

Factors influencing the psychological adjustment of  
young patients with Type 1 diabetes in the first year  
after diagnosis

*By Helen Jennifer Power*

Thesis submitted in partial fulfillment of the  
Doctoral Program in Clinical Psychology  
at Victoria University.

## DECLARATION OF ORIGINAL WORK

### Doctor of Psychology Declaration

“I, Helen Power, declare that the Doctor of Psychology (Clinical) thesis entitled *Factors influencing the psychological adjustment of young patients with Type 1 diabetes in the first year after diagnosis* is no more than 40,000 words in length including quotes and exclusive of tables, figures, appendices, bibliography, references and footnotes. This thesis contains no material that has been submitted previously, in whole or in part, for the award of any other academic degree or diploma. Except where otherwise indicated, this thesis is my own work.”

Signature:

Date:

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## ABSTRACT

**Introduction:** Factors have been identified in association with the psychological adjustment of children and adolescents with Type 1 diabetes such as metabolic control (McDonnell et al., 2007), maternal functioning (Schmidt, 2007) and protective parenting (Mullins et al., 2004). Parenting factors may have an impact on young children (Whittemore et al., 2003; Davis et al., 2001); while other factors such as self-efficacy are important to adolescent patients (Littlefield et al., 1992) as responsibility for diabetes management is gradually transferred from parent to child (Palmer et al., 2004).

Many studies have examined family and peer support in the context of adolescents' capacity to cope with their diabetes (La Greca & Bearman, 2002; Lewandowski & Drotar, 2007), but few have demonstrated the link between diabetes-specific factors for adolescent patients and psychological adjustment in their mothers (Berg et al., 2007). The number of studies on very young patients with Type 1 diabetes is also limited (Grey et al. 1995) in spite of the doubling of incidence of diabetes in children under five years of age in Australia (Taplin et al., 2005).

**Objective:** To examine the child, adolescent and parental factors associated with psychological adjustment and health status in children and adolescents with Type 1 diabetes and their mothers over a post-diagnosis period of 12 months.

**Method:** Sixty-two families of young patients from birth to 18 years of age completed standard measures in a longitudinal analysis on psychological and diabetes-specific variables. Data included child/adolescent measures of adjustment, self-report measures of maternal psychological adjustment, parental protectiveness, maternal separation anxiety, adolescent quality of life, self-efficacy and medical records of metabolic control at the first time point following diagnosis, and repeated at the second time point 12 months post-diagnosis.

**Results:** Increased psychological symptoms in mothers were mildly associated with poor child/adolescent adjustment following diagnosis, and then moderately associated 12 months post-diagnosis. Metabolic control was adequate, although levels declined over time, and adolescent metabolic control was predicted by both maternal and adolescent adjustment. In a separate test, maternal and adolescent adjustment and self-efficacy were associated with quality of life for adolescents. Relatively high levels of maternal separation anxiety and protectiveness were shown; however they were not associated with the other variables.

**Conclusions:** This study highlights the role of mothers in the adjustment of children and adolescents with Type 1 diabetes and the potential risk to the adjustment of a significant minority of young patients and their mothers over time. The influence of maternal adjustment to quality of life and diabetes health status of adolescents was emphasised. Support for families in the first year after diagnosis is indicated.

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## **1 INTRODUCTION**

A diagnosis of diabetes for children and young people in general means learning to live with a medical condition for the rest of their lives. Diabetes is life-changing to the extent that a major adaptation is required to cope with daily routines and regular hospital visits to maintain optimum health and prevent complications. Psychological problems can develop during the period following diagnosis, and may persist in the form of longer-term mental health problems in children who may have been at risk of a poor level of adjustment predating the diagnosis of diabetes.

Understanding the types of changes experienced by children with Type 1 diabetes involves consideration of a range of factors which may influence the psychological adjustment of patient children and adolescents in the process of their adaptation to diabetes.

The current research aimed to identify psychological problems that were present soon after diagnosis and determine the degree to which they conferred a risk for poor adjustment at 12 months post-diagnosis. The study further investigated psychological factors associated with adjustment for young people with diabetes over time. Early identification of psychological problems in this population could facilitate the implementation of treatment programs to optimise psychological adjustment and good health outcomes in the short and longer term.

## **1.1 Diabetes**

### **1.1.1. Diabetes as a health risk**

Diabetes is becoming more prevalent in most countries, particularly in Western countries and is recognised as an important health problem Australia-wide (Mathur, Gajanayake, & Hodgson, 2000). More than one million Australians are expected to develop diabetes over the next fifteen years unless effective prevention strategies are implemented (Mathur et al., 2000). Diabetes is a condition that can lead to poor quality of life, disability and premature mortality.

In a preliminary report, De Courten, Dunstan, Cameron, Welborn, & Zimmet (2000) suggest that in Australia one in four people over twenty-five years of age have an impaired glucose metabolism or diabetes. Treatment of diabetes absorbs a considerable proportion of health care expenditure, and including the on-going complications of the condition, accounts for 2.2% of total health system costs (Mathur et al., 2000).

### **1.1.2 Diabetes - the medical condition**

Diabetes is a chronic illness where either insulin is lacking or there are factors obstructing the action of insulin in the body, shown by lowered levels of energy and raised levels of glucose in the blood. Resultant metabolic abnormalities, including hyperglycaemia and an increase of ketone bodies in the blood can occur (Watkins, 1998). Hyperglycaemia interferes with the normal utilisation of carbohydrate fat and proteins resulting in the build up of toxic substances in the body, which cause serious medical problems in the short term; for example, ketoacidosis or longer term irreversible complications leading to disability and early death (NHMRC, 2005). There are two main types of diabetes:

- Type 1 diabetes mellitus (T1DM): Insulin dependent diabetes mellitus (IDDM) is caused an autoimmune disorder, which means the body has started to see a part of itself as foreign. The body's immune

system destroys beta cells in the pancreas, causing insulin deficiency and pathologically high blood glucose levels.

- Type 2 diabetes mellitus (T2DM): Non-insulin dependent diabetes (NIDDM) has several possible causes including obesity, foetal malnutrition and glucose toxicity. Symptoms are less frequent but may occur as a result of either insulin resistance or beta cell failure.

While both types of diabetes refer to a lack of insulin, T1DM requires intensive medical management including frequent blood testing and insulin administration in order to maintain safe blood glucose levels. T2DM can be as serious, but can usually be managed without the administration of insulin, for example, via diet and exercise (Watkins, 1998).

The current study focuses exclusively on Type 1 diabetes, and throughout the thesis use of the general term 'diabetes' will be referring to Type 1 diabetes.

### 1.1.3 Diabetes aetiology

Both genetics and environmental factors have been implicated in this autoimmune response associated with diabetes. Although diabetes may not be present at birth, some people seem to be born with a tendency to develop diabetes. Monozygotic twins are 50% concordant for diabetes which suggests environmental factors are also involved (Watkins, 1998). A small genetic contribution is suggested by the occurrence of diabetes in biologically related family members (NHMRC, 2005).

Causal theories of factors precipitating the onset of diabetes have included certain viral infections that attack the pancreas, destroying beta cells, and thereby impairing the release of insulin. Many children diagnosed with diabetes have recently recovered from a virus or another condition, although most children do not necessarily develop diabetes after a condition. High levels of stress or even the start of puberty often occur before diabetes

develops (Seiffge-Krenke, 2001). There is general consensus that no definitive cause of Type 1 diabetes has been determined.

## **1.2. Prevalence of diabetes, age of onset, sex ratio**

### **1.2.1 Prevalence of diabetes**

After asthma and cerebral palsy, Type 1 diabetes is the next most common chronic condition in paediatric populations (Betts, Buckley, Davies, McEvilly & Swift, 1996). Currently around one in 700 children in Australia have diabetes. This is a relatively high rate by comparison with many countries, except for the Scandinavian countries which have continued to show the highest rates in the world. Australian figures suggest that while the incidence of many other childhood conditions is declining, diabetes is increasing. During the period from 1990 to 2002, reported incidence trends in New South Wales (Taplin, Craig, Lloyd, Taylor, Crock, Silink, & Howard, 2005) showed a significant 2.8% annual increase in all youth age categories between birth and 14 years of age.

### **1.2.2 Age of onset of diabetes**

Type 1 diabetes (previously termed “juvenile diabetes”) can occur at any age but most commonly onset is in childhood or adolescence. The highest rates of diabetes onset have been found in the 10-14 year age group (Seiffge-Krenke, 2001; Taplin et al., 2005).

Furthermore, recent statistics show that the onset of diabetes in children under five years of age has doubled over the last five years (Taplin et al., 2005). Taplin and colleagues (2005) found that the average rise in annual incidence was significantly higher in the youngest age group (3.9% per year in 0-4 year olds).

### **1.2.3 Sex Ratio of diabetes**

Prevalence rates for males and females tend to vary by age and time period. In an Australian study covering the 13 year period between 1990 and 2002 (Taplin et al., 2005), the incidence of diabetes was significantly higher in girls after adjusting for age group and year. Consistent with results from previous research (Seiffge-Krenke, 2001), the mean age of onset of diabetes

was significantly earlier in girls (8.7 years) compared to boys (9.1 years) (Taplin et al., 2005).

In contrast, a recent annual survey conducted by the Australian Institute of Health and Welfare (AIHW, 2004) reported an equal gender ratio among the 982 newly registered patients between zero and 14 years of age. However, among those patients aged between 15 and 39 years there was a significantly higher rate of males than females (AIHW, 2004). Where the age-adjusted incidence was 15.9 per 100, 000 for males, there was 8.7 per 100, 000 for females in this older age category. Overall, research results tend to be mixed, however in the child to adolescent age group the onset of diabetes appears to occur earlier and more often in girls than boys (Seiffge-Krenke, 2001).

## **1.3 Management of Diabetes**

### **1.3.1 Diabetes complications**

Individuals receiving a diagnosis of Type 1 diabetes can lead a relatively normal life; however they are chronically at risk of vascular complications associated with the condition. Complications such as neuropathy (nerve damage in the extremities), myocardial (heart) and foot ischaemia, renal failure, and retinopathy lead to a general reduction in physical health (Skinner & Hampson, 1998).

The Diabetes Control and Complications Research Group (1994) have shown that improved HbA1c (a long term measure of glycaemic or metabolic control) is significantly associated with the delayed progression and onset of these complications. There are now clear guidelines related to achieving optimal metabolic control, and hence management of the condition of diabetes. The management routine is, however, particularly challenging when diagnosis occurs in childhood.

### **1.3.2 Diabetes and child development**

Children and adolescents with Type 1 diabetes must learn to live with a chronic and complex metabolic disorder, which will touch all life experiences and is likely to affect many aspects of their normal development (Shillitoe, 1988). There is widespread agreement that family functioning is affected adversely by the difficulties of managing a chronic condition in the young patient (Rodrigues & Patterson, 2007).

Parents play a central role in the management of their child's diabetes, but the nature of this involvement is likely to vary according to the age of the child (Eiser, 1993; Palmer, Berg, Wiebe, Beveridge, Korbel, Upchurch, Swinyard, Lindsay, & Donaldson, 2004; Cameron, Smidts, Hesketh, Wake, & Northam, 2003; Greening, Stopplebein, Konishi, Jordan, & Moll, 2007). The daily medical procedures that are associated with the management of Type 1 diabetes include administration of insulin, checking glucose levels and dietary constraints (Skinner & Hampson, 1998). Parents must take total responsibility

for the management of these tasks for very young children (Eiser, 1993; Thomasgard & Metz, 1996) but with adolescents there is generally minimal parental involvement (Pendley, Kasmien, Miller, Donze, Swenson, & Reeves, 2002; Palmer et al., 2004; Cameron et al., 2003).

### 1.3.3 Parents' management of diabetes during infancy

Initially parents must take the full responsibility for all medical regimens, and for the actual provision of this care in early childhood, particularly in the infant and toddler years. In these developmental periods, the difficulties faced by parents include, for example, helping an infant to accept insulin injections when they do not feel ill and cannot make the cognitive association between the medication and the condition. "Their difficulties centre on the impossibility of explaining the need for treatment, particularly in its requirement for frequent and regular meal-times, which is so much at odds with a toddler's preferred eating habits." (Eiser, 1993, p. 24)

As children grow older parents continue to face the challenge of the developmental and behavioural aspects of diabetes management (La Greca, Follansbee, & Skyler, 1990). Conflict in negotiating parent-child responsibility for diabetes care can lead to poorer health outcomes (Klemp & La Greca, 1987; Rubin, Young-Hyman, & Peyrot, 1989; Lewandowski & Drotar, 2007).

### 1.3.4 Parents' management of diabetes during middle childhood

For primary school-aged children or children in middle childhood, the daily treatment tasks such as glucose monitoring can be managed by the child with parental supervision. However, the consequences for failing to comply with the medical regimen are complications, as mentioned, such as hypertension, hypoglycaemia, and nephropathy (Greening et al., 2007). Adherence to the medical regimen has therefore been an important focus of recent research on school aged children with diabetes (Stewart, Lee, Walker, Hughes, Low, Kennard, Cheng, & Huen, 2003; Greening et al., 2007).

According to a recent study (Schmidt, 2007) with the mothers of patients between six and 18 years of age, children's capacity for diabetes self-

care increased with age. Whittemore, Urban, Tamborlane, and Grey (2003) found that children and families coped well with the demands of intensive treatment, however most research has found that managing a complex condition like diabetes can be stressful and difficult for a significant minority of families who may require extra social support (Wallander & Varni, 1989; Pendley et al., 2002; La Greca & Bearman, 2002; Greening et al., 2007).

Parents must negotiate with their child around the level of their participation in the treatment regimen with the aim of increasing the young person's self-care responsibilities from middle childhood through to adolescence and adulthood (Palmer et al., 2004).

#### 1.3.5 Parents' management of diabetes during adolescence

Adolescence is recognised as an important time in development (Ingersoll, 1989), and has been described as "...the stage of transition from dependent childhood to independent adulthood" (Williams, 2002). Many studies have reported difficulties with treatment adherence during this developmental stage (La Greca & Bearman, 2002; Stewart et al., 2003; Palmer et al., 2004; Greening et al., 2007; Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007). In a study based on mothers' reports, older children had more negative attitudes about diabetes than younger children (Schmidt, 2007).

At this developmental stage parental involvement may be confined to emotional and auxiliary support such as driving to consultations, with all daily treatment tasks conducted by the adolescent themselves. However, as has been reported previously (Amiel, Sherwin, Simonson, Lauritano, & Tamborlane, 1986), pubertal changes with the associated increase in hormones may detract from the young adult's capacity to manage their condition. To a lesser or greater extent, parents are involved in the management of their adolescent child's condition, however the way in which this is negotiated has been shown to influence adherence to the medical regimen (Anderson, Ho, Brackett, Finkelstein, & Laffel, 1997).

It has been suggested that the complexity of managing the medical treatment has its own psychological effects (Stewart et al., 2003). For example, conflict in negotiating parent-child responsibility for diabetes care has been shown to result in poorer health outcomes (Klemp & La Greca, 1987; Rubin et al., 1989). Schmidt's study (2007) showed that mothers' perceptions of their child's coping capacity, as in their independence and ability to manage metabolic control, increased with age; however negative attitudes about diabetes also developed. In a recent study, problems in decision-making autonomy have been linked to diabetes health status and levels of mother-adolescent conflict were associated with poor treatment adherence (Lewandowski & Drotar, 2007).

As described above, management of diabetes involves a number of daily medical procedures that begin with full parental involvement for very young children (Eiser, 1993), and gradually reduce to minimal parental involvement for young adults (Pendley et al., 2002). Examination of factors influencing management of diabetes therefore needs to take into account patient age and parental adjustment.

