An Investigation of the Psychosocial Correlates to Optimal Health Management in Young People with Type 1 Diabetes

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Errata

Notice 1

Notice 2

Errata

Professor Margaret Grey
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Dear Professor Grey,

RE: EXAMINER'S REPORT ON DOCTORAL THESIS – KELLY MAREE BUTTIGIEG

Thank you for your examiner's report based on my DPsych thesis. Your time and effort in examining my thesis and preparing a timely report is very much appreciated. Please find below a response to your comments included in the examiner report.

Major – While the topic is interesting and of concern, it is not clear what is really new. The author suggests that these topics have not been studied in Australian children, but what would make them different from those in other developed countries.

Thank you for the opportunity to comment on this point. There are two aspects to your concern. The first relates to the topic, and the second to the Australian population demography. Regarding the topic of my research, there is very little research specifically investigating depression in young children with type 1 diabetes (T1D) globally, including Australia. There is substantially more research into the psychosocial wellbeing of adolescents with T1D, however the intention of my research was to determine whether these issues were apparent in young children, specifically in the years post diagnosis. The findings are of value and have provided novel findings in relation to family functioning, school days missed, coping and depressive systems.

I concede that the demographic characteristics of Australian children bear some similarities to children in other countries. However, Australian children also possess markedly different demographic characteristics to children in other developed countries, and the demographic profiles of other developed countries do not uniformly apply to the Australian population. For instance, Australian children and adolescents are comprised of a multicultural, heterogeneous population. Twenty per cent of the Australian population were born overseas; combined with their Australian-born children, 40% of the Australian population comprise first and second-generation migrants (Department of Immigration and Citizenship, 2012). Current statistical breakdowns of the ancestry of the Australian population suggest that approximately 75% possess Anglo-Celtic heritage, 20% are of other European heritage, 4.5% are of Asian heritage and 1% of Aboriginal Australian heritage (Department of Immigration and Citizenship, 2012). Such demographics differ from other developed countries which also possess a highly multicultural population. For example, the USA possesses a much

substantially higher proportion of the population with Hispanic and African heritage, compared to Australia.

Australia's demographics also differ somewhat from other developed countries in terms of the metropolitan versus rural/regional divide. In this study, data collection was conducted with participants in both types of geographical areas. In addition, the increasing prevalence of T1D in Australian children warrants further investigation as the reasons for this increase are not fully understood. The findings of the current study support the need for further research in this important group.

Major – There is a great deal of self-plagiarism across the 3 papers.

I am not entirely certain of the concerns raised in this respect. While it is generally understood that a certain amount of repetition is to be expected in a DPsych thesis by publication, the three papers included in my thesis each addressed a separate aspect of the research study. There was no repetition in the results reported in each paper. The methodology is repetitious because all three papers are derived from one large study. The DPsych thesis by publication met the content and formatting requirements of Monash University's Faculty of Medicine, Nursing and Health Sciences (Monash University Institute for Graduate Research, 2012).

Major – Some of the sources were not primary sources, especially those related to type 1 diabetes, treatment, and epidemiology.

Where references were not primary sources (and these were few), they related to T1D definitions, treatment and epidemiology. For these aspects, I deliberately used book chapters by esteemed authors in the field (e.g. La Greca & Mackey, 2009, p. 3; Bennett Johnson & Carlson, 2006, p. 3) because I judged these book chapters to be of higher quality and of greater relevance than brief descriptions in journal papers.

Major – More attention needs to be paid to the limitations of cross-sectional data and the small sample.

As the study attempted to determine the psychosocial wellbeing of children and adolescents with T1D, a cross-sectional research design was deemed to be the most appropriate study design. Of course a prospective, longitudinal study is the preferred methodology, however this was not possible in the timeframe of my degree. Indeed, a discussion of the sampling and methodological limitations of my cross-sectional study design comprised the bulk of my discussion in the study limitations section. For instance, the limitations of the small sample were discussed in general in the Discussion (p. 195-197). They were also discussed specifically in relation to Paper 1 (p. 113-114) and Paper 2 (p. 146) within these papers.

Moderate – The age range was wide for such a small sample, and puberty was not included in the analyses. Since pubertal state affects A1c, this should have been considered.

The current research study originally intended to focus on child recruitment, prior to the encountered difficulties in recruiting a sufficiently sized sample of young children.

For this reason, I did not include a measure of pubertal status from the outset, and I am unfortunately unable to retrospectively measure this variable. However, the hormonal effects of pubertal status on HbA1c levels were noted in the Method chapter (p. 73), and contributed to the rationale for the inclusion of a supplementary measure of T1D functioning (p. 73).

Moderate – Diabetes management is not the same as A1c. A1c is the outcome of management. In the future, a measure of diabetes self-care would be more consistent with the name.

This concern is somewhat confusing. HbA1c levels have been consistently and widely used as an objective proxy measure of T1D management (Craig et al., 2011) in research with this population for the past two decades, as well as in clinical settings (IDF/ISPAD, 2011). Perhaps this issue is my definition of diabetes management. To clarify, I used HbA1c as an objective proxy for T1D management (specifically over the preceding 3 months), consistent with its use in the literature.

Thank you for the opportunity to address your comments. I hope I have sufficiently addressed each of these in my responses.

Yours sincerely,

Kelly Maree Buttigieg

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Abstract

Type 1 diabetes (T1D) presents considerable challenges to affected children and their families. Medical complications arising from poorly managed T1D may be present from a young age, and worsen over time. It is imperative that illness management is as optimal as possible from a young age, in order to establish a pattern of positive health management lasting into adulthood. Studies of adults and adolescents also demonstrate psychological complications associated with T1D, with implications for medical outcomes. However, these relationships remain relatively underexplored in Australian children. Investigating psychological wellbeing in children engaged with current treatment options is also needed, as the greater flexibility offered by contemporary treatment regimens may be less psychologically demanding. The aim of the current study was to investigate the role of specific psychosocial factors as barriers to optimal illness management in children and adolescents with T1D. As psychosocial wellbeing has previously been reliably linked to illness management in studies of adults and adolescents with T1D, psychosocial outcomes were also of interest. Eighty child and adolescent participants were recruited from a paediatric outpatient diabetes clinic at an Australian hospital. Participants were aged between 7 and 15 years, and held a diagnosis of T1D for at least twelve months. Participants completed written measures which assessed depressive and anxiety symptoms, family functioning, self-efficacy, coping and T1D knowledge. In order to assess illness functioning, T1D outcomes were determined by HbA1c level, and the number of school days missed. Discriminant function analysis was used to explore differences between groups of children and adolescents on several outcomes. Significant differences between groups on the basis of depressive symptoms, coping, family functioning and school days missed were identified. Glycaemic control was not significantly associated with psychosocial wellbeing. The results are discussed individually with a view to identifying markers of problems in psychosocial and illness functioning in Australian children and adolescents with T1D. The findings highlight the importance of specific individual and family factors in the psychosocial wellbeing and illness functioning in this group. This information may assist in the refinement of existing clinical interventions which aim to improve psychosocial and illness outcomes in young people with T1D.

PART A: General Declaration

Monash University
Monash Research Graduate School

Declaration for thesis based or partially based on conjointly published or unpublished work

General Declaration

In accordance with Monash University Doctorate Regulation 17/ Doctor of Philosophy and Master of Philosophy (MPhil) regulations the following declarations are made:

I hereby declare that this thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

This thesis includes 0 original papers published in peer reviewed journals and 3 unpublished publications. The core theme of the thesis is psychosocial wellbeing in children and adolescents with type 1 diabetes. The ideas, development and writing up of all the papers in the thesis were the principal responsibility of myself, the candidate, working within the School of Psychology and Psychiatry under the supervision of Dr Margaret Hay.

The inclusion of co-authors reflects the fact that the work came from active collaboration between researchers and acknowledges input into team-based research.

In the case of Chapters 4, 5 and 6 my contribution to the work involved the following:

Thesis chapter	Publication title	Publication status*	Nature and extent of candidate's contribution
4	Predictors of coping and family functioning in Australian children and adolescents with type 1 diabetes	Submitted	*Nature of contribution* Participant recruitment, data collection and statistical analysis; conceptualisation and writing of manuscript *Extent of contribution* Co-author (70%)

5	Psychosocial predictors of depressive symptoms in Australian children and adolescents with type 1 diabetes	Submitted	*Nature of contribution* Participant recruitment, data collection and statistical analysis; conceptualisation and writing of manuscript *Extent of contribution* Co-author (70%)
6	School absenteeism and psychosocial wellbeing in Australian youth with type 1 diabetes	Submitted	*Nature of contribution* Participant recruitment, data collection and statistical analysis; conceptualisation and writing of manuscript *Extent of contribution* Co-author (70%)

I have / ~~have not~~ (circle that which applies) renumbered sections of submitted or published papers in order to generate a consistent presentation within the thesis.

Signed: **……**

Date: **……**

Acknowledgments

Firstly, I would like to acknowledge Associate Professor Christine Rodda, Dr Philip Bergman and the medical, allied health and administrative staff at the Diabetes Ambulatory Care Service (DACS) for their support of this research study.

I would also like to express my gratitude to every family from DACS who gave me their time and goodwill by participating in this research. Their genuine interest, hospitality and hand-drawn picture 'presents' were much appreciated. I hope that this thesis may act as a lasting document of the issues encountered by children and adolescents living with type 1 diabetes.

I would like to thank the fellow postgraduate students and staff that I have had the good fortune to meet over the years through my research group affiliations and clinical training. The company of Sophie Aitken, Laura Ash, Emily Berger, Daniella Buordulone, Kelly Chipperfield, Steven de Lisle, Ella Dilkes-Frayne, Ariane Dowd, Belinda Gargaro, Ming-Yun Hsieh, Loretta Garvey, Rafaela Karas, Melissa Mulraney, Joshua Newton, Alicia Tanner, Rebecca Tavares and Ruth Tatnell along the way enriched my experience as a doctoral candidate at Monash University.

I am indebted to Dr Margaret Hay for her truly exceptional support as my doctoral supervisor. Dr Hay has acted as a highly knowledgeable and experienced supervisor, and has undertaken this task with the utmost enthusiasm and a genuine desire for her students to succeed. She brings her interests, questions and passions to her research with the broader community and society always in mind, and encourages her research students to carry these same qualities into our own work.

Her continued encouragement, motivation and ability to ‘see the light’ (of the good kind!) during difficult periods of my candidature will always be greatly appreciated. She has been a true mentor, and a role model for me to aspire to as I take my first steps in the clinical health psychology and behavioural medicine professions.

The words of the Beatles song ‘With a Little Help from My Friends’ have come to mind time and time over during my candidature. I thank my dear friends: Margie Blanch (and Andy Long), Linda Blatt, Kelly Bokowski, Kimberlea Cooper, Felicity Dennis, Ennur Erbasi, Sophie Garland, Ellie Glossop, Rafaela Karas, Catherine Messig, Jodi Salinger, Kate Scalzo and Ursula Smith for their optimism and unwavering understanding over countless cups of Green Refectory coffee - and glasses of wine when coffee would not do! I am looking forward to completing my thesis ‘hermitage’ and thanking each and every one of you in person over the coming months.

Finally, I would like to thank my family from the bottom of my heart: my mother Calca, father Tony, brothers Ronnie and Andrew, darling nephew Nicholas, ‘Zija’ Carmen and ‘Ziju’ Wolfgang, and cousins Steve and Irene. I am especially grateful to my mother and father, who have made many sacrifices, not least migrating from their home country, so that their children could have opportunities in life even they did not foresee. Their unconditional love and the belief they have continually shown in me have been truly humbling. To my dear family, thank you for instilling in me an awareness of the world, and an interest in the lives of those we share it with through your values, daily actions towards others, life stories and stimulating conversations (even the ‘debates’). You have all guided me to where I stand now. I love you all very much, and am so proud to be your daughter, sister, aunt, niece and cousin. *Grazzi ħafna*!

Chapter 1: Overview of Medical and Developmental Factors Relevant to Children and Adolescents with Type 1 Diabetes

Type 1 diabetes[1] (T1D) is one of the most common chronic illnesses experienced among children and adolescents (International Diabetes Federation/International Society for Pediatric and Adolescent Diabetes [IDF/ISPAD], 2011). In Australia, the incidence is the seventh highest worldwide, and the prevalence is the sixth highest globally (Australian Institute of Health and Welfare [AIHW], 2012). These facts suggest that T1D is a chronic illness of particular concern to health professionals and researchers involved in the care of Australian children and adolescents.

T1D is a chronic illness of particular interest for two reasons. First, diagnosis is often in childhood or late adolescence, meaning that living with the illness is a lifelong process. Second, the medical consequences of poorly managed T1D can be life-shortening. It is therefore imperative that management is as optimal as possible from a young age, in order to establish a pattern of positive health management throughout life.

The role of psychologists in multidisciplinary health care teams which aim to improve T1D management is also increasingly recognised. Several prominent reviews of past studies have concluded that reliable associations exist between T1D management and psychosocial functioning in adults (Anderson, Freedland, Clouse, & Lustman, 2001) and adolescents (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009). Surprisingly, little research has been conducted on young children with T1D, despite the established high incidence of the condition in children. This relationship between T1D management and wellbeing suggests that children with this

[1] The term 'type 1 diabetes' has been used in place of 'juvenile diabetes' and 'insulin dependent diabetes mellitus'. This term reflects the most recent conventions within the literature.

condition may also experience psychological complications related to their T1D. However, this area remains relatively under-explored in children. The direction of the relationship between optimal T1D management and physical and psychological wellbeing is circular in nature. Impaired wellbeing can impact negatively on T1D management tasks; conversely, poorly managed T1D may impact on wellbeing. Children with T1D require significant levels of family support (Field & Duchoslav, 2009). Therefore, T1D is a disease that impacts on the entire family (Solowiecjzyk, 2004). Families may experience stress in response to a child's T1D illness and related management tasks, and family conflict may also lead to increased stress around T1D management (La Greca & Mackey, 2009). The direction of cause and effect between other aspects of wellbeing such as coping (Graue, Wentzel-Larsen, Bru, Hanestad, & Sovik, 2004) and glycaemic control has also not been established. It is therefore unknown whether young people adopt a particular coping style in response to poorly controlled T1D, or whether their established coping styles influence glycaemic control.

A recent meta-analysis of the limited studies investigating depression and anxiety in children with T1D concluded that further research should identify those children with T1D who are vulnerable to psychosocial problems (Reynolds & Helgeson, 2011). There is consequently a need for the predictors of psychosocial wellbeing to be further investigated in children to optimise T1D management and psychosocial functioning, as well as to prevent medical complications that may precipitate psychological problems.

Recent advances in T1D management, such as increased use of the insulin pump, have also offered greater flexibility to children and adolescents living with T1D. These treatment advances have had positive consequences in reducing medical complications in Australian children (O'Connell, Cooper, Bulsara, Davis, & Jones, 2011). By better understanding the role of

specific psychosocial factors such as depression, anxiety, coping, self-efficacy, T1D knowledge and family functioning on management of T1D in children, it may be possible to improve T1D management and consequently the wellbeing of affected children.

The management of T1D in children in adolescents occurs in the context of medical and developmental factors. In the next section, medical aspects of T1D are firstly introduced, and the goal of optimal T1D management is considered in relation to child and adolescent development.

1.1. Setting the Context: Medical and Developmental Factors Relevant to Type 1 Diabetes in Children and Adolescents

1.1.1. Medical aspects of type 1 diabetes in children and adolescents.

1.1.1.1. Diabetes mellitus. Diabetes mellitus refers to a set of varied medical conditions which have in common the presence of high blood sugar levels in affected individuals (Bennett Johnson & Carlson, 2006). In T1D, the body's production of insulin is low or absent, and exogenous insulin administration is required. In contrast, type 2 diabetes (T2D) is defined by insulin resistance or a lack of adequate insulin (Bennett Johnson & Carlson, 2006). The focus of this thesis is the medical aspects relevant to children and adolescents with T1D.

1.1.1.2. Definition of type 1 diabetes. T1D is an autoimmune disease in which the pancreatic beta cells that provide insulin are destroyed (La Greca & Mackey, 2009). As such, insulin production is low or non-existent in affected individuals (Bennett Johnson & Carlson, 2006; La Greca & Mackey, 2009). The consequent lack of insulin significantly impairs the body's ability to control blood glucose levels. In the early stage after diagnosis, brief recovery of insulin production, known as the honeymoon period, may occur. This usually occurs in the first

six to 24 months. Individuals with T1D have blood glucose levels that are above normal, and when not well managed are generally very high. While the 'normal' blood glucose level range is generally considered to be 4.4-6.6 mmol, in T1D blood sugar levels can reach well above 11.1 mmol/L (Bennett Johnson & Carlson, 2006), and sometimes can be greater than 20mmol/L.

While T1D may develop at any age, onset is most common by 14 years of age (La Greca & Mackey, 2009), and the highest incidence occurs during the adolescent years (Bennett Johnson & Carlson, 2006). However, T1D can be diagnosed in individuals of any age.

Complications can occur in the short, medium and long term and involve fluctuations in blood sugar levels, and the physiological effects of these fluctuations. Hypoglycaemia, defined as a very low blood glucose level (less than 3.3 mmol/L), is a frequent complication in children and adolescents with T1D (Ambler, Fairchild, Craig, & Cameron, 2006; Bennett Johnson & Carlson, 2006). Although hypoglycaemia may present with no obvious symptoms, especially during the night, severe hypoglycaemia can result in unconsciousness, seizures, coma and even death. Recent Australian data has identified a decrease in rates of severe hypoglycaemia in Australian youth (O'Connell, et al., 2011), however it continues to present in children and adolescents who experience problems maintaining optimal glycaemic control.

In contrast, hyperglycaemia is characterised by a high blood glucose level (greater than 8.9 mmol/L), and occurs when there is insufficient insulin available to maintain optimal blood glucose levels. This complication can result from overeating, the delay or absence of insulin administration, or illness (Bennett Johnson & Carlson, 2006).

Diabetic ketoacidosis (DKA) is a serious complication of T1D and occurs when triglycerides are broken down by the body to provide energy in response to nonexistent insulin production (Haller, Atkinson, & Schatz, 2005). During this process, ketones are produced as by-

products, and affected people often display dehydration, vomiting and disturbances to mental state. DKA, and the related complication of cerebral oedema, is the most common cause of T1D-related mortality in children and adolescents in Australia (Craig, et al., 2011) and in other countries (IDF/ISPAD, 2011).

Medical T1D-related complications are characterised as microvascular or macrovascular in nature. Common microvascular complications may be evident in the short-term and include retinopathy, nephropathy or neuropathy (Craig, et al., 2011). Macrovascular complications may present over the long-term and include cardiovascular disease and cerebrovascular disease (Craig, et al., 2011). While microvascular and macrovascular complications appear to present more commonly in adulthood, early signs of microvascular complications are commonly identified in Australian children and adolescents. In a study of Australian children under 15 years of age who had a T1D diagnosis for six years, 24% had early retinopathy and 18% had an elevated albumin excretion rate (AER) (Donaghue, et al., 2005). This finding indicates the importance of optimal T1D management from diagnosis.

With effective management and metabolic control, most individuals with T1D lead normal lives (La Greca & Mackey, 2009). However, the risk of acute complications may have an additional impact on lifestyle through driving restrictions (including the possible loss of driver's license) and limitations for some career opportunities. Studies exploring complications across the lifespan in those with T1D attest to the important of promoting optimal T1D management in childhood and adolescents (Diabetes Control and Complications Research Group, 1994). Optimal T1D management from the time of diagnosis in childhood or adolescence is an important goal, as the management skills learned from this time will be used over a lifetime. Optimal management can also delay the development of microvascular and

macrovascular complications from a younger age. It is therefore crucial to address suboptimal illness management early, before medical complications worsen as children move into adolescence and adulthood.

1.1.1.3. Epidemiology of type 1 diabetes. Australian children and adolescents have one of the highest rates of T1D worldwide (Ambler, et al., 2006). The most recent Australian data confirms that the local incidence rate in 0-14 year olds is 21.6 per 100,000 in children and adolescents aged up to 14 years (Catanzariti, et al., 2009). Incidence rates are increasing globally, and Australian rates are a part of this trend (Ambler, et al., 2006). Victorian data from 1999-2002 has indicated that the rise in incidence in children appears to be greater than that described by other Australian states (Chong, et al., 2007). This increase is in accordance with international trends in other developed countries (IDF/ISPAD, 2011). It is therefore not surprising that T1D is one of the most common chronic diseases in children (Bennett Johnson & Carlson, 2006).

1.1.1.4. Management of type 1 diabetes. The management of T1D is a lifelong, complex regimen that encompasses tasks in several domains. Management usually comprises exogenous insulin administration, blood glucose monitoring, and appropriate diet and exercise. Insulin administration was commonly achieved using injections, administered using a needle or an insulin pen. Recently, use of continuous subcutaneous insulin infusion (CSII) pump, also known as an insulin pump, has increased. This device releases low-dose insulin in regular administrations throughout the day using plastic tubing known as an ‘infusion line’, with additional units of insulin administered when food is eaten (La Greca & Mackey, 2009). In this

way, the use of the insulin pump can offer greater flexibility to the insulin regimen compared to hypodermic needle and pen injection forms of administration. The insulin pump offers an alternative to multiple daily injections (MDI) for intensive therapy (Craig, et al., 2011) in a discreet form which may be preferable to the hypodermic needle and pen injection devices.

Children managing T1D are also required to monitor their blood glucose levels. This is usually measured multiple times daily, most commonly between four and eight times. This measurement can vary significantly across the day, and at the same time on different days. Measurements are obtained by pricking the skin (usually the fingertips), then placing a drop of blood into a handheld blood glucose meter which then provides an accurate reading of the blood glucose level, usually within seconds.

Diet also ensures blood sugar levels remain stable over the day. Generally, a low-fat, high-carbohydrate diet is encouraged. However, variations on this are possible, depending on the person's lifestyle. For example, one method involves balancing amounts and types of foods, while others may carbohydrate count (La Greca & Mackey, 2009). Specific guidelines have recommended that calories should be obtained from 50-55% from carbohydrates, 15-20% from protein, and 30% from fat (Haller, et al., 2005). Exercise also forms an integral part of T1D management, particularly with recent concerns that obesity may also be affecting children and adolescents with T1D. In terms of time, 30-60 minutes of exercise at least five times per week is recommended (Haller, et al., 2005).

The maintenance of optimal glycaemic control has been typically defined using a measure of glycated haemoglobin (HbA1c, or A1c), a form of haemoglobin that provides an average blood glucose level over the previous three months. This measurement is usually obtained during paediatric clinic reviews for T1D on a quarterly basis. Establishing consistent,

optimal glycaemic control in children and adolescents is a difficult and ongoing process for children, families and clinicians. Current clinical guidelines define optimal levels of HbA1c as less than 7.5% (IDF/ISPAD, 2011). HbA1c levels in the 7.5% to 9% range are considered suboptimal, with insulin stabilisation recommended to address this. HbA1c levels above 9% are categorised as high risk, with insulin stabilisation required. Importantly, the numeric expression of HbA1c is currently in transition in clinical and research settings, from a percentage unit to mmol/L (SI). This revision is in accordance with recent conversion guidelines produced by the International Federation of Clinical Chemistry (IFCC) (IDF/ISPAD, 2011) and adopted worldwide, including by Australian clinicians (Jones, et al., 2011).

1.1.2. Type 1 diabetes and the developmental context. The developmental context of the child or adolescent must be taken into account when assessing the influence and appropriate role of family members and health professionals on adaptation to and living with T1D. The age of the child or adolescent plays an important role in determining appropriate expectations regarding T1D management tasks, and the levels and types of illness knowledge held by the child. This is especially important in the case of T1D, where diagnosis is often made in childhood, a time where family involvement is also critical in optimal medical management. Furthermore, T1D is an insidious condition as affected children appear healthy externally, yet have a serious medical condition. Young peers may not understand this, nor indeed those with the illness.

1.1.2.1. Child and adolescent development and type 1 diabetes management. Diagnosis with a chronic illness such as T1D can be characterised as a developmental "disruption" that can

make the process of developing one's sense of self more difficult (Schur, Gamsu, & Barley, 1999, p. 227). However, this is not always the case (Warner & Hauser, 2009). The impact of a T1D diagnosis, and living with the condition, can be understood in terms of child and adolescent development.

From a developmental perspective, the psychological experience of living with a chronic illness involves two broad categories of developmental changes (Warner & Hauser, 2009). Internal processes include consideration of identity development, changing self and body image, and the onset of and continued changes as a result of puberty in adolescents. Psychosocial processes involve those outside the individual, and include such changes in peer and family relationships, as well as the beginning of romantic and sexual relationships in adolescents.

An understanding of developmental processes is necessary to contextualise developmentally appropriate goals, which may run counter to the specific tasks required to maintain optimal illness management. The developmental transition from childhood to adolescence is characterised by conflicting desires for increased autonomy whilst feeling supported, as well as the desire to differentiate from peers, but also simultaneously 'fit in' with social norms (Warner & Hauser, 2009). Such goals in emerging adolescence include the desire to develop one's sense of identity and to develop greater independence from family members, while also gaining acceptance from peers. In addition, the ability of children and adolescents to incorporate abstracted knowledge related to their illness increases as the child moves into adolescence (Halvorson, Yasuda, Carpenter, & Kaiserman, 2005; Warner & Hauser, 2009). Such developmental considerations provide a context for understanding adaptive individual skills and knowledge held by the child or adolescent, as well as the type and degree of support received by families in diabetes-related management tasks. From a developmental perspective, the

experience of living with T1D not only involves the individual child or adolescent, but also family members, friends and their health care team. Research needs to incorporate these varying 'contexts' (Field & Duchoslav, 2009).

Halvorson et al. (2005) considered differences in specific T1D management tasks according to childhood or adolescent age, defining 13 years of age as the beginning of adolescence. These tasks are reported in Table 1.

TABLE 1

Table 1 from Halverson et al. (2005) highlights several key differences in T1D tasks between children and adolescents. Children's T1D management requires the daily support of parents in adhering to insulin, diet and exercise regimens. While the young adolescent is usually able to manage most daily aspects of their insulin management, periodical support from parents is still typically required. In children, the involvement of family is crucial, and is evident across the insulin management, diet and exercise domains. It is expected that responsibility, knowledge and skills regarding specific tasks are transferred to children over time.

The developmental transition from childhood to adolescence is marked by significant physical and psychological changes that may conflict with the intensive and ongoing demands of T1D management (Edgar & Skinner, 2003; Halvorson, et al., 2005), and decreased glycaemic control is a key clinical issue as children enter adolescence (Edgar & Skinner, 2003). As children enter adolescence, the developmental desire for autonomy and identity is balanced alongside the tasks required to maintain optimal glycaemic control (La Greca & Mackey, 2009). The desire for acceptance by peers is emphasised, particularly in the school environment where insulin administration may take place in the classroom in front of friends. The attainment of developmental goals may conflict with the desire to maintain optimal T1D management. For example, the desire for independence in children entering adolescence may lead to reluctance to maintain the involvement of parents in management tasks, such as assisting with insulin administration at home. This shift in responsibility from the family to the emerging adolescent is considered to be the biggest developmental transition children and adolescents with T1D experience (La Greca & Mackey, 2009).

Other typical adolescent responses that are particularly relevant to chronic illness management include the rejection of medical professionals as part of the wider individuation

process; difficulty in imagining the future; and the perception of oneself as invincible (Suris, Michaud, & Viner, 2004). While developmentally appropriate, such responses clearly have the potential to interfere with their T1D management (Suris, et al., 2004). For adolescents in particular, attempts to fit in with peers and simultaneously accommodate insulin management practices in new settings such as school, sports, and non-supervised time are important themes. Indeed, non-adherence to T1D management tasks should be expected in adolescence, given the developmental processes described (La Greca & Mackey, 2009). Therefore, the achievement of adolescent developmental milestones may involve processes that are incongruent with T1D task adherence and management. For example, limited development of cognitive skills in planning and abstract reasoning, prior to achievement of the cognitive capacity for abstract reasoning, may impede the ability of adolescents to adhere to the intensive self-treatment regimen required (Halvorson, et al., 2005). For this reason, the role of the family in supporting the young person's management is particularly crucial.

According to La Greca and Mackey (2009), the key challenges for adolescents are to keep families involved and communicating appropriately about T1D management. These challenges should be addressed while supporting the adolescent in attaining increased responsibility without compromising their medical outcomes, and the mastery of developmental goals such as the development of friendships and the young person's broader attempts to achieve a sense of autonomy and identity.

Overall, the differences between child and adolescent T1D management demonstrate a gradual transition from assisted to independent management. Family members and health professionals support independence in T1D management over time, whilst also being present to assist if required. This support allows the child or adolescent to gain increasing independence

and autonomy with T1D tasks in a supportive context (Warner & Hauser, 2009). The interplay between developmental processes and specific T1D management tasks is of importance both at the time of diagnosis adjustment, and in the maintenance phase of T1D (Warner & Hauser, 2009). While conflicts between developmental stages and T1D management tasks are possible, the developmental processes experienced by children and adolescents may conversely influence positive illness management outcomes. For example, in adolescence, an increased self-awareness and ability to better see parental perspectives may improve some aspects of T1D management (Warner & Hauser, 2009).

1.1.3. Summary. Living with T1D requires children and adolescents to adapt to an initially unfamiliar and complex regimen of tasks involving insulin administration, blood glucose monitoring and adaptation of diet and exercise regimens. The maintenance of optimal glycaemic control is a critical goal from the time of diagnosis, and if not maintained can result in medical complications that may significantly impact on their health over the short, medium and long term.

Expectations regarding the ability and responsibility of children to complete T1D-related daily management tasks require a consideration of developmental maturity. The developmental goals of children and adolescents discussed in this chapter also highlight key differences between the two groups across family and school settings. The role of family members and health professionals is crucial in supporting the child to accept increased responsibility for their T1D-related management tasks as they enter adolescence and further develop cognitive and emotional maturity. The attainment of developmental goals such as peer acceptance and increasing autonomy may conflict with illness management tasks; however, such conflicts appear to

generally resolve over time. Managing T1D and optimal wellbeing therefore presents considerable challenges for children and adolescents diagnosed with the condition.

1.2. Overview of the Subsequent Chapters

An introduction to the medical and developmental aspects relevant to the experience of children living with T1D is provided in **Chapter Two**. This chapter then reviews the cognitive, mood, behavioural, social and illness functioning factors important to optimal care of children with T1D and contains the study aims and hypotheses. In **Chapter Three**, a comprehensive outline of the research design and methodology of this study is provided. **Chapter Four** presents the research findings for glycaemic control, and a manuscript reporting on the role of coping styles and family functioning on T1D management (Paper 1). **Chapter Five** presents a manuscript reporting on the psychosocial correlates of depression (Paper 2). **Chapter Six** presents a manuscript which reports on predictors of school attendance, and associations between multiple aspects of psychosocial wellbeing (Paper 3). In **Chapter Seven,** an integrated discussion of the results is provided. The implications of the findings on illness management and psychosocial wellbeing in children and adolescents are presented, and the limitations of the study and directions for future research are discussed.

Chapter 2: Psychosocial Factors and Wellbeing in Children and Adolescents with Type 1 Diabetes

Living with a chronic illness involves a degree of psychological adjustment in any young person. From a psychological perspective, T1D is a chronic medical condition of special interest because it is often diagnosed in childhood, and children with T1D, and their families, are required to accept that managing the illness is an ongoing, life-long process. In this chapter the initial child adjustment to a T1D diagnosis will be considered, followed by a discussion of psychosocial factors relevant to children and adolescents with T1D.

2.1. Initial Child Adjustment to Type 1 Diabetes Diagnosis

The initial adjustment to a T1D diagnosis is a significant and stressful event for newly diagnosed children and their families (Grey, Whittemore, & Tamborlane, 2002). In a study of one to 14 year old Australian children investigating psychosocial adjustment following recent T1D diagnosis, mild psychological distress was identified in participants after diagnosis (Northam, Anderson, Adler, Werther, & Warne, 1996). However, this level of psychological distress was clinically insignificant when measured one year later. A study of eight to 14 year old children in the United States also assessed psychological functioning after diagnosis, but followed children for 24 months (Grey, Cameron, Lipman, & Thurber, 1995). This important study also did not identify increased psychological distress after 12 months. However, at 24 months over double the prevalence of depressive symptoms was identified in the children with T1D compared to children without T1D. These findings appear to reflect an initial adjustment to the T1D diagnosis which also resolved within the first 12 months, followed by a second period

where psychosocial difficulties became more salient. It was assumed by the authors that the psychosocial impairments found were related to the difficulties in managing the condition. The second and third years following diagnosis may coincide with the end of the 'honeymoon period', when glycaemic control becomes more difficult. T1D management problems at this time may coincide with increased depressive symptoms in children, as the realisation that T1D will not go away, and the increased difficulty of managing the condition, occurs. The developmental maturity of the young person may also play a role, with older children and adolescents experiencing greater distress due to the more salient impact of the condition on their daily life.

Taken together, these findings suggest that any investigation of psychosocial factors in T1D should account for an initial adjustment reaction of at least 12 months from diagnosis. These research findings are now over a decade old. Changes in treatment, such as the broad uptake of the insulin pump for continuous and consistent insulin administration, may have positively impacted on the psychological wellbeing of children with T1D (Reynolds & Helgeson, 2011). There is, therefore, a need for further studies investigating the psychosocial wellbeing of newly diagnosed children. Previous findings continue to impact on contemporary clinical practice, with current recommendations for routine psychosocial screening to take place for all newly diagnosed children entering paediatric T1D clinics for their medical care (IDF/ISPAD, 2011).

The maintenance phase of T1D refers to the period following initial adjustment to the T1D diagnosis (Warner & Hauser, 2009). The psychosocial status of children in the maintenance phase of T1D has received less clinical attention. In Australian paediatric outpatient settings, psychosocial screening of these children and their families, while recommended (IDF/ISPAD, 2011), is not routine. It is assumed that any psychosocial concerns will be identified during

ongoing clinical appointments, using possible identifiers such as T1D management difficulties. The psychosocial functioning of children and adolescents with T1D comprises the focus of the remainder of this chapter, in order to investigate the current understanding of psychosocial functioning and optimal T1D management.

2.2. Internalising Risk Factors: Depression and Anxiety in Children and Adolescents with Type 1 Diabetes

An understanding of depression and anxiety in children and adolescents with T1D is critical in any attempt to improve psychosocial wellbeing and T1D management in children and adolescents. While the investigation of these factors in youth with T1D has progressed substantially in the last decade, specific and critical gaps remain in the research. In this section, depression and anxiety are defined and their relationships to T1D management and psychosocial wellbeing respectively are discussed.

2.2.1. Studies of depressive and anxiety symptoms in adults with type 1 diabetes.

Associations between T1D and psychosocial functioning were first identified in adults. In a comprehensive meta-analysis of 42 studies of adults with T1D or T2D, Anderson et al. (2001) found that adults with diabetes were twice as likely to have depression. No difference was found in this outcome based on the type of diabetes. This finding demonstrates a substantial psychological burden in adults with diabetes.

Depressive symptoms have also been implicated in suboptimal T1D management in adults. Higher levels of depressive symptoms were significantly related to poor glycaemic control in a study of 30 adults with T1D (Van Tilburg, et al., 2001). Interestingly, no such

relationship was found in a comparison group of adults with T2D. These findings suggest that the association between depression and T1D in adults may be related to illness management.

Anxiety symptoms also appear to be a significant problem for adults with T1D. A study of 161 Turkish adults with T1D or T2D aged between 20 and 60 years (mean age 49, *SD* = 9.74) found that 79% endorsed elevated anxiety symptoms (Tuncay, Musabak, Gok, & Kutlu, 2008). Anxiety was measured using the Spielberger State-Trait Anxiety Inventory (STAI), with the mean score for participants with T1D higher than those with T2D. This finding was thought to be related to the relatively greater demands and complexity of the T1D management regimen (Tuncay, et al., 2008), although a comprehensive review identified a higher anxiety prevalence in adults with T1D or T2D compared to community samples regardless of the type of diabetes (Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002). Anxiety has also been implicated in deleterious medical outcomes in adults. A recent study of 259 adults (aged between 16 and 60) with T1D in the United Kingdom assessed anxiety symptoms using the Hospital Anxiety and Depression Scale (HADS) (Shaban, Fosbury, Cavan, Kerr, & Skinner, 2009). Anxiety symptoms significantly predicted poor glycaemic control. These findings suggest that anxiety affects a significant number of adults with T1D, and is related to poor T1D management.

