SMBI as a result of the pilot study were constructed around eight specific diabetes knowledge areas. The primary function of the semi-structured conversation threads was to facilitate communication between participants, and between participants and the DHCT. Although the semi-structured conversation threads weren't introduced with a goal of educating participants, it was felt that this could be a secondary gain of their inclusion. It was therefore decided to measure participants' diabetes specific knowledge in order to investigate if the introduction of the semi-structured conversation threads resulted in a secondary gain on participants' diabetes knowledge.

There is some evidence that knowledge is associated with adherence for adolescents with chronic illnesses, including diabetes (Koster, Philbert, Winters, & Bouvy, 2015; Nicholas et al., 2012). In order to account for the inclusion of an educational component into the SMBI, it was decided to adjust the theoretical model on which the SMBI is based to include the potential influence of increasing diabetes knowledge on adherence and quality of life. Figure 5.1 highlights the SMBI model with the inclusion of diabetes specific knowledge as a factor. It was also decided to

add an additional secondary hypothesis to the aims of the study to include the educational component of the SMBI. This addition secondary hypothesis is:

- The SMBI will result in an increase in participants' diabetes specific knowledge.

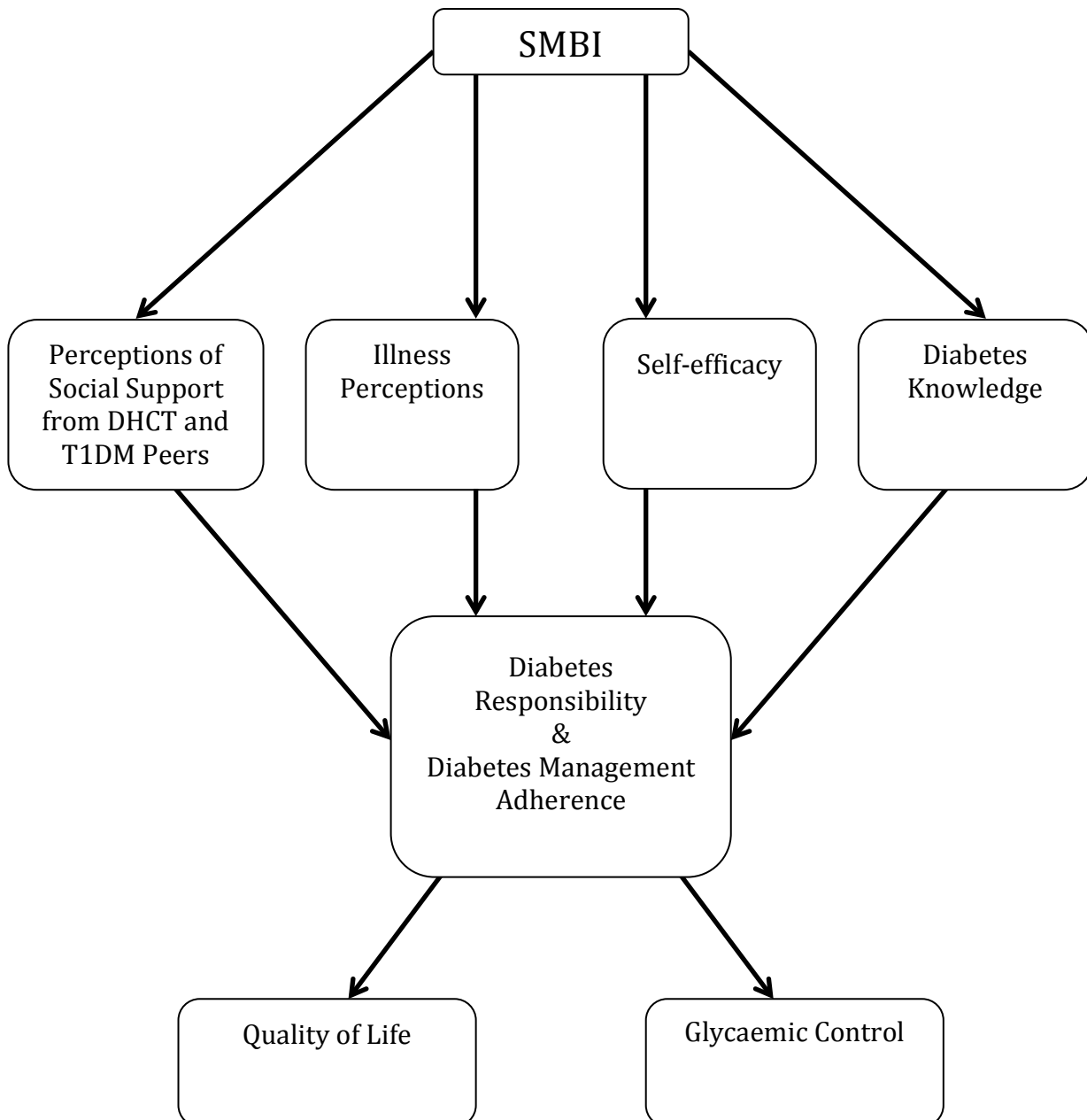


Figure 5.1 Model of SMBI including Diabetes Knowledge

5.5.5 Behaviour-change conversation threads. Although the primary goal of the semi-scripted conversation threads were to facilitate participants' engagement with the Facebook group, given that they were constructed around points of knowledge required for good T1DM management, they also had the potential to increase participants' diabetes knowledge. In order to support the transfer of such knowledge, should it be acquired, to positive changes in diabetes management behaviour, it was decided to develop behaviour change conversation threads. The purpose of the behaviour change conversation threads were to guide participants through small-step behaviour change using some of the basic principles of Motivational Interviewing (Miller, 2002).

Unlike the semi-scripted conversation threads outlined in Section 5.5.4, only the initial posts by the DHCT member in the behaviour-change conversation thread were scripted. However, the posts did follow a set structure and allowed the same flexibility around timing and engagement in off-topic conversations as the semi-structured conversation threads. The behaviour-change conversation threads started with a scripted conversation piece posted by the DHCT member that briefly explained health behaviour change and how it could be facilitated via the Facebook group, following which each participant was asked to identify one small health behaviour change, diabetes related or non-diabetes related, that they would like to accomplish. Participants were then given a period of time to respond with the small health behaviour change (i.e. target behaviour) they would like to accomplish (e.g., "I'd like to eat less biscuits when I arrive home after school"), after which the DHCT member asked each participant in turn what their current level of the target behaviour was (e.g., "So Adam, about how many days a week do you eat biscuits after school and, when

you do, about how many biscuits do you eat?") in order to get an estimate of the baseline level of the target behaviour.

The DHCT member then asked each participant in turn what level of the target behaviour would they like to ultimately achieve (e.g., "How many biscuits a day after school would you like to eventually reduce it down to?") in order to get an estimate of the target behaviour goal. After this was ascertained, the participant was asked to identify a small achievable interim goal between the baseline level of the target behaviour and the target behaviour goal, that they believed they could achieve over the follow week (e.g., "Over the next week what do you think would be an achievable number of biscuits per day after school to bring it down to? Remember, lets start off easy with something that you feel you'll be able to achieve without too much extra work"). Once this interim goal was set with all participants who engaged in the conversation thread, participants were encouraged to support each other in achieving their goals (e.g., "It's much easier to work towards goals when we have other people who are cheering us on. Be sure to encourage each other").

Over the subsequent week the DHCT member regularly enquired into participants' progress (e.g., "So how is everyone getting on with the goals they set on Wednesday?") and provided encouragement (e.g., "That's great progress Adam, keep up the good work"). The DHCT member also used the 'Like' function on Facebook (a feature that allows a user to express that they like certain content) to support encouraging comments from other participants. One week after the interim goals were set, the DHCT member asked participants if they had achieved the goals (e.g., "So Adam, did you reach you goal of not having more than two biscuits per day after school"). Participants who had achieved the interim goal were congratulated on their success and encouraged to set a new interim goal (e.g., "Congratulations Adam, that's

brilliant news. Would you like to set a new goal for next week?"). Participants who did not achieve the interim goal were congratulated on what they did achieve and the setting of a new easier goal was encouraged (e.g., "Reducing the amount of biscuits you had per day after school to four is brilliant. I think the goal of reducing it down to two per day for the first week was a little much. What about setting a slightly easier goal for next week?"). This process of goal setting and reviewing interim goals continued on until the target behaviour goal was achieved or the participant disengaged from the conversation. After a target behaviour goal was achieved the participant was encouraged to select a new target behaviour and the process started over. See Appendix 7 for a breakdown of the behaviour-change conversation thread.

The behaviour-change conversation threads were administered by the clinical psychologist and commenced after the semi-scripted conversation threads had concluded. The concept of the behaviour-change conversation threads was introduced to participants during the fourth *in vivo* group session. This session occurred eight weeks after the commencement of the intervention and following the session the clinical psychologist began administering the behaviour change conversation thread.

5.5.6 Adolescent *in vivo* Group Sessions. The purpose of these four *in vivo* sessions was the development of relationships among participants by facilitating them to communicate with one another in a non-virtual environment. In the pilot study, these sessions followed a set structure that included tasks that encouraged participants to talk about diabetes. In addition to the structured sections of the session, the researcher also facilitated discussion around what had been posted on the group page over the interval since the previous *in vivo* session and encouraged participants to talk about their views about the content that had been posted by the DHCT. During the

pilot study, these unstructured discussions generated the most discussion and engagement from participants, particularly when discussion was around what had been posted to the group page in the preceding week. It was therefore decided that for the main study the structured element of group sessions would be removed and instead focus on discussing what had been occurring on the Facebook group over the previous week.

In addition to an increase in unstructured discussion, the *in vivo* sessions were also modified by the inclusion of the topic of health behaviour change. The researcher introduced this topic during the fourth *in vivo* session and explained how the behaviour change conversation threads would be introduced online after the fourth *in vivo* session. During the fifth and final *in vivo* session, the researcher reviewed the behaviour change conversation threads with participants and encouraged them to continue to utilise them as necessary to support changes to their diabetes management.

Chapter 6: Method

6.1 Design

A prospective non-randomised comparison design was employed.

6.2 Participants

6.2.1 Ethics. The Ethical approval that had been obtained for the pilot study (see section 5.2.2.1 and Appendix 1) also covered the main study. As well as separate information leaflets being given to participants and their parents (Appendix 2), information evenings were held for parents of participants where the study was explained to them in more detail and they were given the opportunity to ask questions of the researcher. All participants and their parents provided written informed assent (adolescents) and consent (parents) prior to study inclusion (Appendix 2).

6.2.2 Participant Eligibility. All adolescents aged between 13 and 16 at the time of recruitment (i.e., 10th July 2013) who were attending the diabetes clinic at the hospital were eligible to take part in the study. Adolescents were excluded from the study if they had been diagnosed with T1DM within twelve months of recruitment or if they had a significant comorbid medical condition that required intensive management (e.g., cystic fibrosis). For the purposes of selecting suitable participants, potential participants electronic patient records were analysed to determine their age, duration of diabetes and presence of a significant co-morbid medical condition.

6.2.3 Participant Selection and Recruitment. 134 adolescents attending the diabetes unit of a large urban paediatric hospital were identified as being eligible to take part in the study. However, not all of the 134 eligible participants resided within

easy commuting distance of the hospital, where the *in vivo* sessions took place for the pilot study. To overcome this, it was decided to subdivide eligible participants by geographic region of the country in which they resided (i.e., East region, Northwest region, West region and Southwest region) and run *in vivo* sessions at local centres in each of the four regions.

Parent and adolescent information leaflets (Appendix 2) that explained what would be involved in taking part in the study were posted to the parents of all eligible participants (n = 134). Information leaflets for participants and their parents who resided in the East region informed them that the *in vivo* sessions would be taking place in the diabetes unit where they normally attended for their diabetes clinics. Information leaflets for participants and their parents who resided in the other three geographical regions informed them that the *in vivo* sessions would be occurring in a local health centre in their region. The parent information leaflets also informed parents that they would be receiving a follow-up telephone call from the researcher to answer any questions they had and to ascertain if their son/daughter wanted to take part in the study. These follow-up telephone calls were undertaken by the researcher within two weeks of the information leaflets being posted.

All 134 parents of eligible participants were contacted by telephone about taking part in the study and 101 agreed for their son/daughter to take part (East region, 64 participants out of a total of 82; Northwest region, 12 participants out of a total of 18; West region 10 participants out of a total of 13; and Southwest region 15 participants out of a total of 21). The parents of participants in the East region were informed that age-matched intervention groups would be commencing on a phased basis over the following months and that their son/daughter would be allocated to an intervention group dependant on their age. They would be contacted again in the

month preceding the commencement of their son/daughter's intervention group, and given the dates and times for the five, hour-long *in vivo* group-based sessions that would be occurring over a twelve-week period and formed part of the intervention.

The parents of participants in the Northwest, West and Southwest regions were informed that intervention groups would be commencing in different regions of the country on a phased basis over the following number of months and that their son/daughter would be allocated to the intervention group for their region. They would be contacted again in the month preceding the commencement of their son/daughter's intervention group, and given the dates and times for the five hour-long *in vivo* group-based sessions that would be occurring over a twelve-week period and formed part of the intervention.

It was explained to all parents that although it was hoped that their son/daughter would be able to attend all five *in vivo* sessions, the researcher understood that this might not be possible due to other commitments. However, if their son/daughter did not attend their first *in vivo* session they would have to drop out of the study, as it would be during this initial *in vivo* session that the Facebook group page for their son/daughter's intervention group would be created, populated by the participants in their intervention group and then group membership locked out, preventing any further participants joining that intervention group.

6.2.4 Assignment to Treatment and Comparison Groups. The names of all participants in the East region (n = 64) were listed in order according to age, starting with the oldest. The first 16 names were placed into the first age-matched group, the second 16 into the second age-matched group and so on until there were four age-matched groups of 16 participants each. The names of the participants in each of the

seven groups (i.e., four age-matched groups in the East region and one group in each of the other three regions) were listed in alphabetical order by surname. Starting with the first name on the list, the parents of each eligible participant were contacted in turn by telephone and informed of the date and time of the first *in vivo* session. If the participant was able to attend the first *in vivo* session they were allocated to the treatment group, while any participant who wasn't available to attend the first *in vivo* session was allocated to the comparison group. This procedure was repeated until the criterion number of participants had been allocated to each treatment group, with all remaining participants being placed allocated to the comparison group. See section 5.5.1 for an explanation of how the criterion number for each group was calculated and Table 6.1 for a breakdown of the number of participants allocated to the treatment and comparison groups in each region.

Table 6.1 *Number of participants initially allocated to the treatment and comparison groups from the total available n in each region*

Group	Region	Available n	Treatment n	Comparison n
1	East	64	10	6
2			10	6
3			10	6
4			10	6
5	Northwest	12	8	4
6	West	10	7	3
7	Southwest	15	10	5
	Total	101	65	36

Of the 101 eligible participants who agreed to participate in the study, 65 were allocated to the treatment condition and 36 were allocated to the comparison condition. For participants allocated to the treatment condition, 22 did not attend the

first *in vivo* session and so were excluded from the study, reducing the total number of participants in the treatment group to 43. A further participant in the treatment condition dropped out after the first *in vivo* session, further reducing the number to 42. There was no further attrition among participants in the treatment condition over the course of the intervention. For participants allocated to the comparison condition, 5 did not attend for their regular diabetes clinic during the period that baseline outcome measures were being collected and so were excluded from the study, reducing the total number of participants in the comparison condition to 31. See Table 6.2 for breakdown of the number of the number of participants in each treatment and comparison group in each region. Figure 6.1 and Figure 6.2 outlines the process of participant selection and allocation to treatment and comparison groups in component diagrams.

Table 6.2 *Number of participants who remained in each treatment and comparison group in each region (i.e., weren't excluded because they didn't attend for baseline data collection)*

Group	Region	Total n	Treatment n	Comparison n
1	East	47	5	6
2			6	4
3			5	5
4			10	6
5	Northwest	10	7	3
6	West	7	4	3
7	Southwest	9	5	4
	Total	73	42	31

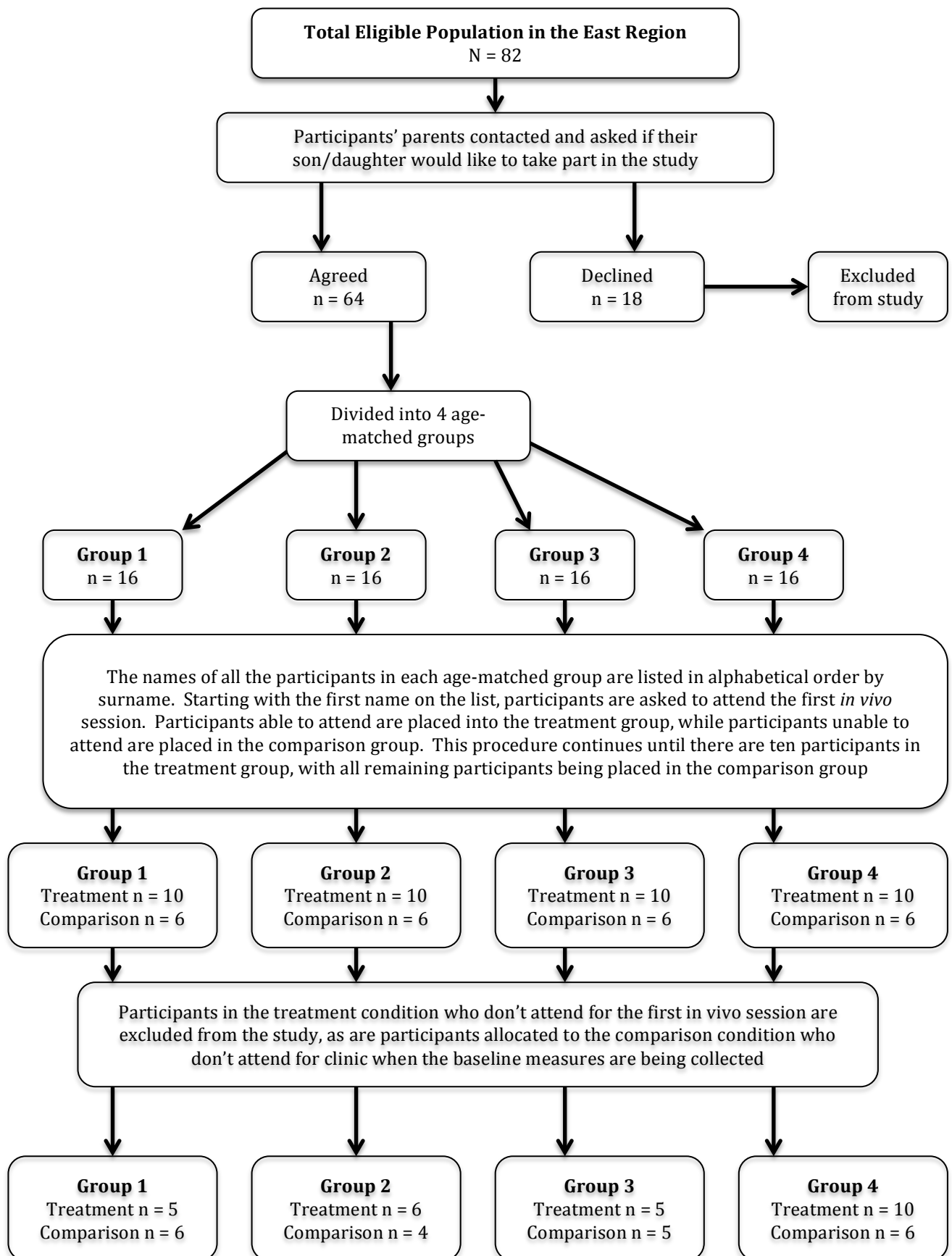


Figure 6.1 Process of participant selection and allocation to treatment and comparison groups in the East region

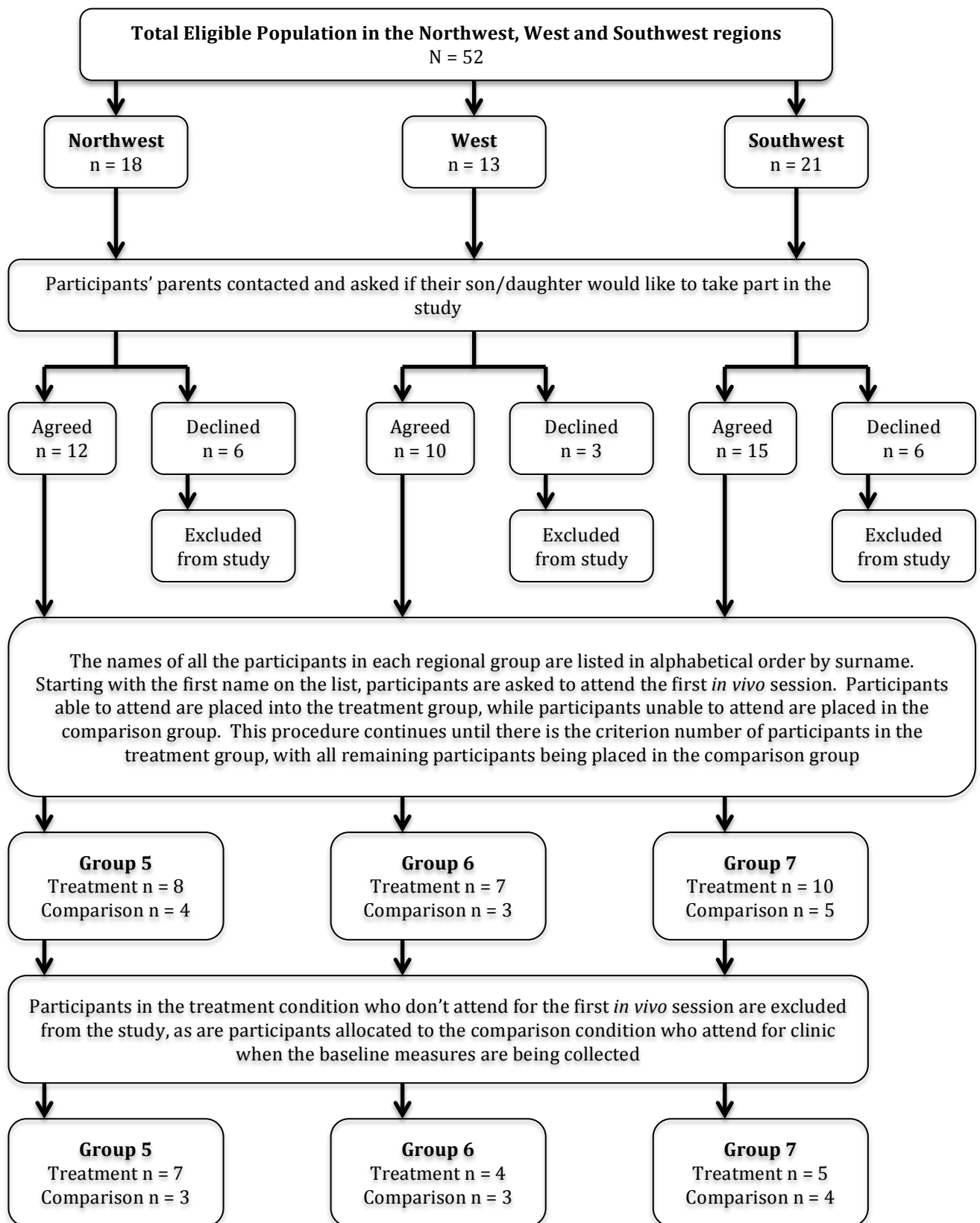


Figure 6.2 Process of participant selection and allocation to treatment and comparison groups in the Northwest, West and Southwest regions

6.3 Measures

The same measures that were used in the pilot study (see section 5.2.4) were also used in the main study, with the addition of the Audit of Diabetes Knowledge Questionnaire (see section 6.3.2) to the adolescent questionnaire battery in order to measure diabetes knowledge.

6.3.1 Historic HbA1c. In order to get a more stable baseline HbA1c measure it was decided to also include historic HbA1c readings with the baseline HbA1c reading. From each participant's electronic patient record their HbA1c readings for the twelve months prior to the baseline HbA1c reading were obtained. The number of historic HbA1c readings obtained for each participant depended on the number of times they had it measured in the diabetes unit in the hospital over the previous twelve-month period, and ranged from one reading to eight readings. For each participant, an average of the historic HbA1c readings and the reading collected at the baseline time point was used for their baseline HbA1c reading.

6.3.2 Diabetes Knowledge. An adapted version of The Audit of Diabetes Knowledge Questionnaire (ADKnowl) (Speight & Bradley, 2001) was used to measure participants' essential knowledge of diabetes and its management. The ADKnowl includes 27 item-sets (114 items) relating to hypoglycaemia, sick days, effects of physical activity, reducing complications risks, smoking/alcohol effects, foot care, and diet & food. It was developed for use with adults (aged 18+) with T1DM or T2DM and is designed in such a way that items not relevant for a particular purpose can be removed without affecting the validity of the instrument. For example,

when using it with patients with T1DM, items and item-sets relating to T2DM can be removed.

For the purpose of our study we removed all items that related specifically to T2DM and its management or issues solely related to adult diabetes care (e.g., foot care). The resulting questionnaire had 81 items (17 item sets), of which 80 items had True/False/Don't Know responses (e.g., "If you are ill and not eating you will need to reduce your insulin"). A single item asked the respondent to choose which one of three insulin regimens they were using (e.g., "4 or more insulin injections a day") and the response to this was used to determine which one of three item sets followed. The resultant questionnaire yielded 8 dimension scores (Diabetes treatment & testing, Management of diabetes when ill, General management of insulin and insulin use, Hypoglycaemia, Effects of physical activity, Diet & food, Reducing the risk of developing diabetes complications and Blood glucose levels and HbA1c), which equated to percentage of correct responses to items within each dimension.

6.4 Assessment

6.4.1 Materials. Participants who attended the *in vivo* sessions in the regional centres (i.e., those in Northwest, West and Southwest treatment groups) had their initial HbA1c readings at baseline measured by laboratory analysis, as the point of care HbA1c testing machines used the diabetes unit in the hospital (i.e., Siemens/Bayer DCA 2000+ Analyzers) were not available in the regional centres. For this HbA1c measurement, the researcher provided each participant with a disposable lancet and BD Microtainer™ tube for capillary blood collection. Participants obtained a finger-prick blood sample using the disposable lancet, or their own personal lancet if they preferred, and collected this blood sample in the BD

Microtainer™ tube. The researcher brought the collection of BD Microtainer™ tubes to the laboratory in the hospital where they were analysed and an HbA1c reading obtained. All other HbA1c readings (i.e. all subsequent readings for those three regional groups and all readings for the East region groups) were measured in the diabetes clinic at the hospital using the same near patient testing machines as were used in the pilot study (see section 5.2.1.1). Four tablet computers (i.e., ipads) were used to administer the digitised questionnaire batteries.

6.4.2 Timing of Assessments. For participants in the treatment group, baseline HbA1c levels were measured, and the adolescent questionnaire batteries administered, during the first *in vivo* session, while the parent questionnaire batteries were administered during the parent information session that occurred just prior to the first *in vivo* session. The subsequent HbA1c levels were measured, and the adolescent and parent questionnaire batteries administered, at participants' standard diabetes clinics. These diabetes clinics occurred every week and were attended by participants once every four months. It was not possible to have participants in the same treatment group attend the same diabetes clinic. Instead, participants in a treatment group were given places in any one of the 9 diabetes clinics that occurred in a window of 12 to 20 weeks after the initial *in vivo* session. Each participant's subsequent diabetes clinics were then scheduled for every four months from this clinic date.

For participants in the comparison group, the baseline HbA1c levels were measured, and the adolescent and parent questionnaire batteries were administered, during their first standard diabetes clinic that occurred after participants in the corresponding treatment group commenced their first *in vivo* session. The subsequent HbA1c levels were measured, and the adolescent and parent questionnaire batteries

administered, at their subsequent standard diabetes clinics, which occurred every four months. If a participant did not show for, or cancelled, their standard diabetes clinic, they were offered an appointment for another diabetes clinic within four weeks. If the participant did not attend, or cancelled, this clinic appointment, their HbA1c reading and questionnaire batteries were regarded as missing for that time point.

6.5 Procedure

6.5.1 Assessment Procedure

For participants in the East region treatment group, baseline HbA1c measures were recorded at the start of the initial *in vivo* session in the same way as in the pilot study (see section 5.2.5.1). For participants in the treatment groups of the other three regions (i.e., those the in Northwest, West and Southwest treatment groups), the baseline HbA1c measures were obtained by means of laboratory analysis of finger-prick blood samples taken during the initial *in vivo* session. After all participants had arrived in the education room in which the *in vivo* session was taking place, the researcher handed each participant a disposable lancet and a BD Microtainer™ tube for capillary blood collection. Participants were instructed to use the disposable lancet, of their own personal lancet if they preferred, to obtain a finger-prick blood sample. After using the lancet to draw a drop of blood, participants were instructed to drop the blood into the BD Microtainer™ tube and seal it. The researcher then collected the sealed BD Microtainer™ tubes from the participants and labelled each tube with the participants name and medical registration number. The researcher brought these blood samples to the laboratory in the hospital the following day, where they were analysed by the laboratory technicians and an HbA1c reading obtained.

The subsequent HbA1c measures (i.e., at 4 months, 8 months and 12 months) for participants in all treatment groups were obtained at participants' standard diabetes clinic visits using the point-of-care HbA1c testing machines in the diabetes unit at OLCHC. For participants in the comparison group, all HbA1c measures (i.e., baseline, 4 months, 8 months and 12 months) were obtained at participants' standard diabetes clinic visits using the same point-of-care HbA1c testing machines.

For participants in the treatment groups, the adolescent questionnaire battery baseline measures were recorded at the start of the first *in vivo* group session, directly after the HbA1c measures were collected. Parents of participants in the treatment group completed the baseline parent questionnaire battery during the parent group-based information session that occurred on the day of, or the day before, the initial *in vivo* session. Parents were handed the tablet computers containing the parent questionnaire battery and asked to complete the questionnaire battery to the end. If more than one parent was present at the parent information session, the researcher asked that the parent who normally accompanies the participant to the diabetes clinic complete the questionnaire battery. If a participant's parent was not present for the parent information session, the researcher emailed the parent a link to the questionnaire battery, along with the participant identification number, and asked them to complete it.

Administration of the adolescent and parent questionnaire batteries for all subsequent time points and for all time points for the comparison group were administered during participants' standard diabetes clinic. When participants and their parent first arrived at the diabetes clinic, the participant was given a tablet computer with the adolescent questionnaire battery loaded onto it and asked to complete the questionnaire battery to the end. The researcher asked the participant to

fill out the questionnaire battery away from their parent and provided them with the participant identification number to be entered at the start of the questionnaire battery. The researcher then asked the parent if they had completed the parent questionnaire battery the previous time. If they responded that they had, they were given a tablet computer with the parent questionnaire battery loaded on it. They were then given the participant identification number to be entered at the start of the questionnaire battery and asked to complete the questionnaire battery away from their son/daughter. If the parent responded that they had not previously completed the questionnaire battery, they were asked for the email address of the parent who had completed the questionnaire battery the previous time. A link to the questionnaire battery on [surveymonkey.com](https://www.surveymonkey.com), along with the participant identification number, was then emailed to the parent with instructions to complete the questionnaire battery. The researcher was able to use the participant identification number to monitor online if the parent questionnaire battery had been completed by the parent, and provide parents with email and phone reminders if necessary.

6.5.2 Parent Group Information Sessions. The format of the parent group information sessions remained the same as the pilot study (see Section 5.2.5.3). For parents of participants in the East region treatment groups, the parent group information sessions occurred the day before the first *in vivo* group-based sessions. Any parent that was unable to attend the first group information session was contacted by phone and the information from the session relayed to them. For parents of participants in the Northwest, West and Southwest region treatment groups, it was not practical for the researcher to run a parent group information session the day before the first *in vivo* group-based sessions, due the commuting distance involved. Instead

the parent group information sessions occurred in the hour preceding the first *in vivo* group-based sessions.

6.5.3 Adolescent *in vivo* Group Sessions. The structure and content of the first *in vivo* group session was the same as for the first *in vivo* session in the pilot study (see Section 5.2.5.5). The structure and content of the four subsequent *in vivo* group session was adjusted slightly for the main study (see section 5.5.6). At the end of the final *in vivo* sessions, the researcher explained to participants that although there would be no further *in vivo* sessions, the Facebook group page would be maintained and that they could continue to communicate with the DHCT and each other via the group page. The ground rules that had been outlined during the first *in vivo* session were reiterated and it was explained that the researcher would be continuing to moderate the page.

6.5.4 Qualitative Interviews with Participants. In order to select a group from which to interview participants about their experience of the SMBI, each of the numbers from one to four was allocated to one of the four East region groups. One of these numbers was then randomly chosen and the corresponding East region group was selected for qualitative interview. The three groups from the other three regions (i.e., Northwest, West and Southwest) were not included in the selection because, given that the participants resided a considerable distance from the hospital, it was not practical to bring them in together for a group interview.

The parents of the six participants in the East region group selected for interview were phoned and asked if their son/daughter would like to take part in a group interview with the researcher about their experience of the SMBI. Five of the

six participants agreed to part in the interview, with the sixth expressing an interesting in taking part but being unable to due to the interview occurring at the same time as a family holiday. On the day of the interview, only four of the five participants attended. The parent of the absent participant phoned after the interview to explain that their son was unable to attend the group interview due to illness. The interviews were conducted with the researcher and used a semi-structured interview format (see Appendix 6)

6.6 Analysis

6.6.1 Data Collection. In order to be able to collate participants' questionnaire batteries (i.e., adolescent and parent), HbA1c readings and demographic information (e.g., age, gender, etc.), the researcher assigned each participant a unique participant identification number. The first question on each questionnaire battery asked the responded for the patient identification number, which was provided to the respondent by the researcher. The assessment battery responses for each respondent (i.e., adolescents and parents) across the different time points (i.e., baseline, 4 months, 8 months and 12 months) were exported from surveymonkey.com onto a spread sheet using the patient identification numbers to separate participants. These patient identification numbers were then used to collate the responses from different respondents (i.e., participant and parent) across the different time points for the same participant, on to a separate spread sheet. A separate spread sheet using these patient identification numbers was used to record HbA1c readings and demographic information for each participant.

6.6.2 Statistical Analysis

6.6.2.1 Power Calculation. Power for the proposed analysis was conservatively estimated using the paired t-test template. Using values for the mean and standard deviation of HbA1c measures from previous studies a sample size of 48 confers a power of 80% to detect a difference of 7.5 mmol/mol, at a statistical significance threshold of 0.05.

6.6.2.2 Missing Values. Missing values were analysed using Little's Missing Completely at Random (MCAR) Test in SPSS. For the purpose of the test each subscale was analysed separately. Little's MCAR Test was found to be non-significant for all variables and indicated that missing values within in each variable were missing in a completely random way.

Missing values were replaced with predicted values using the Expectation Maximization algorithm in SPSS. In order to increase the power of the prediction, the Expectation Maximisation algorithm for each subscale was based only on items associated with that respective subscale. Using this approach, all missing values were replaced with predicted values, giving a complete data set.

The T1DM Peer support questions had >34.1% missing items on each question and so it was not appropriate to use the Expectation Maximization algorithm in SPSS to replace them. Instead a zero was substituted for each missing value.

6.6.2.3 Overview. The results were analysed using IBM SPSS Statistics (SPSS) and aim to assess the effect of the SMBI on the dependent variables; Diabetes Management Adherence, Diabetes Knowledge, Self-efficacy, Illness Perception, Social Support, Diabetes Responsibility and Quality of Life. Sphericity was assessed

using Mauchly's Test of Sphericity and if the assumption of sphericity was not met the Greenhouse-Geisser was applied. Homogeneity of groups was assessed by Levene's Test. For measures that were found to be normally distributed mixed ANOVA's were used to assess the differences between participants in the comparison and treatment conditions. For measures that were found not to be normally distributed a non-parametric Friedman test of difference among repeated measures was conducted to assess differences over time for participants in the treatment and comparison groups. Pairwise comparisons were performed with a Bonferroni correction. Following the main analysis, mediation analysis was conducted on the dependent variables by means of multiple linear regression using the PROCESS macro for SPSS.

6.6.3 Approach to qualitative analysis. Qualitative analysis of the group interview with participants was undertaken using the same approach as the qualitative analysis of the pilot study interviews (see section 5.2.6.2). The results of the qualitative analysis of the main study are presented in Chapter 8.

Chapter 7: Results

7.1 Participant Characteristics

The overall mean age of participants at baseline was 14.27 years ($SD = 0.98$), which was similar across the comparison and treatment groups (comparison $M = 14.35$ years, $SD = 0.95$; treatment $M = 14.21$ years, $SD = 1.00$). Table 7.1 compares the gender, insulin regimen, type of diabetes clinic attended (i.e., public diabetes clinic versus private diabetes clinic) and current contact with a T1DM peer of participants in the comparison and treatment groups. The percentage of participants in the comparison and treatment groups did not differ significantly with regard to gender ($\chi^2 = 3.24$, $p = .072$), insulin regimen ($\chi^2 = 2.66$, $p = .103$) or diabetes clinic attended ($\chi^2 = 0.00$, $p = .982$). The percentage of participants in the comparison and treatment groups did differ significantly with regard to current contact with a T1DM peer at baseline ($\chi^2 = 10.27$, $p = .001$). A significantly higher percentage of participants in the treatment group had current contact with a T1DM peer than participants in the comparison group.

Table 7.1 *Breakdown of gender, insulin regimen, type of diabetes clinic attended and contact with T1DM peer of participants by group*

	Total % (N = 73)	Comparison % (n = 31)	Treatment % (n = 42)
Gender			
Male	58.9 (43)	71 (22)	50 (21)
Female	41.1 (30)	29 (9)	50 (21)
Insulin Regimen			
Injections	53.4 (39)	64.5 (20)	45.2 (19)
CSII	46.6 (34)	35.5 (11)	54.8 (23)
Diabetes Clinic Attended			
Public	90.4 (66)	90.3 (28)	90.5 (38)
Private	9.6 (7)	9.7 (3)	9.5 (4)
Contact with T1DM Peer			
Yes	63 (46)	41.9 (13)	78.6 (33)
No	37 (27)	58.1 (18)	21.4 (9)

For the parent questionnaire battery, 69 (94.5%) of the respondents were mothers of the participant, while only 4 (5.5%) were fathers of the participant. Of the four parent respondents who were fathers of the participant, all were fathers of participants in the comparison condition, meaning that all parent respondents in the treatment group were mothers of the participants.

Of the 134 participants eligible to take part in the study, 33 declined the invitation to take part in the study. Table 7.2 compares the gender, insulin regimen and type of diabetes clinic attended of participants who initially agreed to take part in the study with those who declined the offer to part take in the study. This group of potential participants who declined the invitation to take part in the study did not differ significantly from the group of participants who agreed to take part with regard to gender ($\chi^2 = 0.06, p = .831$) or diabetes clinic attended ($\chi^2 = 3.64, p = .056$). However, the two groups did differ with regard to insulin regimen ($\chi^2 = 4.02, p = .045$), with significantly more potential participants using CSII choosing not to engage in the study.

Table 7.2 *Breakdown of gender, insulin regimen and type of diabetes clinic attended of participants who initially agreed to engage in the study versus those who declined the invitation to engage in the study*

	Total % (N = 134)	Remained % (n = 101)	Dropped Out % (n = 33)
Gender			
Male	56 (75)	55.4 (56)	57.6 (19)
Female	44 (59)	44.6 (45)	42.4 (14)
Insulin Regimen			
Injections	54.5 (73)	59.4 (60)	39.4 (13)
CSII	45.5 (61)	40.6 (41)	60.6 (20)
Diabetes Clinic Attended			
Public	85.8 (115)	89.1 (90)	75.8 (25)
Private	14.2 (19)	10.9 (11)	24.2 (8)

Of the 101 participants who initially agreed to take part in the study, 28 did not attend for the collection of baseline data and so were excluded from the study. Table 7.3 compares the gender, insulin regimen and type of diabetes clinic attended of participants who took part in the study versus those who failed to attend for the baseline data collection and so were excluded from the study. This group of participants who failed to attend for the baseline data collection did not differ significantly from the participants who engaged in the study with regards to gender ($\chi^2 = 1.28, p = .259$) or diabetes clinic attended ($\chi^2 = 0.46, p = .498$). However, the two groups did differ with regard to insulin regimen ($\chi^2 = 3.91, p = .048$), with significantly more participants using CSII not attending for the collection of baseline data.