## **1.4 The Effect of Diabetes on Children and Adolescents**

A diagnosis of Type 1 diabetes can lead to changes in parental, sibling and peer relationships, changes in the way others relate to the child or adolescent, for example, teachers and relatives, changes in self-concept and in overall psychological well-being. Studies have reported the development of psychological problems (e.g., Gowers, Jones, Kiana, North, & Price, 1995; Cameron et al., 2003), more difficult family relationships, and poorer child adjustment according to parents' and teachers' perceptions (e.g., Merydith, 2000) following a diagnosis of diabetes.

These changes may be associated with the modification to daily routines that is required to manage diabetes. Existing factors, including age and stage of development as well as the impact on quality of life and diabetes management for adolescents (Skinner & Hampson, 1998) have also been reported as influential to the psychological adjustment of young patients.

### **1.4.1 Quality of life in children with diabetes**

Quality of life for young people may be reduced by the impact of a daily medical regimen on their general satisfaction with life, and concerns over social and vocational issues related to their diabetes. Satisfaction, impact and worries about diabetes in children between ten and 21 years of age may all influence psychological adjustment (Ingersoll & Marrero, 1991). Skinner and Hampson (1998) showed that the perceived impact of diabetes significantly predicted anxiety and depression in adolescents aged 12 to 18 years.

A cross-sectional study (Whittemore et al., 2003) measuring quality of life for school-aged children and their parents found that good metabolic control had been achieved in these young patients, and families were generally coping well with the demands of treatment. However, there were increased depressive symptoms in 8% of children and 29% of parents (Whittemore et al., 2003). These researchers concluded that the increase in depressive symptoms was an effect of the stress of managing a complex chronic condition (Whittemore et al., 2003).

A reduced quality of life for young people with diabetes may therefore be a diabetes-specific risk factor for psychological problems, which could persist in the form of longstanding clinical disorders (Dantzer, Swendsen, Maurice-Tison, & Salamon, 2003).

#### 1.4.2 Psychological problems in children with diabetes

Psychological problems in children with diabetes are important because they add to the burden of a condition and increase the risk of long-term mental health problems and poor quality of life for the children and their families. In addition, psychological problems are likely to be associated with a higher risk of sub-optimal diabetes management, complications and poor health outcomes in the short and longer term.

Consistent with the reported higher prevalence of psychological disorders associated with chronic conditions such as rheumatoid arthritis and asthma (Wallander & Varni, 1989; Power, Dahlquist, Thompson, & Warren, 2003; Wysocki & Gavin, 2006), it has been suggested that a diagnosis of diabetes puts children 'at risk' for emotional problems (Blanz, Rensch-Riemann, Fritz-Sigmund, & Schmidt, 1993; Lavigne, Traisman, Marr, & Chasnoff, 1982). Blanz et al., (1993) found a particularly high prevalence of psychological disorders in adolescents with diabetes. In a comparison of adolescents with and without diabetes, a third (33%) of the adolescents with diabetes was found to have a psychological disorder compared to 9.7% of the control group (adolescents without diabetes). The latter figure represents the expected proportion of the population with clinical or 'at risk' problems (around 10%), indicating that adolescents with diabetes had a three-fold increased prevalence of psychological disorders compared to the normal population (Blanz et al., 1993).

Many studies have confirmed these earlier findings (Pendley et al., 2002; Stewart et al., 2003; Whittemore et al., 2003; Palmer et al., 2004; Greening et al., 2007).

Particular psychological problems including depression, anxiety, stress, low self-esteem and eating disorders have been associated with diabetes in adolescents (Dantzer et al., 2003; Lernmark, Dahlquist, Fransson, Hagglof, Ivarsson, Ludvigsson, Sjoblad, & Thernlund, 1996). A review by Grey, Whittemore and Tamborlane (2002) also found a significant prevalence of comorbid diabetes and depression in children and adolescents. Another review of recent research (Dantzer et al., 2003) on psychological disorders and diabetes observed more depression in patients of all ages with diabetes than in the general population. Anxiety was also considered in the same review but was reported to be less prevalent, yet still higher than expected (Dantzer et al., 2003).

#### 1.4.3 Sex differences in psychological problems and diabetes management

Gender differences in psychological problems have been reported with comorbidity of diabetes and eating disorders at above chance levels in female but not male adolescents (Rodin, Daneman, Johnson, Kenshole, & Garfinkel, 1985) while adolescent boys were more prone to developing anti-social behaviour and other problem behaviours. For example, Lavigne and colleagues (1982) found that six to 11 year old boys with diabetes were rated higher than controls on measures of hyperactivity, aggression and obsessive-compulsive symptoms. In contrast, Grey and colleagues (2002) found signs of low self-esteem, social withdrawal and avoidance in girls aged between eight and 14 years, and older children in general.

The reported comorbidity of diabetes and clinical disorders needs to be understood in the context of age and gender patterns (Grey et al., 2002). Schmidt (2007) found that according to mothers of children with diabetes aged six to 18 years, girls learned diabetes management earlier than boys, yet had more difficulty adhering to dietary requirements. Earlier research (Littlefield, Craven, Rodin, Daneman, Murray, & Rydall, 1992) found that girls aged 13 to 18 years generally adhered less to treatment than boys in the same age range. These sex differences have been explained by hormonal changes,

especially in the accelerated development of girls and their rates of earlier onset of diabetes (Seiffge-Krenke, 2001).

Psychological problems have been implicated in the psychological outcomes of children and adolescents with diabetes, and these have traditionally been assessed via parental reports and patient self-reports (Cameron et al., 2003).

#### 1.4.4 Informants of adjustment

Research on young people with diabetes has often used parental reports to measure adjustment in children and adolescents (e.g., Grey, Cameron, Lipman, & Thurber, 1995; Doyle, Ostrander, Skare, Crosby, & August, 1997; Berg, Wiebe, Beveridge, Palmer, Korbel, Upchurch, Swinyard, Lindsay, & Donaldson, 2007). However, perceptions of adaptive or problem behaviours may vary depending on the informant. School is a major part of the life of children and adolescents, and teachers' ratings of a child's behaviour offer another important perspective on a child's psychological adjustment in a different context.

A study (Merydith, 2000) on the accuracy of information provided by different informants of child adjustment showed that reports from both teachers and parents were generally consistent, and teacher ratings were actually more stable than parental ratings after a six month interval. Verhulst & Akkerhuis (1989) also found agreement between parents and teachers, although parents reported slightly more psychological problems in their children.

On the other hand, in a study on paediatric physical disorders and informants of adjustment (Lavigne & Faier-Routman, 1992), it was found that assessment of risk varied between teachers, mental health professionals and parents. According to Reynolds & Kamphaus (1998), there can be further variation between teachers due to different classroom settings. Teachers' ratings of psychological adjustment in children have been reported in children

of mothers with diabetes (Hadden, Byrne, Trotter, Harley, McClure, & McAuley, 1984), but not in children and adolescents with diabetes.

For a comprehensive assessment of psychological problems in children and adolescents, collection of data from various sources is helpful, as it may produce different perspectives on the individual's adjustment. Reynolds & Kamphaus (1998) recommend their "multimethod" form of assessment. More than one informant of psychological adjustment may enhance an understanding of young patients with diabetes by the additional perspectives of adjustment from important figures in their life.

#### 1.4.5 Factors influencing psychological adjustment

Research has investigated a range of variables associated with the outcomes for children with diabetes, including peer and family support (La Greca & Bearman, 2002; Pendley et al., 2002), maternal involvement (Palmer et al., 2004; Berg et al., 2007), parental protection (Thomasgard & Metz, 1999), behavioural adjustment (Lavigne et al., 1982), medical status as measured by HbA1c levels (Pendley et al., 2002), emotional distress (Liakopoulou, Alifieraki, Katideniou, Peppas, Maiati, Tzikas, Hibbs, & Dacou-Voutetakis, 2001), adherence behaviour (Littlefield et al., 1992), self-efficacy (Stewart et al., 2003), comorbidity with anxiety and eating disorders (Rodin et al., 1985), school status and patient demographics such as age and gender (Grey et al., 2002).

Parents have a particularly important influence on the psychological adjustment of young people with diabetes (Mullins, Chaney, Hartman, Olson, Youll, Reyes & Blackett, 1995; Berg et al., 2007), yet until recently there have been very few studies on the effect of the psychological functioning of parents on children and adolescents diagnosed with diabetes (e.g., Berg et al., 2007).

## **1.5 Parents of children and adolescents with diabetes**

### **1.5.1 Risk to parental adjustment**

For healthy adults, the clinical severity levels of depression, anxiety and stress in Australian (Lovibond & Lovibond, 1995) and U.K. (Crawford & Henry, 2003) normative samples were estimated at around 87% in the normal to mild range, and 13% in the moderate to extremely severe range. Poor psychological adjustment in parents may have an impact on their children's psychological well-being. Research on parental functioning (Kelley, Herzog-Simmer, & Harris, 1994) has found that maternal anxiety was associated with perceptions of stress in the parenting role for the mother, indicating the issue of risk to parental adjustment.

In a recent study, associations have been found between parental adjustment and the parent-child relationship (Rodrigues & Patterson, 2007). For example, research has shown that depressed mothers were less capable of remaining task focused, and were more hostile with their children of primary school age than non-depressed parents (Weissman, Warner, Wickramarante, Moreau, & Olsson, 1997). In particular, a comparison of mothers of children with a chronic condition with those of healthy children found a significant decrease in the mother's self-reported role performance (Rodrigues & Patterson, 2007) although it was not clear whether this was due to increased demands or distress in the mother.

Other research has reported associations between parenting and behavioural problems in children with spina bifida (Holmbeck, Johnson, Wills, McKernon, Rose, Erkin, & Kemper, 2002). Recent research has begun to demonstrate links between adjustment, including mood symptoms in children (aged 10-15 years) with Type 1 diabetes and their mothers (Berg et al., 2007). Psychological symptoms of depression, anxiety and stress may be risk factors for poor adjustment in parents of children receiving a diagnosis of diabetes.

### 1.5.2 Parenting

Parenting of children diagnosed with diabetes could be affected in both direct and indirect ways (Rodrigues & Patterson, 2007). Davis, Delamater, Shaw, La Greca, Eidson, Perez-Rodriguez and Nemery (2001) examined parenting styles in mothers (84% of sample) and fathers (16%) of children with diabetes. They found an association between parental warmth and treatment adherence in children between the ages of four and ten (Davis et al., 2001). However, adherence did not predict health status as defined by metabolic control. In this U.S. study, black ethnicity and low socio-economic status (SES) were shown to be related to both parental restrictiveness and poor metabolic control (Davis et al., 2001). Chaney, Mullins, Frank, Peterson, Mace, Kashani, and Goldstein (1997) showed that distress in fathers was associated with poor adjustment in children over time. Furthermore, children's and mother's adjustment predicted the fathers' adjustment (Chaney et al., 1997).

In a less direct way, parenting of children with diabetes may be influenced by parental perceptions. A study (Boulton, 1994) comparing the self-rated emotional adjustment of thirty-three children ( $M=11.2$  years old) with diabetes to the ratings given by their parents indicated a trend for parents to consistently perceive poorer adjustment in their children than that reported in ratings provided by the children. In an earlier study (Wallander & Varni, 1989), mothers who felt socially unsupported with the care of their chronically ill child also reported behavioural problems in their children. The impact of a child being diagnosed with a potentially life-threatening condition is likely to make parents more vigilant about that child's well-being, which could lead to heightened perceptions of risk to adjustment. This perception may result in changes to the way parents protect and care for their children.

Young patients may be inadvertently affected by their mother's heightened protectiveness as they adapt to the self-care regimen of diabetes management. Studies have found that overprotective parents are more likely to have dysthymia (low grade depression), anxiety and problems in personal relationships (Thomasgard & Metz, 1999). Of course it is not clear whether

these psychological problems lead to protective parenting, but there has been considerable research (Hock & Schirtzinger, 1992; Holmbeck, Johnson, Wills, McKernon, Rose, Erklin, & Kemper, 2002) addressing the question of how the psychological adjustment of mothers has affected their children. For example, Mullins and colleagues (1995) found that psychological adjustment in children with diabetes was predicted by the adjustment of their mothers.

### 1.5.3 Maternal psychological adjustment

Studies conducted with children who had a chronic condition have provided evidence of the link between maternal psychological adjustment and psychological outcomes for children. For example, in a study comparing mothers of children with (n=55) and without diabetes (n=54) (Liakopoulou et al., 2002) 58% of the mothers of child and adolescent diabetes patients had mild symptoms of anxiety and depression compared to only 9% of the mothers of non-patient children and adolescents. In a study of 153 children with diabetes, arthritis, spina bifida and cerebral palsy and their mothers, Wallander and Varni (1989) found that social support for the mother contributed independently to the variance in behavioural problems. A similar study (Mullins et al., 1995) showed that psychological adjustment in children with cystic fibrosis or diabetes was positively influenced by maternal adjustment.

Maternal psychological adjustment may be a crucial factor to the post diagnosis adaptation of child and adolescent patients with diabetes. In contrast to research on maternal depression and the effects on children, there has been less attention to the effects of maternal anxiety.

### 1.5.4 Maternal anxiety and over-protection

Symptoms of anxiety in mothers, such as hypervigilance and excessive worry, can influence the way mothers relate to their children (Kelley, Herzog-Simmer, & Harris, 1994; Rodrigues & Patterson, 2007). It seems that mothers may transfer their anxiety to their child through demonstrating their difficulty at separations from the child and overprotective behaviours towards the child. In particular, maternal separation anxiety has been related to childhood anxiety

(Hock, McBride, & Gnezda, 1989; Blunk & Williams, 1999). If a mother feels that being apart from her child may affect her ability to protect and comfort her child, any separation may cause her excessive anxiety (Blunk & Williams, 1999) but also may lead to her child experiencing anxiety.

Mothers that tend to be highly anxious have been found to become enmeshed, overprotective and limiting of their child's growth toward individuation (Hock & Schirtzinger, 1992). Normative studies on a sample of new mothers obtained low (55.5%), moderate (36.1%) and high (8.4%) levels of maternal separation anxiety (Hock et al., 1989). A further study on mothers of children between one and six years of age (Hock & Schirtzinger, 1992) found those with high levels of separation anxiety tended to experience depressive symptoms, had fewer coping skills and had a more negative representation of self.

The related concept of parental overprotection involves a highly supervising parent, who also has difficulties separating from the child and encouraging independence. Parental protectiveness results from the parent's perception of their child's increased vulnerability in their age-appropriate growth toward independence, and has been found to affect the behavioural adjustment of the child (Thomasgard & Metz, 1996). Research has supported the hypothesis that overprotective parents are at significant risk of dysthymia (low grade depression), anxiety and problems in personal relationships (Thomasgard & Metz, 1999).

There have been some studies examining parental protectiveness in mothers of patients with diabetes (Holmbeck et al., 2002; Mullins, Fuemmeler, Hoff, Chaney, Van Pelt, & Ewing, 2004), which found that the perception of dependence and vulnerability in children with a chronic condition was heightened in mothers after diagnosis. Maternal separation anxiety has not been investigated in this context, and yet these parental characteristics may contribute to the child's or adolescent's psychological adjustment.

The need for a child to take increasing responsibility as they grow older is an important issue for all children but particularly for those who have a chronic condition. The age appropriate moves to independence exhibited by older children and adolescents may be particularly challenging for mothers who perceive their child as extremely vulnerable. The way in which mothers are involved in the care of their child or adolescent is particularly important to the management of diabetes.

#### 1.5.5 Maternal involvement in diabetes management

Developmental expectations for diabetes management and reasons for transferring responsibility were examined by Palmer and colleagues (2004). Families appear to differ on when the responsibility for diabetes management regime should be transferred from the parent to the child (Palmer et al., 2004). Although adolescents perceived greater overall support from friends and family compared to younger school-aged children (Pendley et al., 2002) some younger adolescents have reported perceptions of less maternal support.