2.4.2. Studies of depressive symptoms in children and adolescents with type 1 diabetes. While the existence of depression in adolescents and adults is widely accepted in contemporary psychology, the existence of depression in children was a controversial notion until the 1990s (Milling, 2001). It is now widely understood that children do experience depression, however, depressive symptoms may present differently compared to adolescents and adults. The current Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) (2000)

notes in particular the reduced ability of children to verbalise their feelings, compared to adolescents and adults. As a result, depressive symptoms may present as physical complaints or irritability, alongside traditional symptoms such as low mood or anhedonia. The measurement of depressive symptoms in children and adolescents requires the use of age-appropriate instruments which reflect the presentation of depressive symptoms characteristic of this age group. For instance, the Children's Depression Inventory (CDI) is a self-report measure that can be administered to children as young as seven years (Kovacs, 1992). It contains items to assess physical symptoms characteristic of depression in children and adolescents that are not characteristic of adult symptomatology. A review of recent studies of depressive symptoms in children and adolescents with and without T1D follows, in order to determine the impact of depression on illness diagnosis and management.

2.4.3. Prevalence of depression in children and adolescents with type 1 diabetes.

Depression is the psychiatric morbidity most common in children and adolescents with T1D (Kovacs, Goldston, Obrosky, & Bonar, 1997). The findings of recent studies are in accordance with a recent meta-analysis of studies of depression in children with T1D by Reynolds and Helgeson (2011), which concluded that these children and adolescents are more likely to experience depressive symptoms in comparison to healthy children and adolescents. This finding was also consistent with an earlier review of the literature of children and adolescents with T1D, which concluded that the prevalence of depression in children with T1D is twice that of other children, and those adolescents with T1D are three times as likely to develop depression (Grey, et al., 2002). Overall, studies of depressive symptoms in youth with T1D suggest that the

psychological burden experienced by children with T1D appears to be greater than that of their healthy peers.

2.4.3.1. Prevalence of depression in Australian children and adolescents with type 1 diabetes. Limited recent information is available regarding the prevalence of depressive symptoms in Australian children with T1D. One of the few studies conducted with Australian youth focused on children and adolescents aged between 11 and 18 years of age (Northam, Matthews, Anderson, Cameron, & Werther, 2005). This study used the Diagnostic Interview for Children – Version IV (DICA-IV) to assess 41 youth attending a Melbourne T1D outpatient clinic, and identified seven (17%) with a depressive disorder. While this data was collected in the 1990s, they represent the most recent depression data available for Australian youth with T1D. A key strength of this research study, the findings of which are reviewed later in this chapter (Sections 2.4.4. and 2.4.5), was the ability to measure depressive disorder using a diagnostic measure.

Symptom-based measures of depressive symptoms have identified higher prevalence rates of depressive symptoms compared to diagnostic tools, regardless of health status (Kessler, Avenevoli, & Ries Merikangas, 2001). Symptom-based data from Australian youth is very limited, however young Australian adults do appear to have a relatively high prevalence of depressive symptoms. Ninety-two young adults aged 18 to 25 who received medical care at a metropolitan Young Adult Diabetes Services (YADS) were administered the Centre for Epidemiological Studies Depression Scale (CES-D) (Hislop, Fegan, Schlaeppi, Duck, & Yeap, 2008). The findings confirmed a high rate of depressive symptoms, with 35.2% found to have elevated depressive symptoms. Of concern is that 23.1% of the young adults endorsed depressive

symptoms of a severe degree. This finding is consistent with an earlier review, which found that the course of depression in children and adolescents with T1D is more severe in nature compared to healthy children and adolescents (Grey, et al., 2002).

The findings of these studies provide some evidence that Australian youth and young adults experience significant problems with depression. However, the youngest age included in these studies was 11 years, limiting the conclusions that can be drawn regarding the experience of young children.

2.4.3.2. Prevalence of depression in international studies of children and adolescents with type 1 diabetes. The majority of studies of depression prevalence have focused on adolescents, or combined children and adolescents. In a unique study conducted in Finland, symptoms of clinical depression were measured in 31 adolescents (aged 13 to 16 years) with T1D, as well as age-matched controls (Kokkonen, Taanila, & Kokkonen, 1997). This study found that 16% of the T1D group were diagnosed with depression using International Classification of Diseases (ICD-10) criteria compared to 5% of the healthy group. Key strengths of this study were the inclusion of age-matched controls and the use of a diagnostic tool to measure depression, however the relatively small sample size and publication date of the study limits the ability to extrapolate this finding to contemporary cohorts of children and adolescents with T1D.

One of the largest studies conducted of depression prevalence in youth with diabetes identified a high number of depressed adolescents. In a study of 2672 American youth (aged 10 to 21 years old) with T1D or T2D, the CES-D was completed by participants. Fourteen per cent of youth endorsed mildly elevated depressive symptoms, and a further 8.6% reported moderately

or severely depressed mood (Lawrence, et al., 2006). In the same year, a separate study also assessed American children and adolescents aged from 10 years (up to 18 years) with T1D. The study identified elevated depressive symptoms in one in seven, or 15.4% of the group (Hood, et al., 2006). This finding was obtained using the CDI.

In comparison, a prevalence of 18% depression was found in a US study of nearly 10,000 healthy school-age youth aged between 11 and 15 (Saluja, et al., 2004). As this finding was made using a brief 10-item measure, the rates of depressive symptoms reported may differ in sensitivity in comparison to more detailed measures, such as the CDI. Up to 25% of healthy adolescents will develop major depression by the end of adolescence (Kessler, et al., 2001).

Studies of depression prevalence in children and preadolescents are less common. In a recent study of 84 American children aged between 9 and 11 years with T1D, elevated depressive symptoms were identified in 15% of children using the CDI (Armstrong, Mackey, & Streisand, 2011). A separate study of 108 school-aged children aged between 8 and 12 years old assessed depressive symptoms as part of baseline measurement for a coping skills intervention. Elevated levels of depressive symptoms were endorsed by 12.3% of children, a prevalence rate also obtained using the CDI (Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2008). A key strength of these two studies is the exclusive recruitment of children who are under-represented in such studies. This is an important strength as prevalence rates differ between children and adolescents in community samples (Garber, 2006). The experience of depression in the general community is more common in adolescents than in children, and from the age of 13 years girls are also more likely than boys to experience depressive symptoms (Garber, 2006). These demographic differences in prevalence rates are also found in youth with T1D. Longitudinal research which tracked the depressive symptoms of 132 adolescents with T1D and 131 healthy

adolescents over a three year period found that girls were more likely to endorse depressive symptoms from approximately the age of 13 and 14 (Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007). Boys, in contrast, reported a decrease in depressive symptoms over time.

Some inconsistencies in the research literature are evident. A comparison of adolescents with and without T1D by Helgeson et al. (2007) found no differences in depressive symptoms. Other research studies of children and adolescents with T1D have compared findings with studies of healthy children to conclude that youth with T1D are no more likely to experience depression than their healthy peers (Lawrence, et al., 2006; Saluja, et al., 2004). For instance, an earlier study of 9863 healthy American adolescents identified an 18% prevalence of depression using a questionnaire (Saluja, et al., 2004), which is higher than that reported in studies of adolescents with T1D. Reviews of the research have reported contradictory findings. For example, a review by Dantzer et al. (2003) reported that the prevalence of depression in youth with T1D was similar to those without T1D, whereas Grey et. al. (2002) reported elevated depression. These findings highlight the importance of the type of depression inventory used and the consideration of demographic factors such as age and gender in research investigating the psychological status of children and adolescents with T1D.

2.4.4. Depressive symptoms and type 1 diabetes management in children and adolescents. Childhood depression in T1D is associated with worse metabolic control, with implications for microvascular and macrovascular complications in adulthood (Grey, et al., 2002). Depressive symptoms such as low mood and decreased motivation may have the added impact of impeding adherence to treatment regimens in those with T1D.

The majority of research studies exploring illness management and depressive symptoms have found that depressed children and adolescents are more likely to have impaired glycaemic control, in comparison to published data for non-depressed children and adolescents with T1D. A longitudinal study of 132 fifth to seventh graders with a mean age of 12 years (range = 10.73 to 14.21) were tracked in relation to several illness and psychological indicators over four years (Helgeson, Siminerio, Escobar, & Becker, 2009). Using an abbreviated form of the CDI, depressive symptoms predicted deterioration of glycaemic control over time. This finding is consistent with a second study of American children and adolescents aged between 10 and 18 years, which also used the CDI to measure depressive symptoms. Hood et al. (2006) found that participants who were depressed were more likely to have worse glycaemic control and less frequent blood glucose monitoring. These results reflect the reported findings for larger samples of youth with T1D, such as the large study of 2672 children and adolescents (aged 10 to 21 years) with T1D or T2D by Lawrence et al. (2006). Using the CES-D and the collation of medical information during a research home visit, depressive symptoms were significantly associated with higher HbA1c levels and a higher frequency of emergency department hospital visits. While the studies by Hood et al. and Lawrence et al. comprised American children and adolescents, they replicate findings obtained in youth in other developed countries, including Sweden (Lernmark, Persson, Fisher, & Rydelius, 1999). The findings of the associations between depression and impaired T1D-related health in youth with T1D have also been extended in research designs that have included a control group. A study of 53 adolescents and young adults (mean age = 15.7, *SD* = 2.2) with T1D compared depressive symptoms using the CES-D to 53 age, gender and/or race-matched controls (Tercyak, et al., 2005). The group with T1D

endorsed higher symptoms of depression using the CES-D, replicating the findings made in studies without a control group.

Depressive symptoms are also predictive of hospitalisation for T1D complications in adolescents. Using the CES-D, depressive symptoms were measured in 231 US adolescents aged between 11 and 18 years (M = 13.87, SD = 1.79) and hospitalisation for medical complications for two years afterwards were recorded (Stewart, Rao, Emslie, Klein, & White, 2005). Adolescents with elevated depressive symptoms demonstrated a higher risk of hospitalisation for T1D complications. Stewart et al. (2005) suggest that interventions to improve depressive symptoms may therefore improve medical outcomes, as well as psychosocial wellbeing.

Most studies assessing the relationship between illness management and depressive symptoms have been conducted in the United States, and the relationship between these factors in Australian youth, especially children, requires further investigation. Northam et al. (2005) assessed psychiatric status and glycaemic control ten years after T1D diagnosis in 41 children and adolescents aged 11 to 18 years. The authors did not identify significant relationships between glycaemic control and depressive disorders, but found that 50% of the poorer glycaemic control group received a psychiatric diagnosis, compared to 25% of the well controlled glycaemic group. While causality was unproven, it was suspected that poorly adjusted individuals were less likely to adhere to management regimens for T1D, reducing control over their condition. The findings, according to Northam et al., highlighted the need for early intervention for people with poor glycaemic control in order to minimise future psychiatric problems and adverse T1D outcomes. Further research with a larger sample was recommended in order to further elucidate the relationships between illness management and mood in Australian children and adolescents.

Other studies of Australian youth remain limited. In a study of young Australian adults aged between 18 and 25 with T1D, mean HBA1c levels were higher in participants with depressive symptoms compared to those participants with normal scores. However, HbA1c levels were not associated with depressive symptoms (Hislop, et al., 2008).

Further research is required to confirm the expected relationship between depressive symptoms and glycaemic control in Australian children. This need is reflective of the limitations of studies conducted in other countries assessing these relationships. The association between children's depressive symptoms and illness management is not as well established as it is in adult studies and, to a lesser extent, studies of adolescents. While Australian studies exploring the relationship between illness management and depressive symptoms in children with T1D are limited, the findings of research in Australian adolescents reviewed in this chapter indicate that poor illness management is at least potentially related to depressive symptoms in children.

2.4.5. Depressive symptoms and psychosocial wellbeing in children and adolescents with type 1 diabetes. As early as 2002, Grey et al. (2002) made several important conclusions in a comprehensive review of psychosocial studies of children with T1D. The course of depression appeared to be more severe in youth with T1D compared to adults, and more likely to reoccur compared to other young people. The combination of T1D and depression was also related to a significant increase in suicidal ideation and suicide behaviours. The conclusions made by these authors are consistent with recent studies of the psychosocial wellbeing of children with T1D, and reiterate the importance of identifying depression in children with T1D.

A study of American children and adolescents aged between 10 and 18 years which used the CDI found that those who were depressed were more likely to be female, and report greater

family conflict (Hood, et al., 2006). Longitudinal research in Australian children followed up since their initial diagnosis suggests that early psychological problems relating to adjustment to T1D may result in adjustment problems and poorer psychological and diabetic outcome up to ten years after diagnosis (Northam, et al., 2005). For instance, young people with T1D are two to three times more likely to attain a DSM-IV diagnosis for a psychiatric disorder. This finding was established in a longitudinal study of 41 children, who were monitored by a large metropolitan children's hospital for ten years after childhood diagnosis of T1D (Northam, et al., 2005). Of this cohort, 37% met the diagnostic criteria for a DSM-IV diagnosis, including depressive (mood) disorder, anxiety disorder, eating disorder and behaviour disorder. While the depressed group were not studied as a subgroup, criteria for a DSM-IV diagnosis were met in half of those with poorly controlled diabetes, compared to only a quarter of those with well-controlled diabetes. Females were also more likely than males to receive a psychiatric diagnosis by the end of the 10-year follow-up period. The findings of the Northam et al. study suggest that children and adolescents with T1D are at a high risk of deleterious outcomes in relation to illness management and psychological functioning, and that the combination of both problems may be additive in nature.

2.4.6. Anxiety in children and adolescents with type 1 diabetes. Anxiety refers to excessive worry or concerns that are experienced to an extent where daily functioning is affected, and is the most common form of childhood psychological disorder according to the DSM-IV-TR (2000). Anxiety is also a common comorbid psychological presentation with depression in children and adolescents (Garber, 2006; Kovacs, et al., 1997). Because symptoms of depression and anxiety frequently co-occur, the assessment of both forms of psychological

distress in studies of children with T1D can aid the correct attribution of depression or anxiety to illness management and psychosocial wellbeing. In this section, research investigating the prevalence of anxiety in children with T1D will be discussed. The relationship of anxiety to illness management and psychosocial functioning will also be discussed.

2.4.7. Prevalence of anxiety symptoms in children and adolescents with type 1 diabetes.

Anxiety, as with depression, also appears to have a higher prevalence in children with T1D (Reynolds & Helgeson, 2011). A recent meta-analysis of 22 studies, of which anxiety was measured in six studies, assessed the prevalence of anxiety symptoms in children with T1D. The comprehensive meta-analysis included recent studies which used a range of anxiety assessment measures, including symptom-based questionnaires such as the Revised Children's Manifest Anxiety Scale (RCMAS) and clinical interviews capable of providing a clinical diagnosis. Children with T1D were significantly more likely to experience anxiety symptoms than those without T1D. The effect size was influenced by the research date of publications included in the analysis, with a reduced effect size found for the recently published studies. The authors attributed this interesting difference to recent treatment advances in the management of T1D, which may indicate that children with T1D are psychologically more like their healthy peers than in older studies.

2.4.7.1. Prevalence of anxiety symptoms in Australian children and adolescents with type 1 diabetes.

Recent prevalence studies of Australian children and adolescents with T1D are very limited. The longitudinal study by Northam et al. (2005) described previously identified seven Australian adolescents (out of 41 participants, or 17%) who met diagnostic criteria for an

anxiety disorder 10 years after T1D diagnosis. While a key strength of their study was the ability to assess anxiety at a diagnostic level, the relatively small sample size prevents any accurate conclusions regarding the true prevalence of anxiety in Australian children and adolescents with T1D.

2.4.7.2. Prevalence of anxiety symptoms in international studies of children and adolescents with type 1 diabetes.

A recent study of 276 American adolescents using the STAI found elevated symptoms of state and trait anxiety, at rates of 17% and 13% respectively (Herzer & Hood, 2010). These recent findings remain consistent with the results of one of the first studies to comprehensively investigate mood and anxiety morbidities in T1D youth (Kovacs, et al., 1997). Using a longitudinal, naturalistic design, 92 children and adolescents aged from 8 to 13 years were followed for 10 years from the time of initial T1D diagnosis. Of concern is that nearly half (47.6%) developed a psychiatric disorder, which was established using a diagnostic interview. Mood disorders were most evident, with 26.1% having a major depressive disorder. Anxiety disorders were the second most common type of psychiatric disorder and were diagnosed in 19.6% of youth. Of the anxiety disorders, the most common was generalised anxiety disorder (GAD). The highest incidence rates were during the first year following T1D diagnosis. While this study is now outdated due to the time of participant recruitment (between 1978 and 1985) and advances in T1D management, the findings demonstrate a high prevalence of anxiety in young people with T1D. This pattern has also emerged in more recent research studies, reviewed below.

2.4.8. Anxiety symptoms and type 1 diabetes management in children and adolescents.

A study by Herzer and Hood (2010) of 276 American adolescents found that higher levels of anxiety symptoms were associated with suboptimal glycaemic control. Importantly, no level of anxiety was associated with optimal glycaemic control. These findings reflect a recent finding in 83 young adults with T1D (M = 22.2, SD = 2.8), which found that greater anxiety and depression (measured using the HADS) was correlated with worse glycaemic control (Lancaster, et al., 2010). A limitation was the inability to attribute the finding to anxiety alone, as differences between depression and anxiety and their respective associations with glycaemic control were not measured. In addition, the sample of young adults may not accurately reflect the experience of children and adolescents, due to developmental differences.

The findings reported by Herzer and Hood (2010) are consistent with the recent meta-analysis of psychological distress, which included six studies of anxiety (among other psychological variables) in children with T1D compared to healthy peers (Reynolds & Helgeson, 2011). Children with T1D were more likely to experience anxiety, although the effect size for this finding was small. The strength of their finding is consistent with published studies regarding the relationship between anxiety and T1D status. The longitudinal study by Helgeson et al. (2007) of 132 adolescents with T1D and 131 healthy adolescents over a three year period found no differences in anxiety symptoms between adolescents with T1D and the healthy group. The authors concluded that T1D was not related to anxiety or depression in early to mid-adolescence. While anxiety symptoms and depression increased in girls and not boys over the study period, this trend was irrespective of T1D status and appeared to reflect the known gender differences for these conditions (Helgeson, et al., 2007). These findings provide some evidence for a relationship between anxiety and T1D management, but this relationship has been less

explored and is therefore less understood in comparison to the role of depression. Further research is required to elucidate the relationship between anxiety and T1D management.

2.4.9. Anxiety symptoms and psychosocial wellbeing in children and adolescents with type 1 diabetes. In the 10 year follow-up study of Australian adolescents with T1D by Northam et al. (2005), a comorbidity of psychological disorders was found in most participants who received a psychiatric diagnosis. While comorbidity with anxiety disorders was not specifically elaborated, 60% of those adolescents who received a psychiatric diagnosis met criteria for two or more psychiatric disorders, and a third met diagnostic criteria for three or more psychiatric disorders. Although anxiety and depression frequently co-occur, further elaboration of the specific psychiatric disorders also found in adolescents with an anxiety disorder would have further strengthened these findings.

2.4.10. Limitations of research investigating depression and anxiety in children and adolescents with type 1 diabetes. The literature exploring the prevalence of depression and anxiety in children requires further research in several areas. Much of the research that has been done in the domain of internalising symptoms has focused on depression, and anxiety has been the focus of less research (Herzer & Hood, 2010). This is an issue because the prevalence of anxiety, and subsequent impact on T1D and wellbeing outcomes, is less well understood by researchers.

It is also important that studies of depression or anxiety consider the comorbid nature of depression and anxiety, in order to make accurate inferences about the relationships of depression or anxiety to illness management. As depressive and anxiety symptoms frequently

present as comorbid psychological conditions across the lifespan (Garber, 2006; Seligman & Ollendick, 1998), the measurement of both aspects can aid the accurate study of psychological functioning to illness management. A recent study of 259 adults (aged between 16 and 60) with T1D in the United Kingdom assessed depressive and anxiety symptoms using the HADS (Shaban, et al., 2009). While depression and anxiety are known to be highly correlated, anxiety symptoms significantly predicted poor glycaemic control in this study, but depressive symptoms did not. While this finding was made in adults and not youth, it demonstrates the general need to assess both depressive and anxiety symptoms in studies of mood factors and T1D management, in order to individually determine the influence of depression and anxiety respectively on T1D management.

While the relationship between illness management and depression and anxiety respectively has been studied in adolescents and young adults, less is known about these issues in children and the relationship to current methods of T1D management. In their recent meta-analysis of depression and anxiety studies, Reynolds and Helgeson (2011) suggest that the smaller effect size for depression and anxiety in more recent studies may be due to the recent treatment advances in the management of T1D. A recent pilot study of 32 Australian children and adolescents at two metropolitan hospitals has provided some data regarding this relationship. Participants aged between 6 and 16 years were administered a measure of general psychological functioning (Behaviour Assessment System for Children – Second Edition) prior to beginning an insulin pump regimen, and six to eight weeks afterwards (Knight, et al., 2009). The measure included a general subscale for internalising symptoms which included depression, anxiety and somatisation items. The study found a reduction in internalising symptoms (including both depression and anxiety) based on self-report, parent and teacher report. While the Knight et al.

study provided some results to address the concerns raised by Reynolds and Helgeson (2011), it did not measure depression and anxiety symptoms separately. The sample size of this pilot study indicates that further research in Australian children and adolescents is required to confirm this relationship.

The consideration of behavioural factors is also important in the study of psychosocial wellbeing in this group, as aspects of behaviour can clearly enhance or detract from T1D management. Behavioural factors are also potentially modifiable, in efforts to improve T1D and psychosocial functioning. In the next section, the related constructs of coping and self-efficacy will be discussed in relation to T1D management and psychosocial wellbeing. Coping and self-efficacy will be the focus as they have been shown to be significant and potentially changeable factors in many chronic illness populations, however gaps remain regarding the relationship of these factors to T1D management in children and adolescents.

2.5. Behavioural Factors: Coping and Self-Efficacy in Children and Adolescents with Type 1 Diabetes

Coping is an important consideration in young people with T1D, as managing T1D is a long-term, constant task for those with this chronic illness (Grey, 2000). Adaptive coping to illness demands and the cultivation of confidence in the ability to manage the demands of the illness are important behavioural skills for children. The implementation of healthy coping strategies and a sense of self-efficacy from childhood may assist in positive medical and psychosocial functioning into adolescence and adulthood. In this section, the related constructs of coping and self-efficacy are defined, and their relationships to illness management and psychosocial wellbeing are discussed.

2.5.1. Theoretical approaches to coping in children and adolescents with type 1 diabetes.

Although slightly different definitions of coping exist, the definition of Folkman and Lazarus (1988) is the most widely used in T1D research. These authors define coping as the "cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of a person" (Folkman & Lazarus, 1988, p. 310; Lazarus, 1984). This definition emphasises that the appraisals used by individuals to cope change with time, experience, context and the type of stressor. According to this definition, the person-environment relationship is continually appraised and reappraised.

The Folkman and Lazarus definition has been applied previously to the study of coping in children and adolescents with T1D, and defines coping behaviours as problem-focused or emotion-focused (Graue, et al., 2004; Grey, 2000). Problem–focused coping is aimed at solving the problem faced by the person and tends to be used when the stressor is appraised by the individual as something that can be changed (Folkman & Lazarus, 1988). In the case of T1D, an example may include difficulties in eating behaviour, with the problem-focused strategy utilised by the child, adolescent or parent possibly involving seeking medical support from the child's allied health team.

Emotion-focused coping is more likely to be used when a situation is appraised as unchangeable, or when the stressor is fleeting and will resolve of its own accord (Folkman & Lazarus, 1988). This method of coping often involves cognitive strategies, such as avoidance, minimisation, distancing and 'finding the positive' in stressful situations (Grey, 2000). For instance, an adolescent may use avoidance of insulin injections as a way of coping with feeling different to peers. While such a strategy may have the effect of alleviating distressing emotions caused by the stressor, such strategies can be problematic for illness management (Grey, 2000).

Some emotion-focused strategies may still be compatible with better medical outcomes. For example, emotional expression and acceptance strategies are related to both better glycaemic control and quality of life in adolescents with T1D (Jaser & White, 2011).

Folkman and Lazarus also distinguish between different kinds of appraisals. Primary appraisals involve assessing what is at stake in the encounter, and help to determine the emotional quality and intensity elicited by an event. For example, if one's physical wellbeing was at stake, worry or fear would be likely salient emotions (Folkman & Lazarus, 1988). Secondary appraisals involve exploring choices in dealing with the stressor, and the response helps to influences the type of coping one adopts. For instance, if a stressor is modifiable or amenable to change, problem-focused forms of coping are likely to be used. However, if a stressor is appraised as unchangeable, emotion-focused forms of coping may be adopted instead.

Individual variables such as motivation and personal resources may also influence whether a stressor is perceived as neutral or threatening (Folkman & Lazarus, 1988). Folkman and Lazarus' definition understands each person as representing a unique combination of individual and environmental variables. Individuals appraise stressful person-environment interactions (situations) and then employ coping strategies.

In a qualitative study of eight adolescents with T1D aged between 16 and 22 years, participants developed self-protective coping strategies to manage perceived threats from their T1D (Schur, et al., 1999). Intrapersonal threats included emotional upset, ambiguity and fear regarding the present and future, and vulnerability. Protective strategies employed by adolescents included adaptive denial to a sense of ambiguity and fear regarding living life with T1D, as well as situations in the present that may also activate fears. Another strategy identified involved having a rosy view of the past, in order to protect from pain associated with the past. This was

hypothesised to reduce potential anger and grief about what their past might have been like if T1D was not involved (Schur, et al., 1999). Adolescents employed such strategies to reduce upsetting emotions regarding their T1D. Control was also identified as one of the most powerful themes, and was seen by adolescents as fundamental in order to protect them. This was psychological, but enhanced by practical control over one's T1D. It was described by participants as control over T1D using practical steps, but also control over anxiety and emotional fears about T1D. A dual quality to the concept of control was therefore evident. Downward comparisons was a strategy used to manage the emotional vulnerability associated with T1D, and involved making comparisons to others worse-off (Schur, et al., 1999).

2.5.2. Coping and type 1 diabetes management in children and adolescents. Emotion-focused coping strategies are generally related to poor glycaemic control in adolescents. A study of 101 Croatian adolescents aged between 11 and 18 years used the Scale of Coping with Stress (SCS) to assess general coping strategies in relation to illness management (Skocic, Rudan, Brajkovic, & Marcinko, 2010). Emotion-focused coping strategies were independently associated with poor glycaemic control. In a study of 103 Norwegian adolescents with T1D (aged between 13 to 18 years), problem and emotion-focused coping styles were investigated, along with relationships to glycaemic control. As the mean time since T1D diagnosis was 7.1 years, the majority of participants had lived with the illness since childhood. Emotion-focused coping was associated with poor metabolic control (Graue, et al., 2004). The relationship between avoidant coping styles and impaired glycaemic control identified in European and American adolescents has also been replicated in longitudinal research. A German study followed 109 adolescents (mean age 13.77 years) for four years. Higher HbA1c levels and higher

levels of internalising and externalising psychological symptoms (measured using the German Youth Self-Report) consistently predicted avoidant coping strategies across time (Luyckx, Seiffge Krenke, & Hampson, 2010).

Relationships between illness management and coping have been studied predominantly in adolescents. At this age, avoidance of managing T1D (a strategy to manage emotions) in adolescents may be a problem, because this strategy might involve behavioural and mental disengagement (Michaud, Suris, & Viner, 2004). For instance, the adolescent may be reluctant to perform blood glucose testing or insulin administration in front of peers (Graue, et al., 2004; Grey, 2000). In a longitudinal study of adolescents with T1D from 14 years of age, those who used less avoidance-based coping strategies in their daily life had good metabolic control, compared to those with poor and satisfactory metabolic control (Seiffge-Krenke & Stemmler, 2003). Medical adaptation and psychosocial adaptation are related, according to such findings. Similarly, another study of 103 adolescents aged from 13 to 18 years identified poorer glycaemic control in those who used emotion-focused coping styles. In contrast, 'active' coping styles that were congruent with problem-focused strategies were related to improved glycaemic control (Graue, et al., 2004).

The relationship between emotion-focused coping styles and impaired glycaemic control is not consistent across all studies. For instance, glycaemic control was not related to avoidant coping styles or 'venting' emotions in a study of 135 adolescents (Hanson, et al., 1989). However, these coping characteristics were predictive of poorer self-care behaviours. Coping with difficult or upsetting aspects of T1D was also not related to HbA1c levels in a separate study of 52 adolescents (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998).

The coping styles of school-aged children with T1D are less understood. Child coping regarding T1D has been most frequently studied by a research team at Yale University, who used the Issues in Coping with Diabetes Scale – Child Version (ICI-C) across several studies (Grey, et al., 1998; Grey, Davidson, Boland, & Tamborlane, 2001; Grey, et al., 2009; Jaser, et al., 2008). This questionnaire assesses coping in relation to T1D tasks perceived as difficult and upsetting, respectively. This research program has found that younger children are more likely to adopt externalising responses such as yelling and arguments as coping strategies (Grey, Lipman, Cameron, & Thurber, 1997). Externalising coping strategies may therefore increase situations of conflict between the child and family members, and potentially have a negative impact on family functioning.

The direction of cause and effect between coping style and glycaemic control has not been established in previous research. It is therefore unknown whether young people choose a particular coping style in response to poorly controlled T1D, or whether their premorbid coping styles cause poor glycaemic control (Graue, et al., 2004). In general, problem-focused coping is associated with more successful medical outcomes than emotion-focused coping in adolescents; specifically better glycaemic control and self-care behaviour. However, the picture is less clear for children with T1D. Given the potential negative impact on family functioning from externalising responses, the impact of T1D-specific coping styles in children requires further investigation.

2.5.3. Coping and psychosocial wellbeing in children and adolescents with type 1 diabetes. Where a child living with T1D perceives their condition as a stressor, this is problematic because the stressor cannot be removed, or safely avoided. As such, coping with

T1D requires finding ways to make living with T1D more manageable (Grey, 2000). This is assumed to be the optimal daily management tasks associated with managing the condition, and the possibility of complications arising. However, a recent study of the daily diaries of 19 children and 33 adolescents with T1D found general life-related stressors such as school and friendship issues to be of greater concern to them than T1D-related stressors (Hema, et al., 2009). This finding confirms the need to focus on the broad wellbeing of children and adolescents with T1D, beyond the management requirement.

Coping styles are related to psychosocial wellbeing in adolescents. Grey et al. (1998) investigated psychosocial factors in 52 adolescents aged between 13 and 20 years with T1D. They found that appraisals that coping with T1D is harder to do and more upsetting were associated with worse quality of life, in terms of worries regarding T1D. More recently, these authors analysed baseline data from 108 eight to 12 year old children with T1D obtained as part of a larger coping skills intervention (Jaser, et al., 2008), and found that depressive symptoms in these children were significantly related to their difficulty coping with hard aspects of their T1D, such as insulin regimens, as well as illness-related issues, such as being in hospital. The authors argue that coping with upsetting aspects of T1D is a potential mediator of depressive symptoms in children and in their mothers. This finding provides evidence that knowing the T1D-related coping styles of children with this condition is important information in relation to mood problems. A strength of this study was the relatively large sample of children recruited, which allowed mediational effects to be explored.

In a study of 84 American children and adolescents (aged 8 to 14 years) who were studied one year after diagnosis, a clear association was found between a greater use of avoidance-based behaviours and poorer overall adjustment to T1D (Grey, et al., 1997). Examples

of avoidance-based behaviours included drinking, smoking, staying away from home, yelling, arguing and fighting. Avoidance-based behaviours were more likely to be used by adolescents and by boys. While the study was unable to identify a relationship between coping styles and illness management, a clear link to psychosocial adjustment was evident. This finding indicates the importance of targeting youth 'at risk' by virtue of their developmental stage (i.e. adolescence) and demographic group (i.e. male gender).

More recently, Graue et al. (2004) studied 103 Norwegian adolescents aged between 13 and 18 and found similar findings to Grey et al. (1997). The mean period since T1D diagnosis was 7.1 years, indicating that the majority of youth had lived with the illness since childhood. Emotion-focused coping was significantly associated with a lower degree of T1D-related quality of life. These findings are consistent with the results of a study of 47 Croatian children with T1D (Jovic, et al., 2009), reviewed previously. Using a general measure of coping (Coping Strategies Inventory for Children and Adolescents), greater use of emotion-focused styles of coping (including avoidant coping) was associated with reduced quality of life. While associations were only analysed at the level of correlations, these findings reiterate those of other studies investigating this relationship.

In general, a substantial body of literature exists for coping in relation to major life events in normal samples. However, less is known about specific coping strategies adolescents with T1D adopt to cope with stressful aspects of their daily life (Seiffge-Krenke & Stemmler, 2003). Problem-focused strategies appear related to greater levels of psychological wellbeing, while avoidance-based behaviours have been associated with poorer psychological outcomes. These findings have been obtained in studies of adolescents (or mixed samples of children and adolescents), and there is limited data regarding such relationships in Australian children.

A limitation of the existing literature on psychosocial factors in young people with T1D is the lack of research into the role of the self in T1D (Johnston-Brooks, Lewis, & Garg, 2002). In the next section, the role of self-efficacy in illness management and psychosocial wellbeing in the context of T1D is discussed.

2.5.4. Self-efficacy in children and adolescents with type 1 diabetes. Self-efficacy is related to coping, and refers to the cognitive perception of one's ability to engage in a specific behaviour (Bandura, 1977). Self-efficacy is informed by four major sources: performance accomplishments, vicarious experience, verbal persuasion and emotional arousal (Bandura, 1977). Through these information sources, defensive behaviour is reduced and mastery expectations take shape, as confidence in their ability to undertake specific behaviours improves (Bandura, 1977; Bandura, 1997). This is especially important in relation to optimal T1D management as affected children need to develop sense of confidence in their ability to master essential management tasks, as they move into adolescence and increased ownership of their T1D management. Self-efficacy is derived from Social Learning Theory (SLT). SLT states that greater self-efficacy may improve outcomes through particular behaviours that allow individuals to control or avoid situations that lead to exacerbations or worsening of medical outcomes (Mancuso, Rincon, McCulloch, & Charlson, 2001).

Self-efficacy is clearly influenced by developmental stage. A study of self-efficacy in 168 youth aged 10-16 years found that adolescents report a greater sense of self-efficacy compared to children in relation to their T1D (Iannotti, Schneider, Nansel, & Haynie, 2006). This was attributed to the greater parental involvement evidenced in younger children for their T1D management, relative to adolescents who have greater responsibility for such tasks. The

relationship between self-efficacy and T1D management was moderated by holding a belief that their T1D management would help them achieve positive medical outcomes. This finding indicates that children who strongly believe that adherence to their management tasks will improve their T1D outcomes demonstrate a greater association between their self-efficacy and T1D management.

The definition of self-efficacy introduced in this section indicates a clear potential for application to varied health outcomes, where management behaviours require sustained persistence to long-term goals like T1D management. Children and adolescents with greater self-efficacy are assumed to be more resilient when faced with T1D-related setbacks or barriers. The findings of studies in T1D management are now presented.

2.5.5. Self-efficacy and type 1 diabetes management in children and adolescents.

Self-efficacy has been shown to improve medical outcomes in adults living with chronic illness. In a prospective cohort study, 224 American adult patients with moderate asthma were followed for approximately two years. It was shown that less asthma self-efficacy predicted worse asthma outcomes, the latter being measured by the Asthma Quality of Life Questionnaire and the SF-36 health survey (Mancuso, et al., 2001).

The relationship of self-efficacy to illness management, particularly glycaemic control, has received mixed findings in individuals with T1D (Nouwen, Law, Hussain, McGovern, & Napier, 2009). For instance, self-efficacy did not predict glycaemic control in a study of 52 adults who used an insulin pump, but did predict psychosocial functioning in this group (Aberle, et al., 2009). However, self-care as a meditating variable was found to help account for an association between greater self-efficacy and greater self-care in a study of 110 young adults

with T1D aged 18 to 35 years, where self-efficacy was a better predictor than self-esteem of all aspects of optimal self-care and HbA1c levels (Johnston-Brooks, et al., 2002). Self-efficacy for T1D was also associated with glycaemic control and treatment adherence in adolescents and young adults aged 15 to 25 (Griva, Myers, & Newman, 2000). However, the sample size for this study was small, with 64 participants included in a multiple regression analysis involving several variables. Taken together, the findings of studies in adults and young people indicate that self-efficacy plays an important role in illness management, but associations to glycaemic control are less consistent.