Table 7.3 *Breakdown of gender, insulin regimen and type of diabetes clinic attended of participants who took part in the study versus those who failed to attend for the baseline data collection and so were excluded from the study*

	Total % (N = 101)	Remained % (n = 73)	Dropped Out % (n = 28)
Gender			
Male	55.4 (56)	58.9 (43)	46.4 (13)
Female	44.6 (45)	41.1 (30)	53.6 (15)
Insulin Regimen			
Injections	59.4 (60)	53.4 (39)	75 (21)
CSII	40.6 (41)	46.6 (34)	25 (7)
Diabetes Clinic Attended			
Public	89.1 (90)	90.4 (66)	85.7 (24)
Private	10.9 (11)	9.6 (7)	14.3 (4)

7.2 Glycaemic Control

HbA1c scores were used as a measure of glycaemic control. Descriptive statistics for HbA1c for each group over time are presented in Table 7.4. There was no statistically significant interaction effect: $F(2.684, 187.885) = 0.524, p = .646$, partial $\eta^2 = .007$). Neither

the main effect of group, $F(1, 70) = 0.271, p = .604$, partial $\eta^2 = .004$, nor time were significant: $F(2.684, 187.885) = 1.733, p = .167$, partial $\eta^2 = .024$).

Table 7.4 *Descriptive statistics (Mean and Standard Deviation) for HbA1c (DCCT%) by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	8.22	0.83	8.19	0.80	8.05	1.03	7.95	0.96
Treatment	7.97	1.01	8.1	0.98	8.03	1.02	7.91	1.04

As can be seen in Table 7.2, the mean HbA1c at baseline (Time 1) was slightly higher in the comparison group compared to the treatment group. Over the four time points the mean HbA1c in the comparison group reduced slightly, while the mean HbA1c in the treatment group stayed relatively constant. Overall, mean HbA1c was lower at each of the four time points in the treatment group relative to the comparison group, indicating better glycaemic control among participants in the treatment group.

7.3 Quality of Life

Participants' quality of life was measured using four different versions of the Pediatric Quality of Life Inventory (PedsQL); the PedsQL – Generic Core (Child Score), the PedsQL – Generic Core (Parent Score), the PedsQL – Diabetes Module (Child Score) and the PedsQL – Diabetes Module (Parent Score). Both versions of the PedsQL – Generic Core (i.e., child score and parent score) elicit an overall total score and four subscale scores, while the two versions of the PedsQL – Diabetes Module (i.e., child score and parent score) elicit a total score and five subscale scores. However, only the total scores and not the subscale scores were included in the analysis. Mixed ANOVA's were performed to assess the effect of SMBI on the Quality of Life measures.

7.3.1 PedsQL – Generic Core (Child Score) Total Score. Descriptive statistics for the PedsQL - Generic Core (Child Score) Total Score scale for each group over time are presented in Table 7.5. A statistically significant interaction effect was not found: $F(2.418, 169.273) = 0.514, p = .634, \text{partial } \eta^2 = 0.007$. Main effect for time was not significant: $F(2.418, 169.273) = 0.644, p = .555, \text{partial } \eta^2 = 0.009$. The main effect for group was not significant: $F(1, 70) = 0.364, p = .548, \text{partial } \eta^2 = 0.005$.

Table 7.5 *Descriptive statistics (Mean and Standard Deviation) for the PedsQL - Generic Core (Child Score) Total Score scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	80.84	11.67	81.63	12.13	80.35	11.68	80.37	12.48
Treatment	80.54	12.87	78.82	13.97	78.38	12.68	78.97	11.10

7.3.2 PedsQL – Generic Core (Parent Score) Total Score. Descriptive statistics for the PedsQL - Generic Core (Parent Score) Total Score scale for each group over time are presented in Table 7.6. The PedsQL - Generic Core (Parent Score) Total Score scale was found to be not normally distributed following Skewness and Kurtosis assessment, therefore the results should be interpreted with caution. A statistically significant interaction effect was not observed: $F(16.329,9039.771) = 0.126, p = .928, \text{partial } \eta^2 = 0.002$. The main effect for time was significant: $F(16.329,9039.771) = 4.109, p = .010, \text{partial } \eta^2 = 0.055$. The pairwise comparison of total (comparison and treatment) mean scores suggests a significant decrease in the mean scores between the Time 3 (M = 77.44) and Time 4 (M = 74.34) assessments ($p = .17$). The main effect for group was not significant: $F(1,70) = 0.123, p = .727, \text{partial } \eta^2 = 0.002$.

Table 7.6 *Descriptive statistics (Mean and Standard Deviation) for the PedsQL - Generic Core (Parent Score) Total Score scale by group over time.*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	76.98	11.27	76.72	11.58	77.25	12.25	73.45	12.17
Treatment	77.72	13.69	78.11	15.40	77.58	13.88	74.98	13.19

7.3.3 PedsQL – Diabetes Module (Child Score) Total Score. Descriptive statistics for the PedsQL – Diabetes Module (Child Score) Total Score scale for each group over time are presented in Table 7.7. A statistically significant interaction effect was found: $F(2.296, 160.725) = 3.547, p = .025, \text{partial } \eta^2 = 0.048$. Thus, 4.8% of variance in this scale may be explained by the SMBI. Given the significant interaction effect the mean scores were plotted and a disordinal interaction was detected (Figure 7.1).

Table 7.7 *Descriptive statistics (Mean and Standard Deviation) for the PedsQL – Diabetes Module (Child Score) Total Score scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	63.98	14.51	67.99	13.52	66.99	12.66	66.90	12.37
Treatment	68.91	13.66	66.88	11.80	66.15	11.01	67.52	10.92

The Test of Simple Effects did not detect significant differences between the mean scores of the comparison group ($F(2.296, 160.725) = 1.77, p > .05$) or treatment group ($F(3,210) = 1.15, p > .05$). Group scores differed significantly on Time 1 ($F(1,70) = 8.46, p < .05$), but not on Time 2 ($F(1,70) = 0.429, p > .05$), Time 3 ($F(1,70) = 0.246, p > .05$), or Time 4 ($F(1,70) = 0.133, p > .05$). This suggests that at baseline participants in the comparison group rated themselves as having lower problems with regard to how diabetes impacts their

quality of life compared to the treatment group. However, by Time 2 both groups rated themselves as having similar problems with regard to how diabetes impacts their quality of life and remained similar at Time 3 and Time 4.

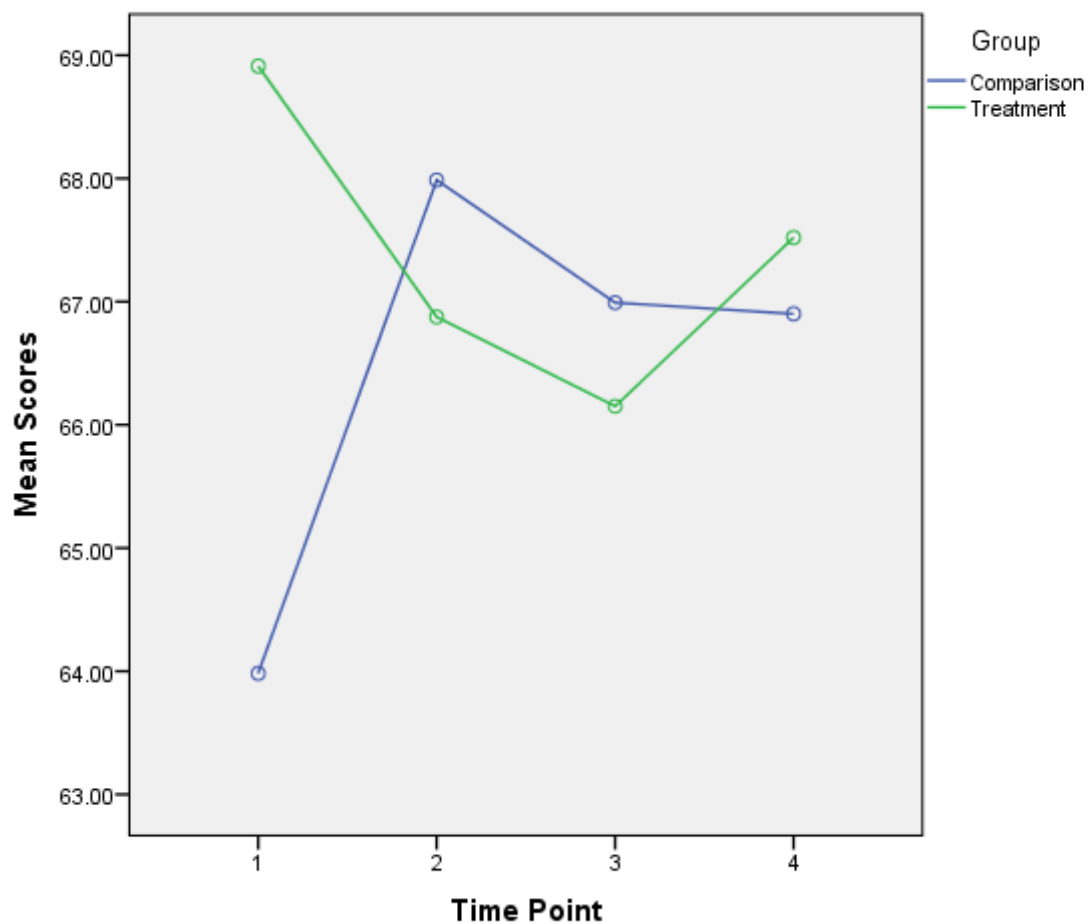


Figure 7.1 Illustration of the interaction effect between the treatment and comparison group’s scores over time for the PedsQL – Diabetes Module (Child Score) Total Score scale.

7.3.4 PedsQL – Diabetes Module (Parent Score) Total Score. Descriptive statistics for the PedsQL – Diabetes Module (Parent Score) Total Score scale for each group over time are presented in Table 7.8. The PedsQL – Diabetes Module (Parent Score) Total Score scale

was not normally distributed, as assessed by Skewness and Kurtosis, and so the results should be interpreted with caution. There was no statistically significant interaction effect: $F(3,210) = 0.162, p = .922, \text{partial } \eta^2 = 0.002$. The main effect for time was not significant: $F(3,210) = 1.787, p = .151, \text{partial } \eta^2 = 0.025$. The main effect for group was significant: $F(1,70) = 5.764, p = .019, \text{partial } \eta^2 = 0.076$.

Table 7.8 *Descriptive statistics (Mean and Standard Deviation) for the PedsQL – Diabetes Module (Parent Score) Total Score scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	62.19	11.85	62.18	12.04	62.19	11.63	59.84	11.27
Treatment	68.59	12.45	69.12	15.76	67.42	12.69	66.15	11.73

7.4 Social Support

Perceptions of social support was measured using the parent version of the Healthcare Climate Questionnaire (HCCQ-Parent), the adolescent version of the Healthcare Climate Questionnaire (HCCQ-Adolescent) and a T1DM peer support questionnaire that asked participants to respond on a seven point Likert scale the degree to which they agreed with statements about the support provided by T1DM peers. An average of the seventeen Likert responses was then obtained to get an overall measure of participants’ perceptions of the level of support they receive from peers with T1DM. The T1DM peer support questionnaire and both versions of the HCCQ elicited overall total scores. Parametric analysis (i.e. Mixed ANOVA) and non-parametric analysis (i.e. Friedman’s test) were applied to determine the effect on the SMBI on the Social Support.

7.4.1 HCCQ-Parent. Descriptive statistics for the HCCQ-Parent scale for each group over time are presented in Table 7.9. A non-parametric Friedman test of differences among repeated measures was conducted to assess the differences on the HCCQ-Parent scale over time. A statistically significant difference over time was not observed for the comparison group: $\chi^2(3) = 3.295, p = .348$. However, treatment group scores differed significantly over time $\chi^2(3) = 10.003, p = .019$. Pairwise comparisons suggested a significant increase in scores between Time 1 and Time 3 ($p = .024$).

Table 7.9 *Descriptive statistics (Mean Rank and Median) for the HCCQ-Parent scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn
Comparison	35.93	5.96	33.70	6.07	32.23	6.27	31.52	5.86
Treatment	36.90	6.1	38.50	6.33	39.55	6.51	40.06	6.47

As can be seen from Table 7.9, the mean rank scores in the treatment group increased gradually at each subsequent time point. Whereas in the comparison group the mean rank score decreased over each subsequent time point.

7.4.2 HCCQ-Adolescent. Descriptive statistics for the HCCQ-Adolescent scale for each group over time are presented in Table 7.10. There was no statistically significant interaction effect: $F(2.102, 147.169) = 0.076, p = .934, \text{partial } \eta^2 = 0.001$. The main effect for time did demonstrate a statistically significant difference in participants scores: $F(2.102, 147.169) = 3.390, p = .034, \text{partial } \eta^2 = 0.046$. The pairwise comparison of total group (comparison and treatment) mean scores, suggests that participant's scores had significantly decreased ($p < .01$) between the Time 3 (Mean= 4.68) and Time 4 (M = 4.40) time points. There was no significant main effect for group: $F(1, 70) = 0.090, p = .765, \text{partial } \eta^2 = 0.001$.

Table 7.10 *Descriptive statistics (Mean and Standard Deviation) for the HCCQ-Adolescent scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	4.65	2.84	4.03	2.59	4.55	2.70	4.38	2.67
Treatment	3.87	2.81	4.06	2.78	4.78	2.52	4.42	2.56

7.4.3 T1DM Peer Support Questionnaire. Descriptive statistics for the Peer Support Questionnaire for each group over time are presented in Table 7.11. A non-parametric Friedman test of differences among repeated measures was conducted to assess the differences between the comparison and treatment groups on the T1DM Peer Support Questionnaire over time. A statistically significant difference on the T1DM Peer Support questionnaire over time was not observed for the comparison group: $\chi^2(3) = 1.536, p = .674$. A statistically significant difference on the T1DM Peer Support questionnaire over time was also not observed for the treatment group: $\chi^2(3) = 5.133, p = .162$.

Table 7.11 *Descriptive statistics (Mean Rank and Median) for the Peer Support Question by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn
Comparison	2.45	0	2.57	02.35	0	7	2.63	0
Treatment	2.12	78.5	2.65	85.5	2.64	76	2.58	77

As can be seen in Table 7.11, there was a non-significant increase in the median ranks in the treatment group as time 2, 3 and 4 relative to time 1. The T1DM Peer Support Questionnaire completed by the comparison group contained a significant number of missing values. Because of the significant number of missing values it was not possible to use

expectation maximisation to impute the missing values, as had been done with the other questionnaires, instead each missing value was replaced with 0. This is why the median value in the comparison group at times 1, 3 and 4 is 0.

7.5 Illness Perceptions

Participants' illness perceptions were measured using the Brief Illness Perceptions Questionnaire (Brief IPQ). The Brief IPQ elicits eight subscales: Consequences, Timeline, Personal Control, Treatment Control, Identity, Illness Concern, Coherence and Emotional Representation. However, only the Personal Control, Identity, Coherence and Emotional Representation subscales were included in the analysis, as the other subscales were not relevant to the theoretical model. Mixed ANOVA's, with one repeated independent variable (time) and one non-repeated independent variable (group), were used to assess the effect of the SMBI on each subscale of the Brief IPQ.

7.5.1 Personal Control. Descriptive statistics for the Personal Control subscale for each group over time are presented in Table 7.12. The treatment groups' mean perceptions of personal control became less threatening at each subsequent time point after the introduction on the SMBI, whereas the comparison groups' mean perceptions of personal control became more threatening at each subsequent time point.

Table 7.12 *Descriptive statistics for the Brief IPQ Personal Control subscale (Mean and Standard Deviation) by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	6.54	2.08	6.84	1.94	7.50	1.36	7.54	1.32
Treatment	7.15	1.7	7.11	1.41	6.98	1.20	7.05	1.60

A statistically significant interaction effect was found: $F(2.421, 169.457) = 4.331, p = .010$, partial $\eta^2 = 0.058$. Given the significant interaction effect, the mean scores were plotted and a disordinal interaction was detected (Figure 7.2).

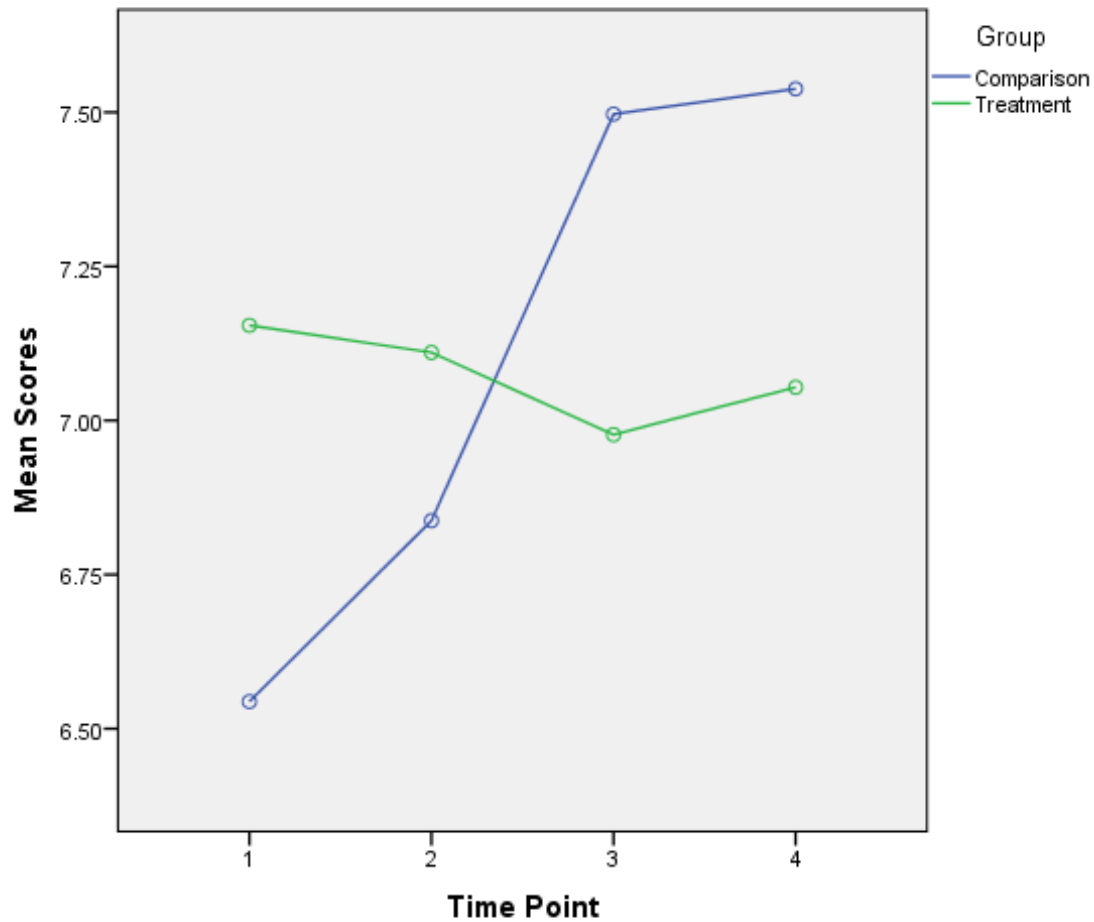


Figure 7.2 Illustration of the interaction effect between the treatment and comparison group's scores over time for the Personal Comparison subscale of the Brief IPQ

A Statistically significant difference was observed between scores taken at different time points in the comparison condition: $F(2.421, 169.457) = 288.23, p < .05$. However, participants' scores in the treatment condition did not significantly differ over time:

$F(2.421, 169.457) = 0.18, p > .05$. Group scores did not significantly differ at the Time 1 [$F(1, 70) = 4.11, p > .05$], Time 2 [$F(1, 70) = 0.80, p > .05$], or Time 3 [$F(1, 70) = 2.98, p > .05$] time points. A significant difference between the groups was evident at Time 4: $F(1, 70) = 549.58, p < .05$. This suggests that participants' perceptions of illness control changed significantly in the comparison group over the four time points but remained relatively stable in the treatment group.

7.5.2 Identity. Descriptive statistics for the Identity subscale for each group over time are presented in Table 7.13. A statistically significant interaction effect was not observed: $F(2.526, 176.812) = 1.123, p = .336$, partial $\eta^2 = 0.016$. The main effect of time was not significant: $F(2.526, 176.812) = 1.415, p = .244$, partial $\eta^2 = 0.020$. The main effect of group was also not significant: $F(1, 70) = 0.051, p = .822$, partial $\eta^2 = 0.001$.

Table 7.13 *Descriptive statistics for the Brief IPQ Identity subscale (Mean and Standard Deviation) by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	4.53	1.88	4.62	1.75	4.87	1.99	4.55	1.99
Treatment	4.40	2.01	4.49	1.81	4.83	2.03	5.19	2.28

7.5.3 Coherence. Descriptive statistics for the Coherence subscale for each group over time are presented in Table 7.14. The Brief IPQ Coherence scale wasn't normally distributed as assessed by Skewness and Kurtosis; thus the results should be treated with caution. There was no statistically significant interaction effect: $F(2.263, 158.408) = 0.971, p = .390, \eta^2 = .014$. The main effect for time was not significant: $F(2.263, 158.408) = 0.531, p$

= .611, $\eta^2 = 0.008$. The main effect for group was also not significant: $F(1, 70) = 0.667, p = .576, \eta^2 = 0.009$.

Table 7.14 *Descriptive statistics for the Brief IPQ Coherence subscale (Mean and Standard Deviation) by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	7.64	2.12	8.03	1.39	8.02	1.52	7.77	1.86
Treatment	8.19	1.73	7.93	1.87	8.28	1.57	8.15	1.48

7.5.4 Emotional Representation. Descriptive statistics for the Emotional Representation subscale for each group over time are presented in Table 7.15. There was no statistically significant interaction effect: $F(2.724, 190.688) = 1.160, p = .324$, partial $\eta^2 = 0.016$. The main effect for time was not significant: $F(2.724, 190.688) = 1.568, p = .202$, partial $\eta^2 = 0.022$. There was also no significant main effect for group: $F(1, 70) = 0.052, p = .820$, partial $\eta^2 = 0.001$.

Table 7.15 *Descriptive statistics for the Brief IPQ Emotional Representation subscale (Mean and Standard Deviation) by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	4.65	2.84	4.03	2.59	4.55	2.70	4.38	2.67
Treatment	3.87	2.81	4.06	2.78	4.78	2.52	4.42	2.56

7.6 Self-Efficacy

Participants' self-efficacy was measured using the Self-Efficacy for Diabetes Scale (SED). The SED scale elicits an overall total score as well as three subscale scores.

However, only the total score was included in the analysis. A mixed ANOVA was performed to assess the effect of the SMBI on the self- efficacy. Descriptive statistics for the SED total scale for each group over time are presented in Table 7.16.

There was no statistically significant interaction effect: $F(2.704, 189.265) = 0.939, p = .415$, partial $\eta^2 = 0.013$. However, the main effect for time showed statistically significant differences over the four time points: $F(2.704, 189.265) = 6.050, p < .01$, partial $\eta^2 = 0.080$. Pairwise comparisons of the total group (comparison and treatment) mean scores at each time point detected a significant increase ($p = .029$) between the Time 1 (M = 4.66) and Time 2 (M = 4.88) time points, between the Time 1 and Time 3 (M = 4.86) time points ($p = .035$) and between the Time 1 and Time 4 (M = 4.91) time points ($p < .01$). The main effect of group was not significant: $F(1, 70) = 0.301, p = .585$, partial $\eta^2 = 0.004$.

Table 7.16 *Descriptive Statistics (Mean and Standard Deviation) for the SED total scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	4.54	0.743	4.88	0.73	4.80	0.69	4.90	0.65
Treatment	4.74	0.63	4.87	0.68	4.90	0.68	4.91	0.52

7.7 Diabetes Knowledge

Diabetes Knowledge was measured using the ADKnowl. An average of the eight subscales of the ADKnowl (i.e., Diabetes Treatment and Testing, Management of Diabetes when Ill, General Management of Insulin and Insulin use, Hypoglycaemia, Physical Activity, Diet and Food, Reducing the Risk of Developing Diabetes Complications, and Blood Glucose Levels and HbA1c) was obtained for each participant to give an overall total ADKnowl

score. This total score did not fulfil the assumptions of ANOVA and so Friedman’s test was used.

Descriptive statistics for the ADKnowl total score for each group over time are presented in Table 7.17. A non-parametric Friedman test of differences among repeated measures was conducted to assess if there were differences in the ADKnowl total scores over time for the comparison and the treatment groups. A statistically significant difference in the ADKnowl total score over time was not observed for the comparison group: $\chi^2(3) = 1.92, p = .59$. However, a statistically significant difference in the ADKnowl score over time was observed for the treatment group: $\chi^2(3) = 19.10, p < .001$. Pairwise comparison with a Bonferroni correction suggested significant increase in scores between Time 1 and Time 2 ($p < .001$), Time 1 and Time 3 ($p = .001$) and Time 1 and Time 4 ($p < .001$).

Table 7.17 *Descriptive statistics (Mean Rank and Median) for the ADKnowl total score for each group over time*

	Time 1		Time 2		Time 3		Time 4	
	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn
Comparison	2.23	81.76	2.61	85.66	2.55	83.4	2.61	86.25
Treatment	1.83	80.11	2.98	87.91	2.37	85.12	2.82	88.84

As can be seen from Table 7.17, the mean rank scores in the treatment group increased significantly after the introduction of the SMBI (i.e., from Time 1 to Time 2). This increase was maintained at the subsequent time points. Although the mean rank scores in the comparison group also increased after the introduction of the SMBI, it was to a much smaller extent and not statistically significant.

7.8 Diabetes Responsibility

Participants' diabetes responsibility was measured using two separate diabetes responsibility scales; the adolescent version of the Diabetes Family Responsibility Scale (DFRQ-Adolescent) and the parent version of the Diabetes Family Responsibility Scale (DFRQ-Parent). The DFRQ-Adolescent and DFRQ-Parent each elicits single overall total scores. A mixed ANOVA was performed to assess the effect of SMBI on the parent version of the Diabetes Responsibility scales. The adolescent version of the Diabetes Family Responsibility Scale did not fulfil the ANOVA's assumptions and so was assessed using the non-parametric Friedman's test.

7.8.1 DFRQ-Adolescent. Descriptive statistics for the DFRQ-Adolescent total scores for each group over time are presented in Table 7.18. A non-parametric Friedman test of differences among repeated measures was conducted to assess the differences on the DFRQ-Adolescent scale over time for the comparison and treatment groups. A statistically significant difference in the DFRQ-Adolescent scale over time was not observed for the comparison group: $\chi^2(3) = 7.155$, $p = .067$. A statistically significant difference in the DFRQ-Adolescent scale over time was also not observed for the treatment group: $\chi^2(3) = 4.975$, $p = .174$.

Table 7.18 *Descriptive statistics (Mean Rank and Median) for the DFRQ-Adolescent scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn
Comparison	3	33.14	2.48	31	2.26	30	2.26	30
Treatment	2.82	30	2.21	29	2.49	28	2.48	29

As can be seen from Table 7.18, the mean rank scores in the treatment group increased slightly over each subsequent time point. In the comparison group the mean rank scores decreased over each subsequent time point.

7.8.2 DFRQ-Parent. Descriptive statistics for the DFRQ-Parent scale for each group over time are presented in Table 7.19. There was no statistically significant interaction effect: $F(3, 210) = 2.231, p = .368, \text{partial } \eta^2 = 0.005$. The main effect of time showed statistically significant differences between participants' scores over time: $F(3,210) = 9.525, p < .01, \text{partial } \eta^2 = 0.120$. Pairwise comparisons of the total group (comparison and treatment) means for each time point, suggest a significant decrease in scores between the Time 1 (M = 35.40) and Time 3 (M = 33.52) time points ($p < .01$) and the Time 1 and Time 4 (M = 34.09) time points ($p = .027$). The main effect of group was not significant: $F(1, 70) = 7, p = .010, \text{partial } \eta^2 = 0.091$.

Table 7.19 *Descriptive statistics (Mean and Standard Deviation) for the DFRQ-Parent scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M	SD	M	SD	M	SD	M	SD
Comparison	36.95	4.15	36.37	4.48	34.66	4.06	35.55	4.99
Treatment	34.30	4.90	33.97	4.43	32.70	3.85	33.05	4.55

7.9 Diabetes Management Adherence

Participants' diabetes management adherence was measured using the Self-Care Inventory (SCI). The SCI elicits an overall total score and four subscale scores. However, only the total score was included in the analysis. The SCI did not fulfil the ANOVA's assumptions and so was assessed using the non-parametric Friedman's test.

7.9.1 SCI-Total. Descriptive statistics for the SCI-Total scale for each group over time are presented in Table 7.20. A non-parametric Friedman test of differences among repeated measures was conducted to assess the differences between scores on the SCI-Total scale over time for the comparison and treatment groups. A statistically significant difference in the SCI-Total scale over time was observed for the comparison group: $\chi^2(3) = 3.106$, $p = .376$. A statistically significant difference in the SCI-Total scale over time was also not observed for the treatment group: $\chi^2(3) = 3.716$, $p = .294$.

Table 7.20 *Descriptive statistics (Mean Rank and Median) for the SCI-Total scale by group over time*

	Time 1		Time 2		Time 3		Time 4	
	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn	M Rank	Mdn
Comparison	38.65	4.14	42.65	4.23	38.55	4.20	39.23	4.16
Treatment	34.96	4	32.11	3.86	35.04	4.01	34.55	3.87

7.10 Mediation Analysis

The SMBI was hypothesised to result in an overall improvement in glycaemic control and quality of life for participants undergoing the intervention. The underlying model through which the SMBI was hypothesised to effect glycaemic control and quality of life is summarised in Figure 7.3. According to the model, the SMBI leads to an increase in social support, self-efficacy and diabetes knowledge and better illness perceptions. It was hypothesised that the positive change in these psychosocial variables would result in specific changes in the participants' behaviour, namely they will begin to take more responsibility for their diabetes management and be more adherent to their diabetes management. This increase in diabetes management responsibility and adherence was then hypothesised to result in an increase in quality of life and a decrease in HbA1c.

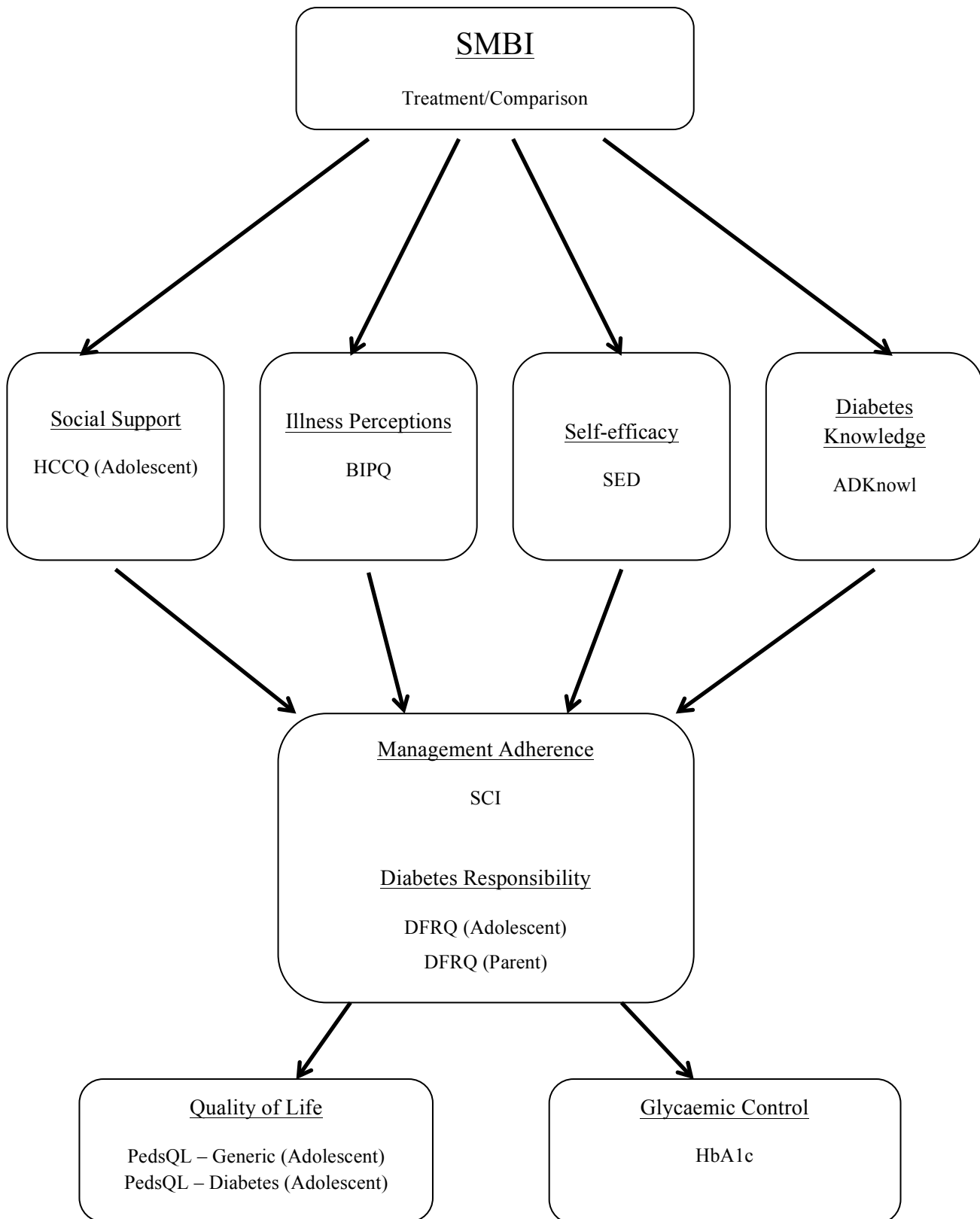


Figure 7.3 Model of SMBI including measures used for dependent variables

Table 7.21 *Groupings of IV (independent variable), DV (dependent variable) and mediators used in the multiple mediation analysis*

IV Group	DV Measure	Mediator	Mediator Measures
Group	SCI	Social Support	HCCQ (Adolescent)
		Illness Perceptions	Brief IPQ
		Self-efficacy	SED
		Diabetes Knowledge	ADKnowl
Group	DRFQ (Adolescent)	Social Support	HCCQ (Adolescent)
		Illness Perceptions	Brief IPQ
		Self-efficacy	SED
		Diabetes Knowledge	ADKnowl
Group	DRFQ (Parent)	Social Support	HCCQ (Adolescent)
		Illness Perceptions	Brief IPQ
		Self-efficacy	SED
		Diabetes Knowledge	ADKnowl
Group	HbA1c	Management Adherence	SCI
		Diabetes Responsibility	DFRQ (Adolescent)
			DFRQ (Parent)
Group	PedsQL – Diabetes (Adolescent)	Management Adherence	SCI
		Diabetes Responsibility	DFRQ (Adolescent)
			DFRQ (Parent)
Group	PedsQL – Generic (Adolescent)	Management Adherence	SCI
		Diabetes Responsibility	DFRQ (Adolescent)
			DFRQ (Parent)

This model assumes a mediating effect of social support, illness perceptions, self-efficacy and diabetes knowledge on diabetes management adherence and diabetes responsibility. It also assumes a mediating effect of diabetes management adherence and diabetes responsibility on glycaemic control and quality of life. To test this model, multiple mediation analyses were undertaken using the PROCESS macro for SPSS. This macro allowed for mediation analysis to be carried out simultaneously for related dependent variables. Indirect effects that have a 95% bootstrap confidence interval (BCI) which do not contain zero indicate statistically significant mediated relationships between the SMBI and the particular outcome variable (i.e., quality of life, glycaemic control, diabetes management

adherence and diabetes responsibility) through the indirect effects of the particular mediators (i.e., social support, illness perceptions, self-efficacy, diabetes knowledge, management adherence and diabetes responsibility). Table 7.21 outlines the groupings of dependent variables (i.e., questionnaire scales) that were combined for the mediation analysis, while the measures that were used for each dependent variable in the model can be seen in Figure 7.3.

7.10.1 Social Support, Illness Perceptions, Self-efficacy and Diabetes Knowledge as Mediators of Management Adherence and Diabetes Responsibility. The effect of social support, illness perceptions, self-efficacy and diabetes knowledge as mediators of the SMBI on management adherence and diabetes responsibility was analysed. The HCCQ completed by adolescents was used as the measure of social support in the mediation analysis rather than the HCCQ completed by the parents or the peer support questionnaire, as it was felt that adolescents' perceptions of the support they received from the DHCT was the primary aspect of social support targeted by the SMBI. Separate mediation analysis was undertaken for each outcome variable (i.e., management adherence, adolescent reports of diabetes responsibility and parent reports of diabetes responsibility).

The mediation analysis model used for analysing social support, illness perceptions, self-efficacy and diabetes knowledge as a mediator of the SMBI on management adherence is summarised in Figure 7.4, with the SMBI group (i.e., treatment versus comparison) as the independent variable (X), management adherence as the dependent variables (Y) and the measures of social support, illness perceptions, self-efficacy and diabetes knowledge as the mediators (M).

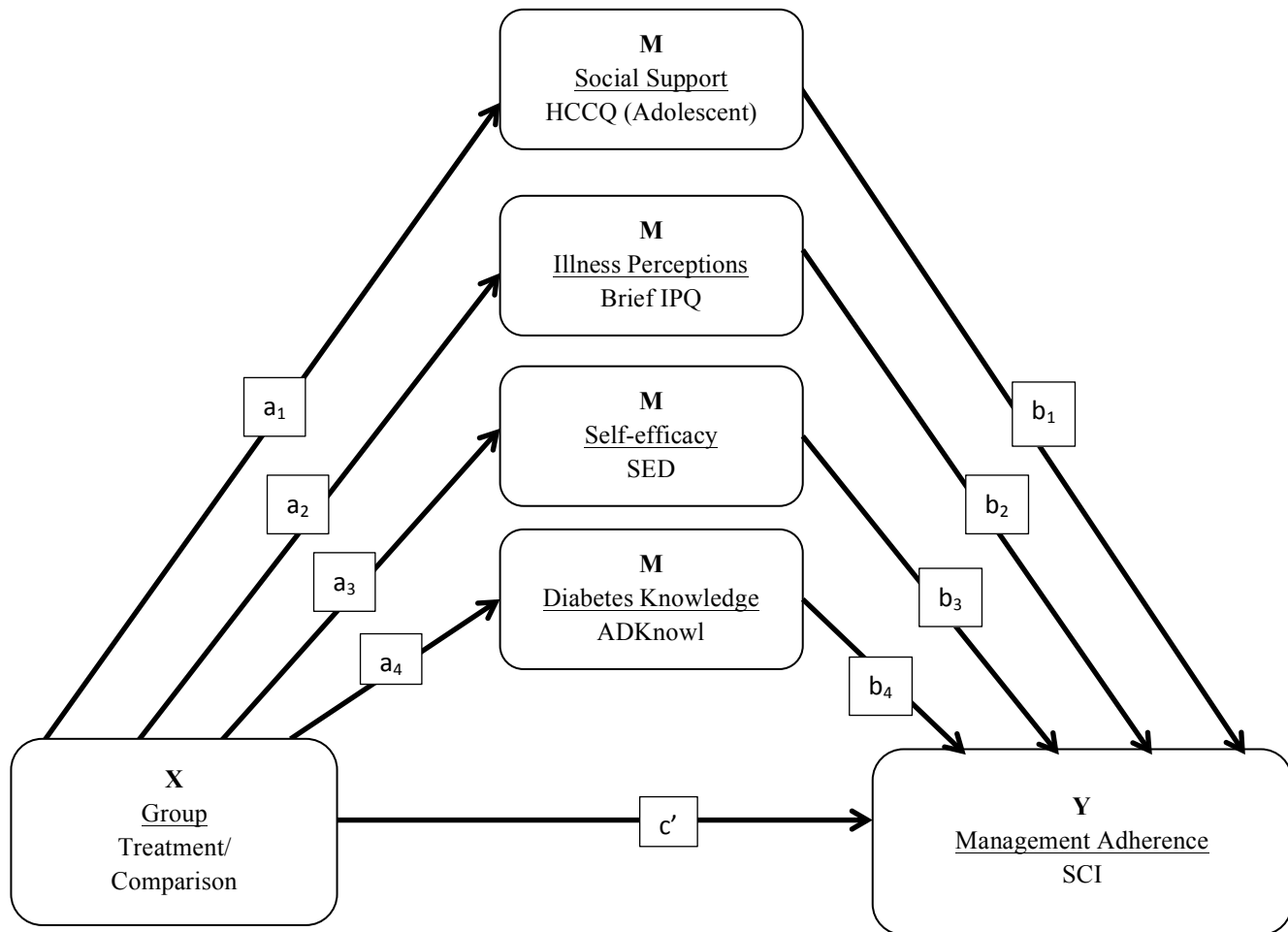


Figure 7.4 Mediation analysis path model of group as a predictor of management adherence, mediated by social support, illness perceptions, self-efficacy and diabetes knowledge, where path ab represents the indirect effect (mediation effect) and path c represents the direct effect

An overall significant indirect effect of social support, illness perceptions, self-efficacy and diabetes knowledge on management adherence was not found (indirect effect of X on Y; effect = .04, confidence intervals = -.10, 0.27). This suggests that social support, illness perceptions, self-efficacy and diabetes knowledge did not mediate the effect of the SMBI on management adherence.