However, comparison between children's and adolescents' perceptions of support is complicated by the issue of maternal involvement in diabetes management. A recent study has found that when children's appraisals of their mother's involvement were supportive, less depression and a more positive mood in children were reported by both the mothers and the children (Berg et al., 2007).

It may be important to consider whether psychological problems are more likely to occur in adolescents, and whether very young children are at-risk for separation anxiety issues post-diagnosis in relation to parenting characteristics. Children with pre-existing psychological issues may be further vulnerable to increased anxiety and depression depending on the parent-child relationship (Whittemore et al., 2003). For these reasons, the complex associations between parenting factors such as protectiveness, diabetes-specific factors such as medical status and psychological adjustment are considered important to the overall well-being of the young patient.

## **1.6 Psychological Factors and Metabolic control**

While there is evidence to support the relationship between psychological disorders such as anxiety and depression and Type 1 diabetes in children (Dantzer et al., 2003), results from studies examining medical status in relation to these disorders have not been conclusive (Pendley et al., 2002; Stewart et al., 2003). Across cross-sectional and longitudinal studies results regarding the associations between psychological disorders, diabetes management and metabolic control have been mixed (Davis et al., 2001; Eiser, 2001; Dantzer et al., 2003; Leonard, Jang, Savik, & Plumbo, 2005; Lewandowski & Drotar, 2007).

### **1.6.1 Metabolic control**

Several psychological factors have been associated with metabolic control. HbA1c, a measure of blood glucose over the past two-three months, is the most widely used indicator of diabetes health status (Lewandowski & Drotar, 2007; Northam, Anderson, Adler, Werther, & Warne, 1996; Pendley et al., 2002; Skinner & Hampson, 1998; Stewart et al., 2003). Poor metabolic control in children and adolescents with diabetes has been linked to risk for poor cognitive functioning (Northam, Anderson, Adler, Werther, Warne, & Andrewes, 1999), affective functioning (Littlefield et al., 1992; Grey et al., 1995), social relations (Pendley et al., 2002) and specifically, autonomy and conflict issues in parent-child relations (Palmer et al., 2004; Lewandowski & Drotar, 2007) in children and adolescents with diabetes.

For example, transfer of treatment responsibility from mothers to children who are in the first stages of puberty correlated with poor metabolic control (Palmer et al., 2004). Discrepancies between parents and their adolescents (aged 13 -18 years) regarding decision-making autonomy were associated with poor metabolic control (Lewandowski & Drotar, 2007). In contrast, no relationship was found between metabolic control and a diabetes-specific measure of quality of life adapted for adolescents aged 10 to 21 years (Ingersoll & Marrero, 1991). The mixed results in this area have raised the

question as to whether particular moderating factors may influence the relationship between metabolic control and other diabetes-specific variables.

### 1.6.2 Treatment adherence

In a recent study, Lewandowski & Drotar (2007) found that mother-adolescent conflict was associated with compliance or adherence to the treatment of diabetes. Treatment adherence is another diabetes-specific factor which has been linked to metabolic control (Pendley et al., 2002); although in the context of other psychological factors, the association is complex (Littlefield et al., 1992).

Adolescents have been shown to be far less treatment-adherent than preadolescent children (La Greca & Bearman, 2002). Littlefield and colleagues (1992) questioned which psychological factors would predict an adolescent's capacity to adhere to their diabetes management regimen. They found that in adolescents aged 13 to 18 years, variables associated with self-concept were highly correlated with metabolic control, and concluded that adherence to medical regimens was not sufficient to explain health outcomes (Littlefield et al., 1992; Stewart et al., 2003). Littlefield and colleagues (1992) found that low self-esteem and depressive symptoms reported in adolescents were linked to poor adherence to the treatment regimen. 'Self-efficacy', or confidence in diabetes management, showed a strong association with adherence and psychological factors. This study (Littlefield et al., 1992) was the first to clearly demonstrate the influence of psychological and behavioural variables in the complex relationship between treatment adherence and diabetes health status.

### 1.6.3 Self-efficacy on adherence

Stewart and colleagues (2003) found that self-efficacy moderated the effects of emotional distress on treatment adherence behaviour in a sample of young patients aged 10 to 23 years. Their research indicated that self-efficacy was more predictive of metabolic control than strict compliance with the medical regimen. They concluded that psychological disorders such as

depression might vary in their effect on compliance to the medical regimen, depending on the individual's level of self-efficacy (Stewart et al., 2003).

Pendley and colleagues (2002) were able to demonstrate two significant associations; the first was between adherence and metabolic control, and the second was an inverse relation between conflict around diabetes management and metabolic control. Other researchers (La Greca & Bearman, 2002; Skinner & Hampson, 1998) have identified the link between emotional distress, self-efficacy and metabolic control. In light of these findings it has been suggested (Stewart et al., 2003) that self-efficacy on adherence might explain to some extent the association between psychological adjustment and metabolic control in adolescents with diabetes.

## **1.7 Psychological adjustment over time**

While it is possible that children diagnosed with diabetes may have a pre-existing psychological disorder, it has been shown that problems can also develop during the period following diagnosis (Pendley et al., 2002; Dantzer et al., 2003) and throughout childhood.

### **1.7.1 Research on children with diabetes**

Cross-sectional and longitudinal studies (e.g., Whittemore et al., 2003; Grey et al., 1995; Kovacs, Kass, Schnell, Goldston, & Marsh, 1989) have examined variables such as support and quality of life (Grey et al., 2002) in families of children with diabetes. For example, Pendley and colleagues (2002) examined diabetes-related support for children between eight and 14 years of age over a period of 15 months post-diagnosis, and found that practical support was provided by families, whereas emotional support tended to come from peers. In contrast to cross-sectional studies longitudinal research has the advantage of observing changes to psychological adjustment over time, but with some exceptions (Grey et al., 1995; Chaney et al., 1997; Northam et al., 1999) few studies have provided data both at diagnosis and post-diagnosis.

In a longitudinal study, Grey and colleagues (1995) compared a group of newly diagnosed children with a group of children without diabetes, and found significant differences in the pattern of psychological adjustment over two years. Depression, dependency, withdrawal and difficulties with self-esteem were higher in children with diabetes over the study period, and the differences between the two groups increased from the first to the second year. The results suggested a critical period of between one and two years after diagnosis for the development of symptoms (Grey et al., 1995).

Assessment of psychological factors at more than one time point is necessary to determine any patterns in patient psychological adjustment following a diagnosis of diabetes.

### 1.7.2 Adaptation and psychological functioning

An important question is the degree to which functioning soon after diagnosis predicts later psychological outcomes in adapting to diabetes. Consideration of this question may include the impact of receiving a diagnosis, which is often after a period of illness preceding the young patient's diagnosis. Past research has usually omitted the temporal aspect of psychological adjustment before and after diagnosis. Stewart and colleagues (2003) have been critical of the lack of comprehensive longitudinal studies, which could demonstrate the range of difficulties in adaptation to the condition over time.

One longitudinal study (Jacobson, Hauser, Willett, Wolfsdorf, Dvorak, Herman, & De Groot, 1997) which did not find increased psychiatric symptoms in patients with Type 1 diabetes was criticised by Northam and colleagues (1999), who argued that symptoms were merely lessened over time with maturity and adaptation. That is, it was not clear whether adjustment had actually improved, or whether psychological functioning was consistent with adaptation over the period following diagnosis. Considering factors of psychological adjustment in terms of pre-existing risk and further vulnerability at post-diagnosis may therefore be important to the treatment of young, developing individuals with diabetes.

Another longitudinal study (Kovacs, Iyengar, Goldston, Obrosky, Stewart & Marsh, 1990) found that the psychological adjustment of mothers of children with diabetes at six years post-diagnosis was predicted by maternal adjustment soon after diagnosis. However, symptoms were not associated with medical aspects such as metabolic control, nor were they associated with psychological problems in their children (Kovacs et al., 1990). Contradictory results do appear in the literature, but more recent evidence (Chaney et al., 1997) has supported the notion that maternal psychological adjustment plays a crucial role in the long-term adjustment of young patients with diabetes.

Despite diabetes being represented in the majority of studies (62%) of psychological problems associated with chronic illness in children and

adolescents (Seiffge-Krenke, 2001), research investigating psychological adjustment in children with diabetes has been limited in several ways. As described above, there have been mixed results from studies examining the associations between psychological variables and metabolic control (Ingersoll & Marrero, 1991). A major limitation of previous research on family factors influencing diabetes management as noted by Grey and colleagues (1995) is the failure to control for length of time after diagnosis (e.g., Burns, Green, & Chase, 1986).

Studies have varied in regard to the time points of data collection. For example, Pendley and colleagues (2002) included patients at 15 months post-diagnosis in the attempt to control for the so called 'honeymoon period', which refers to the phase of partial remission following a diagnosis (NHMRC, 2005). The initial impact on psychological adjustment of receiving a diagnosis seems to be offset to an extent by the initial intense support of professional services. Time points for data collection have varied between studies, and previous studies have not reported why particular time points were chosen for data collection (Grey et al., 1995; Cameron et al., 2003).

### 1.7.3 Premorbid psychological adjustment

Research cannot clearly distinguish psychological problems that may have been present before diagnosis from those which have developed after diagnosis. There is a logical problem in determining what sorts of psychological issues predate a diagnosis of Type 1 diabetes because collection of such information would have to be retrospective. However, while it appears that the onset of diabetes can involve secondary effects (Dantzer et al., 2003), it is also important to consider that some psychological problems may have existed before the diagnosis.

One way of approaching this problem has been to conduct testing soon after receiving the diagnosis (Northam et al., 1999), when the impact of the diagnosis on the clinical status of the patient and their parents may be balanced by a 'honeymoon effect'. The validity of taking the time point soon after diagnosis as representing the premorbid general psychological status of

the patient and their parent has not been established. However, collecting data at this time does provide a base-line against which to measure subsequent change.

## 1.8 Summary

### 1.8.1 Overview of literature

Although research has pointed to poor adjustment in children with diabetes (Jacobson et al., 1997; La Greca & Bearman, 2002; Dantzer et al., 2003), there have been few studies that have compared adjustment at different time points; that is, soon after diagnosis and one to two years post-diagnosis (e.g., Grey et al., 1995; Northam et al., 1999). The effect of the family's adjustment on the patient's diabetes health and management has been examined more often in cross-sectional (Berg et al., 2007; Schmidt, 2007; Mullins et al., 1995; Whittemore et al., 2003) than in longitudinal studies (Lavigne et al., 1982; Chaney et al., 1997; Rodrigues & Patterson, 2007).

Parents of children diagnosed with diabetes have been found to influence their child's psychological adjustment in various ways (Rodrigues & Patterson, 2007). Both parental self-reports of adjustment (Berg et al., 2007) and parenting characteristics have been associated with the adjustment of young patients (Mullins et al., 2004). Conflict in parent-child relations has been associated with issues in self-care for adolescents (Lewandowski & Drotar, 2007). Furthermore, developmental shifts in perceptions of social support from family to peers in relation to diabetes management has not necessarily resulted in improved health outcomes for adolescents (Pendley et al., 2002).

An understanding of these changes for young people with diabetes may lie within parental styles or characteristics (Palmer et al., 2004). For example, it has been demonstrated that the child's sense of autonomy and appraisal of parental support (Berg et al., 2007) is beneficial to the transfer of responsibility for diabetes-related tasks. On the other hand, parental protectiveness (Mullins, Wolfe-Christensen, Hoff Pai, Carpentier, Gillaspay, Cheek, & Page, 2007; Thomasgard & Metz, 1999) and separation anxiety (Hock et al., 1989) have also been associated with child psychological adjustment. While parental protectiveness has been examined in relation to young children with diabetes (Mullins et al., 2007), no studies were located

that had examined maternal separation anxiety in samples of young children with diabetes.

There has been more research on diabetes-specific factors such as quality of life and self-efficacy in relation to parental factors (Lewandowski & Drotar, 2007; Whittemore et al., 2003). Family factors are known to influence psychological outcomes of adolescents, particularly young adolescents, as they negotiate the shared responsibility of diabetes care (Berg et al., 2007; Lewandowski & Drotar, 2007; Pendley et al., 2002). These issues are important to the normal development of young patients with diabetes, making the associations between psychological and physiological variables complex (Littlefield et al., 1992), particularly in the context of family relationships (Palmer et al., 2004).

Overall, a range of psychological symptoms has been found in children with diabetes (Compas, Orosan, & Grant 1993; Eiser, 1993; Jacobson et al., 1997; Dantzer et al., 2003). Research on the psychological and behavioural variables associated with diabetes such as self-efficacy, quality of life, emotional stress, and clinical disorders has shown mixed results (Dantzer et al., 2003; Stewart et al., 2003) partly because of the variation in methodology. Despite a higher prevalence of anxiety and depression in young patients after the onset of diabetes, the influence of psychological symptoms on metabolic control is not clear (Skinner & Hampson, 1998).

In other words, it cannot be said that the better metabolic control there is, the less anxious or depressed a child with diabetes will be. Nor can it be said that a psychological disorder determines poorer metabolic control. General statements have been made based on mainly cross-sectional studies (Dantzer et al., 2003; Rodrigues & Patterson, 2007; Whittemore et al., 2003) and a few longitudinal studies (Grey et al., 1995; Johnson, Kelly, Henretta, Cunningham, Tomer, & Silverstein, 1992; McDonnell, Northam, Donath, Werther, & Cameron, 2007; Northam et al., 1999). However research to date has seldom identified the associations between variables that influence the psychological adjustment of children and adolescents with diabetes over time.

The incidence of Type 1 diabetes in Australia is increasing each year (Taplin et al., 2005). Improvement to diabetes health status may be achieved by understanding the risk factors to psychological adjustment associated with diabetes. In particular, knowledge of the influence of these risk factors over time could reduce the risk of psychological problems in young patients.

### 1.8.2 Research questions of the current study

Does psychological adjustment in children and adolescents with Type 1 diabetes change one year after diagnosis? There may be factors specific to diabetes health and mental health that contribute to the management of the condition over time. Can some of these factors be identified by comparing parental and child/adolescent adjustment following diagnosis (Time one) with parental and child/adolescent adjustment at 12 months post-diagnosis (Time two)? If so, which of those factors are associated with psychological adjustment in children and adolescents with diabetes?

What levels of psychological adjustment can be observed in mothers of young people with Type 1 diabetes? In recognition of the intensive involvement of mothers of young children in the management of their child's diabetes, a further question is whether there are changes in the maternal-child relationship, as reflected in maternal separation-anxiety and parental protectiveness, following a diagnosis of diabetes.

### 1.8.3 Aims of the study

1. To provide a profile of children and adolescents within two months of being diagnosed with Type 1 diabetes. The profile will include psychological adjustment, maternal psychological adjustment and level of metabolic control. Further information specific to young children, parental protectiveness and separation-anxiety in the mother-child relationship, and to older children (from 10 years) and adolescents (up to 18 years), diabetes-specific factors of quality of life, self-efficacy and their medical outcomes such as metabolic control will also be provided.

2. To examine change in psychological adjustment and diabetes health status across time, from a baseline following diagnosis to 12 months post-diagnosis.

3. To determine predictors of adjustment of child and adolescent patients and management of diabetes at 12 months post-diagnosis from measures taken following diagnosis (Time one), and repeated 12 months later (Time two).

#### 1.8.4 Hypotheses

1. Child/adolescent psychological adjustment, as measured by the Behavioural Assessment Scale for Children (BASC-PRS), will be associated with maternal psychological adjustment as measured by the Depression, Anxiety and Stress Scale (DASS) and General Health Questionnaire (GHQ) within two months following diagnosis.