Research conducted in adolescents suggests that self-efficacy is one of the strongest psychological predictors of treatment adherence. A study of 143 eleven to 18 year old adolescents with T1D found that self-efficacy mediated the relationship between mastery relating to T1D treatment and adherence to treatment (Ott, Greening, Palardy, Holderby, & DeBell, 2000). Similarly, in Nouwen's (2009) study of 354 adolescents aged 12 to 18 years, self-efficacy was measured using a scale developed by the authors. It was found to be a significant predictor of dietary self-care. This finding suggests that adolescents who are less confident in their ability to negotiate the dietary requirements and/or do not believe that following their recommended dietary recommendations to control their T1D will improve control, are less likely to comply with their recommended dietary activities.

Gender differences also appear evident in the relationship between self-efficacy and glycaemic control in adolescents, with positive associations identified between self-efficacy and metabolic control, but only in girls (Grossman, Brink, & Hauser, 1987). In this study, an overall relationship was identified between self-efficacy and metabolic control. However, this study was limited by the use of average blood glucose level, not HbA1c, to measure glycaemic control.

This measure is considered to be more vulnerable to fluctuations in comparison to HbA1c level, and has been superseded by the latter measure in recent studies.

A limitation of the self-efficacy literature is the relative lack of studies including children. While children receive family support in illness management, the development of self-efficacy from a young age is an important goal in order to ensure lifelong optimal illness management. Understanding T1D-related self-efficacy in children may also aid the development of psychosocial interventions, due to the potentially modifiable nature of confidence in illness management tasks.

Overall, an association between self-efficacy and psychological distress, and self-efficacy and self-management behaviours in adolescents appears evident from the studies in this field, however, the association between self-efficacy and glycaemic control is unclear. This has been attributed to the fact that other factors, such as medical aspects (e.g. infections, hormonal changes) can impact on HbA1c levels, the current standard measure for assessing glycaemic control (Nouwen, et al., 2009). HbA1c levels may therefore pose an issue if used as a sole outcome measure of T1D management, due to the potential for influence from these factors. As poorly managed T1D is clearly linked to impaired medical and psychosocial outcomes, non-attendance at school can be used as an indicator of the impact of T1D-related illness on children's functioning. It is also possible that increased school days missed negatively impacts on family functioning. Missed school attendance may also affect children's wellbeing due to associated difficulties in keeping up with schoolwork, missing friends, and 'standing out' as ill (this is further expanded in Section 2.8).

2.5.6. Self-efficacy and psychosocial wellbeing in children and adolescents with type 1 diabetes. Self-efficacy is a powerful predictor of diabetes-related psychosocial functioning in adults with T1D (Aberle, et al., 2009). In a study of 52 adults using an insulin pump, self-efficacy predicted depressive symptoms, treatment satisfaction and quality of life, and was the most powerful predictor of psychological wellbeing. However, self-efficacy was not predictive of glycaemic control. Similarly, in Nouwen's (2009) study of 354 adolescents aged 12 to18 years self-efficacy was measured using a scale developed by the authors, which has not been validated. Self-efficacy was found to be a significant predictor of T1D-related distress.

Fewer studies have investigated self-efficacy in children with T1D. In a recent study which attempted to address this gap, 84 preadolescents aged between 9 and 11 years completed the Self-Efficacy for Diabetes Scale (SED) to assess T1D-specific self-efficacy, among several measures of psychosocial and illness functioning (Armstrong, et al., 2011). Using regression methods, self-efficacy fully mediated the relationship between depressive symptoms and self-care behaviours. More depressive symptoms were associated with lower self-efficacy, which was related to fewer self-care behaviours. These findings are limited by the statistical power of the analyses, due to the sample size of 84 preadolescents.

A recent study attempted to explore the role of self-efficacy in relation to other psychosocial variables to test a biopsychosocial model of metabolic control and health behaviours (Holmes, et al., 2006). In a study of 222 youths (mean age 12.6, *SD* = 1.9), self-efficacy was measured using the SED scale, and relationships explored using structural equation modelling. Interestingly, the researchers found that greater self-efficacy was related to less illness knowledge, not more knowledge as expected. Problem-solving, an aspect of T1D knowledge included in the study was significantly related to greater self-efficacy. According to

the authors, problem-solving may therefore be a more important measure of T1D knowledge than general knowledge, as problem-solving allows for the application of learned information to new T1D management situations (Holmes, et al., 2006). Self-efficacy was not significantly associated with family environment, youth stress and internalising or externalising behaviour problems. Problem-solving is also related to coping styles, and problem-focused coping strategies have been previously discussed as adaptive for both glycaemic control and self-care behaviour outcomes (see Section 2.5.2).

In a study investigating quality of life outcomes, out of a range of psychosocial variables considered, self-efficacy was one of the strongest predictors of quality of life outcomes in 98 adolescents with T1D (Seiffge-Krenke & Stemmler, 2003). Greater self-efficacy may make favourable T1D outcomes more likely through specific behaviours. For instance, the authors suggest that greater self-efficacy may lead individuals to be more motivated to adhere to medication regimens. Greater self-efficacy may also increase the likelihood of utilising problem-focused coping strategies to address distressing situations related to T1D, as these strategies are used when a situation is appraised as changeable (Folkman & Lazarus, 1988).

2.5.7. Limitations in coping and self-efficacy research. The understanding of coping strategies and self-efficacy in children remains less understood relative to adolescents and adults, who have been the focus of the majority of psychological studies in this area. Furthermore, research studies exploring coping in relation to improved T1D outcomes have provided inconsistent findings. From a theoretical perspective, some coping measures have also been developed in a way that treats coping strategies as adaptive or problematic across situations. Recent advances in the coping literature indicate that the same type of coping style can be

adaptive or maladaptive, depending on the situation in which it is utilised (Wagner & Tennen, 2007).

Coping strategies to deal with upsetting emotions such as avoidance can be problematic for T1D management. Such strategies might involve behavioural and psychological disengagement, for example, not performing blood glucose testing or administering injections, or denial of T1D-related issues. Problem-focused coping is generally associated with more successful medical outcomes (better self-management, better glycaemic control, psychosocial wellbeing) than emotion-focused coping in children and adolescents. The problem-focused coping style is also related to greater self-efficacy, as confidence in the ability to change a distressing situation is required to engage in problem-solving strategies. Conversely, negative emotion-focused coping strategies such as avoidance are associated with poor self-efficacy (Bandura, 1977). However, helpful emotion-focused strategies of humour or "looking for the silver lining" can help relieve emotional distress without negatively influencing medical outcomes (Grey, 2000, p. 167). Although the impact of coping styles and T1D management has been studied in adolescents, the findings are inconsistent. Even less is known about how children cope with stressful aspects of their T1D, particularly in Australian children. Further research is therefore needed to clarify the role of coping styles on T1D management and wellbeing in children and adolescents, particularly in the Australian context.

Self-efficacy is also less understood in children with T1D. Self-efficacy is higher in adolescents, compared to children, due to developmental differences. However, understanding the extent of self-efficacy in children and its relationship to T1D management is beneficial. For example, low levels of self-efficacy shown to be detrimental to T1D outcomes would provide an impetus to develop psychological interventions to increase children's sense of self-efficacy, and

influence their adoption of positive coping styles, since these are modifiable factors. Alternatively, self-efficacy and coping could be targeted on an individual basis to children who demonstrate a lesser sense of self-efficacy and negative coping styles, with the goal of improving their health outcomes.

2.6. Social Factors: Family Functioning in Children and Adolescents with Type 1 Diabetes

The intensive management requirements of T1D place additional demands on the family members of young people with the illness. In the years following initial adjustment to T1D diagnosis, the condition typically becomes a normal aspect of family life, but continues to involve and affect family members as well as the effected child or adolescent (Wennick, Lundqvist, & Hallstrm, 2009). It is also expected that children will usually turn to their parents in times of crisis or difficulty, however in adolescence the opposite may be true and they may withdraw from support offered by their caregivers (Warner & Hauser, 2009). Furthermore, the developmental transition from childhood to adolescence is marked by significant psychological and other changes that may conflict with the intensive and ongoing demands of T1D management. It is therefore understandable that age is an important moderator in the relationship between family support and glycaemic control (Lewin, et al., 2009). In Australia, YADS clinics are offered to support adolescents and their families through the transition from supported paediatric care, to independent adolescent management (Craig, et al., 2011). In this section, family functioning is defined and its associations with T1D management and psychosocial wellbeing respectively are discussed.

2.6.1. Defining family functioning. In the study of family functioning, two dimensions have been defined in terms of the parenting style. These are the guidance, or control, shown by parents towards their child, and the warmth, or caring, from the parent towards the child. The study of these dimensions is based on parenting theory which promotes the adaptive role of authoritative parenting in comparison to authoritative and permissive parenting styles, and has been applied by several researchers to the case of T1D (Anderson, 2004; Greene, Mandleco, Roper, Marshall, & Dyches, 2010). In the context of children living with T1D, it has been hypothesised that children who perceive their parents to show a guiding, yet warm, approach to their T1D management will experience improved medical outcomes and psychosocial wellbeing. The research findings relevant to these forms of family support are now discussed.

2.6.2. Family functioning and type 1 diabetes management in children and adolescents. Parent-child relationships characterised by guidance and warmth appear to be important in predicting positive medical outcomes of children and adolescents with T1D. Hocking and Lochman (2005) reviewed 27 studies exploring psychosocial factors in youth with T1D, including family functioning in four of these studies. These authors concluded that young people with optimal glycaemic control have more controlling, structured, supportive and cohesive family environments.

In a prospective study, 116 children and adolescents aged between 6 and 17 years were studied at baseline (mean of three years post-T1D diagnosis) and at follow-up (3.8 years on average from baseline) (Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004). Cohen et al. found that higher levels of family cohesion at baseline predicted better glycaemic control at follow-up. In a recent study, family cohesion was assessed in 257 youth-parent dyads (Mackey,

et al., 2011). Family cohesion was indirectly associated with better glycaemic control, and this association was mediated by better T1D self-care behaviours. A pilot study of 29 adolescents with a mean age of 14.1 years also found that an authoritative mothering style (characterised by mothers' warmth and guidance) was associated with better glycaemic control and self-care behaviours (Greene, et al., 2010).

The relative contribution of parental warmth and guidance to T1D management in comparison to other aspects of family functioning is not clearly understood. For instance, a recent study of 120 eight to 18 year olds and their parents found that family warmth and guidance did not predict HbA1c levels in participants (Duke, et al., 2008). However, critical parenting fully mediated the relationship between parent-reported behavioural problems and HbA1c level. A further study which explored the role of family factors in children also aged between 8 and 18 years found that parental warmth and guidance did not directly predict HbA1c levels, at baseline or over time. However, the combination of types of family functioning studied also included the additional construct of critical parenting style. This style was characterised by the perception of the child or adolescent that their parent was critical or negative, and was measured in addition to parental warmth and guidance (Grabill, et al., 2010). The combined effect of the family measures was a significant indirect effect on the glycaemic control at baseline. The authors suggested that critical parenting was the main reason for this effect.

Recent studies of family functioning have assessed constructs related to parental warmth and guidance, and identified associations with a range of T1D management outcomes. For example, a collaborative parenting style was associated with better glycaemic control and treatment adherence in a recent US study of 309 children and adolescents aged between 9 and 14.5 years (Wysocki, et al., 2009).

As a measure of family functioning, parental warmth and guidance has been less widely studied in comparison to other aspects of family functioning. One of the largest studies to be conducted in the field of T1D management and psychosocial wellbeing was conducted by the Hvidoere Study Group on Childhood Diabetes, which includes data from over 2000 children and adolescents from 19 countries including Australia (Hoey, 2009). This study did not explicitly measure parental guidance and warmth, however parental over-involvement was significantly correlated with worse glycaemic control (Hoey, 2009), indicating the importance of understanding the influence of parenting on T1D management, especially in children.

Family conflict is also consistently associated with poorer medical outcomes, including impaired glycaemic control (Ingerski, Anderson, Dolan, & Hood, 2010; Miller-Johnson, et al., 1994; Williams, Laffel, & Hood, 2009) and adherence (Miller-Johnson, et al., 1994), including specific behaviours such as blood glucose monitoring frequency (Ingerski, et al., 2010). These findings are consistent with child and adolescent development. Some family conflict is understandable, even expected, during adolescence, given the psychological tasks of attaining autonomy and identity (Warner & Hauser, 2009). Despite this caveat, family conflict clearly has a negative effect on the child's health in T1D, and needs to be addressed to optimise T1D management.

2.6.3. Family functioning and psychosocial wellbeing in children and adolescents with type 1 diabetes. The investigation of family functioning in relation to psychosocial wellbeing has largely involved the use of constructs closely related to, but not equivalent to parental warmth and guidance. For example, a recent study of preadolescents found that critical

parenting was related to increased psychological distress, including depression (Armstrong, et al., 2011).

Wysocki et al.'s recent study (2009) of collaborative parenting styles also assessed relationships between this construct and aspects of psychosocial wellbeing, including depressive symptoms and self-efficacy. Higher collaborative involvement was associated with fewer depressive symptoms and higher reported levels of self-efficacy. As a result, this study found that both better T1D management and psychosocial wellbeing outcomes were related to a more collaborative style of parenting.

Family conflict is reliably linked to increased psychological distress, including depression (Hood, et al., 2006; Williams, et al., 2009) and anxiety (Herzer, Vesco, Ingerski, Dolan, & Hood, 2011). A study of 163 adolescents aged between 13 and 18 explored whether individual psychosocial variables mediated the relationship between family conflict and glycaemic control (Herzer, et al., 2011). Anxiety symptoms (measured using the STAI) mediated this relationship, but depression and T1D-specific worry did not. Herzer et al. suggest that home environments characterised by family conflict may increase anxiety in adolescents, a relationship that is extremely problematic for optimal glycaemic control. It is difficult to definitely explain the direction of such relationships in the studies just reviewed. Families may experience additional stress due to the T1D regimen of the child, but general family conflict may also lead to increased stress regarding T1D management (La Greca & Mackey, 2009). Either way, intervention points are required to reduce the negative health outcomes.

2.6.4. Limitations of family functioning research. The research in family functioning has been conducted in children and adolescents to investigate the changing role of family

support, as the child and adolescent increasingly gains mastery of their T1D management tasks. Several key studies in this area have confirmed such an association between aspects of family functioning and in children as young as 4 years of age (Anderson, 2004; Duke, et al., 2008; Lewin, et al., 2009). These findings indicate that critical parenting and family conflict appears to be reliably associated with a range of illness management measures. However, the relationship between parental warmth and guidance and illness management is less clear and requires further research. While there are studies that have explored the specific role of parental guidance and warmth as a measure of functioning, the results of studies measuring this facet are less consistent than findings in related areas of family functioning such as critical parenting and family conflict. More research in the area of parental warmth and guidance would be useful in better understanding this aspect of the parent-child relationship in children and adolescents, as there is a clear potential for the targeted intervention for family support styles required, to facilitate better T1D outcomes and improved psychosocial wellbeing in children and adolescents.

2.7. Cognitive Factors in Children and Adolescents with Type 1 Diabetes

Knowledge of the requirements of T1D management in children and adolescents with T1D is usually assumed to be associated with T1D outcomes, but has been rarely tested. While children and adolescents may know how to undertake management tasks such as injecting insulin and monitoring blood glucose levels, it is not clear precisely what they understand about these management tasks, in terms of why they are performing them. In this section, research findings regarding illness knowledge are discussed with reference to medical and psychosocial outcomes.

2.7.1. Type 1 diabetes knowledge and illness management in children and adolescents.

T1D management involves daily adherence to insulin administration, alongside diet and exercise monitoring in order to maintain optimal glycaemic control. At the time of T1D diagnosis, the paediatric T1D clinic is typically the main knowledge provider for newly diagnosed children, adolescents and their parents. Consultation and education usually involves information provision regarding diet, exercise and insulin administration from a range of health professionals, including the paediatric endocrinologist, T1D nurse educator and dietitian. During follow-up appointments, young people and their families can seek clarification of management issues if and when required. The assumption of this process is that the knowledge obtained at the time of diagnosis is retained and remains accessible and useful to the child over time. However, there is limited research assessing the actual type and level of T1D knowledge held by children and adolescents. As such, knowledge surrounding T1D management in young people is generally assumed by health professionals. However, this assumption has been rarely tested. There appears to be a lack of research including T1D knowledge as a factor worthy of consideration.

The ability to understand and integrate T1D knowledge is also dependent on age. For example, the child may have an understanding of what to do, but not why; whilst the preadolescent and adolescent have developed the cognitive skills to better integrate T1D knowledge with an understanding of why and how they are integral to T1D management. This may have an impact on management, as children may not fully understand the medical consequences of not adhering to illness management tasks.

One of the few studies conducted into knowledge among children and adolescents with T1D distinguished between general T1D knowledge and problem solving ability in 53 children and adolescents (aged between 2.2 and 18 years) and their families (Auslander, Hairejoshu,

Rogge, Haire Joshu, & Santiago, 1991). These constructs were researched in children and adolescents aged 9 years old or above, and one or both parents. The percentage of correct general knowledge scores was higher in adolescents aged between 15 and 18 and lowest in children aged between 9 and 11, with 12 to 14 year olds obtaining an intermediary percentage. The percentage of correct problem solving scores was also lowest in the 9 to 11 year olds, but interestingly 12 to 14 year olds obtained a higher percentage than the oldest group. By assessing both aspects of knowledge, general information and problem-solving knowledge were both predicted by several factors: age, socioeconomic status of the family, family stress levels, family communication abilities and financial resources. Problem-solving knowledge may also be linked to positive coping styles utilising problem-focused strategies and family functioning. Importantly, poorer glycaemic control, as measured by HbA1c levels, was associated with lower levels of general knowledge. While the findings of this study are now outdated, it appears to be the only published study to explicitly measure T1D knowledge in children and adolescents in relation to glycaemic control.

There has been limited research undertaken exploring the role of T1D knowledge in children and adolescents, in relation to their T1D management. Further research is needed to explore the impact of T1D-specific knowledge on glycaemic control. In a study of 670 adults with T1D or T2D, illness knowledge and self-care activities were investigated (Persell, et al., 2004). Self-management activities were more likely to be performed by knowledgeable patients, Knowledgeable patients were more likely to perform self-management activities, but not to reach metabolic outcome goals.

2.7.2. Type 1 diabetes knowledge and psychosocial wellbeing in children and adolescents.

No research study specifically investigating the relationship of T1D knowledge to key aspects of psychosocial wellbeing in affected children and adolescents was identified. One study has explored the role of hospital environmental knowledge to wellbeing. A qualitative study of six 10 to 13 year olds hospitalised for their chronic illness in a Canadian hospital's gastroenterology, neurosurgery or nephrology units found that knowledge of the hospital environment was used as an adaptive cognitive coping strategy for most participants (Boyd & Hunsberger, 1998). According to the authors, for a minority of participants knowledge regarding potential complications also had the potential to cause additional worry. The findings of this study are limited in that it did not specifically investigate children and adolescents with T1D. It did not explore T1D knowledge at all, focusing only on environmental knowledge.

While past studies have explored T1D knowledge in relation to medical outcomes, further research focussing on psychosocial outcomes in youth with T1D is clearly needed. Such research would clarify if T1D-related knowledge can play a role in improving the psychosocial wellbeing of this group, and if so, provide a rationale for the inclusion of knowledge content in interventions designed to improve psychosocial wellbeing.

2.7.3. Limitations of type 1 diabetes knowledge research in children and adolescents.

Recent studies have noted the lack of research in the field exploring the role of T1D knowledge as a factor in psychosocial studies in this population (Roper, et al., 2009). Specifically, there is a lack of information regarding what children and adolescents know, as well as what they would like to know about their T1D. Roper et al. also note that there have been mixed findings regarding the prediction of glycaemic control based on knowledge. While knowledge is seen as a

necessary factor in attaining regimen adherence, it is not a sufficient condition, within and of itself, for adherence to occur. Their recent qualitative study 58 children and adolescents conducted in 2005 identified gaps in certain areas of T1D knowledge (Roper, et al., 2009). For example, T1D care and physiology were identified during study interviews as areas of sufficient knowledge; however, participants as a whole suggested that areas such as consequences, a T1D cure, effects on the family, and experience at diagnosis were of greater concern. One of the limitations of this study was that the accuracy of the participants' knowledge was not assessed.

Further research is required to determine if an association between T1D knowledge and glycaemic control exists (Roper, et al., 2009). In addition, Roper et al., suggest that the future consideration of factors such as gender, age and T1D management practices would also extend this work. Nevertheless, the study remains the most recent contribution to the literature in this area to date.

2.8. School Absenteeism in Children and Adolescents with Type 1 Diabetes

The child with T1D usually has to perform T1D-related tasks such as insulin administration and blood glucose monitoring within the school environment. However, developmental considerations, such as the desire to fit in with one's peer group, may affect the child's adherence to such tasks in the school environment. In the study of outcomes for children with T1D, glycaemic control (usually measured using HbA1c levels) has prevailed as the dominant measure of a child's T1D management. While the research literature continues to use this measure to assess medical outcomes in this population, recent Australian recommendations have encouraged the assessment of children's' T1D management using additional aspects of life functioning (Ambler, et al., 2006). This recommendation is consistent with the findings of a

recent study investigating self-management characteristics in 69 adolescents, which found no differences in areas such as self-efficacy using established categories of glycaemic control (Kichler, Kaugars, Ellis, & Alemzadeh, 2010). In this section, studies investigating associations between school absenteeism and T1D management are reviewed.

2.8.1. School absenteeism as a supplementary measure of T1D functioning in children and adolescents. Children and adolescents with T1D who experience school absenteeism are presumed to have difficulties in their T1D management. Using this rationale, school absenteeism may reflect poor T1D management, and school attendance has been recommended as a functional measure of T1D functioning in school-aged children. Whilst the limitations of relying solely on glycaemic control as a measure of T1D management have been acknowledged in recent studies, research designs incorporating additional functional measures such as school attendance – or, more accurately, school absenteeism – have been limited in the study of children with T1D.

A recent review of school absenteeism in children with T1D noted a lack of research exploring this aspect of functioning (Wodrich, Hasan, & Parent, 2011). Of the studies conducted to date, it appears that children with T1D appear to miss more school days per academic year than both siblings and peers (Wodrich, et al., 2011). In fact, the mean number of school days missed by 95 children with T1D in a key study was 10 school days more than their healthy siblings (Parent, Wodrich, & Hasan, 2009). According to Wodrich et al., (2011) the percentage of mean school days missed for this group of children was large enough to approach the threshold for repeating the academic year (i.e. more than 10% of the school year missed). While the investigation of school absenteeism is limited in studies of children with T1D, the few studies

incorporating such a measure also identify a significant difference between children with T1D and both their siblings (Glaab, Brown, & Daneman, 2005; Parent, et al., 2009; Vetiska, Glaab, Perlman, & Daneman, 2000) and their school-aged peers (Fowler, Johnson, & Atkinson, 1985; Glaab, et al., 2005; Ryan, Longstreet, & Morrow, 1985). School absenteeism may therefore have the potential to be a supplementary measure of T1D management and psychosocial wellbeing in children and adolescents.

2.8.2. School absenteeism and type 1 diabetes management in children and adolescents. The first studies exploring school absenteeism in the context of chronic illnesses, including T1D, were first published in the 1980s. Since this time, the few studies incorporating a measure of school absenteeism have generally identified associations between school absenteeism in T1D and impaired glycaemic control. For example, in a study of 78 children with T1D, an association was identified between the number of school days missed and poorer glycaemic control (Glaab, et al., 2005). The authors hypothesised that this relationship was likely to reflect the need to attend medical appointments, and problems with T1D management would necessitate sick days and additional medical support would further affect school attendance. Although such studies have identified an association, this trend is not consistently significant, with a recent study unable to confirm a significant association (Parent, et al., 2009).

2.8.3. School absenteeism and psychosocial wellbeing in children and adolescents with type 1 diabetes. Research findings relating school absenteeism to psychosocial wellbeing are limited. A recent review of school absenteeism in children with T1D noted that no studies to date have explored school absenteeism in relation to psychosocial status in children and

adolescents with T1D (Wodrich, et al., 2011). An early study which measured school absences and psychosocial adjustment in 47 preadolescents in the United Kingdom (UK) with T1D found that participants with general psychological adjustment difficulties were more likely to be absent from school. A limitation of this finding was the generality of the parent-reported item used to measure school absenteeism (i.e. "Stays at home a lot") (Chisholm, 2003, p. 344). In contrast, relationships between school absenteeism and aspects of psychosocial wellbeing such as family functioning have been widely explored in healthy children and adolescents. A recent review of this area concluded that a relationship does exist between school absenteeism and psychological disorders in both directions, with psychological disorders contributing to school absenteeism or alternatively occurring as a result of school absenteeism (Kearney, 2008). In children and adolescents with T1D, school absenteeism similarly may be a reflection of T1D management problems. Conversely, it has the potential to negatively impact on psychosocial wellbeing when children fall behind in their academic workload, miss their friends or 'stand out' as ill.

2.8.4. Limitations of school absenteeism research in children and adolescents with type 1 diabetes. There are two key limitations in this area of research. Firstly, the studies that have been conducted to date incorporating a measure of school absenteeism are few and largely dated. As a result, the limited findings in the literature may not be reflective of recent advances in the medical management of T1D. For example, the evolution of insulin pumps and their uptake may limit the extrapolation of older studies to current populations where insulin pump use offers greater flexibility in T1D management (Wodrich, et al., 2011). This argument was also recently made in relation to levels of psychological distress in children with T1D (Reynolds & Helgeson, 2011). It has been suggested that future research into this area may identify reduced

school absenteeism, relative to the data provided in the few studies available, as management practices continue to develop in flexibility and effectiveness for T1D management; however, these studies are yet to be undertaken (Wodrich, et al., 2011). Second, there is a noticeable lack of reported research exploring the associations between school absenteeism and psychosocial status in children and adolescents with T1D.

2.9. Overview of Gaps in the Research Literature

Psychological research exploring the correlates of optimal management in T1D has made substantial progress in the last 20 years, but specific gaps remain. In the past, depressive and anxiety symptoms were studied primarily from the perspective of establishing prevalence of psychological symptoms in T1D populations, and the relationship of these symptoms to glycaemic control. Most of these studies were conducted in samples comprising adults and adolescents, and studies in children remain limited. The current understanding of mood factors associated with suboptimal T1D management is well established through studies of adults with T1D (Anderson, et al., 2001; Van Tilburg, et al., 2001). Recent research has extended this work in adults with T1D, and investigated these associations in light of recent management advances, such as the insulin pump (Aberle, et al., 2009). An understanding of these relationships has also been undertaken to a significant extent in past studies of adolescents (Grey, et al., 1998), and has continued in several recently published studies of adolescents (Herzer & Hood, 2010; Luyckx, et al., 2010; Skocic, et al., 2010). The developmental milestones that characterise childhood and adolescence and their subsequent relationship to illness management tasks imply that it is insufficient to extrapolate findings previously obtained in adolescents with T1D to children.

The relative amount of recent research undertaken investigating depressive and anxiety symptoms in children is limited, particularly in the Australian context. These limitations were reflected in a recent comprehensive meta-analysis of studies, which investigated depressive and anxiety symptoms in children with T1D (Reynolds & Helgeson, 2011). Of the eight studies included that specifically assessed depressive or anxiety symptoms in this age group, only two were published within the last decade (Helgeson, et al., 2007; Tercyak, et al., 2005), confirming the need for contemporary research.

The nature of psychological concerns in children and their relationship to illness management is less understood. The lack of recent studies comprises a gap in the current research literature, since older studies may not fully reflect recent medical treatment advances, and changes in family structure and functioning. These include the medical advances of intensive treatment regimens and the insulin pump, as well as the support provided through YADS clinics, diabetes nurse educators and psychosocial workers (e.g. social workers and psychologists), increased single parent families, and working parents. The impact of recent treatment advances on medical outcomes already appears promising. The greater flexibility offered by relatively recent options such as the insulin pump has been put forward as an explanation for reduced medical complications such as severe hypoglycaemia in Australian children within the last decade (O'Connell, et al., 2011), as well as reduced internalising psychological symptoms in an Australian pilot study (Knight, et al., 2009).

If the burden of managing T1D is related to the experience of depressive or anxiety symptoms, it is possible that such treatment advances may be related to concomitant changes in psychosocial outcomes. By investigating psychological wellbeing in a contemporary sample of Australian children and adolescents with T1D, a reduction in psychological symptoms such as

depression or anxiety may be observed in children currently engaged with such treatment regimens. The most recent published study which comprehensively investigated depressive and anxiety symptoms in Australian children with T1D included data collected in the 1990s (Northam, et al., 2005), and data to test this hypothesis is currently limited (Knight, et al., 2009). A recent review of Australian children and adolescents with T1D highlighted the exploration of psychosocial issues in the context of such treatment advances as an important area which required further research and understanding, particularly as early psychological complications may be more amenable to modification than early microvascular complications (Ambler, et al., 2006).

The relative lack of research in children is also of concern from a medical perspective. The skills which require mastery for the long-term management of T1D are learned from the time of illness diagnosis. If psychosocial concerns are related to poor illness management from childhood, the child may be placed at a greater risk of illness management problems and medical complications earlier in life.

The relationship of mood factors to related psychosocial factors, such as coping, self-efficacy, and illness knowledge, also remains relatively unexplored in children with T1D. Further empirical research regarding these relationships may assist in the continued development of clinical interventions which target modifiable risk factors, with the aim of optimising T1D management in children and adolescents. Clinical interventions which aim to address psychosocial skills in youth and/or their families hold much promise in improving psychosocial and medical outcomes in children and adolescents with T1D. While some interventions have shown promise, psychosocial improvements have not necessarily resulted in concordant improvements in illness management outcomes (Grey, Jaser, Whittemore, Jeon, & Lindemann,

2011). A recent review by Winkley et al. (2006) included 29 studies which involved psychological interventions in children and adolescents with T1D, and conducted a further meta-analysis based on 10 trials in children and adolescents with T1D. A slight improvement was reported in the analysis of child and adolescent outcomes based on the effect size obtained. Further research is required to build on this promising finding. By better targeting the psychosocial variables included in such interventions, it may be possible to further increase improvements in psychosocial outcomes, and indirectly optimise T1D management.

2.10. Chapter Summary: Rationale for the Current Study

The psychological sequelae experienced by children and adolescents with T1D have been aptly described as a hidden complication of living with the illness (Ambler, et al., 2006). The research discussed in this chapter indicates that children and adolescents with T1D appear more likely to experience depression and anxiety, and that these responses persist beyond the initial adjustment period following diagnosis. Furthermore, coping, self-efficacy, and family functioning are implicated in T1D management and overall wellbeing, but little is known about the role of T1D knowledge to these two outcomes.

The need to address psychological concerns in this group from a young age is critical, as psychological complications may be more amenable to prevention and early intervention, compared to known medical complications such as early microvascular complications (Ambler, et al., 2006). It is therefore important to identify these problems in order to intervene as early as possible.

The research literature reviewed in this chapter indicates that the relationship between psychosocial wellbeing and T1D management is less studied and therefore understood in children, compared to adolescents and adults.

2.11. Conceptualisation of the Current Study

Living with T1D presents considerable challenges to children, adolescents and their families. As diagnosis is typically in childhood and management requires daily intervention, living with the condition is a lifelong process. The medical consequences of poorly managed T1D (e.g. severe hypoglycaemia, microvascular complications) can also present from a young age, and exacerbate into adulthood. Past research in adults and adolescents has reliably linked psychosocial issues to impaired diabetes management, particularly in relation to glycaemic control (Anderson, et al., 2001; Lawrence, et al., 2006). Current research focusing on children engaged in modern treatment regimens is relatively limited. By better understanding the role of specific psychosocial factors on management of T1D in children, it may be possible to improve illness management.

2.12. Aim

The aim of this study was to assess the impact of psychosocial factors, specifically depression, anxiety, coping, self-efficacy, T1D knowledge and family functioning on children's T1D management. T1D management was operationalised as glycaemic control (HbA1c levels) and school absenteeism.

2.13. Research Questions and Hypotheses

This research investigated the psychosocial predictors of optimal T1D management in children; specifically relationships between:

1. Depression, anxiety, coping, self-efficacy, family functioning, T1D knowledge and glycaemic control.
2. Depression, anxiety, coping, self-efficacy, family functioning, T1D knowledge and school absenteeism.

The hypotheses relevant to T1D management outcomes were:

1. Greater depression and anxiety will predict worse glycaemic control and greater school absenteeism.
2. Enhanced coping with T1D and sense of self-efficacy related to T1D will predict better glycaemic control and less school absenteeism.
3. Better T1D-related family functioning will predict better glycaemic control and less school absenteeism.
4. Greater knowledge of T1D will predict better glycaemic control and less school absenteeism.

The hypotheses related to psychosocial wellbeing outcomes were:

1. Greater depression and anxiety will predict worse coping with T1D, less self-efficacy related to T1D, worse T1D-related family functioning and less T1D knowledge.
2. Enhanced coping with T1D and sense of self-efficacy related to T1D will predict lower levels of depression and anxiety, better T1D-related family functioning and greater T1D knowledge.
3. Improved T1D-related family functioning will predict lower levels of depression and anxiety, better coping with T1D, higher levels of self-efficacy and greater T1D knowledge.

4. Greater knowledge of T1D will predict less depression and anxiety, better coping with T1D, greater self-efficacy regarding T1D and better family functioning regarding T1D.

In the next chapter, the research design and methodology employed in the current research is described.

Chapter 3: Method

3.1. Participants

Two groups of participants were recruited for this study from the Diabetes Ambulatory Care Service (DACS) clinic at a tertiary metropolitan hospital in Melbourne, Victoria, Australia. Group one comprised children and adolescents with T1D. Group two were parents or guardians of youth participating in this study. In most cases, this was the adult who generally accompanied the young person to their T1D clinic appointments, and was considered to be the most involved of both parents (if applicable) in the young person's T1D care. Throughout the remainder of this thesis, group one are referred to as 'participants', and group two as 'parents'.

The DACS clinic provides multidisciplinary clinic reviews to patients aged 0 to 15 years with T1D or T2D. The clinic offers one government-funded clinic on a weekday morning, as well as private appointments across other weekdays. Families may reside in metropolitan or regional Victoria, and usually visit the clinic once every three months for a routine appointment with the child's paediatric endocrinologist. At the age of approximately 16 years, clinic patients are transitioned to adult care through the YADS clinic.

3.1.1. Participant inclusion and exclusion criteria. Only children and adolescents aged between 7 and 15 years, with a clinically confirmed T1D diagnosis for at least 12 months prior to recruitment time were eligible. The minimum 12 months from diagnosis allowed for psychological adjustment to the diagnosis by the participant and their family. This timeframe has been well established by Northam, Anderson, Adler, Werther and Warne (1996), who identified increased symptoms of psychological distress in children and adolescents aged up to 15 years.

While increased symptoms were identified for up to 12 months after T1D diagnosis, they had mostly resolved at 12 month follow-up. English proficiency and an absence of medical or psychological conditions affecting a participant's ability to complete the study requirements were further inclusion criteria.

While participants aged between 7 and 15 years were sought, recruitment was initially focused on children aged between 7 to 10 years of age, as there is a relative dearth of T1D research in Australian children. Soon after the recruitment process began in approximately July 2009, difficulty in obtaining an appropriate sample size with this restricted age range led to the utilisation of the 7 to 15 years age range to ensure an appropriate sample size.

The study initially offered data collection at the hospital site only, however feedback from prospective participating families indicated that completing data collection after their child or adolescent's routine T1D medical appointment was inconvenient. This was reflected in the low number of participants tested in the first six months of data collection in July to December 2009 (n = 4). Home visits were subsequently added to the research protocol to allow greater flexibility to families, and to increase the sample size. The success of the home visits option was reflected in the final sample, with 90.1% (n = 64) taking part using this method. Home visits were offered by the student researcher after school on weekdays, and during the day on weekends and school holidays. The home visit option also required a substantial time commitment by the student researcher due to the regional location of some families, which was up to 3.5 hours in each direction. In some cases, data collection for one participant would require a full day including travel. The mean return distance travelled for each home visit was 53.1 km (range: 9-292 km), and totalled over 3028 kms during the data collection period.

The data collection process was anticipated to be completed within one year. Due to the lack of sufficient participants after 12 months for the required statistical analyses, the data collection period was extended to 26 months in total.

3.1.2. Descriptors of participants. Participants initially comprised 80 children. Following data cleaning, the sample for statistical analyses comprised 71 participants. Participant and parent descriptors reported in this thesis are based on the final sample. There were slightly more females (52.1%), and most (69%) were adolescents (M = 11.62, SD = 1.9), with 31% of the sample aged between 7 and 10 years of age.