The mediation analysis model used for analysing social support, illness perceptions, self-efficacy and diabetes knowledge as a mediator of the SMBI on adolescent reports of diabetes responsibility is summarised in Figure 7.5, with the SMBI group (i.e., treatment versus comparison) as the independent variable (X), adolescent reports of diabetes responsibility as the dependent variables (Y) and the measures of social support, illness perceptions, self-efficacy and diabetes knowledge as the mediators (M).

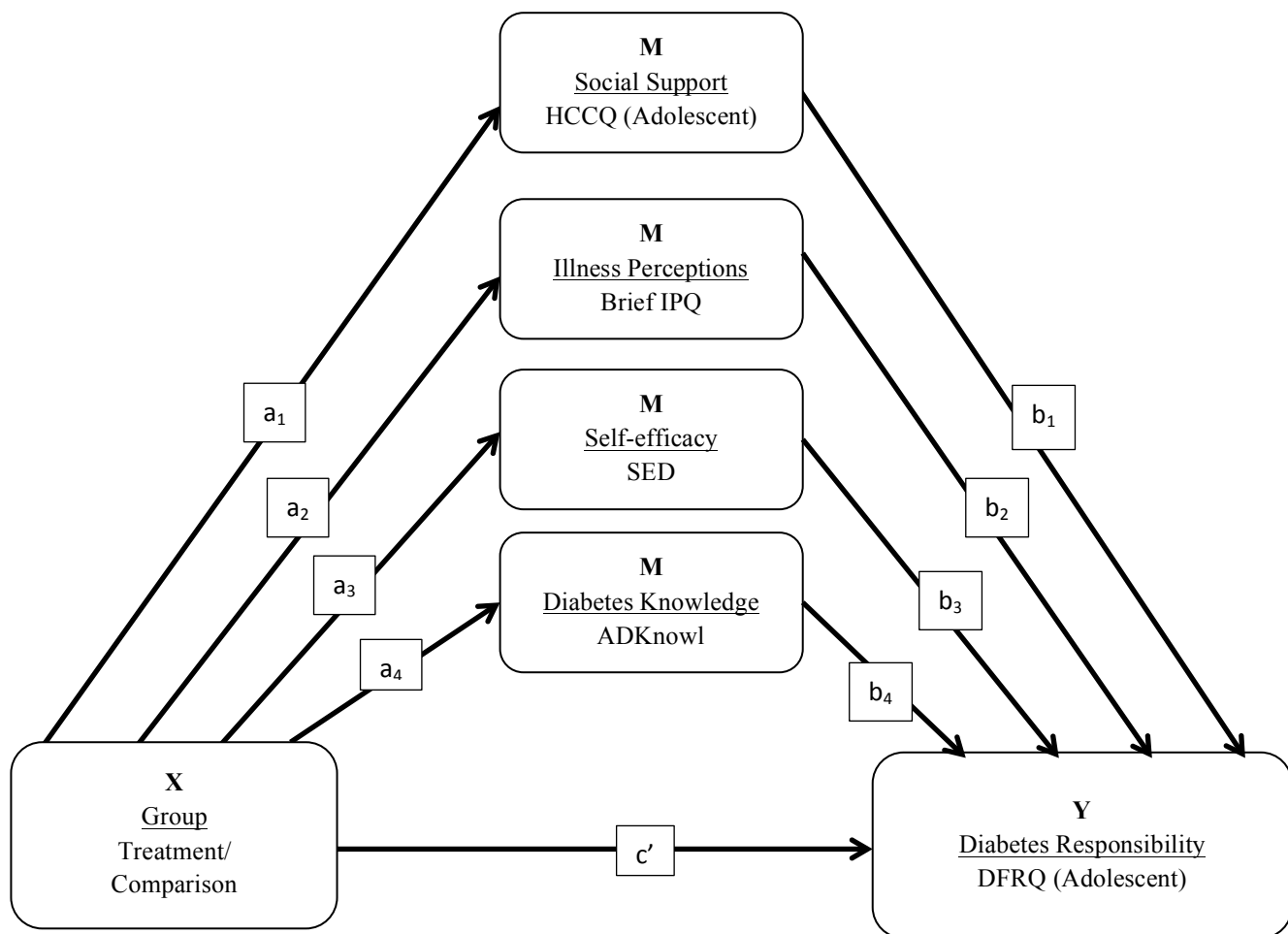


Figure 7.5 Mediation analysis path model of group as a predictor of parent reports of diabetes responsibility, mediated by social support, illness perceptions, self-efficacy and diabetes knowledge, where path ab represents the indirect effect (mediation effect) and path c represents the direct effect

An overall significant indirect effect of social support, illness perceptions, self-efficacy and diabetes knowledge on adolescent reports of diabetes responsibility was not found (indirect effect of X on Y; effect = -.11, confidence intervals = -1.22, 0.80). This suggests that social support, illness perceptions, self-efficacy and diabetes knowledge did not mediate the effect of the SMBI on adolescent reports of diabetes responsibility.

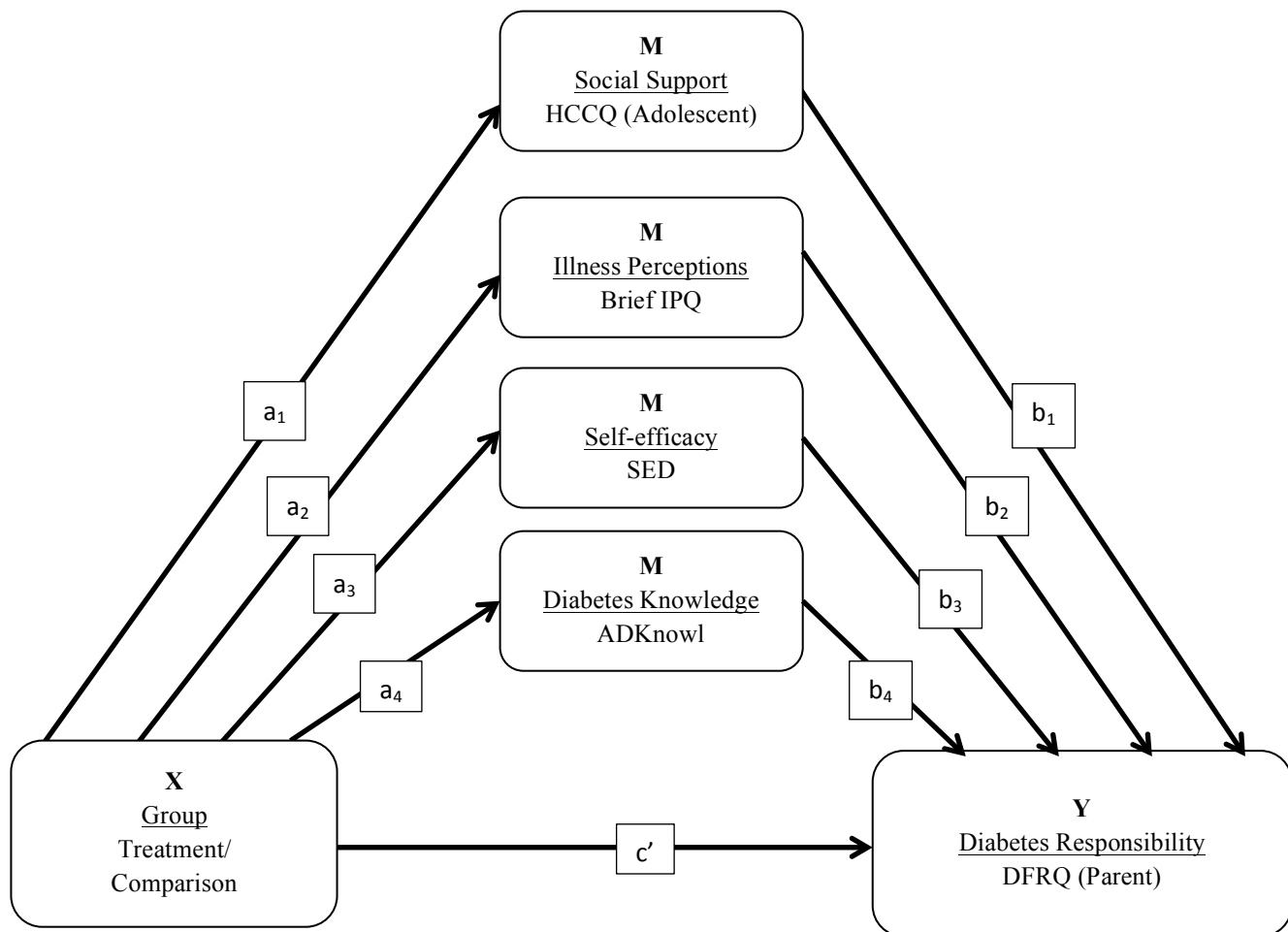


Figure 7.6 Mediation analysis path model of group as a predictor of adolescents reports of diabetes responsibility, mediated by social support, illness perceptions, self-efficacy and diabetes knowledge, where path ab represents the indirect effect (mediation effect) and path c represents the direct effect

The mediation analysis model used for analysing social support, illness perceptions, self-efficacy and diabetes knowledge as a mediator of the SMBI on parent reports of diabetes responsibility is summarised in Figure 7.6, with the SMBI group (i.e., treatment versus comparison) as the independent variable (X), parent reports of diabetes responsibility as the dependent variables (Y) and the measures of social support, illness perceptions, self-efficacy and diabetes knowledge as the mediators (M).

An overall significant indirect effect of social support, illness perceptions, self-efficacy and diabetes knowledge on parent reports of diabetes responsibility was not found (indirect effect of X on Y; effect = -.08, confidence intervals = -1.03, 0.78). This suggests that social support, illness perceptions, self-efficacy and diabetes knowledge did not mediate the effect of the SMBI on parent reports of diabetes responsibility.

7.10.2 Management Adherence and Diabetes responsibility as Mediators of Glycaemic Control and Quality of Life. The effect of management adherence and diabetes responsibility as mediators of the SMBI on glycaemic control and quality of life was analysed. The PedsQL (both Generic Core and Diabetes specific) completed by the adolescents were used as the measures of quality of life in the mediation analysis rather than the versions completed by the parents, as it was felt that adolescents' perceptions of their quality of life was the primary aspect of quality of life targeted by the SMBI. Separate mediation analysis was undertaken for each outcome variable (i.e., glycaemic control, diabetes specific quality of life and generic quality of life).

The mediation analysis model used for analysing management adherence and diabetes responsibility as a mediator of the SMBI on glycaemic control is summarised in Figure 7.7, with the SMBI group (i.e., treatment versus comparison) as the independent variable (X),

glycaemic control as the dependent variables (Y) and the measures of management adherence and diabetes responsibility as the mediators (M).

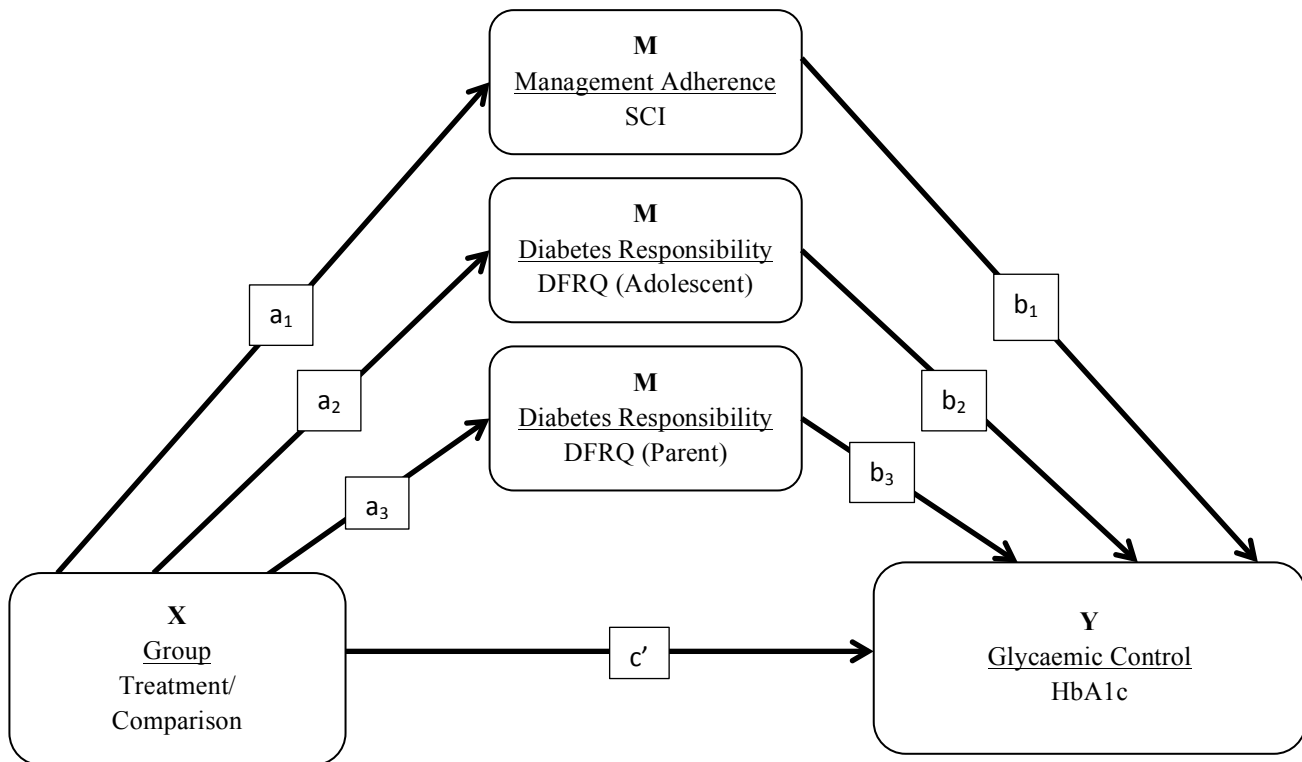


Figure 7.7 Mediation analysis path model of group as a predictor of glycaemic Control, mediated by management adherence and adolescent and parent reports of diabetes responsibility, where path *ab* represents the indirect effect (mediation effect) and path *c* represents the direct effect

An overall significant indirect effect of management adherence and diabetes responsibility on glycaemic control was not found (indirect effect of X on Y; effect = .06, confidence intervals = -0.21, 0.32). This suggests that management adherence and diabetes responsibility did not mediate the effect of the SMBI on glycaemic control.

The mediation analysis model used for analysing management adherence and diabetes responsibility as a mediator of the SMBI on diabetes specific quality of life is summarised in Figure 7.8, with the SMBI group (i.e., treatment versus comparison) as the independent variable (X), diabetes specific quality of life as the dependent variables (Y) and the measures of management adherence and diabetes responsibility as the mediators (M).

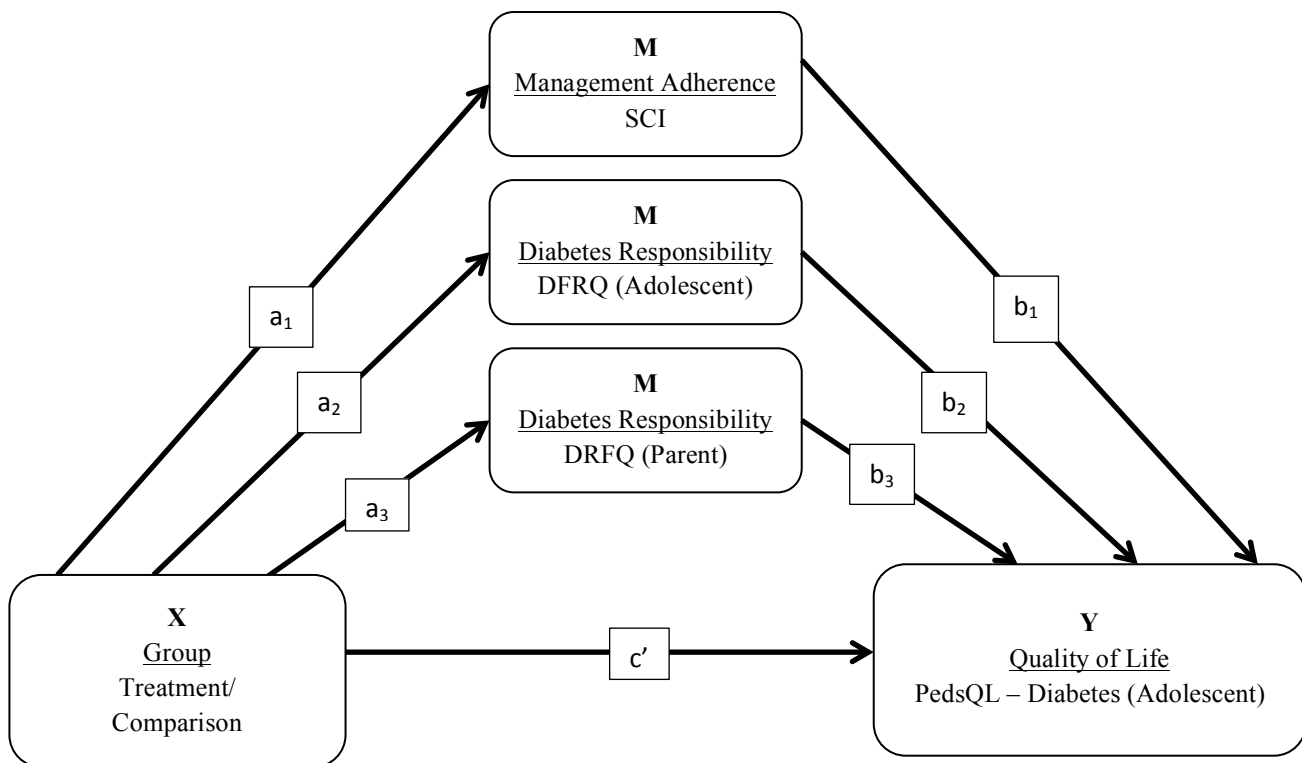


Figure 7.8 Mediation analysis path model of group as a predictor of diabetes specific quality of life, mediated by management adherence and adolescent and parent reports of diabetes responsibility, where path ab represents the indirect effect (mediation effect) and path c represents the direct effect

An overall significant indirect effect of management adherence and diabetes responsibility on diabetes specific quality of life was not found (indirect effect of X on Y;

effect = .60, confidence intervals = -3.80, 5.08). This suggests that management adherence and diabetes responsibility did not mediate the effect of the SMBI on diabetes specific quality of life.

The mediation analysis model used for analysing management adherence and diabetes responsibility as a mediator of the SMBI on generic quality of life is summarised in Figure 7.9, with the SMBI group (i.e., treatment versus comparison) as the independent variable (X), generic quality of life as the dependent variables (Y) and the measures of management adherence and diabetes responsibility as the mediators (M).

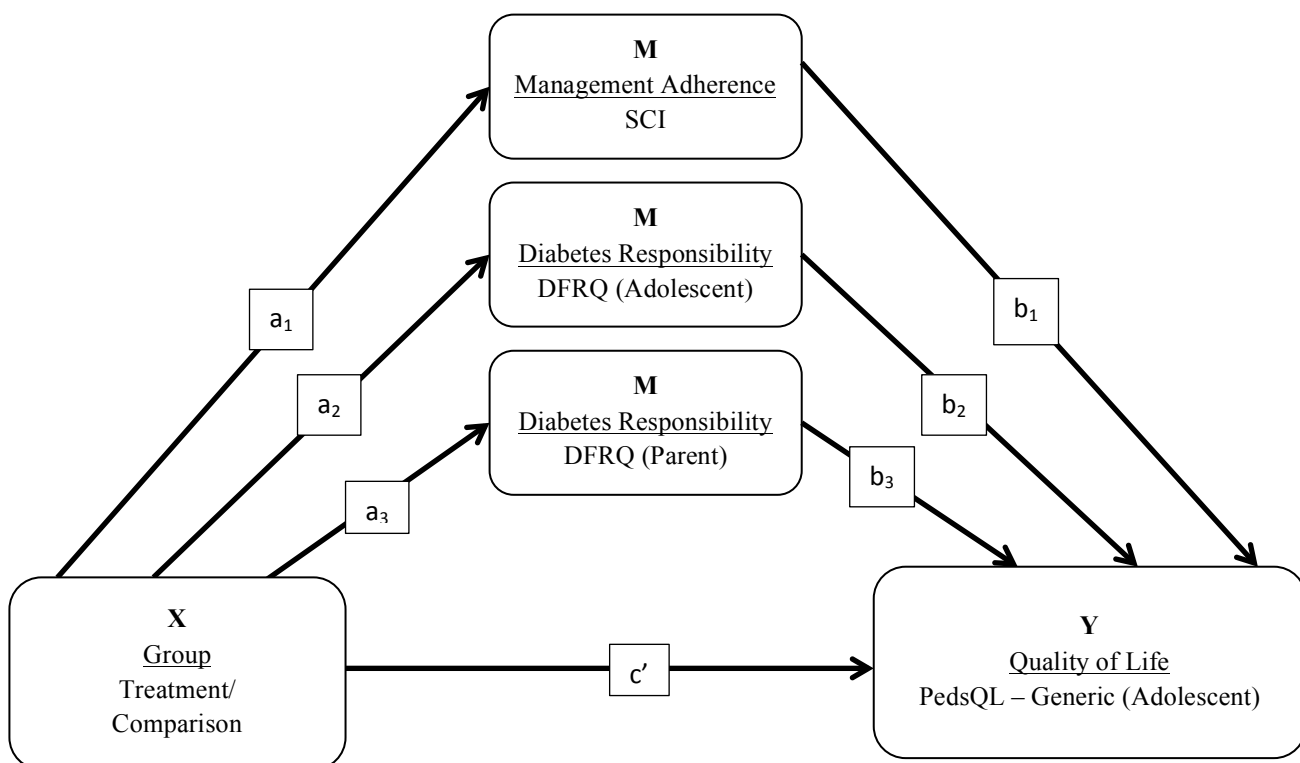


Figure 7.9 Mediation analysis path model of group as a predictor of quality of life, mediated by management adherence and adolescent and parent reports of diabetes responsibility, where path ab represents the indirect effect (mediation effect) and path c represents the direct effect

An overall significant indirect effect of management adherence and diabetes responsibility on generic quality of life was not found (indirect effect of X on Y; effect = -.56, confidence intervals = -5.47, 3.77). This suggests that management adherence and diabetes responsibility did not mediate the effect of the SMBI on generic quality of life.

Chapter 8: Qualitative Analysis

8.1 Introduction

This chapter outlines the main findings selected from analysis of the interview with a group of four participants who underwent the intervention. Pseudonyms have been used in order to maintain the anonymity of the participants. Table 8.1 lists the pseudonym, age, age at diagnosis and current insulin regimen for each of the four participants.

Table 8.1 Participants' pseudonyms, age, age at diagnosis and current insulin regimen at commencement of SMBI

Pseudonym	Age (years)	Age at diagnosis (years)	Insulin regimen
Ethan	15	7	Insulin pump
Jane	16	6	Multiple daily injections
Sarah	15	10	Multiple daily injections
Tracey	15	12	Insulin pump

Section 6.5.4 outlines the procedure by which the participants were chosen for qualitative interview. In terms of the representativeness of the group of participants who underwent the qualitative interview, Table 8.2 compares the gender and insulin regimen of the qualitative interview group with the overall treatment group. As the treatment group from which the participants for qualitative interview were chosen was an age-matched group, the spread of ages in the qualitative interview group (i.e., 15 to 16) was not representative of the spread of ages in the overall treatment group (i.e., 13 to 16). In terms of primary outcome measures, as can be seen from Table 8.3, HbA1c and PedsQL scores of the qualitative interview group were similar to those of the overall treatment group at baseline.

Table 8.2 *Breakdown of gender and insulin regimen of the qualitative interview group compared to the overall treatment group*

	Qualitative Interview Group % (n = 4)	Overall Treatment Group % (n = 42)
Gender		
Male	25 (1)	50 (21)
Female	75 (3)	50 (21)
Insulin Regimen		
Injections	50 (2)	45.2 (19)
CSII	50 (2)	54.8 (23)

Table 8.3 *Comparison of descriptive statistics (Mean and Standard Deviation) of glycaemic control (HbA1c) and quality of life (PedsQL Generic and Diabetes – Child Versions) at baseline for the qualitative interview group and overall treatment group.*

	Qualitative Interview Group Mean (SD)	Overall Treatment Group Mean (SD)
Glycaemic Control		
HbA1c	8.1 (1.03)	7.97 (1.01)
Quality of Life		
Generic	77.72 (19.66)	80.54 (12.87)
Diabetes	71.13 (17.45)	68.91 (13.66)

Three superordinate themes and four subordinate themes were selected from the interview and are highlighted in Table 8.4. These themes are introduced and elaborated on using illustrative quotes. All quotes are attributable to either one of the four participants who undertook the interview or the interviewer. The participant to whom a quote is attributable is identified by their pseudonym.

Quotes attributable to the interviewer are identifiable by “Interviewer” preceding the quote. In some instances, the four participants responded in unison, in these instances the particular quote is preceded by “Ethan, Jane, Sarah and Tracey”.

Laughing by the participants is indicated in parentheses. Line numbers indicate the location of the quotes in the original transcript (see Appendix 6).

Table 8.4 *Superordinate and subordinate themes selected from the interview*

Superordinate themes	Subordinate themes
<ul style="list-style-type: none"> • Peer relations 	<ul style="list-style-type: none"> • Shared Experience • Humour
<ul style="list-style-type: none"> • Relationship with the DHCT 	<ul style="list-style-type: none"> • Humanising the DHCT • Ease of communication
<ul style="list-style-type: none"> • Operation of the Facebook page 	

8.2 Peer relations

The first superordinate theme, peer relations, reflects participants' views of their relationships with peers with T1DM. Although this theme relates mainly to participants' relationships with the peers in the intervention group with them, all four participants identified themselves as having previously been members of a separate Facebook page for adolescents with T1DM that was composed of young people from all over the world called Type One Teens. Their reports on their experiences with peers on this Facebook group suggested a degree of trepidation in relation to their interactions with them. Sarah had a mixed description of the members of the group.

Sarah: There's some of them really cool like kind of people and some of them are really weird. (306-307)

Ethan described an experience of being castigated by members of the group for an apparent lack of awareness of a diabetes related issue.

Ethan: And apparently there's someone in England that has diabetes. She's like some blogger that I should have known, that I didn't know and I got given out to for not knowing her. (318-320)

Tracey and Sarah both described uneasiness about interacting with peers on the page and reluctance to accept Facebook friend requests from them.

Tracey: I've got so many people adding me off that and I'm like, "Who are you?"

Sarah: Like I won't really add them, like I'll talk to them on the page but I won't add them because I don't know who they are. (309-311)

Despite participants' apprehension towards interacting with peers on the Type One Teens Facebook page, all four participants identified these peers as providing a supportive function to one another.

Sarah: Yeah, they're all kind of really supportive like that.

Ethan, Jane, Sarah and Tracey: Yeah. (344-345)

Tracey also highlighted the appealing nature of being part of a Facebook group composed of adolescents with T1DM from all over the world.

Tracey: It's actually really interesting. (305)

She particularly noted the experience of being able to see how health systems operate for young people with T1DM in other parts of the world, in addition to how they support one another.

Tracey: It's really interesting to see how like medical systems work in like other countries as well because there was a guy this morning and he posted... He was really angry because he'd moved to an adult clinic and they said that he could only have one box of fifty test strips for fifty days or something, so that meant one test strip per day. And then loads and loads of people were like, "Oh, I'll send you something if you need it". And he was from like, Bosnia and Herzegovina or something like that. (337-343)

Participants' descriptions of their experiences of using the Facebook group in the present study were qualitatively different from their descriptions of their experiences of using the Type One Teens Facebook group, particularly with regard to peer relations. Participants appeared more open to developing peer relations in the present study's Facebook group and didn't report any of the concerns or trepidations about engaging with peers in this group that they had reported for the Type One Teens Facebook group. Prior to the first *in vivo* group session the participants didn't know one another; however, they actively attempted to develop relationships after this session. They explained that after the first *in vivo* session the members of the Facebook group added each other as friends on Facebook, which is in contrast to their reluctance to accept members of the Type One Teens group as Facebook friends.

Interviewer: Well everyone seems to know each other a lot better than they did then when we started.

Jane: We all like added each other as a friend obviously.

Interviewer: Did that happen straight away or over time?

Ethan: I think it happened the first day.

Tracey: Yeah, the day we met each other we went home and added each other.

Ethan, Jane, Sarah and Tracey: (laughs). (293-299)

Although the Facebook group in the present study differed on many aspects from the Type One Teens Facebook group (e.g., number of participants, inclusion of the DHCT, homogeneity of the adolescents with regard to age and geography, etc.), one specific aspect of the Facebook group in the present study that all four participants identified as facilitating the development of peer relationships among the

group was the inclusion of *in vivo* sessions. They also saw them as being an integral part of the intervention.

Interviewer: Did meeting others in the group sessions help you get to know them better? So you know the times when we actually came in here, was that beneficial in terms of getting to know the other people or was just Facebook enough?

Ethan, Jane, Sarah and Tracey: No.

Ethan: Coming in here was better.

Jane: No, I think we needed both.

Tracey: We definitely needed both. (267-274)

The quality of the peer relationships that developed among the participants is suggested by the fact that they tried to meet each other, albeit unsuccessfully, outside of *in vivo* group sessions. Sarah highlighted the difficulties that they had with meeting up.

Sarah: I think we've tried to meet up a few times but it's just always been difficult because we'd all go and then Tracey would go "Oh, I can't do it" and then we'd do another one and Ethan's like "I actually can't make that" and then it's just...

Tracey: I seem to be always away. (450-453)

Although the participants were unable to meet up outside of the *in vivo* sessions, this is not necessarily an indication of trepidation in the peer relations, but more likely a reflection of the normal constraints of geography and time that limit the utility of *in vivo* group sessions for adolescents with chronic illnesses.

Some participants also reported creating a parallel Facebook group for peers that they met while on an excursion for adolescents with T1DM. Compared to the

Type One Teens Facebook group, this parallel Facebook group shared more characteristics with the Facebook group in the present study in that it had a smaller and limited number of participants and the group was much more homogenous with regard to age and geography. In addition, all the members of the parallel Facebook group attended the same diabetes service and therefore had the same DHCT, although the DHCT were not part of the parallel Facebook group. While it did not include formalised *in vivo* sessions, the parallel Facebook group was created by a group of adolescents who had met on an excursion and so the members of the group did have some non-virtual contact prior to joining the group.

The fact that the participants joined this parallel Facebook group, which was created some time after they had joined the Facebook group in the present study, could be seen to suggest that they found the Facebook group in the present study as a useful medium for developing relations with peers with T1DM. However, once initiated the parallel Facebook group didn't generate the same level of interest as the Facebook group in the present study and was quickly abandoned.

Interviewer: Because I thought that the ones who went on the cycle started a group?

Sarah: Oh yeah we did but that really didn't go anywhere.

Interviewer: Oh, it didn't?

Sarah: We posted like for about a weekend and then everyone just got bored.

(354-358)

From the outside it would appear that the most significant difference between the Facebook group in the present study and the parallel Facebook group was the inclusion of the members of the DHCT and the structure they provided to the

Facebook group in the present study, and this may be the reason why it failed to generate traction with the participants.

8.2.1 Shared Experience. The subordinate theme of shared experience relates to participants' sense of understanding from their peers in the Facebook group about what it's like to live with T1DM. Although all participants were aware in advance of commencing the intervention that they would be interacting with other young people with T1DM, they were all surprised that there were commonalities in their experiences of living with T1DM and suggests a previous lack of any significant relationships with peers with T1DM.

Interviewer: Were you surprised to find out that other people had similar experiences to yourself?

Ethan, Jane, Sarah and Tracey: Yeah.

Sarah: Like, I wasn't worried about it but I just... To kind of know more people felt like you.

Ethan, Jane, Sarah and Tracey: Yeah. (424-429)

All participants identified this sense of the shared experience of having T1DM as creating an understanding that is not present in their relationships with their peers without diabetes. Jane highlighted this and how it was initially unusual interacting with other people who had this shared experience.

Jane: It was unusual because all the people you interact with normally, they don't, like, they do understand but they don't, whereas you're talking to people that fully understand everything. They understand how you feel all the time. (6-8)

Through the use of the Facebook page participants began to see that the others in the Facebook group were experiencing the same issues and difficulties with diabetes management as themselves.

Tracey: Yeah, exactly. It was just you could see that other people go through the exact same thing as you do.

Jane: Yeah, I didn't feel alone.

Tracey: Yeah, exactly. (430-433)

This understanding provided a forum for participants to express their upsets and concerns online in an environment where they felt understood.

Jane: So say if I was upset or something, all I have to do is just go on, have a random conversation with someone who understands.

Tracey: Yeah, exactly. (109-111)

Jane further highlighted the appeal of being able to converse with someone with a shared experience.

Jane: I think just like being able to talk to someone who knows what you feel. (107)

This form of social support was noted by Jane to be qualitatively different from the support provided by friends without diabetes. She also noted that this shared experience can help negate the sense of loneliness that can be experienced from managing T1DM.

Jane: Whereas if you talk to like, say your best friend, they're there but they don't understand. So you don't feel like you're alone. (112-113)

As well as providing a forum for participants to express their upsets and concerns in relation to living with and managing T1DM, the shared experience had a

positive impact on their perceptions of themselves as a person with T1DM. Jane identified it as making her feel prouder.

Jane: It made me feel a bit prouder, I think, to be a diabetic. (435)

Sarah also identified a positive impact of the sense of shared experience on her perceptions of herself as someone with T1DM.

Sarah: Yeah, just because you've kind of got... It's like you've got an army of people behind you.

Ethan, Jane, Sarah and Tracey: (laughs) Yeah.

Sarah: It's like, if you say something to me I've got all these. (437-440)

Sarah's identification of the shared experience being manifest in very strong feelings of support was confirmed by the other participants and suggests the utility of the Facebook group as a credible source of social support.

8.2.2 Humour. The subordinate theme of humour relates to participants' perceptions of the Facebook page being medium where they could share a diabetes related sense of humour. All four participants agreed that having T1DM gave them an appreciation of diabetes related jokes that others do not understand.

Jane: I think because we're all kind of like... There's jokes that we'd understand and that other people wouldn't understand and I find them really funny.

Ethan, Jane, Sarah and Tracey: (laughs). (34-36)

Further to this, they identified the sharing of humorous T1DM memes online as being a particularly enjoyable feature of using the Facebook page.

Interviewer: Was it fun?

Ethan, Jane, Sarah and Tracey: Yeah.

Ethan: Yeah, it was.

Interviewer: What aspects of it were fun?

Ethan: The memes were fun.

Ethan, Jane, Sarah and Tracey: (laughs). (94-99)

Participants' descriptions of the enjoyment they experienced from diabetes related memes and jokes were countered by their descriptions of how friends without diabetes don't understand their diabetes related jokes.

Jane: They wouldn't find it funny though.

Tracey: No, no.

Jane: We could be like cracked up laughing and no one knows why.

Ethan, Jane, Sarah and Tracey: (laughs). (50-53)

They also highlighted the disconnect they feel when their friends without diabetes respond to diabetes related humorous memes they post to their Facebook pages.

Tracey: It's like if you posted a photo or something related to diabetes...

Ethan, Jane, Sarah and Tracey: Yeah.

Jane: You're like, "Oh My god".

Ethan, Jane, Sarah and Tracey: Yeah (laughs).

Tracey: We would understand it all but other people would be like "What are you like, oh yeah, hahaha". (37-42)

Jane highlighted this disconnect by giving an example of a humorous diabetes related meme that she found particularly funny but that none of her friends understood.

Jane: There's actually a really funny one I just remember and it was of a photo of a man and he had ice-cream in his hand and he's just like "let's get high" and no one else understood that but me.

Ethan, Jane, Sarah and Tracey: (laughs).

Jane: It was just really, really funny like. (73-77)

Tracey further described how this lack of shared diabetes related humour can also extend to parents.

Tracey: Even photos that I would like that are related to diabetes when I show them to my Mum... I thought they were hilarious but then when my Mum saw them she was like... Yeaaaaaah. (59-61)

8.3 Relationships with the DHCT

The second superordinate theme, relationships with the DHCT, reflects participants' views of their changed relationships with the members of the DHCT from engaging with them on the Facebook group. Being part of the intervention allowed participants to interact with the members of the DHCT via Facebook, as well as conventional methods (e.g., phone, email, clinic visits, etc.). This appears to have impacted on participants' relationships with the members of the DHCT and was reflected in their discussions. Two subordinate themes were identified within this theme, humanising the DHCT and ease of communication.

8.3.1 Humanising the DHCT. The subordinate theme of humanising the DHCT relates to participants' change in perceptions of the members of the DHCT to be more human as a result of interacting with them on Facebook. Participants began to see the members of the DHCT as being more than just the professional roles that they occupied. Sarah described it as the DHCT being more like real people.

Sarah: Yeah, they kind of seem more like, like... This sounds kind of weird but like real people. Before you used to think they're just nurses. They just live in the hospital kind of thing.

Ethan, Jane, Sarah and Tracey: (laughs).

Sarah: After you see that they're not like. (151-155)

Tracey also articulated the experience of seeing the members of the DHCT as being more than just their clinical roles.

Tracey: I think it makes it feel like they're not just like your doctors or your nurses. (147)

This broadening of participants' perceptions of the DHCT to being more than just their just their clinical roles appears to have been associated with participants viewing the DHCT as being more approachable as a result of interacting with them on the Facebook page. This sense of the DHCT being more approachable was confirmed by all four participants.

Jane: You see, it sounds kind of bad but they seem more approachable, I think.

Ethan, Jane, Sarah and Tracey: Yeah. (149-150)

The aspect of the online interactions with the DHCT that led to participants perceiving the DHCT to be more approachable appears to be what participants saw as the informal nature of the online communications. Participants identified what they perceived as the informal nature of the online interactions with the DHCT as the primary differential from their conventional interactions with the DHCT.

Interviewer: How does it differ from interacting with them in the clinic?

Jane: It's less formal.

Ethan, Jane, Sarah and Tracey: Yeah. (195-197)

They also reported that they preferred the informal interaction with the DHCT that characterised the Facebook page.

Interviewer: Is that better or worse?

Ethan, Jane, Sarah and Tracey: Better. (198-199)

The change in the perceptions of formality of online communications between participants and the DHCT appears to have been more noticeable to participants for their communications with the doctors than with the nurses.

Tracey: I think maybe it's less formal with the doctors more than the nurses because like with the nurses they're more kind of on your side.

Ethan, Jane, Sarah and Tracey: Yeah.

Tracey: Trying to help you in a way, whereas the doctors are more kind of like...

Ethan: Strict.

Tracey: Yeah, the kind of look scary in a way. (200-205)

It is not that participants' online interactions with the doctors were more informal than the nurses, but rather that the doctors' conventional interactions (i.e., in the clinic or ward situation) with participants were perceived as being significantly more formal than the nurses, and as such the change to the more informal online interactions for doctors was more evident to participants. Jane further elaborated on her perceptions of the differences in her relationship with the nurses compared to the doctors.