2. Child/adolescent psychological adjustment as measured by parental reports (BASC-PRS), teacher reports (BASC-TRS) and adolescent self-reports (SRP) at 12 months post-diagnosis will be poorer than child/adolescent psychological adjustment (BASC-PRS; BASC-TRS; BASC-SRP) within two months following diagnosis.

3. Child/adolescent psychological adjustment (BASC-PRS) at 12 months post-diagnosis will be predicted by maternal psychological adjustment (DASS) within two months following diagnosis.

4. Diabetes health status as measured by metabolic control (HbA1c) at 12 months post-diagnosis will be predicted by adolescent psychological adjustment as measured by adolescent self-reports (BASC-SRP) and maternal psychological adjustment (DASS) within two months following diagnosis.

5. Quality of life for adolescents between 12 and 18 years of age as

measured by the Diabetes Quality of Life - Youth scale (DQOL-Y) at 12 months post-diagnosis will be associated with self-efficacy as measured by the Self-Efficacy on adherence scale (SE), adolescent psychological adjustment, maternal adjustment and diabetes health status at 12 months post-diagnosis.

6. For children under eight years of age, parental protectiveness as measured by the Parent Protection Scale (PPS) and separation anxiety as measured by the Maternal Separation Anxiety Scale (MSAS) at 12 months post-diagnosis will be greater than parental protectiveness and separation anxiety measured within two months following diagnosis.

7. For adolescents between 10 and 18 years of age, quality of life, self-efficacy and diabetes health status will be poorer at 12 months post-diagnosis than two months following diagnosis.

## **2 METHOD**

### **2.1 Participants**

The focus of the current study was children aged from birth to 18 years attending the Diabetes Ambulatory Care Service (DACS) and Young Adults Diabetes Service (YADS) at Monash Medical Centre who had received a diagnosis of Type 1 diabetes within the previous two months. The parents of these children (and the child patient if over 8 years) were active participants in the study. Over a 21-month period, from April, 2005, to December, 2006, all 88 new patient families of children who had received a diagnosis of Type 1 diabetes were scheduled for their first outpatient consultation.

Of the 88 potential participant families, seven families were not approached because of failure to attend their clinic appointment or unavailability of the researcher at the time of the appointment. Of the 81 families invited, four new patients were unable to meet the criterion of newly diagnosed as they had been transferred from another hospital, having been diagnosed more than three months previously. A further five families were excluded from the study when the young patient's diagnosis was changed from Type 1 to Type 2 diabetes.

Seventy-two families were invited to participate in the current study. Ten families declined to participate for various reasons including lack of time and/ or lack of interest. A total sample of 62 patients (and families) was recruited for the study (N=62).

Crèche carers and kindergarten teachers of preschool children aged two and a half years to five years were asked to provide information concerning the child. School teachers of children in Grade Prep to Year 12 were also asked to provide information. A total of 55 teachers participated at Time one and 49 teachers participated at Time two.

### 2.1.1 Final sample (N=62)

The sample of 62 children was comprised of 33 girls ( $M = 8.70$  years,  $SD = 4.41$  years) and 29 boys ( $M = 9.38$  years,  $SD = 5.07$  years) and their mothers and teachers. Age at first assessment ranged from one to seventeen years ( $M = 9.05$  years,  $SD = 4.72$  years). There was a mean post-diagnosis period of five weeks before being invited to participate in the research within a range of four to six weeks.

### 2.1.2 Demographics of participating patients

Table 1: Age and Sex of Patient Participants

Age categories	Patient Participants	Male patient participants	Female patient participants
0-2.4 years	6	3	3
2.5-5 years	11	4	7
6-9 years	12	7	5
10-11 years	12	3	9
12-18 years	21	12	9
Totals	62	29	33

$N = 62$

Table 1 shows sex of patient participants within the designated age categories (determined by the associated age versions of questionnaires such as the BASC). There was a similar number of males ( $n=29$ ) and females ( $n=33$ ) in the total sample but a higher number of females than males in the preschool (2.5-5 years) and middle childhood age (10-11 years) and slightly more males than females in the 12-18 years category. The majority of families

resided in the Southern Eastern area of the Melbourne metropolitan suburbs, while a small number lived in rural areas further South and East of Melbourne.

### 2.1.3 Data collected

Clinical data regarding all participants' glycosylated haemoglobin (HbA1c levels) were obtained from medical records.

## **2.2 Measures**

### **2.2.1 The Behavioural Assessment System for Children (BASC)**

(Reynolds & Kamphaus, 1992). See Appendices D1-D7.

The BASC was designed to assess a number of dimensions in adaptive behaviours (social and leadership skills) and problem behaviours, including internalising (depression, anxiety and somatisation) and externalising problems (conduct disorder, hyperactivity and aggression). Separate versions are available for three age groups (preschool, child and adolescent) and for different informants (parent, teacher and self-report). Cameron and colleagues (2003) have recommended the BASC as a screening tool to help identify children with diabetes 'at risk' for poor adjustment and poor health outcomes post-diagnosis.

Convergent validity with other measures, for example, Achenbach's child behaviour checklist (CBCL: 1991, cited in Doyle et al., 1997), has been supported with the Behavioural Assessment System for Children-Parent Rating Scales (BASC-PRS) on aggression ( $r=.70$ ), attentional problems ( $r=.49$ ), withdrawal ( $r=.50$ ), somatisation ( $r=.40$ ), depression ( $r=.55$ ) and anxiety ( $r=.54$ ). Test-retest reliability was reported as ranging from .84 to .92 and internal consistency was .64 to .90 (Doyle et al., 1997). Discriminant function analyses further evaluated the predictive capacity of the BASC-PRS to assign participants to three diagnostic groups, although only the first discriminant function was significant. It clearly differentiated the "no diagnosis" group from the group combining ADHD, conduct and oppositional defiant disorder symptoms with a canonical correlation of .57 (Doyle et al., 1997).

The number of items on each scale varied according to the age-group category; that is, BASC-PRS had between 126 and 138 items, the Behavioural Assessment System for Children-Teacher Rating Scales (BASC-TRS) had between 109 and 148 items, and the self-report form for adolescents (BASC-SRP-A) had 186 items. The item response options to statements were provided on a four-point scale of N = 'never', S = 'sometimes', O = 'often' and A = 'almost always'. Examples of statements for

the middle child group category (6 to 11 years of age) included item one on the BASC-PRS-C “Adjusts well to new teachers”, which is the same for the BASC-TRS-C, and item two: “Argues when denied own way”. For the parent-rating preschool (2.5 to 5 years) age category (BASC-PRS-P), item one was “Shares toys or possessions with other children”, and the first two teacher-rating items were “Tries new things” and “Bullies others” (Reynolds & Kamphaus, 1992).

Where the first two age categories used two forms for two different respondents’ perspectives, three forms were employed in the current study for the adolescent age group (12 to 18 years), which included self-report as well as the parent and teacher forms. Examples of statements for this category were item one on the BASC-PRS-A: “Compliments others”, item one on the BASC-TRS-A: “Shows interest in others’ ideas”, and item one on the BASC-SRP-A: “I am good at making new friends”. Scoring on each item’s four-point scale ranged from zero for ‘never’ to three for ‘almost always’.

Item scores were entered into a computer software scoring program, “BASC Enhanced - Assist” (American Guidance Service, 1999). Raw scores were then converted to T-scores for the data analysis.

The T-scores were represented in the Behavioural Symptom Index (BSI) as reflective of adjustment on several clinical scales, including anxiety, depression, somatisation, conduct, hyperactivity and other behavioural problems. Anxiety, depression and somatisation comprised the ‘internalising problem composite’, and conduct, aggression and hyperactivity comprised the ‘externalising problem composite’. The BASC-SRP-A (adolescent self-report) included school adjustment variables such as attitude to teachers and sensation-seeking, which contributed to the composite T-score for the Emotional Symptom Index (ESI). Only the BSI and ESI were used for the analyses conducted in this study.

The BSI is treated as an indication of clinical severity, where high scores represented greater severity of a clinical problem or problems and low

scores meant less or no reported problems (American Guidance Service, 1999).

Cut-off points for T-scores are as follows:

- a) 70 and above - 'clinically significant' range (high level of maladjustment).
- b) 60 to 70 - 'at-risk' range (a problem not significant enough to require treatment but needs to be monitored).
- c) 40 and 60 - 'average' range.
- d) below 40 - below average levels of difficulty in behavioural adjustment.

#### 2.2.2 Self-efficacy on adherence scale (SE) (Littlefield et al., 1992)

See Appendix D13.

The SE scale is a diabetes-specific measure, which was designed to examine self-efficacy in patients aged between 13 and 18 years. Respondents are asked to rate their confidence in their own ability to follow treatment prescriptions; for example, "Grade yourself on how well you could do each of these tasks if you could get yourself as organised as you could be" (Littlefield et al., 1992, p. 91). Four categories of diabetes management were represented in this adherence measure, including diet (e.g., "Following your food plan"), blood glucose monitoring (e.g., "Keeping your blood glucose at the right level"), insulin injections (e.g., "Taking your insulin on schedule") and exercise (e.g., "Fitting exercise into your treatment plan"). There was also an item on treating an insulin reaction.

On a seven-item measure of self-efficacy on adherence, Cronbach's alpha coefficient was .78 (Littlefield et al., 1992). Validity was obtained at expected rates of -.24 and -.26 for negative correlations with metabolic level (Littlefield et al., 1992); that is, a moderate inverse correlation was found between high scores and low metabolic levels, and vice versa. In a more recent study with patients aged between ten and 21 years in Hong Kong, Cronbach's alpha remained high for self-efficacy, .86 (Stewart et al., 2003).

The SE items were rated on a nine-point scale. The Total score could range from seven to 63 with high scores indicating greater self-efficacy in adherence to the diabetes treatment regimen. These totals were divided by seven, the number of items, to obtain item mean scores for each respondent in order to compare with the Littlefield and colleagues' (1992) original patient sample of adolescents with Type 1 diabetes ( $M=7.80$ ,  $N=177$ ).

### 2.2.3 General Health Questionnaire (GHQ) (Goldberg, 1978)

See Appendix D9.

The GHQ is a well-established self-report measure which assesses perceptions of general health and psychological symptoms of emotional distress. It has been used in diabetes research as a measure of psychological adjustment in adults (Lawlor, Ben-Shlomo, Ebrahim, Davey Smith, Stansfeld, Yarnell, & Gallacher, 2005), but only seldom in mothers of children or adolescents with diabetes (e.g., Northam et al., 1996). It includes items such as "Have you recently been feeling unhappy or depressed?" and is available in 12 and 28 item versions (Goldberg & Williams, 1988) as well as the original 60 item version. The 28-item version of the GHQ was used in the current study.

Several studies have established the reliability of the GHQ through wide usage as a clinical research tool (Goldberg, 1978; Goldberg & Hillier, 1979). In a pilot study on a sample of 523 in the United Kingdom (Goldberg & Hillier, 1979) a principal components analysis produced six dimensions that represented general condition, somatic symptoms, sleep disturbance, social dysfunction, anxiety and dysphoria, and severe depression.

The final four factors: Scale A - somatic symptoms (e.g., "pains in the head"); second, Scale B - anxiety and insomnia (e.g., "lost sleep over worry"); third, Scale C - social dysfunction (e.g., "busy and occupied"); and fourth, Scale D - severe depression (e.g., "thinking yourself worthless") accounted for over 50% of the variance. Split-half reliability was found to be .95, and concurrent validity with psychiatric assessments of anxiety and depression was .76 (Goldberg, 1978).

The designers recommended a scoring method by "...counting the number of symptoms, thus completely avoiding problems due to 'middle users', weighting the columns 0, 0, 1, 1" (Goldberg & Williams, 1988, p. 19). Next to each item statement was a choice of four responses, e.g., (A1 - been feeling perfectly well and in good health?) "Better than usual", "Same as usual", "Worse than usual", or "Much worse than usual".

The scoring of items in each of the four scales is zero for either of the first two option responses and one for the third or fourth response options (See the form in Appendix D9). If "Better than usual" was chosen, then the score for that item would be zero. The same result is given to the response: "Same as usual". On the other hand, if "Worse than usual" was chosen, the score would be one. A score of one is given to the response: "Much worse than usual".

The entire questionnaire has a range of potential scores between zero and 28, where higher scores indicate severe clinical symptoms and lower scores indicate mild clinical symptoms. Zero indicated no self-report of clinical symptoms. The proportion of scores greater than 12 represented high scores in clinical symptom severity, and those below 12 were considered in the low to normal range of severity (Goldberg, 1978).

#### 2.2.4 Diabetes Quality of Life measure for Youths (DQOL-Y) (Ingersoll & Marrero, 1991) See Appendix D12.

The original DQOL "...was designed to evaluate the burden of an intense diabetes treatment regimen...on quality of life" (Bradley, 1994, p. 65). Jacobson and the Diabetes Control and Complications Trial Research Group (DCCT, 1988) had evaluated their diabetes-specific measure using predominantly adult subjects but the sample also included adolescents aged from 12 years. Four subscales represented satisfaction with life; impact of diabetes on life; social and work-related worries; and worries related to having a long term condition.

Ingersoll and Marrero (1991) adapted the DQOL to suit children and adolescents from 11 to 18 years of age by excluding items such as “How often do you worry about whether you will be denied insurance?” They added school-related items, simplified the wording, and changed the response format to a 5-point Likert scale. The final version included three subscales of Diabetes Life Satisfaction (e.g., “How satisfied are you with your current treatment?”), Diabetes Impact (e.g., “How often do you feel restricted with your diet?”), and Diabetes-related Worries (e.g., “How often do you worry about whether you will pass out?”).

Ingersoll and Marrero’s (1991) reported Cronbach’s alpha provided .82, .83 and .85 coefficients. The researchers also confirmed concurrent validity of the DQOL-Y scales, finding that a multiple correlation of .54 accounted for 29% of the variance in self-rated health (Ingersoll and Marrero, 1991). However, the authors also found that their adapted scales did not correlate significantly with metabolic control.

Items on the DQOL-Y were rated one to five according to frequency ‘never’, ‘rarely’, ‘sometimes’, ‘often’ or ‘most often’. Item scores for each subscale were added to provide a Sub-scale total. Some items required reverse scoring - see Appendix D12. Sub-scale scores on the three subscales Diabetes Life Satisfaction, Diabetes Impact and Diabetes-related Worries were summed to provide an Effect on Quality of Life Score (with high scores indicating a greater effect of diabetes on the respondent’s quality of life). The DQOL-Y (Youth) measure, as adapted by Ingersoll and Marrero (1991), was deemed appropriate in the current study.

#### 2.2.5 Parent Protection Scale (PPS) (Thomasgard, Metz, Edelbrock, & Shonkoff, 1995) See Appendix D10.

This parent-completed questionnaire includes questions regarding parents’ perceptions of their child’s health, behaviour and development (Thomasgard & Metz, 1999). As a measure of parenting characteristics, the PPS assesses parental protectiveness in mothers of children between the ages of two and eight years.

The PPS consists of 25 items which are rated according to their relevance ('never', 'rarely', 'sometimes' or 'often') and scored from zero to three on a four-point scale (some items were reverse scored - see Appendix D10). Item scores are summed to produce a Total score with higher scores, indicating more frequent protective behaviours in relation to their child. According to Thomasgard & Metz (1996), an aggregate score of one or more standard deviations above the mean may be interpreted as "overprotective behaviour". In the original normal sample, 14.6% of parents reported clinically significant levels of protectiveness (Thomasgard et al., 1995).

The PPS has been used with children up to the age of ten years (Thomasgard & Metz, 1999) but for older children the face validity of some items, for example, item 23 - "I decide when my child goes to the bathroom" seems questionable. Hence in the current study, only parents of patients aged two to eight years completed the PPS.