The majority of participants lived with both parents (78.9%), with fewer living with a single parent (14.1%), and the remainder living with step-parents, other family members or a '50/50' arrangement with both biological parents. Most families reported a middle-class income of $50,001-$100,000 (44.3%), however low-income families with an income of less than $50,000 (18.5%) and high-income families earning over $100,000 (37.1%) were a substantial percentage of the final sample.

3.1.3. Descriptors of parents. Parent demographic information was obtained from 70 of the 71 families included in the final sample. The majority (84.3%, n = 59) were mothers of the participants, and more than half were aged between 35 and 44 years, with 40% aged between 45 and 54 years. Most parent respondents were employed in paid work (81.4%), and a small number were stay-at-home parents (16.7%) or not employed in paid work (2.6%).

3.1.4. Descriptors of type 1 diabetes management. Nearly half (48.5%) of the sample received their insulin using continuous subcutaneous insulin infusion therapy (CSII), whilst other reported methods were insulin injections via hypodermic needle (27.9%) or via pen (23.5%) forms. In the DACS clinic, the majority of patients using hypodermic needles were on a twice daily (referred to as BD) regimen, and the majority of patients using pens were on a MDI regimen. The mean HbA1c level of participants was within the 'suboptimal' range of greater than 7.5% and less than 9.0% (M = 8.8%, SD = 1.1), as suggested in current clinical guidelines published by the International Society for Pediatric and Adolescent Diabetes (ISPAD) and the International Diabetes Federation (IDF) (2011). The participant sample was therefore representative of the clinic population across this age range for glycaemic control (M = 8.8%, SD = 1.4).

3.2. Measures

3.2.1. Demographic information. Each participant completed a written questionnaire including all research measures (see Appendix A). The questionnaire contained a demographics section, measuring participants' age and insulin regimen.

3.2.1.1. Diabetes self-care. The Summary of Diabetes Self-Care Activities (SDSCA) (Toobert & Glasgow, 2001) was used to assess participants' diabetes self-care activities. The SDSCA is a self-report measure of the frequency of participating in different diabetes self-care activities in the seven days prior to test administration. The areas of self-care activities include four subscales: Diet Amount, Diet Type, Exercise and Glucose Testing. An example item for the diet category included "How often did you follow your recommended diet over the last 7 days?" Responses were on a 5-point Likert scale ranging from 'Always' to 'Never'.

Parents were asked to complete a brief demographic questionnaire regarding the participant's diabetes functioning and family demographics (see Appendix B). The demographic information obtained in the parent instrument included: parent/guardian age group, occupation, range of household income and household location. The last three items were collected to assess socioeconomic status of the family. Family structure was explored using items that assessed the participant's living arrangements and number of siblings.

3.2.2. Type 1 diabetes management.

3.2.2.1 . HbA1c levels. Glycated haemoglobin (HbA1c) is the standard form of assessing blood glucose levels in the previous three months win youth with T1D, and is therefore used as a proxy measure of T1D management. The closest HbA1c level available to the time of data collection was obtained from the medical record of each participant by medical staff at the paediatric diabetes clinic. Since HbA1c is subject to fluctuations that are unrelated to T1D management in children and adolescents, such as infections and hormonal changes (Nouwen, et al., 2009), a supplementary measure of illness management, school days missed, was also included in this study.

3.2.2.1. School days missed. Parents were asked to record whether two or more days of school were missed by their child or adolescent with T1D in the preceding school term ('Yes' or 'No'). Parent participants completed this brief measure independently at the time of data collection.

3.2.3. Depressive symptoms. The Children's Depression Inventory (CDI) (Kovacs, 1992) was used to assess the level of depressive symptomatology in participants. The CDI is a

widely used measure of depressive symptoms in children and adolescents, in both research studies and clinical assessments. It is designed specifically for use with children and adolescents of school age, and requires the lowest reading level of any self-report measure of depressive symptoms for this group. As such, it was an appropriate measure for this study, given the age range of children and adolescents in sample.

Importantly, the CDI has been widely used to measure the extent of depressive symptoms in both physically well and chronically ill samples, including children and adolescents with T1D (Grey, et al., 2001; Jaser, et al., 2008; Reynolds & Helgeson, 2011). The CDI discriminates between young people with symptoms of major depressive or dysthymic disorder from young people with other psychiatric conditions and well-functioning children. The CDI does not diagnose depressive disorders. Rather, it is a measure of the extent of depressive symptoms experienced by the individual, and this information is compared to age- and gender-based norms to establish if depressive symptoms are elevated.

Good internal consistency has been obtained on the CDI in various samples, with reported Cronbach's alpha coefficients ranging from .71 to .89 (Kovacs, 1992). The item-total score undertaken during test development also demonstrate an acceptable internal consistency and test-retest reliability. The validity of the CDI is also sound, as it has been well established over hundreds of clinical and experimental studies since its development 20 years ago. In the current study, the Cronbach's alpha coefficient was .80, demonstrating good internal consistency.

The full version of the CDI comprises 27 items across five subscales assessing different aspects of depressive symptoms in children. These are: Negative Mood, Interpersonal Problems, Ineffectiveness, Anhedonia and Negative Self-Esteem. These subscales collectively assess

disturbed mood, hedonic capacity, vegetative functions, self-evaluation and interpersonal behaviours.

Each CDI item has three choices: 0, 1 or 2. Higher scores indicate increasing severity, where 0 indicates the absence of a symptom, 1 refers to a mild symptom, and 2 indicates a definite symptom. The raw CDI total score can range from 0 to 54. Approximately half of the items begin with the choice that reflects the greatest severity of symptoms, and the remaining choices are listed in reverse. Participants rated the extent of his or her symptom experience for the past two weeks.

The CDI is scored using a QuikScore Form that allows for the scoring of individual items and the transfer of these responses to a Profile Form to provide a total raw score and conversion to T-Scores. The cut-off score used for elevated depressive symptoms is a raw CDI score of 13 or higher. This cut-off has also been widely used in research studies utilising the CDI in children and adolescents with T1D (e.g. Jaser, et al., 2008), and was therefore adopted in this study.

3.2.4. Anxiety symptoms. Anxiety symptoms were measured using the Revised Children's Manifest Anxiety Scale, Second Edition (RCMAS-2) (Reynolds & Richmond, 2008). The RCMAS-2 is a 49-item self-report measure of anxiety. It comprises six scales, including two validity scales. These are the Inconsistent Responding Index (INC), which consist of nine items, and the Defensiveness Scale (DEF). The remaining four scales comprise a Total Anxiety Score (TOT), and scores for three anxiety-related scales. These are Physiological Anxiety (PHY), Worry (WOR) and Social Anxiety (SOC).

The theoretical basis of the RCMAS-2 is derived from the well-established theory of trait anxiety, in contrast to state anxiety. For this reason, the test developers state that test scores

should be stable over time. This is supported by research completed during the development of the RCMAS-2 (and its predecessor, the RCMAS) (Reynolds & Richmond, 2008).

The RCMAS-2 can be administered to children aged between 6 and 19 years old, and was therefore applicable for use in this study. Participants respond by selecting 'Yes' or 'No' to each item. The instructions request that the child select 'Yes' if they feel that the item describes their feelings or actions. A response of 'No' indicates that the item is generally not descriptive. The RCMAS-2 is scored manually using the test form and summing the scale item totals. The total raw score can range from 0 to 40. The RCMAS-2 is a relatively new measure with specific cut-off scores not yet available for children and adolescents with T1D. As such, the manual's specified cut-off for elevated symptoms, a total T Score greater than 60, was used in this study.

The RCMAS-2 has a Cronbach's alpha of .92 for the total score and values between .75 and.86 for the scale scores. In the current study, the Cronbach's alpha coefficient was .83, demonstrating good internal consistency. According to the test authors, the test-retest reliability is also higher for the Total score (.76) than the test-retest scores obtained for each subscale. The validity of the RCMAS-2 is also well-established.

3.2.5. Coping with type 1 diabetes. The Issues with Coping with Insulin Dependent Diabetes Mellitus scale, Child Version (ICI-C) (Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986; Kovacs, et al., 1990), was used to assess coping with T1D. The ICI-C is a standardised self-report questionnaire, and is divided into a two-part form. Part 1 comprises 15 items requiring the participant to rate "how hard" it is to do certain tasks related to T1D management using a 4-point scale. An included task is to give insulin shots. These items form the subscale for Part 1, titled 'Things Hard to Do' (How Hard). Part 2 comprises 11 items requiring the participant to

answer ‘how upsetting’ it is to do certain tasks using a 3-point scale, for example having blood samples taken. Collectively, these items form the subscale titled ‘Issues that Upset’ (How Upsetting).

Individual scores for each part are then summed to provide a total score for each part of the ICI-C. Part 1 has a possible score range of 0 (all items scored ‘I don’t do this’) to 45 (all items/tasks are ‘very hard to do’). Part 2 has a possible score range of 11 (all items not upsetting) to 33 (all items very upsetting). No cut-off points have been established for this measure. As such, a cut-off score for this study was established for each subscale using the median score of the participant group.

The ICI-C subscale for Part 1, Things that are Hard to Do, showed poor internal consistency in the current study, with a Cronbach’s alpha coefficient of .53. The ICI-C subscale for Part 2, Issues that Upset, showed acceptable internal consistency for the current study, with a Cronbach’s alpha coefficient of .71.

3.2.6. Type 1 diabetes self-efficacy. The Australian-English version of the Diabetes Management Self-Efficacy Scale (DMSES) (McDowell, Courtney, Edwards, & Shortridge-Baggett, 2005) was used to assess self-efficacy relating to T1D.

The DMSES comprises twenty items that are rated on an 11-point Likert scale with the anchors ‘Cannot do at all’ (0), ‘Maybe yes/maybe no’ (5) and ‘Certain can do’ (10). The items assess confidence in a range of activities relevant to diabetes management. The measure has no subscale, and comprises 20 items that assess self-efficacy in areas covering blood sugar level, foot care, medication, diet and level of physical activity.

The scale was developed for adults, therefore one item was modified and two items were removed to improve comprehension for children and adolescents in this study. First, Item 18 was modified to reflect the expected frequency of visits made by child/adolescent participants to their paediatrician at the recruitment hospital (i.e. three-monthly, not yearly) ('I am able to visit my doctor once a year to monitor my diabetes'). In addition, Items 19 and 20, which assessed self-efficacy related to 'medication', were removed from the final analyses as the medication subscale was developed for a T2D audience, and was not relevant to the current sample. Responses were then summed to provide a total score for illness-related self-efficacy ranging from 0 to 180 (following removal of the medication items). A higher score indicated greater self-efficacy.

The DMSES has previously been used in English-speaking adult populations, and the version used in this study was a revision for an Australian population (McDowell, et al., 2005). The Cronbach's alpha coefficient reported by the test authors .91 was obtained in an Australian sample of adults with T2D. In the current study, the Cronbach's alpha coefficient was .90, demonstrating high reliability.

3.2.7. Family functioning in the context of type 1 diabetes. The revised Diabetes Family Behavior Scale (DFBS) was used to measure T1D-specific family support (McKelvey, et al., 1993). The revised DFBS comprises 47 items, which the test authors retained from a total of 60 items in the original version. The total score range is 47 to 235 using a Likert scale response format. The DFBS has two subscales: Guidance-Control, which refers to consistent guidance provided by one's family, and Warmth-Caring, which refers to nurturance provided by family members. An example item for the Guidance-Control subscale is 'My parent(s) watches while I

test for sugar'. An example item for the Warmth-Caring subscale is 'My parent(s) understands how I feel about having diabetes'.

The revised DFBS has acceptable reliability with Cronbach's alpha coefficient of .86 for the total score, .81 and .79 for the guidance-control subscale (.81) and warmth-caring subscales respectively (.79). In the current study, the Cronbach alpha coefficient was .72, demonstrating acceptable reliability.

Previous research has identified associations between higher diabetes-specific family support scores, and better glycaemic control (as measured by HbA1c) (McKelvey, et al., 1993). This relationship was confirmed statistically between the DFBS total score and HbA1c levels, and was also found for the guidance-control subscale score and HbA1c. However, the relationship between the warmth-caring subscale and HbA1cs was not statistically significant. These findings support the use of the DFBS total score as a measure of diabetes-specific family support (McKelvey, et al., 1993).

As this study was investigating the overall relationship of family functioning to depression, anxiety, coping, self-efficacy, knowledge, glycaemic control and school absenteeism the total DFBS score was used. The DFBS does not have a cut-off score to determine better or worse levels of family functioning. As no cut-off has been determined, the median total score was used to separate participants into 'better' and 'worse' family functioning categories for statistical analyses.

3.2.8. Type 1 diabetes knowledge. The Diabetes Knowledge Scale (DKN) (Beeney, Dunn, & Welch, 2001) was developed to assess levels of diabetes knowledge in adults with both T1D and T2D in five categories. These are: basic physiology of diabetes (e.g. insulin action),

hypoglycaemia, food groups and food substitutions, sick day management, and general diabetes care.

A modified version of the DKN 'Form A' (one of three versions developed by the test authors) was used to allow administration to children and adolescents. Form A included 15 items. An example item included 'The NORMAL range for blood glucose control is…'. The modifications included substituting an imperial measure of food for a general term in Items 14 and 15. For example, in Item 14, the sentence 'One portion (1oz) bread = 4 cracker biscuits (e.g. Sao biscuits)' was changed to 'One portion (slice) bread = 4 cracker biscuits (e.g. Sao biscuits)'.

Participants were asked to identify the correct answer for each item using a multiple-choice response format, comprising four or five response choices. A score of 1 for a correct response, and a score of 0 for an incorrect response were assigned. Items 1 to 12 required a single correct answer. For items 13 to 15, several answers were correct and all correct answers had to be selected to obtain a 'correct' answer. Where incorrect response was selected, a score of 0 was provided. A total knowledge score was then calculated by summing the scores across the fifteen items. Possible scores ranged from 0 to 15, with higher scores indicating better diabetes knowledge.

The only youth version of a T1D knowledge scale found was relatively dated (Johnson, et al., 1982), therefore the DKN measure was used as it was recent. Despite modifying this measure for a younger audience to allow administration to all participants in the current study, it was apparent that the measure was not able to be understood by younger participants once data collection began. Therefore, it was only administered to participants at an appropriate reading level. This was determined by making this measure optional for participants aged 10 years old or below, as well as being optional for older participants who were unable to easily read the items.

The unmodified version of the DKN Form A has a moderate reliability (0.74) when validated with an adult T1D sample. However, in the present study, very poor reliability was demonstrated, with a Cronbach's alpha of .39. Despite modification of this measure for a young Australian audience, difficulties were noted in comprehension of the measure during test administration. This was especially evident in the younger group of participants, who appeared to be guessing the correct responses. While many participants attempted items on this measure (n = 61 in the initial dataset of 80 participants), not all items were completed due to comprehension difficulties. The low Cronbach's alpha obtained therefore reflects the low reliability of this measure.

3.3. Design

A correlational study design with predictor variables of depression, anxiety, T1D-related coping, T1D-related self-efficacy, T1D-related family functioning and T1D knowledge was used. Depressive symptoms were operationalised as a continuous variable using the CDI total raw score, and as a dichotomous variable using the CDI raw score cut-off of 13 or higher. Anxiety was operationalised as a continuous variable using the RCMAS-2 total raw score, and as a dichotomous variable using the cut-off of a T Score greater than 60. Family functioning, self-efficacy and coping in the context of T1D were operationalised as continuous variables as the total score for the DFBS, DMSES and ICI-C (Issues that Upset subscale) respectively. Dichotomous forms of family functioning and coping were created using the respective median cut-off score for the sample. Diabetes knowledge was operationalised as a continuous variable as the participant's total score on the DKN. T1D management was assessed using one continuous

variable and one dichotomous variable respectively. Table 2 provides a summary of the operationalised variables used in this study.

Table 2

Operationalisation of Study Constructs as Continuous and Grouping Variables

Variable	Continuous Measure	Continuous Variable Score Range	Dichotomous Measure	Cut-off Score(s) (Dichotomous Measure Score Range)	Grouping Variables
Depression	CDI total raw score	0 to 54	CDI total raw score	CDI raw total score cut-off ≥ 13 (0 to 54)	Not depressed: 0 to 12 Depressed: 13 to 54
Anxiety	RCMAS-2 total raw score	0 to 40	RCMAS-2 total T score	RCMAS-2 total T Score > 60 (RCMAS-2 total T score range <30 to >80)	Not anxious: Total T Score ≤ 60 Anxious: Total T Score > 60
Coping with T1D	ICI-C How Hard total subscale score	0 to 45	ICI-C How Hard total subscale score		
	ICI-C How Upsetting total subscale score	11 to 33	ICI-C How Upsetting total subscale score	ICI-C How Upsetting total subscale sample median of 15 (11 to 33)	Better coping: 15 or less Poorer coping: Above 15
T1D self-efficacy	DMSES total score	0 to 180			
T1D family functioning	DFBS total score	47 - 235	DFBS total score	DFBS total sample median of 160 (47-235)	Poorer family functioning: 159 or less Better family functioning: 160 or higher
T1D knowledge	DKN total score	0 to 15			
Glycaemic control	Recent HbA1c level	Sample range: 6.7-11.4%		Sample range: 6.7-11.4%	Optimal HbA1c range: <7.5% Suboptimal HbA1c range: 7.5-9% High risk HbA1c range: >9%
School absenteeism			School days missed item response	2 or more school days missed	School absenteeism: 2 or more school days missed No school absenteeism: 2 or more school days not missed

3.4. Procedure

3.4.1. Ethical approval and recruitment. This study received ethics approval from the Human Research Ethics Committees at Monash University and the participating hospital (see Appendices C and D). Two types of recruitment, mail and direct approach, were used. Families were sent by surface mail an information pack including letters of invitation from the head of the clinic and the student researcher, participant information and consent forms for both parents and participants and a study pamphlet (see Appendices E-I). Families were also approached by the student researcher directly in the clinic on the day of their appointment. In some cases, families were also contacted by phone prior to or following their clinic appointment to discuss participation in the study.

In total, 282 families were approached. Of these, 80 families consented and participated, providing a final response rate of 28.4%. A further 11 families provided verbal consent to participate, but did not attend data collection or respond to follow-up from phone calls by the student researcher to obtain written consent and proceed with data collection. Nine families were excluded after verbal consent was obtained as the participant did not meet inclusion criteria. These reasons included English language difficulties (n = 2), did not have T1D (n = 1), was aged 16 years old (n = 1), or was diagnosed with a comorbid developmental disorder or intellectual disability affecting participation (n = 5). Across the mail and direct contact recruitment methods, no reply was received from 144 families. A further 38 families declined to participate. The reasons cited by these families included lack of time, lack of interest, and concern for their child regarding participating in psychological research as he/she was already receiving psychological support.

The questionnaire was administered by the student researcher. Adolescent participants generally completed the questionnaire on their own in the presence of the student researcher, and child participants had the questionnaire read to them by the student researcher. This allowed each participant to discuss any potential issue during administration, such as the disclosure of psychological distress. Parents observed the administration procedure in six cases, at the joint request of the participant and their parent.

3.4.2. Data collection. Collection of data was in the home for most (90.1%) participants. Data collection was initially attempted at the clinic alone. However, the busy nature of the clinic limited the capacity for data collection to take place within the timeframe required (approximately 60 minutes). As such, home visits were added to the research protocol in February 2010 to offer families a more convenient opportunity to participate.

Where data collection occurred at the clinic, parents completed their questionnaire in the waiting area while the child's appointment took place. Each participant was seated with the researcher in a clinic room to allow administration of the questionnaire. Parents were seated in the waiting area outside the clinic.

In both the clinic and home settings, the project was reintroduced verbally to the participant and his or her parent/guardian. During the obtaining of informed consent prior to questionnaire administration, participants were assured that their results would remain confidential unless elevated test scores and/or any other results of psychological concern were identified.

During questionnaire administration, some test items referred to insulin administration via a hypodermic needle only (for example, the ICI-C). Participants were verbally prompted to consider their own insulin regimen (i.e. insulin pump, insulin pen or hypodermic needle) before providing a response.

Participants experiencing psychological distress had their results provided to their paediatrician for follow-up and further assessment, including referral to a clinical psychologist (*n* = 20, 25%). Participants were automatically followed up for further assessment if they had an elevated total score for depression (*n* = 9) or anxiety (*n* = 5) symptoms, or endorsed the suicidal ideation item of the CDI (*n* = 8). The remaining participants in the follow-up group (*n* = 5) comprised those who disclosed other psychological concerns (e.g. T1D management difficulties, school problems) during questionnaire administration.

Parents were asked to complete the parent questionnaire in a separate area, while the researcher and participant completed the child/adolescent questionnaire in a quiet area of the home. During the questionnaire administration, participants were asked to answer each question as honestly as possible. The range in time of home visits was 45 to 90 minutes, with up to three hours with younger participants (aged 7 to 10 years old). Participant responses were scored immediately following data collection to identify cases requiring follow-up and referral.

Two iPod© Touch 8GB were offered as an incentive for participation. Winners were identified via a random number generation system following completion of data collection. All participating families who consented to receiving a copy of the overall research findings also received a two-page summary of the study's main findings.

3.5. Statistical Analyses

3.5.1. Power analysis. A sample size of approximately 100 to 150 participants was sought to achieve an acceptable ratio of cases to independent variables for multiple regression. Research Question One investigated the relationships between depression, anxiety, coping, self-efficacy, family functioning, T1D knowledge and glycaemic control. Research Question Two investigated the relationships between depression, anxiety, coping, self-efficacy, family functioning, T1D knowledge and school absenteeism. Therefore, the independent variables for Research Questions One and Two using multiple regression were: depression, anxiety, family support, self-efficacy, coping (How Hard subscale), coping (How Upsetting subscale), and diabetes knowledge. The dependent variables for Research Questions One were HbA1c levels and school absenteeism respectively. Tabachnick and Fidell (2007) recommend the use of the rule $N \geq 50 + 8m$ (where m = number of independent variables) for testing individual predictors. Therefore, 106 participants were required to answer Research Questions One and Two respectively.

3.5.2. Data cleaning. SPSS v.18 was used to clean the data prior to conducting all statistical analyses. The initial sample of 80 participants was subject to data cleaning for removal of outliers that would affect multivariate analyses, and the removal of cases with significant missing data.

3.5.2.1. Treatment of missing data. At the beginning of data collection, an error was made in the printing of a CDI item (Item 8) on the questionnaire administered to the first 24

participants, of the 80 who took part. This item was treated as a missing value due to this error. It was corrected during data collection by prorating the score for this item (0, 1 or 2) using the participant's other scores for the relevant subscale (Negative Mood), prior to manual calculation of the CDI Total Score.

At the end of the data cleaning process (see 3.5.2.2. and 3.5.2.3) a Missing Values Analysis was performed using the regression substitution function in SPSS. Regression substitution was selected because of the type of missing data in this dataset, in accordance with Tabachnick and Fidell (2007).

3.5.2.2. Preparation of key variable totals in SPSS. Total scores for depression and anxiety were the total CDI and RCMAS-2 scores. Total scores were summed for coping (both subscales) (Kovacs, et al., 1990), self-efficacy (McDowell, et al., 2005), family functioning (McKelvey, et al., 1993) and knowledge (Beeney, et al., 2001) according to each test's standard protocol, which included reversal of negative items where applicable, prior to summing to obtain total scores. The generation of a self-efficacy total score also involved the removal of the medication subscale of the DMSES (two items).

3.5.2.3. Removal of outliers based on key research variables. Using the Explore function in SPSS, box plots were generated for all HbA1c levels, depression, anxiety, coping (both subscales), T1D-related self-efficacy and knowledge to identify outliers. Four cases were removed from the dataset using this method. One case was an outlier for HbA1c, depression, family functioning and self-efficacy. An additional three cases were removed after as they were

identified as outliers for one variable total respectively: anxiety, coping (How Upset) subscale, and T1D knowledge.

As HbA1c levels were the outcome variable for Research Question One, missing data for HbA1c levels was thoroughly examined using SPSS v.18 Explore and Missing Values Analysis functions. HbA1c levels could not be obtained for six participants (7.5% of the initial dataset), as the clinic did not have an HbA1c result for the three month period preceding the date of data collection in the medical records. The main reason for this missing information was lack of recent attendance at the clinic. An additional three participants reported recent attendance at a different clinic located closer to the participant's home (n = 3). For these participants, HbA1c levels were requested from the participant's treating health professional, and were obtained for two of the three participants.

Significant missing data was also identified to the knowledge variable. In the initial dataset of 80 participants, 19 cases (23.8%) were found to have missing data. Therefore, knowledge was only included in descriptive analyses and one discriminant function analysis (DFA) for this study (see Chapter Four), and was removed from all subsequent statistical analyses.

Of the original 80 cases, nine were therefore removed from the dataset because of missing HbA1c data (n = 6) and/or because they were outliers (n = 4). One case was both an outlier and had a missing HbA1c level, leaving a final dataset for analysis of N = 71.

3.5.3. Plan for statistical analyses. Using the Explore function in SPSS, histograms were generated for all key variable totals to assess normality of the variable totals. Non-normal

distributions were identified for most key variables including depressive symptoms, anxiety symptoms, self-efficacy, coping with hard and upsetting aspects of T1D, and knowledge. Spearman correlations were therefore conducted to examine associations between all variables before proceeding to specific tests for each research question.

As the final dataset comprised 71 participants, it was not possible to perform a multiple regression analysis. DFA was therefore used as an alternative form of statistical analysis. DFA is used to predict group membership from several predictor variables (Tabachnick & Fidell, 2007). DFA was therefore able to answer the research questions by predicting participant membership to groups based on glycaemic control and school absenteeism. DFA also does not require a specific ratio of cases for each variable, a key criterion for multiple regression. According to Tabachnick and Fidell (2007), the sample size of the smallest group in a DFA must exceed the number of predictor variables, regardless of the sample size. DFA was also appropriate for this study as the non-normal distribution of almost key variables, final sample size and treatment of outliers and missing data did not violate the requirements for DFA.

Research Question One investigated relationships between depression, anxiety, T1D-related coping, T1D-related self-efficacy, T1D-related family functioning, T1D knowledge and glycaemic control. Firstly, descriptive statistics using Spearman correlations were conducted for all variable totals. DFA was conducted using three HbA1c categories (suboptimal, optimal, and 'at risk') designated as the grouping variable for this analysis. Mann-Whitney U tests were used to assess group differences using depression and anxiety as the grouping variables. Based on the significant associations identified using both Spearman correlations and Mann-Whitney U tests, DFA was used to identify significant predictors of membership to participant groups based

specifically on depressive symptoms, coping with upsetting aspects of T1D, and family functioning. **Research Question Two** investigated relationships between depression, anxiety, T1D-related coping, T1D-related self-efficacy, T1D-related family functioning, T1D knowledge and school absenteeism. This question was investigated using DFA, with school absenteeism used as the grouping variable in the analysis.

Chapter 4: Psychosocial Predictors of Coping and Family Functioning in Children and Adolescents with Type 1 Diabetes

4.1 Preamble to all Papers

4.1.1. Summary of descriptive statistics. As this is a thesis by publication, a summary of descriptive statistics for the variables used in all statistical analyses is presented in Table 3. This summary is provided for the final sample (N = 71) that was used for all analyses.

Table 3
Summary of Descriptive Statistics of Study Variables for Final Sample (N = 71)

Variable	Continuous Measurement	*M*	*SD*	*Md*	Min	Max	Dichotomous Measurement	Group Frequencies (*n*)
Depression	CDI total raw score	5.49	4.61	4	0	17	Depressed	7
							Not depressed	63
							Missing	1
Anxiety	RCMAS-2 total raw score	8.39	6.75	6	0	26	Anxious	3
							Not anxious	68
Coping with T1D	ICI-C How Hard total subscale score	18.07	3.58	18	9	25		
	ICI-C How Upsetting total subscale score	15.72	3.65	15	11	25	Better coping	37
							Poorer coping	33
T1D self-efficacy	DMSES total score	147.83	20.08	151	89	182		
T1D family functioning	DFBS total score	161.31	16.55	160	131	204	Low family functioning	35
							High family functioning	36
T1D knowledge	DKN total score	9.51	2.34	9.83	3	14		
Glycaemic control	Recent HbA1c level	8.81	1.12	8.70	6.7	11.4	Optimal	6
							Suboptimal	39
							High risk	26
School absenteeism							2 or more school days missed	54
							2 or more school days not missed	16
							Missing	1

4.1.2. Psychosocial predictors of 'optimal,' 'suboptimal' and 'high risk' glycaemic control. To investigate Research Question One, relationships were explored between depressive symptoms, anxiety symptoms, T1D-related family functioning, T1D-related self-efficacy, coping with T1D tasks (How Hard subscale) and upsetting aspects of T1D (How Upsetting subscale), T1D knowledge and glycaemic control.

DFA was used to explore psychosocial predictors of membership to three groups of glycaemic control. For this analysis, recent international clinical guidelines jointly published by ISPAD and the IDF (2011) were used to distinguish between 'optimal', 'suboptimal' and 'high risk' HbA1c ranges. In accordance with the guidelines, HbA1c levels were defined as 'optimal' if the percentage was less than 7.5%, as 'suboptimal' if it was between 7.5% and 9%, and as 'high risk' if it was greater than 9%.

In the 71 cases used in this analysis, only six participants had optimal HbA1c levels according to these criteria. The majority had a 'suboptimal' (n = 39) or 'high risk' (n = 26) HbA1c level. The evaluation of assumptions of linearity, multicollinearity and singularity required for DFA were not violated. The assumption of normality was not met for most of the variables in this analysis. According to Tabachnick and Fidell (2007), significance tests for DFA are robust when non-normality is due to skewness rather than outliers. As outliers had been removed in the data cleaning process, analysis was able to proceed for all DFA analyses.

Two discriminant functions were calculated, and neither was significant (Wilks' lambda = .73, df = 14, $p > .05$. [Function 1], Wilks' lambda = .916, df = 6, $p > .05$ [Function 2]). Therefore, it was not possible to significantly distinguish between the sample on the basis of 'optimal', 'suboptimal' and 'high risk' HbA1c levels using depression, anxiety, and illness-

related coping, self-efficacy, family functioning and knowledge. As the group means between the three groups were not found to be statistically significant, classification of variables was not able to be undertaken. Therefore, glycaemic control was not predictive of psychosocial wellbeing in this sample.

Knowledge was included in the DFA analysis reported above, however the poor reliability of the modified DKN measure was of concern. Subsequent DFA analyses in this study therefore did not include knowledge as a predictor variable.

4.1.3. Overview of statistical analyses reported in papers. In a brief overview of the statistical analyses for this study, Research Question One was investigated using DFA, which found that participants' membership of 'suboptimal', 'optimal' and 'at risk' HbA1c levels were not predicted by any aspect of psychosocial wellbeing. As the results of correlational analyses (reported in Paper 3) and Mann-Whitney U tests (reported in Paper 2) identified significant associations between depression, anxiety, coping types, self-efficacy and family functioning, a second set of DFA analyses were conducted. The remainder of this chapter (Paper 1) reports on the psychosocial predictors of coping and family functioning in Australian children and adolescents with T1D. Chapter Five, Paper 2 reports on the psychosocial predictors of. depressive symptoms. Research Question Two is addressed in Chapter Six, Paper 3 which reports on the psychosocial predictors of school absenteeism.

4.2. Preamble to Paper 1

Past research has linked positive coping styles and optimal family functioning to better psychosocial and T1D management outcomes in adolescents. These aspects of wellbeing have not been specifically investigated in previous studies of psychosocial wellbeing in Australian children and adolescents with T1D. In order to further elucidate the nature of the relationships between different aspects of wellbeing in this study, coping styles and family functioning were analysed further. The psychosocial predictors of family functioning and coping are reported in Paper 1.

The How Hard coping subscale showed poor internal consistency in the current study, with a Cronbach's alpha coefficient of .53. The How Upsetting subscale showed acceptable internal consistency for the current study, with a Cronbach's alpha coefficient of .71. The How Upsetting subscale was therefore used to define coping in Paper 1, where coping was an outcome measure. This manuscript was submitted to the journal *Diabetes Care*.

PART B: Declaration for Thesis Chapter

Monash University

Declaration for Thesis Chapter 4

Declaration by candidate

In the case of Chapter 4, the nature and extent of my contribution to the work was the following:

Nature of contribution	**Extent of contribution (%)**
Conceptualisation of research, and writing of manuscript (Title: 'Predictors of coping and family functioning in Australian children and adolescents with type 1 diabetes') Participant recruitment, data collection and statistical analysis	70

The following co-authors contributed to the work. Co-authors who are students at Monash University must also indicate the extent of their contribution in percentage terms:

Name	**Nature of contribution**	**Extent of contribution (%) for student co-authors only**
Dr Margaret Hay	Guidance regarding statistical analysis; assisted with conceptualisation of manuscript; review of manuscript draft	
Dr Philip Bergman	Assisted with participant recruitment and interpretation of clinical data, review of manuscript draft	
A/Prof Christine Rodda	Assisted with participant recruitment and interpretation of clinical data, review of manuscript draft	

Candidate's Signature		**Date**

Declaration by co-authors

The undersigned hereby certify that:

(1) the above declaration correctly reflects the nature and extent of the candidate's contribution to this work, and the nature of the contribution of each of the co-authors.

(2) they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;

(3) they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;

(4) there are no other authors of the publication according to these criteria;

(5) potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit; and

(6) the original data are stored at the following location(s) and will be held for at least five years from the date indicated below:

Location(s)	**School of Psychology and Psychiatry, Monash University, Clayton**

Signature 1		**Date**
Signature 2		
Signature 3		

TITLE PAGE

Predictors of coping and family functioning in Australian children and adolescents with type 1 diabetes

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Abstract

Objective: The aim of this study was to explore the psychosocial factors related to coping and family functioning in children and adolescents with type 1 diabetes. It was hypothesised that poor coping and less family support would be predicted by poorer psychological and family functioning.

Research Design and Methods: 80 participants were recruited from a pediatric diabetes outpatient clinic in metropolitan Melbourne, Australia. Participants completed a written questionnaire including measures of internalising symptoms (depression and anxiety), coping styles, family support and self-efficacy. HbA1c levels were obtained from participants' medical records. A final sample of 71 participants (52.1% female), aged between 7 and 15 years (M = 11.62, SD = 1.9) was used in analyses.

Results: Participants who used positive coping strategies reported lower levels of depression and anxiety, coped better with diabetes tasks that were hard to do, and reported higher diabetes self-efficacy (Wilks' lambda = 0.613, chi square (6) = 31.760, p = 0.000). Similarly, participants who reported less family support were older, had higher levels of depressive and anxiety symptoms, and had reduced diabetes self-efficacy (Wilks' lambda = 0.803, chi square (6) = 14.451, p = 0.025).

Conclusions: These findings suggest that positive coping strategies and higher levels of family support are associated with multiple facets of psychosocial wellbeing in children and adolescents. Clinical interventions to reduce depression and anxiety in this population may benefit from a multifaceted approach which encourages the development of positive coping skills and family involvement in T1D.

Keywords: family functioning, coping, type 1 diabetes, children, adolescents, psychosocial

Australian children and adolescents experience a high incidence of type 1 diabetes. Every year, 23 cases per 100,000 are diagnosed nationally, representing an increase from previous years (1). Optimal management of type 1 diabetes from the time of diagnosis is crucial to prevent the onset of early complications from a young age (2). The influence of psychosocial factors such as depression, anxiety, coping and family functioning in achieving optimal type 1 diabetes management is increasingly recognised (3). It is now clear that aspects of wellbeing, such as depression and anxiety, are linked to poor glycaemic control in children and adolescents (4). This means that optimal type 1 diabetes management also requires consideration of the psychosocial wellbeing on children and adolescents with the condition.

Coping has been commonly defined using Folkman and Lazurus' definition, which refers to one's adaptation to stressful events (external and/or internal), using cognitive and behavioural efforts (5-7). The framework categorises coping strategies as problem-focused, i.e. strategies that directly address the stressor, and emotion-focused, i.e. strategies that address unpleasant emotions related to one's appraisal of the stressful event. These strategies may be demonstrated in relation to T1D management difficulties through positive coping skills such as seeking help from family and health professionals (problem focused), or using emotional expression or acceptance strategies (emotion focused) (8). The use of other strategies, such as avoidance of medical issues (emotion focused), may be detrimental to diabetes management, although it may temporarily alleviate feelings of distress (9). Problem-focused strategies are related to fewer depressive symptoms and improved glycaemic control in adolescents (10), while emotion-focused coping styles have been associated with poor glycaemic control in adolescents (11), including the use of avoidant coping strategies (12). The related construct of self-efficacy refers to confidence in performing illness-related behaviours, and is an important factor in maintaining

optimal illness regimens over a person's lifetime (13). These findings suggest that an awareness of the coping styles used by children and adolescents is important for both their medical and psychosocial wellbeing. While these studies have been conducted in developed countries, no previously published studies have explored the relationship of coping styles to other facets of psychosocial wellbeing in Australian children and adolescents with type 1 diabetes.