Jane: Yeah, like the nurses can give you a hug but you don't feel that way about the doctor if I'm being honest. (208-209)

Although participants found the DHCT to be more approachable as a result of the informal nature of their online interactions, it didn't appear to have any impact on how open their communication with the members of the DHCT was. Both Tracey and Ethan reported that they felt that they were as open in their online communications with the DHCT as they were in their communications at clinic visits.

Interviewer: How open was your online communication compared to the clinic. So, did you feel it was... Could you be more open with the diabetes team online or less open?

Tracey: The same.

Ethan: Yeah, the same. (216-220)

This would seem to indicate that although the Facebook group facilitated more communication between participants and the DHCT, it did not have any impact on the defensiveness of participants in their communications about their diabetes with the DHCT.

8.3.2 Ease of communication. The subordinate theme of ease of communication relates to participants' perceptions of the ease with they could communicate with the DHCT through the Facebook group page. Ethan reported that even before using the page, he perceived that it would be easier to communicate using it.

Interviewer: What were your thoughts about using the Facebook page before it actually started?

Ethan: Different, like easier to communicate. (1-3)

In response to Tracey's statement about the Facebook group page being helpful for contacting the DHCT, all the participants agreed that it allowed for easier communication.

Tracey: It's really helpful because if you had any sort of problem you could just ask someone, you wouldn't necessarily have to, like you could put it even privately or something. You could message one of the nurses or something if you needed help with anything. It's just much easier than having to like... I suppose you could call but... I don't know it's just...

Ethan: Easier.

Tracey: Yeah, easier.

Ethan, Jane, Sarah and Tracey: Yeah, easier. (15-22)

This ease of communication was most evident in participants' reports of the difference between asking questions on the Facebook group page compared to in clinic. Sarah reported feeling less pressure when asking questions on the Facebook group page and being therefore able to more accurately express her queries.

Sarah: No, when you're like on Facebook you can say your question and blah, blah, blah and you can say it kind of how you want to. But when you're in like, clinic, and they're talking to you, you kind of forget how to talk. It's like scary.

Interviewer: Okay.

Ethan: You just let them say whatever. (226-231)

Ethan also reported feeling less pressure when asking questions on the Facebook page and that it allowed him the time to properly construct his questions.

Ethan: Like... Communicating... Like... Asking questions across Facebook... Like being able to take your time to word it... Easier than just straight out.

And it's easier to do it, like, because you're behind... Like it's easier to ask a question on Facebook than it would be in person, as well, cause it's easier to word it, like, you wouldn't know how to word it straight away. (89-93)

Tracey found that because the questions she posed on Facebook received written as opposed to verbal answers, she was able to reread the answers, allowing for a greater understanding.

Tracey: Or else if you ask a question and like... I don't know which doctor it was, I think it was (name of DHCT member). But he like answered and there was like a really, really long answer. Whereas like, if he was to say it in downstairs, like you mightn't remember everything, whereas with Facebook you could read through it again and again. (232-236)

Whereas all the participants identified the ease of the written nature of the communications on the Facebook page as a central component of the ease of communication, Ethan also identified anonymity as being an important component.

Ethan: It's easier to do it behind the Internet like, because, it's not like you're... You're obviously not anonymous cause they know your name and that but it's... You feel like you have a sense of anonymity when you're on the Internet so it's easier to do everything. (158-161)

However, none of the other participants identified anonymity as a component of the ease of communication.

8.4 Operation of the Facebook page

The third superordinate theme, operation of the Facebook page, reflects participants' views on the setup and workings of the Facebook page. Although

participants described the Facebook group very positively, they also suggested changes that they felt would improve the experience of using the Facebook group.

Participants identified increasing the number of adolescents in the group from the six participants that were in their group as something they felt would make the group better.

Interviewer: What do you think would make the page better?

Ethan: I don't know.

Tracey: Maybe more people.

Sarah: Yeah.

Ethan: Yeah. (470-474)

Although participants recommended an increased number of adolescents in the group, they did not recommend a significant increase. With regard to optimum size of the online group, participants came to a consensus that about ten adolescents in the group would be an ideal size.

Interviewer: What do you think would be the ideal size group?

Jane: Ten.

Ethan: Ten or eleven, yeah ten.

Sarah: Yeah, ten. (480-483)

Sarah identified this number as being the best size that still maintained the intimacy of the group.

Sarah: Ten would probably be about perfect for that.

Ethan: Yeah.

Sarah: Because we'd be still kind of... It'd be kind of personal and all and it's not too much. (493-496)

As mentioned earlier, participants had all previously been part of a much larger Type One Teens Facebook group where they appeared to have some trepidation about interacting with the other members of the group. Participants' recommendation for a relatively small group in comparison may highlight that the smaller size of the Facebook group in the present study is something that they see as advantages.

With regard to the content that the DHCT posted to the Facebook page that participants felt were important or enjoyable, different participants highlighted different things, which they all agreed with. Tracey identified the goal setting as being the postings to the page from the DHCT that she found particularly beneficial.

Tracey: I think the goals thing was good.

Sarah: Yeah, it was.

Jane: Yeah.

Tracey: Because at the start, like, one of the things was like have a goal for every week then like if you got, if you hit the target or whatever, it felt really good. (530-534)

Jane identified the random conversations that were generated from the posting of random facts to page by the DHCT as enjoyable.

Jane: You know what was good. We had like random conversations. Like you were posting random facts or stuff. I thought it was good.

Ethan, Jane, Sarah and Tracey: Yeah. (538-540)

Jane also identified the posting of information about new equipment in diabetes management by the DHCT as interesting.

Jane: I really liked the different equipment.

Ethan: Yeah, that's cool.

Jane: I thought that was really good.

Interviewer: The equipment like new inventions and stuff?

Ethan, Jane, Sarah and Tracey: Yeah.

Jane: Like you wouldn't have heard of otherwise. (545-550)

As well as the type of content posted to the page, participants also identified the frequency of posting to the Facebook page by the DHCT as important. Sarah noted unhappily that the frequency of posting to the Facebook page by the DHCT had reduced significantly since the start of the intervention.

Sarah: At the start you were more kind of active like. You kind of posted things about diet and insulin and all and after that you just stopped. Stopped doing it. (527-528)

As well as a reduction in the frequency of postings to the page by the DHCT, participants also identified a reduction in the variety of members of the DHCT posting to the page as something they were unhappy with.

Sarah: But like more because like, it's like hardly ever kind of these days. The only posted things by people from the team is by you.

Tracey: Yeah.

Sarah: Things like about equipment, none of the nurses or anything post anything.

Tracey: Yeah, the nurses just kind of comment on stuff. (565-569)

Although participants didn't come to a consensus about how frequently the DHCT should ideally be posting content to the page, they did suggest that it did need not to be every day.

Interviewer: How often should we post?

Ethan: Every second or third day. Like, not every day.

Tracey: Maybe like twice a week or...

Sarah: Not a few time a day but like... (560-563)

Although participants spoke about enjoying the Facebook page and identified numerous positive aspects about engaging with it, they were unable to identify any changes in behaviour with regard to their diabetes management that occurred as a result of using the page.

Interviewer: Did using the Facebook page change anything in the way that you manage your diabetes? Like did anybody get any advice that they tried out? Did it make it more likely to change things yourself?

Ethan: No.

Sarah: Not really, no.

Jane: Some, I don't know. (392-397)

This would indicate that although participants enjoyed using the Facebook group page and perceived it as helping develop relationships with peers with T1DM and facilitating easier communication with the DHCT, they did not perceive it to result in any change in behaviour with regard to their diabetes management.

8.5 Summary

Overall Qualitative analysis with the four participants indicated that they found engagement with the SMBI to be a very positive experience. Participants developed supportive relationships with the other adolescents in their SMBI Facebook group relatively quickly and easily, and found the experience of interacting with peers who had the shared experience of living with T1DM to be beneficial. The Facebook

group provided them with a forum in which they felt understood and they particularly enjoyed the opportunity to share a joint sense of humour with T1DM peers that the group provided.

Participants found that communicating with the DHCT via the Facebook page allowed them to see the DHCT in a more human light. As a result they viewed the DHCT as more approachable and were better able to engage them around issues in relation to T1DM. They also found that the Facebook page provided a less formal means of communicating with the DHCT, which made them feel more comfortable in posing questions to the DHCT.

Participants were generally happy with the operation of the Facebook page but felt it might benefit from a slightly larger group of adolescents. They enjoyed the content posted by the DHCT to the Facebook page but felt posting should be more frequent. Despite reporting that the SMBI helped them develop relationships with T1DM peers and facilitated better communication with the DHCT, they did not feel that it resulted in any change in their behaviour with regard to their diabetes management. For a full discussion of this qualitative analysis see Chapter 9.

Chapter 9: Discussion

9.1 Introduction

The current research aimed to develop a social media-based intervention (SMBI) for adolescents with T1DM to support their diabetes management and investigate its efficacy in improving glycaemic control and quality of life. After creating, piloting and refining the SMBI, it was implemented with a group of participants, and measures of psychological and physiological wellbeing were recorded over a twelve-month period. Quantitative analysis of the glycaemic control and quality of life measures did not find any significant increase in either of these measures as a result of undergoing the SMBI relative to a comparison group. However, qualitative interview with a group of participants who underwent the SMBI indicated that participants' perceptions of the support they received from the DHCT and T1DM peers increased as a result of the SMBI. The following sections will explore in more detail these results.

9.2 Primary Hypothesis

9.2.1 Glycaemic Control. The primary hypothesis that the SMBI would result in a significant reduction in HbA1c in the treatment group relative to the comparison group was not supported. HbA1c was used as a measure of glycaemic control. Analysis of the HbA1c data found that there was no significant change in HbA1c as a result of the SMBI. Visual inspection of the HbA1c scores indicated that the average HbA1c score of the treatment group was slightly lower than the comparison group at baseline (7.97/8.22) but this levelled out at the subsequent three

time points. Although the difference between the average HbA1c scores at baseline was not significant, it may indicate a selection bias in the treatment group.

9.2.2 Quality of Life. The primary hypothesis that the SMBI would lead to increased quality of life was not supported. Generic and diabetes specific quality of life were examined and were rated by both participants and by their parents using the PedsQL. Including total scores for both the participant and parent versions of generic and diabetes specific PedsQL, four separate quality of life measures were recorded and analysed. Upon analysis, only one of these four separate quality of life measures was found to have a statistically significant interaction effect, the Total Score of the diabetes specific PedsQL as completed by the participants. However, this interaction was found to be disordinal and there was no significant change in the quality of life measure that could be attributed to the SMBI.

9.3 Secondary Hypothesis

9.3.1 Social Support. The secondary hypothesis that the SMBI would lead to an increase in participants' perceptions of the social support they received from the DHCT was partially supported. DHCT support was measured using parent and adolescent versions of HCCQ. Analysis of HCCQ completed by parents did demonstrate a slight increase in perceptions of DHCT support at four, eight and twelve months relative to baseline that was not evident in the comparison group. However, the HCCQ completed by participants found no significant change in DHCT support as a result of the SMBI.

The secondary hypothesis that the SMBI would lead to an increase in participants' perceptions of the social support they received from T1DM peers was not supported. Participants' T1DM peer support scores were not significantly different between the treatment and comparison groups at any time point, nor was there a significant difference in the scores of the treatment group across the time points. This suggests that participants' perceptions of T1DM peer support did not change as a result of engaging in the SMBI.

9.3.2 Illness Perceptions. The secondary hypothesis that the SMBI would lead to more positive illness perceptions was not supported. Illness perceptions were measured using the Personal Control, Identity, Coherence and Emotional Representation subscales of the BIPQ. Analysis of these subscales found that only one of the BIPQ subscales, Personal Control, had a significant interaction effect. However, this interaction was found to be disordinal and there was no significant change in this illness perceptions dimension that could be attributed to the SMBI.

9.3.3 Self-efficacy. The secondary hypothesis that the SMBI would lead to an increase in participants' self-efficacy was not supported. Self-efficacy was measured by the SED, which elicited four separate measures of self-efficacy, a Total Score and three dimension scores (i.e., Diabetes Specific, Medical Situations and General Situations). Analysis of the responses on this questionnaire found no significant change in any of the four measures of self-efficacy as a result of the SMBI.

9.3.4 Diabetes Knowledge. The hypothesis that the SMBI would lead to an increase in diabetes specific knowledge was supported. On the ADKnowl the mean rank scores in the treatment group increased significantly after the introduction of the SMBI (i.e., at four months) and maintained at eight and twelve months. Although the mean rank scores in the comparison group did not differ significantly over time, visual inspection indicated that they increased at four months relative to baseline and stayed at roughly this level at eight and twelve months. Visual inspection also indicated that the mean rank score in the treatment group was somewhat lower at baseline than the comparison group but was higher at four and twelve months. Overall this indicates that the treatment group's diabetes knowledge increased after the introduction of the SMBI and maintained at eight and twelve months, whereas the comparison group's diabetes knowledge remained at roughly the same level at each time point.

9.3.5 Diabetes Responsibility. The hypothesis that the SMBI would lead to increased diabetes responsibility was not supported. Diabetes responsibility was measured using the parent and adolescent versions of the DRFQ. The parent and adolescent versions of the DRFQ elicit a single Total Score each, leading to two separate measures of diabetes responsibility. Separate analysis of these two measures of diabetes responsibility did not find any significant change in diabetes responsibility as a result of the SMBI.

9.3.6 Diabetes Management Adherence. The hypothesis that the SMBI would lead to increased diabetes management adherence was not supported. Diabetes management adherence was measured using the SCI. The SCI elicits a Total Score and four dimension scores (i.e., Blood Glucose Regulation, Insulin and Food Regulation, Exercise, and Emergency Precautions), leading to five separate measures of diabetes management adherence. Separate analysis of these five measures of diabetes management adherence did not find any significant change in adherence as a result of the SMBI.

9.4 Testing the Theoretical Model

The SMBI was based on a theoretical model whereby the introduction of the SMBI would target four separate aspects of participants' diabetes related functioning: perceptions of social support from T1DM peers and the DHCT, illness perceptions, self-efficacy and knowledge. Each of these factors would then act separately and in parallel on participants' diabetes responsibility and diabetes management adherence, which would in turn act separately and in parallel on participants' glycaemic control and quality of life. In order to test the robustness of the model mediation analysis was undertaken.

Six separate mediation analyses was undertaken to test the model, none of which indicated any significant mediating effects. Social support, illness perception, self-efficacy and diabetes knowledge were not found to have a mediating effect on the relationship between the SMBI and management adherence or diabetes responsibility. Management adherence and diabetes responsibility were not found to have a mediating effect on the relationship between the SMBI and glycaemic control or

quality of life. Overall, mediation analysis indicates that the model does not hold up to describe the action of the SMBI on glycaemic control and quality of life.

9.5 Implementation of the SMBI

At the core of the implementation of the SMBI was the objective of increasing the social support participants received from T1DM peers and the DHCT through an online forum. Increasing these two arms of social support in this way was envisioned to increase participants' perceptions of diabetes related social support from T1DM peers and the DHCT, create more positive illness perceptions, increase self-efficacy and increase diabetes knowledge. These would then in turn increase participants' diabetes responsibility and diabetes management adherence, leading to improved glycaemic control and quality of life.

9.5.1 T1DM Peer Support. Of the three main types of socially supportive interactions identified by Hogan, Linden, and Najarian (2002), peers primarily have the potential to provide emotional support and informational support to adolescents with T1DM and it was envisioned that these would be targeted by the SMBI. To be able to provide emotional support to another person requires an understanding of the issues affecting that person. One of the reasons that adolescents often find peers to be a significant source of emotional support is the mutual understanding of the common issues that face adolescents that comes from shared experience.

The shared experience of living with T1DM as a distinct feature of the social support provided by peers with T1DM was identified in qualitative interview with

participants in the present study. Participants identified this sense of the shared experience of having T1DM as creating an understanding that is not present in their relationships with peers without diabetes. In particular, they identified the novelty of seeing that others were experiencing the same difficulties as themselves in managing their diabetes. They reported that this led to them being able to express their upset and concerns within the online forum as they felt it was an environment where they felt understood. They identified these emotionally supportive interactions as negating the sense of loneliness that can be experienced from managing T1DM and also as having a positive impact on their perceptions of themselves as a person living with T1DM. This finding that the SMBI provided emotional support through the shared experience of the challenges of living with T1DM is consistent with Liang (2011)'s study which identified health SNS as providing the informational and educational support to help people cope with health-related problems and being rich with personal experiences of problems that people face in everyday situations.

As well as being a source of emotional support around some of the negative emotions associated with living with T1DM, such as loneliness, participants also identified the SMBI as being a source of emotional support with regard to diabetes related humour, as another facet of the shared experience of living with T1DM. Humour is a subjective experience that, as well as being culturally sensitive, is sensitive to the distinct experiences of individuals. Because living with T1DM provides unique life experiences it can also be the source of a unique type of humour that is largely inaccessible to individuals without T1DM. In interview, all participants reported being able to engage in a shared sense of humour around diabetes related topics as one of the most enjoyable features of the SMBI. They also identified their inability to share diabetes related humour as a source of disconnect between

themselves and their peers without T1DM. This sharing of diabetes related humour is a form of emotional support from peers that participants appeared to find particularly engaging and facilitated the development of peer relations among the group. There is some evidence of the efficacy of humour to facilitate patient-healthcare provider communication (Schopf, Martin, & Keating, 2015) and in behaviour interventions for children with T1DM (Sim, 2015); however, there appears to be little, if any, research on humour as a means of fostering emotionally supportive relationships among adolescents with similar chronic illnesses, particularly T1DM.

9.5.1.1 Type of Peer Support Offered by the SMBI. Qualitative interview with participants indicated that they found the SMBI to be a significant and beneficial source of emotional support from peers, which they had not pre-empted. Although they knew that through engaging with the SMBI they would be interacting with peers with T1DM, they appeared to be surprised by the level of emotional support it provided. This is interesting given the fact that all participants interviewed reported already being part of a Facebook group called Type One Teens, which connected young people with T1DM from all over the world, at the commencement of the SMBI. The fact that they were already members of a diabetes specific Facebook group, yet were surprised to find that the SMBI Facebook group provided a significant degree of emotional support from T1DM peers, suggests that they did not perceive themselves as receiving significant emotional support from the Type One Teens group. Indeed, qualitative interviews with participants about the Type One Teens Facebook group found that they spoke about it primarily in terms of informational support (e.g., how health systems work in other parts of the world) and to a lesser extent instrumental support (e.g., getting blood testing strips from others), rather than emotional support.

Also, the fact that participants had all independently become members of a separate T1DM specific Facebook group suggests that they had actively sought out at least some degree of T1DM peer support prior to the SMBI. However, if participants were unaware that online interactions with T1DM peers could be emotionally supportive, as was suggested from qualitative interview, it suggests that their motivation for seeking online interactions with T1DM peers was the provision of informational support, rather than emotional support.

Greene, Choudhry, Kilabuk, and Shrank (2011)'s qualitative analysis of the communication on the fifteen largest diabetes management Facebook groups identified the provision of emotional support as a significant component of the communication within these groups, with almost 29% of posts featuring an effort by the poster to provide emotional support to others members of the group. This seems somewhat in contradiction to the interview with participants in the present study who appeared to find a similar large Facebook group (i.e., the Type One Teens Facebook group) only minimally emotionally supportive. However, Green et al.'s analysis of the Facebook groups was undertaken without reference to the type of diabetes (i.e., T1DM or T2DM) or age profile of users of the groups. Given that the incidence of T2DM is significantly higher than the incidence of T1DM and that the age profile of individuals with T2DM is significantly older than that of individuals with T1DM (Pinhas-Hamiel & Zeitler, 2005), it is likely that the Facebook groups they analysed were populated predominantly by adults with T2DM. The researchers also noted that as well as being populated by individuals with diabetes, the Facebook groups they analysed were also populated by family members and friends of individuals with diabetes, who were also looking for support around the condition. The Type One Teens group, on the other hand, is a group specifically for adolescents with T1DM

and as such, is likely to have a very different user profile to the groups in Greene et al.'s analysis. Therefore the seeming contradiction between Greens et al.'s analysis and the reports of participants in our study may actually be a reflection of different social support motivations for engaging in an online forum around diabetes between adolescents and adults.

From the results of the present study it would appear that adolescents are less aware that an online forum with T1DM peers can provide significant emotional support and so their motivations for engaging in such a forum may be primarily for informational support. Even when part of such a forum they don't appear to derive the same level of emotional support from the forum as adults. This is not to say that adolescents with T1DM will not, or are not interested in, engaging in emotionally supportive T1DM peer interactions online or that they won't find them beneficial. In fact, the present study highlights the fact that adolescents will engage in emotionally supportive T1DM peer interactions online and that they perceive these interactions to be beneficial to their wellbeing. Instead it would appear that adolescents may not be receptive to emotional support from T1DM peers on online forums simply because they are not aware that these forums can be emotionally supportive and consequently don't engage in online interactions that would generate significant emotional support. Adults on the other hand, through experience and emotional maturity, may be more open to the idea that such forums can be emotionally supportive and consequently engage in online interactions that promote emotional support.

The number of diabetes specific SNS, and in particular Facebook pages, is significant and ever expanding (Greene et al., 2011; Shrank et al., 2011). In 2011, when Facebook had approximately half the number of users it has today, a simple search of Facebook elicited over five hundred diabetes related groups (Shaw &

Johnson, 2011). Such forums provide an easily accessible environment for patients with diabetes to engage with peers with diabetes and avail of the emotional support that such environments can provide. However, it would appear from the present study that, unlike adults, adolescents do not perceive online interactions with T1DM peers as a significant source of emotional support, nor do they usually utilise such forums for the provision of emotional support when engaged in them.

Management of T1DM requires informational, instrumental and emotional support and according to Peters, Nawijn, and van Kesteren (2014) in order for social support to have a positive impact on physiological and psychological wellbeing, both the type and the amount of support available must be in line with the individual's needs. T1DM peer support can provide all three types of social support; however, if adolescents with T1DM see online T1DM peer support as being primarily a source of informational support, then they are less likely to seek out online T1DM peers when they require emotional support around their diabetes management. As such, adolescents with T1DM may not be availing of a significant and beneficial source of emotional support around their T1DM.

9.5.1.2 Differences with other Diabetes Specific SNS. Although adolescents may not perceive, and consequently utilise, online forums, such as Facebook, for the provision of emotional support from T1DM peers, participants did utilise the SMBI for the provision of emotional support. This raises the question as to what differentiates the SMBI from other diabetes specific Facebook groups, such as Type One Teens, that engaged participants in emotionally supportive interactions with T1DM peers.

One significant difference between the SMBI and other diabetes specific Facebook groups was the inclusion of an element of *in vivo* contact. The SMBI provided participants with two sources of contact with peers with T1DM, online interaction through the Facebook group and *in vivo* contact in the five group-based sessions. The SMBI was primarily focused on creating peer support through the online forum, and the *in vivo* contact, which was limited to five sessions over the first twelve weeks of the SMBI, was included in order to facilitate the development of this. By allowing participants to become familiar with one another in the *in vivo* group sessions, it was hoped that they would become more comfortable in their online interactions.

All participants reported a degree of trepidation around engaging with T1DM peers on the Type One Teens forum and a tendency to refuse online friend requests from other members of this group, suggesting a perceived barrier to the development of peer relationships on the forum and consequently an obstacle to the provision of emotional support. In contrast, there was no evidence of a similar degree of trepidation engaging with peers in the SMBI and after the first *in vivo* group session they all added each other as friends on Facebook. Although this would seem to suggest that the *in vivo* group sessions were effective in facilitating the development of online peer relationships, it must be noted that the Facebook group in the SMBI differed from the Type One Teens group on a number of significant aspects, including number of participants, inclusion of the DHCT, and homogeneity of the group with regard to age and geography, that could equally well account for this. However, all the participants interviewed identified the *in vivo* group sessions as facilitating the development of online peer relationships and being integral to the SMBI.

Although participants identified the *in vivo* aspect of the SMBI as facilitating the development of the online peer relationships, it by itself does not appear to be the catalyst for the development of an emotionally supportive online T1DM peer group. In interview some participants reported creating a parallel Facebook group for peers that they met while on an excursion for adolescents with T1DM. Given that the members of this online group had initial *in vivo* contact with one another through the excursion, it bore more similarities to the SMBI than the Type One Teens Group. In addition, this parallel online group, by nature of the opportunity through which they met (i.e., an excursion for adolescents of a certain age who all attended the same diabetes unit), was also more homogenous than the Type One Teens group and more similar in size. However, participants reported that this Facebook group was quickly abandoned due to adolescents' lack of engagement with it. This would suggest that *in vivo* contact, homogeneity of the group and group size cannot by themselves account for the difference between the SMBI and the Type One Teens group in the level of emotional support they provide. One other very significant difference between the SMBI and other diabetes specific SNS was the inclusion of the DHCT, which will be discussed later.

9.5.1.3 Quantitative Analysis of T1DM Peer Support. Although qualitative interviews with participants suggested that the SMBI was effective in increasing T1DM support, this was not demonstrated in quantitative analysis. T1DM peer support was measured by a set of seventeen questions that asked participants to rate on a seven-point Likert scale the degree to which they agreed with statements about the support provided by peers with T1DM (e.g., "I feel able to share my feelings about diabetes with another young person with diabetes that I know"). An average of

the seventeen Likert responses was then obtained to get an overall measure of participants' perceptions of the level of support they receive from peers with T1DM. Participants' scores on this measure were not significantly different between the treatment and comparison groups at any time point, nor was there a significant difference in the scores of the treatment group across the time points. This indicates that perceptions of T1DM peer support of participants did not change as a result of engaging in the SMBI.

The seeming inconsistency between the quantitative T1DM peer support measure and the qualitative analysis of the interview with participants may be due to limitations of the quantitative T1DM peer support measure. As highlighted in Chapter 7 (see section 7.4.3), there were a significant number of omitted items on the T1DM peer support questionnaire. Because of the number of omitted items it was not possible to impute the missing values in the analysis and instead they were replaced with zeros, significantly reducing the sensitivity of the questionnaire. The reason the T1DM peer support questionnaire evidenced so many missing items (none of the other questionnaires in the battery evidenced a similar level of omitted items and so it was possible to impute missing values for them) is unclear but is likely to be an artefact of its placement order in the participant questionnaire battery. As the entire questionnaire battery was digitised and administered to participants via a tablet computer, the order in which participants completed the questionnaires that composed the battery was pre-set. Although participants were asked to complete the test battery until the end, they could abandon it at any point, unbeknownst to the researcher. As the T1DM peer support questionnaire was the last questionnaire within the order of questionnaires in the battery, omitted items caused by participants abandoning the battery before completion affected it the most.

Notwithstanding the reduced sensitivity of the T1DM peer support questionnaire, the inconsistencies between the qualitative and quantitative measures of T1DM peer support may also be reflective of differences in their underlying conceptualisations of peer support. The review by Palladino and Helgeson (2012) of peer influence on self-care and glycaemic control in adolescents with T1DM also found differences between the results of qualitative and quantitative studies. The qualitative studies found that adolescents believe peers have an impact on diabetes behaviour, whereas the quantitative findings were inconclusive. Their review included qualitative studies that described the ways peers affect self-care and quantitative studies that linked peer relationships to self-care and glycaemic control. Peers in their review referred to similar aged adolescents and did not include studies of peers with T1DM. The lack of inclusion of studies of T1DM peers is understandable given that there are few, if any, suitable studies that could be included. Although the type of peer support examined in their review is qualitatively different from the T1DM peer support in our study, their review does highlight the challenges of trying to quantify perceptions of peer support. Peer support is a broad category that includes informational, instrumental and emotional aspects of social support from peers. In our study interview with participants indicated that the SMBI increased emotional support from peers significantly more than informational or instrumental support. In order to measure such a change in perceptions of peer support quantitatively, the quantitative measure of T1DM peer support would need to be sensitive to this specific conceptualisation of peer support. Therefore, an expansion of the conceptualisation of peer support may be required when developing a quantitative T1DM peer support measure.

9.5.1.4 Influence of Online T1DM Peer Support. As reported in Chapter 3, the conceptualisation of peer relationships is somewhat subjective and the type and level of social support that adolescents with T1DM receive from peers can vary greatly according to the nature of their interactions. Kyngas, Hentinen, and Barlow (1998)'s study found that when adolescents with T1DM were dominated by their peers they adopted their peers' lifestyle. If this lifestyle was incongruent with good diabetes management the adolescents tended to depart from diabetes management regimens. Therefore when looking at the influence of T1DM peer support, we need to take into account the level of dominance in the T1DM peer relationships. Dominant T1DM peers who adhere to good diabetes management practices may have a positive influence on the diabetes management of adolescents with T1DM, whereas dominant peers who do not adhere to good diabetes management practices may have the opposite effect. In our study, the nature of the relationship between T1DM peers was not assessed and so it is not clear the extent to which factors such as dominance mediated the relationship between T1DM peer support and wellbeing.

In the SMBI peer support was enacted primarily via an online forum. However, the influence of peer social support on diabetes management behaviours is likely to be disproportionately weighted towards management behaviours that occur in the presence of those peers and this is particularly so during adolescence (Thomas, Peterson, & Goldstein, 1997). Hains et al. (2007)'s study found that adolescents who make negative attributions about the reactions of peers find adherence difficult in peer social situations. These results raise questions with regard to the efficacy of online T1DM peer support to impact on diabetes management behaviours that occur in real-world peer environments. Although participants in our study perceived the online

interaction with T1DM peers to be supportive, this support may not impact on their diabetes management behaviour in real-world interactions with peers without T1DM.

Lu et al. (2015)'s study, which looked to identify attitudes and topics relevant to peer mentoring as an adherence promoting intervention for adolescents with T1DM, noted that non-adherence due to embarrassment in social settings was significantly more prevalent among adolescents and suggested that young adults who have overcome social embarrassment may be able to share this experience with adolescents. This peer-mentoring role could translate the potential positive impact of online T1DM peer support to real-world peer environments. T1DM peers are likely to have experienced the perceived competing demands of good diabetes management and peer approval, and as such they may possess knowledge of strategies for managing peer approval with diabetes management that can be implemented in real-world peer interactions.

Although the SMBI did not directly target the development of peer mentoring among participants, it was seen as a potential type of peer support that could emerge from providing participants with T1DM peer support. In the context of the three broad categorisations of social support (i.e., instrumental, informational and emotional), peer mentoring would be primarily informational support, as mentoring is at its core the transferral of knowledge or information from a more knowledgeable to a less knowledgeable individual in a guided way. However, qualitative interview with participants suggested that the provision of online T1DM peer support led to a significant increase in perceptions of emotional support from T1DM peers rather than informational support. This would suggest that peer mentoring wasn't a significant form of peer support that emerged from the SMBI.

Suh et al. (2014)'s study of an Internet-based mentoring programme for adults with T1DM focused specifically on increasing informational support from mentors, all of who had T1DM or were parents of a child with T1DM. They had mentors provide advice and feedback on blood sugar data uploaded to a website every two weeks but did not find any improvement in HbA1c or quality of life. This would seem to suggest that online informational peer support on it's own may be ineffective in leading to better diabetes management outcomes.

9.5.2 DHCT Support

Prior to the commencement of the SMBI participants received support from the DHCT in the form of three to four monthly clinic visits, additional appointments with individual members of the DHCT between clinic visits as necessary and access to DHCT members via phone and email. Although all participants would have attended three to four monthly clinic visits, the extent to which they accessed the DHCT outside of this differed from participant to participant. In addition, some of the available support (i.e., phone and email access) may have been taken up by the participants' parents rather than by the participants themselves.

The SMBI was designed to increase participants' perceptions of the social support they received from the DHCT through increasing the availability and utilisation of social support from the DHCT. Connecting participants to the members of the DHCT via Facebook gave participants an additional medium with which to contact the DHCT and gave them direct access to all members of the DHCT, thereby increasing the availability of social support from the DHCT. Engaging participants in semi-scripted conversation threads and behaviour change conversation threads with

the DHCT required them to communicate with the DHCT around particular diabetes management topics, thereby increasing their utilisation of social support from the DHCT.

9.5.2.1 Quality of Communication. The SMBI was designed to increase participants' perceptions of the social support they received from the DHCT through increasing the quality of the communication between the DHCT and participants. The semi-scripted conversation threads and behaviour change conversation threads were designed from a patient-centred communication perspective with a focus on empathy, partnership building, interpersonal sensitivity and information giving, all of which are characteristics of patient-centred communication (Erickson, Gerstle, & Feldstein, 2005). The SMBI also provided a forum for participants to engage the DHCT in less formal conversation and questions around diabetes and non-diabetes related topics, thereby encouraging the discussion of psychosocial issues and further increasing the quality of the communication between the DHCT and participants.

Qualitative interview with participants indicated a very definite change in their views of the nature of their relationships with the members of the DHCT as a result of undergoing the SMBI. This was highlighted in the theme of "humanising the DHCT" that was selected from the interview transcript. Participants' perceptions of the DHCT broadened to viewing them as being more than just the clinical roles they occupied, in essence seeing them as being more human. The fact that participants had previously viewed the nature of their relationships with the members of the DHCT primarily in terms of the DHCT members' clinical roles suggests that the type of social support they perceived themselves as receiving from these relationships was instrumental and informational rather than emotional. The SMBI therefore appeared

to increase participant's perceptions of the degree of emotional support they received from the DHCT. Croom et al. (2011)'s study found that increased levels of emotional support from the DHCT are associated with greater perceptions of control and competence for adolescents with T1DM. As such, we would expect to see similar increases in participants' illness perceptions. However, quantitative analysis did not indicate any change in participants' illness perceptions as a result of the SMBI and indicates that the relationship between certain illness perceptions and emotional support from healthcare providers may not be as straight forward as Croom et al. suggest.

9.5.2.2 Content of Communication. The perceptions of the nature of the supportive relationship between a patient and a healthcare team member are determined in a large part by the content of the interactions between them. If the content of the interactions is based almost exclusively on the clinical issues of the particular medical condition, with little or no regard to the wider psychosocial environment of the patient, then the nature of the supportive relationship will understandably be perceived by the patient as being almost exclusively instrumental or informational. However, if the content of the interactions also encompasses the wider psychosocial environment, then the nature of the supportive relationship is more likely to be perceived by the patient as also being emotionally supportive (Erickson et al., 2005). Unfortunately given the significant time demands on healthcare teams, for expediency team members may overlook the psychosocial environment in their interactions with patients in favour of focus almost exclusively on the specific clinical issues at hand, which may be seen as more relevant to supporting the patient to manage their healthcare needs. There may also be an

element of a self-fulfilling prophecy to situations where the interactions between the healthcare team member and the patient become based almost exclusively on clinical information. Patients expect that healthcare team members are not interested in non-clinical information and so don't provide it, and because patients only provide clinical information healthcare team members assume that patients do not want to engage in conversation about non-clinical information and don't ask for it.

The fact that participants perceived the DHCT as being more emotionally supportive as a result of the SMBI indicates that the content of the communication between the DHCT and participants shifted to encompass more of the participants' psychosocial environment. However, neither the DHCT nor the participants were instructed to expand the content of their communications outside of clinical information. This raises the question as to what aspect of the SMBI facilitated the content of the communications between participants and the DHCT to include more of participants' psychosocial environment. In interview participants identified what they perceived as the less formal nature of the online communication with the DHCT as the primary differential from their conventional communication with the DHCT. Prior to the commencement of the SMBI participants' communication with the DHCT was primarily through consultations during clinic visits. The content of these interactions can understandably be quite clinical in nature, with the limited time available during consultations restricting the amount of non-clinical information that can be discussed. Interactions that are primarily focused on the exchange of clinical information are understandably going to be seen as more formal in nature. As the online communications were an adjunct to the conventional forms of communication (e.g., clinic visits) where the necessary clinical information was obtained by the DHCT, there was less pressure on both participants and the DHCT to focus on the

exchange of clinical information in their online communications. This allowed more opportunity for the content of communication to include participants' psychosocial environment and therefore the interactions to be perceived as more informal in nature.

The less formal nature of the online communications appeared to be most noticeable to participants in their interactions with the doctors. This is not to suggest that participants' online interactions with the doctors were less formal than with the nurses, but rather that the doctors' conventional interactions (i.e., in the clinic or ward situation) with participants were perceived as being significantly more formal than with the nurses, and as such the change to the less formal online interactions was more evident to participants. In general, when attending their normal diabetes clinics the participants in the present study will spend about the same amount of time in face-to-face interactions with the doctors as with the nurses. However, any contact they have with the DHCT outside of clinic visits (e.g., for additional support in relation to their diabetes management) is significantly more likely to be with the nurses than with the doctors. Given that, as already outlined, the level of perceived formality of the relationship between a patient and a healthcare provider might be a function of the frequency and duration of their interactions, participants' perceptions of their online relationships with the doctors being less formal may be as a result of the increased communication this medium offers.

Just because participants viewed their interactions with the DHCT as less formal does not necessarily mean that these interactions were better or that they preferred less formal interactions with the DHCT. However, all the participants interviewed identified the less formal interactions as better and felt that this made the DHCT more approachable. Being more approachable means that participants felt more comfortable instigating and engaging in interactions with the DHCT. This

approachability may also facilitate the content of the communications between participants and the DHCT to include more of participants' psychosocial environment.

9.5.2.3 Ease of Communication. A separate but related concept to approachability is ease of communication, which was also identified by participants as another aspect of the SMBI that impacted on their relationships with the DHCT. If patients find communication with their healthcare team to be socially supportive, then their perceptions of the ease with which they can communicate with their healthcare team is going to impact on their perceptions of the level of social support available from the healthcare team. In the present study participants identified a number of aspects of online communication with the DHCT that supported ease of communication. In particular, participants found posing questions to members of the DHCT to be significantly easier when communicating with them online. Although participants always had the option of contacting any member of the DHCT by phone or email to ask them a question, they seldom, if ever, used these methods of communication. Therefore, prior to engaging in the SMBI participants' main forum for posing questions to the DHCT was during clinic visits. However, they identified the pressure and anxiety they sometimes feel during these visits as limiting the utility of this forum to adequately address their questions. Participants reported being unable to accurately express their questions due to the pressure of the clinic setting or just forgetting them completely because of all the other information that gets discussed during these consultations. Also, having the clinic as the only forum where participants asked questions meant that they had to wait until clinic visits to get answers to their questions. Given that a participants' next clinic visit could be a

number of months away, such a forum was not practical for questions that needed a more immediate answer.

Participants reported that the online communication with the DHCT provided a forum that addressed the limitations of the clinic environment as a forum for posing questions to the DHCT. By having an online forum to ask questions participants were able to negate the pressure they felt asking questions in clinic. This allowed them the opportunity to take the time to accurately construct and express their questions. The combination of the online forum with portable smartphone technology allowed participants pose questions to the DHCT as and when they occurred to them and get more immediate answers than having to wait for their next clinic visit. In addition, in the online forum participants were able to reread over the DHCT members' responses to their questions at their leisure and so better understand them.

9.5.2.4 Quantitative Analysis of DHCT Support. Although qualitative interviews with participants suggested that the SMBI was effective in increasing their perceptions of the support they received from the DHCT, support for this this was only partially supported in quantitative analysis. The quantitative measure of participants' perceptions of DHCT support that was used in the study was the Healthcare Climate Questionnaire (HCCQ), which measures perceived autonomy support from a healthcare team. Analysis of the results of this questionnaire found no change in participants' perceptions of autonomy support from the DHCT as a result of engaging in the SMBI. However, an equivalent version of the questionnaire was also administered to participants' parents to assess their perceptions of autonomy support

from the DHCT and this did demonstrate a small but significant increase in their perceptions of the DHCT as a result of the SMBI.

Although there were no changes in participants' perceptions of autonomy support as a result of the SMBI, it needs to be acknowledged that autonomy support is just one type of social support, albeit an important one, that a healthcare team can provide. Social support is a much broader concept and although the HCCQ scores indicated that there were no changes in participants' perceptions of autonomy support from the DHCT as a result of the SMBI, this does not necessarily mean that there were no changes in participants' perceptions of social support in general from the DHCT.