Internal reliability has been reported as .73, with test re-test reliability (three to five weeks later) of .86, and criterion validity high in terms of comparisons between clinical observations, criterion-referenced clinical history and independently-administered questionnaire scores (Thomasgard & Metz, 1996). Sensitivity (71%), specificity (94%) and positive predictive value (92%) were reported in an earlier study on child and maternal adaptation to diabetes (Mullins et al., 1995).

#### 2.2.6 Maternal Separation Anxiety Scale (MSAS) (Hock et al., 1989)

See Appendix D11.

The MSAS was developed as a self-report questionnaire to measure the degree to which a mother experiences anxiety when separated from her young child. According to the authors "Maternal separation anxiety is defined as an unpleasant emotional state tied to the separation experience: it may be evidenced by expressions of worry, sadness, or guilt" (Hock et al., 1989, p. 794).

The MSAS comprises 35 items which are rated on a 1-5 point Likert scale by respondents according to the extent of their agreement with the statement ('strongly disagree', 'disagree', 'somewhat agree', 'agree' or 'strongly agree'). Using data from a study of new mothers, factor analysis revealed three subscales: Maternal separation anxiety (e.g., item one - "I miss holding or cuddling my child when I am away from him/her."), Perceptions of separation effects on the child (e.g., item 14 - "A child is likely to get upset when he/she is left with a babysitter.") and Employment-related concerns (e.g., item ten - "I would resent my job if it meant I had to be away from my child.").

The scales were found to be reliable, and correlation analyses showed a mild association ( $r = .34$ ) with generalised anxiety (Hock et al., 1989). Concurrent and construct validity was demonstrated on a smaller sample and reported in the same publication. Internal consistency of the total MSAS was found to be .88 (Hock et al., 1989). In a recent study, internal consistency for the three subscales was reported as .94, .69 and .62 respectively (Blunk & Williams, 1999).

In the current study, the MSAS was completed by mothers of patient children aged six years and under in the current study. Some of the items were reverse scored (See Appendix D11) and then sub-scale scores were produced by summing scores for all of the items in that sub-scale. The Total score was the sum of all items with high scores indicating higher levels of maternal separation anxiety. Only the total score was used in the current study. For descriptive purposes, the range of scores according to item ratings represented low (35-70), mild to moderate (71-105) and high (106-175) response categories, these were interpreted as little concern, mild to moderate concern and much concern in the respondent (Hock et al., 1989).

#### 2.2.7 Depression Anxiety Stress Scales (DASS) (Lovibond & Lovibond, 1995) See Appendix D8.

The DASS, a 42-item self-report questionnaire measuring depression, anxiety and stress, was developed on an Australian sample (N= 2,914).

Respondents are asked to rate each item according to how they felt during the previous week on a scale of zero (“Did not apply to me at all”) to three (“Applied to me very much, or most of the time”).

The three subscales: Depression, Anxiety and Stress, are comprised of seven items each. Examples of items include, “I felt that I had nothing to look forward to” (Depression subscale), “I had a feeling of faintness” (Anxiety subscale) and “I found it difficult to relax” (Stress subscale). The subscales were further tested on a large U.K. sample. The three-factor model was confirmed with correlations reported as .75 for Depression and Anxiety, .77 for Depression and Stress, and .74 for Anxiety and Stress (Crawford & Henry, 2003). Because the DASS is a self-report symptom-based scale, it is transparent and therefore subject to faking good or bad. The authors recommended administering another instrument to minimise the bias in responding as the DASS does not contain a lie scale (Lovibond & Lovibond, 1995). It was deemed appropriate to use with the GHQ as a measure of maternal adjustment.

Unlike the GHQ, the authors intentionally omitted symptoms that form diagnostic criteria (Lovibond & Lovibond, 1995) such as changes in appetite, sleep, mood, concentration and libido which refer more to biological symptoms rather than affective symptoms (Crawford & Henry, 2003). The constructs of the DASS are viewed as dimensional rather than categorical (or part of a syndrome) because of the expected correlations between them. The advantage is that while the subscales can represent psychological symptoms of anxiety, depression and stress, an aggregate total score also provides a general index of psychological distress or level of psychological adjustment (Crawford & Henry, 2003).

Cronbach’s alpha coefficients for internal consistency have been reported as .91 for Depression, .84 for Anxiety and .90 for Stress with non-clinical adult samples (including students) and other psychometric properties (convergent, discriminant and construct validity) have been reported as adequate in both clinical and non-clinical samples (Crawford & Henry, 2003).

The DASS has only recently been applied to research on maternal psychological adjustment in a health setting (Gibson, Byrne, Davis, Blair, Jacoby, & Zubrick, 2007), although not as yet to clinical research on parents in paediatric populations.

For the current study, subscale scores were calculated by summing the responses to items within each subscale and the Total score was the sum of all items. Cut-off points for clinical severity have been proposed using percentile scores: 0-78 Normal range, 79-87 Mild range, 88-95 Moderate range, 96-98 Severe range and 98-100 Extremely Severe range (Crawford & Henry, 2003).

#### 2.2.8 Diabetes health status: Metabolic control

Research on Type 1 diabetes has measured health status in different ways; from treatment adherence to measures of blood glucose levels. For example, Skinner and Hampson (1998) correlated frequency of blood glucose monitoring with insulin injections in order to determine the health status of each participant. This method has been used by some researchers (Northam et al., 1999; Palmer et al., 2004, Stewart et al., 2003) in conjunction with a percentage measure of Glycosylated haemoglobin as an index of metabolic control, which is reported in medical records as the HbA1c value last taken at hospital visits (Eiser et al., 2001; Pendley et al., 2002; Whittemore et al., 2003). The index of metabolic control was regarded as a suitable indicator of diabetes health status in the current study.

In Pendley and colleagues' study (2002) participants were classified into four groups based on level of metabolic control. Level one described the individual as "well-controlled" when their HbA1c value was below 7.3 percent. A similar interpretation of HbA1c values below 7.5 percent were deemed "well-controlled" by Whittemore and colleagues (2003). Level two in Pendley and colleagues' study (2002) indicated that patients had "good to fair control" for HbA1c values ranging from 7.4 to 9.3 percent. Level three described patients as having "fair to poor control" if their HbA1c value was between 9.4 and 11.3

percent. Level four represented “poor control”, where HbA1c values of patient participants were greater than 11.4 percent (Pendley et al., 2002).

Further corroboration of diagnostic categories according to the American Diabetes Association (ADA) was obtained with “very good control” at 6.1-7.0%, “adequate control” at 7.1%-8.0%, “suboptimal control” at 8.1-9.0%, and “poor control” at greater than 9.0% (Harris, Eastman, Cowie, Flegal, & Eberhardt, 1997). Guided by ADA recommendations (Harris et al., 1997), the current study represented severity levels of metabolic control using these descriptors. For this study, HbA1c values were obtained from medical records for the period following diagnosis (Time one), and then again at twelve months post-diagnosis (Time two).

## **2.3 Procedure**

### **2.3.1 Ethics approval**

This study received full review and approval from the Human Research Ethics Committee of Southern Health and Victoria University (See Appendix A1 & A2). All patient families included in the study provided signed and informed consent (See Appendix C1). Subsequently, a minor change to the thesis title (excluding the word “families”) was made in order to reflect the main focus of the study (See Appendix A3).

### **2.3.2 Recruitment of participants**

Between four and six weeks after diagnosis, the families of Diabetes Ambulatory Care Service (DACs) and Young Adults Diabetes Service (YADS) patients were invited to participate in the study. Participant information was provided to parents of all participants, and adolescents between ten and 18 years of age (See Appendix B1 & B2).

Written consent was obtained from all parent participants, including those of very young children at crèche or kindergarten. Written consent was also obtained from children between ten and eighteen years of age (See Appendix C1). The parent’s written consent was obtained for one questionnaire to be sent to their child’s teacher with an introduction letter (See Appendix C4 & C5). All participant data remained confidential to the extent that a case number was allocated to each participant family and teacher, which allowed the data to be stored separately from personal details, as prescribed in the Victoria University regulations.

When consent was provided, mothers, and children aged 10 years and over were asked to complete a number of questionnaires as detailed in Table 1 below. Completion of questionnaires (between 1 & 5) took between ten and 40 minutes, depending on the number of questionnaires. The same questionnaires were administered again 12 months later.

Table 2: Questionnaires Administered to Children and Adolescents According to Age, and Parent and Teacher Respondents

<i>Questionnaires</i>	<i>Children and adolescents grouped by age</i>					<i>Respondents</i>	
	<i>Children</i>		<i>Adol.</i>			<i>Mother</i>	<i>Teacher</i>
	<i>0-2.4 yrs</i>	<i>2.5-5 yrs</i>	<i>6-9 yrs</i>	<i>10-11 yrs</i>	<i>12-18 yrs</i>		
<i>BASC-PRS</i>						<i>X &gt;2.5yrs</i>	
<i>BASC-TRS</i>							<i>X &gt;2.5yrs</i>
<i>BASC-SR</i>					<i>X</i>		
<i>SE</i>				<i>X</i>	<i>X</i>		
<i>GHQ</i>						<i>X</i>	
<i>DQOL-Y</i>					<i>X</i>		
<i>PPS</i>						<i>X &lt;9yrs</i>	
<i>MSAS</i>						<i>X &lt;7yrs</i>	
<i>DASS</i>						<i>X</i>	

Table 2 shows who completed the questionnaires. Children under ten years of age did not complete any questionnaires. Children of at least ten years of age were asked to complete one questionnaire, while children twelve years of age and over were asked to complete three questionnaires. Mothers were asked to complete three to five questionnaires, and teachers were asked to complete one questionnaire.

Procedural aspects of the recruitment were important to this study for two reasons. First, participants were children and adolescents at an outpatient clinic whose medical needs were of primary concern at the time of diagnosis. Second, each participant was expected to involve their family and school in the process. The initial details provided to the researcher about the new family were limited to the name and age of the patient, and the time of their second consultation at the clinic. Recruitment needed to be at the second consultation (4-6 weeks post-diagnosis) because it was agreed that families required some time after first receiving the diagnosis of Type 1 diabetes.

At the new patient's clinic appointment time, families were approached between their consultations with several medical professionals, including the doctor, dietician and diabetes nurse educator, and invited to participate in the study. Information was provided (See Appendix B1 & B2) and consent obtained (See Appendix C1) before proceeding to a later scheduled time for administration (2 months post-diagnosis). It was important to keep the researcher's information about the patient's clinic attendance to a minimum so as to optimise patient confidentiality if the invitation to participate was declined. The voluntary nature of participation by the family was clarified from the outset, including the extent of involvement and management of the information gathered.

### 2.3.3 Data collection

After written consent was obtained (Appendix C1), an instruction sheet was provided including contact details (Appendix C6). Questionnaires (Appendix D) were administered to participating families in a separate room from the clinic. An introductory letter (Appendix C5) and parental consent (Appendix C4) and questionnaire (BASC-TRS) was sent to the participant's teacher for completion. For administration 12 months later (Time two), telephone contact was made directly to the participant family and an appointment was arranged for administration of the questionnaires at their next scheduled hospital consultation. The BASC-TRS, parental consent and introductory letter was sent to the patient's current school teacher. Data collection for Time one and Time two occurred over a period of 31 months from April, 2005 until October, 2007.

## **2.4 Statistical analyses**

### **2.4.1 Research design**

The study was a longitudinal design with information collected at two time-points, that is, two months after diagnosis (Time one) and at 12 months post-diagnosis (Time two). Data were obtained via the self-report measures and medical records. Stability of psychological adjustment of patients and their mothers over time was tested in a repeated measures within-subjects design. Psychological adjustment of children and adolescents was measured by the BASC, where high scores related to poorer adjustment and low scores to greater adjustment.

The BASC results were correlated with diabetes quality of life for adolescents (DQOL-Y), maternal adjustment (DASS), self-efficacy on adherence (SE), maternal separation anxiety (MSAS), maternal general health (GHQ), parental protectiveness (PPS) and diabetes health status (HbA1c).

A total of 60 or more patients were expected to enter this study. Statistical considerations were made for studying the effect of one variable on another, as prior information on standard deviations of all measures was unavailable. In general terms, the probability was 80 percent that the study would detect a relationship between the independent and dependent variables at a five percent significance level, if the true change in the dependent variables was 0.368 standard deviations per one standard deviation change in the independent variable. A minimum number of 48 participants were required for the analysis with a target of 60 to allow for attrition between the two data collection stages. An approximate 75-80 percent participation rate was expected as in past studies on patient samples within hospital settings (Eiser, 1993).

#### 2.4.2 Hypothesis testing

The variables operationalised by the measures outlined above for the quantitative analyses were child/adolescent psychological adjustment (BASC), maternal psychological adjustment (DASS), maternal general health (GHQ), maternal separation anxiety (MSAS), parental protectiveness (PPS), diabetes quality of life for adolescents (DQOL-Y), self-efficacy on adherence (SE) and diabetes health status (HbA1c). Correlation analyses were used to measure the bivariate associations between variables and within variables across the two time points; that is, following diagnosis and at 12 months.

Multiple regression analyses were applied to the same variables which were treated as independent, while the BASC scores on the three forms for child/adolescent adjustment were included as independent and dependent variables in the hypothesis testing. Diabetes quality of life for adolescents and diabetes health status as metabolic control were the dependent variables for testing some hypotheses. The regression analyses were conducted in order to determine the contribution of various factors to the adjustment of young patients. T-tests were used to compare the difference between variable group means at Time one and two. Bivariate correlations were conducted to test the associations between variables at Time one and Time two.

## 3 RESULTS

### 3.1 Descriptive statistics

This section reports descriptive statistics on sample characteristics, variable characteristics and reliability analyses of the various measures used in the current study. Levels of severity are also considered for the BASC, the DASS and metabolic control. Some of the more established scale measures were compared to original normative data, while Cronbach's alpha coefficient was calculated as an indication of internal consistency for less established measures. The BASC results and obtained data from all other questionnaires were analysed using the standard statistics program for psychological research, SPSS/PC for WINDOWS, Version 14.0.

#### 3.1.1 Sample characteristics

Four patient families assessed at Time one did not participate at Time two of the study for various reasons. There were 33 girls and 29 boys in the sample ( $N=62$ ) at Time one, and 30 girls and 28 boys ( $N=58$ ) at Time two. Patient age at Time one ranged from one to 17 years ( $M = 9.2$  years,  $SD = 4.69$ ), and age at Time two ranged from two to 18 years ( $M = 10.2$  years,  $SD = 4.69$ ).

Of those that did not continue after the baseline assessment at Time one, there were three female patients; one in the 4-6 age group, one in the 10-11 age category and one in the 16-18 age category. One male patient from the 16-18 age category also discontinued. These participants were included in the testing of hypotheses pertaining to Time one only ( $N=62$ ). All further

analyses used the patient families who provided data at both Time one and two ( $N=58$ ), which was 94% of the original sample. The table below shows descriptive data on the study measures at Time one and Time two.