Type 1 diabetes has also been described as a condition that impacts on the entire family, not only the diagnosed child, due to the crucial role of family members in type 1 diabetes management in children and preadolescents (3, 14). Recent research in this area has suggested that some family factors, such as critical parenting, can adversely affect diabetes medical outcomes (15-17); while parental warmth, in conjunction with a more authoritative parenting style that offers guidance to children and adolescents, can improve glycaemic control and management adherence (17-19). Related constructs such as family cohesion (20) and collaborative parenting styles (21) are also associated with better psychosocial outcomes, including fewer depressive symptoms and greater self-efficacy. No previously published studies of psychosocial wellbeing in Australian children and adolescents have measured parental guidance and warmth in this group. A greater understanding is required as there is a potential to use this information to better target clinical interventions for this important group (3).

The psychological literature has established that young people with type 1 diabetes are at higher risk of psychological disorders, such as depression and anxiety (4). However, much of this research has focused on establishing prevalence rates, with less attention paid to understanding the relationships between psychosocial factors *within* young people with type 1 diabetes (4). In a recent meta-analysis, Reynolds and Helgeson (4) concluded that most youth with type 1 diabetes do relatively 'well' from a psychological perspective; however, an important

subset of this pediatric population remain vulnerable to psychosocial issues. Further research is required to better understand the intrapersonal and interpersonal characteristics that differentiate those who experiencing optimal psychosocial wellbeing from those who experience problems, as psychosocial wellbeing is known to be associated with optimal type 1 diabetes management (22, 23). Poor management from a young age can also result in medical complications evident in youth. There is therefore a long-term potential for microvascular and macrovascular complications in later life, as a result of ongoing difficulties in diabetes management (2).

A better understanding of the psychosocial characteristics of those youth with type 1 diabetes with positive coping styles and adaptive family styles may lead to targeted health interventions with psychosocial and management outcomes. We also sought to include children aged from seven years old, in order to address the relative lack of research exploring psychosocial wellbeing in children, compared to adolescents (24).

This study explored the psychosocial factors that best differentiated those coping well in a sample of Australian children and adolescents with type 1 diabetes. Aspects of psychosocial wellbeing that differentiated youth with better family functioning from those with worse family functioning were also investigated. The research questions were as follows: (i) which psychosocial factors best predict youth coping well with their T1D from those who are coping poorly? And (ii) which psychosocial factors best predict youth experiencing higher levels of family functioning from those with reduced family functioning? It was hypothesised that those coping poorly would have higher levels of depression and anxiety, less self-efficacy and poorer family functioning. It was also hypothesised that participants with reduced family functioning would experience higher levels of depression and anxiety, greater coping difficulties and reduced self-efficacy.

Research Design and Methods

Participants

Participants were 80 children and adolescents with type 1 diabetes, who were recruited from a paediatric diabetes outpatient clinic based at a tertiary Australian metropolitan hospital. Participants were part of a doctoral research study exploring psychosocial factors in Australian children and adolescents with T1D, including depression and school absenteeism outcomes. Following data cleaning to remove outliers (n = 4) and cases with missing recent HbA1c levels (n = 6, with one case meeting both criteria for removal), a final sample of 71 participants was obtained. There were slightly more females (52.1%), and the sample were aged between 7 and 15 years old (M = 11.62, SD = 1.9). Nearly half used subcutaneous insulin infusion (SCII) (48.5%), with syringes (27.9%) and injection pen device (23.5%) insulin administration less common. The mean HbA1c level of 8.8% (SD = 1.1) was suboptimal, compared to the clinic's target range of <7.5% (25). Most (90.1%) were tested during a home visit, and the remainder at a clinic appointment. The majority of participants lived with both biological parents (78.9%) or with a single parent (14.1%), with the remainder living with step-parents, other family members or a '50/50' arrangement with both biological parents. Eligibility criteria were being aged between 7 and 15 years, and having a diagnosis of type 1 diabetes for at least 12 months. The latter requirement allowed for initial psychological adjustment to diabetes diagnosis (26). Exclusion criteria included the presence of clinically significant psychological comorbidities or other medical conditions affecting their ability to participate, and a lack of oral and written English. Of the 282 eligible families contacted, 80 provided consent and participated in the study, providing a final response rate of 28.4%.

Procedure

Ethical approval was obtained from the human research ethics committees of Monash University (HREC Approval No: CF08/1477-2008000755) and Southern Health (HREC Approval No: *07205C). The research was conducted in accordance with the Declaration of Helsinki. Data collection involved two methods: direct mail and in-person contact at the recruitment clinic. Introductory information packs were sent to each family; with the aim of contacting participants immediately prior to their next scheduled clinic visit. Follow-up was then conducted in person at the clinic visit, and/or by phone if required to determine consent to participate. Participants who consented were then offered the choice of a home visit or a post-clinic appointment to obtain data collection. All participants were also placed in a raffle draw for one of two electronic accessories (Apple iPod Touch™ 8GB) which was drawn using a random number generation calculator.

KB administered the written questionnaire to participants. Home visits generally took approximately 45 to 90 minutes. Twenty participants were followed up for referral to a clinical psychologist as results indicated elevated depressive (n = 9) or anxiety (n = 5) symptoms, an endorsement of the suicidal ideation item of the CDI (n = 8), or the disclosure of other psychological concerns (n = 5).

Measures

Demographic and medical data. Each child/adolescent participant completed a brief demographic questionnaire which included their insulin regimen. HbA1c levels were obtained from the participant's medical record.

Depressive symptoms. Participants completed the *Children's Depression Inventory* (27), which comprises 27 items to assess depressive symptoms experienced in the past two weeks. The CDI has been used to measure the extent of depressive symptoms in both physically well and chronically ill samples, including children and adolescents with type 1 diabetes (28, 29). In the current study, the Cronbach's alpha coefficient was 0.80, demonstrating good internal consistency. Elevated depressive symptoms were defined by a raw total CDI score of 13 or higher, in accordance with other studies using this measure in children and adolescents with type 1 diabetes.

Anxiety symptoms. The Revised Children's Manifest Anxiety Scale – Second Edition (30) is a 49-item self-report measure of anxiety symptoms based on a state/trait anxiety framework (30). Participants were asked to endorse each item with 'Yes' or 'No'. The RCMAS-2 can be administered to children aged between 6 and 19 years old. A child responds by selecting 'Yes' or 'No' to the item. In the current study the Cronbach's alpha coefficient was 0.83, demonstrating good internal consistency. An elevated total score was defined using the author's criteria as a Total T Score greater than 60 (30).

Family functioning. The revised Diabetes Family Behavior Scale (DFBS) (31) was used to measure diabetes-specific family support. The revised DFBS comprises 47 items which form two subscales: Guidance-Control, which refers to consistent guidance provided by one's family, and Warmth-Caring, which refers to nurturance provided by family members. In the current study, the Cronbach's alpha coefficient was 0.72, demonstrating an acceptable internal

consistency. As no cutoff has been determined for this measure, the median score was used as the cutoff score in this sample.

Coping. The Issues with Coping with IDDM scale, Child Version (ICI-C) (32, 33), was used to assess coping with type 1 diabetes tasks, and the feelings associated with managing the condition. The ICI-C is a standardised self-report questionnaire. The nature of the items in Part 1 appear to assess problem-focused coping, and comprised 15 items requiring the participant to rate 'how hard' it is to do certain things (e.g. 'Giving myself needles [getting needles]'). These items form the subscale for Part 1, Things Hard to Do (How Hard). The 11 items which comprised Part 2 appear to assess emotion-focused coping, requiring the participant to answer 'how upsetting' it is to do certain tasks (e.g. 'Thinking that I may have to be in the hospital'), and form the subscale Issues that Upset (How Upsetting). Where a test item referred to insulin administration via a hypodermic needle only, participants were verbally prompted to consider their own insulin regimen (i.e. insulin pump, insulin pen or hypodermic needle) before responding. The ICI-C How Hard subscale showed poor internal consistency for the current study, with a Cronbach's alpha coefficient of 0.53. Therefore, it was excluded from the analysis as a measure of coping outcomes. The ICI-C How Upsetting subscale demonstrated acceptable internal consistency, with a Cronbach's alpha coefficient of 0.71 obtained. Therefore, the How Upsetting subscale was used to define coping in the statistical analysis. As no cut-off points have been established for this measure, the median cut-off score was used.

Self-efficacy. The Australian-English version of the Diabetes Management Self-Efficacy Scale (DMSES) (34) was used to assess self-efficacy related to diabetes. The DMSES comprises

20 items that are rated on an 11-point Likert scale which assess confidence in a range of activities relevant to diabetes management. The DMSES comprises 20 items that assess self-efficacy in areas covering blood sugar level, foot care, medication, diet and level of physical activity. As the scale was developed to assess self-efficacy for adults with type 2 diabetes, a modified version of this measure was included in the present study, which included the removal of medication items and an amendment of an item to reflect the three-monthly cycle of clinic reviews in the recruitment clinic. In the current study, the Cronbach's alpha coefficient was 0.90, demonstrating high internal consistency.

Results

Overview of Data Analysis Procedures

Preliminary analysis of the variable distributions was conducted using SPSS v.18, which included the use of histograms and significance tests for skewness and kurtosis. Kolmogorov-Smirnov and Shapiro-Wilk tests confirmed significant deviations for depression and anxiety raw scores, and coping (How Upsetting subscale). Non-parametric tests were therefore used for statistical analyses.

Spearman correlations were performed to explore relationships between depression, anxiety, coping (How Hard subscale), coping (How Upsetting subscale), self-efficacy and family functioning. Two sets of discriminant function analysis were undertaken, using the coping subscale 'How Upsetting' and the family functioning total score as the key grouping variables in each analysis. The operationalisation of psychosocial factors for statistical analyses is described in Table 1.

INSERT TABLE 1 HERE

Sample Characteristics

Overall, participants had a 'suboptimal' HbA1c level (*M* = 8.8%, *SD* = 1.1). This was not at a 'high risk' level using international criteria, and the attainment of optimal levels of HbA1c in this age group is widely reported as variable and difficult (25). The final sample was representative of clinic patients in this age range for HbA1c levels (*M* = 8.8%, *SD* = 1.4) and geographic region, but the percentage of CSII pump use in the final sample was higher compared to clinic patients in the same age group (28% prevalence). Median total depression (*Md* = 4) and anxiety (*Md* = 6) raw scores for the overall sample were not high, suggesting that the sample represented a psychologically 'well' group overall.

Analysis of Relationships between Depression, Anxiety, Coping, Self-Efficacy and Family Functioning

Research question 1: Predictors of better and worse coping. A direct discriminant function analysis was performed using six variables as predictors of membership as 'coping well

or ‘poor coping’ with upsetting aspects of diabetes. Predictors were depressive symptoms, anxiety symptoms, diabetes-specific family functioning, diabetes-specific self-efficacy, coping with ‘hard’ aspects of diabetes (‘How Hard’ subscale) and age.

One discriminant function was calculated, which indicated that the function significantly distinguished between the better and worse coping groups (Wilks’ lambda = 0.613, chi square (6) = 31.760, p = 0.000). As the differences between the group means were found to be statistically significant, classification of variables was also undertaken, with 75.7% of the original grouped cases correctly classified.

INSERT TABLES 2 & 3 HERE

The structure matrix coefficients are also presented in Table 2. According to the coefficients, the function appears to mainly represent depression, anxiety, coping with ‘hard’ aspects of diabetes, and self-efficacy. The functions at group centroids data (Table 3) suggests that those participants who appeared to be coping better were less depressed and anxious, coped better with things that were hard to do, and reported a greater sense of self-efficacy with regards to their type 1 diabetes management.

Research question 2: Differentiators between high and low family functioning groups. A second direct discriminant analysis was performed using the following predictors: depression, anxiety, self-efficacy, coping 'How Hard' subscale, coping 'How Upsetting' subscale, and age. One discriminant function was calculated, and this was significant. The function indicated a significant difference between the 'high family functioning' and 'low family functioning' groups (Wilks' lambda = 0.803, chi square (6) = 14.451, $p = 0.025$).

INSERT TABLES 4 & 5 HERE

As the group means were found to be statistically significant, classification of variables was also undertaken and 64.8% of the original grouped cases were correctly classified. The structure matrix (Table 4) shows that the variables that best differentiated the groups were depression, anxiety, self-efficacy and age. Interpretation of the group centroids data (Table 5) suggested that participants who reported less family support were older, had higher levels of depressive and anxiety symptoms, and had a lesser sense of self-efficacy with regards to their diabetes management.

Conclusions

This study found that youth who appeared to be coping better with their T1D were less depressed and anxious, coped better with 'hard' diabetes tasks, and reported a greater sense of self-efficacy. In addition, participants who reported better family functioning were younger, endorsed lower levels of depressive and anxiety symptoms, and reported greater diabetes-related self-efficacy. The coping and family styles experienced by Australian children and adolescents are therefore related to depression, anxiety and diabetes-related self-efficacy. These findings are novel, as they are the first to identify psychosocial predictors of adaptive coping and parental styles in an Australian youth cohort. They also provide a broader picture of the overall psychosocial functioning of youth with type 1 diabetes, who were clearly distinguished on the basis of their coping skills and family support.

Both findings are consistent with past research which has identified increased symptoms of psychological distress in adolescents, where there were difficulties in coping and family functioning respectively (35). The finding based on coping outcomes comprise a contribution to the coping literature, as this construct has not been studied explicitly in Australian children and adolescents. While the direction of influence was unable to be assessed in this study, an explanation for this finding is that difficulties coping with upsetting aspects of T1D may predispose the onset of depression and anxiety symptoms, and reduce confidence in ability to complete tasks. This finding may alternatively reflect a relationship in these youth in which feelings of depression, anxiety and low confidence in completing management tasks may result in increased difficulties coping with emotions related to T1D.

The finding based on family functioning outcomes is also consistent with past studies in children and adolescents with type 1 diabetes, which have highlighted the importance of family

support in achieving positive psychological outcomes in this group. An explanation for this finding may be that young people with type 1 diabetes living in family environments characterised by warmth and guidance are less likely to feel distressed by their illness, and that such family support also aids their ability to build confidence in illness tasks through a supportive environment. However, it is also plausible that family problems identified using this measure may have an adverse impact on youth, resulting in increased symptoms of depression and anxiety and a reduced sense of confidence in their ability to complete illness tasks. The direction of this relationship was unable to be confirmed in the study. This study's findings therefore support the evidence base from studies in other developed countries, which affirm the importance of family functioning to other aspects of psychosocial wellbeing, such as depression and self-efficacy (21). While family functioning has been studied in young Australians at the time of T1D and subsequent adjustment (26), previously published studies of Australian samples have not assessed family functioning in the years post-diagnosis.

Limitations and Future Research

A limitation of this study was sampling bias resulting from the low response rate. This limitation prevents the extrapolation of the findings to other children and adolescents with T1D. It is possible that children and adolescents, and their families, with positive coping skills for their illness and a high degree of family functioning were more likely to participate in the study. Therefore, the findings may not capture the full extent of coping and family difficulties within the recruitment clinic, and youth with type 1 diabetes generally. Future research conducted on a representative sample is needed to validate the current findings to the paediatric population with

type 1 diabetes, and to determine if coping and family functioning difficulties are more problematic than identified in this study.

A second limitation was the inclusion of both children and adolescents in the final sample, due to difficulties recruiting more participants. A larger sample would have enabled patterns between both children and adolescents to be compared. For example, the level of family support reported by participants was expected to be higher in younger compared to older participants, due to the expected developmental changes in family involvement, and the growing independence of the young person upon entering adolescence. Future studies that are large enough to make comparisons between Australian children and adolescents based on coping types and family factors would extend the current findings.

There is scope for research studies to better target clinical interventions which aim to improve psychosocial wellbeing. For example, the inclusion of coping skills and parental warmth and guidance components in interventions to prevent depression and anxiety may be warranted. These findings are also relevant to psychosocial interventions with the aim of improving coping and family styles in this group. The implementation of a recent coping skills intervention in American youth with type 1 diabetes improved psychosocial wellbeing, however the intervention did not result in improvements in glycaemic control (6), despite past research findings which have clearly linked coping to glycaemic control and diabetes adherence. Interventions to target coping skills in parents are also indicated by these findings. Although coping skills were not specifically assessed in parents in this study, higher levels of family functioning were clearly linked to better psychosocial wellbeing in children and adolescents. Interventions to improve coping using coping skills training (CST) have achieved improvements in parental coping (36),

however improvements to child and adolescent T1D management outcomes remain difficult to achieve (36).

In summary, this study has contributed to a better understanding of the coping and parenting styles of Australian children and adolescents with T1D. Efforts to improve the efficacy of existing psychosocial interventions using a multifaceted approach guided by these findings comprise an avenue for further research into the wellbeing of affected children and their families.

Acknowledgments

K.B. conceptualised this project with M.H., collected and analysed the data presented in this paper, and wrote the manuscript. M.H. reviewed and edited the manuscript, and guided the analysis. P.B. and C.R reviewed the manuscript, and provided conceptual input from a medical perspective and practical support related to data collection. K.B. is the guarantor of this work, and as such, had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Table 1

Operationalisation of Psychosocial Constructs for Coping and Family Functioning Analyses

Variable	Continuous Measure	Continuous Variable Score Range	Dichotomous Measure	Cut-off Score(s) (Dichotomous Measure Score Range)	Grouping Variables
Depression	CDI total raw score	0 to 54	CDI total raw score		
Anxiety	RCMAS-2 total raw score	0 to 40	RCMAS-2 total T score		
Coping with T1D	ICI-C How Hard total subscale score	0 to 45	ICI-C How Hard total subscale score		
	ICI-C How Upsetting total subscale score	11 to 33	ICI-C How Upsetting total subscale score	ICI-C How Upsetting total subscale sample median of 15 (11 to 33)	Better coping: 15 or less Poorer coping: Above 15
T1D self-efficacy	DMSES total score	0 to 180			
T1D family functioning	DFBS total score	47 - 235	DFBS total score	DFBS total sample median of 160 (47-235)	Low family functioning: 159 or less High family functioning: 160 or higher

Table 2

Standardised Canonical Discriminant Function Coefficients and Structure Matrix Coefficients as a Prediction of Membership to Better Coping (n = 37) and Poorer Coping (n = 33)

	Discriminant Function Coefficient	Structure Matrix Coefficient
Anxiety	0.590	**0.739**
Self-efficacy	-0.342	**-0.460**
Family support	0.393	0.000
Depression	0.311	**0.586**
Coping (How Hard)	0.463	**0.473**
Age	0.111	0.046

Note: Analysis conducted on $N = 70$.

Table 3

Group Centroids for Better Coping and Poorer Coping

	Function 1
Better Coping	-0.739
Poorer Coping	0.828

Table 4

Standardised Canonical Discriminant Function Coefficients and Structure Matrix Coefficients as a Prediction of Membership to High Family Functioning (n = 35) and Low Family Functioning (n = 36)

	Discriminant Function Coefficient	Structure Matrix Coefficient
Depression	0.199	**0.538**
Self-efficacy	-0.498	**-0.524**
Anxiety	0.403	**0.538**
Coping (How Upsetting)	-0.098	0.250
Coping (How Hard)	-0.215	0.025
Age	0.709	**0.627**

Table 5

Group Centroids for Low and High Family Functioning

	Function 1
Low Family Functioning	0.495
High Family Functioning	-0.481

Chapter 5: Psychosocial Predictors of Depressive Symptoms in Children and Adolescents with Type 1 Diabetes

5.1. Preamble to Paper 2

Past research has explored associations between psychosocial wellbeing in adolescents with T1D, but these relationships remain less understood in children. One hypothesis was that non-depressed and non-anxious children and adolescents respectively would be more likely to report higher levels of family functioning, self-efficacy, coping and illness knowledge.

The final sample included a smaller number of depressed (n = 7) and anxious (n = 3) participants after data cleaning was completed. Mann-Whitney U tests were used to determine median differences between anxious (n = 3) and non-anxious (n = 68) participants on levels of coping, self-efficacy, family support and age. A Mann-Whitney U Test revealed that difficulties coping with upsetting aspects of T1D were significantly higher in the anxious group (*Md = 20.83, n = 3)* compared to the non-anxious group (*Md* = 15.00, n = 68), U = 14.00, z = *-2.527*, p = .01, r = .30. The effect size was medium. Median levels of family functioning were also found to be significantly lower for the anxious group (*Md* = 135.00, n = 3) compared to the non-anxious group (*Md* = 160.50, n = 68) participants, U = 3.00, z = -2.832, p = .00, r = .34. The effect size was medium.

Due to the low number (n = 3, 4%) of anxious participants in the sample, it was not possible to proceed with DFA with the aim of identifying predictors of anxious versus non-anxious children and adolescents. However, the number of depressed children and adolescents (n = 7, 10%) was sufficient for further analysis using DFA to proceed. Paper 2 reports on the

psychosocial predictors of depressive symptoms in Australian children and adolescents. This paper was submitted to the *Journal of Pediatric Psychology*.

PART B: Declaration for Thesis Chapter

Monash University

Declaration for Thesis Chapter 5

Declaration by candidate

In the case of Chapter 5, the nature and extent of my contribution to the work was the following:

Nature of contribution	**Extent of contribution (%)**
Conceptualisation of research, and writing of manuscript (Title: 'Psychosocial predictors of depressive symptoms in Australian children and adolescents with type 1 diabetes'). Participant recruitment, data collection and statistical analysis	70

The following co-authors contributed to the work. Co-authors who are students at Monash University must also indicate the extent of their contribution in percentage terms:

Name	**Nature of contribution**	**Extent of contribution (%) for student co-authors only**
Dr Margaret Hay	Guidance regarding statistical analysis; assisted with conceptualisation of manuscript; review of manuscript draft	
Dr Philip Bergman	Assisted with participant recruitment and interpretation of clinical data, review of manuscript draft	
A/Prof Christine Rodda	Assisted with participant recruitment and interpretation of clinical data, review of manuscript draft	

Candidate's Signature		**Date**

Declaration by co-authors

The undersigned hereby certify that:

(1) the above declaration correctly reflects the nature and extent of the candidate's contribution to this work, and the nature of the contribution of each of the co-authors.

(2) they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;

(3) they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;

(4) there are no other authors of the publication according to these criteria;

(5) potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit; and

(6) the original data are stored at the following location(s) and will be held for at least five years from the date indicated below:

Location(s)	**School of Psychology and Psychiatry, Monash University, Clayton**

Signature 1		**Date**
Signature 2		
Signature 3		

Psychosocial Predictors of Depressive Symptoms in Australian Children and Adolescents with Type 1 Diabetes

Kelly Buttigieg, BSc(Hons), Philip Bergman, MD, Christine Rodda, PhD

and Margaret Hay, PhD

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Abstract

Objective: This study investigated the impact of psychosocial factors on the presence of depressive symptoms in children and adolescents with type 1 diabetes (T1D).

Methods: 80 children and adolescents completed questionnaire measures of depression, anxiety, family functioning, self-efficacy and coping. A final sample of 71 participants was obtained after data cleaning (M_{age} = 11.62, *SD* = 1.9). HbA1c levels were used as an objective marker of T1D management.

Results: Discriminant function analysis was used to predict depressive symptoms. The model was significant (Wilks' lambda = .686, chi square (6) = 24.488, *p* = .000). Depressive symptoms were predicted by higher levels of anxiety, poorer coping and reduced family functioning.

Conclusions: Youth with T1D who experience depression are more likely to have difficulties with anxiety, T1D-related coping and family functioning. These findings indicate the need to include anxiety, family functioning and coping strategies in interventions to assist optimal management of T1D.

Keywords: depression, gender, type 1 diabetes, children, adolescents, psychosocial

Type 1 diabetes (T1D) is an autoimmune disorder in which insulin production is severely reduced or absent, impairing the ability to regulate blood glucose. It increasingly affects more children and adolescents each year globally. In Australia, the incidence of T1D in children is the sixth highest worldwide (Australian Institute of Health and Welfare [AIHW], 2010), and has risen in the last decade to 22 cases per 100,000 in children aged 0-15 years in 2009, in comparison to 19 cases per 100,000 in 2000 (AIHW, 2012). This increase is in accordance with international trends (International Diabetes Federation/International Society for Pediatric and Adolescent Diabetes [IDF/ISPAD], 2011).

Living with T1D requires children and adolescents to manage blood glucose levels within an optimal range using a combination of insulin administration, diet and exercise. Such a commitment is required multiple times daily and can be demanding. Furthermore, commitment to this regimen is life-long, as there is presently no cure for T1D. The consequences of non-adherence include microvascular and macrovascular complications, coma, seizures and decreased life expectancy. Therefore, children and adolescents living with a chronic illness such as T1D are an important pediatric group for research regarding both medical and psychosocial outcomes, because of the need to promote optimal management from childhood to reduce adverse medical and psychological outcomes.

The psychological sequelae of living with T1D have been well researched in adolescents, yet little is known about children (Mackey, et al., 2011). A recent meta-analysis of 22 studies published since 1990 concluded that children and adolescents with diabetes were more likely to experience a range of psychological difficulties, including depression. Numerous studies have also demonstrated an association between elevated psychological symptoms and poor glycaemic control in young people with T1D (Kakleas, Kandyla, Karayianni, & Karavanaki, 2009). The

consensus among international clinical guidelines regarding the psychosocial care of young people with T1D is that screening for depression and anxiety in pediatric diabetes clinics should be standard practice (IDF/ISPAD, 2011).

Recent studies of depression in Australian cohorts with T1D are limited. A key study conducted by Northam and colleagues (2005) followed 41 children and adolescents for ten years post-diagnosis of T1D, and found that 17% met the diagnostic criteria for a depressive disorder, and over a third (37%) met diagnostic criteria for a psychiatric diagnosis of some kind. These findings suggest that Australian youth with T1D, as per youth in other developed countries, are more likely to experience depression compared to healthy peers (Grey, Whittemore, & Tamborlane, 2002; Northam, et al., 2005). More recently, an Australian pilot study of psychological functioning and continuous subcutaneous insulin infusion (CSII) pump use also found that the commencement of insulin pump use was related to an improvement in psychological functioning, including depression symptoms (Knight, et al., 2009).

Australian studies have identified depression as an issue for youth with T1D, however the relationship of depression to behavioural and family factors is understudied in this group. Reynolds and Helgeson (2011) argue for a better understanding of what differentiates young people with T1D who are psychologically well from those who are not. For example, the relationship between depression and other aspects of young peoples' psychosocial functioning such as illness-related coping, self-efficacy and family functioning is not fully understood, and further exploration of the relationships between contributing psychological factors is needed.

Within-person (intrapersonal) psychological factors, alongside the outside-person (interpersonal) nature of family support, can be characterised theoretically using the social ecological model of child development (Bronfenbrenner, 1986). This model acknowledges the

role of multiple levels of interaction and support across the individual, family, peer and medical contexts, and has been implemented in several recent psychosocial studies of youth with T1D (Armstrong, Mackey, & Streisand, 2011; Mackey, et al., 2011; Naar-King, Podolski, Ellis, Frey, & Templin, 2006).

In their recent meta-analysis of depression and anxiety in children with T1D, Reynolds and Helgeson (2011) suggested further research is needed to explore differences *within* samples of children with T1D, in comparison to controlled research designs. By better understanding the mood, behavioural and family characteristics that influence the presence of depression, health professionals may more easily identify children and adolescents most at risk of psychological distress. Furthermore, this information would strengthen interventions which aim to improve psychosocial functioning and/or illness outcomes, by developing more targeted intervention programs. Psychosocial wellbeing in youth has focused on adolescents, and the understanding of relationships between depression, anxiety, coping, self-efficacy and family functioning in children and preadolescents is understudied (Armstrong, et al., 2011). As such, our study sought to include children aged from seven years old, in order to add to the research knowledge for this age group.

Our aim was to assess the psychosocial wellbeing of children and adolescents with type 1 diabetes. It was hypothesised that depressed children and adolescents would experience less family support, report poorer coping, and a lesser sense of self-efficacy. An additional hypothesis was that anxiety would best predict depression, due to the well-established comorbidity of depression and anxiety across the lifespan.

Method

Participants and Procedure

Participants were 80 children and adolescents with T1D, who were recruited from a paediatric diabetes outpatient clinic based at a tertiary metropolitan hospital in Melbourne, Australia. Participants were recruited for a doctoral research study exploring psychosocial factors in Australian children and adolescents with T1D, including family functioning, coping and school absenteeism outcomes. Following data cleaning, a final sample of 71 participants was obtained. There were slightly more female participants (52.1%), with the full sample aged between 7 and 15 years old (M = 11.62, SD = 1.9). Nearly half used the continuous subcutaneous insulin infusion (CSII) pump (48.5%) to administer insulin, with hypodermic needle (27.9%) and pen injection devices (23.5%) less widely used. Data collection for most participants (90.1%) took part during a home visit, with the remainder at a clinic appointment.

Eligibility to participate was being aged between 7 and 15 years, and a confirmed T1D diagnosis for at least 12 months at the time of testing. The length of diagnosis requirement allowed for initial psychological adjustment to the T1D diagnosis (Northam, Anderson, Adler, Werther, & Warne, 1996). Understanding English, and being free of medical or psychological conditions affecting their ability to participate were additional inclusion criteria.

Ethics approval for the study was obtained from the relevant hospital and university ethics committees. The study was conducted in accordance with the Declaration of Helsinki. Information packs were mailed to the families of eligible participants. Where possible, this was undertaken in the month preceding the participant's three-monthly scheduled paediatric clinic review. Information packs contained letters of introduction, participant information and consent forms for the participant and a parent/guardian, study brochure and a postage-paid envelope for

consent form return. Mailouts were followed up in person at the participating hospital and/or by phone to establish consent to participate. Of the 282 eligible families contacted, 80 provided consent and participated in the study, providing a final response rate of 28.4%. Reasons for lack of participation were obtained from non-participating families where possible, and included lack of time, lack of interest, and concern for their child regarding participating in psychological research as he/she was already receiving psychological support.

Participants were offered the choice of a home visit or a hospital appointment for data collection. KB administered the participant measures using a written questionnaire during a home visit or clinic appointment. Questionnaire administration took between 45 to 90 minutes. All participants were placed in a raffle draw for one of two electronic music players (Apple iPod Touch™ 8GB), with winners drawn using a random number generation computer application.

Participant responses were scored following data collection. Elevated total scores for depressive (n = 9) or anxiety (n = 5) symptoms, an endorsement of the suicidal ideation item of the CDI (n = 8), or the disclosure of other psychological concerns or distress during questionnaire administration (n = 5) received follow-up with the parent/guardian and the child's paediatrician, including referral to a clinical psychologist.

Measures

Demographic and medical data. Each youth participant completed a brief demographic questionnaire regarding their mode of insulin administration. HbA1c levels were obtained from the participant's medical record where possible.

Depressive symptoms. Participants completed the Children's Depression Inventory (Kovacs, 1992), which comprises 27 items to assess depressive symptoms experienced in the

past two weeks using a Likert scale ranging from zero to two. Total raw scores range from zero to 54. The items belong to one of five subscales assessing negative mood, interpersonal problems, ineffectiveness, anhedonia and negative self-esteem. The CDI has been used to measure the extent of depressive symptoms in both physically well and chronically ill samples, including children and adolescents with T1D (Grey, Boland, Yu, Sullivan-Bolyai, & Tamborlane, 1998; Jaser, Whittemore, Ambrosino, Lindemann, & Grey, 2008). Participants were defined as having an elevated total score if they had a raw CDI score of 13 or higher, in accordance with other studies of youth with T1D (e.g. Jaser, et al., 2008). In this study, the Cronbach's alpha coefficient was .80.

Anxiety symptoms. The Revised Children's Manifest Anxiety Scale – Second Edition (Reynolds & Richmond, 2008) is a 49-item self-report measure of anxiety symptoms. Participants were asked to endorse each item with 'Yes' or 'No'. The RCMAS-2 is a 49-item self-report measure of anxiety. The instructions request that the child select 'Yes' if they feel that the item describes their feelings or actions, and to select 'No' if the item is not descriptive. The RCMAS-2 has a reliability score of .92 for the Total score and values between .75 and .86 for the scale scores. For this reason, it is recommended by the test authors that the Total score should be used. Participants were classified as having an elevated total score using the test author's scoring criteria (defined as a T Score greater than 60) (Reynolds & Richmond, 2008). In the current study, the Cronbach's alpha coefficient was .83, demonstrating good internal consistency.

Family functioning. The revised Diabetes Family Behavior Scale (DFBS) (McKelvey, et al., 1993) was used to measure diabetes-specific family support. The revised DFBS comprises 47 items which belong to two subscales: guidance-control, which refers to consistent guidance

provided by one's family, and warmth-caring, which measures nurturance provided by family. In this study, the Cronbach's alpha coefficient was .72.

Self-efficacy. The Australian-English version of the Diabetes Management Self-Efficacy Scale (DMSES) (McDowell, Courtney, Edwards, & Shortridge-Baggett, 2005) was used to assess self-efficacy with regards to diabetes management tasks. The measure has no subscale, and instead comprises 20 items that assess self-efficacy in areas covering blood sugar level, foot care, medication, diet and level of physical activity. The scale was initially developed to assess self-efficacy in adults managing type 2 diabetes. A modified version of this measure was therefore included in this study. In the current study, the Cronbach's alpha coefficient was .90.

Coping. The Issues with Coping with IDDM scale, Child Version (ICI-C) (Kovacs, Brent, Steinberg, Paulauskas, & Reid, 1986; Kovacs, et al., 1990), was used to assess coping with T1D tasks and emotions related to illness. Part 1 comprised 15 items requiring the participant to rate 'how hard' it is to do certain things, e.g. give insulin shots. These items form the subscale for Part 1, Things hard to do (How Hard). Part 2 comprised 11 items requiring the participant to answer 'how upsetting' it is to do certain tasks, e.g. having blood samples taken. These items form the subscale Issues that upset (How Upsetting). The How Hard subscale showed poor internal consistency for the current study, with a Cronbach's alpha coefficient of .53. The How Upsetting subscale demonstrated acceptable internal consistency, with a Cronbach's alpha coefficient of .71. As this measure included specific references to hypodermic needles (e.g. 'insulin shots'), participants were given a verbal prompt to consider their insulin regimen (i.e. insulin pump, insulin pen or hypodermic needle) when required.

Results

Overview of Data Analysis Procedures

Data cleaning was performed using SPSS v.18 on the initial dataset of 80 cases to remove outliers and cases with missing HbA1c levels, to met statistical assumptions for all analyses conducted for the larger doctoral study. A final dataset comprising 71 participants was obtained. Analysis of the key variables using histograms and analysis of skewness and kurtosis using Kolmogovrov-Smirnov and Shapiro-Wilk tests indicated that depression and anxiety raw total scores, and the coping (How Upsetting) total subscale score were non-normally distributed. Non-parametric tests were therefore used for all statistical analyses.

Mann-Whitney U tests were performed to explore differences on indices of psychosocial functioning between depressed and non-depressed participants. Discriminant function analysis (DFA) was then conducted, to determine psychosocial predictors of membership to depressed and non-depressed groups within the sample. The operationalisation of psychosocial factors for statistical analyses is described in Table 1.

Table 1
Operationalisation of Study Constructs as Continuous and Grouping Variables for Depression Analysis

Variable	Continuous Measure	Continuous Variable Score Range	Dichotomous Measure	Cut-off Score(s) (Dichotomous Measure Score Range)	Grouping Variables
Depression	CDI total raw score	0 to 54	CDI total raw score	CDI raw total score cut-off ≥ 13 (0 to 54)	Not depressed: 0 to 12 Depressed: 13 to 54
Anxiety	RCMAS-2 total raw score	0 to 40			
Coping with T1D	ICI-C How Hard total subscale score	0 to 45			
	ICI-C How Upsetting total subscale score	11 to 33			
T1D self-efficacy	DMSES total score	0 to 180			
T1D family functioning	DFBS total score	47 - 235			

Sample Characteristics

Overall, participants had a suboptimal HbA1c level (*Md* = 8.7%, range: 6.7-11.4%); however, this was not at a 'high risk' level using international criteria. The attainment of optimal levels of HbA1c in also known to be difficult (IDF/ISPAD, 2011). The final sample was representative of clinic patients in this age range for HbA1c levels (*Md* = 8.6%) and geographic region, however the percentage of CSII pump use in the final sample was much higher compared to clinic patients in this age group (28%).