It also needs to be acknowledged that participants in the comparison condition were aware of, and had agreed to engage in, the SMBI. It was only as a result of the procedure for allocating participants to the treatment and comparison conditions (see section 6.2.4) that they ended up not undergoing the SMBI. They may have seen the SMBI as indicative of autonomy supporting behaviour from the DHCT and consequently rated the DHCT as more autonomy supportive on the HCCQ even though they didn't actually engage in the SMBI.

The fact that participants' parents' perceptions of autonomy support increased as a result of the SMBI is interesting given that the SMBI didn't have any direct impact on their communication with the DHCT. However, participants reported in interview that the SMBI facilitated them to ask more questions of the DHCT, which would be suggestive of them becoming more independent in their diabetes management. Given that parents often take responsibility for communicating with the DHCT on behalf of their son or daughter, as participants began to directly

communicate with the DHCT themselves in order to have their questions answered, parents may have noticed that there was less of need for them to contact the DHCT on their behalf and consequently viewed this as autonomy supportive behaviour from the DHCT.

9.5.3 Education

As originally envisioned and piloted the SMBI did not include an educational component. However, as a result of the pilot study an educational component was added to the SMBI, primarily as a means of facilitating communication. Shaw and Johnson (2011) suggested that SNS could be an appropriate way to deliver diabetes education. Although there is some evidence that diabetes education can be delivered online to adolescents (Nicholas et al., 2012), SNS as a medium for delivering this education does not appear to have been empirically tested.

Participants' level of diabetes knowledge was assessed using the ADKnow. Quantitative analysis of ADKnowl scores found a significant increase in participants' diabetes specific knowledge as a result of the SMBI. In addition, the increase in knowledge scores maintained at eight and twelve months. This indicates that SNS, and the SMBI in particular, can be an effective tool for delivering diabetes education to adolescents with T1DM.

In the SMBI, education was delivered by means of semi-scripted conversation threads (see section 5.5.4). These were designed specifically for the SMBI with the goal of engaging participants in diabetes related communication with the DHCT and with each other but while also minimising the resource implications for the DHCT of

engaging in multiple online conversations with participants. Prior to instigating the semi-scripted conversation threads it was unclear whether participants would actually engage with them or if they would find the conversations too diabetes specific. However, interview with participants and observation of their online engagement with the semi-scripted conversation threads indicated that they both engaged with and enjoyed the communication that the semi-scripted conversation threads facilitated.

Because of their nature, the semi-scripted conversation threads were finite in length and all were delivered over the first eight weeks of the SMBI. As a result, the level of communication initiated by members of the DHCT decreased once the semi-scripted conversation threads were complete. Although participants were unaware of the semi-scripted nature of the conversation threads, in interview they noted the decrease in communication from the DHCT after the first eight weeks. They also reported to preferring the level of online engagement that the semi-scripted conversation threads facilitated.

9.5.4 Behaviour Change

After completion of the semi-scripted conversation threads, participants were engaged in behaviour change conversation threads by the researcher (see section 5.5.5). As with the semi-scripted conversation threads, participants were free to choose their level of engagement with the conversation. These behaviour change conversation threads were based on the principles of motivational interviewing and envisioned to increase diabetes management adherence through increasing self-efficacy. However, quantitative analysis indicated that there was no change in self-efficacy as a result of the SMBI.

In interviewer only one of the participants identified the behaviour change exercises as something they enjoyed and suggests that participants were not engaged by the behaviour change conversation threads. In addition, participants reported that they did not believe they changed their behaviour with regard to their diabetes management as a result of the SMBI. This would suggest that the behaviour change conversation threads designed for the SMBI were neither engaging nor effective.

9.5.5 Impact on DHCT Resources

From the outset the SMBI was designed so as not to place any significant extra demands on the resources of the DHCT. One of the issues identified during the pilot study was the amount of time it was taking the DHCT to source content to post to the Facebook group page. The semi-scripted conversation threads were developed in part to address this, as they provided pre-sourced content for the DHCT to post to the Facebook group pages and eliminated the need for them to source content themselves. The semi-scripted conversation threads also allowed the members of the DHCT to mirror their conversations across the groups, which reduced the demands of DHCT members engaging in conversations across multiple online groups.

Feedback from the DHCT during the main study indicated that the introduction of the semi-scripted conversation threads significantly reduced the demands placed on them to the extent that engaging in the SMBI didn't place significant additional demands on DHCT resources. Although the amount of time the DHCT spent engaging with the SMBI on a daily basis was not recorded, feedback from the DHCT and observations of their online interactions with the Facebook group pages suggested that they spent less than ten minutes per day engaging with the SMBI.

In the initial eight weeks after the commencement of a group, the DHCT members' engagement with the SMBI was primarily around delivering the semi-scripted conversation threads. Each semi-scripted conversation thread generally took anything from one to four weeks to complete, depending on the extent to which the DHCT member running the particular conversation thread engaged in non-scripted conversation with the participants. All semi-structured conversation threads had to be complete within eight weeks of the commencement of the group, meaning that DHCT members did not have any pre-sourced content to post to the Facebook group page after the first eight weeks of that group had elapsed. This appeared to have a significant impact on the DHCT's level of engagement with the SMBI, as a decrease in frequency of DHCT members' postings to the Facebook group pages was observed after each group's first eight weeks.

As well as well as reducing the demands placed on the resources of the DHCT, the semi-scripted conversation threads were also developed to facilitate online engagement between participants and between participants and the DHCT. To this end, the level of interaction between participants and between participants and the DHCT was observed to be relatively high while the semi-scripted conversation threads were running. However, just as there was an observed decrease in the frequency of the DHCT's postings to the Facebook group pages after each group's first eight weeks, there was also an observable decrease in the level of online interactions, both between participants and between participants and the DHCT.

As identified in the pilot study, sourcing content to post to the Facebook group pages is time consuming for the DHCT, as is engaging in unscripted online communications. In the present study the DHCT did not have the resources to source additional content after the semi-scripted conversation threads had finished and so

their level of engagement with the SMBI decreased. As the members of the DHCT were engaged in a number of different Facebook groups simultaneously and participants between each group were independent of each other, members of the DHCT were able to use content sourced by participants in one group to post to all the other groups. For example, if a participant in one group posted a link to an interesting diabetes related article to their Facebook group page a member of the DHCT could copy the link and post it to all the other Facebook groups that were running simultaneously. Although this “cross-pollination” of content facilitated members of the DHCT to continue posting content to the Facebook group pages after the semi-scripted conversation threads had finished without placing significant extra demands on their resources, it did not provide anywhere near the same level of content as when they were engaged in the semi-structured conversation threads.

Overall, the semi-structured conversation threads allowed the DHCT to engage in the SMBI at a relatively high level with minimal impact on the resources of the DHCT and facilitated interaction between participants and between participants and the DHCT. However, it was not possible for the DHCT to engage with the SMBI at the same level after the semi-structured conversation threads were complete without placing significant extra demands on the resources of the DHCT. Given that the DHCT’s engagement with the SMBI is one of its central components and also appears to impact on participants’ engagement with the SMBI, it may have been of benefit to provide the DHCT with additional pre-sourced content to be used after the initial eight semi-scripted conversation threads.

9.5.6 Engagement with the SMBI

The semi-scripted conversation threads were the only formalised postings to the Facebook group pages, both in terms of content and interactions, and were developed as a catalyst to initiate participants and the DHCT to spontaneously post other forms of content and engage in other forms of interactions on the Facebook group pages. Observation of the postings to the Facebook group pages demonstrated that both participants and the DHCT posted a variety of different types of content and engaged in multiple interaction types far beyond the semi-scripted conversation threads. This would seem to indicate that the semi-scripted conversation threads were effective in generating activity on the Facebook group pages. Although these additional content postings and interaction types were not formally assessed, observation of them indicated significant variety in types of content and interactions. These included questions directed at each other, questions directed at the DHCT, links to diabetes related articles and websites for verification from the DHCT, and humorous diabetes related cartoons and videos.

For the most part, participants' engagement with the SMBI outside of the semi-scripted conversation threads tended to be either spontaneous conversations or specific requests for information. The spontaneous conversations were usually instigated in response to one of the participants or the DHCT posting diabetes specific content, such as memes or videos, to the page. Participants initiated conversation around the topic of the content that had been posted and, although the conversations would often meander off into areas tangential to the original content, they tended to stay diabetes focused. Specific requests for information usually involved participants posing questions, mostly diabetes related, to the DHCT and other participants. Although participants had the option of posting the questions privately to the DHCP,

they very seldom availed of this, preferring instead to allow other participants to observe and contribute to the discussion generated by their questions.

It had been decided prior to the pilot study that no diabetes related content would be posted to the Facebook group page for the first two weeks in order to allow participants to get comfortable using the page. However, it was only when diabetes related content was posted to the Facebook group page that participants began to engage with the SMBI. This indicated that rather than diabetes related content and conversations impeding initial engagement with the SMBI, they actually drove it. While engagement with the DHCT and T1DM peers in non-diabetes related content and conversations did not generate any real initial engagement with the SMBI. For the main study the initial engagement was facilitated through diabetes related content and conversation in the form of the semi-scripted conversation threads. However, from the outset participants were informed that, within reason, they could post whatever they liked to the Facebook group pages and that the content or the conversations didn't have to be diabetes related. Despite this, very little non-diabetes related content was posted to the Facebook group pages by any of the participants and conversations were mostly T1DM related. This indicates that, as well as their initial engagement, participants longer-term engagement with the SMBI was specifically diabetes related. This is understandable given that most participants were already active Facebook users through which they had multiple forums to engage with peers and others around non-diabetes related content and conversations. The unique selling point of the SMBI was that it provided an online forum to engage in diabetes related content and conversations.

9.6 Theoretical Implications

As described earlier, at the core of the SMBI was increasing T1DM peer support and DHCT support. Applying social cognitive theory it was envisioned that increasing these two arms of social support would increase participants' self-efficacy, illness perceptions, knowledge and perceptions of social support received from T1DM peers and the DHCT. These four factors would then act directly and in parallel on diabetes responsibility and management adherence, which would act directly and in parallel on diabetes glycaemic control and quality of life. Individual components of the SMBI model are plausible in the context of previous research on diabetes management behaviour. However, the data did not support the use of the SMBI model in explaining the impact of the SMBI on diabetes management adherence and quality of life.

Applying social cognitive theory to chronic illness we would expect to see an association between self-efficacy and adherence behaviour. In other words, we would expect people who are more adherent to chronic illness management behaviours to be more confident in their ability to carry out those behaviours as needed or as directed by their healthcare professional. Indeed, the meta-analysis conducted by Gherman et al. (2011) on the association between beliefs related to diabetes and adherence identified self-efficacy beliefs as one of the beliefs most strongly associated with adherence. Applied to adolescents with T1DM we would expect that adolescents who are more confident in their ability to manage their T1DM (i.e., diabetes self-efficacy) to demonstrate better diabetes management adherence. Therefore in order to increase an adolescent's diabetes management adherence, we target their confidence in their ability to undertake adherence behaviours, otherwise known as their self-efficacy.

In the SMBI the increase in T1DM Peer and DHCT social support that were at the core of the intervention were envisioned to target participants' self-efficacy through a number of parallel mechanisms. Looking first at DHCT support, the SMBI increased the quality and the frequency the DHCT's communication with participants. Participants reported more patient-centred communication with the DHCT, as well as increased access to the DHCT. Participants also engaged in a behaviour change exercise online based on the principles of motivational interviewing. In terms of T1DM peer support, the SMBI created a forum where participants could acquire diabetes management skills from T1DM peers. However, as the SMBI was not found to have an effect on either self-efficacy or diabetes management adherence, it is not possible to make any inferences on the underlying theory about the association between self-efficacy and adherence.

As previously noted, the relationship between illness perceptions and self-efficacy is unclear. Griva, Myers, and Newman (2000) found self-efficacy in conjunction with certain illness beliefs can be a predictor of physiological and behavioural outcomes in T1DM. In the SMBI the increases in T1DM Peer and DHCT social support that were at the core of the intervention were also envisioned to target participants' illness perceptions through a number of parallel mechanisms, such as self-efficacy. Using the BIPQ four separate illness perceptions were assessed. However, again the SMBI was not found to have any effect on illness perceptions as measured by the IPQ and so it is not possible to make any inferences about the association between illness perceptions and adherence.

The model underlying the SMBI also envisioned that through increasing T1DM Peer and DHCT social support, participants' perceptions of the social support they received from T1DM peers and the DHCT would also increase. In Gallant

(2003)'s review, she found a modest positive relationship between social support and chronic illness self-management. Although the potential mechanism of the relationship between social support and self-management remains unclear, Gallant (2003) suggested that social support influences on self-efficacy may be particularly salient for diabetes self-management. Interview with participants indicated that the SMBI did result in an increase in perceptions of social support received from both T1DM peers and from the DHCT; however, this was not demonstrated in the data. From the data, given that the SMBI was not found to have any effect on quantitative measures of self-efficacy or social support, it is not possible to make any inferences on the association between social support and self-efficacy.

9.7 Practical Implications

The potential of SNS to support adolescents with T1DM has been highlighted by a number of studies (Cooper, Cooper, & Milton, 2009; Sutcliffe et al., 2011; Toma, Athanasiou, Harling, Darzi, & Ashrafian, 2014). However, Toma et al. (2014), in their review of SNS in the management of patients with diabetes, noted that of the thirty-four intervention studies they examined, none of them used any of the larger established SNS. The reluctance of researchers, and even clinicians, to use any of the larger established SNS is understandable given the concerns over the security and confidentiality of using such forums to engage patients. By using custom or bespoke SNS researchers have greater control over the platform and can usually tailor the features of the SNS to the needs of their interventions. However, avoidance of the larger established SNS avoids the SNS that patients are most likely to already be engaged with. Both Nordfeldt, Angarne-Lindberg, and Bertero (2012) and

McPherson (2012), in their studies of SNS to support adolescents with T1DM, used custom designed SNS that adolescents found beneficial. However, they both reported that adolescents abandoned the SNS because it differed from the social media platform they normally engaged with, thereby eliminating any potential benefits of the custom designed SNS.

In the present study the SMBI was purposely designed using a large established SNS (i.e., Facebook) so as to overcome this problem. It was envisioned that by utilising a commonly used, established SNS participants would be better predisposed to engaging with the intervention, both in terms of frequency of access and longer-term interest. However, by using an established rather than a custom SNS, the SMBI had to address the issues, such as security and privacy, which led previous researchers to develop custom SNS. The present study demonstrates that it is possible to use an established SNS to support the management of adolescents with T1DM. By being mindful of the privacy settings of the SNS and educating patients about potential security breaches, the security and privacy risks can be minimised. Another reason that previous researchers may have avoided established SNS is the limited functionality they offer. By developing bespoke SNS researchers are able to tailor the functionality of the SNS to the needs of their interventions. The present study demonstrated that the pre-set functionality of an established SNS can be adapted to deliver an intervention to support adolescents with T1DM.

The influence of SNS on healthcare is increasing (Randeree, 2009) and this has led to the development of patient led, disease specific online forums. As such forums generally do not contain the relevant healthcare professionals, the patients in these forums are both the information seekers and the information providers. There is therefore some understandable concern about the accuracy of such information and

whether it is being substituted for health information provided by healthcare teams (Griffiths et al., 2012; Powell, Inglis, Ronnie, & Large, 2011). Despite these concerns, healthcare professionals have been slow to engage SNS as a forum to support patients. Healthcare professionals' reluctance to engage with such forums is understandable given the informal structure of the groups and consequential lack of control or oversight. The SMBI demonstrates that it is possible to use an established SNS to create a closed, secure forum for adolescents with T1DM that has oversight from the DHCT.

The SMBI was demonstrated to be an effective medium for providing diabetes education to adolescents. The education was delivered via the semi-scripted conversation threads that were developed specifically for the SMBI. As such their efficacy as an educational tool was previously unknown. However, the fact that they were found to be effective in increasing participants' knowledge in certain diabetes knowledge areas suggests that they may have some efficacy as an educational medium and could potentially be applied to SNS educational interventions for a range of chronic illnesses.

The semi-scripted conversation threads were designed to facilitate communication between participants and between participants and the DHCT, which they did. However, they were also designed in such a way as to do so without overburdening the resource demands of the DHCT. One of the potential barriers to healthcare professionals utilising SNS to engage with patients is the resource impact. If the goal of engaging patients via SNS is to increase patient-centred communication, then effective use of SNS in this way is likely to see an increase in communication with patients, thereby placing extra demands on healthcare team resources. The semi-scripted conversation threads are a novel method of engaging with patients on SNS in

a way that minimises the impact on healthcare team resources and could be applied to a variety of patient groups.

Despite evidence of the increased use of SNS in adolescent diabetes management, there is a lack of empirical studies on their efficacy. The present study was designed to address this by empirically assessing the effectiveness of the SMBI on diabetes management adherence and quality of life, in addition to other secondary outcome measures. Although empirical analysis found that the SMBI did not result in any noticeable increase in glycaemic control or quality of life, it must also be acknowledged that the SMBI did not result in any decrease in glycaemic control or quality of life. This is consistent with the reports of participants, who felt that the SMBI didn't result in any changes with regard to their diabetes management behaviour. Research has demonstrated that where new technologies can examine diabetes management similar to regular clinic visits, adolescents prefer to communicate with their healthcare providers using SNS (Petrovski et al., 2012). Indeed participants in the present study rated the SMBI highly and felt that the increased support from T1DM peers and the DHCT was beneficial. As such, the SMBI continues to hold potential as a useful tool for increasing the support adolescents with T1DM receive from the DHCT and T1DM peers.

9.8 Limitations

The findings of the current study must be interpreted in the light of several limitations. One of the most notable limitations of the study was the inability to differentiate between passive users of the SMBI and non-users. From the outset it was acknowledged that there would be both active and passive users of the SMBI.

Active users are participants who actively engage with the SMBI by asking questions online, replying to the questions of others, ‘using Facebook ‘likes’ to demonstrate interest in other peoples posts, etc. In essence their interaction with the Facebook group page is directly observable to anybody using the page through their postings to the page. Passive users read all the postings to the page but do not interact with it in such a way as to demonstrate their presence to other members of the group. Although passive users may not interact with the page, they can still benefit vicariously from the postings of others. Indeed, participants reported that being able to observe the questions that their peers posed online and their responses to be beneficial, both in terms of knowledge acquisition and the awareness of the shared experience of dealing with the same T1DM related problems. However, there is another type of user of the SMBI that was not accounted for, non-users. Non-users are participants who agreed to take part in the SMBI and attended at least the initial *in vivo* group session but didn’t engage any further, or else minimally engaged, with the Facebook group page. As Facebook does not provide users with any metrics with regard to the number of views that a particular post or page has gotten from specific users, it was not possible to differentiate passive users from non-users. Although consent was obtained from participants, as well as from their parents, to take part in the SMBI, some participants may have been disinterested in the SMBI but agreed to take part because they felt pressured to do so by their parents. As such they may attended the *in vivo* adolescent group sessions but didn’t engage with the SMBI any further. This is potentially a significant confounding variable as non-users would be more similar to participants in the comparison group with regard to their level of engagement with the SMBI. As such, if there were a significant number of non-users in the treatment group, it will have had the effect of potentially masking the effect, if any, of the SMBI. As it was

not possible to differentiate passive users from non-users, this remains a very real possibility.

Qualitative interview with participants indicated that their perceptions of the level of social support they received from the DHCT and from T1DM peers increased as a result of the SMBI and that they found this additional support beneficial. However, this was not reflected in the quantitative measures of social support completed by participants. Assuming that participants did actually experience an increase in their perceptions of the level of social support they received from the DHCT and T1DM, as was suggested in interview with participants, this would mean that questionnaires selected to assess social support were not sensitive to the aspects of social support that were being impacted on by the SMBI. As previously outlined, the HCCQ is a measure of autonomy support from the DHCT and as such may be too specific to detect the changes in DHCT social support that result from the SMBI. The T1DM peer support questionnaire completed by participants, as previously mentioned, contained a significant number of omitted items. As it was not possible to impute the missing values due to the significant number of them, the missing values were replaced with zero's, significantly reducing the sensitivity of the questionnaire. As a result this questionnaire may well not have been able to detect any changes in T1DM social support resulting from the SMBI.

Glycaemic control was measured using HbA1c as a proxy. Although HbA1c is a commonly used proxy of glycaemic control in T1DM research, it has significant limitations in this regard, which are outlined in Chapter 1. A better measure of glycaemic control might have been to use longitudinal SMBG readings.

Although all adolescents attending the diabetes unit at the hospital who met the study's inclusion criteria were invited to take part, only those who actually agreed to take part were included in the study sample. By their very nature, patients who agree to take part in a study related to their medical condition are likely to be more motivated towards their medical condition. In the present study adolescents who were least motivated towards managing T1DM may have been less likely to agree to take part in the SMBI study. As such, the present study sample may not have included a representative sample of adolescents who are less motivated towards T1DM management and consequently the effect of the SMBI on this sample (i.e., adolescents with poorer motivation towards T1DM management) is overlooked.

Because of the nature of the design of the study it was not possible to run a randomised controlled trial, instead a non-randomised comparison design was employed. Within this design, participants were allocated to the treatment or comparison conditions depending on their availability for the first *in vivo* adolescent group session (see section 6.2.4). If participants were available for the first *in vivo* session they were allocated to the treatment condition, if not they were allocated to the comparison condition. Although participants had already agreed to take part in the SMBI, if at this point they were no longer interested in taking part in the SMBI they could simply say that they were unavailable for the first *in vivo* session. As such, participants in the treatment condition may have been more positively predisposed towards engaging in the SMBI, thereby biasing the sample.

9.9 Future Research

The present study found that the SMBI can be used to support adolescents with T1DM. However, due to a number of limitations, as described above, the efficacy of the SMBI remains unclear. In order to determine the effect of the SMBI on adolescents who actually engage with the SMBI, as opposed to adolescents who sign up for the SMBI but don't actually use the SNS aspect of it, future research would benefit from being able to differentiate passive users from no-users. In this regard it would also be useful to differentiate active users from passive users to determine whether type of engagement with the SMBI affects its outcomes. However, as Facebook does not currently provide metrics on passive use, future research on this will require self-report measures or use of a SNS that does support this functionality.

As highlighted earlier, the quantitative measures used to assess participants' perceptions of social support received from the DHCT and T1DM peers do not appear to have been sensitive to the changes in social support that resulted from the SMBI. Future research would benefit from using suitable quantitative instruments that specifically assess perceptions of social support received from the DHCT and social support received from T1DM peers.

The semi-scripted conversation threads were demonstrated to be an effective way of delivering education to adolescents with T1DM without overburdening the resource demands of the DHCT. They were also found to be an effective engagement tool for adolescents. Although they were developed specifically for the SMBI, there is no reason why they couldn't be applied to other chronic illnesses. Future research would benefit from further exploring the efficacy of semi-scripted conversation threads as a tool for educating and engaging adolescents with chronic illnesses.

With regards to the actual practicalities of being able to include SNS as part of normal diabetes care, the SMBI proved that this was feasible, both in terms of resource implications and engagement from the DHCT and adolescents with T1DM. Although the SMBI as a whole wasn't found to have any impact on glycaemic control or quality of life, it had so many 'moving parts', including peer support, behaviour change, education, vicarious learning and modelling among others, that it was difficult to determine what was and wasn't working at any particular time. Future research would benefit from attempting to separate out the different elements of the SMBI and investigate them individually. This way future iterations of SMBI could be streamlined to include only the most effective components.

9.10 Conclusions

The aim of this thesis was to develop and assess a SMBI to support the management of adolescents with T1DM. Previous research had suggested that social media, and in particular SNS, have potential in providing support to adolescents with T1DM. This thesis aimed to take the potential of SNS as a medium to increase social support and target it specifically at two somewhat underutilised sources of social support for adolescents with T1DM, namely T1DM peer support and DHCT support. Applying social cognitive theory, we predicted that increasing these two sources of social support would ultimately result in better glycaemic control and improved quality of life.

The first part of this process was to construct the SMBI and determine its efficacy as a tool that could be incorporated into a standard clinical environment (i.e., a multidisciplinary DHCT) and engage the DHCT and adolescents with T1DM. In

order to achieve this the SMBI had to demonstrate itself to be safe, secure, usable and engaging, and not to overburden the resources of the DHCT. The pilot study of the SMBI found that with a bit of adjustment the SMBI was able to meet this first objective. We can therefore conclude that the SMBI that was developed in the present thesis can be incorporated into a standard clinical environment and engage the DHCT and adolescents with T1DM.

The second part of this process was to determine the efficacy of the SMBI as a tool to affect the desired change in adolescents with T1DM. We constructed a model to demonstrate the mechanism by which it was believed the SMBI would result in improved glycaemic control and quality of life, and then tested this model empirically. However, neither the model, nor any part of it, stood up to empirical assessment and we conclude that SMBI model cannot be supported.

Quantitative analysis did not find any significant change in glycaemic control or quality of life as a result of the SMBI. Neither did it demonstrate any significant change in any of the intermediary factors (e.g., self-efficacy, illness perceptions, etc.) as predicted in the model. However, qualitative interview with participants indicated positive effects of the SMBI that were not evident in empirical assessment. Participants consistently reported that the SMBI resulted in changes in their relationships with the DHCT and T1DM peers that they found beneficial. From this we conclude that although the SMBI did not impact on glycaemic control or quality of life as had been predicted, it did impact positively on aspects of participants' wellbeing not empirically assessed in the present thesis. Future research would benefit from investigating the mechanisms by which the SMBI impacts participants' perceptions of the support they receive from the DHCT and T1DM peers. By identifying these mechanisms it may be possible to refine the SMBI to better support

adolescents with T1DM and result in a positive impact on glycaemic control and quality of life.

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Appendix 1
Ethical Approval Letters



15th January 2013

F.A.O. Vincent McDarby

School of Psychology Research Ethics Committee

Dear Vincent,

I am pleased to inform your inclusion on the application entitled "Adolescent Support Systems Increasing Self-efficacy Trial (ASSIST)" has been approved by the School of Psychology Research Ethics Committee.

It is not routine policy of the Committee to issue duplicate or replacement letters confirming ethical approval. It is therefore the responsibility of the applicant to keep the approval letter safe.

Yours sincerely,

Prof. Richard Carson
Chair
School of Psychology Research Ethics Committee

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Dr Declan Cody
Consultant Paediatric Endocrinologist
Our Lady's Children's Hospital
Crumlin
Dublin 12

15th March 2012

REC Reference: GEN/259/12

Adolescent Support Systems Increasing Self-efficacy Trial
Principal Investigators: Dr. Declan Cody, Mr. Vincent McDarby.

Dear Dr Cody

The Ethics (Medical Research) Committee reviewed and approved the above project at its meeting which was held on 13th March 2012.

The Committee noted that the project has not yet been approved for funding from the National Children's Research Centre.

The Committee would like to thank you and Mr. Vincent McDarby for being present at the meeting.

Yours sincerely

Claire Rice
Secretary
Ethics (Medical Research) Committee

CC: Mr. Vincent McDarby, Senior Clinical Psychologist, OLCHC.

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ETHICS (MEDICAL RESEARCH) COMMITTEE OFFICE

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Mr Vincent McDarby
Senior Clinical Psychologist
Our Lady's Children's Hospital
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Dublin 12

23rd January 2014

REC Reference: GEN/259/12

Adolescent Support Systems Increasing Self-efficacy Trial
Principal Investigators: Dr. Declan Cody, Mr. Vincent McDarby.

Dear Mr McDarby

The Chairperson of the Ethics (Medical Research) Committee, Professor Andrew Green, at a meeting which was held on 22nd January 2014, reviewed and approved two amendments to the above study, based on the documentation submitted, as follows:

- Your cover letter dated, 14th January 2014;
- The completed REC Application Form;
- Parent Information Leaflet; Adolescent Information Leaflet; Parent Consent Form; Adolescent Consent Form, as well as the questions being used to guide the discussion.

Yours sincerely

Claire Rice
Secretary
Ethics (Medical Research) Committee

CC: Dr. Declan Cody, Consultant Paediatric Endocrinologist, OLCHC.

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17th February 2014

REC Reference: GEN/365/14

Adolescent Support Systems Increasing Self-efficacy Trial
Principal Investigators: Dr. Declan Cody, Mr. Vincent McDarby.

Dear Mr McDarby

The Ethics (Medical Research) Committee of this hospital, at a meeting which took place on, 11th February 2014, gave approval for two further extensions to this study, as outlined in your cover letter dated, 14th January 2014.

The following documentation was also reviewed:

- Completed REC Standard Application Form;
- Letter for Parent/Guardian;
- Parent Information Leaflet;
- Adolescent Information Leaflet;
- ASSIST – Questions to be used to Guide Qualitative Discussion with the Pilot Group.

Yours sincerely

Claire Rice
Secretary
Ethics (Medical Research) Committee

CC: Dr. Declan Cody, Consultant Paediatric Endocrinologist, OLCHC.

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Appendix 2

Consent Forms and Information Sheets

Disclaimer for use of Facebook in ASSIST

As part of the ASSIST project being conducted by Dr Declan Cody, Consultant Paediatrician, and Mr Vincent Mc Darby, Senior Clinical Psychologist, at Our Lady's Children's Hospital, Crumlin your child will be provided with an opportunity to interact via Facebook with members of the diabetes team and other adolescent's with diabetes attending the hospital. While we will attempt to ensure that this is a safe secure means for your child to communicate, Facebook is not operated or controlled by Our Lady's Children's Hospital, Crumlin and as such we do not have control over the storage or dissemination of information placed on the website. As part of the project your child may communicate with members of the diabetes team in relation to their medical condition. This communication involves the placing of private medical information on an unsecured platform and therefore this information is not being stored in accordance with the Irish data protection acts of 1988 and 2003.

The Facebook communication with the members of the diabetes team is meant to compliment normal clinical care and not be a substitution for it. Children and their parents are still expected to attend clinic appointments as per normal and to contact the team through conventional methods (i.e. telephone and drop-in visits) as necessary to support good clinical management. Facebook is not a means of communication in emergencies as communications via Facebook may not be checked for a number of days. In the event of an emergency please telephone the hospital as per normal instructions.

Although some of the communications between the adolescents will be monitored and moderated by members of the diabetes team, it will not be possible to monitor all adolescents' communications. Using Facebook exposes adolescents to the possibility of cyber-bullying, inappropriate conversations and inappropriate disclosures. Members of the diabetes team will try and reduce the possibility of such issues arising within the forum created for the project and will alert parents if they feel that their child has been exposed to such issues. However, it is important that parents understand that regardless of this the potential for exposure to such issues remains.

Allowing your child to partake in the ASSIST project exposes them to the potential of the issues outlined in the above paragraphs. If you are not comfortable with this you are free to withdraw your child from the project now or at any time in the future without explanation.

Please sign and date below to indicate you have read and understand the above.

Signed _____

Date _____

Parent/Caregiver Consent Form

I _____ give consent for _____, of whom I am legal guardian, to participate in the research study Adolescent Support Systems Increasing Self-efficacy Trial being conducted by Dr Declan Cody, Consultant Paediatric Endocrinologist, and Mr Vincent Mc Darby, Senior Clinical Psychologist, at Our Lady's Children's Hospital, Crumlin. I have been provided with adequate information on the rationale and purpose of the study as well as what will be required of my child and myself as participants. I have also been made aware that I may withdraw my child from the study at any point without explanation.

Signed _____

Date _____

Adolescent Consent Form

I _____ consent to participate in the research study Adolescent Support Systems Increasing Self-efficacy Trial being conducted by Dr Declan Cody, Consultant Paediatric Endocrinologist, and Mr Vincent Mc Darby, Senior Clinical Psychologist, at Our Lady's Children's Hospital, Crumlin. I have been provided with adequate information on the rationale and purpose of the study as well as what will be required of me as a participants. I have also been made aware that I may withdraw from the study at any point without explanation.

Signed _____

Date _____

Dear Parent/Guardian

As part of our on-going initiatives to improve the physiological and psychological wellbeing of the children attending the diabetes unit at Our Lady's Children's Hospital we are proposing to undertake a research study that aims to investigate a new approach to supporting the diabetes management of adolescents. Please find enclosed separate information leaflets for yourself and you child outlining the details of the study as well as consent forms should you decide to participate in the study. We will contact you again by telephone over the next two weeks to answer any questions you may have and to ascertain if you are interested in participating in the research. However, feel free to contact us in the meantime if you would like to discuss this in more detail.

Yours Sincerely,

Dr Declan Cody
Consultant Paediatric Endocrinologist

Vincent Mc Darby
Senior Clinical Psychologist

Parent Information Leaflet

Medical advances have led to significant improvements in the quality of life of individuals with Type 1 Diabetes. However, poor adherence to diabetes management regimens continues to be a significant problem and places individuals at risk of short-term and long-term complications. Adherence to diabetes management regimens has been found to be particularly poor during adolescence and as such we are always looking at new ways to support good diabetes management during this stage of a child's life.

One factor that has been found to be a strong predictor of adherence at this age is an adolescent's confidence in their ability to carry out the tasks involved in good diabetes management. Interventions aimed at increasing the adherence of adolescents have tended to focus on increasing this confidence. However, to date these interventions have tended to be costly and any improvements in adherence have often been small and short-lived.

We plan to use a new approach to increase adolescents' confidence in their ability to carry out the tasks involved in good diabetes management by focusing on developing better relationships between the adolescent and their caregivers, between the adolescent and the members of the diabetes team and between the adolescent and other young people with diabetes. In order to do this we plan to run five structured adolescent group-based sessions lasting one hour each. The sessions will be run by Vincent Mc Darby, Senior Clinical Psychologist, over a twelve-week period.

These groups will contain six to eight adolescents of the same gender and of similar age. The sessions will focus on strategies to help adolescents utilise the support of parents, diabetes team members and other members of the group to better manage their diabetes. In addition, a secure page on a social network site (i.e., Facebook) will be created to allow the adolescents to communicate with each other outside the group and with members of the diabetes team.

In order to evaluate the effectiveness of this intervention we will be asking parents and adolescents to complete questionnaires every four months that examine the adolescent's physical and psychological wellbeing. We will also examine the HbA1C readings that are measured at routine clinic visits.

If you and your child are willing to participate in this research study you will be randomly assigned to a 'treatment' or 'control' group. Those in the 'treatment' group will undergo the intervention outlined above. Those in the 'control' group will continue to attend their routine diabetes clinic appointments, the only difference being that they will complete the questionnaires outlined above at these clinic visits. After completion of the study those in the 'control' group will be offered the opportunity to undergo the intervention should it be found to

have a significant positive impact on the adolescents' physiological or psychological wellbeing.

Should you agree to participate in the research study you are free to withdraw from the study at any point without explanation. All personal information gathered during the study will be anonymised, stored securely and destroyed at the end of the study. In addition, all information gathered during the study will be collated and as such when the results of the study are being disseminated no identifying information will be present.

Should you require any further information in relation to this research study please feel free to contact Dr Declan Cody, Consultant Paediatric Endocrinologist, or Vincent Mc Darby, Senior Clinical Psychologist.

Dr Declan Cody
Consultant Paediatric Endocrinologist

Vincent Mc Darby
Senior Clinical Psychologist

Adolescent Information Leaflet

The amount of work involved in diabetes management is significant and as a result good diabetes management can at times be hard to achieve and even harder to maintain. Adolescence can be a particularly difficult time with regard to diabetes management as you start to take more responsibility for managing your own diabetes, not to mention all the other stresses of adolescence (e.g. exams, friends, family, etc.). Because the pressures of adolescence can interfere with diabetes management we are always looking at new ways to help adolescents be able to better manage their diabetes. One thing that has often found to help adolescents better manage their diabetes is the support that they receive from parents, from friends and from the diabetes team.

We are planning to do a study that will try and improve the support provided to adolescents by their parents and by the diabetes team to see if it will help them be better able to manage their diabetes. This study will involve adolescents coming into the hospital for five hour-long group sessions over a twelve-week period. These groups will be made up of six to eight adolescents of the same gender and similar age and would be run by Vincent Mc Darby, the psychologist on the diabetes team. The sessions will involve learning about different ways of looking at diabetes management. A special page will also be set up on Facebook where you would be able to contact other young people in the group and the members of the diabetes team.

In order to see if what we are doing is helping you and your parents we will have you and your parents fill out some questionnaires that look at how you are feeling and how well your diabetes management is going. Any information collected in these questionnaires will not be seen by anyone but Vincent and Dr Cody and will be destroyed at the end of the study.

If you would be interested in taking part in this study you can discuss it with your parents and then make a decision together about whether you would like to get involved. If you do decide to get involved you can withdraw from the study at any point without having to explain why. Please feel free to contact Vincent or Dr Cody if you have any questions about this study.

Dr Declan Cody
Consultant Paediatric Endocrinologist

Vincent Mc Darby
Senior Clinical Psychologist

Appendix 3

Outline for *In Vivo* Adolescent Group Sessions for Pilot Study

Adolescent Session 1 - Breakdown

- *Overview of Intervention*
 - Number of sessions and timeline
 - Goal of the intervention
 - Adolescents role in the intervention
- *Ground Rules*
 - Confidentiality
 - Inappropriate disclosures
 - Cyberbullying
 - Not allowing friends access the page through their accounts
- *How to utilise the Facebook page*
 - How a secret group page works
 - How to interact with diabetes team on the group page
 - How to interact with each other on the group page
 - How to create a poll on Facebook
 - Using the 'Like' button
 - Difference between private and semi-open online communication
 - What to post to the group page
 - What the group page is not suitable for (i.e. emergencies)
- *Creation of the Facebook page*
 - Facebook secret group page created and named during the session
 - Each adolescent is given computer access to join the group page
 - Once everyone has joined the group page it is made secret
- *Explanation of exercises to facilitate posting to the page*
 - It will be explained that over the course of the following two weeks they will be given instructions on the page of things of interest to post to the page and that the goal of this is to help get to know them better.
- *Explanation of exercises to facilitate interaction with each other*
 - It will be explained that we will be doing exercises to help them get to know one another better.
- *Explanation of exercise to facilitate interaction with clinicians.*
 - It will be explained that we will also be doing exercises to help them get to know the clinicians better as well.
- *Review and Finish*
 - The importance of engaging in the Facebook page.
 - The more they put in the more they get out.
 - Date of next meeting.

Adolescent Session 2 – Breakdown

- *Review of Previous Session*
 - Ground rules
 - Goal of the intervention
 - Adolescents role in the intervention
- *Discussion*
 - Each adolescent in turn tells something about each of the other members of the group.
 - Discussion about what are the most common interests among the group
- *Discussion*
 - What was the most unusual true statement
 - What was the most unusual false statement
 - How did they deduce which statements were true.
- *How the Facebook page can be used to gather information about diabetes*
 - How to ask the clinicians questions online
 - What kind of questions can be asked online
 - How to check the accuracy of information found online
- *Explanation of exercise to facilitate using Facebook to find diabetes related information.*
 - It will be explained that we will also be doing exercises to help them use Facebook to find out information about diabetes.
- *The benefits of sharing personal diabetes information*
 - How to share diabetes related personal information on Facebook
 - How to support peers who post diabetes related information on Facebook
 - How to request support from peers about diabetes related issues
- *Review and Finish*
 - Using the support offered through the page will help them develop independence.
 - Date of next meeting.

Adolescent Session 3 – Breakdown

- *Review of Previous Session*
 - Ground rules
 - Posting and obtaining diabetes related information online
 - Using the support of the diabetes team and peers online

- *Discussion from Previous Week*
 - Each adolescent in turn tells about something new they learned about diabetes
 - Discussion about what are the most common myths in diabetes

- *What is required in good diabetes management*
 - Insulin, diet and blood sugar checking
 - List of everything that someone can do that is not consistent with good management.
 - Everyone is then asked to confirm from the list everything that they have done in the past and are currently doing.

- *Why diabetes management is so hard?*
 - The barriers to good diabetes management
 - Moving away from HbA1c as a measure of compliance
 - The positive role of support in diabetes management

- *Review and Finish*
 - Focus on the goal at hand and the larger goal will take care of itself
 - Date of next meeting.

Adolescent Session 4 - Breakdown

- *Review of Previous Session*
 - Ground rules
 - Posting and obtaining diabetes related information online
 - Using the support of the diabetes team and peers online

- *Motivation*
 - Why we are least motivated when we need it most.
 - The benefits of routine
 - The benefits of support

- *How to review goals?*
 - Goals that are too hard
 - Goals that are too easy
 - When to adjust goals

- *Review and Finish*
 - Goal setting and motivation
 - Date of next meeting.