### 3.1.2 Variable characteristics

Table 3: Means, Standard Deviations and Range of Scores on the Measures at Time One and Time Two

Variables	Total	Time One	Total	Time Two
	<i>n</i>	<i>M, SD (Range)</i>	<i>n</i>	<i>M, SD (Range)</i>
Child/Adolescent adjustment - parent (BASC-PRS)	55	52.2, 12.38 (32-78)	54	49.9, 12.16 (30-78)
Child/Adolescent adjustment - teacher (BASC-TRS)	55	48.6, 9.43 (37-74)	49	49.5, 8.79 (35-68)
Child/Adolescent adjustment - self-report (BASC-SRP)	22	47.55, 10.23 (36-70)	21	46.1, 9.51 (38-65)
Maternal psychological adjustment (DASS)	62	23.3, 21.42 (0-104)	58	19.2, 20.69 (0-93)
Maternal general health (GHQ)	62	6.3, 5.89 (0-24)	58	3.7, 5.45 (0-21)
Parental protectiveness (PPS)	24	35.7, 5.08 (26-43)	23	34.0, 7.22 (22-50)
Maternal separation anxiety (MSAS)	19	100.7, 17.26 (70-152)	15	101.3, 16.67 (77-150)
Diabetes quality of life (DQOL-Y)	23	104.4, 30.76 (55-150)	21	107.5, 30.66 (57-169)
Self efficacy on adherence (SE)* (items)	34	7.74, 0.77 (5.86-8.71)	32	7.31, 0.93 (4.71-8.86)
Metabolic control (HbA1c)	53	7.26, 1.08 (5.1-11.2)	55	7.77, 1.22 (5.2-11.9)

Higher variable mean scores indicate greater distress on the variable, except for self efficacy\* where low item scores indicate distress

Table 3 displays descriptive data for the study measures from Time one to Time two. BASC - PRS scores varied more than the other BASC ratings, and the mean score was slightly higher than that obtained by Reynolds & Kamphaus (1992) in their original normative sample. DASS symptoms appear to have decreased between Time one and Time two.

### 3.1.3 Behaviour Assessment System for Children (BASC)

Frequencies of cases in each clinical severity range in the BASC indices of Behavioural Symptom Index (BSI) and Emotional Symptom Index (ESI) are shown below for the current sample.

Table 4: Frequencies of Severity BASC indices for the Parental (PRS), Teacher (TRS) and Self-report (SRP) Ratings with Percentages in Parentheses

BASC Severity Levels: Range	PRS rating (n=55) BSI	TRS rating (n=55) BSI	SRP rating (n=22) ESI
Low: 0-39	11 (19.6)	8 (15.1)	8 (38.1)
Average: 40-59	31 (55.4)	36 (67.9)	9 (42.9)
At-risk: 60-69	9 (16.1)	7 (13.2)	4 (19)
Clinical: 70-79	5 (8.9)	2 (3.8)	0 (0)
Totals	55 (100)	55 (100)	22 (100)

As Table 4 shows at Time one, more than three quarters of the Parental, Teacher and Self-report ratings fell into the Low and Average levels of severity. As seen in the above table, 25% of the sample had psychological symptoms in the at-risk and clinical categories according to ratings on the PRS.

Based on TRS ratings 16% of the sample obtained scores in the at-risk and clinical cases, which was lower than PRS ratings by 9%. SRP ratings showed that 19% of adolescents reported at-risk symptoms. Time two ratings were similar; where PRS at-risk and clinical frequencies comprised 22.2% of

the sample, and adolescent and teacher ratings were lower than Time one, 10% and 15.9% respectively.

### 3.1.4 Self-efficacy on adherence scale (SE)

Reliability and descriptive analyses were compared, as the SE has been applied to clinical research more often recently (Stewart et al., 2003) than when it was originally developed in Canada (Littlefield et al., 1992). Item mean scores were examined because of the wide range of item response options on the nine point scale. Item statistics for the SE scale were similar between the Canadian norms ( $\underline{M}=7.80$ ,  $\underline{N}=177$ ) (Littlefield et al., 1992) and both time points of the current study respectively ( $\underline{M}=7.74$ ,  $\underline{n}=34$ ;  $\underline{M}=7.31$ ,  $\underline{n}=32$ ), although this sample was slightly poorer on the SE, decreasing at Time two. Reliability coefficients were also similar and therefore adequate, where the current sample  $\underline{\alpha} = 0.74$ .

### 3.1.5 General Health Questionnaire (GHQ)

Means ( $\underline{M}$ ) and standard deviations ( $\underline{SD}$ ) of the GHQ were compared between original and previous U.K. studies (Goldberg & Hillier, 1979; Goldberg, 1978). Total severity scores of patient mothers including high and low scoring percentages are presented below in Table 5.

Table 5: GHQ Means ( $\underline{M}$ ) and Standard Deviations ( $\underline{SD}$ ) for the Maternal Ratings and U.K. Samples

GHQ total severity scores	Maternal ratings at Time one ( $\underline{N}=62$ )	U.K. norms ( $\underline{N}=213$ ) (Goldberg & Hillier, 1979)
$\underline{M}$	6.3	6.3
$\underline{SD}$	5.89	9.1
Proportion >12	22.6%	21.6%

Table 5 shows the total severity scores of the total sample of patient mothers ( $\underline{N}=62$ ) on the GHQ with means and standard deviations. The means of total severity scores of patient mothers were found to be identical with Goldberg's original U.K. studies (Goldberg & Hillier, 1979; Goldberg, 1978), but there was greater variation in the U.K. sample. The proportion of scores in

the upper range was also similar to the normative sample (Goldberg, 1978) at Time one.

### 3.1.6 Diabetes Quality of Life measure for Youths (DQOL-Y)

Reliability analyses were performed on each of the three subscales: Diabetes Impact, Diabetes-related Worries and Diabetes Life Satisfaction to assess item consistency within subscales. Reliability was excellent on all subscales ( $\alpha=0.93$ ; 0.88; 0.82) in the current sample. Descriptive statistics between Ingersoll and Marrero's figures (1991) and the current study were similar, although means were higher at both time points with a further slight increase at Time two. The results indicated that the level of quality of life for adolescents between 12 and 18 years of age was consistent with patient normative samples (Ingersoll & Marrero, 1991).

### 3.1.7 Parent Protection Scale (PPS)

The PPS was used with mothers of patients aged two to eight years. Reliability, means and standard deviations were compared with normative and recent studies in the table below.

Table 6: PPS Means (M), Standard Deviations (SD) and Cronbach's alpha ( $\alpha$ ) for the Parental Ratings and U.S. Samples

PPS total scores	Patient parents of 2-8 y.o. ( <u>n</u> =24)	U.S. patient parents ( <u>N</u> =164) (Mullins et al., 2007)	U.S. norms ( <u>N</u> =114) (Thomasgard & Metz, 1996)
<u>M</u>	35.7	26.10	*
<u>SD</u>	5.08	6.16	*
<u><math>\alpha</math></u>	0.43	0.77	0.73

\*Not reported

Table 6 shows a comparison of descriptive and reliability statistics between the current and previous studies (Thomasgard & Metz, 1996; Mullins et al., 2007) on the PPS. The means were found to be higher in the current sample by almost two standard deviations than in the U.S. sample (Mullins et al., 2007). It is further noted that in the U.S. study of children with diabetes

(Mullins et al., 2007) the PPS data was for children diagnosed at various time points, and included children in an older age range. Internal reliability, using Cronbach's alpha ( $\alpha$ ), was found to be low compared to that reported for the original sample (Thomasgard & Metz, 1996).

Scores higher than one SD above the mean were deemed clinically significant in accordance with guidelines in the original article (Thomasgard et al., 1995). In the current sample, 16% ( $n=25$ ) were reported in the high-scoring category at Time one compared to 14.6% ( $N=114$ ) in the original sample (Thomasgard & Metz, 1996). At Time two the proportion of high scoring cases in this study was 12.5% ( $n=24$ ).

### 3.1.8 Maternal Separation Anxiety Scale (MSAS)

Descriptive statistics and reliability analyses of the MSAS were compared to the original norms (Hock et al., 1989). Only mothers of young patients aged from birth to six years completed the MSAS ( $n=19$ ). Cronbach's alpha coefficient for the current sample was excellent ( $\alpha=0.89$ ) and almost identical to the result ( $\alpha=0.88$ ) obtained by Hock and her colleagues (1989). The MSAS total score means at Time one ( $M=100.7$ ,  $SD=17.26$ ) were similar to Time two ( $M=101.3$ ,  $SD=16.67$ ), as were the proportions of scores in each of the response categories.

Only one participant scored in the low response category (5%), 14 participants scored in the middle category (75%) and four scored in the high range (20%). The percentage of the current sample in the low range was small (5%) in comparison with normative data (55%) on new mothers (Hock et al., 1989), which meant few cases had low levels of maternal separation anxiety in the current study. The percentage in the mild to moderate range was much larger in the current sample (75%) than normative data (36%) (Hock et al., 1989), indicating that in this study many respondents had mild symptoms of separation anxiety. The proportion of high ranging scores (20%) was higher than norms (8%).

### 3.1.9 Depression Anxiety Stress Scales (DASS)

Because the DASS was originally researched in Australia (Lovibond & Lovibond, 1995), and has been widely used in clinical settings on adults, adequate consistency was expected in the current study. In the table below, means (M) and standard deviations (SD) for the total sample of patient mothers in the current sample are shown together with Australian normative data (Lovibond & Lovibond, 1995) on the three scales, Depression, Anxiety and Stress, as well as the DASS total scores.

Table 7: Time one DASS subscale Means (M) and Standard Deviations (SD) for Parental Scores, Australian and U.K. Samples

DASS subscales	DASS Descriptives	Parental ratings (N=62)	Australian sample (N=2914) (Lovibond & Lovibond, 1995)
Depression	<u>M</u>	6.39	6.34
	<u>SD</u>	7.02	6.97
Anxiety	<u>M</u>	4.47	4.70
	<u>SD</u>	5.74	4.91
Stress	<u>M</u>	11.56	10.11
	<u>SD</u>	9.70	7.91
Totals	<u>M</u>	23.26	*
	<u>SD</u>	21.42	*

\* DASS Total figures not reported

Subscale results for all patients' mothers in the current sample were similar to means reported for the Australian normative data with the mean for the Stress subscale slightly higher. Table 8 below shows the frequency of cases according to level of severity on each DASS subscale and total.

Table 8: Frequencies and percentages in parentheses of Severity at Time One for Maternal Ratings on DASS Subscales and Totals

DASS Severity levels	Subscales			Totals
	Depression	Anxiety	Stress	
Normal	44	43	44	42 (68%)
Mild	9	5	7	6 (10%)
Moderate	6	8	5	8 (13%)
Severe	2	5	1	4 (6%)
Extremely severe	1	1	5	4 (3%)

*N=62*

It can be seen that most scores are in the normal range for all subscales. The proportion of severe and extremely severe scores was relatively low by comparison with the mild and moderate levels respectively; for example, where the number of cases reporting Mild and Moderate Depression was nine and six respectively, the Severe and Extremely Severe cases only numbered three. There were more cases in the Extremely Severe range for the Stress subscale, and this corresponded with the relatively high mean scores for Time one shown in Table 7.

The combined proportion of the sample in the normal to mild categories of clinical severity was 78%, and the frequency of scores in the moderate to extremely severe categories was 22%, as seen above in Table 8. For Time two, the proportion of the sample in the normal to mild categories was 83%, and the frequency of scores in the moderate to extremely severe categories was 17%. It was noted that compared with the U.K. normative data (Crawford & Henry, 2003), using the same criterion for cut-off scores, the prevalence of clinical psychological symptoms in the current sample was higher by 9% following diagnosis, and remained higher by 4% at 12 months post-diagnosis.

### 3.1.10 Metabolic control

Table 9: Frequencies of Glycosylated Haemoglobin Severity Levels with

Metabolic control - HbA1c severity levels (ADA: Harris et al., 1997)	Frequencies Time one	Frequencies Time two
1. Very good control (<7.0%)	19 (36%)	12 (21%)
2. Adequate control (7.0-8.0%)	21 (40%)	20 (38%)
3. Suboptimal control (8.1%-9.0%)	11(20%)	17 (30%)
4. Poor control (>9.0%)	2 (4%)	6 (11%)
Total N	53	55

Sample Proportion in Parentheses

Table 9 shows the number of participants in each severity level according to their HbA1c value at two months following diagnosis (Time one), and again 12 months post-diagnosis (Time two). Most cases had “adequate control” (level two), according to ADA diagnostic categories (Harris et al., 1997) for patients diagnosed with Type 1 diabetes. A change was noted in the higher frequency of cases in the ‘suboptimal control’ range, while fewer cases occurred at the ‘very good control’ level at Time two. The percentage of children and adolescents with suboptimal or poor control increased from 24% at Time one to 41% at Time two.

Comparisons were made between the current and previous research samples (Northam et al., 1999) on mean Glycosylated Haemoglobin levels (HbA1c) in order to assess preliminary results of metabolic control for diabetes health status. Time one results ( $\bar{M}=7.3\%$ ,  $n=53$ ) were similar to another Australian sample ( $\bar{M}=7.4\%$ ,  $N=116$ ) of patient children aged between three and 14 years (Northam et al., 1999), however at Time two HbA1c levels increased slightly in the current sample ( $\bar{M}=7.8\%$ ,  $n=55$ ). Using ADA descriptors (Harris et al., 1997), the total sample means at both time points fell into the second category of adequate metabolic control.

### **3.2 Time one child/adolescent and maternal psychological adjustment**

This section presents analyses using the sample set ( $N=55$ ) of patient participants' mothers at Time one administered the DASS and the BASC for children aged two and a half to 17 years in relation to the first hypothesis:

1. Child/adolescent psychological adjustment will be associated with maternal psychological adjustment following diagnosis (Time one).

Bivariate and regression analyses were conducted on the BASC-PRS, BSI (Behavioural Symptom Index) T-scores, GHQ and DASS Total scores in order to examine the contribution of the maternal psychological adjustment of mothers to the adjustment of their child or adolescent following diagnosis of Type 1 diabetes; that is, at Time one.

#### **3.2.1 Preliminary analyses of child/adolescent and maternal adjustment**

Tests of normality on the Parent, Teacher and Self-report forms of the BASC revealed a small positive skewness (.292 to .956), which meant that there were a greater number of low scores relative to the number of high scores in the Time one sample. Kurtosis was low or flat (.084 to -.935), where the average ranged scores were found to be spread out around the mean. This result was in keeping with the wide range of scores expected within the normal level of child and adolescent adjustment (Normal T-scores between 40 and 60). Overall, the BASC data did not violate the assumption of normality. It was therefore assumed that linearity and homoscedasticity were satisfactory for the t-test and regression analyses.

The distribution of scores on the DASS total was positively skewed (2.566) with relatively low to expected kurtosis (.599), and again the distribution peaked on the Anxiety scale (4.450). The DASS total approximated normal distribution, therefore it was considered adequate with minimal violations. There was also a small amount of skewness to the right in the distribution of scores on the GHQ (0.826), which meant most scores were low. Kurtosis was relatively flat (-.028) again, indicating a wide spread of

scores in the middle. It was therefore assumed that linearity and homoscedasticity was satisfactory for the regression analyses.

### 3.2.2 Bivariate correlations of child/adolescent and maternal adjustment

Pearson's r product moment correlation coefficients were computed between one child/adolescent adjustment variable (Parent ratings of the BASC (BASC-PRS) and two maternal adjustment variables (GHQ & DASS total). The small sample size available for the MSAS and PPS meant that it was not reasonable to include these variables in the multiple regression analyses to test hypothesis one. Patient age was included to check to what extent it related to any of the measures. The results in the table below display associations between child/adolescent adjustment and maternal adjustment.

Table 10: Pearson's r Product Moment Correlation Coefficients between Child/adolescent Adjustment and Maternal Adjustment at Time One

Adjustment variables	1.	2.	3.	4.
1. BASC-PRS	1.00	0.29*	0.43***	-0.27*
N	55	55	55	55
2. GHQ	-	1.00	0.71***	-0.08
N		55	55	55
3. DASS-Total	-	-	1.00	0.04
N			55	55
4. Patient Age	-	-	-	1.00
N				55

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

Table 10 shows several significant correlations between maternal adjustment and child adjustment following diagnosis. The strongest relationships were between the DASS-Total and the GHQ ( $r= 0.71$ ), the DASS-Total and the BASC-PRS BSI scores ( $r= 0.43$ ). There were further significant but small correlations (Hair, Anderson, Tatham, & Black, 1995) between the BASC-PRS and the GHQ ( $r= 0.29$ ), and the BASC-PRS and age ( $r= -0.27$ ). The correlation coefficient between the DASS and the GHQ was

high; therefore due to collinearity the GHQ was removed from the multiple regression analyses reported below.