In the week prior to data collection, 79.1% reported following their recommended diet, and 70.4% reported meeting their paediatrician's exercise recommendations usually or all of the time. Most or all of the recommended number of blood glucose tests were also performed by the most participants (85.3%), and 70.4% reported taking all of their required insulin administrations (by pump, needle or pen) in the week prior to participation. Median depression (*Md* = 4) and

anxiety (*Md* = 6) raw scores for the overall sample were not high, and suggested that the sample represented a psychologically 'well' group.

Results for 'Depressed' and 'Not Depressed' Groups

Mann-Whitney *U* tests were used to determine differences between the depressed (*n* = 7) and non-depressed (*n* = 63) participants in relation to anxiety, coping, self-efficacy, family support and age, and revealed that levels of anxiety were significantly higher in the depressed group (*Md = 23.00, n = 7)* compared to the non-depressed group (*Md* = 6.00, *n* = 63), *U* = 65.00, *z = -3.055, p = .00*. The effect size (*r* = .37) was medium.

Median levels of family functioning were also found to be significantly lower for the depressed group (*Md* = 146.00, *n* = 7) and higher for the non-depressed group (*Md* = 162.00, n = 63) participants, *U* = 112.50, *z* = -2.116, *p* = .03. The effect size (*r* = .25) was small.

Median levels of coping difficulties (How Upsetting subscale) were higher in the depressed group (*Md* = 18.00, *n* = 7) compared to the non-depressed group (*Md* = 15.00, *n* = 63) groups, *U* = 126.50, *z* = -1.849, *p* = .06, *r* = .22. While this analysis approached the 95% significance level, it was not significant.

Psychosocial Predictors of Depressive Symptoms

The first hypothesis stated that depressed children and adolescents would experience less family support, report poorer coping, and report a lesser sense of self-efficacy. This was tested using a direct discriminant function analysis to identify significant predictors of membership to depressed and non-depressed groups. The predictors were anxiety symptoms, family functioning, self-efficacy, coping (How Hard), coping (How Upsetting) and age. One case was removed due

to a missing value for the outcome variable (depressive symptoms), resulting in 70 cases included in the final analysis.

The discriminant function calculated significantly distinguished between the depressed (*n* = 7) and non-depressed (*n* = 63) groups (Wilks' lambda = .686, chi square (6) = 24.488, *p* = .000). As the group means were statistically significant, classification of variables was also undertaken, and 94.3% of the original grouped cases were correctly classified.

Table 2

Standardised Canonical Discriminant Function Coefficients and Structure Matrix Coefficients as a Prediction of Membership to Depressed (n = 63) and Non-Depressed (n =7) Groups

	Discriminant Function Coefficient	Structure Matrix Coefficient
Anxiety	.959	**.858**
Self-Efficacy	.423	.022
Family Functioning	-.337	**-.412**
Coping (How Upsetting)	.060	**.351**
Coping (How Hard)	-.118	.000
Age	.081	.102

Note: Analysis conducted on *N* = 70.

The structure matrix (see Table 2) indicates that the variables that were the best predictors of depressed versus non-depressed youth were anxiety symptoms, family support, and

coping with upsetting aspects of T1D. Analysis of the group centroids data (Table 3) indicated that higher levels of anxiety, lower levels of family functioning and poorer coping with issues that upset predicted membership of the depressed group.

Table 3

Group Centroids for Depressed and Non-Depressed Groups

	Function 1
Non-Depressed	-.222
Depressed	2.000

Discussion

The findings demonstrated that higher levels of anxiety, poorer family functioning and coping difficulties were significant predictors of depression in our sample of children and adolescents with T1D. The observed relationship may have influence in several directions. For example, children may develop depression over a period of time in response to ongoing difficulties in T1D management, which may be 'flagged' initially through anxiety, illness-related family problems and individual coping issues with their illness. Alternatively, depression may contribute to a young person feeling less supported by parents through depressive cognitions and/or actual withdrawal of parents from T1D management, make upsetting aspects of their illness more salient, and worsen feelings of anxiety. While it was not possible to establish a direction in this study, associations between this set of factors were clearly identified.

Interestingly, the findings were obtained in a sample of largely psychologically 'well' youth with a median HbA1c level in the suboptimal range. Therefore, blood sugar levels as an indicator of T1D management did not act as a potential identifier of psychosocial concerns in this group.

These findings are novel as psychosocial predictors of depression have not been previously studied in Australian children and adolescents with T1D. This study adds to the understanding of the psychosocial wellbeing of Australian children and adolescents with T1D. This is an important contribution, as few studies which account for modern treatment regimens (e.g. Knight, et al., 2009) have been recently published in this group. The present findings are consistent with research in other developed countries, which has identified coping and family functioning as important aspects of a young person's psychosocial wellbeing.

These findings also provide a broader picture of how a child experiencing psychological distress might be identified in a clinical setting. In addition to monitoring depression issues in children and adolescents with T1D, difficulties with anxiety, coping and family functioning might also act as a potential marker of depression. These same factors might also be considered as additional points for intervention in programs aimed at reducing depressive symptoms in young people with T1D. The implications for practice are two-fold. Clinicians conducting screening programs for depression might consider the inclusion of family and coping factors in such assessments. An intervention program with this aim might also involve family members, and address coping strategies, to provide a multifaceted approach to improving psychological wellbeing and reducing distress in the subset of youth in T1D services experiencing depression (Reynolds & Helgeson, 2011). This recommendation is consistent with the inclusion of family

members in recent psychological interventions to improve aspects of psychosocial functioning such as coping skills (Grey, Jaser, Whittemore, Jeon, & Lindemann, 2011).

Limitations and Future Research

The analysis presented requires some caution in interpretation due to sampling bias. The low response rate prevents extrapolation of the findings to the clinic population, and other children and adolescents with T1D. It is possible that participating children and adolescents were more proactive with their T1D management. This possibility is supported by the observation that only seven participants (10%) reported elevated symptoms of depression, a prevalence slightly lower than recently reported studies also utilising the CDI of 12.3% (Jaser, et al., 2008) and 15% (Armstrong, et al., 2011), and much lower than studies which have assessed depression in large samples (Lawrence, et al., 2006). An important implication is the prevalence of depression may have been much higher with a representative sample, if reasons for non-participation included psychosocial or T1D management difficulties. As reasons for refusal were not captured for all prospective participants who did not enrol, it was not possible to confirm this possibility.

T1D management practices may have also influenced the findings. The current sample was recruited from a paediatric T1D clinic with a dedicated insulin pump clinic, and nearly half of participants used the insulin pump. It is therefore possible that the modern treatment options available to the children and adolescents in the study have had a lesser impact on their psychosocial wellbeing (Reynolds & Helgeson, 2011), in comparison to older and less flexible treatment forms such as the hypodermic needle. This explanation is consistent with the relatively low prevalence of depressive symptoms identified in the final sample, and the reduction in depressive symptoms identified in Knight et al.'s (2009) pilot study of insulin pump users.

Future research might therefore explore the addition of anxiety management, coping skills training and family-based components to clinical interventions which aim to prevent or reduce depression in this group. Further investigation of the role of anxiety, coping and self-efficacy in a more representative sample of children and adolescents is also recommended.

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Chapter 6: Psychosocial Predictors of School Absenteeism in Children and Adolescents with Type 1 Diabetes

6.1. Preamble to Paper 3

Previous research has identified limitations in the reliance on HbA1c levels as a measure of T1D functioning in children and adolescents. School absenteeism is one aspect largely understudied in children and adolescents with T1D (Wodrich, et al., 2011), despite the well established link between school absenteeism and psychosocial impairment in healthy children and adolescents (Kearney, 2008).

This study included a measure of missed school days as a supplementary measure of illness functioning. Information obtained by parent report indicated that 77.1% of young participants had missed two or more days of school in the immediately preceding school term. A hypothesis from Research Question Two was that children and adolescents who experience school absenteeism would be more likely to report depressive and anxiety symptoms, lower levels of coping and self-efficacy, worse family functioning and illness knowledge. This hypothesis was tested using DFA to identify predictors of membership to 'school absenteeism' and 'non school-absenteeism' groups. Paper 3 reports on the psychosocial predictors of school absenteeism in Australian children and adolescents with T1D, and was submitted to the journal *Pediatric Diabetes*.

PART B: Declaration for Thesis Chapter

Monash University

Declaration for Thesis Chapter 6

Declaration by candidate

In the case of Chapter 6, the nature and extent of my contribution to the work was the following:

Nature of contribution	**Extent of contribution (%)**
Conceptualisation of research, and writing of manuscript (Title: 'School absenteeism and psychosocial wellbeing in Australian youth with type 1 diabetes') Participant recruitment, data collection and statistical analysis	70

The following co-authors contributed to the work. Co-authors who are students at Monash University must also indicate the extent of their contribution in percentage terms:

Name	**Nature of contribution**	**Extent of contribution (%) for student co-authors only**
Dr Margaret Hay	Guidance regarding statistical analysis; assisted with conceptualisation of manuscript; review of manuscript draft	
Dr Philip Bergman	Assisted with participant recruitment and interpretation of clinical data, review of manuscript draft	
A/Prof Christine Rodda	Assisted with participant recruitment and interpretation of clinical data, review of manuscript draft	

Candidate's Signature		**Date**

Declaration by co-authors

The undersigned hereby certify that:

(1) the above declaration correctly reflects the nature and extent of the candidate's contribution to this work, and the nature of the contribution of each of the co-authors.

(2) they meet the criteria for authorship in that they have participated in the conception, execution, or interpretation, of at least that part of the publication in their field of expertise;

(3) they take public responsibility for their part of the publication, except for the responsible author who accepts overall responsibility for the publication;

(4) there are no other authors of the publication according to these criteria;

(5) potential conflicts of interest have been disclosed to (a) granting bodies, (b) the editor or publisher of journals or other publications, and (c) the head of the responsible academic unit; and

(6) the original data are stored at the following location(s) and will be held for at least five years from the date indicated below:

Location(s)	**School of Psychology and Psychiatry, Monash University, Clayton**

Signature 1		**Date**
Signature 2		
Signature 3		

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School absenteeism and psychosocial wellbeing in Australian youth with type 1 diabetes

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ABSTRACT AND KEY WORDS PAGE

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Objective: Recent advances in type 1 diabetes (T1D) management have provided greater flexibility to children and adolescents managing their condition in home and school settings. Previous studies of school absenteeism in this group have identified school attendance as an area of concern, however recent findings are limited. Little is also known about the psychosocial wellbeing of young people with T1D who miss school days. Our aim was to explore the influence of psychosocial wellbeing of Australian children and adolescents with T1D as predictors of school absenteeism.

Methods: 80 children and adolescents (n = 71 included in analyses, M_{age} = 11.62, SD = 1.9) completed self-report measures of depression (CDI), anxiety (RCMAS-2), family functioning (DFBS), self-efficacy (DMSES) and coping (ICI-C). Parents also completed a brief demographic questionnaire, which asked them to recall if their child had missed two or more days of school in the previous school term. Most recent HbA1c levels were also collected.

Results: Using discriminant function analysis (DFA), significant group differences were found on the reported number of school days missed (Wilks' lambda = .741, chi square (7) = 19.373, p = .007). The group who missed more than two days of school reported higher levels of anxiety symptoms, greater difficulties in coping with issues that upset, and endorsed higher levels of depressive symptoms.

Conclusions: School absenteeism may be a viable marker of psychosocial functioning in children and adolescents with T1D.

Type 1 diabetes (T1D) is a chronic illness that is often diagnosed in childhood. It is increasing in incidence, both within Australia (1-3) and in other countries (4). Managing T1D requires affected youth and their families to engage in daily management tasks focusing on insulin administration (along with diet and exercise regiments) to maintain optimal glycaemic control. The consequences of not adhering to optimal management regimens include short-term acute complications evident in the young child, such as hypo/hyperglycaemia and diabetic ketoacidosis (DKA) (5). Of concern is the established link between poor glycaemic control in youth, and the risk of serious microvascular and macrovascular complications later in life (6).

Children and adolescents living with T1D are expected to maintain their T1D-related management regimens. This is despite the developmental processes, especially during adolescence, that may interfere with T1D management (7). For example, the developmental tasks of achieving autonomy and identity may result in the young person minimising family support in their diabetes regimen, even if such support is needed to maintain optimal management. Adolescence is also a time characterised by a desire to conform to peer norms, whilst developing their own sense of identity and individuation (8). Children and adolescents may conform to peer group norms by hiding blood glucose monitoring (BGM) and insulin administration from their classroom peers, a practice that may result in missed checks or delayed insulin administration. Managing the demands of T1D in this group is therefore a complex process that involves the young person's family and the school environment.

School attendance

The advent of the continuous subcutaneous insulin infusion (CSII) pump and newer short and long-acting insulin analogues have provided greater flexibility in insulin administration

regimens. These important advances may have reduced the impact of T1D management on the young person, and it is possible that such advances may have resulted in improved school attendance, due to a lesser need for missed school days due to T1D-related illness. In a recent review (9), the authors suggest that markers of school functioning will have improved for young people with T1D over time with the advent of these changes. However, recent studies exploring school absenteeism in this group are limited.

The relationship between school absenteeism and glycaemic control is also inconsistent. In an important pilot study of 56 Canadian children with T1D, no correlation was found between HbA1c levels and school absenteeism, as measured using childrens' report cards (10). However, glycaemic control was related to school absenteeism when this study was expanded to include more participants (11).

School absenteeism can have deleterious impacts on all school children. For example, it is possible that missed school days may have a detrimental effect on knowledge acquisition generally; one study has shown increased difficulties in school-specific knowledge in children with T1D compared to healthy peers (12), confirming a need to investigate this group.

The relationship between school absenteeism and psychosocial wellbeing in youth with T1D is also understudied. A recent review of school absenteeism in healthy children confirms that there are well-established association between school absenteeism and psychosocial distress on a range of outcomes (13). Psychosocial wellbeing refers to the general psychological state of the young person, and is typically defined in research studies using depression and anxiety, however behavioural and social factors such as coping, self-efficacy and family functioning also play a role. Despite the fact that past research has suggested that children and adolescents with

T1D do indeed miss more school than healthy peers (12), the psychosocial wellbeing of youth with T1D has received less attention in these studies.

A study published in 2003 investigated school absence and psychosocial adjustment in preadolescents living in the United Kingdom (UK), and found that general psychological adjustment problems were related to school absence (14). Information regarding school absenteeism in youth who have access to modern T1D management regimens was recommended in a recent review (9). Furthermore, the relationship between school absenteeism and psychosocial wellbeing in this group remains poorly understood, including in Australian youth.

Psychosocial wellbeing in children and adolescents with T1D

Youth with T1D experience more missed school days than their healthy peers (12) due to their health regime. The insidious nature of their condition is also of concern, as they appear healthy externally, yet are living with a chronic illness that requires daily management. Their illness may be poorly understood by the child with T1D, as well as their friends and peers. The additional burden of managing T1D and the increased likelihood of school absenteeism because of their illness warrant further investigation. While studies have focused on aspects such as academic functioning (15), differences in psychosocial wellbeing in relation to school absenteeism are not well understood and remain understudied.

Depression and anxiety are key markers of psychosocial wellbeing in youth. An increased presentation of both types of psychopathology is reported in children and adolescents with T1D, compared to healthy youth (16, 17). Furthermore, the presence of depression and anxiety is reliably linked to poor glycaemic control for these youth (17). Further studies exploring sources of differences in psychological wellbeing within samples of youth with T1D

have been encouraged (16). In the context of school functioning, it is possible that those children experiencing depression or anxiety may also be at risk of school absenteeism, due to the impact on their psychosocial functioning.

Coping is another aspect of psychosocial wellbeing that has been related to poorer medical and psychosocial outcomes in youth with T1D (18). Problem-focused coping strategies have been linked to improvements in glycaemic control (18), with specific forms of emotion-focused coping such as avoidance strategies known to reduce emotional distress, at the expense of optimal glycaemic control (19). In the young person experiencing coping difficulties, school absenteeism may present as a surrogate marker for these difficulties. To our knowledge, no studies appear to have assessed both school absenteeism and coping in youth with T1D.

While school absenteeism has been studied with regards to school functioning, the relationship with psychosocial functioning is less clear. Past research has suggested that children and adolescents with T1D miss more school than healthy peers (12). However, less is known about the psychosocial wellbeing of this group in relation to school absenteeism. The aim of this study was to explore differences, if any, in the psychosocial wellbeing of children and adolescents with T1D, in relation to their school attendance. It was hypothesised that worse psychosocial functioning would be associated with increased school days missed.

Method

Participants and Procedure

Participants were 80 children and adolescents with T1D. All participants were recruited from a paediatric diabetes outpatient clinic in metropolitan Melbourne, Australia. Study participants were part of a doctoral research study exploring psychosocial factors in Australian children and adolescents with T1D, including family functioning, coping and depression outcomes. From an initial sample of 80, a final sample of 71 participants aged between 7 and 15 years old (M = 11.62, SD = 1.9) was obtained following the removal of outliers (n = 4) and participants with missing HbA1c levels (n = 6), with one case meeting both criteria for removal. The sample consisted of 52.1% females, and the CSII pump was the most common form of insulin administration (48.5%), with hypodermic needle (27.9%) and injection pen devices (23.5%) also reported. The median HbA1c level for the sample was 8.7% (range: 6.7-11.4%) which is in the suboptimal range, according to recent international guidelines by the International Diabetes Federation (IDF) and International Society for Pediatric and Adolescent Diabetes (ISPAD) (4). The majority of participants completed data collection during a home visit (90.1%), and the remainder during a clinic appointment. Most lived with both biological parents (78.9%) or with a single parent (14.1%). The remainder lived with step-parents, other family members or reported a '50/50' arrangement with both biological parents.

Participants were eligible to participate if they were aged between 7 and 15 years of age, and held a diagnosis of T1D for at least twelve months. The latter requirement allowed for initial psychological adjustment to diabetes diagnosis (20). Exclusion criteria included difficulties with oral and written English, and the presence of medical or psychological conditions affecting their ability to participate.

Ethical approval for the study was obtained from the human research ethics committees at the relevant institutions. The study was conducted in accordance with the Declaration of Helsinki. Introductory information packs were mailed out to each eligible participant's family. Where possible, this was targeted prior to the participant's next scheduled paediatric clinic review. A follow-up was then conducted in person at the clinic visit and/or by phone if necessary to determine consent to participate. Participants who consented were then offered the choice of a home visit or a post-clinic appointment for data collection to occur. Participants were also placed in a raffle draw for one of two electronic accessories (Apple iPod Touch™ 8GB), which was drawn using a random number generation computer application.

Of the 282 eligible families contacted using this protocol, 80 provided consent and participated in the study, providing a final response rate of 28.4%.

KB administered the child measures using a written questionnaire, and participants were asked to answer as honestly as possible. Data collection took between 45-90 minutes. Participant responses were scored following data collection. Elevated total scores for depressive (n = 9) or anxiety (n = 5) symptoms, an endorsement of the suicidal ideation item of the CDI (n = 8), or the disclosure of other psychological concerns or distress during questionnaire administration (n = 5) were followed up with the participant's parent/guardian and paediatrician, including referral to a clinical psychologist.

Measures

Demographic and medical data. Each child/adolescent participant completed a brief demographic questionnaire regarding their mode of insulin administration. Each parent demographic questionnaire provided data on number of school days missed by the child in the previous term, family and income information. HbA1c levels were obtained from the participant's medical record where possible.

Depressive symptoms. Participants completed the Children's Depression Inventory (21), which comprises 27 items to assess depressive symptoms experienced in the past 2 weeks using a Likert scale ranging from 0 to 2. Total raw scores range from 0 to 54. An elevated score was defined as a raw CDI score of 13 or higher, in accordance with similar studies in youth with diabetes (22, 23). In the current study, the Cronbach's alpha coefficient was .80.

Anxiety symptoms. The Revised Children's Manifest Anxiety Scale – Second Edition (24) is a 49-item self-report measure of anxiety symptoms. The RCMAS-2 can be administered to children aged between 6 and 19 years old. The participant selects 'Yes' if they feel that the item describes their feelings or actions, or 'No' if it does not. In this study, the Cronbach's alpha coefficient was .83. Participants were classified as having an elevated score using the test author's criteria, defined as a T Score greater than 60 (24).

Family functioning. The revised Diabetes Family Behavior Scale (DFBS) (25) was used to measure diabetes-specific family support. The revised DFBS comprises 47 items, which were kept from a total of 60 items from the original version. The DFBS has two subscales: guidance-control, which refers to consistent guidance provided by one's family, and warmth-caring, which refers to nurturance provided by family members. An example item for the guidance-control subscale included 'My parent(s) watches while I test for sugar'. One example item for the

warmth-caring subscale included My parent(s) understands how I feel about having diabetes. A Cronbach's alpha coefficient of .72 was obtained for this study.

Self-efficacy. The Australian-English version of the Diabetes Management Self-Efficacy Scale (DMSES) (26) was used to assess self-efficacy with regards to diabetes. The DMSES comprises twenty items that are rated on an 11-point Likert scale with the anchors 'Cannot do at all' (0), 'Maybe yes/maybe no' (5) and 'Certain can do' (10). A higher score indicated greater self-efficacy. As the scale was developed to assess self-efficacy with regards to behaviours involved in Australian adults managing type 2 diabetes a modified version of this measure was used. A Cronbach's alpha coefficient of .90 was obtained.

Coping. The Issues with Coping with IDDM scale, Child Version (ICI-C) (27, 28), was used to assess coping with T1D tasks, specifically the difficulty in completing tasks and the degree of upset caused to and the feelings associated with managing the condition. The ICI-C is a standardised self-report questionnaire, and comprises two subscales. Part 1 consisted of 15 items which required the participant to rate "how hard" it is to do certain things, e.g. give insulin shots. These items form the subscale for Part 1, Things Hard to Do (How Hard). Part 2 comprised 11 items requiring the participant to answer "how upsetting" it is to do certain tasks, e.g. having blood samples taken. Collectively, these items form the subscale Issues that Upset (How Upsetting). The scores for each part are then summed to provide a total score for each subscale. No cut-off points have been established for this measure. The ICI-C subscale for the How Hard subscale showed poor internal consistency for the current study, with a Cronbach's alpha coefficient of .53. The ICI-C subscale for the How Upsetting subscale showed demonstrated acceptable internal consistency for the current study, with a Cronbach's alpha coefficient of .71 obtained. Where a test item referred to insulin administration via a hypodermic

needle only (e.g. ‘insulin shots’), participants were verbally prompted to consider their own insulin regimen (i.e. insulin pump, insulin pen or hypodermic needle) before responding.

School attendance. Parents completed a self-report measure asking if their child had missed two or more days of school within the previous full school term.

Results

Overview of Data Analysis Procedures

Depression, anxiety, and coping (How Upsetting subscale) variables were non normally distributed, therefore non-parametric tests were used for statistical analyses. Due to the small sample size, a discriminant function analysis (DFA) was used to identify significant predictors of membership to two groups, using school absenteeism as the grouping variable. The operationalisation of psychosocial factors for statistical analyses are described in Table 1.

INSERT TABLE 1 HERE

Sample Characteristics

Most young people (77.1%) had missed two or more days of school in the school term just prior to data collection. Overall, participants had a suboptimal HbA1c level (*Md* = 8.7%, range: 6.7-11.4%), however, this was not at a 'high risk' level using international criteria (4). The attainment of optimal levels of HbA1c in children and adolescents is known to be difficult, due to adherence issues and hormonal changes in adolescence (4, 29). The final sample was representative of clinic patients in this age range for HbA1c levels (*Md* = 8.6%) and geographic region, however the percentage of CSII use in the final sample (48.5%) was much higher compared to clinic patients in this age range (28%).

Most participants (79.1%) reported following their recommended diet in the week prior to study participation, as well as meeting their paediatrician's exercise recommendations usually or all of the time (70.4%). Most or all of the recommended number of blood glucose tests were performed by the majority of participants (85.3%), and 70.4% reported taking all of their required insulin administrations (by CSII pump, syringe or pen injection) in the week prior to participation. Median depression (*Md* = 4) and anxiety (*Md* = 6) raw scores for the sample were not high, suggesting that the sample represented a psychologically 'well' group overall.

Relationships between Psychosocial Variables

Associations between HbA1c levels and the psychosocial factors of depression (using CDI raw scores), anxiety (using RCMAS-2 raw scores), coping with hard aspects of T1D, coping with upsetting aspects of T1D, self-efficacy and family functioning were explored using Spearman correlations (Table 1). Several significant correlations in expected directions were identified. Depression and anxiety had a significant positive correlation, and accounted for 50%

of the variance in this relationship. Depression was also significantly positively correlated with one of the coping subscales, How Upsetting, with 16% of variance accounted for in this relationship. Depression was also significantly negatively correlated with family functioning and self-efficacy, but only contributed 8% to variance respectively.

Anxiety demonstrated several significant associations with psychosocial factors. Anxiety was significantly associated with both coping subscales, and associations with the How Hard and How Upsetting subscales accounted for 4% and 31% of unique variance respectively. Anxiety was also significantly negatively correlated with self-efficacy (8% contribution to variance) and family functioning (4% contribution to variance).

Significant associations were also obtained between behavioural and family variables. Family functioning was significantly positively correlated with self-efficacy, and accounted for 6% of variance. Self-efficacy was significantly negatively correlated with both coping subscale, How Hard and How Upsetting, and accounted for 4% and 9% of the variance respectively. As expected, the coping subscales were significantly positively correlated with one another, and accounted for 17% of variance. The significant correlations identified in the current analysis suggested that depression and anxiety experienced the most associations with other psychosocial variables.

INSERT TABLE 2 HERE

Psychosocial Predictors of School Absenteeism

A direct discriminant analysis was performed using six variables as predictors of membership as 'absent from school' (n = 54) or 'not absent from school' (n = 16). Predictors were depressive symptoms, anxiety symptoms, T1D-specific family functioning, T1D-specific self-efficacy, coping with T1D (How Hard), coping with T1D (How Upsetting) and age.

The calculated discriminant function significantly distinguished between the groups on school absenteeism (Wilks' lambda = .741, chi square (7) = 19.373, p = .007). As the group means were found to be statistically significant, classification of variables was undertaken, with 82.9% of the original grouped cases correctly classified. The structure matrix is shown in Table 2.

INSERT TABLES 3 & 4 HERE

The structure matrix revealed that the most important differentiating factors in predicting membership to 'missed school' or 'not missed school' were anxiety symptoms, coping with issues that upset, and depressive symptoms. Interpretation of the group centroid data (Table 3) suggests that the group who missed more than two days of school, on average, tended to have higher levels of anxiety symptoms, report more difficulties in coping with issues that upset, and also tended to have higher levels of depressive symptoms. In contrast, the group that did not miss two or more days of school, on average, tended to have lower levels of anxiety symptoms, report less difficulties in coping with issues that are upsetting, and also report lower levels of depressive symptoms.

Discussion

The current study's findings supported our hypothesis that youth who missed more days of school have poorer psychosocial wellbeing. Specifically, school days missed was predicted by higher levels of depression and anxiety, and greater coping difficulties related to upsetting aspects of T1D. This finding is novel, as to the authors' knowledge no other study of school attendance in Australian youth with T1D has investigated psychosocial wellbeing. These findings therefore add to the existing research literature regarding school absenteeism in the context of T1D, which has previously studied outcomes based on T1D management and academic functioning. The study also identified significant associations between aspects of psychosocial wellbeing. For example, participants with higher levels of depression also reported higher levels of anxiety, greater difficulties in coping with upsetting aspects of illness, and reduced self-efficacy and family functioning, with higher levels of anxiety associated with reduced family functioning, reduced self-efficacy and greater difficulties coping with illness-related tasks and emotions. Participants with higher levels of family functioning also reported a greater self-efficacy for their T1D. The relationships between the constellation of psychosocial variables in the study, and the predictive ability of depression, anxiety and coping support the use of school days missed as an overall marker of psychosocial wellbeing in this sample.

Young people with T1D are reported to miss more school than their peers without T1D (12). This finding is interesting from a T1D management perspective, as the median level of glycaemic control for both groups represented a typical (suboptimal) level of glycaemic control for this age group. Our analyses of glycaemic control with this sample as part of a larger research study also found that HbA1c levels were not predictive of psychosocial functioning for this group. The predictive validity of the depression, anxiety and coping difficulties with upsetting

aspects of T1D might therefore be useful for the early detection of psychosocial difficulties in youth with T1D in clinic settings, as school absenteeism may be used in addition to glycaemic control as an alternative 'red flag' for potential psychosocial issues.

Several limitations must be noted. This study focused on children and adolescents with T1D, and it is not possible to extrapolate these findings to healthy children and adolescents. It was not also possible to discriminate between school days missed due to T1D-specific or other reasons. As most (77.1%) of the sample fell into the school absenteeism group, it is possible that the cut-off score used (two days or more) was too low. An alternative explanation could be that missed school days was high in the sample overall. However, despite this relatively low cut-off, meaningful differences in psychosocial functioning were still identified in comparison to participants who had missed no school days. Our method of obtaining the number of school days missed was also subject to parental recall bias (11). Future studies should include an objective measure, such as school report data or confirmation of parental recall data with school records, and an identification of the reasons for absenteeism (9).

In conclusion, this study found that school absenteeism was a useful indicator of psychological wellbeing in children and adolescents with T1D, with the constructs used to assess psychosocial wellbeing also highly interrelated. School attendance may therefore be a potential 'marker' for psychosocial issues in young people with T1D in clinical settings.

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Table 1

Operationalisation of Psychosocial Constructs for School Absenteeism Analysis

Variable	Continuous Measure	Continuous Variable Score Range	Dichotomous Measure	Cut-off Score(s) (Dichotomous Measure Score Range)	Grouping Variables
Depression	CDI total raw score	0 to 54			
Anxiety	RCMAS-2 total raw score	0 to 40			
Coping with T1D	ICI-C How Hard total subscale score	0 to 45			
	ICI-C How Upsetting total subscale score	11 to 33			
T1D self-efficacy	DMSES total score	0 to 180			
T1D family functioning	DFBS total score	47 - 235			
T1D knowledge	DKN total score	0 to 15			
School absenteeism			School days missed item response	2 or more school days missed	School absenteeism: 2 or more school days missed No school absenteeism: 2 or more school days not missed

Table 2

Significant Spearman Correlations between Psychosocial Wellbeing Variables

	Depression	Anxiety	Family functioning	Self-efficacy	Coping (How Hard)	Coping (How Upsetting)
Depression						
Anxiety	.71**					
Family support	-.29**	-.21*				
Self-efficacy	-.29**	-.28**	.24*			
Coping (How Hard)	.07	.20*	-.03	-.20*		
Coping (How Upsetting)	.40**	.56**	-.08	-.30**	.41**	

Note. ** $p < .01$ (1-tailed).
* $p < .05$ (1-tailed).
***Analysis was conducted on $N = 70$

Table 3

Standardised Canonical Discriminant Function Coefficients and Structure Matrix Coefficients as a Prediction of Membership to School Absenteeism (n=54) and No School Absenteeism (n=16) Groups

	Discriminant Function Coefficient	Structure Matrix Coefficient
Depression	-.145	**.512**
Anxiety	.806	**.759**
Self-efficacy	-.002	-.250
Family support	.407	.035
Coping (How Upsetting)	.492	**.692**
Coping (How Hard)	-.175	.155
Age	.481	.280

Table 4

Group Centroids for Schools Absenteeism and No School Absenteeism Groups

	Function 1
School Absenteeism	0.318
No School Absenteeism	-1.072

Chapter 7: Integrated Discussion

The primary aim of this study was to identify the psychosocial predictors of optimal T1D management in Australian children with T1D. The investigation resulted in three manuscripts (see Chapters Four to Six). Paper 1 reported on the role of depression, anxiety, self-efficacy and family functioning predictors of coping with T1D. This paper also reported on the role of depression, anxiety, coping and self-efficacy as predictors of family functioning. Paper 2 reported on the role of anxiety, coping, self-efficacy and family functioning as predictors of depression. In Paper 3, the role of depression, anxiety, coping, self-efficacy and family functioning as predictors of school absenteeism was reported.

This chapter begins by summarising the aims and principal findings in relation to illness management and psychosocial wellbeing respectively. The implications of these findings are discussed, with reference to screening programs for psychological problems in paediatric T1D settings and clinical interventions which aim to improve medical and psychosocial outcomes. The chapter concludes with a summary of recommendations for psychosocial screening programs and clinical interventions which aim to improve T1D management and psychosocial outcomes in Australian children and adolescents.

7.1. Review of Study Aims and Major Findings

7.1.1. Psychosocial predictors of type 1 diabetes management. Limited recent research has investigated psychosocial predictors of illness management in Australian children with T1D. Research in Australian adolescents has focused on establishing prevalence rates for psychological concerns such as depression and anxiety, and the constellation of psychosocial

factors that influence T1D management in this population is understudied. This study explored the relationship between depression, anxiety, coping, self-efficacy, family functioning and T1D knowledge on two indicators of illness functioning, glycaemic control and school absenteeism.

7.1.1.1. Psychosocial predictors of glycaemic control. Using current clinical guidelines as a basis for group membership, psychosocial predictors of 'optimal', 'suboptimal' and 'high risk' HbA1c levels were analysed in a final sample of 71 children and adolescents with T1D. Psychosocial factors which are related to optimal glycaemic control in adults and in adolescents were included in this analysis. It was found that none of the psychosocial factors significantly predicted HbA1c levels according to the three groups of glycaemic control. Accordingly, the hypothesis that levels of glycaemic control would be predicted by psychosocial functioning was not supported. This finding is inconsistent with past studies of adults (Anderson, et al., 2001; Van Tilburg, et al., 2001) and adolescents (Lawrence, et al., 2006), which have identified a link between poorer glycaemic control and greater depression (Helgeson, et al., 2009; Lawrence, et al., 2006), greater anxiety (Herzer & Hood, 2010), poorer coping (Graue, et al., 2004; Skocic, et al., 2010) and reduced family functioning (Greene, et al., 2010). Relationships to self-efficacy and T1D knowledge are less clearly understood.

These finding may reflect unique characteristics of this study's sample. The sample was characterised by a mean suboptimal level of glycaemic control. Nearly half (48.5%) of the participants used the insulin pump, whereas only 28% of the clinic population use the insulin pump. Therefore, this method of insulin administration was over-represented in the study sample relative to the overall clinic population. Patients are typically required to demonstrate high levels

of motivation and good self-management behaviours to be considered successful candidates for insulin pump therapy (Craig, et al., 2011), therefore the sample may have been biased towards those children and adolescents who have a history of desirable T1D self-management. Insulin pump users also demonstrate more stable HbA1c levels compared to MDI using the hypodermic needle or pen injection devices (Craig, et al., 2011), therefore contributing to more stable HbA1c levels in this sample. A more representative sample of the clinic population may have yielded differences consistent with past research which has identified significant associations between glycaemic control and depression, anxiety, coping and family functioning. Nevertheless, these findings provide some indication of the optimal health outcomes associated with this method of insulin administration. Further studies comparing the psychosocial outcomes of the pump compared to traditional methods of insulin administration is required to empirically establish pump-related optimal management and health-related outcomes.

This finding may also reflect previously noted difficulties in confirming significant associations between glycaemic control and psychosocial factors in children and adolescents with T1D. A recent meta-analysis of depression and anxiety research in children with T1D found a significant association with glycaemic control, however the effect size was reduced in recently published studies. This was attributed to the possible impact of recent treatment advances such as the insulin pump on T1D management and the associated increased flexibility in insulin regimens, as well as other recent advances in treatment such as the advent of psychosocial support in paediatric T1D clinics.

The non-significant finding for the hypothesis predicting that higher levels of depression and anxiety, poorer coping and family functioning, and lower self-efficacy and illness knowledge

would be associated with worse glycaemic control may alternatively be explained by non-T1D related fluctuations in HbA1c levels. The current sample was characterised by a suboptimal median level of glycaemic control, reflecting the difficulties inherent in improving glycaemic control in youth, particularly in adolescents. While HbA1c levels are currently the standard form of assessing glycaemic control in children and adolescents, HbA1c levels may also be influenced by hormonal changes and other factors, such as a minor medical illness (e.g. cold and flu) (Nouwen, et al., 2009). Developmental processes in adolescents such as the striving for identity and autonomy may further complicate T1D regimens aiming to improve glycaemic control (Anderson, 2004; Suris, et al., 2004). Accordingly, the ongoing attainment of optimal glycaemic control in adolescents in particular is a known clinical problem for paediatricians working with this group, where such fluctuations in HbA1c can play a role. The difficulty in translating HbA1c recommendations into 'real life' T1D management was demonstrated by Kichler et al. (2010), who found that adolescent membership of HbA1c categories similar to those used in this study were not related to self-management practices. The authors concluded that adolescents in different categories may not be as different in their T1D management practices as previously thought.