Adolescent Session 5 – Breakdown

- *Review of Previous Session*
 - Ground rules
 - Posting and obtaining diabetes related information online
 - Using the support of the diabetes team and peers online
- *Discussion*
 - Each adolescent in turn tells about their experience of working towards a goal
 - How they felt about achieving their goal
- *Relapse Prevention*
 - What causes things to go bad
 - How to reduce the chances of things going bad
 - What to do when things do go bad
- *Ongoing Utilisation of the Facebook support*
 - The importance of Facebook in the intervention
 - How to keep using Facebook to maintain good management
 - How to use Facebook to support others when they need it
- *Overview of the Entire Intervention*
 - What we have achieved
 - What has been learned
 - The role of support
- *Review and Finish*
 - Continuing to utilise the Facebook support

Appendix 4

T1DM Peer Support Questionnaire

13. I feel that another young person with diabetes that I know understands the difficulties of diabetes management better than my parents.

1 2 3 4 5 6 7
strongly neutral strongly
disagree agree

14. I feel that another young person with diabetes that I know understands the difficulties of diabetes management better than my doctors and nurses.

1 2 3 4 5 6 7
strongly neutral strongly
disagree agree

15. I feel able to share my feelings about diabetes with another young person with diabetes that I know.

1 2 3 4 5 6 7
strongly neutral strongly
disagree agree

16. I regularly contact another young person with diabetes to help me make decisions around my diabetes management.

1 2 3 4 5 6 7
strongly neutral strongly
disagree agree

17. Having contact with another young person with diabetes makes me feel more motivated towards managing my diabetes better.

1 2 3 4 5 6 7
strongly neutral strongly
disagree agree

Appendix 5

Semi-Structured Conversation Threads

Conversation Thread 1 - What is Diabetes

Sub Topics

- The difference between type 1 and type 2 diabetes.
- What we need insulin for?
- Where do we get sugar from?

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

The Difference Between Type 1 and Type 2 Diabetes

WHAT IS DIABETES

Hi guys, I'm going to cover some information about what diabetes is. A lot of it you probably already know but some of it might be new to you. Please join in answering some of the questions and feel free to ask any questions you have.

Lots of people who don't have much experience with diabetes don't know the difference between Type 1 and Type 2 diabetes and can end up saying stupid things or asking stupid questions like, "Did you get diabetes from eating too many sweets?". Has anyone had anybody say something stupid like this to them about diabetes?

Although Type 1 and Type 2 diabetes are very different conditions the difference can be a bit confusing. What are some of the difference between Type 1 and Type 2 diabetes?

There are two main types of diabetes, Type 1 and Type 2. Children usually develop Type 1 and this results in a total lack of insulin production and always requires insulin injections. Type 2 diabetes, or non-insulin dependant Diabetes, is more associated with adults and usually happens when you are overweight and have reduced insulin production and/or effectiveness.

Is there anything a person can do to prevent Type 1 diabetes?

In Type 1 Diabetes, the person's own body has destroyed the insulin-producing beta cells in the pancreas. Diabetes Type 1 is not preventable and it is in no way the result of a person's lifestyle. Whether a person is fat, thin, fit or unfit makes no difference to his or her risk of developing Type 1. The vast majority of people who develop Type 1 Diabetes are not overweight, and are otherwise healthy when they first get it. You cannot reverse or prevent Type 1 by doing lots of exercise or eating carefully. Quite simply, a person with Type 1 Diabetes has lost his/her beta cells, which are in the pancreas and produce insulin and therefore can't produce insulin.

What about Type 2 diabetes, is there anything that can be done to prevent it?

In the case of Type 2 Diabetes, much of its onset is the result of bodyweight, diet fitness and lifestyle. People with Type 2 diabetes usually either are resistant to the actions of insulin due to their obesity or later on fail to produce sufficient insulin... This type of diabetes tends to appear later on in life. Type 2 diabetes can be prevented or delayed with a healthy lifestyle, including maintaining a healthy weight, eating sensibly, and exercising regularly. It is treated by diet, exercise, weight loss, medication and in some cases, insulin injections.

What we Need Insulin for?

As all of you know diabetes is all about your body not making insulin. Does anyone know what your body needs insulin for?

Insulin is a hormone and its function is to transport sugar (glucose) from the blood into the cells of the body. Sugar or glucose is the cells food and from this the cells make energy. The following pages from Pete the Pancreas explain this in more detail:

Post the PDF of page 6 to 9 of Pete the Pancreas to the thread

What is diabetes?



Your body is made up of tiny, tiny bits called CELLS



These cells need GLUCOSE (sugar) to give them ENERGY - so you can feel good and do things!



You get glucose (sugar) from the FOOD you eat

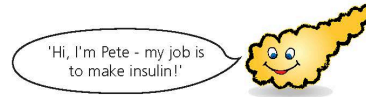


INSULIN is a hormone in your body that acts like a KEY to open the cells and let the glucose in

Insulin is made in a part of your body called your PANCREAS

Your pancreas is an organ (like your heart) and it lives near your tummy

We like to call him PETE!



6

7



When you have diabetes, Pete can't make any insulin



Without the insulin key, glucose from your food can't get into your cells. Your cells will feel sad because they have no energy



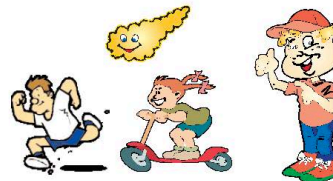
All the glucose from your food will stay in your blood and make you feel unwell.



When you have diabetes, you need to inject insulin to make Pete and all your cells happy again



Then you will feel well and have energy to play!



8

9

Where do we get sugar from?

Most people who don't have diabetes think that we only get sugar from sweet things like sweets and fizzy drinks but as you know sugar is actually present in lots of other things as well. What things have you come across outside of sweets and fizzy drinks that contain a lot of sugar?

Another word for sugar is Carbohydrates. There are two main types of Carbohydrate; simple sugars and starches. Simple sugars are the sugars found in sweets, cakes and normal fizzy drinks

and these sugars are rapidly absorbed and therefore can cause your blood sugar to increase relatively quickly. Starches are found in bread, potatoes, pasta, and rice. Starches are broken down slowly in the digestive system and absorbed more slowly into the blood stream. As this process takes time starches are longer acting carbohydrates and better for you as your blood sugars don't go up so quickly.

Conversation Thread 2 - Insulin

Sub Topics

- Types of Insulin
- Insulin Administration
- Frequency of Insulin Injections
- Injection sites

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

Types of Insulin

There are actually loads of different types of insulin that are used to manage diabetes. Can everyone please post the type/types of insulin they are currently using and we will look at the difference between the different insulin?

Has anyone used any different type of insulin in the past?

Use the information below to describe each of the different insulin's posted by the adolescents.

There are essentially two major types of insulin which are rapid-acting and slow-acting. The insulins shown below are the main types we use in our clinic

- Lantus and Levemir. Clear in appearance, these are long acting insulins, which lasts approximately 24 hours and is usually given in conjunction with Novorapid, Humalog or Actrapid insulins.
- Insulatard: Is cloudy in appearance, is a medium acting insulin which starts to work about 1.5hours after you take it, and last approximately 12 hours.
-
- Actrapid: This is a short acting insulin, which starts to work within a half an hour and last approximately 6 to 8 hours.
- Novorapid/Humalog: These are rapid acting insulins which starts to work within 10-20minutes, peaks between 1 and 3 hours and last 3 to 5 hours
- WE also use pre-filled mixtures of insulin (novomix, humulin) which are essentially a mixture of slow and fast acting insulin and which last in general 12 hours.

Anytime you change the type of insulin you are using it can throw you blood sugars off for a bit until things get settled. Has anyone found that after changing the type of insulin they were using their blood sugars went a bit off for a while?

Why do you think this was?

As you'll notice, the main difference between different types of insulin is the speed at which they start to work and for how long they work for. There are generally four different types of insulin that are used:

Fast-Acting Insulin. (Humalog, Novo Rapid, Novolog) These insulins can lower blood sugar fairly quickly, usually within 30 minutes after injection. Insulin peaks in about 1-2hours and continues to work for about 4 more hours. This rapid action reduces the risk for hypoglycemic events after eating. Optimal timing for administering this insulin is about 15 minutes before a meal. Fast-acting insulins may be especially useful for meals with high carbohydrates.

Short Acting Insulin. Begins to act 30 minutes after injection, reaches its peak in 2 - 4 hours, and lasts about 6 hours. Short Acting insulin may be administered before a meal and may be better for high-fat meals.

Medium Acting Insulin. Works within 2 - 4 hours, peaks 4 - 12 hours later, and lasts up to 18 hours.

Long-Acting Insulin. (Lantus) Released slowly. Long-acting insulin peaks at 10 hours and lasts up to 20 hours. These long-acting or basal insulins as they are called and more often used in a multiple-injection approach usually involving 4 insulin shots a day.

Insulin Administration

There are three types of devices that can be used to give insulin. Does anyone know what they are?

Insulin can be given using a syringe, a pen device or an insulin pump, which you leave on you all the time.

Pens devices are like syringes except that you don't have to draw up the insulin and are a lot more flexible so you can put them in your pocket or throw them into your bag. However, you can't mix insulins in a pen, they only come in certain premixes. So you might have to use a syringe if your mix of insulin isn't available in a pen.

An insulin pump is really just a way to drip small amounts of insulin into the body all the time, just like the pancreas normally does in someone without diabetes. This keeps blood sugar steadier, eliminating some of the highs and lows. The pump itself is about the size a deck of cards. It also comes with an infusion set, which is a long, thin, plastic tube that carries insulin into the body through a needle or a plastic piece called a cannula. Inserting the needle or cannula is a lot like inserting the needle for an injection, except the infusion set stays in the skin for about two or three days. The insulin pump gives insulin in two different ways. It delivers a "basal rate" of insulin to imitate the small amount of insulin the pancreas secretes all the time. The basal rates can be preprogrammed and changed, depending on your level of activity. By pressing a button, you can also deliver a "bolus" of insulin, which replaces the extra insulin the pancreas would normally crank out at mealtimes.

Can everyone please post what devices they are using to give insulin?

Frequency of Insulin Injections

If you are using pens/syringes, how often you have an insulin injection will depend on a number of things including your age, lifestyle and diet. For everyone that is using pens and/or syringes can you please post how often each day you use each?

The timing and frequency of insulin injections depend upon a number of factors:

- The type of insulin you are using (short-acting, medium-acting, long-acting and rapid-acting)

- The amount and type of food eaten. Ingestion of food makes the blood glucose level rise.

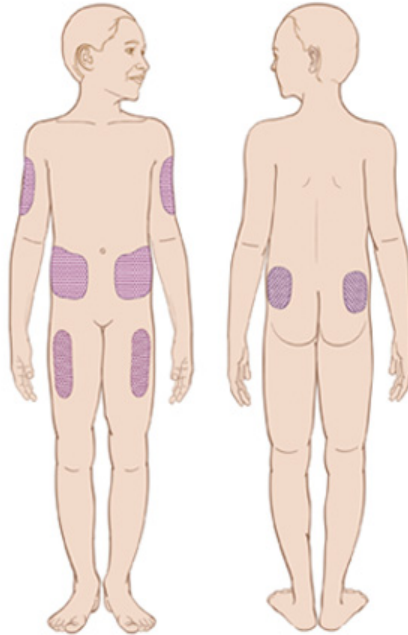
- Your level of physical activity.

If you are on three or less injections per day you will need to eat snacks between meals to match the action of the insulin you are using. When you are using this insulin regimen you need make sure you eat and take your injections at the same time every day. This can be difficult, particularly during school holidays when you often get up and have your meals at different times than when you are at school. If you are on four or more injections a day you don't eat snacks and don't have to eat at set times. However, you do have to take an injection every time you eat and this can be disruptive, particularly in school. It is important that you use the insulin regimen that best suits your lifestyle and you can talk to the doctors and nurses about the regimen that would best suit you.

Injections Sites

There are a number of different places in the body that we can give insulin injections, what are they?

Post the jpeg of injection sites to the thread



Has anyone noticed that sometimes if they keep giving injections in the same place it starts to get lumpy?

Moving to a new injection site can be difficult at first because we're not used to getting injections there. However, it's important to not keep using the same injection sites all the times otherwise they will start to get lumpy. When we continue to injection into lumpy injection sites they get even lumpier until the lumps start becoming more noticeable. Also, when we inject into lumpy injection sites not all the insulin is able to get through and this results in higher blood sugars.

Everyone generally has favourite places that they like to give their injections and can find it difficult to move to places they don't use as often. What places do you least like to give injections in?

When we inject into any area for the first time it is uncomfortable because our body is not used to it and therefore we tend to avoid injecting into areas that we don't use that often. However, if you inject into a new area every day your body starts to get used to feeling and it very quickly it doesn't feel much different from injecting into the area you had been using.

Conversation Thread 3 - Hypoglycaemia

Sub Topics

- What is Hypoglycaemia?
- Causes of Hypoglycaemia
- Treatment of Hypoglycaemia

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

What is Hypoglycaemia?

Different people have different sensitivities to low blood sugar and therefore notice they are going low at different blood sugar levels. At what blood sugar level do you normally start to feel low and what are the signs that you notice?

Hypoglycaemia, or low blood sugar, is a blood sugar that reads under 4mmols. As we know there are three main factors that affect blood sugar levels there are insulin, food and exercise. Illness is also a factor but it is not constant. The body usually adjusts the amount of insulin produced to match the blood glucose concentration and therefore keeping blood glucose within a narrow range. For some one with diabetes, this same balancing act must be achieved by matching injected insulin doses to both the food we plan to eat, and the exercise we plan to take. When the balance between food, insulin and exercise is upset blood glucose levels can move out of the target range. Hypoglycaemia or low blood glucose may occur.

Causes of Hypoglycaemia

There are a number of different things that can cause blood sugar to go low. Can people give an example of something that caused them to go low recently?

There are many reasons for hypoglycaemia but the most common include:

- Not eating enough Carbohydrate at meal or snack time.
- Being late for or missing a meal or snack.
- Taking too much insulin.
- Taking insulin at the wrong time.
- Taking the wrong type of insulin.
- Taking extra exercise and too little food.
- During times of illness when food is not being adsorbed, for example vomiting bug.

A reason can usually be found but sometimes a hypo may occur without obvious cause.

Treatment of Hypoglycaemia

What do people normally do when they start to feel low?

During a mild Low you may feel shaky, hungry, pale, or get a stomach or headache. If you feel like this at any time you must stop and check your blood sugar. If your blood sugar is below 4.0mmols you must take some fast acting carbohydrate like 50mls (two mouthfuls) of the original Lucozade, 100mls of a normal fizzy drink or orange/apple juice or three dextrose sweets. Wait ten minutes, it is really important to wait the 10 minutes to give the Lucozade a chance to

get absorbed. If you feel ok after the ten minutes you must have something to eat, if you are due a meal or a snack have it, if you are not due any food you must take something like a yoghurt, digestive biscuit, cereal bar, piece of fruit or slice of bread to prevent the blood sugar from dropping again. If you do not feel better after the first go of Lucozade, check your blood sugar again. If you are still low repeat the dose of Lucozade, and wait ten minutes. Do not rush in with food, as it will take the Lucozade longer to get absorbed and take you longer to recover from the low. Once blood sugar has come back up follow on with food.

Post the PDF of page 18 to 19 of Pete the Pancreas to the thread

What is a HYPO?
(Hypoglycaemia)

How do you know you're having a hypo?

A hypo is when your blood glucose level falls too low. A hypo is normally a blood glucose level less than 4.5 or 4.0 depending on your clinic. Your doctor or nurse will tell you what is too low for you.

You may:
Be pale
Feel sweaty
Be hungry
Have 'wobbly legs'
Be shivery or shaky
Feel tired and drowsy
Have blurred vision
Feel worried or afraid
Just feel funny!
Or sometimes you may not have any of these feelings.

If you are having a HYPO
(blood glucose level less than 4.5 or 4.0 as advised by your doctor or nurse)

what must you do?

- 1 Tell somebody straight away - mum, dad or a nearby adult
- 2 Eat or drink something sugary,
FOR EXAMPLE:
Lucozade sweets or Glucogel **OR**
A sugary drink - Lucozade (original), 7UP, Fanta, Coke or juice (not a diet drink) **OR**
Some other kind of sugar - jam, honey **PLUS**
Eat a snack (biscuits, bread - check with mum or dad).
- 3 Re-check your blood glucose levels in 15 minutes
- 4 If your blood glucose level is still low - drink some more sugary drink and have another snack
- 5 If you still feel unwell, tell the adult looking after you.

Has anyone had a low where they became confused and had difficulty treating themselves?

During a moderate low you may feel the same as above however you become more confused and unable to treat the low yourself. Treatment of a moderate low at this stage is the same as the treatment of a mild low. Sometimes if you do not feel like drinking anything try jam or honey on a spoon.

Has anyone ever had a severe low where someone else had to treat them or a doctor/ambulance had to be called?

A severe low is uncommon but it can happen. It is also important to realise that even without any help the body will recover from most lows by releasing sugar from the stores in the liver and muscles. But we do not want these stores to get used up as they take a while to build up again, that is why you must treat all lows no exception. The liver stores carbohydrate for times when immediate energy needs cannot be provided by food such as overnight when asleep. When the glucose concentration has fallen very low, the body responds by making hormones that restore the glucose level. One such hormone is glucagon – the same substance that can be injected in times of emergency. Glucagon works by releasing the livers stores of glucose into the blood stream, so increasing the blood glucose available.

The brain has no ability to store glucose unlike the liver and muscles therefore it needs a constant supply in the blood. The brain needs glucose to function. Severe lows occur when the

blood glucose level is so that the brain no longer functions properly. The concentration of blood glucose at which this occurs is different from person to person. Agitation, aggression and unconsciousness may occur. Sometimes the blood glucose level may drop so low that a fit, or convulsion, occurs. This can be very frightening at the time but does not mean there will be any permanent problem and full recovery is to be expected. Glucagon works by making the liver release its stores of glucose.

If a low is untreated it can progress to a severe low, this is a medical emergency. During a severe low you may become too confused to drink anything, may have slurred speech, may be unsteady on your feet or become very sleepy and difficult to arouse. Because of the lack of sugar getting to the brain you may also get some jerky movements. In this instance you will have to be given the emergency injection of glucagon. Once you have responded to the glucagon, solid food containing carbohydrate should be given to prevent a further drop blood in blood glucose. While tempting, chocolate is not recommended as the fat in chocolate slows down glucose absorption into the blood.

Conversation Thread 4 - Hyperglycaemia

Sub Topics

- What is Hyperglycaemia?
- Causes of Hyperglycaemia
- Treatment of Hyperglycaemia
- What is DKA
- Signs and Symptoms of DKA
- What Happens to Someone in DKA?
- What are the causes of DKA?

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

What is Hyperglycaemia?

Some people are able to notice if their blood sugars are high because of the way they feel but many people don't. Does anyone notice when their blood sugar is high by the way they feel and if so what sort of things do they notice?

When blood sugar levels are too high, it's called hyperglycemia. Glucose is a sugar that comes from foods, and is formed and stored inside the body. It's the main source of energy for the body's cells and is carried through the bloodstream. But even though we need glucose for energy, too much glucose in the blood can be unhealthy. Too much sugar in the bloodstream for long periods of time can cause damage to the vessels that supply blood to vital organs, which can increase the risk of heart disease, kidney disease, vision problems, and nerve problems in people with diabetes. These problems don't usually show up in kids or teens with diabetes who have had the disease for only a few years. However, they can occur in adulthood in some people, particularly if they haven't managed or controlled their diabetes properly.

High blood sugars also have short-term affects that we may or may not notice including

- Difficulties concentrating
- Slower reaction times
- Not being able to run as fast
- Poorer performance in sport
- Feeling sad/miserable
- Being in a bad mood
- Getting frustrated or into arguments easily

If your blood sugars have been high for a long time you can start becoming used to experiencing some of the above symptoms and not realise that they are occurring.

Causes of Hyperglycaemia

Everyone gets high blood sugars from time to time and there are lots of causes. What sort of things have you noticed that make your blood sugar high?

The causes of high blood sugar are:

- Eating too much food relative to the amount of insulin injected
- Missing an insulin injection (for people on the pump missing a bolus or a failure of the pump to deliver insulin)
- Illness/stress

Treatment of Hyperglycaemia

When your blood sugars are high what kind of things do you do to try and bring them down?

Post the PDF of page 20 to 21 of Pete the Pancreas to the thread

What is a HIGH?
(Hyperglycaemia)

How do you know you are high?

This is when your blood glucose level is more than 15

How might you be feeling?

Flushed
Not well
Thirsty
Going to the toilet a lot
Grumpy
Tummy pains
Off form
No energy

BUT it is important to remember you may also feel normal!

20

When you are HIGH
(blood glucose level more than 15)
what must you do?

- 1 Tell mum or dad or a nearby adult straight away
- 2 Wash your hands and dry well
- 3 Recheck your blood glucose level
- 4 **Check for ketones**
- 5 Think - did you eat any extra sugary food?
- 6 Remember - did you take your insulin?
- 7 Drink plenty of water/fluids
- 8 If your blood glucose level stays high, or if you have ketones, you need to tell the adult looking after you

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What is DKA?

Has anyone heard of a thing called DKA in relation to diabetes?

Diabetic ketoacidosis (or DKA) is a serious condition caused by ketones building up in your blood. This is a problem because if a lot of ketones build up in your bloodstream they can be poisonous and make your blood become acidic. This usually happens if your diabetes isn't being controlled very well and your blood sugar starts to get really high. This means there isn't enough insulin around, so your body can't use sugar (glucose) for energy. Instead, your body starts to use fat for energy. But when your body does this, ketones are made as a waste product. Extra insulin is needed to prevent further ketone production and to prevent further deterioration in condition. The situation may worsen dramatically if not dealt with rapidly and effectively, making the person concerned seriously ill. This condition is known as Diabetic Ketoacidosis, and often abbreviated to letters "DKA".

Signs and Symptoms of DKA

How do you think you might know if you were experiencing DKA?

These are some of the signs that might indicate the development of ketoacidosis:

- High blood sugar readings (usually).
- Ketones present in the blood and urine
- Dehydration

- Vomiting
- Abdominal pain/ cramps
- Rapid breathing rate
- Sweet smelling breath
- Increasing sleepiness/drowsiness, lack of energy

What are the causes of DKA?

Thankfully DKA is relatively rare in people whose diabetes is well managed. What kind of things do you think might cause DKA?

There are a number of situations where DKA is more likely to occur. After diagnosis, probably the most common time is during another illness (i.e. gastro or chest infection). The increased stresses means that the body's need for insulin increases and without taking a sensible increase in insulin if needed DKA may develop. Another situation where DKA is more likely to occur is where someone starts missing insulin injections and therefore their body is not getting the insulin that it needs. If someone's diabetes control is good DKA is much less likely to develop than in someone with poor control.

Conversation Thread 5 – Blood Sugar Testing

Sub Topics

- Why Test Blood Sugar?
- What Affects Blood Sugars?
- Frequency of Blood Sugar Testing
- Recording Blood Sugars
- HbA1c
- What are Complications?
- What are the Potential Complications of Diabetes?
- What Causes Diabetes Complications?
- Will I Get Diabetes Complications?

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

Why Test Blood Sugar?

Often young people find that having to check blood sugars annoying and it can end up causing a lot of rows with parents when they are not done. Has anyone found themselves getting into arguments with their parents over not checking blood sugars?

Keeping the level of sugar, or glucose, in your blood as close to normal as possible is one of the most important things you can do to stay healthy and to avoid the complications of diabetes. Watching and trying to balance what you eat, how much you exercise, and how much insulin you take is all part of the job. Checking your blood sugar, or monitoring it, by pricking your fingers four or more times per day, is the best way to tell if you are keeping your blood sugar levels in the normal range.

Post the PDF of page 14 to 15 of Pete the Pancreas to the thread

Blood glucose (or sugar) levels

When you have diabetes, people talk a lot about your BLOOD GLUCOSE or BLOOD SUGAR LEVEL

This means how much glucose is in your blood

You will need to check this regularly, around 4 times a day

If there is a lot of glucose in your blood, that means there isn't enough insulin in your body

Your cells will be sad and you will feel unwell

Your doctor or nurse will show you how to check your blood glucose level

It's easy - just a little finger prick test!



Checking your blood glucose level



1

Wash your hands and dry well



2

Get your meter ready



3

Prick your finger at the side



4

Put a drop of blood on to the strip in your meter



5

Write the numbers into your diary so you can show your diabetes team at your next visit!



What Affects Blood Sugars?

Everyone knows that food affects blood sugar, does anyone know of the other things that can affect blood sugar?

There are three main things that affect blood sugars:

1. Insulin
2. Food
3. Exercise.

Illness also affects blood sugars but it is not constant

Frequency of Blood-Sugar Testing

About how often do you check your blood sugar?

It's important to check blood sugars regularly to know that they are in the range that keeps you healthy and safe. Ideally you should check blood sugars before meals, before going to bed, before and after exercising and if you feel low or unwell.

Recording Blood Sugars

Very often young people check their blood sugars but don't record it into the book. This is another thing that can cause rows with parents as they don't understand the annoyance of having to fill in the book. Very often young people only fill in the book on their way into a clinic visit. Has anyone found themselves filling in the book on the way into a clinic visit?

Recording blood glucose results is an essential part in managing diabetes well. Writing down results may not be the most exciting of tasks, but only by knowing how blood glucose responds to diet, exercise and insulin doses, can you make sure your diabetes control is the very best possible.

Regularly recording and then reviewing blood sugars over a few days allows you to see trends in blood sugar patterns and make the necessary adjustments. For example, if you check your blood sugar every morning when you get up and started to notice that your blood sugars were high in the mornings you might look at changing your night time insulin. If you are going to the trouble of checking your blood sugars it is important that you can use these blood sugar readings to keep your diabetes well managed. If writing the blood sugars into a book is too much of an annoyance you can use a smartphone app, use a meter that connects to a computer and uploads the readings or you can ask a parent to write them in the book for you. It's important to choose the approach that you think will work best for you.

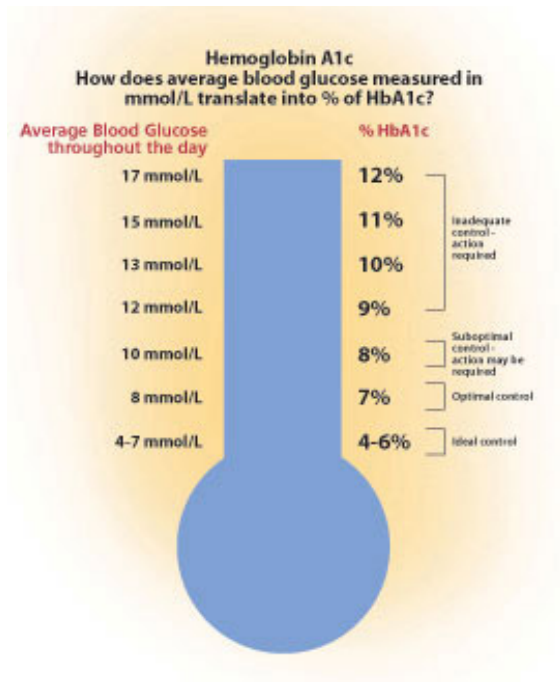
Does anyone use a smart phone app or a computer to record their blood sugars?

HbA1c

Every time you come to clinic you have your HbA1c checked. The machine counts down from six minutes before giving you your HbA1c reading. This reading is then used by the diabetes team to get an idea of how your diabetes management is going. However, most people don't really know what HbA1c is. Does anyone know what HbA1c is?

The HbA1c test is a blood test that measures how much sugar has become stuck onto your red blood cells. The HbA1c result is a reflection of what the blood sugar levels have been over the previous six to eight weeks. Basically the higher your average blood sugars have been over the past six to eight weeks the higher your HbA1c will be.

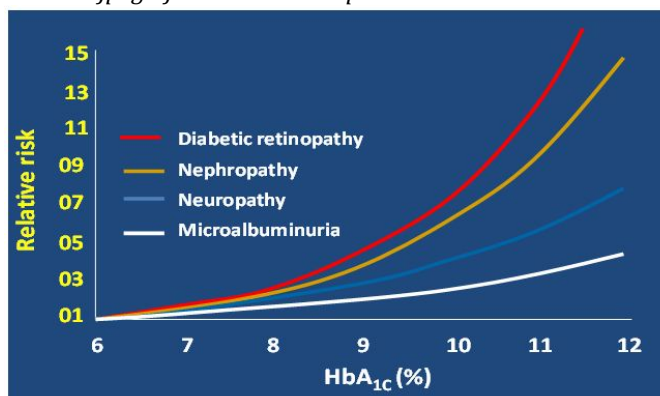
Post the jpeg of the HbA1c chart to the thread



What is the target HbA1c range that we try and aim for?

We aim to try and keep HbA1c below 7.5 as research has shown that by keeping HbA1c below this level we minimise the risk of complications later in life. You'll see from the picture below that your risk of different complications shoots up as your HbA1c goes above 8. In the picture below retinopathy means damage to the eyes, nephropathy means damage to the kidneys and neuropathy means damage to the nerves in the feet.

Post the jpeg of the HbA1c complications risk chart to the thread



What are Complications?

In diabetes we are always trying keep blood sugars under control so that we can prevent complications. What do you think do we mean by complications?

Sometimes, when you have a disease, it makes it harder for your body to do some of its other work properly. This can lead to the body developing other problems, which are known as "complications."

What are the Potential Complications of Diabetes?

What are the diabetes complications that you have heard of?

Hypoglycemia, or low blood sugar, is the most basic complication of diabetes. If you have diabetes, you are probably dealing with low blood sugar on a day-to-day basis. But many complications of diabetes are longer-term. That means that the body of a person with diabetes develops them over a long period of time. These longer-term complications can include heart, kidney, eye, and nerve problems.

What Causes Diabetes Complications?

What sort of things do you think causes complications for people with diabetes when they get older?

Scientists are still not completely sure why diabetes complications occur, but they seem to be caused by too much sugar, or glucose, in the blood, which then causes problems in the body's cells. For example, over time, having extra glucose in the blood can cause damage to the small blood vessels in organs like your eyes and kidneys, which can cause affect your vision or cause kidney problems.

Will I Get Diabetes Complications?

Lots of young people and adults with diabetes worry about developing complications of diabetes when they are older. What sort of worries would you have about diabetes complications?

Not everyone who has diabetes gets diabetes complications. It is very hard to say who will have them and who will not. But there is some good news. Keeping good control of your blood sugar levels does seem to help prevent complications from developing. Research has shown that the more diabetes patients are able to control their blood sugar levels, the less they develop complications. Research also tells us that small changes in blood sugar control and therefore your overall HbA1c can result in huge reductions in the risk of complications developing later on. The message therefore is always to try to do better and to aim for good blood sugars as much as possible.

Conversation Thread 6 – Insulin Adjustment

Sub Topics

- Why adjust insulin?
- Information Needed to Adjust Insulin
- How to Adjust Insulin

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

Why Adjust Insulin?

Is anyone on the same amount of insulin that they were five years ago or when they were first diagnosed?

The amount of insulin you need is constantly changing and depends on your age, your weight, your diet and how active you are. As all these things change as you grow so to do your insulin requirements. In order to keep your blood sugars within the normal ranges we need to adjust your insulin to match the other changes in your life.

Information Needed to Adjust Insulin

What information do you think we need to adjust insulin?

The only way you can adjust the insulin you give is by taking accurate blood sugars. To do this you must have a two-hour gap between food and a blood sugar.

How to Adjust Insulin

What do you generally do if your blood sugar is running high or low for a few days in a row?

When your blood sugar is running high you need to adjust your insulin. To do this you must establish which insulin is peaking at the time. Look for patterns in the blood sugar over two to three days. Ensure there is a two-hour gap between food and blood sugar. Ensure there is no other explanation for the high blood sugar like extra food, timing of test is wrong or lack of usual insulin. If the blood sugars are high increase the insulin peaking at that time by 10%.

If your blood sugar is low you must also adjust your insulin. When the blood sugar is less than 4mmols you will need to lower the insulin peaking at that particular time by 10%. The only exception to this would be if you had missed a meal or snack or had sudden unplanned exercise without extra food.

Conversation Thread 7 – Diet

Sub Topics

- Why is diet important for children and adults with diabetes?
- Organising a Meal Plan
- Types of Carbohydrates
- Difference Between Carbohydrates, Fats and Proteins
- Using food labels
- Treats

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

Why is diet important for children and adults with Diabetes?

Hi guys, I'm going to be posting some information on diet. To help me explain things I'm going to be asking some questions about your diet, so please join in. Feel free to ask me any questions, make comments, or hit like if there's anything you're particularly interested in.

Ok, for starters, what do people find is the biggest difference between what they eat and what their friends without diabetes eat?

Everyone, kids and adults with or without diabetes, can improve their health by following a nutritious and balanced diet. People who have diabetes don't need to be on strict diets, but they do need to pay attention to when they eat and what's on their plates. Why? Because it helps them keep their blood sugar levels steady. If you have diabetes, keeping an eye on the food you eat is especially important because food has such a big effect on your blood sugar levels. Still, you may be surprised to learn how many different foods can be included in the diet of a person with diabetes. In fact, there are very little foods that a person with diabetes can't eat – it's the timing and portion size of the meal/food that is most important. To make sure you're eating in the most healthful way you can, you need to have a little information, some good self-control, and a big helping of common sense.

Organising a Meal Plan

What kind of foods do you like to eat that are good for you?

What kind of foods do you really like to eat that are not so good for you?

Meal plans give people with diabetes ideas for healthy food choices in a structure that is suited to the insulin regime they are on. Meal plans don't tell you exactly which foods to eat, but they might give you general information like which food groups to choose from and when you should eat. Don't worry that this plan might include stuff you don't like. Your meal plan will also include the foods that you already eat and like. The dietitian will probably ask you to write down all the foods you eat in a food diary for a few days so that they know your tastes. Remember to write down everything you like to eat and drink (even if you think it's bad for you) – you may be surprised to find they can be incorporated into your meal plan in a healthy way.

Some people are on a meal plan where they eat at the same time every day and some people are on meal plans where they can eat at different times but give themselves insulin with each meal. Can people post which type of meal plan they use?

There are two types of meal plans and the diabetes team will help you decide which one is best for you. The plan really depends on the insulin regimen that you are on. If you are on fixed doses of insulin twice or three times per day at set times you may be on a set meal plan. This involves eating a main meal or a snack every 2-3 hours during the day. The amount of carbohydrate eaten at the meals and snacks should be similar from day to day to help keep blood sugars steady. Your dietitian will help you determine what foods have similar carbohydrate contents. Food labels and carb counting books can also help with this.

Another option is the carbohydrate counting meal plan. With this plan, people with diabetes count carbs so they can match their insulin doses with the amount of carbohydrates that they eat. Counting carbs means the person counts the number of carbohydrate grams being eaten. Food labels can tell you how many grams of carbohydrate are in a food. There are also picture books which can give you an accurate estimate of the amount of carbohydrates present in each snack or meal. Knowing that, a person then matches the insulin dose with the amount of carbohydrates that he or she eats. This plan works best for people who take a dose of insulin (as an injection or with an insulin pump) with each meal.

Types of Carbohydrates

Have you noticed that certain carbohydrates make your blood sugars go up much higher and much faster than others?

All foods containing carbohydrates will cause the blood sugars to rise. Sugary carbohydrates (glucose) e.g. sugar, sweets, jellies, sugary drinks, ice-pops, lucozade etc will cause the blood sugars to rise rapidly. Sugary foods should be limited in all healthy diets to prevent weight gain and tooth decay. If you have diabetes is even more important to limit these foods as this will help to control blood sugar levels.

Starchy carbohydrates e.g. bread, cereals, potato, rice, pasta and noodles, will also cause the blood sugar to rise as they are broken down to glucose. However, this happens much more slowly. This makes them a good choice to help control blood sugars. High fibre/wholegrain starchy foods are the best choice.

Fruit sugars (fructose – found in fruit) and milk sugars (lactose – found in milk and yogurts) act very like starchy carbohydrate and cause the blood sugar to rise slowly. An added benefit is that they are bursting with nutrients e.g. vitamins, calcium and protein so should be included in every healthy diet.

Carbohydrate free foods will have very little or no effect on the blood sugar. Carb free foods include most vegetables and salads, cheese, fish, meat, chicken, eggs, nuts, olives and sugar free drinks e.g. coke zero, 7-up free, pepsi max, diet club orange, mi wadi no added sugar or Robinsons special R. These foods can be very useful to eat if you are hungry but are not due to have a meal/snack. Make sure not to over do it though as eating too many of these foods can lead to weight gain.

Difference between Carbohydrates, Fats and Proteins

As well as carbohydrates, our diet is also made up of fats and proteins. What foods do you eat that are fats or protein?

Fat is important in the diet to provide essential nutrients (Vitamin ADEK and essential fatty acids) but most Irish people tend to eat more fat than is necessary. Fat is digested much more slowly by the body than other nutrients. Eating foods high in fat e.g. pizza, take-away foods can cause the blood sugars to rise and stay high for several hours. You may have noticed this before

when you have had a pizza or a Chinese take-away. Eating excess fatty foods can also lead to weight gain and high cholesterol. Choosing unsaturated fats e.g. polyunsaturated/monounsaturated spreads and low fat dairy products is a healthier option. Also choosing fresh foods, lean meats and avoiding frying will reduce the fat content of your diet.

Protein foods provide the essential building blocks for the body to create muscle. Foods high in protein are milk, cheese, yogurt, meat, chicken, fish, eggs and nuts. Many of these foods are carb free. Having protein foods twice per day is important for growth. Protein foods often provide many other nutrients e.g. iron is found in meat and eggs. Although protein foods are good for us, having too much protein can lead to weight gain.

Using Food Labels

Sometimes the information on food packages and wrappers can be helpful in helping you manage your diabetes. What kind of information could you get from food labels that might be helpful?

You will find food labels on most packaged and some fresh foods. Once you know what you are looking for, food labels are easy to read. They list a food's ingredients and nutritional information, so anyone concerned about eating healthy can learn a lot from them. For people with diabetes, food labels also may provide information they can use to keep their blood sugar on track. It will tell you how many grams of carbs you are about to eat. When counting carbs, it is best to look at the values for carbohydrate rather than sugar as this tells us the total carbs we are going to eat. Many food labels will give the nutritional information "per serving". Be sure to check that the serving is actually what you are eating. Some labels will only give the information "per 100g". In this situation, you will need to calculate the carbs in the portion you are eating by weighing the food. This can be a little tricky so always ask your dietitian to advise you on this.

If you're on a pump, MDI or a basal bolus regime, knowing the amount of carbs you are eating can help you determine how much insulin to take. If you are on a fixed dose insulin regime, knowing the amount of carbs you are eating can help keep your blood sugars steady. On food labels, you'll also find information on the amount of fat, the type of fat, and the total calories in a food. It's a good idea for everyone, including people who don't have diabetes, to keep an eye on these. Eating too much of certain fats can make someone more likely to have heart and blood vessel problems. And eating too many calories can cause weight gain.

Treats

What treats do you like to have?

The good news is that treat foods e.g. chocolate, sweet biscuits, cakes, ice-creams, sweets etc should be a part of every healthy meal plan. Even if you have diabetes, it is important to have a treat! Treat foods can be incorporated into your diet so that they won't effect your blood sugar control. If you have lots of treats in big portions, you will notice your sugars will be high. If, however, you eat a small portion e.g. a fun size bar, an ice-cream cone or a small slice of cake after your meal (even if it's every day) your blood sugars should stay steady. Remember though, having too many treats can lead to weight gain and tooth decay so to stay healthy, keep treats as "treats".

Conversation Thread 8 – Exercise

Sub Topics

- The Benefits of Exercise
- The Impact of Exercise on Blood Sugar
- Managing Blood Sugars while Exercising

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

The Benefits of Exercise

Sport and exercise is something that is good for everyone as it's an important part of a healthy lifestyle. Exercise is particularly beneficial for people with diabetes and diabetes shouldn't prevent you from taking part in any sport. What sort of sports or exercise do you do and how is it affected by your diabetes?