### 3.2.3 Regression analyses of child/adolescent and maternal adjustment

Of the maternal adjustment variables, maternal psychological adjustment (DASS) was entered for the prediction of child/adolescent adjustment (BASC-PRS). Results of the regression analysis are presented in Table 11.

The maternal psychological adjustment variable explained a significant, although modest (Hair et al., 1995) proportion of the variance in child/adolescent adjustment ( $R^2 = 0.18$ ;  $F(1, 53) = 11.90$ ,  $p = .001$ ). Further support was therefore provided for an association between maternal adjustment and child/adolescent adjustment at Time one.

Review of the standardised coefficients indicated that an increase in the degree of the mother's psychological adjustment was associated with an increase in the child's or the adolescent's adjustment at the time point following diagnosis. In Table 11 below, the standardised coefficient (Beta=.428,  $p < .01$ ) confirms the significant contribution of maternal psychological adjustment to child/adolescent adjustment.

Table 11: Summary of Multiple Regression Analysis for the Prediction of Time One Child/Adolescent Adjustment by Maternal Predictor Variables

Predictor Variable	<u>B</u>	<u>SE.B</u>	Beta	<u>t</u>	<u>p</u>
Maternal Psychological Adjustment (DASS)	.239	.069	.428	3.449	.001***

\*\*\*  $p < .001$   $N=55$

The hypothesis that child/adolescent psychological adjustment will be associated with maternal psychological adjustment following diagnosis was therefore supported by the modest but significant result obtained in the regression analyses.

### 3.3 Time one and two child/adolescent psychological adjustment

This section presents analyses using the BASC for the sample set ( $N=52$ ) of patient participants between the ages of two and a half and 17 years at Time one and two in relation to the second hypothesis:

2. Child/adolescent psychological adjustment at 12 months post-diagnosis (Time two) of Type 1 diabetes will be poorer than child/adolescent psychological adjustment following diagnosis (Time one).

BASC BSI (Behavioural Symptom Index) T-score ratings by parents (BASC-PRS), teachers (BASC-TRS) and self-reporting adolescents (BASC-SRP) are compared using three separate paired samples t-tests for examining the difference between means at Time one and Time two. A pattern of higher BSI T-scores (indicating poorer adjustment) is predicted at 12 months follow up (Time two).

#### 3.3.1 Comparison between Time one and Time two BASC parental ratings

The tables below show the sample number, standard deviations, standard errors and the means assessed in dependent samples t-tests on the child/adolescent psychological adjustment ratings (BASC) of parent, teacher and self-reporting adolescents following diagnosis of Type 1 diabetes (Time one) and at 12 months post-diagnosis (Time two).

Table 12: Paired Samples Statistics for Parent Ratings of Child/adolescent Adjustment following Diagnosis and at 12 months Post-diagnosis

Parental ratings	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	51.87	52	12.576	1.744
Time Two	50.27	52	12.276	1.702

Table 12 shows that parents rated a slight decrease in their child's/adolescent's behavioural symptoms of child/adolescent psychological adjustment 12 months after diagnosis. The mean difference between Time one and Time two parental ratings of child/adolescent psychological adjustment ( $\underline{M}=1.569$ ,  $\underline{SD}=7.827$ ) was not significant,  $t(51) = 1.471$ ,  $p = .148$ .

### 3.3.2 Comparison between Time one and Time two BASC teacher ratings

Table 13: Paired Samples Statistics for Teacher Ratings of Child/adolescent Adjustment following Diagnosis and at 12 months Post-diagnosis

Teacher Ratings	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	49.42	48	9.734	1.405
Time Two	49.54	48	8.875	1.281

Table 13 shows that as rated by teacher behavioural symptoms of child/adolescent psychological adjustment were stable across the 12 months after diagnosis of Type 1 diabetes. There was only a small mean difference between Time one and two teacher ratings of child/adolescent psychological adjustment ( $M=-.125$ ,  $SD=11.414$ ), and no significant difference was found between mean ratings on the BASC-TRS,  $t(47) = -.076$ ,  $p = .940$ .

### 3.3.3 Comparison of Time one and Time two BASC adolescent self-report ratings

Table 14: Paired Samples Statistics for Self-report Ratings of Adolescent Adjustment following Diagnosis and at 12 months Post-diagnosis

Self-report Ratings	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	48.35	20	10.338	2.312
Time Two	46.40	20	9.654	2.159

Table 14 shows that adolescents reported fewer behavioural symptoms of psychological adjustment 12 months after diagnosis. There was no significant difference between Time one and Time two self-reported ratings of adolescent adjustment ( $M=1.950$ ,  $SD=7.104$ ) on the BASC-SRP,  $t(19) = 1.228$ ,  $p = .235$ .

### 3.3.4 Summary of results of paired samples statistics at two time points

The results of the paired-sample t-tests for parents, teachers and self-reporting adolescents indicated that there were no significant differences between BASC Behavioural Symptom Index (BSI) scores of child/adolescent

psychological adjustment at Time one and Time two. Parents and adolescents rated slightly better child/adolescent psychological adjustment at Time two compared to Time one, and teacher ratings of child/adolescent psychological adjustment were almost the same. Correlations between parent ratings at Time 1 and Time 2, teacher ratings at Time 1 and Time 2 and self-reported adolescent ratings at Time 1 and Time 2 were .802, .250 and .749 respectively.

The hypothesis that child/adolescent psychological adjustment at 12 months post-diagnosis will be poorer than child/adolescent psychological adjustment within two months following diagnosis was therefore not supported.

### **3.4 Time two child/adolescent and maternal psychological adjustment**

This section presents analyses based on DASS scores and BASC scores as reported by mothers of children and adolescents aged from two and a half to 18 years at Time one and Time two in relation to the third hypothesis:

3. Child/adolescent psychological adjustment at 12 months post-diagnosis (Time two) will be predicted by maternal psychological adjustment following diagnosis (Time one).

Regression analyses were applied to the BASC-PRS T-scores (Parental ratings) at Time two and the Depression, Anxiety, Stress Scale (DASS) total clinical symptom severity scores at Time one in order to test the influence of maternal psychological adjustment on the psychological adjustment of two and a half to 18 year old patients at 12 months post-diagnosis. The independent variable is the DASS and the parent-rated child/adolescent adjustment (BASC-PRS) is the dependent measure.

#### **3.4.1 Preliminary analyses of child/adolescent and maternal adjustment**

Tests of normality on the BSI scores revealed a small positive skewness (.392 to 1.043), which again meant that there were a greater number of low scores relative to the number of high scores in the Time two sample. Kurtosis was also low or flat (-.345 to -.990) with average ranged scores spread out around the mean. The BASC data did not violate the assumption of normality.

#### **3.4.2 Bivariate correlations of child/adolescent and maternal adjustment**

Pearson's  $r$  product moment correlation coefficients were computed between maternal adjustment at Time one (DASS total score) and child/adolescent adjustment at Time two according to the BASC-PRS. The results in the table below display associations between child/adolescent adjustment and maternal adjustment.

Table 15: Pearson's r Product Moment Correlation Coefficients between Maternal Adjustment at Time one and Child/adolescent Adjustment at Time Two

Adjustment variables	Time	1.	2.
1. DASS-Total	one	1.00	0.50***
N		54	54
2. BASC-PRS (BSI)	two	-	1.00
N			54

\*\*\* $p < .001$

Table 15 shows a significant correlation between reported maternal adjustment following diagnosis of Type 1 diabetes and Behavioural Symptom Index (BSI) scores of child/adolescent adjustment 12 months post-diagnosis.

### 3.4.3 Regression analyses of child/adolescent and maternal adjustment

Maternal psychological adjustment (DASS) at Time one was the maternal adjustment variable entered for the prediction of child/adolescent adjustment (BASC-PRS) at Time two. Results of the regression analysis are presented in Table 16 below.

The maternal adjustment variable explained a significant and moderate proportion (Hair et al., 1995) of the variance in child/adolescent adjustment ( $R^2 = 0.25$ ;  $F(1, 52) = 17.261$ ,  $p = .000$ ). Further support was therefore provided for an association between maternal adjustment and child/adolescent adjustment.

Review of the standardised coefficients indicated that an increase in the degree of the mother's psychological adjustment following her child's diagnosis was associated with an increase in the child's or the adolescent's adjustment 12 months post-diagnosis. The explanatory power of maternal psychological adjustment was found to be significant, as shown by the standardised coefficient (Beta=.499,  $p < .001$ ) in Table 16 below.

Table 16: Summary of Multiple Regression Analysis for the Prediction of Time  
Two Child/Adolescent Adjustment by Maternal Adjustment at Time one

Predictor Variable	<u>B</u>	<u>SE.B</u>	Beta	<u>t</u>	<u>p</u>
Maternal Psychological Adjustment (DASS)	.277	.067	.499	4.155	.000***

\*\*\* p<.001 N=54

The hypothesis that child/adolescent psychological adjustment at 12 months post-diagnosis will be predicted by maternal psychological adjustment within two months following diagnosis was supported by the moderate, significant result obtained in the regression analyses.

### **3.5 Time one adjustment and Time two health status**

This section presents analyses using adolescent adjustment self-reports (BASC-SRP), maternal adjustment self-reports (DASS) at Time one, and metabolic control at Time two for patient participants between the ages of twelve and eighteen years in relation to the fourth hypothesis:

4. Diabetes health status (as measured by metabolic control) at 12 months post-diagnosis will be predicted by adolescent psychological adjustment and maternal psychological adjustment following diagnosis.

Bivariate and regression analyses included adolescent adjustment (BASC-SRP) T-scores and maternal psychological adjustment (DASS) scores at Time one as independent variables in order to test the associations with and contribution to diabetes health status as measured by glycosylated haemoglobin levels (HbA1c) at Time two. Step-wise multiple regression analyses were used.

#### **3.5.1 Preliminary analyses of metabolic control (HbA1c)**

The percentage levels for metabolic control at Time two were also normally distributed with skewness slightly positive (.546), and kurtosis slightly raised but within the acceptable range (1.181). The spread of variance in HbA1c values was appropriate in the preliminary tests. Previous analyses of the adjustment variables had found minimal violations to the assumptions of normality in the current study. It was therefore assumed that linearity and homoscedasticity were satisfactory for the regression and t-test analyses.

#### **3.5.2 Bivariate correlations of adjustment and metabolic control**

Pearson's  $r$  product moment correlation coefficients were computed between adolescent adjustment variable (BASC-SRP), maternal adjustment (DASS total) and metabolic control (HbA1c levels). The results in the table below show the associations between adolescent adjustment and maternal adjustment at the time point following diagnosis, and metabolic control (HbA1c) at 12 months post-diagnosis.

Table 17: Pearson's r Product Moment Correlation Coefficients between Time one Adjustment Variables and Time two Metabolic Control

Variables	Time	1.	2.	3.
1. HbA1c	two	1.00	.47*	.09
N		21	21	21
2. DASS-Total	one	-	1.00	.13
N			21	21
3. BASC-SRP	one	-	-	1.00
N				21

\* $p < .05$

Table 17 shows a significant association between maternal psychological adjustment following diagnosis (Time one), and metabolic control at 12 months post-diagnosis (Time two). There was no collinearity between the DASS-Total and the BASC-SRP at Time one, and there was no significant association between adolescent psychological adjustment at Time one and HbA1c levels at Time two.

### 3.5.3 Regression analyses of adjustment and health status

Adolescent adjustment (BASC-SRP) and maternal psychological adjustment (DASS) were the variables entered using the step-wise method for the prediction of metabolic control (HbA1c levels). Results of the regression analysis are presented in Table 18.

Maternal psychological adjustment explained a significant, moderate proportion of the variance in diabetes health status ( $R_2 = 0.22$ ;  $F(2, 19) = 5.356$ ,  $p = .032$ ). Review of the standardised coefficients indicated that the degree of clinical severity in the mother's psychological adjustment two months after diagnosis was associated with an increase in HbA1c levels at 12 months post-diagnosis. However, no support was provided for a relationship between Time one adolescent psychological adjustment and Time two HbA1c levels.

Table 18 below shows that maternal psychological adjustment made a significant independent contribution to metabolic control at Time two, standardised coefficient (Beta=.469,  $p < .05$ ).

Table 18: Summary of Multiple Regression Analysis for the Prediction of Time Two Health Status by Maternal Adjustment at Time one

Predictor Variable	<u>B</u>	<u>SE.B</u>	Beta	<u>t</u>	<u>p</u>
Maternal Psychological Adjustment (DASS)	.028	.012	.469	2.314	.032*

\*  $p < .05$   $N=21$

The hypothesis that diabetes health status (as measured by metabolic control) at 12 months post-diagnosis will be predicted by adolescent psychological adjustment and maternal psychological adjustment within two months following diagnosis was supported in part. Maternal adjustment predicted metabolic control over time with a moderate, significant result, but adolescent adjustment did not predict metabolic control in the regression analyses.

### **3.6 Time two adjustment, self-efficacy, health status and quality of life**

This section presents analyses based on adolescent adjustment (BASC-SRP), maternal adjustment (DASS), self-efficacy (SE) and adolescent quality of life (DQOL-Y) at Time two for patient participants between the ages of 12 and 18 years in relation to the fifth hypothesis:

5. Quality of life for adolescents between 12 and 18 years of age at 12 months post-diagnosis (Time two) will be associated with self-efficacy, adolescent psychological adjustment, maternal adjustment and diabetes health status at Time two.

The scores of the BASC, GHQ, DASS, SE and glycosylated haemoglobin (HbA1c) levels at time point two were entered into regression analyses as independent variables in order to test their contribution to the dependent variable, the adolescent patients' diabetes quality of life (DQOL-Y), 12 months after receiving a diagnosis of diabetes.

#### **3.6.1 Preliminary analyses of quality of life and self-efficacy**

Tests of normality on the DQOL-Y at Time two revealed negligible positive skewness (0.495), which meant that scores on this measure were normally distributed. Kurtosis was slightly flat (-0.587). Using item means, the SE distribution at Time two was slightly skewed to the left (-0.573), which was expected and kurtosis was low to normal (0.548).

As mentioned, preliminary analyses of the adjustment variables had found the child/adolescent adjustment measure (BASC) and metabolic control (HbA1c) to be normally distributed, and this was consistent with Time two, however there was some non-normality in the slight positive skewness of data as previously mentioned in the maternal psychological adjustment measure (DASS). Overall, it was assumed that linearity and homoscedasticity were satisfactory for the regression and t-test analyses.

### 3.6.2 Bivariate correlations of adjustment, health status, quality of life and self-efficacy

Pearson's r product moment correlation coefficients were computed between the child/adolescent adjustment (BASC-SRP) and maternal adjustment (DASS total), metabolic control (DQOL-Y), impact on diabetes quality of life DQOL-Y and self-efficacy (SE). Results of these bivariate analyses are shown in the table below.