7.1.1.2. Psychosocial predictors of school absenteeism. As the assessment of T1D management using HbA1c may be subject to non-illness related fluctuations (Nouwen, et al., 2009), T1D management was also investigated using school absenteeism. The second hypothesis related to illness management, which stated that school absenteeism would be predicted by levels of psychosocial wellbeing, was supported. This finding means that young people with T1D with

school absenteeism are also at risk of poorer psychosocial wellbeing. An explanation for this finding might be that missed school days might increase difficulties in keeping up with academic workload and in consolidating peer friendships, thereby increasing feelings of anxiety and depression and exacerbating T1D-related coping difficulties. Alternatively, feelings of depression, anxiety and coping difficulties related to T1D might result in reduced school attendance. This study finding is of interest as it appears to be only the second study, along with Chisholm (2003), to have explored psychosocial wellbeing on the context of school absenteeism. As the sample was functioning well from an overall psychosocial perspective and comprised a high percentage of insulin pump users, children and adolescents with T1D who did not participate may have reported even greater issues with school absenteeism and psychosocial functioning.

7.1.2. Psychosocial predictors of overall psychosocial wellbeing.

7.1.2.1. Psychosocial predictors of coping. This study hypothesised that children and adolescents who reported better coping with their illness would be characterised by better overall psychosocial wellbeing, and this hypothesis was supported. Participants who reported better coping with upsetting aspects of T1D were predicted by lower levels of depression and anxiety, better coping with T1D tasks that were hard to do, and a greater sense of self-efficacy. This finding was also supported by results reported in Paper 3, which indicated that difficulties coping with upsetting aspects of T1D were highly intercorrelated with the same factors.

The prediction of adaptive coping using reduced depression and anxiety, better coping with T1D tasks and greater self-efficacy is consistent with the findings of studies in other

developed countries, which have demonstrated significant relationships between coping with upsetting aspects of T1D and other aspects of psychosocial wellbeing in this important group (Grey, et al., 1998; Jaser & White, 2011). Better coping with emotions related to T1D may ameliorate feelings of depression and anxiety, and improve confidence in T1D tasks. An alternative explanation is that feelings of depression, anxiety and lack of confidence in T1D management tasks may predispose young people to coping difficulties. As coping with upsetting aspects of T1D draws on the emotion-focused coping literature, supporting young people in developing adaptive emotion-focused strategies, such as emotional expression (Grey, 2000) and acceptance (Jaser & White, 2011) appears to be more problematic for this sample than problem-focused strategies, which are related to coping with T1D tasks. The subscale used to assess coping with T1D tasks demonstrated poor reliability, but was still found to be highly intercorrelated with anxiety and self-efficacy (Paper 3). This finding suggests that difficulties coping with illness tasks might lead to increased anxiety and reduced confidence in ability to complete such tasks. Conversely, feelings of anxiety and low self-efficacy may exacerbate these coping difficulties. Supporting young people to develop adaptive problem-focused strategies also appears to be a requirement for optimal psychosocial wellbeing. Coping skills training to develop adaptive emotion-focused and problem-focused coping strategies should therefore be considered as part of multifaceted interventions targeting overall psychosocial wellbeing. These findings are underscored by the overall status of the sample as 'psychologically well', as it is likely that greater coping difficulties would have been identified in a representative sample.

7.1.2.2. Psychosocial predictors of family functioning. Paper 1 also reported on the hypothesis that family functioning would be predicted by overall psychosocial wellbeing, and this prediction was supported. Participants with families characterised by warmth and guidance regarding their T1D reported significantly lower levels of depression, anxiety and higher levels of self-efficacy. These participants were also significantly more likely to be younger. The relationship of family functioning to overall psychosocial wellbeing was also reported in Paper 3, which found that family functioning was clearly related to overall psychosocial wellbeing.

This finding suggests that the role of parental guidance and warmth is closely linked to the psychosocial wellbeing of young people with T1D. This relationship may be explained by the supportive parenting style reducing the potential for depression and anxiety in the young person, and providing support in building competence in their T1D management tasks. An alternative explanation is the presence of depression, anxiety and lack of confidence in T1D management tasks having a potentially negative impact on the young person's relationship with their parents. This finding is interesting, because the majority of studies of family functioning in young people with T1D have focused on glycaemic control as an outcome. The role of family functioning in achieving optimal glycaemic control is widely recognised (Anderson, 2012), and a recent meta-analysis found that family-based interventions appeared to have a greater effect on glycaemic control than individually targeted interventions (Winkley, et al., 2006). While family functioning was not related to glycaemic control in this study's sample, it was found to be closely linked with participants' psychosocial wellbeing.

7.1.2.3. Psychosocial predictors of depressive symptoms. The hypothesis that depressive symptoms would be predicted by lower levels of psychosocial wellbeing was supported, as children who endorsed elevated depressive symptoms also reported significantly higher levels of anxiety symptoms, greater difficulties coping with upsetting aspects of their illness, and lower levels of illness-related family support. The current study also identified a very low prevalence of depressive and anxiety symptoms in the final sample. These prevalence rates were lower than those obtained in recent studies of children and adolescents with T1D (Armstrong, et al., 2011; Jaser, et al., 2008) and healthy adolescents (Saluja, et al., 2004).

These findings suggest that the children and adolescents in the current study represented a 'psychologically well' group, and may be the result of a sample bias, with higher levels of depression and anxiety likely to have been found if a more representative sample had been obtained. The children and adolescents approached for participation during recruitment but who did not take part in the study represent an important group for inclusion in future research and intervention on this topic, as it is likely that higher levels of depression and anxiety would be identified in a more inclusive sample. A solution to this issue would involve the ability of future studies to offer data collection through mail or online questionnaires, or multi-site studies to increase improve sample representativeness. Other studies of depression and/or anxiety in young people with T1D have successfully recruited larger samples using mail (Armstrong, et al., 2011) and multi-site (Lawrence, et al., 2006) methods. The greater use of the insulin pump may have also resulted in lower levels of depression and anxiety symptoms due to reduced illness management demands (Knight, et al., 2009; Reynolds & Helgeson, 2011).

The use of the CDI raw score cut-off of 13 or higher in young people with type 1 diabetes was also strengthened by the referrals for this study. The CDI manual states that a T Score of 65 or higher should be generally used in children and adolescents as a cut-off score for elevated symptoms depressive symptoms (Kovacs, 1992). The CDI raw score cut-off of 13 or higher represents a relatively lower threshold compared to the T Score cut-off and is used widely in research studies of depression in young people with T1D (Armstrong, et al., 2011; Jaser, et al., 2008). A comparison of all of the study participants in the full sample (n = 80, prior to data cleaning) who met the CDI raw score cut-off (n = 9, 11.3% of the full sample) found that almost all (n = 7) also met the criteria for referral based on other criteria used in this study, specifically their RCMAS-2 total score results, endorsement of the suicidal ideation item of the CDI, or disclosure of other psychological distress during the data collection appointment. Only one participant (1.3% of the full sample) met the criteria for elevated depressive symptoms using the CDI T Score cut-off criteria. Therefore, the use of the CDI raw score cut-off of 13 or higher in young people with T1D was supported by this observation. The findings also highlight the benefit of face-to-face data collection in providing study participants with an opportunity to raise other psychological distress warranting referral that might not have been detected using test results alone.

7.2 Implications Arising from the Current Study

7.2.1. Implications for the screening of psychosocial problems in paediatric type 1 diabetes settings.

The findings of this study have important implications for the screening for psychosocial problems in Australian paediatric T1D settings. Routine screening for depressive

and anxiety symptoms from the time of entry to a paediatric T1D clinic is currently recommended in evidence-based clinical guidelines for youth with T1D (IDF/ISPAD, 2011). The findings presented in Chapter Five (including Paper 2) identified a subset of Australian children and adolescents who experienced depression and anxiety symptoms in the maintenance phase of their illness. The findings also demonstrate that children and adolescents with T1D may experience symptoms of depression and anxiety that may not be identified and addressed in regular clinic appointments, even when multidisciplinary health services including a clinical psychologist are available. Accordingly, a more proactive approach to identifying psychological issues in the maintenance phase of T1D, such as routine screening, might assist in the continued early identification and intervention of depression and anxiety symptoms. The findings discussed in Paper 2 therefore provide some support for existing guidelines which recommend routine psychological screening in paediatric T1D settings. The prevalence of depression and anxiety were not as high as expected, and it has been argued that the prevalence of psychological problems needs to be high enough to warrant screening all children and adolescents in T1D clinics (Cameron, Northam, Ambler, & Daneman, 2007). Despite the low prevalences found, routine psychological screening is currently being introduced to the recruitment clinic (K. Hildebrandt, personal communication, December 28, 2011). Further research in a larger sample of Australian children and adolescents would further elucidate the prevalence of depression and anxiety in Australian youth with T1D, as the prevalence rates of depression and anxiety identified in this study suggest the sample were characterised by overall ‘good’ psychosocial wellbeing, and might not be representative of other Australian children and adolescents with T1D.

The subset of youth experiencing depression and/or anxiety was not able to be distinguished from other participants in the based on their glycaemic control. The lack of significant associations between any psychosocial factors and glycaemic control in a group characterised by 'suboptimal' glycaemic control suggests that psychological problems may be present, even in the absence of concerns regarding glycaemic control.

The findings discussed in Paper 3 also have implications for the screening of psychosocial problems. Psychosocial wellbeing, particularly internalising symptoms and coping with 'upsetting' aspects of illness, significantly predicted two or more missed school days in the preceding Australian school term. Accordingly, school functioning may be useful as a potential early 'red flag' for psychosocial issues. Early detection of psychological concerns is critical, as the psychological sequelae of T1D are potentially more amenable to clinical intervention than the medical complications associated with the illness (Ambler, et al., 2006).

The findings presented in Paper 3 provide support for the use of school absenteeism as a supplementary measure of illness functioning, in addition to HbA1c levels. School absenteeism may potentially serve as a useful marker for psychosocial impairment and should be considered during clinic appointments.

7.2.2. Implications for clinical interventions to improve psychosocial functioning.

The findings discussed in Papers 2 and 3 have a number of important implications for clinical interventions which aim to address depressive symptoms, coping or family functioning in youth with T1D. The multifaceted nature of psychosocial wellbeing, and conversely, psychosocial problems, was highlighted in the current findings. For instance, psychological interventions

which aim to prevent or reduce depressive symptoms might include an assessment of anxiety, coping and parental warmth and guidance. Such interventions might also be better targeted by providing components to help manage feelings of anxiety and coping with illness, as well as parental involvement to provide education and skills related to optimal family functioning. The need for clinical interventions to address coping and family functioning was also confirmed. The efficacy of psychosocial interventions which aim to improve the T1D-related coping skills in young people may be improved by including an assessment of depression, anxiety, and parental warmth and guidance in T1D management. Coping skills interventions may be better targeted by providing psychological support and skills training to manage feelings of depression, anxiety and coping with tasks related to illness, as well as parental involvement to provide education and skills to ensure optimal family functioning.

Psychosocial interventions to improve family functioning might also include components to assess depression, anxiety and self-efficacy. These interventions may be better targeted by providing psychological support and skills training to manage feelings of depression, anxiety and confidence in undertaking illness management tasks.

These findings are consistent with the current research on clinical interventions in young people with T1D. The importance of including related factors such as family involvement in the development of evidence-based clinical interventions is a clear priority (Anderson, 2012). Recent studies of clinical interventions targeting outcomes such as illness-related coping have demonstrated the potential of such interventions to improve coping, despite non-significant findings (Grey, et al., 2011). In summary, clinical interventions which aim to reduce depressive symptoms or improve illness-related coping or family functioning may benefit from a

multifaceted intervention design, which specifically targets the psychosocial factors related to each of these outcome areas.

7.3 Limitations of the Current Study

Limitations associated with the findings reported in Papers 1, 2 and 3 were discussed in each manuscript. This section will therefore review limitations of this study overall.

7.3.1. Sampling limitations. It was initially hoped that approximately 150 children with T1D would be recruited, to address the lack of Australian research on children relative to adolescent samples. The study recruitment involved 7 to 15 year olds, and it was difficult to recruit a sufficient number of participants, even with an extended data collection phase. The final size of the sample was therefore smaller than anticipated. An additional difficulty was the recruitment of sufficient numbers of younger children despite attempts to recruit children.

While the choice of the recruitment hospital or participant home was offered for data collection, the response rate was much lower than anticipated and was achieved after several cycles of participant approaches via mail and direct methods. The recruitment rate may have been higher through the use of a questionnaire mail-out, a methodology that has been successfully implemented in other psychosocial studies of youth with T1D (Jaser, et al., 2008). The low response rate may also be partly attributable to the recruitment of several other T1D research studies within the recruitment hospital during the data collection period, which may have contributed to 'research fatigue' or confusion regarding the different research studies

underway at the time. The difficulties in recruitment in similar clinical settings have been noted in the literature (Sullivan-Bolyai, et al., 2007).

The relatively low response rate of 28.4% has important implications for the extrapolation of the findings to other youth with T1D. A self-selection bias may be evident in the current sample, as participants had to 'opt in' to the study. The psychological nature of the research may have appealed to participants who experienced psychosocial issues, but this was not consistent with this study's findings overall. An alternative explanation consistent with the findings obtained is that participation may have been avoided by others who did not take part due to a reluctance to disclose psychosocial problems. This last possibility is supported by the observation that the prevalence of depression and anxiety in the sample was lower than other recently published studies (as previously discussed in Section 7.1.2.3). The sample comprised a high percentage of insulin pump users, a subgroup highly motivated to manage their T1D optimally (as discussed in 7.1.1.1). These sample characteristics suggest that proactive parenting styles and young people with positive coping style were more likely to be represented. Taken together, the sampling limitations discussed suggest that the current sample comprised children and adolescents who were generally functioning well from a psychological and T1D management perspective. The sampling bias prevents extrapolation of the study findings to the recruitment clinic population, as well as other young people with T1D. The implication of this sampling bias is that the difficulties with depression, coping, family functioning and school absenteeism identified in this sample likely to be worse in the remainder of the clinic population. It also means that youth that appear psychologically 'well' overall may still experience

difficulties in these areas of wellbeing and T1D management, which are problematic enough to distinguish them from others who also appear psychologically 'well'.

The investigation of school absenteeism reported in Paper 3 was also limited by the lack of a comparison group of healthy children. This limitation prevented the number of school days missed in participants to be compared to healthy peers. As the reason for missed school days was not specifically attributed to T1D issues, it is possible that the number of school days missed may not be higher than that reported in healthy children. Further research with a comparison group of healthy youth would address this limitation.

An additional limitation regarding the representativeness of the sample involved the recruitment of participants from one clinic. Differences in demographic and other characteristics across clinics mean that the sample may not be representative of children and adolescents with T1D receiving care at other services.

7.3.2. Methodological limitations. A methodological limitation was evident in the choice of some measures prior to data collection. The knowledge measure used in the current study demonstrated poor reliability, even after adaptation for younger ages. Since the current study's conceptualisation in 2007, more appropriate measures of self-care and self-efficacy have also been published. For instance, the SDSCA used in the current study has been superseded by the Self-Care Inventory (SCI) (Lewin, et al., 2009). While the self-efficacy measure used in the current study showed good reliability, the Self-Efficacy for Diabetes (SED) measure (Grossman, et al., 1987) continues to be used in recent studies of children and adolescents with T1D (Armstrong, et al., 2011) and has displayed good psychometric properties. Finally, the structure

of the coping measure was recently criticised as not measuring coping, but instead the perceived upsetting and difficult aspects of living with T1D (Warner & Hauser, 2009). However, it remains a widely used measure of coping in youth with T1D (Grey, et al., 2001). The assessment of school absenteeism would have also been enhanced with school data, such as school report to verify parent recall.

7.4 Future Research

Future research deriving from the findings of this study, presented in Papers 1, 2 and 3, were noted in the manuscripts presented in Chapters Four to Six. Therefore, this section will identify two pathways for future research to best clarify and extend the study's main findings.

First, future research of clinical interventions to improve health and psychosocial outcomes for children and adolescents with T1D might consider the inclusion of multiple psychosocial components to address outcomes investigated in this study. For example, a coping intervention might focus on the development of emotion-focused and problem-focused coping skills, and include measures and components to prevent and/or reduce problems related to depression, anxiety and self-efficacy. The inclusion of intervention components based on this study's findings may further improve the efficacy of multifaceted interventions which address related aspects of wellbeing, compared to those that focus on the modification of the intervention outcome variable alone. A recent systematic review of randomised control trials (RCTs) targeting T1D and psychosocial outcomes in young people with T1D identified mixed outcomes for psychosocial and family-based interventions targeting T1D management and psychosocial variables, including mental health problems, coping and family functioning (Savage, Farrell,

McManus, & Grey, 2010). There is therefore scope to incorporate multiple components into psychosocial and family-based interventions for young people with T1D, to achieve better efficacy for specific intervention outcomes investigated in this study. Furthermore, future studies in this area need to refine translate promising intervention study outcomes that demonstrate good efficacy to interventions that are effective for this population in the clinical setting (Savage, et al., 2010).

Second, the investigation of differences between groups of children and adolescents with T1D using different management regimens could be extended further. Reynolds and Helgeson (2011) suggest that advances in T1D treatment might explain the reduced effect size for depression and anxiety in their recent meta-analysis. A pilot study of Australian children and adolescents (Knight, et al., 2009) found that a reduction in internalising symptoms (including depression, anxiety and somatisation) was observed after commencement of insulin pump use. However, modern treatment advances extend beyond merely treatment regimens, and include developments such as the inclusion of psychosocial support in paediatric T1D services. A comparison of Australian children and adolescents on psychosocial functioning which accounts for insulin regimen and degree of regimen intensivity (i.e. BD or MDI) might provide further information regarding the influence of specific T1D management factors on psychosocial wellbeing.

7.5 Concluding Remarks

A key strength of this study was the use of a range of psychosocial factors to assess T1D management and psychosocial wellbeing, as the role of coping difficulties, self-efficacy, family

functioning and knowledge in T1D management is understudied in Australian children and adolescents. The inclusion of children from seven years of age provides further information for an age group who remain relatively under-represented in studies of T1D management and psychosocial functioning. This lack of representation is particularly evident in Australian research in this field, which has generally focused on older children and adolescents.

Savage et al. (2010) argue for the direct translation of research findings to health interventions delivered in real-life settings. The results from this research provide several recommendations for clinical screening and interventions to improve T1D management and ultimately the psychosocial wellbeing of young people with this chronic health condition. The findings indicate the need for clinical interventions for depression, coping and family functioning that take a multifaceted approach. This can include family, skills, and therapy-based components. The use of 'early identifier' external markers for potential psychosocial problems, such as school attendance, may also assist clinical efforts to identify such problems at an early stage, and address concerns before they worsen. This study, with a relative healthy sample still showed indicators of psychosocial issues that were not related to HbA1c levels. There remains a need to target younger patients to ensure early detection and intervention of psychosocial issues, and their optimal health management and wellbeing throughout the lifespan.

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Appendix A – Research Questionnaire – Child/Adolescent Version

Office use only: 0 1 2 4 8 | 0 1 2 4 8 | 0 1 2 4 8

Instructions

1. *This survey is designed to be scanned by a computer. For this to work, the survey must remain uncreased, so please do not bend or fold this survey.*
2. *Unless otherwise instructed, please provide only ONE response to each question.*
3. *Questions should be completed using a HB pencil.*
4. *To respond to a question, darken the appropriate circle as follows:*

○ ○ ○ ● ○ ○ ○

5. *If you wish to change your response to a question, COMPLETELY ERASE the circle that you have darkened.*

Demographics

1. What is your name?

A ○○○○○○○○○○○○○○○○○○○○○○○○○○
B ○○○○○○○○○○○○○○○○○○○○○○○○○○
C ○○○○○○○○○○○○○○○○○○○○○○○○○○
D ○○○○○○○○○○○○○○○○○○○○○○○○○○
E ○○○○○○○○○○○○○○○○○○○○○○○○○○
F ○○○○○○○○○○○○○○○○○○○○○○○○○○
G ○○○○○○○○○○○○○○○○○○○○○○○○○○
H ○○○○○○○○○○○○○○○○○○○○○○○○○○
I ○○○○○○○○○○○○○○○○○○○○○○○○○○
J ○○○○○○○○○○○○○○○○○○○○○○○○○○
K ○○○○○○○○○○○○○○○○○○○○○○○○○○
L ○○○○○○○○○○○○○○○○○○○○○○○○○○
M ○○○○○○○○○○○○○○○○○○○○○○○○○○
N ○○○○○○○○○○○○○○○○○○○○○○○○○○
O ○○○○○○○○○○○○○○○○○○○○○○○○○○
P ○○○○○○○○○○○○○○○○○○○○○○○○○○
Q ○○○○○○○○○○○○○○○○○○○○○○○○○○
R ○○○○○○○○○○○○○○○○○○○○○○○○○○
S ○○○○○○○○○○○○○○○○○○○○○○○○○○
T ○○○○○○○○○○○○○○○○○○○○○○○○○○
U ○○○○○○○○○○○○○○○○○○○○○○○○○○
V ○○○○○○○○○○○○○○○○○○○○○○○○○○
W ○○○○○○○○○○○○○○○○○○○○○○○○○○
X ○○○○○○○○○○○○○○○○○○○○○○○○○○
Y ○○○○○○○○○○○○○○○○○○○○○○○○○○
Z ○○○○○○○○○○○○○○○○○○○○○○○○○○

2. How do you take your insulin?

○ *Needle*
○ *Pen*
○ *Pump*

3. How old are you?

7	*8*	*9*
○	○	○
10	*11*	*12*
○	○	○
13	*14*	*15*
○	○	○

4. What is the date of your birth?

	D	*D*	*M*	*M*	*Y*	*Y*	*Y*	*Y*
0	○	○	○	○	○	○	○	○
1	○	○	○	○	○	○	○	○
2	○	○	○	○	○	○	○	○
3	○	○	○	○	○	○	○	○
4	○	○	○	○	○	○	○	○
5	○	○	○	○	○	○	○	○
6	○	○	○	○	○	○	○	○
7	○	○	○	○	○	○	○	○
8	○	○	○	○	○	○	○	○
9	○	○	○	○	○	○	○	○

5. What is today's date?

	D	*D*	*M*	*M*	*Y*	*Y*	*Y*	*Y*
0	○	○	○	○	○	○	○	○
1	○	○	○	○	○	○	○	○
2	○	○	○	○	○	○	○	○
3	○	○	○	○	○	○	○	○
4	○	○	○	○	○	○	○	○
5	○	○	○	○	○	○	○	○
6	○	○	○	○	○	○	○	○
7	○	○	○	○	○	○	○	○
8	○	○	○	○	○	○	○	○
9	○	○	○	○	○	○	○	○

Appendix A – Research Questionnaire – Child/Adolescent Version

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Instructions - How I Think and Feel (Part 1)

Kids sometimes have different feelings and ideas. This form lists the feelings and ideas in groups. From each group, pick one sentence that described you best for the past two weeks. After you pick a sentence from the first group, go on to the next group. There is no right answer or wrong answer. Just pick the sentence that best describes the way you have been recently. Fill in the circle next to the sentence that you pick.

Here is an example of how this form works. Try it. Fill in the circle next to the sentence that describes you best.

Example:
- ○ I read books all the time.
- ○ I read books once in a while.
- ○ I never read books.

Remember, pick out the sentences that describe your feelings and ideas in the past two weeks.

How I Think and Feel (Part 1)

Item 1
- ○ I am sad once in a while.
- ○ I am sad many times.
- ○ I am sad all the time.

Item 2
- ○ Nothing will ever work out for me.
- ○ I am not sure if things will work out for me.
- ○ Things will work out for me OK.

Item 3
- ○ I do most things OK.
- ○ I do many things wrong.
- ○ I do everything wrong.

Item 4
- ○ I have fun in many things.
- ○ I have fun in some things.
- ○ Nothing is fun at all.

Item 5
- ○ I am bad all the time.
- ○ I am bad many times.
- ○ I am bad once in a while.

Item 6
- ○ I think about bad things happening to me once in a while.
- ○ I worry that bad things will happen to me.
- ○ I am sure that terrible things will happen to me.

Item 7
- ○ I hate myself.
- ○ I do not like myself.
- ○ I like myself.

Item 8
- ○ All bad things are my fault.
- ○ Many bad things are my fault.
- ○ Bad things are not usually my fault.

Item 9
- ○ I do not think about killing myself.
- ○ I think about killing myself but would not do it.
- ○ I want to kill myself.

Item 10
- ○ I feel like crying every day.
- ○ I feel like crying many days.
- ○ I feel like crying once in a while.

Item 11
- ○ Things bother me all the time.
- ○ Things bother me many times.
- ○ Things bother me once in a while.

Item 12
- ○ I like being with people.
- ○ I do not like being with people many times.
- ○ I do not want to be with people at all.

How I Think and Feel (Part 1) - continued

Item 13
- ○ I cannot make up my mind about things.
- ○ It is hard to make up my mind about things.
- ○ I make up my mind about things easily.

Item 14
- ○ I look OK.
- ○ There are some bad things about my looks.
- ○ I look ugly.

Item 15
- ○ I have to push myself all the time to do my schoolwork.
- ○ I have to push myself many times to do my schoolwork.
- ○ Doing schoolwork is not a big problem.

Remember, describe how you have been in the past two weeks.....

Item 16
- ○ I have trouble sleeping every night.
- ○ I have trouble sleeping many nights.
- ○ I sleep pretty well.

Item 17
- ○ I am tired once in a while.
- ○ I am tired many days.
- ○ I am tired all the time.

Item 18
- ○ Most days I do not feel like eating.
- ○ Many days I do not feel like eating.
- ○ I eat pretty well.

Item 19
- ○ I do not worry about aches and pains.
- ○ I worry about aches and pains many times.
- ○ I worry about aches and pains all the time.

Item 20
- ○ I do not feel alone.
- ○ I feel alone many times.
- ○ I feel alone all the time.

Item 21
- ○ I never have fun at school.
- ○ I have fun at school only once in a while.
- ○ I have fun at school many times.

Item 22
- ○ I have plenty of friends.
- ○ I have some friends but I wish I had more.
- ○ I do not have any friends.

Item 23
- ○ My schoolwork is alright.
- ○ My schoolwork is not as good as before.
- ○ I do very badly in subjects I used to be good in.

Item 24
- ○ I can never be as good as other kids.
- ○ I can be as good as other kids if I want to.
- ○ I am just as good as other kids.

Item 25
- ○ Nobody really loves me.
- ○ I am not sure if anybody loves me.
- ○ I am sure that somebody loves me.

Item 26
- ○ I usually do what I am told.
- ○ I do not do what I am told most times.
- ○ I never do what I am told.

Item 27
- ○ I get along with other people.
- ○ I get into fights many times.
- ○ I get into fights all the time.

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Instructions - How I Think and Feel (Part 2)

The sentences on this form tell how some people think and feel about themselves. Read each sentence carefully, then fill in the circle for the word that shows your answer. Fill in YES if you think the sentence is TRUE about you. Fill in NO if you think it is NOT TRUE about you. Give an answer for every sentence, even if it is hard to choose one that fits you. Do not fill in the circles for both YES and NO for the same sentence. If you want to change an answer, erase your first answer and then fill in the circle for your new choice. There are no right or wrong answers. Only you can tell us how you think and feel about yourself. Remember, after you read each sentence, ask yourself "Is it true about me? If it is, fill in the circle for YES. If it is not, fill in the circle for NO.

How I Think and Feel (Part 2)

YES	NO	
○	○	1. Often I feel sick in my stomach.
○	○	2. I am nervous.
○	○	3. I often worry about something bad happening to me.
○	○	4. I fear other kids will laugh at me in class.
○	○	5. I have too many headaches.
○	○	6. I worry that others do not like me.
○	○	7. I wake up scared sometimes.
○	○	8. I get nervous around people.
○	○	9. I feel someone will tell me I do things the wrong way.
○	○	10. I fear other people will laugh at me.

Continue with Item 11 unless you have been told to stop here.

YES	NO	
○	○	11. I have trouble making up my mind.
○	○	12. I get nervous when things do not go the right way for me.
○	○	13. Others seem to do things easier than I can.
○	○	14. I like everyone I know.
○	○	15. Often I have trouble getting my breath.
○	○	16. I worry a lot of the time.
○	○	17. I feel bad if people laugh at me.
○	○	18. I am afraid to do a lot of things.
○	○	19. I am always kind.
○	○	20. I get mad easily.
○	○	21. I worry about what my parents will say to me.
○	○	22. I feel that others do not like the way I do things.
○	○	23. I am afraid to give a talk to my class.
○	○	24. I always have good manners.
○	○	25. It is hard for me to get to sleep at night.
○	○	26. I worry about what other people think about me.
○	○	27. I feel alone even when other people are with me.
○	○	28. I get teased at school.
○	○	29. I am always good.
○	○	30. My feelings get hurt easily.
○	○	31. My hands feel sweaty.
○	○	32. I worry about making mistakes in front of people.
○	○	33. I am always nice to everyone.
○	○	34. I am tired a lot.
○	○	35. I worry about what is going to happen.
○	○	36. Other people are happier than I am.

How I Think and Feel (Part 2) - continued

YES	NO	
○	○	37. I am afraid to speak up in a group.
○	○	38. I tell the truth every single time.
○	○	39. I have bad dreams.
○	○	40. I get angry sometimes.
○	○	41. I worry about being called on in class.
○	○	42. I worry when I go to bed at night.
○	○	43. It is hard for me to keep my mind on my schoolwork.
○	○	44. I sometimes say things I should not say.
○	○	45. I worry about someone beating me up.
○	○	46. I wiggle in my seat a lot.
○	○	47. A lot of people are against me.
○	○	48. I have told a lie.
○	○	49. I worry about saying something dumb.

My Family and my Diabetes

Circle the answer that best tells how often these things happen or don't happen in your family. There are no right or wrong answers. If you are not certain, make your best guess. No one else in your family will see your answers.

All the time	Most of the time	Some time	Hardly ever	Never	
○	○	○	○	○	1. My parent(s) watches while I test for sugar.
○	○	○	○	○	2. When there is a problem about the diabetes, we call the doctor.
○	○	○	○	○	3. My mother decides what I'm going to eat.
○	○	○	○	○	4. My parent(s) understands how I feel about having diabetes.
○	○	○	○	○	5. I ask my parent(s) for advice about my diabetes.
○	○	○	○	○	6. My parent(s) talks about my diabetes.
○	○	○	○	○	7. We know when there are problems with my diabetes.
○	○	○	○	○	8. My parent(s) does things for me that I could do myself in taking care of my diabetes.
○	○	○	○	○	9. My parent(s) reads books about diabetes.
○	○	○	○	○	10. My parent(s) reminds me to test for sugar.
○	○	○	○	○	11. My parent(s) encourages me to get some exercise every day.
○	○	○	○	○	12. My parent(s) buys sweet snacks for the family.
○	○	○	○	○	13. My parent(s) gives me rewards for taking care of my diabetes.
○	○	○	○	○	14. At home, my family eats food that is not on my diabetic diet.
○	○	○	○	○	15. My diabetes makes my parent(s) real nervous.

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My Family and my Diabetes - Continued

All the time	Most of the time	Some time	Hardly ever	Never	
○	○	○	○	○	16. My parent(s) tests my sugar.
○	○	○	○	○	17. When my sugar runs high for several days, we wait and don't make any changes until my next scheduled doctor's appointment.
○	○	○	○	○	18. We wait to call the doctor until I'm very sick with my diabetes.
○	○	○	○	○	19. I take care of my diabetes myself.
○	○	○	○	○	20. My parent(s) makes sure I don't run out of insulin.
○	○	○	○	○	21. My parent(s) writes down the sugar tests.
○	○	○	○	○	22. My parent(s) listens to my ideas about taking care of my diabetes.
○	○	○	○	○	23. If we're not sure what to do we call for help.
○	○	○	○	○	24. My parent(s) and I argue about whether I'm sticking to my diabetes diet.
○	○	○	○	○	25. My family has regular meal times.
○	○	○	○	○	26. My parent(s) seems embarrassed that I have diabetes.
○	○	○	○	○	27. My parent(s) listens to my problems about having diabetes.
○	○	○	○	○	28. My parent(s) makes my snacks.
○	○	○	○	○	29. My parent(s) fill the insulin syringe.
○	○	○	○	○	30. My parent(s) makes me feel good about taking care of my diabetes.
○	○	○	○	○	31. My parent(s) gives my insulin shots.
○	○	○	○	○	32. My family embarrasses me by talking about diabetes with other people.
○	○	○	○	○	33. When we go out to eat, I choose things from the menu in line with my exchange diet.
○	○	○	○	○	34. Other family members eat sweets in front of me.
○	○	○	○	○	35. I feel all alone with my diabetes.
○	○	○	○	○	36. My parent(s) encourages (wants) me to do the kinds of things other kids do.
○	○	○	○	○	37. My parent(s) believes (feels) that testing for sugar is up to me.
○	○	○	○	○	38. My parent(s) is always ready to help with my diabetes if I need it.
○	○	○	○	○	39. My parent(s) tells me to stop acting as if I'm sick.

My Family and my Diabetes - Continued

All the time	Most of the time	Some time	Hardly ever	Never	
○	○	○	○	○	40. My parent(s) reminds me to give my insulin shots.
○	○	○	○	○	41. I don't worry about what my sugar test shows unless I start feeling bad.
○	○	○	○	○	42. My parent(s) knows how well I'm taking care of my diabetes.
○	○	○	○	○	43. I have someone in my family to talk to about my diabetes.
○	○	○	○	○	44. My parent(s) get angry with me when I make a slip in taking care of my diabetes (don't take care of my diabetes).
○	○	○	○	○	45. If my sugar test is too high, we check for acetone.
○	○	○	○	○	46. My family talks about diabetes.
○	○	○	○	○	47. My parent(s) is afraid to give me insulin shots.

The Control I Feel About my Diabetes

I am confident that:

1. I am able to check my blood sugar if necessary

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

2. I am able to correct my blood sugar when the sugar level is too high (e.g. eat different food)

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

3. I am able to correct my blood sugar when the sugar level is too low (e.g. eat different food)

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

4. I am able to choose foods that are best for my health

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

5. I am able to choose different foods and maintain a healthy eating plan

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

6. I am able to keep my weight under control

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

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The Control I Feel About my Diabetes - Continued

I am confident that:

7. I am able to examine my feet (e.g. for cuts or blisters)

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

8. I am able to do enough physical activity

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

9. I am able to maintain my eating plan when I am ill

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

10. I am able to follow a healthy eating plan most of the time

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

11. I am able to do more physical activity if the doctor advises me to

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

12. When doing more physical activity I am able to maintain my eating plan

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

13. I am able to follow a healthy eating plan when away from home

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

14. I am able to choose different foods and maintain my eating plan when I am away from home

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

15. I am able to follow a healthy eating plan when I am on holidays

○ 0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9 ○ 10

Cannot do at all *Maybe yes/maybe no* *Certain can do*

My Family and my Diabetes - Continued

I am confident that:

16. I am able to choose different foods and maintain a healthy eating plan when I am eating out or at a party

○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
Cannot do at all				Maybe yes/maybe no						Certain can do

17. I am able to maintain my eating plan when I am feeling stressed or anxious

○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
Cannot do at all				Maybe yes/maybe no						Certain can do

18. I am able to visit my doctor once every three months to monitor my diabetes

○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
Cannot do at all				Maybe yes/maybe no						Certain can do

19. I am able to maintain my medication as prescribed

○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
Cannot do at all				Maybe yes/maybe no						Certain can do

20. I am able to maintain my medication when I am ill

○ 0	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6	○ 7	○ 8	○ 9	○ 10
Cannot do at all				Maybe yes/maybe no						Certain can do

Living with my Diabetes

There are many things that kids with diabetes have to learn and do. Here is a list of important things. Fill in the circle to show how hard each thing has been for you.

I don't do this	Not that hard to do	A little hard to do	Very hard to do	
○	○	○	○	1. Giving myself needles (getting needles)
○	○	○	○	2. Testing my urine
○	○	○	○	3. Recording the results of my blood sugar levels
○	○	○	○	4. REMEMBERING to give myself the needle
○	○	○	○	5. REMEMBERING to record the results of my blood sugar levels
○	○	○	○	6. Having to eat my snack
○	○	○	○	7. REMEMBERING to eat my snack
○	○	○	○	8. Not eating "sweets", candy, cakes
○	○	○	○	9. Getting up early

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Living with my Diabetes - Continued

I don't do this	Not that hard to do	A little hard to do	Very hard to do	
○	○	○	○	10. Doing things on time
○	○	○	○	11. Exercising
○	○	○	○	12. Going for clinic visits
○	○	○	○	13. Doing the 24-hour urine test
○	○	○	○	14. Telling my friends about my diabetes
○	○	○	○	15. Telling teachers and grown-ups about my diabetes
○	○	○	○	16. Doing blood glucose testing at home

NOW, fill in one of the cricles for each sentence below to show how much the rest of these things have UPSET you recently. Pick the answer that describes you best.