Like healthy eating, exercise is important for everyone, whether or not they have diabetes. When you're living with diabetes, exercise helps lower blood sugar levels and keeps them under control. Plus, exercise can be a lot of fun. When you're active, your mood tends to get better, which helps you take better care of yourself. For many people, the more exercise, the less insulin they need, too.

Exercise has general health benefits and health benefits specific to diabetes. These include:

Better health for life. Exercise strengthens bones and muscles and reduces the risk of heart disease and some types of cancer.

Greater physical abilities. With exercise, people can gain better coordination, balance, strength, and endurance. Exercise can increase energy levels, too.

Better response to insulin and better blood sugar control. Exercise makes insulin work better in the body, which helps someone with diabetes keep their blood sugar levels in a healthier range.

Weight management. To reach and maintain a healthy weight eating right isn't enough, people need to exercise too. Exercise burns calories and builds muscle, which in turn helps the body burn more calories. In people with diabetes, having too much body fat keeps insulin from working as well to control blood sugar levels.

Life experience. When people get out of the house and go outdoors or visit a gym, they get a chance to meet new people and have new, interesting experiences. If they try a sport, they also learn about teamwork, sportsmanship, and competition.

Increased confidence. Exercise helps boost peoples' self-esteem and confidence. By mastering a skill, improving physical abilities, or helping a team, people learn about what they're capable of achieving.

Mental boost. Exercise can help relieve tension and stress, encourage relaxation, and improve mood. Exercise can even help clear the mind and make it easier to pay attention.

The Impact of Exercise on Blood Sugar

Has anyone found that playing certain sports can send blood sugars all over the place?

When people with diabetes exercise, they can experience low blood sugar, called hypoglycemia, or high blood sugar, called hyperglycemia. Hypoglycemia can occur during or after exercise, when the body has used up much of its stored sugar, especially if insulin levels in the body are

still high following an injection. People with diabetes may need to check blood sugar levels and have an extra snack to prevent low blood sugar levels. Or if you are starting a rigorous exercise schedule, like training for a sport, the doctor may recommend a reduced insulin dosage to help prevent hypoglycemia.

High blood sugar levels may also have to be addressed before or during exercise. The muscles need more energy during exercise, so the body responds by releasing extra sugar, or glucose into the blood. If the body doesn't have enough insulin to use the glucose, then the sugar will stay in the blood. This can cause a person to urinate more, which can lead to dehydration, especially when someone is losing more water from the body from sweating and breathing hard during exercise. Other signs of high blood sugar include excessive thirst, fatigue, weakness, and blurry vision.

There are other reasons that people with diabetes shouldn't exercise if they don't have enough insulin in their blood. If a person has insufficient levels of insulin in the blood, substances called ketones may show up in a urine or blood test. Ketones build up in the blood when the body doesn't have enough insulin to use sugar in the blood for energy, so the body is forced to burn fat for fuel. When someone with too little insulin in the blood exercises, ketone levels in the blood can rise to high levels, putting the person at risk for diabetic ketoacidosis, or DKA.

Managing Blood Sugars while Exercising

What sort of things do you do to keep your blood sugars under control when playing sport or exercising?

The diabetes team can give you specific suggestions to help you manage your diabetes while playing sport or exercising, but here are a few general tips:

Adjust blood testing schedules. It is important that you check your blood sugars just before and just after playing sport or exercising. You may also need to check your blood sugar in a break during exercise or sport if you feel you are getting too high or too low.

Take insulin on schedule. Your doctor or nurse might recommend adjusting the insulin dosage for exercise or sports. If you inject insulin, try to avoid giving injections in the part of the body most used in that sport (like injecting the leg right before soccer practice). This could cause the insulin to be absorbed more quickly, increasing the chances of hypoglycemia. If you wear an insulin pump, be sure that it won't be in the way for exercise and won't get disconnected or damaged. Talk to the doctor or nurses about what to do if you need or want to take off the pump during exercise.

Eat right. The dietitian will help you adjust your meal plan to provide the extra energy needed during exercise. For example, they might recommend extra snacks before, during, or after exercise. It is important to stick to the recommendations to prevent things like low blood sugars. Some people may be tempted to try strategies like carb loading before running or reducing calories or water to get down to a certain weight for boxing. However, these behaviors can cause problems because they can increase the likelihood of either hyperglycemia or hypoglycemia.

Bring snacks and water. Whether playing football in the back garden or swimming in the local pool, you should always have snacks and water on hand. Some quick sugar will help if blood sugar dips too low and drinking water will help prevent dehydration.

Pack it up. If you will be playing sport or exercising away from home, pack testing supplies, insulin, and Lucozade (or equivalent). It helps to keep these things in a special backpack or other bag so that you don't have to pack and repack them every time you go out.

Tell the coaches. If you play organised sports, tell the coaches about your diabetes and give them written instructions so they can respond to problems. They should also understand that you might need to take steps, like having a snack or taking insulin, to control diabetes before, during, or after a game.

Take control. People with diabetes need to take control of their own health. This can present a challenge at times when you're in a group of other young people being supervised by an authority figure like a teacher or coach. But managing your diabetes

properly may mean interrupting a teacher or coach, and that's OK. You should always feel free to stop playing a sport or exercising to attend to your diabetes needs, like eating a snack for low blood sugar symptoms or checking blood glucose levels.

Conversation Thread 9 – Behaviour Change

Text in coloured fonts are postings to the conversation threads

Blue Text – Questions for adolescents to respond to

Red Text – Educational material related to the topic

Green Text – Facebook poll

What are the different things you

What are the different things you can do or not do that get in the way of good management?

There are basically eight different things that people with diabetes do that prevent good diabetes management.

1. Missing insulin injections/bolus'
2. Not changing injection sites
3. Not checking blood sugars
4. Not making insulin adjustments
5. Not taking insulin at the right time
6. Eating a lot of unhealthy foods
7. Eating the wrong amounts of food
8. Eating food at the wrong times

Nobody with diabetes has perfect management all the time. Everybody has times when at least one, and usually more, of the eight above is a problem for them. This is completely normal. To get on top of management the first thing we need to do is identify which of the eight above are problems for us. Can everyone please put a tick beside any of the eight things that get in the way of good management listed above that was a problem for you at any time in the past?

Create a Facebook poll with the following eight options

1. Missing insulin injections/bolus'
2. Not changing injection sites
3. Not checking blood sugars
4. Not making insulin adjustments
5. Not taking insulin at the right time
6. Eating a lot of unhealthy foods
7. Eating the wrong amounts of food
8. Eating food at the wrong times

As you can see everyone has had problems with some of these areas at some point or another. What we are going to do now is look at which of these are problems areas for you at the moment. Can everyone please put a tick beside any of the eight things that get in the way of good management listed above that are a problem for you at the moment?

Create a Facebook poll with the following eight options

1. Missing insulin injections/bolus'
2. Not changing injection sites
3. Not checking blood sugars
4. Not making insulin adjustments
5. Not taking insulin at the right time
6. Eating a lot of unhealthy foods
7. Eating the wrong amounts of food
8. Eating food at the wrong times

When we want to change behaviour in a way that lasts we start with small steps. All too often people try to take too big a step and change too many things at once. Although we might be able to keep this up over a short period of time, it usually doesn't last. A much better way is to look at one small change that we can make and focus on doing that until we feel that we can continue on doing it without too much extra effort. This is when it starts to become routine. Generally if you do something every single day for two weeks it starts to become routine and you start to do it without thinking.

From the things above that you've identified that are getting in the way of good diabetes management for you at the moment can you pick the one that you think might be the easiest for you to change at the moment?

When we decide on an area where we want to change our behaviour the first thing we need to do, before we start changing our behaviour, is to work out what our current behaviour in that area is. For example, if the area that you decided to change was how often you check your blood sugars per day, the first thing you would do is record how many times per day you check your blood sugar at the moment. To do this it is usually best to keep doing what you are doing at the moment for the next few days and record how often you are doing or not doing the behaviour.

For the area of diabetes management above that you identified as being the easiest for you to change at the moment, can you record over the next three days how often you do or don't do the behaviour?

So how did everyone get on recording how often they did or didn't do the behaviour over the past three days?

It's also important that we are aware of what we want to achieve at the end in relation to the particular behaviour. In other words we need to know what our overall goal is in relation to that particular behaviour. For instance, if the behaviour we wanted to change was to increase how often we check blood sugars every day, we would need to know how many blood sugar checks per day we would be completely happy with. This goal will differ from person to person even for the same behaviour. It's the goal that you would like to have achieved in relation to this behaviour by the end, not the goal your parents or the diabetes team may have.

For the area of diabetes management above that you identified as being the easiest for you to change at the moment, what would be your overall goal in relation to this behaviour? In other words what would you be completely happy with in relation to this behaviour?

Although it is good to know the overall goal of what we want to achieve in relation to a particular behaviour, as it lets us know we have reached our target, this is not the goal we focus on. The goal we focus on is whatever the next small step we have decided to take. As I was saying earlier, one of the biggest mistakes people make when they decide to change their behaviour in order to be healthier is that they try to change too many things at once. Every time people focus on just changing one thing, another common mistake they make is to try and take too big a step with regard to that one thing. If we want the changes we make to last it's really important that the first step we take is a relatively easy one. In other words we set ourselves up for success. If our first step is a relatively easy one then we are more likely to achieve it than if the first step was more difficult. And if we achieve the first step we set out we start to feel positive about our ability to change our behaviour and this motivates us towards taking the next steps.

Can everyone decide for the thing that they have decided to change what would be an achievable first step for the next week? In other words can you write down what your goal is for this day next week? Make sure it's a goal that you think you can achieve.

For adolescents who achieved their behaviour change goal

Well done on achieving the goal you set out! You should be extremely proud of yourself. It feels good when we set out a goal for ourselves and then achieve it. The next step is to capitalise on the

sense of achievement and set out your next goal in relation to the same behaviour. Again you need to make sure that it's a goal that you feel that we can achieve.

Can you decide on a new, slightly harder goal for the thing that you have decided to change? In other words change the goal that you set out last week to make it slightly harder.

For adolescents who didn't achieve their behaviour change goal

Sometimes when we set out a goal for ourselves we can be a bit over-enthusiastic and make the goals a little beyond what we are able to achieve at that point in time. How we feel at the time we set goals can be very different to how we feel when we are actually working on the goals. That's why sometimes when we set goals we think that we will be able to achieve them easily but when we come to do them when find them very challenging and aren't able to achieve them. This is not something to worry about and happens to everybody at some point or another when they are trying to make their behaviour healthier. It tells us that the goal we set was a little too much for us at this point in time and instead we need to set out a more achievable. This doesn't mean that we are not going to achieve this or our overall goal, we are just adjusting the path by which we are going to achieve the goal.

Can you decide on a new, slightly easier goal for the thing that you have decided to change? In other words change the goal that you set out last week to make it slightly easier.

When an adolescent achieves the overall behaviour target goal.

Well done, you've now achieved the target you set out for this behaviour. Did you notice how much easier it is to achieve a goal when we break it down into small achievable steps. Now we are going to use the same steps to change our behaviour in relation to another area of diabetes management.

Do you remember the list of things that get in the way of good management and are a problem for you at the moment that you identified? What thing on that list do you think is the next easiest to try and change?

Great we are now going to use the exact same steps that we used above to help you change your behaviour in this area

Appendix 6

Qualitative Interview Questions & Transcripts

Questions for Pilot Study Qualitative Interview

Introduction

- Interview will take approximately an hour and will consist of a group discussion of spoken questions
- No right or wrong answers – it's about participants experiences of using the Facebook page
- Everyone is free to leave at any time
- Confidentiality and respect for all opinions
- Interview recorded – interviews transcribed anonymously and tapes will be erased following transcription
- No identifying information will be included in the transcripts
- Interview may takes notes to help shape interview

Experiences with using the Facebook Page

- What were your initial expectations of using Face book to communicate with the diabetes team?
- What were your initial expectations of using the Facebook page to interact with peers with diabetes?
- Did you find your communication with diabetes team members through Facebook to be more open or less open and why?
- How did you find being able to see other people's conversations with members of the diabetes team?
- How did you find other people being able to see your conversations with the diabetes team?
- Did using the Facebook page change your behaviour in any way with regard to your diabetes management?
- Were there any aspects of the diabetes page that made you less likely to use it?
- Were there any aspects of the diabetes page that made you more likely to use it?
- Did you find anything beneficial about using the Facebook page?
- How, if at all, would Facebook be incorporated into your ideal diabetes service?
 - Members of the group
 - Size of group
 - Topics of communication
 - Level of interaction
 - Type of interaction

Final Question

- Is there anything that we haven't discussed that you think is important?

Sub-Questions – These may be used to Expand upon the Questions Above

Personal Experiences of the Diabetes Service

- What is your experience of the diabetes team?
- Are there any aspects of the diabetes service that make it easier for you to manage your diabetes?
- Are there any aspects of the diabetes service that make it more difficult for you to manage your diabetes?
- If you were able to design a diabetes service exactly as you think it should be what would it look like?

Communication with Diabetes Team

- Is it important to be comfortable to talk openly with members of the diabetes team, if so why?
- How well are you able to communicate with the different members of the diabetes team?
- What are the biggest barriers to being able to communicate openly with members of the diabetes team?

Interaction with Peers with diabetes

- What is your experience of interacting with other people your age with diabetes?
- What effect, if any, does contact with other young people with diabetes have on your experience of diabetes?

Pilot Study Interview Transcript

Interview with Lisa (pseudonym)

1 **Interviewer: What were your initial expectations of using Facebook to**
2 **communicate with the Diabetes team? What were your thoughts before you**
3 **used it about being able to contact the doctors and nurses?**

4 Lisa: I don't know, I thought everyone was going to be writing in it all the time and
5 giving ideas and stuff.

6 **Interviewer: Were you a bit weary of being able to talk to the diabetes team on**
7 **Facebook?**

8 Lisa: No, I was looking forward to it

9 **Interviewer: What were your initial expectations about using Facebook to**
10 **interact with other young people your age with diabetes?**

11 Lisa: I didn't mind that. Giving advice and stuff and get it back.

12 **Interviewer: You weren't put off by talking to other people with diabetes?**

13 Lisa: No

14 **Interviewer: Did you find your communication with the diabetes team members**
15 **through Facebook to be more open or less open and why?**

16 Lisa: It was harder to take to them on Facebook

17 **Interviewer: Why was that?**

18 Lisa: I don't know, I feel more comfortable and stuff when I'm with them, it's better
19 to ask and stuff.

20 **Interviewer: Is it easier to ask a question in clinic or on Facebook?**

21 Lisa: It's easier in clinic.

22 **Interviewer: Why do you think that is?**

23 Lisa: I don't know, I just do. I'm better in person

24 **Interviewer: How did you find being able to see other people's conversations**
25 **with members of the diabetes team?**

26 Lisa: Brilliant.

27 **Interviewer: Why?**

28 Lisa: Because I didn't have to ask the questions.

29 **Interviewer: So you liked being able to read other peoples conversations?**

30 Lisa: It was much easier because I could just read over their conversations. It was
31 interesting.

32 **Interviewer: How did you find other people being able to see your conversations**
33 **with the diabetes team?**

34 Lisa: I didn't like it... Sometimes, it depended on what I had to ask.

35 **Interviewer: Like what?**

36 Lisa: If my sugars and stuff were all over the place and I'm the only one going
37 through this.

38 **Interviewer: Things like that you wouldn't like to put up on Facebook?**

39 Lisa: Yeah.

40 **Interviewer: Did using the Facebook page change your behaviour in any way**
41 **with regard to your diabetes management?**

42 Lisa: No.

43 **Interviewer: Were there any aspects of the diabetes page that made you less**
44 **likely to use it?**

45 Lisa: No, I liked it cause there were videos and stuff put into it... Information off all
46 of you.

47 **Interviewer: Were there any aspects of the diabetes page that made you more**
48 **likely to use it?**

49 Lisa: Just everyone giving information... People asking questions.

50 **Interviewer: Did you find anything beneficial about using the Facebook page?**

51 Lisa: I don't know, what everyone was putting into it, and writing about it, and the
52 information you put in as well

53 **Interviewer: How, if at all, would Facebook be incorporated into your ideal**
54 **diabetes service? Who would be in the group, the whole diabetes team or just**
55 **certain members?**

56 Lisa: Who they get on with better I suppose, and then if they can have their own little
57 group they can sort all their problems out.

58 **Interviewer: So even smaller groups?**

59 Lisa: Yeah, because you probably feel more comfortable with a smaller group of
60 people or people they get along with.

61 **Interviewer: And what about having other young people with diabetes in the**
62 **group?**

63 **If you were setting up a group in the morning, who would you have in it?**

64 Lisa: I'd set it up like ours, I'd have everyone in it and I'd have all of you in it as
65 well in case there was an important question, to ask one of you... If they wanted to
66 put questions in I'd have the friend they were closest to, to talk to.

67 **Interviewer: The member of the team they're closest to?**

68 Lisa: Yeah, and if they had like a friend in it and the two of them were going through
69 like the same thing.

70 **Interviewer: A friend with diabetes?**

71 Lisa: Yeah.

72 **Interviewer: And what about the size of the group, how big should it be? Should**
73 **it be bigger or smaller than your group?**

74 Lisa: I don't think you should put more than ten in it... Including the doctors in it.

75 **Interviewer: So there was six of you and four or five of us, so you wouldn't go**
76 **any bigger than that?**

77 Lisa: No, I just think it gets more confusing.

78 Everyone posting, I don't know, maybe I'm wrong but I prefer it small.

79 **Interviewer: What are the topics of communication that should be covered?**
80 **Should it be diabetes or non-diabetes related?**

81 Lisa: A bit of both... I'd put mostly diabetes stuff into it

82 **Interviewer: Any particular types of diabetes stuff?**

83 Lisa: I don't know, like your lifestyle.

84 **Interviewer: How often should the diabetes team be posting stuff?**

85 Lisa: Probably like a few times a week. I wouldn't post up stuff every day... Because
86 people would just like... Lose their interest or something. But at least a few times a
87 week... But not to go any less.

88 **Interviewer: How should people be interacting? Should they be talking on the**
89 **page or in one-to-one, or just posting videos, or links to websites?**

90 Lisa: I think we should all just put in stuff we think we should put in and then be
91 talking in the group about it.

92 **Interviewer: Is there anything that we haven't discussed that you think is**
93 **important? Any other advice you'd give to us setting up a Facebook group?**

94 Lisa: You should do it but I think a different age group. Like a younger age group...
95 I'd put twelve to sixteen year olds together, or maybe twelve to fifteen and then
96 sixteen to eighteen, or whatever age you leave here.

97 **Interviewer: Why do you think they should go in another group?**

98 Lisa: I really don't know

99 **Interviewer: Any other advice?**

100 Lisa: Just posting things in, keep the group going.

101 **Interviewer: Okay, thanks for that. I'm going to stop the reorder now so.**

Pilot Study Interview Transcript

Interview with Sam (pseudonym)

1 **Interviewer: What were your initial expectations of using Facebook to**
2 **communicate with the Diabetes team? What were your thoughts before you used**
3 **it about being able to contact the doctors and nurses?**

4 Sam: It would be handy enough; it would give you a different view because you'd be
5 talking to other kids your age with diabetes... Because you know you'd just be talking
6 to nurses and doctors in here. I wouldn't know many kids my age with diabetes and
7 its good to have a chance to talk to them.

8 **Interviewer: How did you feel about being able to talk to the team? Nurses,**
9 **doctors, dietitians, etcetera?**

10 Sam: I wouldn't have a problem giving them a call, but sometimes if it's not a serious
11 question you might feel like you are annoying them or they might be busy... So if you
12 leave it on Facebook they can get back to you whenever they can. It seems a better
13 way.

14 **Interviewer: What were your initial expectations about using Facebook to**
15 **interact other young people your age with diabetes?**

16 Sam: I thought it was a good idea.

17 **Interviewer: Were you apprehensive at first?**

18 Sam: A little bit yeah. I wouldn't use Facebook too much myself anyway. I suppose
19 with anything if you're meeting new people you'd be a bit hesitant but I didn't think it
20 was too bad then after a few sessions when we got together.

21 **Interviewer: Did you find communication with the diabetes team members**
22 **through Facebook to be more or less open?**

23 Sam: Probably more open, because you weren't talking about anything serious. Just
24 say if something was wrong with you, you'd call them straight away but if you just
25 had a question you could give it to them and they could answer it and help you out.

26 **Interviewer: Does that mean you were more comfortable talking to them on**
27 **Facebook?**

28 Sam: Yeah, it is easier to talk to them... More open and just less serious.

29 **Interviewer: Did you find you were more able to bring up things that you**
30 **wouldn't be able to talk about in clinic?**

31 Sam: Not really, just little questions that you might forget to ask. You'd be going
32 along and say I meant to ask about that and now you can just give them a message on
33 Facebook.

34 **Interviewer: How did you find being able to see other peoples' comments on**
35 **Facebook?**

36 Sam: It was good because a lot of what they were asking about were questions that I
37 had myself. The problems they'd have, I'd have myself. As good as they'd ask it I'd
38 benefit from it.

39 **Interviewer: Did using Facebook encourage you to change your behaviour in any**
40 **way with regard to your diabetes management?**

41 Sam: I suppose if you are talking to other kids and they are trying to manage better I
42 suppose it'll help you and motivate you a bit more. If you see well... They're trying
43 to look after themselves.

44 **Interviewer: Where the any aspects of the diabetes page that made you less likely**
45 **to use it?**

46 Sam: No I don't think so, other than the fact that I don't use Facebook too much
47 myself. But not really on the page itself.

48 **Interviewer: Was there any aspects of the diabetes page that made you more**
49 **likely to use it?**

50 Sam: I thought the links and stuff, even the interesting stories that were put up about
51 developments in diabetes and that... You could click on and see... Read through it
52 and see what people are talking about

53 **Interviewer: Did you find anything beneficial about using the Facebook page?**

54 Sam: Definitely, like little questions that would come up and forget to ask. Then
55 you'd going along doing your normal stuff and you'd run into it again, a problem, you
56 could just give them a message, and it'd mostly be about a food stuff or different little
57 things that'd be helpful.

58 **Interviewer: How, if at all, would Facebook be incorporated in to your ideal**
59 **diabetes service?**

60 Sam: I think that the way we did it was good for just small things. It definitely helped
61 I thought.

62 **Interviewer: In terms of creating a group in an ideal way, who should be part of**
63 **it?**

64 Sam: I think we had a good number because I talked to... (name of the dietitian on the
65 DHCT) about food... Or if I'd any question about sites or finger checks I could talk
66 to... (name of the nurse on the DHCT), and... (name of the doctor on the DHCT)
67 there as well.

68 **Interviewer: You were happy with the mix?**

69 Sam: Yeah.

70 **Interviewer: In terms of the size of the group, because there was only six of you**
71 **in the group, do you think it should be that size, smaller, bigger?**

72 Sam: I think it's hard to bring a big number of people together and get them talking to
73 each other. Unless they did something like... I know when I went to Donegal a few
74 years ago and I came back and in a few days later I added one or two lads on
75 Facebook and I got talking to them. I don't talk to them anymore but if they sort of
76 know each other coming in and the group was maybe a bit bigger... Probably because
77 then you'd have more people asking questions. Yeah, if they know each other coming
78 in it would make things easier.

79 **Interviewer: How much bigger, is there a point at which you think it'd be too**
80 **big?**

81 Sam: I'd say at least over ten fifteen. If they knew each other coming in it'd be a lot
82 easier. If you brought a big group of people in and they didn't know it other then it'd
83 be hard to get on.

84 **Interviewer: What about the topic of communication? Anything you would add?**

85 Sam: I thought what was on it was grand... It wasn't... Like again it was the small
86 stuff... That helps a lot... More than people might think. But it definitely does. The
87 serious stuff you might cover when you're in with your appointments, so stuff like
88 that... Little things that help make a big difference.

89 **Interviewer: What about the level of interaction? Should the staff be posting
90 more to the page?**

91 Sam: Maybe a bit like. They mightn't think people see them but I think everyone
92 looks at their Facebook at least once a day, so they do be reading them.

93 **Interviewer: What about the type of interaction? Should it be one-to-one
94 conversations, posting links, putting videos up?**

95 Sam: It depends on what people are comfortable with I suppose. For young people
96 talking to nurses... If they're comfortable with posting it where everyone can see
97 that's grand but if they rather maybe message them privately I think that's grand as
98 well. It's up to them. But definitely if the nurses and doctors put stuff up for
99 everyone to see and then if there's a little thing they see that they know someone's
100 struggling with they might send that to them in a message saying, I know you're
101 having trouble with this, this could help.

102 **Interviewer: Is there anything we haven't discussed that you think is important?**

103 Sam: No, I don't think so.

104 **Interviewer: That's great. Thanks for that Sam. I'm just going to stop the
105 recorder now.**

Pilot Study Interview Transcript
Interview with Martin and Dean (pseudonyms)

1 **Interviewer: What were your initial expectations about using Facebook to**
2 **communicate with the Diabetes team? Before you joined the group, what were**
3 **your thoughts? Obviously you all have Facebook accounts so you would already**
4 **be communicating with friends, but with the Diabetes team, is it very different?**
5 **Anybody any thoughts?**

6 Martin. Thought it was a good idea, a very good idea.

7 **Interviewer: Would you have been hesitant at the fact that you would be talking**
8 **to the diabetes team in a place than you would be talking with your friends?**
9 **Would that have put you off or would you have been concerned that this is a**
10 **cross over into your personal life that you don't like?**

11 Martin. Slightly, but it's not really a big factor.

12 **Interviewer: What about yourself Dean, what are your thoughts?**

13 Dean. I thought it was a good idea as well because even when I had a problem, I was
14 like... I can't talk to anyone on the phone, that's a weird thing I have, so on Facebook
15 it was a lot easier, to communicate with people, even though it is weird having
16 something really formal on Facebook because it's a hospital... Even though it is, they
17 encourage you to be informal... There's still kind of a formality about it.

18 **Interviewer: I suppose the way the hospital is set up, it doesn't help, it's a less**
19 **relaxed environment.**

20 **Interviewer: What would your thoughts have been before joining, any**
21 **expectations either positive or negative?**

22 Dean: It was mostly positive I think, or probably even all positive because it's
23 probably the best way to communicate with adolescents... Is through social media

24 **Interviewer: So before you were on it was there any worries or concerns or was**
25 **it generally positive?**

26 Martin: The bit that I had was just not knowing people and I felt a bit awkward doing
27 it.

28 **Interviewer: That was with the other people more so than the diabetes team?**

29 Martin: Yeah.

30 **Interviewer: Specifically, in relation to the diabetes team, so your thoughts**
31 **generally just before joining the group, what you are saying is they were**
32 **positives, this is an option of communicating with the team?**

33 Martin: Yeah.

34 **Interviewer: What about your initial expectations, before you started, about**
35 **interacting with other young people with diabetes on the group? So these are**
36 **people that you definitely did not know.**

37 Martin: I think that there probably should be two separate things. One with a group
38 of all the diabetic people and then another group that you can talk to the doctors and
39 all. If they all have one account maybe... And you can message them in private.

40 **Interviewer: So one page for interaction with other young people with diabetes**
41 **and a separate page for interaction with the diabetes team.**

42 **What were your thoughts on that Dean? Had you any expectations about**
43 **interacting with other people that you don't know on Facebook?**

44 Dean: Probably nervous about meeting a lot of new people all at once. I am very
45 awkward when it comes to that. So I don't think I will be the only one... When you
46 are put into a room with strangers, you tend to go into your own little corner.

47 **Interviewer: Yeah, I think most people are like that. If you put people in a room,**
48 **regardless of what age they are, if they do not know each other, people are going**
49 **to be quiet and, as you said, go to their own corner.**

50 **Interviewer: Had you any particular expectations about, more so than meeting**
51 **them in the room, but being linked into these people on Facebook, even though**
52 **you are not connected Facebook friends, but on the same page as them?**

53 Dean: I didn't really mind that. That was the weird thing. When you're put in the
54 same room as a couple of strangers, you're kind of like who are these people but
55 when you're put into a Facebook group, it's kind of like that barrier is like, taken
56 down. Because like you're not stuck in a room where it's kind of like everybody's
57 awkwardly looking around. It's more like... It's probably easier to communicate.

58 **Interviewer: So you think it's a different experience being on a Facebook group**
59 **with a group of strangers than being in a room with a group of strangers?**

60 Dean: That would be my opinion, yeah.

61 **Interviewer: What about yourself Martin?**

62 Martin: Yeah, I would definitely agree with that. It'd be easier on Facebook. I'd say
63 that it is for most people but for some people it could be harder.

64 **Interviewer: Yeah, I think you're right there. What about, is it easier or harder**
65 **to ask questions in the room, like when we met in the room, or on the Facebook**
66 **page?**

67 Martin: I'd say probably on the Facebook page.

68 **Interviewer: Why would you think that?**

69 Martin: It's just... You have time to think about it as well, you don't have to...
70 You're not put on the spot.

71 **Interviewer: What would you think?**

72 Dean: Probably the same yeah. It's easier to put on Facebook than... And also like,
73 if you come into the clinic and then you forget what your question was, which I've
74 done plenty of times. I've a question I have to ask them, then I forget, and then I go
75 home and be like, crap, I have to wait for another six months.

76 **Interviewer: So you would have an idea of something you'd like to ask at clinic**
77 **but by the time you'd get in you'd have forgotten?**

78 Dean: Yeah.

79 **Interviewer: Would you ever find something like that?**

80 Martin: I am terrible at asking questions in general so, yeah.

81 **Interviewer: As in you prefer to keep your head down or just forgetting them?**

82 Martin: Just keep my head down really.

83 **Interviewer: Did you find your communication with the diabetes team through**
84 **Facebook to be more or less open?**

85 Martin: I'd say less open, slightly.

86 **Interviewer: Why do you think that was?**

87 Martin: It's just... ah, I don't know, there's... I can't really explain it, I think there's
88 a...

89 **Interviewer: Would you find it easier to say to them when you meet them in**
90 **person at the clinic for a visit than on the Facebook page?**

91 Dean: It depends on the topic really. I'd say the most if it's completely general,
92 Facebook would be completely fine for that.

93 **Interviewer: Just say it was about your management. For instance, my blood**
94 **sugars are a bit all over the place or my diet is a bit off. Would you think is that**
95 **easier to communicate in person at a clinic visit or would it be easier on the**
96 **Facebook page?**

97 Martin: Yeah, I'd say it would, Facebook. It probably would be Facebook. I've
98 personally been afraid to say that my diet's bad or whatever to their face.

99 **Interviewer: Why would you find you would be afraid to say it?**

100 Martin: I'd just be a bit nervous. Well really you just don't want to let them down, so
101 yeah.

102 **Interviewer: I don't think you'd be alone in that. What about yourself Dean?**

103 Dean: I am the same, yeah. But when it comes to personal questions, I'd probably
104 rather ask them in person, when it's just me and like the nurse or the doctor, rather
105 than on the Facebook group. So that'd be the only time I'd ask anyone in person.
106 Other than that I'd ask them anything on Facebook.

107 **Interviewer: With Facebook would your communication in general be more or**
108 **less open with the nurses and the doctors on Facebook than at clinic? Which**
109 **would you find most comfortable?**

110 Dean: I don't really... I'm not fussy either way.

111 **Interviewer: What about if you were talking about something like, if you were**
112 **struggling with aspects of management? Like I'm missing injections, or I'm**
113 **forgetting blood sugars or my diet is a bit off? Would you be more comfortable**
114 **saying that in person or on Facebook?**

115 Dean: Probably on Facebook.

116 **Interviewer: Okay, and why do you think that might be?**

117 Dean: Probably the same reasons as Martin, like you'd let them down.... for like why
118 are you missing the... Because I have gotten the talk... Ah you let us down. When I
119 go I feel like, guilty.

120 **Interviewer: Out of curiosity, on Facebook you don't feel guilty or they can't**
121 **give you the talk, or what kind of buffers or protects you on Facebook?**

122 Dean: Well you can't see their expression when you're typing it.

123 **Interviewer: That's actually really interesting. So that kind of not being there**
124 **makes it easier to disclose things.**

125 **Interviewer: On Facebook you can communicate on the wall where the rest of**
126 **the group can see or you can communicate directly with specific members of the**
127 **team. Had you any thoughts or are there certain things you prefer to**
128 **communicate directly with members of the team or certain things you're more**
129 **happy to put on the wall for the whole group?**

130 Martin: Not really sure.... Ah... I'd say....

131 **Personal things?**

132 Martin: Yeah, that would have to be a message, if it's personal. If it's a general
133 message about managing diabetes, I'd say just put it on the wall. Then either any
134 jokes or anything else, just put it on the wall.

135 **Interviewer: And what about yourself Dean?**

136 Dean: If I feel the answer to the question will benefit everyone else I'll put it on the
137 wall. But if I feel like this is a personal thing that it's really only to me and everyone
138 else seems to have that under control, I'll probably private message.

139 **Interviewer: How did you find being able to see other people's conversations**
140 **with the members of the diabetes team?**

141 Dean: Didn't really mind to be honest. If anything like, interesting to look at because
142 you could relate to them. I suppose because we all suffer the same things. If we get
143 insulin we all feel the exact same way once we forget our insulin.

144 **Interviewer: What about yourself Martin, how do you feel about being able to**
145 **see other people's conversations?**

146 Martin: I'd say it's interesting really. You get to learn as well, yeah.

147 **Interviewer: Would you even bother looking at other people's conversations or is**
148 **there a curiosity?**

149 Martin: No, there is a curiosity I'd say, yeah. Which is... Me personally, I find that
150 benefits because I don't really think of many questions to ask. I can just have a look
151 through and say, ah I never thought of that.

152 **Interviewer: Would you pick anything up from what you see other people**
153 **asking?**

154 Martin: I remember, I think it was actually Dean that asked it, it was the lancets,
155 using lancets the same time, it was because... I'm terrible at changing lancets and I
156 didn't actually realise it was a big thing. You're meant to change them regularly.

157 Dean: Yeah, I don't do that either, it becomes habit... You just forget to change.

158 **Interviewer: You found that question was an example of "Ah I didn't know**
159 **that"?**

160 Martin: I didn't think, I just did it without even.... I saw a post about Lancets, using
161 them at the same time because I am terrible at changing the lancets. The small
162 needles for your finger. I didn't realise you were meant to change them regularly.

163 Dean: I don't do that either, it becomes habit, you just forget to change.

164 **Interviewer: Did you find from the some of the conversations other people were**
165 **having, would you ever kind of go, actually that's something I've experienced, I**
166 **didn't realise it was that common. Did you find it rings a bell with some things?**

167 Dean: Yeah, especially I think someone mentioned the book, and I thought I was the
168 only one that like when I got the book, just like throw it in the corner. I don't want to
169 see you again. And I'd fill it out the night before. Like I didn't think that was
170 common, I thought that was just me.

171 **Interviewer: You thought you were unique to that?**

172 Dean: Yeah

173 **Interviewer: What about yourself Martin?**

174 Martin: Well, the book as well, definitely.

175 **Interviewer: Would you have thought you were unique to that?**

176 Martin: I never really thought about it to be honest.

177 **Interviewer: Did using the Facebook page change your behaviour in any way**
178 **with regards to your diabetes management?**

179 Dean: Probably, because if you do have a problem, like I always thought, if I ever run
180 into something the Facebook group is there. I don't have to wait like another couple
181 of months to come back in. So like it was probably easier to manage. I never had to
182 use it for my management but like it's there, if I had to.

183 **Interviewer: So it was actually its availability rather than actually having to use**
184 **it?**

185 Dean: Yeah, it was always there. There's Wi-Fi everywhere now, so...

186 **Interviewer: What about yourself?**

187 Martin: I'd say... Yeah, the availability as well.

188 **Interviewer: Would you find it changed your behaviour in any way ?**

189 Dean: Yeah, I'd say so. It kind of made me realise that literally there's a lot of us that
190 has diabetes and all kind of stick together in a way we can.

191 **Interviewer: Was there any aspects of the diabetes page that would make you**
192 **less likely to use it?**

193 Dean: I can't think of anything. Like there was no major turn offs on it that I found.
194 Other people could be different but I found there's nothing wrong with it.

195 **Interviewer: What about yourself Martin?**

196 Martin: Yeah well all the healthcare team being on it is obviously a huge plus. Just
197 the fact that it actually will be used and like, by doctors and all.

198 **Interviewer: How do you mean?**

199 Martin: Like they won't just leave it, they'll actually respond to your question.

200 **Interviewer: Would you have found there were any particular things that you**
201 **would have looked at or that would have caught your eye? Any things that made**
202 **you more likely to go and see if there's any more of that there?**

203 Martin: I'd say like all the jokes on it as well, the memes. Just even some... I think
204 it was... The tattoo ink that changed colour with blood sugar. Stuff like that... Just
205 interesting.

206 **Interviewer: What about yourself Dean. Was there anything that you found that**
207 **made you more likely to go to the page or things that you had a particular**
208 **interest in or like on it?**

209 Martin: Probably, that you have the nurses and doctors there. Just if I had a question
210 they'd be able to answer it, like not straight away but like soon enough.

211 **Interviewer: Anything else that you gravitated towards or liked on it?**

212 Martin: I'd say that'd probably be the main one.

213 **Interviewer: Did you find anything beneficial about using the Facebook page?**
214 **Did you find anything positive that you got out of it that helped yourself?**

215 Dean: I remember asking a question once. I can't remember what the question was
216 but I remember it helped me. I can't remember like... If it's no longer... If I can't
217 think of it then that problem's been sorted. It was definitely something to do with my
218 Lantus. I can't remember what it was but like it's controlled now thanks to the
219 Facebook group.

220 **Interviewer: What about yourself Martin. Did you find anything beneficial you**
221 **got out of it?**

222 Martin: Just the whole page in general really, it's just complete benefit.

223 **Interviewer: How, if at all, would Facebook been incorporated into your ideal**
224 **diabetes service. So if you were designing a perfect diabetes service that had**
225 **Facebook, in what way would you incorporate it, how would it work? First of all,**
226 **who would you have as the members of the group?**

227 Dean: As in members of the team?

228 **Interviewer: Yeah, members of the team and who else?**

229 Martin: I'd say maybe just the people that you have and maybe the receptionist as
230 well, so you can organise different dates for your appointments and all.

231 **Interviewer: And outside of the diabetes team? Would you specify all the other**
232 **young people or age groups or what?**

233 Martin: Roughly around the same age. Probably more the same year in school than
234 age.

235 **Interviewer: What about yourself Dean. If you were able to design your ideal**
236 **diabetes service using Facebook, what would you look at first of all in terms of**
237 **group?**

238 Dean: Same thing, everything that Martin said. I'd probably add in someone who's
239 high up in the Diabetes Federation of Ireland, so they could keep us updated on
240 what's happening. I think that might be beneficial to everybody.

241 **Interviewer: Would you still include other young people in the group?**

242 Dean: Yeah.

243 Martin: Yes

244 **Interviewer: Would you try and keep the group to a similar school year or have**
245 **you any thoughts on that?**

246 Dean: I don't really mind like what age they are. To be honest, like, because if
247 they're younger I'll probably see myself as more experienced. That's about it.

248 **Interviewer: About what size of group, any ideas, should it be very big, should it**
249 **be very small, if you were designing an ideal group, how big would you have the**
250 **group?**

251 Dean: Probably in between big and small because if it's too big you would probably
252 be bombarded with messages but if it's too small that awkwardness might be there. If
253 it was medium sized people might be more comfortable posting.

254 **Interviewer: So you said in between a big and a small group. Numbers wise**
255 **what do you think that would be?**

256 Dean: Good question. Ah, thirty maybe forty. To be honest I'm not sure.

257 **Interviewer: What about yourself Martin, any thoughts on the size of the group.**

258 Martin: Ah, size of group, I'd probably say around twenty-five, around that.

259 **Interviewer: What about in terms of topics of communication. We did topics on**
260 **things like high blood sugars and low blood sugars. Would you have any topics**
261 **of communication that you think would be important in the group or that you'd**
262 **like to see on a Facebook group in an ideal service?**

263 Dean: Maybe updates on how to control your diabetes more efficiently maybe. My
264 blood monitor, all I have to do is like... The new one I got where you just type in how
265 much you're eating and it tells you how much to take. Stuff like that, just
266 encouraging people to move onto stuff like that. And better like over the pump or the
267 pen and just to make life... Because the pen's made my life easier... If it makes
268 someone else's life easier...