Not very upsetting	A little upsetting	Very upsetting	
○	○	○	17. Thinking that I may have to be in the hospital
○	○	○	18. Life restrictions - can't be an airline pilot
○	○	○	19. Being "different" from other kids
○	○	○	20. Wearing Medic-Alert bracelet/necklace
○	○	○	21. Having my blood taken for tests
○	○	○	22. Thinking about my health
○	○	○	23. My parents telling me what to do about diabetes
○	○	○	24. Thinking about why I got diabetes
○	○	○	25. Insulin reactions, getting "shaky"
○	○	○	26. Other people knowing that I have diabetes
○	○	○	27. Reading or seeing stuff on TV about diabetes
○	○	○	28. Doing blood glucose testing at home

Diabetes Quiz

This is a short quiz to find out how much you know about diabetes. There are 15 questions and each one has several possible answers. For questions 1 to 12 only one answer is correct. If you know the right answer, fill in the circle in front of it. If you don't know the answer, fill in the circle in front of "I don't know". Notice that Questions 13, 14 and 15 have more than one correct answer, so you should fill in the circles for all the answers you think are right.

1. In uncontrolled diabetes the blood sugar is:
   - ○ Normal
   - ○ Increased
   - ○ Decreased
   - ○ I don't know

2. Which one of the following is true?:
   - ○ It does not matter if your diabetes is not fully controlled, as long as you do not have a coma
   - ○ It is best to show some sugar in the urine in order to avoid hypoglycaemia
   - ○ Poor control of diabetes could result in a greater chance of complications later
   - ○ I don't know

3. The NORMAL range for blood glucose is:
   - ○ 4-8 mmol/l
   - ○ 7-15 mmol/l
   - ○ 2-10 mmol/l
   - ○ I don't know

4. Butter is mainly:
   - ○ Protein
   - ○ Carbohydrate
   - ○ Fat
   - ○ Mineral and vitamin
   - ○ I don't know

5. Rice is mainly:
   - ○ Protein
   - ○ Carbohydrate
   - ○ Fat
   - ○ Mineral and vitamin
   - ○ I don't know

6. The presence of ketones in the urine is:
   - ○ A good sign
   - ○ A bad sign
   - ○ A usual finding in diabetes
   - ○ I don't know

7. Which of the following possible complications is usually not associated with diabetes?
   - ○ Changes in vision
   - ○ Changes in the kidney
   - ○ Changes in the lung
   - ○ I don't know

8. If a person on insulin has a high blood or urine sugar level and ketones were present they should:
   - ○ Increase insulin
   - ○ Decrease insulin
   - ○ Keep insulin and diet the same, and test blood/urine later
   - ○ I don't know

9. When people with diabetes on insulin become ill and unable to eat the prescribed diet:
   - ○ They should immediately stop taking insulin
   - ○ They must continue to take insulin
   - ○ They should use diabetic tablets instead of insulin
   - ○ I don't know

10. If you feel the beginnings of hypoglycaemia you should:
    - ○ Immediately take some insulin or tablets
    - ○ Immediately lie down and rest
    - ○ Immediately eat or drink something sweet
    - ○ I don't know

11. You can eat as much as you like of which of the following foods:
    - ○ Apples
    - ○ Celery
    - ○ Meat
    - ○ Honey
    - ○ I don't know

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Diabetes Quiz - Continued

12. Hypoglycaemia is caused by:
- ○ Too much insulin
- ○ Too little insulin
- ○ Too little exercise
- ○ I don't know

In these last three questions, there will be more than one correct answer. Please fill in the circles in front of all the answers you think are correct.

13. A kilogram is:
- ○ A metric unit of weight
- ○ Equal to 10 pounds
- ○ A metric unit of energy
- ○ A little more than two pounds
- ○ I don't know

14. Two of the following substitutions are right:
- ○ One portion (slice) bread = 4 cracker biscuits (e.g. Sao biscuits)
- ○ One egg = one portion of mince
- ○ 1 glass milk = 1 glass orange juice
- ○ ¾ cup cornflakes = ¾ cup cooked porridge
- ○ I don't know

15. If I don't feel like the egg allowed on my diet for breakfast I can:
- ○ Have extra toast
- ○ Substitute one small lamb cutlet
- ○ Have a small portion of cheese instead
- ○ Forget about it
- ○ I don't know

How I Take Care of my Diabetes

Thankyou for taking the time to fill this out. The questions below ask you about your diabetes self-care activities DURING THE PAST 7 DAYS. If you were sick during the past 7 days, please think back to the last 7 days you were not sick. Please answer the questions as honestly and accurately as you can. Your responses will be confidential.

The first few questions ask about your eating habits over the last 7 days. If you have not been given a specific diet by your doctor or dietitian, answer Question 1 according to the general guidelines you have received.

1. How often did you follow your recommended diet over the last 7 days?
- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Rarely
- ○ Never

2. What percentage of the time did you successfully limit your calories as recommended in healthy eating for diabetes control?
- ○ 0% (none)
- ○ 25% (1/4)
- ○ 50% (1/2)
- ○ 75% (3/4)
- ○ 100% (all)

3. During the past week, what percentage of your meals included high fibre foods such as fresh fruits, fresh vegetables, wholegrain breads, dried beans and peas, bran?:
- ○ 0% (none)
- ○ 25% (1/4)
- ○ 50% (1/2)
- ○ 75% (3/4)
- ○ 100% (all)

4. During the past week, what percentage of your meals included high fat foods such as butter, icecream, nuts and seeds, mayonnaise, avocado, deep-fried food, salad dressing, bacon, other meat with fat or skin?
- ○ 0% (none)
- ○ 25% (1/4)
- ○ 50% (1/2)
- ○ 75% (3/4)
- ○ 100% (all)

My Family and my Diabetes - Continued

5. During the past week what percentage of your meals included sweets and desserts such as pie, jelly, soft drinks, (regular, not diet soft drinks), cookies?
   - ○ 0% (none)
   - ○ 25% (1/4)
   - ○ 50% (1/2)
   - ○ 75% (3/4)
   - ○ 100% (all)

6. On how many days did you participate in at least 20 minutes of physical exercise?

   ○ ○ ○ ○ ○ ○ ○ ○
   0 1 2 3 4 5 6 7

7. What percentage of the time did you exercise the amount suggested by your doctor? (For example, if your doctor recommended 30 minutes of exercise)
   - ○ 0% (none)
   - ○ 25% (1/4)
   - ○ 50% (1/2)
   - ○ 75% (3/4)
   - ○ 100% (all)

8. On how many of the last 7 days did you participate in a specific exercise session other than what you do around the house or as part of your work?

   ○ ○ ○ ○ ○ ○ ○ ○
   0 1 2 3 4 5 6 7

9. On how many of the last 7 days (that you were not sick) did you test your glucose (blood sugar) level?
   - ○ Every day
   - ○ Most days
   - ○ Some days
   - ○ None of the days

10. Over the last 7 days (that you were not sick) what percentage of the glucose (blood sugar or urine) tests recommended by your doctor did you actually perform?
    - ○ 0% (none)
    - ○ 25% (1/4)
    - ○ 50% (1/2)
    - ○ 75% (3/4)
    - ○ 100% (all)

11. How many of your recommended insulin injections did you take in the last 7 days that you were supposed to?
    - ○ All of them
    - ○ Most of them
    - ○ Some of them
    - ○ None of them
    - ○ I do not take insulin

12. How many of the recommended number of pills to control diabetes did you take that you were supposed to?
    - ○ All of them
    - ○ Most of them
    - ○ Some of them
    - ○ None of them
    - ○ I do not take pills to control my diabetes

This is the end of the questionnaire - thankyou!

Appendix B – Research Questionnaire – Parent Version

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Instructions

1. *This survey is designed to be scanned by a computer. For this to work, the survey must remain uncreased, so please do not bend or fold this survey.*
2. *Unless otherwise instructed, please provide only ONE response to each question.*
3. *Questions should be completed using a HB pencil.*
4. *To respond to a question, darken the appropriate circle as follows:*

○ ○ ○ ● ○ ○ ○

5. *If you wish to change your response to a question, COMPLETELY ERASE the circle that you have darkened.*

Demographics

Demographic Questionnaire for Parents:

An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus (IDDM)

1. What is your name?

A ○○○○○○○○○○○○○○○○○○○○○○○○○○
B ○○○○○○○○○○○○○○○○○○○○○○○○○○
C ○○○○○○○○○○○○○○○○○○○○○○○○○○
D ○○○○○○○○○○○○○○○○○○○○○○○○○○
E ○○○○○○○○○○○○○○○○○○○○○○○○○○
F ○○○○○○○○○○○○○○○○○○○○○○○○○○
G ○○○○○○○○○○○○○○○○○○○○○○○○○○
H ○○○○○○○○○○○○○○○○○○○○○○○○○○
I ○○○○○○○○○○○○○○○○○○○○○○○○○○
J ○○○○○○○○○○○○○○○○○○○○○○○○○○
K ○○○○○○○○○○○○○○○○○○○○○○○○○○
L ○○○○○○○○○○○○○○○○○○○○○○○○○○
M ○○○○○○○○○○○○○○○○○○○○○○○○○○
N ○○○○○○○○○○○○○○○○○○○○○○○○○○
O ○○○○○○○○○○○○○○○○○○○○○○○○○○
P ○○○○○○○○○○○○○○○○○○○○○○○○○○
Q ○○○○○○○○○○○○○○○○○○○○○○○○○○
R ○○○○○○○○○○○○○○○○○○○○○○○○○○
S ○○○○○○○○○○○○○○○○○○○○○○○○○○
T ○○○○○○○○○○○○○○○○○○○○○○○○○○
U ○○○○○○○○○○○○○○○○○○○○○○○○○○
V ○○○○○○○○○○○○○○○○○○○○○○○○○○
W ○○○○○○○○○○○○○○○○○○○○○○○○○○
X ○○○○○○○○○○○○○○○○○○○○○○○○○○
Y ○○○○○○○○○○○○○○○○○○○○○○○○○○
Z ○○○○○○○○○○○○○○○○○○○○○○○○○○

2. How old are you?

0 ○○
1 ○○
2 ○○
3 ○○
4 ○○
5 ○○
6 ○○
7 ○○
8 ○○
9 ○○

3. What is today's date?

D D M M Y Y Y Y

0 ○○○○○○○○
1 ○○○○○○○○
2 ○○○○○○○○
3 ○○○○○○○○
4 ○○○○○○○○
5 ○○○○○○○○
6 ○○○○○○○○
7 ○○○○○○○○
8 ○○○○○○○○
9 ○○○○○○○○

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Demographic Questionnaire for Parents: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus (IDDM)

Principal Researcher: Dr. Margaret Hay
Doctor of Psychology Student Researcher: Ms Kelly Buttigieg

Instructions
Please answer the questions below by writing your response in the space provided or by darkening the relevant circle, as follows:

○ ○ ○ ● ○ ○ ○

Demographic questionnaire for parents

1. Your relationship to the child / adolescent taking part in this study:
- ○ *Mother*
- ○ *Father*
- ○ *Other - Please state relationship type:* _____

2. Your gender:
- ○ Male
- ○ Female

3. Your age:
- ○ 20 - 24
- ○ 25 - 34
- ○ 35 - 44
- ○ 45 - 54
- ○ 55 - 64

4. Household income:
- ○ Less than $20,000
- ○ $20,000 - $30,000
- ○ $30,001 - $50,000
- ○ $50,001 - $100,000
- ○ More than $100,000

5. Living arrangments of your child with diabetes:
- ○ Living with biological parents
- ○ With step-parents
- ○ Single parent
- ○ Other family members
- ○ Alone
- ○ With partner

6. Did your child miss two or more days of school in the last school term?
- ○ Yes
- ○ No

7. Employment status:
- ○ Unemployed
- ○ Employed → If yes, what is your occupation? _____
- ○ Not in the workforce

8. Your education level:
- ○ Less than Year 10
- ○ Year 10
- ○ High School
- ○ TAFE/vocational studies
- ○ Undergraduate university studies
- ○ Postgraduate university studies

9. Your relationship status:
- ○ Single
- ○ In a relationship
- ○ De facto / living with a partner
- ○ Married
- ○ Separated or divorced
- ○ Widowed

11. How many children do you have?
0 ○ 1 ○ 2 ○ 3 ○ 4 ○ 5 ○

12. Postcode:
0 ○○○○ 1 ○○○○ 2 ○○○○ 3 ○○○○ 4 ○○○○ 5 ○○○○ 6 ○○○○ 7 ○○○○ 8 ○○○○ 9 ○○○○

Thankyou for your family's involvement in this study!

Appendix C – Monash University Ethics Approval Letter

MONASH University

Standing Committee on Ethics in Research Involving Humans (SCERH)
Research Office

Human Ethics Certificate of Approval

Date:	**29 May 2008**
Project Number:	**CF08/1477 - 2008000755**
Project Title:	**An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent Diabetes Melitus (IDDM)**
Chief Investigator:	**Dr Margaret Hay**
Approved:	**From: 29 May 2008 To: 7 May 2011**

Terms of approval

1. The Chief investigator is responsible for ensuring that permission letters are obtained and a copy forwarded to SCERH before any data collection can occur at the specified organisation. **Failure to provide permission letters to SCERH before data collection commences is in breach of the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research.**
2. Approval is only valid whilst you hold a position at Monash University.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by SCERH.
4. You should notify SCERH immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. The Explanatory Statement must be on Monash University letterhead and the Monash University complaints clause must contain your project number.
6. **Amendments to the approved project:** Requires the submission of a Request for Amendment form to SCERH and must not begin without written approval from SCERH. Substantial variations may require a new application.
7. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
8. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. This is determined by the date of your letter of approval.
9. **Final report:** A Final Report should be provided at the conclusion of the project. SCERH should be notified if the project is discontinued before the expected date of completion.
10. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by SCERH at any time.
11. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

[redacted]

Professor Ben Canny
Chair, SCERH

Cc: Dr Christine Rodda; Dr Philip Bergman; Dr Justin Brown; Kelly Buttigieg

Postal – Monash University, Vic 3800, Australia
Building 3E, Room 111, Clayton Campus, Wellington Road, Clayton
Telephone +61 3 9905 5490 Facsimile +61 3 9905 1420
Email scerh@adm.monash.edu.au www.monash.edu/research/ethics/human/index/html
ABN 12 377 614 012 CRICOS Provider #00008C

Appendix D – Southern Health Ethics Approval Letter

Southern Health

246 Clayton Road
Clayton, Victoria 3168
Australia

Postal address:
Locked Bag 29
Clayton South, Victoria 3169
Australia

tel 03 9594 6666
fax 03 9594 6727

HUMAN RESEARCH ETHICS COMMITTEE C
CERTIFICATE OF APPROVAL

DATE	07 May 2008
PROJECT NO.	*07205C
PROJECT TITLE	An Investigation of the Psychosocial Correlates to Optimal Health Management in Young People with Insulin-Dependent Diabetes Mellitus (IDDM).

Parent/Guardian Participant Information Sheet Version No. 03 dated 06 May 2008
Parent/Guardian Consent Form Version No. 03 dated 06 May 2008
Participant Information Sheet Version No. 03 dated 06 May 2008
Consent Form Version No. 03 dated 06 May 2008

INVESTIGATOR(S)	Dr Margaret Hay
HREC MEETING DATE	20.12.07
APPROVAL	07.05.2008 – 07.05.2011

The Principal Investigator is required to notify the Manager of Research Directorate of:

1. Any change in protocol and the reason for that change together with an indication of ethical implications (if any)
2. Serious or unexpected adverse effects of project on subjects and steps taken to deal with them
3. Any unforeseen events that might affect continued ethical acceptability of the project
4. Any expiry of the insurance coverage provided in respect of sponsored trials
5. Discontinuation of the project before the expected date of completion, giving reasons
6. Any change in personnel involved in the research project including any study member resigning from Southern Health &/or the study team.

At the conclusion of the project or every twelve months if the project continues, the Principal Investigator is required to complete and forward an annual report to the Committee.

Annual report forms [redacted] the researcher.

SIGNED ..... **DATE** 07 May 2008
Committee Representative

Please quote Project No. and Title for all correspondence

Appendix E – Letter of Introduction from Head of Clinic

Dear X family,

As Head of the Diabetes and Ambulatory Care Service (DACS) at Monash Medical Centre, may I invite you to consider involvement in a research study, which is currently being carried out at DACS. You and your child X have been contacted on the basis of your son/daughter's attendance at DACS for diabetes care. This study will investigate the interaction between psychosocial factors and metabolic control in young people with insulin-dependent diabetes mellitus (IDDM). This study involves asking you and your son/daughter to complete some questionnaires (either by hand or verbally). The questions relate to psychological and social aspects of living with diabetes. This information may help enable future research to identify appropriate interventions to improve diabetes management in young people with IDDM.

This study has been approved by the Southern Health Research Ethics Committee, which has allowed your contact details to be provided to the researchers by Southern Health (in accordance with the Health Records Act 2001 [Vic]), so that they may contact you regarding this study. Your child's health information has been used to identify them as suitable for participation in this study being conducted by Southern Health and Monash University. Please note that if your son/daughter is happy to take part, he/she is free at any time to refuse consent for further involvement in the research. Please also note that the Health Records Act 2001 (Vic) will apply to protect the privacy and confidentiality of all individuals participating in the study, and none of your treating doctors will be aware of your individual results unless a major psychiatric condition or other problem is identified requiring support from the DACS team.

Should you be interested in having your child participate in this project, I invite you to read the enclosed Participant Information Consent Form, which provides further information about this project. Please note that your and your child's involvement in the study is entirely voluntary. Any information provided by you, your child, and clinical records will be treated in the strictest confidence. Identifying personal information from returned questionnaires and clinical records will be removed before inclusion in the study. Participants will not be individually identifiable in the resulting report or other publications. You are entirely free to discontinue you and your child's participation at any time, or to decline to answer particular questions on the questionnaire.

However, if you and your child are happy to take part in this study, involvement would require attendance of you and your child at one appointment for completion of questionnaires. This would be organised at a convenient time for you and your child, and the session will take approximately 60 minutes. *Alternatively, the student researcher will be happy to visit you and your child at home, or call you and your child, to administer the questionnaire if this is more convenient.* At the completion of the study, a summary of the overall results and findings will be made available to you.

If you and your son/daughter are not interested in being involved in this research, and do not wish to receive a phone call follow-up within the next month, please complete and return one of the "Removal from study database" slips at the end of the Information forms included with this letter. These slips can be completed by you or your son/daughter, and returned to the researchers using the reply-paid envelope we have provided.

If you have specific questions regarding this study and what participation may involve, please contact the researcher Ms Kelly Buttigieg on (03) 9902 4070. Thank you for your time and assistance.

Yours sincerely,

[redacted]

Associate Professor Christine Rodda - Head, Diabetes and Ambulatory Care Service (DACS)

Appendix F – Letter of Introduction from Student Researcher

Dear X family,

My name is Kelly Buttigieg and I am a postgraduate psychology student at Monash University. I am currently undertaking a research project in collaboration with paediatricians in the Diabetes and Ambulatory Care Service (DACS), Monash Medical Centre. This project aims to find out more about psychosocial factors that help young people optimally manage their insulin-dependent diabetes, and is supervised by Dr Margaret Hay (health psychologist). I am writing to request the involvement of you and your child/adolescent in this research, which we hope will lead to a greater understanding of what can be done to improve diabetes management in young people.

Participation in this project by you and your child/adolescent would involve a once-only session with me following a routine consultation with DACS. **Alternatively, if your child would prefer to complete the questionnaire at home or over the phone, I would be happy to visit your residence or call you with the questionnaire.**

This session would involve the completion of some questionnaires (verbally or in writing, depending on your child's age and preference) by your child in the presence of me, the researcher. I would also be grateful if you would complete a brief demographic questionnaire in the DACS waiting room while your child is in session. If you do not usually attend your child's visits to DACS, I can mail this questionnaire to you for completion at a time convenient to you. Please note that your decision to participate or not in this project will in no way affect the treatment your child receives at Southern Health.

This research project has been developed in consultation with DACS, who are supporting this project. This project has also been approved by the ethics committees at Southern Health and Monash University.

Thankyou for taking the time to read this letter and consider involvement in this research, which we hope will help improve future management of children and adolescents with diabetes. If you are interested in participating, could you please return the enclosed slip indicating that you are happy to be called by myself to discuss a possible time for this session. If you have any questions regarding this project, please do not hesitate to contact me directly at any time on (03) 9902 4070. Alternatively, my main supervisor Dr Margaret Hay can be contacted during office hours on 0407 044 625.

Yours sincerely,

Ms Kelly Buttigieg
Doctor of Clinical Psychology Candidate

Parent/Guardian Participant Information and Consent Form

Version: 7 Dated: 11 October, 2010 Site: Monash Medical Centre

Full Project Title: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus

Principal Researcher: Dr. Margaret Hay

Assoc Researchers: A/Prof Christine Rodda, Dr Philip Bergman, Dr Justin Brown

Doctor of Psychology Student Researcher: Ms Kelly Buttigieg

This Participant Information and Consent Form is 5 pages long. Please make sure you have all the pages.

1. Your Consent

As the 'person responsible' for your child, you are invited to consider your child's participation in a research project.

Victorian law allows the person responsible for a patient to consent to the patient taking part in medical research where the patient is unable to provide consent for themselves.

You are invited to consider your child's participation in this research project as he or she has insulin-dependent diabetes mellitus but is otherwise well. It is planned to enrol up to 150 children and adolescents in this project.

When you and your child attend the Diabetes Ambulatory Care Service (DACS), you will be given the Participant Information Form and Consent Form inviting your child to participate in this project. If you are happy for your child to participate in our research project, please complete the attached consent form and contact Ms. Buttigieg on (03) 9902 4070.

This Participant Information contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to permit your child to take part in it.

Please read this Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Please feel free to do this also.

Once you understand what the project is about and if you agree for your child to take part in it, you and your child will be asked to sign the Consent Form. We would like you to complete a brief demographic questionnaire, and therefore require your consent to participate in this research project. By signing the Consent Form, you indicate that you understand the information and that: (i) you give your consent to agree to participate in the project, and (ii) you give your consent to agree that your child participates in the research project.

You will be given a copy of the Parent/Guardian Participant Information and Consent Form to keep as a record.

The research team will follow up this mail-out to you with a phone call to ask you if you would like to take part in this project. If you DO NOT wish to receive a phone call or future correspondence from the research team regarding this project, please complete the slip at the end of this form and return it to the research team using the reply-paid envelope provided.

2. Background and Purpose

It is important to establish optimal management of IDDM in children and adolescents in order to provide a foundation for continuing management into adulthood. By understanding the role of modifiable psychosocial factors on management of IDDM in young people, it is hoped that this will improve the management of IDDM in young people in future.

The purpose of this project is to identify ways to help your child/adolescent best manage your diabetes both now and as they grow up. To do this we will measure things that we know are important to diabetes management. These include your child/adolescent's knowledge of diabetes, and how they and your family feel about managing the condition.

3. Procedures

This research is being conducted by a psychologist (Ms Kelly Buttigieg) who is undertaking her Doctor of Psychology – Clinical (DPsych) degree, under the supervision of a health psychologist (Dr Margaret Hay) and in collaboration with paediatric endocrinologists (Dr's Rodda, Bergman and Brown). Ms Buttigieg will be responsible for collecting all medical and psychological data.

Participation in this project will involve completion of questionnaires on one occasion at a time and place (a private room in Psychological Medicine, MMC or via a home visit by the researcher) that is convenient to you. The questionnaire will look at your child's mood and feelings generally, and will attempt to learn how well your child is managing with their diabetes management generally. Completion of these questionnaires should take no longer than 60 minutes.

4. Possible Benefits

Possible benefits include improving your child's understanding of his/her insulin-dependent diabetes mellitus and its management across the lifespan. There may be no immediate benefits to you and your child but it is hoped that the results of this research will assist in improving the care of children and adolescents with insulin-dependent diabetes mellitus.

Every child/adolescent participant who takes part in this research will also be placed in a raffle draw to win an iPod Touch 8GB (valued at approximately $289). Two iPods will be drawn in the raffle prize draw, which will take place after all participants have completed the research questionnaire. The two winners will be notified by phone and/or mail, and the prizes will be posted using Registered Post.

5. Possible Risks

We foresee no risks involved apart from the time required to complete the questionnaires. If your child is distressed by any of the aspects of the questionnaires, we will tell your family doctor and /or paediatrician who may make a referral to the Children & Adolescents Mental Health Service (MMC 246 Clayton Road, 3168; tel: 9594 1300) or other convenient regional CAMHS.

6. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this research project that identifies your child will remain confidential and will only be used for the purpose of this research project. Your child's record in the Diabetes and Ambulatory Care Service (DACS) database will be accessed by the researchers and de-identified information will be used in our research.

If you ask about your child's individual result, we are not able to disclose this to you. The only results that will be disclosed will be depression and anxiety results in the event that your child has elevated scores on these measures. These results will be disclosed to your child's clinician at DACS. This will allow your child's clinician to inform you and/or your child of these results, and ensure appropriate follow-up is provided for your child (e.g. referral to the DACS clinical psychologist). We will provide a summary of the findings at the conclusion of the project.

The information will be retained for 15 years after publication and 7 years after finishing this project. All information relating to this project will be kept in a locked filing cabinet in offices in the Centre for Developmental Psychiatry and Psychology, Monash University. Digitised information will be on a password protected computer with access restricted to the research team.

If the findings are published, any information given will be in such a way that your and your child cannot be identified. Only group data will be shown in any publication. You and your child's name will be removed from all data and identified by code only. In accordance with the *Freedom of Information Act* 1982 (Vic), you have the right to access and to request correction of information held about you or your child by Monash University.

7. Results of Project

A summary of the main findings will be provided to you on request when this project is completed.

8. Further Information or Any Problems

If you require further information or if you have any problems concerning this project (for example, further information about the questionnaires your child will be asked to complete), you can contact the principal researcher or student researcher. The researchers responsible for this project are: Ms Kelly Buttigieg: (Dr Margaret Hay: [redacted]

9. Other Issues

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact

Name: Malar Thiagarajan Position: Director of Research Services Tel: [redacted]

You will need to tell Malar the name of one of the researchers given in section 8 above.

10. Participation is Voluntary

Participation in any research project is voluntary. If you or your child do not wish to take part you are not obliged to. If you decide to consent for you and your child's participation and later change your mind, you are free to withdraw yourself and your child from the project at any stage. **Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your child's routine treatment, your relationship with those treating your child or your relationship with DACS and Monash Medical Centre.** Your child can withdraw at any stage, and there will be no consequences if he/she does not complete all the questions in the questionnaire or provide all the information requested on the demographics sheet. Before you make your decision, a member of the research team will be available so that you can ask any questions that you have about the research project. You can ask for any additional information you want. Sign the Consent Form only after you have had a chance to ask any additional questions and have received satisfactory answers.

11. Reimbursement for your costs

You will not be paid for your child's participation in this project.

12. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (NHMRC, 2007). This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethical aspects of this research project have been approved by the Human Research Ethics Committee of the Southern Health and Monash University.

Appendix G – Participant Information and Consent Form – Parent Version

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Appendix G – Participant Information and Consent Form – Parent Version

Parent/Guardian Consent Form
Version: 7 Dated: 11 October, 2010 Site: Monash Medical Centre
Full Project Title: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus

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I have read, or have had read to me, and I understand the Participant Information Version 6 dated 11 October, 2010.

1. I am the Person Responsible for _____. I consent to the participation of _____ in the research project named above, according to the conditions in the Participant Information. I believe involvement of me and my son/daughter in this project is not contrary to the best interests of my child. I will be given a copy of the Person Responsible Information and Consent Form to keep. The researcher has agreed not to reveal my child's identity and personal details if information about this project is published or presented in any public form.
2. I, the Parent/Guardian of the child named above, also consent to participate in the research project, according to the conditions in the Participant Information.

I would like a one page summary of findings of this research project. Please circle: Yes No

I am prepared to be contacted for potential involvement in future research projects that may arise from the findings of this project. Please circle: Yes No

Participant's Name (printed): ……

Name of Person Responsible (printed): …… Relationship to participant: ……

Signature: Date:

Witness to Signature (printed): ……

Signature: Date:

I have given a verbal explanation of the research project, its procedures and risks and I believe that the person named above as the Third Party has understood that explanation.

Researcher's Name (printed): ……. Signature: Date:

…….

Parent/Guardian Form – Removal from Study Database
Version: 7 Dated: 11 October, 2010 Site: Monash Medical Centre
Full Project Title: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus

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I have read, or have had read to me, and I understand the Parent/Guardian Participant Information Version 7 dated 11 October, 2010. I am the Person Responsible for _____. I do not wish to take part in this study. As such, I do not wish to receive a follow-up phone call from the research team regarding taking part in this study.

Participant's Name (printed) ……

Signature Date

Name of Witness to Participant's Signature (printed) ……

Signature Date

Child/Adolescent Participant Information and Consent Form

Version: 7 Dated: 11 October, 2010 Site: Monash Medical Centre

Full Project Title: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus

Principal Researcher: Dr Margaret Hay

Assoc Researchers: A/Prof Christine Rodda, Dr Philip Bergman, Dr Justin Brown

Doctor of Psychology Student Researcher: Ms Kelly Buttigieg

This Participant Information and Consent Form is 5 pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in the research project because of your insulin-dependent diabetes mellitus (IDDM). A total of up to 150 children and adolescents with IDDM will be enrolled.

This Participant Information will tell you what your involvement in this project will mean, and what we would like you do. Please read this Participant Information carefully. Feel free to ask questions and talk with your parents, friends or your local health worker.

If you and your parent/guardian are happy to join our research project, please complete the attached consent form and contact Ms Buttigieg on (03) 9902 4070. By signing the Consent Form, you indicate that you understand the information and agree to take part in this project.

You will be given a copy of the Participant Information and Consent Form to keep as a record.

The research team will follow up this mail-out to you with a phone call to ask you if you would like to take part in this project. If you DO NOT wish to receive a phone call or future correspondence from the research team regarding this project, please complete the slip at the end of this form and return it to the research team using the reply-paid envelope provided.

2. Background and Purpose

It is important to help children and adolescents manage their diabetes as best as they can. By doing this, young people will hopefully be able to continue good management of their diabetes when they grow older.

The purpose of this project is to identify ways to help you best manage your diabetes both now and as you grow up. To do this we will measure things that we know are important to diabetes management. These include your knowledge of diabetes, and how you and your family feel about managing the condition.

3. Procedures

This research is being conducted by a psychologist (Ms Kelly Buttigieg) who is undertaking her Doctor of Psychology – Clinical (DPsych) degree under the supervision of a health

psychologist (Dr Margaret Hay) and in collaboration with paediatric endocrinologists (Dr's Rodda, Bergman and Brown). Ms Buttigieg will be responsible for collecting all medical and psychological data.

Participation in this project will involve you answering a series of questions on one occasion at a time and place (a private room in Psychological Medicine, MMC or via a home visit by the researcher) that is convenient to you and your parents. These questions will ask about your mood and feelings generally, and how well you are managing your diabetes. Completion of these questions should take no longer than 60 minutes. Some of the data obtained in the questionnaires may also be used in a similar project also being run in DACS.

4. Possible Benefits

This project may help us develop ways to improve your management of your diabetes both now and into the future. It may also help other children and adolescents with diabetes to better manage their condition.

If you take part in this study, you will also be placed in a raffle draw to win an iPod Touch 8GB (valued at approximately $289). Two iPods will be drawn in the raffle prize draw, which will take place after all participants have completed the research questionnaire. The two winners will be notified by phone and/or mail, and the prizes will be posted using Registered Post.

5. Possible Risks

Completing this questionnaire should not pose any risks.

However, if you are distressed by any of the aspects of the questionnaires, we will tell your DACS paediatrician who may make a referral to the Children & Adolescents Mental Health Service (MMC 246 Clayton Road, 3168. Tele. No. 95941300) or other convenient regional CAMHS.

6. Privacy, Confidentiality and Disclosure of Information

Your medical records will be assessed only by the researchers and de-identified information will be used in our research. All information about you will remain confidential and only be used in this project. Only group data will be shown in publications. Your name will not be included on any data and your data will be identified by code number only.

The information you give will not be told to your parents/guardian, unless your mood (depression and/or anxiety) results are elevated*. If this happens, the student researcher will pass on these results to your DACS clinician, who will tell you and your parent/guardian. This will allow you to receive help for these feelings.*

The information will be retained for 15 years after publication and 7 years after finishing this project. All information relating to this project will be kept in a locked filing cabinet in locked offices in the Centre for Developmental Psychiatry and Psychology. Digitised information will be on a password protected computer with access restricted to the research team.

7. Results of Project

A summary of results will be posted to you on request when this project is completed.

8. Further Information or Any Problems

If you want to know more information or ask more questions about this project, you can contact the principal or associate researchers. They are:

Ms Kelly Buttigieg: [redacted]

Dr Margaret Hay: mobile no. [redacted] (business and after hours)

9. Other Issues

If you are unhappy about this project or any questions about your right as a research participant, you may contact

Name: Malar Thiagarajan

Position: Director of Research Services

Telephone: [redacted]

You will need to tell Malar the name of one of the researchers given in section 8 above.

10. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with DACS and Monash Medical Centre. You can withdraw at any stage, and there will be no consequences if you do not complete all the questions in the questionnaire or provide all the information requested on the demographics sheet.

11. Reimbursement for your costs

You will not be paid for your participation in this project.

12. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research (NHMRC, 2007)*. This statement has been developed to protect the interests of people who agree to participate in human research studies.

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of the Southern Health and Monash University.

Appendix H – Participant Information and Consent Form – Child/Adolescent Version

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Appendix H – Participant Information and Consent Form – Child/Adolescent Version

Southern Health

Child/Adolescent Participant Consent Form
Version: 7 Dated: 11 October, 2010 Site: Monash Medical Centre
Full Project Title: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus (IDDM).

I have read, or have had read to me, and I understand the Participant Information Version 7 dated 11 October, 2010. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I freely agree to take part in this project according to the conditions in the Participant Information. I will be given a copy of the Participant Information and Consent Form to keep. I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

I would like a one page summary of the findings of this research project. Please circle: Yes No

Participant's Name (printed) ……

Signature Date

Name of Witness to Participant's Signature (printed) ……

Signature Date

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed) ……

Signature Date

……

Participant Form – Removal from Study Database
Version: 7 Dated: 11 October, 2010 Site: Monash Medical Centre
Full Project Title: An investigation of the psychosocial correlates to optimal health management in young people with insulin-dependent diabetes mellitus (IDDM).

I have read, or have had read to me, and I understand the Participant Information Version 7 dated 11 October, 2010. I do not wish to take part in this study. As such, I do not wish to receive a follow-up phone call from the research team regarding taking part in this study.

Participant's Name (printed) ……

Signature Date

Name of Witness to Participant's Signature (printed) ……

Signature Date

Southern Health

MONASH University

Clinical Psychology & Type 1 Diabetes Research at DACS

How can I be involved?

Please contact:

Ms Kelly Buttigieg
Psychologist
Doctor of Clinical Psychology Candidate
Ph [redacted]
Email: [redacted]

Alternatively, you can also speak to a member of the DACS team, who will organise for Kelly to contact you.

MONASH University

Southern Health

What is this study about?

The DACS team is collaborating with the School of Psychology and Psychiatry at Monash University, to investigate what psychological, social and other factors help young people with diabetes manage their condition well.

What happens if I decide to be involved?

Young people taking part will complete a 60-minute questionnaire at: DACS (before or after their routine paediatric appointment), at their home, or via a phone call with the researcher.

The questionnaire explores some of the psychological, social and other factors that may help young people manage their diabetes better.

One parent will also complete a brief demographic questionnaire at the same time.

Can I, or my son/daughter, take part in this study?

We are looking for children and teenagers:

- **Aged between 7 and 15 years of age, and**
- **Have been diagnosed for at least one year with Type 1 diabetes.**

What benefits do I receive from being involved?

Every young person who takes part in this study will be placed in a raffle draw to win an iPod Touch 8GB, valued at $289.

Two iPods will be drawn randomly in the raffle, and both winners will notified by phone.