269 **Interviewer: Any other topics you think would be important?**

270 Dean: Probably high or low blood sugar would be a decent one to have. Like if
271 you're in a certain situation, you have high blood sugar, what do you do. I think,
272 especially made for our age, alcohol would be a big thing because I know that's
273 effected my blood sugar a good couple of times. And ah... Off the top of my head...
274 Probably missing an insulin shot.

275 **Interviewer: What to do is it?**

276 Dean: Exactly. Because one morning I woke up tired, didn't realise I accidentally
277 took my Lantis, when I took it the night before. So my blood sugars were a bit...
278 That was an interesting day.

279 **Interviewer: What about yourself Martin, would you have any suggestions for**
280 **topics for communication? If you were designing an ideal service what topics do**
281 **you think would be important to include on Facebook?**

282 Martin: Further updates on just the developments in diabetes, like. Just any new
283 inventions or any handy meters as well like. See I don't know about the high and low
284 because, like, after you get it once it might just get repetitive. But maybe just like
285 explain diabetes a bit better for people who have diabetes.

286 **Interviewer: In terms of level of interaction. Again your designing your ideal**
287 **service, what level of interaction would you like to see? Basically, how often do**
288 **you think, particularly the diabetes team should be posting on it or**
289 **communicating? Should it be all the time? Any thoughts?**

290 Dean: Once a week, once every two weeks, just in case like, just to let people know
291 you're still there because when people have a bunch of groups on Facebook they tend
292 to forget about one or two groups. Like I forget one or two groups I'm signed up to
293 now and again. Maybe twice ah... Once ever two weeks.

294 **Interviewer: Ideally should it be more, should it be every day?**

295 Dean: I wouldn't say every day because if you bombard people they might get kind
296 of like fed up of the group. So I wouldn't recommend once every day but once a
297 week I'd say would be ideal.

298 **Interviewer: What about yourself?**

299 Martin: I'd say once a week, once every two weeks yeah as well.

300 **Interviewer: You think more than that would start to become annoying?**

301 Martin: Yeah.

302 **Interviewer: What about the types of interaction in an ideal service? What**
303 **should the members of the diabetes team be communicating with the young**
304 **people on the group about? Should they just be making general statements,**
305 **putting up memes, or saying, "Hey, how is your blood sugars", "How are you**
306 **getting on with this". What should the interaction be in an ideal service?**

307 Dean: Probably the memes, you know, keep things like informal so they don't feel
308 like they have to be formal all the time. That's kind of to encourage them to talk to
309 people. And yeah, just like daily updates, like how you're doing with the blood
310 sugars. Like if they had an issue with the blood sugars, like how is that sorting out. If
311 the dietitian recommended something, like, how's that working out for you. Do you
312 want any changes, are you not liking it. Stuff like that.

313 **Interviewer: Just say for instance someone came into clinic and there HbA1c was**
314 **high, should they be following up that with them maybe a week or two later,**
315 **saying "Hey, I know your HbA1c was high, how are getting on with, you know,**
316 **the diet or checking the blood sugars or whatever? Something like that or do**
317 **you think that's too invasive?**

318 Dean: Well, if it's a private message its not. It'd be nice like to follow up on them
319 because every three months... If you're put on a diet, after a month you forget about it.
320 And then you come back two months later and then you've gone back to square one.
321 So if you keep following it up, on what they're doing, it encourages them more to
322 keep it up and they'll get better hopefully.

323 **Interviewer: What about yourself Martin, any thoughts on what type of**
324 **interaction would be most beneficial if you were designing an ideal service?**

325 Martin: Not too many no, basically just what Dean said. But the whole... I can't even
326 remember what I was going to say, sorry.

327 **Interviewer: You're okay. So just in terms of interaction, what do you think**
328 **would be beneficial in terms of the diabetes team? Would it be a case that they**
329 **would just be posting memes and things like that or being more directive saying**

330 **“Hey, how’s the blood sugar going” or “I hear your HbA1c was high, how are**
331 **you getting on with this”? What type of interaction, what level of interaction?**

332 Martin: I don’t think that they should do the follow really because I think then the...
333 Just... There’d be a lot of notifications... And I don’t know, it could get annoying for
334 some people. And maybe just the odd time like, but not continuous, asking them how
335 it’s going.

336 **Interviewer: And what about in a private message? After you come to clinic in a**
337 **private message someone following up and just checking in on how certain things**
338 **are going. Would that be annoying? Someone coming in every week or so**
339 **touching base, would that be beneficial or would it be annoying?**

340 Martin: I’d say it depends on how often like. For the most part I’d say it’d be grand.
341 But it just... If it goes on for like a long while it might get annoying like. Say if
342 you’re thirteen then if it happens until you’re eighteen, it’ll get annoying.

343 Dean: Sorry, in that thing as well groups, maybe separate pumps and injections.

344 **Interviewer: Thanks, that’s actually a good idea.**

345 Dean: Yeah, they’d be completely different management.

346 **Interviewer: What about you, because your on the pump, would you have found**
347 **any difference from the other side of the table or would it have been beneficial to**
348 **split pumps and injections or would you have found benefit from seeing, okay**
349 **that’s what happens with the pump?**

350 Martin: To be honest I would notice. I wouldn’t mind but if the group gets bigger
351 you might want to split them up. Because the group is small at the moment, so at the
352 moment it won’t be a problem but it could in the near future.

353 **Interviewer: So you’re both saying an ideal size group is twenty to thirty, so if**
354 **you’re running a group bigger, at that point do you think it’d be wise to split**
355 **pumps and injections?**

356 Dean: Probably yeah, because if you’re in a group and you’re posting about like, how
357 to manage your pen and everyone else is using a pump, they’re going to be like,
358 “What are you saying, I don’t understand”.

359 **Interviewer: Forgetting about Facebook for a second, what are the biggest**
360 **barriers to communicating openly with the members of the diabetes team?**

361 Martin: The disappointment.

362 Dean: Probably yeah, the disappointment. You feel like you let them down if you
363 don’t do what they tell you to do. Letting them down.

364 **Interviewer: Again forgetting about Facebook, what is your experience of**
365 **interacting with other young people your age your age with diabetes?**

366 Martin: None.

367 Dean: I know a few people with diabetes, yeah.

368 **Interviewer: What’s your experience with that?**

369 Dean: It does help, it helps a good bit, yeah. Like you’re able to talk to them and all.
370 You feel better in your own skin like, as in you’re not completely awkward about it in
371 front of others. Like I was completely awkward about it in public. Since I know
372 people, no. I got a lot better.

373 **Interviewer: Is there anything else that we haven’t discussed that you think is**
374 **important?**

375 Dean: Probably something to do with the adult services. Because that was a big
376 shock for me. They told me it was going to be something different but you just brush

377 it off. Then you go in and it's like whoa. Their weighing scales are like as big as the
378 table. They were like on you go and I was like what is this and they were it's the
379 weighing scales. You just feel different, you just feel out of place. So I think just
380 letting you know that things are going to be different. Like I'm in the adult services
381 now, so someone going in I could tell them what it's like. It's a completely different
382 world.

383 **Interviewer: Do you have any thoughts on that Martin?**

384 Martin: No.

385 **Interviewer: You're not in adult services yet?**

386 Martin: No, but I have my appointment.

387 **Interviewer: Okay, thanks guys for doing the interview with me. That was great**

Questions to be used to Guide Qualitative Discussion with Participants from Main Study

Introduction

- Interview will take approximately half an hour to an hour and will consist of a group discussion of spoken questions.
- No right or wrong answers – it's about participants experiences of using the Facebook group page.
- Everyone is free to leave at any time.
- Confidentiality and respect for all opinions.
- Interview recorded – interviews transcribed anonymously and tapes will be erased following transcription.
- No identifying information will be included in the transcripts.
- Interviewer may take notes to help shape interview.

Thoughts before using the Facebook page

- What were your thoughts about using the Facebook page before it actually started?

Impressions of first using the Facebook page

- What were your initial impressions about actually using the Facebook page?

Views on interacting with the diabetes team online

- What was it like interacting with members of the diabetes team on Facebook?

Views on interacting with other peers with diabetes online

- How did you find interacting with other young people with diabetes on the Facebook page?

Any changes in behaviour

- Did using the Facebook page change anything in the way that you manage your diabetes?

Changes in thoughts and beliefs

- Did using the Facebook page make you think any different about your diabetes or diabetes in general?

Views on the operation of the page

- What do you think would make the page better?
- What do you think would be the ideal size group?
- Who should be in the group?
- What are the types of things that should be posted to the page?
- How often should we be posting to the page?

Final Question

- Is there anything that we haven't discussed that you think is important?

Main Study Interview Transcript

Group Interview with Four Participants; Ethan, Jane, Sarah and Tracey (pseudonyms)

1 **Interviewer: What were your thoughts about using the Facebook page before it**
2 **actually started?**

3 Ethan: Different, like easier to communicate.

4 **Interviewer: What were your thoughts about the fact that you were going to**
5 **communicating with some of the diabetes team on Facebook?**

6 Jane: It was unusual because all the people you interact with normally, they don't, like,
7 they do understand but they don't, whereas you're talking to people that fully
8 understand everything. They understand how you feel all the time.

9 **Interviewer: Is that the other people in the group or the diabetes team?**

10 Jane: The team and the other people.

11 **Interviewer: Anybody else any thoughts on what they...**

12 Sarah: I couldn't wait to talk to...(name of DHCT member).

13 **Interviewer: Did anybody think it was going to be enjoyable?**

14 Ethan, Jane, Sarah and Tracey: Yeah.

15 Tracey: It's really helpful because if you had any sort of problem you could just ask
16 someone, you wouldn't necessarily have to, like you could put it even privately or
17 something. You could message one of the nurses or something if you needed help
18 with anything. It's just much easier than having to like... I suppose you could call
19 but... I don't know it's just...

20 Ethan: Easier.

21 Tracey: Yeah, easier.

22 Ethan, Jane, Sarah and Tracey: Yeah, easier.

23 **Interviewer: Was there anything that put you off? So before you started was**
24 **there anything you thought, "Erm... I don't know about this?"**

25 Ethan: No.

26 Jane: Not really, no.

27 Ethan, Jane, Sarah and Tracey: No.

28 **Interviewer: What were your initial impressions about actually using the page?**
29 **Like, did you find it was different from... Everyone here was on Facebook**
30 **before they started?**

31 Ethan, Jane, Sarah and Tracey: Yeah.

32 **Interviewer: Did you find it was any different from the interactions you would**
33 **have normally had on Facebook with friends and that?**

34 Jane: I think because we're all kind of like... There's jokes that we'd understand and
35 that other people wouldn't understand and I find them really funny.

36 Ethan, Jane, Sarah and Tracey: (laughs).

37 Tracey: It's like if you posted a photo or something related to diabetes...

38 Ethan, Jane, Sarah and Tracey: Yeah.

39 Jane: You're like, "Oh My god".

40 Ethan, Jane, Sarah and Tracey: Yeah (laughs).

41 Tracey: We would understand it all but other people would be like "What are you
42 like, oh yeah, hahaha".

43 **Interviewer: That's a good point actually. I never thought about that because I**
44 **suppose I'm used to you putting up the memes and that. It's only when you say**

45 **it there, if you put up a meme just on your regular page a lot of them people**
46 **without diabetes don't make the connection. They don't see why it's funny.**
47 Ethan: Unless they do science or something in school.
48 **Interviewer: Well that's it and even with science they mightn't make the**
49 **connection.**
50 Jane: They wouldn't find it funny though.
51 Tracey: No, no.
52 Jane: We could be like cracked up laughing and no one knows why.
53 Ethan, Jane, Sarah and Tracey: (laughs)
54 **Interviewer: Well that's a good point. Obviously because we see diabetes a lot**
55 **here, so we can usually see what's funny in the meme. We obviously don't**
56 **experience it like yourselves but we forget about the fact that someone that**
57 **doesn't have diabetes... It makes no connection. It's not funny to them.**
58 Ethan, Jane, Sarah and Tracey: Yeah.
59 Tracey: Even photos that I would like that are related to diabetes when I show them
60 to my Mum... I thought they were hilarious but then when my Mum saw them she
61 was like... Yeaaaaaah.
62 Ethan, Jane, Sarah and Tracey: (laughs).
63 **Interviewer: Didn't get the joke?**
64 Tracey: (laughs) No.
65 Sarah: You see where I put up the photo that says "out of order"?
66 **Interviewer: That's very good actually.**
67 Sarah: I posted that on Facebook and someone goes "what, your stomach doesn't
68 work", I'm like "Ahh".
69 Ethan, Jane, Sarah and Tracey: (laughs).
70 **Interviewer: But that's a perfect example. Someone without... That doesn't**
71 **understand diabetes. That makes no sense to them.**
72 Sarah: Yeah
73 Jane: There's actually a really funny one I just remember and it was of a photo of a
74 man and he had ice-cream in his hand and he's just like "let's get high" and no one
75 else understood that but me.
76 Ethan, Jane, Sarah and Tracey: (laughs).
77 Jane: It was just really, really funny like.
78 **Interviewer: And that could be completely misinterpreted.**
79 Ethan, Jane, Sarah and Tracey: (laughs).
80 Tracey: Yeah, like what's in your ice-cream?
81 Ethan, Jane, Sarah and Tracey: (laughs).
82 **Interviewer: Drug filled cone or something?**
83 Ethan, Jane, Sarah and Tracey: (laughs).
84 **Interviewer: Did people find it interesting starting to use it?**
85 Ethan, Jane, Sarah and Tracey: Yeah.
86 **Interviewer: What was interesting about it?**
87 Ethan: Like... It's hard to... I don't know... I'll try to say what I'm trying to think.
88 **Interviewer: Okay.**
89 Ethan: Like... Communicating... Like... Asking questions across Facebook... Like
90 being able to take your time to word it... Easier than just straight out. And it's easier
91 to do it, like, because you're behind... Like it's easier to ask a question on Facebook
92 than it would be in person, as well, cause it's easier to word it, like, you wouldn't
93 know how to word it straight away.
94 **Interviewer: Was it fun?**

95 Ethan, Jane, Sarah and Tracey: Yeah.
96 Ethan: Yeah, it was.
97 **Interviewer: What aspects of it were fun?**
98 Ethan: The memes were fun.
99 Ethan, Jane, Sarah and Tracey: (laughs).
100 **Interviewer: The memes obviously.**
101 Ethan, Jane, Sarah and Tracey: (laughs).
102 **Interviewer: Any other aspects?**
103 Sarah: (name of DHCT member).
104 Ethan, Jane, Sarah and Tracey: (laughs).
105 **Interviewer: Well obviously when you've got a soft spot for (name of DHCT member). Okay.**
106 Jane: I think just like being able to talk to someone who knows what you feel.
107 **Interviewer: Yeah.**
108 Jane: So say if I was upset or something, all I have to do is just go on, have a random
109 conversation with someone who understands.
110 Tracey: Yeah, exactly.
111 Jane: Whereas if you talk to like, say your best friend, they're there but they don't
112 understand. So you don't feel like you're alone.
113 Tracey: Yeah, I agree. Because there's a girl in my year and she was diagnosed three
114 days before Christmas. Just like in 2014 and in the New Year when we came back to
115 school she was like saying... On the first day back she took out a salad out of her bag
116 and then all her friends were like "Oh, no carbs" and I was like "Oh, there's like a
117 new year's diet".
118 Ethan, Jane, Sarah and Tracey: (laughs).
119 Tracey: And she's like, "No, I got diabetes". And I thought she was joking, because
120 like, you know some people would be like, "Oh, I can't eat anything except for, like,
121 salad because you're diabetic" but no she actually was.
122 **Interviewer: So she had just got diagnosed with diabetes?**
123 Tracey: Yeah, so I'd say it was pretty tough for her three days before Christmas.
124 Jane: Yeah
125 **Interviewer: Did you find your interests in the page changed over time?**
126 Sarah: What do you mean?
127 **Interviewer: That you got less interested, more interested?**
128 Ethan: I'd say kind of the same.
129 Sarah: Kind of the same, yeah.

131 **Interviewer: What was it like interacting with members of the diabetes team on**
132 **Facebook?**
133 Sarah: Am I allowed to answer this?
134 Ethan, Jane, Sarah and Tracey: (laughs).
135 Sarah: It's great fun talking to (name of DHCT member). I love talking to (name of
136 DHCT member). I talk to (name of DHCT member) for hours and like, well she
137 probably gets annoyed but I don't.
138 **Interviewer: Well she's talking back so she mustn't be.**
139 Sarah: Yeah but like she...
140 Ethan: Or she talks back just to talk back.
141 Jane: Or she has to.
142 **Interviewer: No, she doesn't have to.**
143 Sarah: Well then, she's just that nice that she feels she has to, you know.

144 **Interviewer: I'm sure she enjoys it. How do other people feel about interacting**
145 **with members of the diabetes team on Facebook? Because it's a different way of**
146 **interacting. It's a bit... I'm sure it was probably strange or something at first?**
147 Tracey: I think it makes it feel like they're not just like your doctors or your nurses.
148 **Interviewer: They're kind of there for you more than before?**
149 Jane: You see, it sounds kind of bad but they seem more approachable, I think.
150 Ethan, Jane, Sarah and Tracey: Yeah.
151 Sarah: Yeah, they kind of seem more like, like... This sounds kind of weird but like
152 real people. Before you used to think they're just nurses. They just live in the
153 hospital kind of thing.
154 Ethan, Jane, Sarah and Tracey: (laughs).
155 Sarah: After you see that they're not like.
156 **Interviewer: Yeah.**
157 Sarah: If that makes sense?
158 Ethan: It's easier to do it behind the Internet like, because, it's not like you're...
159 You're obviously not anonymous cause they know your name and that but it's... You
160 feel like you have a sense of anonymity when you're on the Internet so it's easier to
161 do everything.
162 **Interviewer: Was it weird?**
163 Sarah: No.
164 Ethan: No.
165 Tracey: It was unusual at first I think.
166 Ethan, Jane, Sarah and Tracey: Yeah.
167 Tracey: But it was fine after a while.
168 **Interviewer: Was it a bit too invasive? Did you feel like it was kind of invading**
169 **your space, you know, to have all of a sudden, you've got the diabetes team**
170 **invading your Facebook?**
171 Ethan: No.
172 Tracey: No, because they're not like your Facebook friends, so they can't see you.
173 It's not like... Well not that there's any...
174 Ethan: And it wasn't like spam on your newsfeed.
175 Ethan, Jane, Sarah and Tracey: Yeah.
176 Ethan: It was just like there, somewhere you could go like.
177 **Interviewer: Did you find it supportive?**
178 Ethan, Jane, Sarah and Tracey: Yeah.
179 **Interviewer: So not just the support you got from each other, but from having**
180 **the diabetes team there?**
181 Ethan, Jane, Sarah and Tracey: Yeah.
182 **Interviewer: Did you see team members differently after interacting with them**
183 **on the page? So would you have seen (names of DHCT members)... Would**
184 **you have seen them differently, you know, after having interacted... Did it**
185 **change, kind of the way you saw them?**
186 Sarah: Yeah, (name of DHCT member) is a lot more mad than I thought.
187 Ethan, Jane, Sarah and Tracey: (laughs).
188 Sarah: She is.
189 Interviewer: I'll have to do a separate interview with you Sarah.
190 Ethan, Jane, Sarah and Tracey: (laughs).
191 Sarah: Okay, I'll start talking about someone else.
192 Interviewer: No, no.
193 Ethan, Jane, Sarah and Tracey: (laughs).

194 Ethan: I didn't see her either.
195 **Interviewer: How does it differ from interacting with them in the clinic?**
196 Jane: It's less formal.
197 Ethan, Jane, Sarah and Tracey: Yeah.
198 **Interviewer: Is that better or worse?**
199 Ethan, Jane, Sarah and Tracey: Better.
200 Tracey: I think maybe it's less formal with the doctors more than the nurses because
201 like with the nurses they're more kind of on your side.
202 Ethan, Jane, Sarah and Tracey: Yeah.
203 Tracey: Trying to help you in a way, whereas the doctors are more kind of like...
204 Ethan: Strict.
205 Tracey: Yeah, the kind of look scary in a way.
206 **Interviewer: They're kind of the Simon Cowell sort of.**
207 Ethan, Jane, Sarah and Tracey: (laughs).
208 Jane: Yeah, like the nurses can give you a hug but you don't feel that way about the
209 doctor if I'm being honest.
210 Ethan, Jane, Sarah and Tracey: (laughs).
211 Ethan: I must be the only person that doesn't see that.
212 **Interviewer: How do you mean Ethan?**
213 Ethan: Like on the other group, the Type One Teens that we joined, everyone else is
214 like "Oh God I'm going to the clinic", "Oh God I'm scared of the nurses" and I'm just
215 sitting there like "why", "What's wrong"?
216 **Interviewer: How open was your online communication compared to the clinic.**
217 **So, did you feel it was... Could you be more open with the diabetes team online**
218 **or less open?**
219 Tracey: The same.
220 Ethan: Yeah, the same
221 **Interviewer: So it didn't make any difference? You could say as much to the**
222 **nurse on Facebook as you could when you came to clinic?**
223 Sarah: To the nurses yeah, but to the doctors you... Like when I... When you're on
224 Facebook you can kind of just...
225 Ethan: I thought she was going to say (name of DHCT member).
226 Sarah: No, I won't this time. No, when you're like on Facebook you can say your
227 question and blah, blah, blah and you can say it kind of how you want to. But when
228 you're in like, clinic, and they're talking to you, you kind of forget how to talk. It's
229 like scary.
230 **Interviewer: Okay.**
231 Ethan: You just let them say whatever.
232 Tracey: Or else if you ask a question and like... I don't know which doctor it was, I
233 think it was (name of DHCT member). But he like answered and there was like a
234 really, really long answer. Whereas like, if he was to say it in downstairs, like you
235 mightn't remember everything, whereas with Facebook you could read through it
236 again and again
237 **Interviewer: So it stays there and it's easier to go through it.**

238 **Interviewer: How did you find interacting with other young people with**
239 **diabetes on the Facebook page?**
240 Jane: Good.
241 Sarah: I think it was great.
242 Ethan: Yeah.

243 **Interviewer: Was it difficult because you didn't know them?**
244 Ethan, Jane, Sarah and Tracey: No.
245 Tracey: I think at first it was kind of...
246 Sarah: Yeah, a little bit awkward.
247 Tracey: I remember when we had the meeting it was like...
248 Jane: What's your name and what's your age.
249 Ethan, Jane, Sarah and Tracey: (laughs).
250 Jane: And what year are you in.
251 **Interviewer: But it was a little bit artificial at first. I don't think anyone here**
252 **knew anyone else, did they?**
253 Ethan, Jane, Sarah and Tracey: No.
254 **Interviewer: No. So obviously it's a bit kind of... Well anytime you go to a**
255 **group with people you don't know it's a bit strange kind of at first.**
256 Ethan You knew Noelle from the...
257 Sarah: Well apparently I knew Noelle but I didn't... I actually knew Ethan as well
258 but I just didn't remember them.
259 **Interviewer: From the...**
260 Sarah: From the Carlingford camp.
261 Ethan: Apparently the three of us went to Carlingford and I don't remember either.
262 Sarah: I just remember Noelle being a really noisy loud one.
263 **Interviewer: Okay, she'll be glad to hear.**
264 Ethan, Jane, Sarah and Tracey: (laughs).
265 Sarah: She knows, I've told her often.
266 Ethan, Jane, Sarah and Tracey: (laughs).
267 **Interviewer: Did meeting others in the group sessions help you get to know them**
268 **better? So you know the times when we actually came in here, was that**
269 **beneficial in terms of getting to know the other people or was just Facebook**
270 **enough?**
271 Ethan, Jane, Sarah and Tracey: No.
272 Ethan: Coming in here was better.
273 Jane: No, I think we needed both.
274 Tracey: We definitely needed both.
275 **Interviewer: Was there enough sessions? Should there have been less, more, or**
276 **what do you think? Because we had five over ten or twelve weeks.**
277 Sarah: Was it not more time? I thought it felt more longer.
278 **Interviewer: It was twelve weeks. From the first session to the last was twelve**
279 **weeks and there were five sessions over the course of that.**
280 Sarah: I think maybe another one or something might have been better. I think we
281 kind of just stopped and broke for ages.
282 Tracey: Maybe if they were spread out a bit more because at the start it was like week
283 after week. It was like every Wednesday and stuff like that.
284 **Interviewer: So over a much longer period of time? Same number of sessions**
285 **but over kind of bigger gaps?**
286 Ethan, Jane, Sarah and Tracey: Yeah.
287 **Interviewer: Did you find you got to know some of the others better from being**
288 **on the page?**
289 Ethan, Jane, Sarah and Tracey: Yeah.
290 Ethan: Yeah, you got to like see what they were... Like what they liked. What they
291 were into.
292 Ethan, Jane, Sarah and Tracey: Yeah.

293 **Interviewer: Well everyone seems to know each other a lot better than they did**
294 **then when we started.**
295 Jane: We all like added each other as a friend obviously.
296 **Interviewer: Did that happen straight away or over time?**
297 Ethan: I think it happened the first day.
298 Tracey: Yeah, the day we met each other we went home and added each other.
299 Ethan, Jane, Sarah and Tracey: (laughs).
300 **Interviewer: So it happened pretty quickly. So you were saying there's another**
301 **group call Teens...**
302 Ethan: Type One Teens.
303 **Interviewer: Is that just people from Crumlin Hospital or people who...**
304 Ethan, Jane, Sarah and Tracey: No.
305 Tracey: It's actually really interesting.
306 Sarah: There's some of them really cool like kind of people and some of them are
307 really weird.
308 Ethan, Jane, Sarah and Tracey: (laughs).
309 Tracey: I've got so many people adding me off that and I'm like, "Who are you?"
310 Sarah: Like I won't really add them, like I'll talk to them on the page but I won't add
311 them because I don't know who they are.
312 **Interviewer: I'm assuming then that group must have thousands of like...**
313 Tracey: Oh yeah, it has like one thousand seven hundred.
314 Jane: It has so many people.
315 **Interviewer: Okay, so that's obviously a pretty active page but that's all over the**
316 **world, like the States and everywhere.**
317 Ethan, Jane, Sarah and Tracey: Yeah
318 Ethan: And apparently there's someone in England that has diabetes. She's like
319 some blogger that I should have known, that I didn't know and I got given out to for
320 not knowing her.
321 Ethan, Jane, Sarah and Tracey: (laughs).
322 **Interviewer: She works in Radio one, is that her?**
323 Ethan: I don't know.
324 Jane: I've never heard her name.
325 **Interviewer: There's a blogger that works on Radio One and she's involved in**
326 **bands and that and she has Type 1 diabetes. I think I posted a link to some blog**
327 **she had. Because she tried on the new glucometer...**
328 Jane: Oh the sensor.
329 **Interviewer: Yeah, the Libre. She had done a trial on that. Is that the one**
330 **you're on about?**
331 Tracey: The Freestyle Libre.
332 **Interviewer: Yeah, that's the one, yeah.**
333 Jane: That looked really good.
334 Tracey: Yeah.
335 **Interviewer: It does actually, yeah. It still hasn't gotten the official release yet**
336 **but it's got the go ahead so it should be coming out pretty soon.**
337 Tracey: It's really interesting to see how like medical systems work in like other
338 countries as well because there was a guy this morning and he posted... He was
339 really angry because he'd moved to an adult clinic and they said that he could only
340 have one box of fifty test strips for fifty days or something, so that meant one test strip
341 per day. And then loads and loads of people were like, "Oh, I'll send you something
342 if you need it". And he was from like, Bosnia and Herzegovina or something like that.

343 Sarah: Yeah, they're all kind of really supportive like that.
344 Ethan, Jane, Sarah and Tracey: Yeah
345 **Interviewer: Okay, that's very nice. Is there another Facebook group then that**
346 **you're part of that's more local, that just Ireland or Dublin or Crumlin Hospital.**
347 Ethan, Jane, Sarah and Tracey: No
348 **Interviewer: No, so it's just the one group.**
349 Ethan, Jane, Sarah and Tracey: Yeah.
350 Jane: We have a chat, like all of us, that's it though.
351 **Interviewer: You have a group chat?**
352 Ethan, Jane, Sarah and Tracey: Yeah.
353 **Interviewer: Because I thought that the ones who went on the cycle started a**
354 **group?**
355 Sarah: Oh yeah we did but that really didn't go anywhere.
356 **Interviewer: Oh, it didn't?**
357 Sarah: We posted like for about a weekend and then everyone just got bored.
358 **Interviewer: What was it like being able to see other people's conversations,**
359 **either with the team or with each other? So that fact that you could see on the**
360 **Facebook page if you were having a conversation with me or (name of DHCT**
361 **member). The fact that conversations were visible, how did you find that?**
362 Ethan: Like, if you read it through and they were asking questions, like you could
363 help them by answering their questions.
364 Ethan, Jane, Sarah and Tracey: Yeah.
365 Tracey: Or else you could learn something new, if they had asked something.
366 **Interviewer: So it didn't put you off that fact that the conversations were**
367 **visible?**
368 Sarah: No.
369 **Interviewer: Did you lean anything from other people's conversations?**
370 Ethan: Yeah.
371 Sarah: Yeah, you did but I can't really think of anything on the spot but it kind of
372 went in anyway.
373 **Interviewer: Were you able to jump in and answer other people's questions?**
374 Sarah: Yeah, sometimes but it depends on what it was.
375 **Interviewer: Would you have felt comfortable? If you knew the answer would**
376 **you have been comfortable enough to go in and say well actually...**
377 Ethan, Jane, Sarah and Tracey: Yeah.
378 **Interviewer: Did it prevent you from asking questions the fact that other people**
379 **could see the questions?**
380 Ethan: No.
381 Sarah: No.
382 Tracey: I don't think it did because if you needed to ask, say, one of the doctors or
383 nurses, you could message them privately or something. Or even just post it but you
384 could change the privacy settings so that it can only be seen by them.
385 **Interviewer: Can you do that with a post?**
386 Tracey: Yeah.
387 **Interviewer: I didn't know that. I need to brush up on it.**
388 Ethan, Jane, Sarah and Tracey: (laughs)
389 Sarah: I didn't know about that either.
390 **Interviewer: Well there you go, I don't feel so bad now so.**

391 **Interviewer: Did using the Facebook page change anything in the way that you**
392 **manage your diabetes? Like did anybody get any advice that they tried out?**
393 **Did it make it more likely to change things yourself?**

394 Ethan: No.

395 Sarah: Not really, no.

396 Jane: Some, I don't know.

397 **Interviewer: Okay. I was just wondering out of curiosity, like did anyone find**
398 **that they changed anything as a result of something on Facebook?**

399 Jane: Yeah, like if I needed like, you know, advice on like to change any of my
400 ratios...

401 Tracey: Yeah.

402 Jane: I think yeah. I think I did that once.

403 Tracey: It was just like motivation as well kind of. If like your numbers weren't very
404 good at like at certain point... Maybe something... I don't know.

405 **Interviewer: Yeah, okay.**

406 Ethan: Was it you or Noelle that put up a goal in like the first week or two? Someone
407 put up a goal in like the first week or two.

408 Sarah: I don't know. I can't remember it was so long ago.

409 **Interviewer: Did they reach the goal?**

410 Ethan: I think so.

411 Sarah: What was it?

412 Ethan: I can't remember. It was like some thirty-day thing or something wasn't it?

413 Sarah: I think I did no sweets for a whole month. I actually did it but my A1c ended
414 up being higher because it was before I got my MDI and only when I got on the MDI
415 I realised that some foods were really bad when I thought they were good. I was
416 substituting them for sweets. So I ended up being higher, so I was like, okay. So I
417 was quite annoyed.

418 **Interviewer: Did using the Facebook page make you think any different about**
419 **your diabetes or diabetes in general?**

420 Jane: It made me think that it's not so bad.

421 Sarah: Yeah.

422 Ethan: No, I've never worried about it.

423 **Interviewer: Were you surprised to find out that other people had similar**
424 **experiences to yourself?**

425 Ethan, Jane, Sarah and Tracey: Yeah.

426 Sarah: Like, I wasn't worried about it but I just... To kind of know more people felt
427 like you.

428 Ethan, Jane, Sarah and Tracey: Yeah.

429 Tracey: Yeah, exactly. It was just you could see that other people go through the
430 exact same thing as you do.

431 Jane: Yeah, I didn't feel alone.

432 Tracey: Yeah, exactly.

433 **Interviewer: Did it make you feel more confident about anything?**

434 Jane: It made me feel a bit prouder, I think, to be a diabetic.

435 **Interviewer: Okay.**

436 Sarah: Yeah, just because you've kind of got... It's like you've got an army of
437 people behind you.

438 Ethan, Jane, Sarah and Tracey: (laughs) Yeah.

439 Sarah: It's like, if you say something to me I've got all these.

440 **Interviewer: The diabetes army. Don't mess with my mob.**
441 Ethan, Jane, Sarah and Tracey: (laughs).
442 **Interviewer: Do you have any contact with each other outside of the page?**
443 Ethan, Jane, Sarah and Tracey: Yeah.
444 **Interviewer: Yeah, I think you said earlier that everyone kind of linked in...**
445 Ethan: Yeah, in group chat.
446 **Interviewer: So you would have some chat outside of the page or some**
447 **conversations outside of the page. In terms of other social media or meet up or**
448 **text or... Just on Facebook or would you have any other contact?**
449 Sarah: I think we've tried to meet up a few times but it's just always been difficult
450 because we'd all go and then Tracey would go "Oh, I can't do it" and then we'd do
451 another one and Ethan's like "I actually can't make that" and then it's just...
452 Tracey: I seem to be always away.
453 **Interviewer: I feel very proud that you all made it in today then. Thank you**
454 **very much.**
455 Ethan, Jane, Sarah and Tracey: (Laughs).
456 Tracey: I'm on Instagram as well though.
457 Ethan: No, no.
458 Jane: I'm not on that.
459 **Interviewer: So some people use Instagram and some people don't. Does**
460 **everyone use Snapchat?**
461 Tracey: Yeah.
462 Ethan: No.
463 Jane: Yeah.
464 Sarah: I deleted it.
465 **Interviewer: It just seems to be getting really popular at the moment.**
466 Ethan: I don't have time.
467 **Interviewer: So it's mainly through Facebook.**

468 **Interviewer: In your opinion what do you think might or could make the page**
469 **better?**
470 Ethan: I don't know.
471 Tracey: Maybe more people.
472 Sarah: Yeah.
473 Ethan: Yeah.
474 Tracey: A bit more younger people.
475 Sarah: Younger?
476 Tracey: I mean more like patients rather than...
477 Sarah: Oh, I thought you meant like ten year olds.
478 Ethan, Jane, Sarah and Tracey: (laughs).
479 **Interviewer: What do you think would be the ideal size group?**
480 Jane: Ten.
481 Ethan: Ten or eleven, yeah ten.
482 Sarah: Yeah, ten.
483 **Interviewer: Your group size was six. We didn't actually pick six. Initially we**
484 **had set about ten or something and a couple dropped out and then I don't know**
485 **who it was that dropped out before we started but we ended up with six. We**
486 **were wondering is the ideal group size bigger or smaller? With more people in it**
487 **there's more interaction, there's more happening. But the problem is with more**
488 **people it becomes less personal. You know, if you're on that Teens with diabetes,**

489 **if there's a thousand odd people on it, it's less personal, you know. So that's why**
490 **we're saying like, what do people feel is like an optimal number or good**
491 **number?**
492 Sarah: Ten would probably be about perfect for that.
493 Ethan: Yeah.
494 Sarah: Because we'd be still kind of... It'd be kind of personal and all and it's not
495 too much.
496 **Interviewer: Okay. Who should be in the group? So as well as, in terms of**
497 **yourselves, who should be in in terms of the team, you know, what members of**
498 **the team?**
499 Ethan: Pretty much what's already there.
500 Ethan, Jane, Sarah and Tracey: (laughs).
501 Ethan: Pretty much it's already there.
502 Jane: Yeah.
503 Tracey: Yeah.
504 **Interviewer: For instance, do you think the consultants should not be on it, the**
505 **doctors, are they a bit intimidating on it or should there be more of them on it?**
506 Sarah: They don't really comment on anything, they just look. You see it's seen
507 by...
508 Ethan: And then when they do comment it's just...
509 Sarah: Yeah.
510 Ethan, Jane, Sarah and Tracey: (laughs).
511 **Interviewer: So there's no one else you think that isn't on it that should be or**
512 **someone that is but shouldn't?**
513 Sarah: Some nurses that are here that aren't on it, isn't there?
514 **Interviewer: Well, you see the only ones that are on the team are myself, (names**
515 **of DHCT members). (Name of DHCT member) was on it but she's gone on**
516 **maternity leave because you know (name of DHCT member) had twins. So she's**
517 **gone and you get nearly two years maternity leave with twins because you take**
518 **one child's maternity leave and then the next twin's maternity leave starts. So**
519 **she she's not on it. And the dietitians have changed because... Remember there**
520 **was (name of DHCT member)? She was here for a couple of months in between.**
521 **(Name of DHCT member) was very active on it because (name of DHCT**
522 **member) really enjoyed Facebook.**
523 **Interviewer: What are the types of things that should be posted to the page? So**
524 **what sort of things should we be posting to the page?**
525 Ethan: Just diabetes related stuff,
526 Sarah: At the start you were more kind of active like. You kind of posted things
527 about diet and insulin and all and after that you just stopped. Stopped doing it.
528 **Interviewer: Yeah.**
529 Tracey: I think the goals thing was good.
530 Sarah: Yeah, it was.
531 Jane: Yeah.
532 Tracey: Because at the start, like, one of the things was like have a goal for every
533 week then like if you got, if you hit the target or whatever, it felt really good.
534 **Interviewer: Okay. So they were good. I know when we first started we started**
535 **conversations about different, you know... Blood sugars and hypoglycaemia**
536 **and... Different exercises and those sort of things.**
537 Jane: You know what was good. We had like random conversations. Like you were
538 posting random facts or stuff. I thought it was good.

539 Ethan, Jane, Sarah and Tracey: Yeah.
540 **Interviewer: Yeah, okay. So those sorts of things. Anything else?**
541 Ethan: Not that I can think of.
542 **Interviewer: Anything that we posted that you wouldn't bother posting, you'd**
543 **say, "No, I'd give that a skip from now on?"**
544 Jane: I really liked the different equipment.
545 Ethan: Yeah, that's cool.
546 Jane: I though that was really good.
547 **Interviewer: The equipment like new inventions and stuff?**
548 Ethan, Jane, Sarah and Tracey: Yeah.
549 Jane: Like you wouldn't have heard of otherwise.
550 **Interviewer: Okay, so links to those kind of new inventions and things that are**
551 **coming down the line.**
552 **Interviewer: How often should we be posting to the page. Because if you notice,**
553 **when we started off we posted a lot more frequently and now it's not as**
554 **frequently. Should we be posting a couple of times a day, every week, you know**
555 **because we're always conscious of the fact that we don't want that every time**
556 **you pick up your phone you like, "Agh, another ten alerts from the diabetes**
557 **team".**
558 Ethan, Jane, Sarah and Tracey: (laughs).
559 **Interviewer: How often should we post?**
560 Ethan: Every second or third day. Like, not every day.
561 Tracey: Maybe like twice a week or...
562 Sarah: Not a few time a day but like...
563 Ethan, Jane, Sarah and Tracey: (laughs).
564 Sarah: But like more because like, it's like hardly ever kind of these days. The only
565 posted things by people from the team is by you.
566 Tracey: Yeah.
567 Sarah: Things like about equipment, none of the nurses or anything post anything.
568 Tracey: Yeah, the nurses just kind of comment on stuff.
569 **Interviewer: Yeah, the nurses tend to get involved now when you ask them**
570 **something or if they're needed. They don't tend to spontaneously do it.**

571 **Interviewer: Is there anything else that we haven't discussed that you think is**
572 **important?**
573 Ethan: No.
574 Sarah: I don't think so.
575 **Interviewer: No?**
576 Ethan, Jane, Sarah and Tracey: No
577 **Interviewer: Okay, I'm going to stop the reorder now so**