Table 19: Pearson's r Product Moment Correlation Coefficients between Adjustment Variables, Metabolic Control and Quality of Life

Variables	Time	1.	2.	3.	4.	5.
1. DQOL-Y	two	1.00	-.51*	.06	.58**	.83***
N		20	20	20	20	20
2. SE	two	-	1.00	.24	-.01	-.50*
N			20	20	20	20
3. HbA1c	two	-	-	1.00	.25	-.16
N				20	20	20
4. DASS-Total	two	-	-	-	1.00	.40*
N					20	20
5. BASC-SRP	two	-	-	-	-	1.00
N						20

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

Table 19 shows moderate correlations (Hair et al., 1995) between self-efficacy and diabetes quality of life, maternal adjustment and diabetes quality of life for adolescents 12 months after diagnosis. There were also several significant relationships between the DASS-Total and the BASC-SRP, SE and BASC-SRP, and the same variables correlated with DQOL-Y. The highest amount of overlapping variance was found between the BASC-SRP and DQOL-Y ( $r=0.83$ ), which meant there was a strong association between adolescent adjustment and diabetes quality of life for adolescents at Time two of the study.

### 3.6.3 Regression analyses of adjustment, health status, quality of life and self-efficacy

Maternal psychological adjustment (DASS), adolescent adjustment (BASC-SRP), self-efficacy (SE), and metabolic control (HbA1c) were the variables entered for the prediction of diabetes quality of life in adolescents. Results of the regression analysis are presented in Table 20.

As a set, the two psychological adjustment variables explained a significant, large proportion of the variance in adolescent diabetes quality of life ( $R^2 = .81$ ;  $F(4, 15) = 15.859$ ,  $p = .000$ ). Further support was therefore provided for the previously reported associations of maternal adjustment and adolescent adjustment with diabetes quality of life at Time two. Review of the standardised coefficients indicated that an increase in the degree of the mother's psychological adjustment and adolescent psychological adjustment was associated with an increase in the adolescent's quality of life.

In contrast to the bivariate analyses in which self-efficacy was significantly correlated with quality of life, self-efficacy did not make a significant independent contribution to the outcome variable diabetes quality of life (Beta=-.231,  $p > .10$ ). In both analyses there was no tendency for metabolic control to be associated with quality of life. As can be seen below in Table 20, the independent contributions of maternal adjustment (Beta=.292,  $p < .05$ ) and adolescent adjustment (Beta=.619,  $p < .01$ ) to diabetes quality of life were found to be significant.

Table 20: Summary of Multiple Regression Analysis for the Prediction of Time Two Quality of Life by Adjustment Variables, Self-efficacy and Metabolic Control

Predictor Variable	<u>B</u>	<u>SE.B</u>	Beta	<u>t</u>	<u>p</u>
Adolescent Adjustment (BASC-SRP)	1.993	.480	.619*	4.155	.001***
Maternal Psychological Adjustment (DASS)	.366	.168	.292*	2.181	.046*
Self-efficacy on adherence (SE)	-6.770	3.941	-.231	-1.718	.106
Metabolic control (HbA1c)	2.900	2.470	.144	1.174	.259
* $p < .05$ ** $p < .01$ *** $p < .001$					<i>N=20</i>

The hypothesis that quality of life for adolescents between 12 and 18 years of age at 12 months post-diagnosis will be associated with self-efficacy, adolescent psychological adjustment, maternal psychological adjustment and diabetes health status was supported in part by the strong, significant association between adolescent adjustment, maternal adjustment and quality of life for adolescents. Self-efficacy and metabolic control were not associated with quality of life for adolescents in the regression analyses.

### **3.7 Time one and two parental protectiveness and separation anxiety**

This section presents analyses using the PPS and the MSAS for the sub-set ( $n=20$ ) of mothers of child patients between the ages of 18 months and eight years at Time one in relation to the sixth hypothesis:

6. For children under eight years of age, parental protectiveness and maternal separation anxiety at 12 months post-diagnosis (Time two) of Type 1 diabetes will be greater than parental protectiveness and separation anxiety following diagnosis (Time one).

Maternal separation anxiety scores (MSAS) and parental over-protectiveness scores (PPS) were compared using two separate paired samples t-tests to examine the difference between group means at Time one and Time two. A pattern of higher scores on the two parental characteristics measures was predicted at 12 months follow up (Time two).

#### **3.7.1 Preliminary analyses of parental protectiveness and separation anxiety**

The distribution scores on the Parent Protection Scale (PPS) were normal with negligible skewness (-0.323) and flat to expected kurtosis (-1.024). The scores on the Maternal Separation Anxiety Scale (MSAS) were also normally distributed with skewness slightly positive (1.416), and kurtosis slightly higher than acceptable (4.141), which meant scores were clustered at the mean. The two measures for parental characteristics were found to be sufficient in the preliminary analyses for t-tests but not for the regression analyses.

#### **3.7.2 Comparison of Time one and two parental protectiveness**

The tables below show the sample number, standard deviations, standard errors and the means assessed in dependent samples t-tests on the Parental Protection Scale (PPS) and the Maternal Separation Anxiety Scale (MSAS) following diagnosis of Type 1 diabetes (Time one) and at 12 months post-diagnosis follow-up (Time two).

Table 21: Paired Samples Statistics for Ratings of Parental Protection following Diagnosis and 12 months Post-diagnosis

Parental Protection scores	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	35.80	20	4.969	1.111
Time Two	33.95	20	7.430	1.661

Table 21 shows that parents rated a slight decrease in over-protective behaviour with their patient child 12 months after diagnosis. The mean difference (M = 1.850, SD = 6.201) between Time one and Time two self-report ratings of parental protectiveness (PPS) was not significant,  $t(19) = 1.334$ ,  $p = .198$ .

### 3.7.3 Comparison of Time one and two maternal separation anxiety

Table 22: Paired Samples Statistics for Maternal Separation Anxiety following Diagnosis and 12 months Post-diagnosis

Separation Anxiety scores	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	103.60	15	16.944	4.375
Time Two	101.33	15	16.672	4.305

Table 22 shows that mothers rated a slight decrease in their level of separation anxiety 12 months after their child's diagnosis. The mean difference (M = 2.267, SD = 6.777) between Time one and Time two ratings of maternal separation anxiety (MSAS) was not significant,  $t(14) = 1.295$ ,  $p = .216$ .

### 3.7.4 Summary of results of paired samples statistics at the two time points

The results of the paired-sample t-tests for patient mothers indicated that there were no significant differences between Parental Protection Scale (PPS) scores at Time one and two, and Maternal Separation Anxiety Scale (MSAS) scores at Time one and two. Correlations between time points for the PPS parent ratings and MSAS parent ratings were .56 and .92 respectively.

The hypothesis that for children under eight years of age, parental protectiveness and maternal separation anxiety at 12 months post-diagnosis of Type 1 diabetes will be greater than parental protectiveness and separation anxiety within two months following diagnosis was therefore not supported.

### **3.8 Time one and two quality of life, self-efficacy and diabetes health status**

This section presents analyses using DQOL-Y and SE for the sub-set ( $n=31$ ) of adolescent patients between the ages of ten and 18 years and HbA1c levels for the broader sample range of birth to 18 years ( $n=52$ ) at Time one and two in relation to the seventh hypothesis:

7. For adolescents between ten and eighteen years of age, quality of life, self-efficacy and metabolic control will be poorer at 12 months post-diagnosis (Time two) than quality of life, self-efficacy and metabolic control following diagnosis (Time one).

Three separate paired samples t-tests were conducted to examine the differences between Time one and Time two scores for diabetes quality of life (DQOL-Y), self-efficacy on adherence scores (SE) and metabolic control (HbA1c) levels. A pattern of lower scores on SE and higher scores on DQOL-Y and HbA1c was predicted at 12 months follow up (Time two).

#### **3.8.1 Preliminary analyses of quality of life, self-efficacy and metabolic control**

The distribution scores on the Diabetes Quality of Life - Youth scale (DQOL-Y) at Time one was normal with negligible skewness (0.072) and low to expected kurtosis (-1.342). The scores on the Self-efficacy on adherence scale (SE) at Time one were also normally distributed with skewness slightly negative (-0.552), and kurtosis within the acceptable range (-0.432). The range of percentage values for glycosylated haemoglobin levels (HbA1c) at Time one was normally distributed with negligible skewness (0.784) and expected kurtosis (2.222). The three diabetes-specific measures were found to be robust in the preliminary analyses for the tests of difference between means.

#### **3.8.2 Comparison of Time one and two quality of life**

The tables below show the standard deviations, standard errors and the means for Diabetes Quality of Life - Youth (DQOL-Y), Self-efficacy on

adherence (SE) and metabolic control (HbA1c) following diagnosis of Type 1 diabetes (Time one) and at 12 months post-diagnosis follow-up (Time two).

Table 23: Paired Samples Statistics for Scores on Diabetes Quality of Life following Diagnosis and at 12 months Post-diagnosis

Diabetes Quality of Life scores	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	109.45	20	29.231	6.536
Time Two	109.00	20	30.629	6.849

Table 23 shows that adolescents' ratings on the DQOL-Y were similar at Time 1 and Time 2. Results of dependent samples t-tests revealed no significant difference between Time one and Time two mean ( $\underline{M} = .450$ ,  $\underline{SD} = 25.034$ ) self-report ratings of adolescent quality of life (DQOL-Y),  $t(19) = .080$ ,  $p = .937$ .

### 3.8.3 Comparison of Time one and two self-efficacy

Table 24: Paired Samples Statistics for Self-efficacy following Diagnosis and at 12 months Post-diagnosis

Self-efficacy scores	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	7.67	31	.7652	.1374
Time Two	7.30	31	.9481	.1703

Table 24 shows that adolescents reported a poorer level of self-efficacy on adherence to the medical regimen 12 months after diagnosis. There was a significant difference on mean item ratings ( $\underline{M} = .364$ ,  $\underline{SD} = .8466$ ) between Time one and Time two for self-report ratings of adolescent self-efficacy (SE),  $t(30) = 2.394$ ,  $p < .05$ .

### 3.8.4 Comparison of Time one and two metabolic control

Table 25: Paired Samples Statistics for Metabolic Control following Diagnosis and at 12 months Post-diagnosis

Metabolic Control levels	<u>M</u>	<u>N</u>	<u>SD</u>	<u>SE</u>
Time One	7.25	52	1.094	.1517
Time Two	7.77	52	1.251	.1735

Table 25 shows that metabolic control in children/adolescents ( $n=52$ ) had declined in the 12 months after diagnosis. There was a significant mean difference ( $M = -0.5192$ ,  $SD = 1.4036$ ) between Time one and Time two metabolic control levels (HbA1c),  $t(51) = -2.668$ ,  $p < .01$ .

### 3.8.5 Summary of results on paired samples statistics at the two time points

The results of the paired-sample t-tests for quality of life, self-efficacy and metabolic control for adolescents indicated that there were significant differences between Time one and two for Self-efficacy on adherence (SE) scores and metabolic control levels (HbA1c).

Self-efficacy scores were significantly lower at Time two indicating a decline in self-efficacy over time. Metabolic control was also poorer, as HbA1c values were found to have increased significantly over time. There was no significant difference in adolescent patients' ratings of Diabetes Quality of Life - Youth (DQOL-Y) across the two time points. Correlations for the diabetes-specific variables, quality of life, self-efficacy and metabolic control between the time points were .65, .53 and .29 respectively.

The hypothesis that for adolescents between ten and 18 years of age, quality of life, self-efficacy and metabolic control will be poorer at 12 months post-diagnosis than quality of life, self-efficacy and metabolic control within two months following diagnosis was supported for self-efficacy and metabolic control, but not supported in the comparison of scores between the two time points for quality of life.

### **3.9 Brief summary of results**

There were two types of analyses on the data in the current study. First was a comparison of the mean scores of measures at the time point following diagnosis (Time one) with the same measures at 12 months post-diagnosis (Time two). Child/adolescent psychological adjustment, adolescent diabetes quality of life, parental protectiveness and maternal separation anxiety did not change over time, however self-efficacy and metabolic control did decrease significantly from Time one to Time two.

The second type of analyses tested for associations between variables at one or both time points. Child/adolescent psychological adjustment and maternal psychological adjustment were significantly associated at Time one, as was maternal adjustment at Time one associated with Time two child/adolescent psychological adjustment. For adolescents, psychological adjustment and quality of life were significantly associated with maternal adjustment, self-efficacy and metabolic control.

#### **3.9.1 Time one psychological adjustment**

Hypothesis 1: Child/adolescent psychological adjustment, as measured by the Behavioural Assessment Scale for Children (BASC-PRS), will be associated with maternal psychological adjustment as measured by the Depression, Anxiety and Stress Scale (DASS) and General Health Questionnaire (GHQ) within two months following diagnosis.

The first hypothesis was supported in that maternal psychological adjustment was significantly correlated with child/adolescent adjustment at Time one with 18% overlapping variance. Child/adolescent psychological adjustment was therefore associated with maternal psychological adjustment as measured by the Depression, Anxiety and Stress Scale (DASS) (GHQ was not included in the regression analysis because of collinearity between the GHQ and the DASS) following diagnosis of Type 1 diabetes to a small but significant extent in the regression analyses.

### 3.9.2 Time one and two child/adolescent adjustment

Hypothesis 2: Child/adolescent psychological adjustment as measured by parental reports (BASC-PRS), teacher reports (BASC-TRS) and adolescent self-reports (SRP) at 12 months post-diagnosis will be poorer than child/adolescent psychological adjustment (BASC-PRS; BASC-TRS; BASC-SRP) within two months following diagnosis.

Contrary to expectations, the second hypothesis was not supported as there was no significant change in behavioural symptoms over time according to parent, teacher ratings and adolescent self-reports on the BASC. Child/adolescent psychological adjustment at 12 months post-diagnosis of Type 1 diabetes (Time two) was not poorer than child/adolescent psychological adjustment following diagnosis (Time one).

### 3.9.3 Time one maternal adjustment and Time two child/adolescent adjustment

Hypothesis 3: Child/adolescent psychological adjustment (BASC-PRS) at 12 months post-diagnosis will be predicted by maternal psychological adjustment (DASS) within two months following diagnosis.

As expected in the third hypothesis, maternal psychological adjustment at Time one significantly predicted child/adolescent adjustment at Time two with 25% overlapping variance. Child/adolescent psychological adjustment at 12 months post-diagnosis was therefore significantly predicted by maternal adjustment following diagnosis to a moderate extent in the regression analyses.

### 3.9.4 Time one psychological adjustment and Time two metabolic control

Hypothesis 4: Diabetes health status as measured by metabolic control (HbA1c) at 12 months post-diagnosis will be predicted by adolescent psychological adjustment as measured by adolescent self-reports (BASC-SRP) and maternal psychological adjustment (DASS) within

two months following diagnosis.

As expected in the fourth hypothesis, metabolic control at Time two was significantly predicted by maternal psychological adjustment at Time one contributing 22% of the variance. Metabolic control at 12 months post-diagnosis was significantly predicted by maternal psychological adjustment following diagnosis of Type 1 diabetes, with a moderate association between the adjustment predictor variable and metabolic control.

Contrary to expectations, Time one adolescent psychological adjustment according to adolescent self-ratings did not predict Time two metabolic control in the regression analyses.

### 3.9.5 Time two quality of life, self-efficacy, adjustment and metabolic control

Hypothesis 5: Quality of life for adolescents between twelve and eighteen years of age as measured by the Diabetes Quality of Life - Youth scale (DQOL-Y) will be associated with self-efficacy as measured by the Self-Efficacy on adherence scale (SE), adolescent psychological adjustment, maternal adjustment and diabetes health status at 12 months post-diagnosis.

As expected in the fifth hypothesis, quality of life for adolescents was significantly predicted by adolescent psychological adjustment and maternal adjustment at Time two contributing 81% of variance. However, contrary to expectations in the same hypothesis, metabolic control did not correlate with the other variables. Self-efficacy was significant at a bivariate level but did not retain a significant independent contribution in the regression analyses.

Quality of life for adolescents between 12 and 18 years of age at 12 months post-diagnosis (Time two) was significantly predicted by self-efficacy, adolescent psychological adjustment and maternal adjustment at Time two, and this was supported by the strong associations obtained in the analyses.

### 3.9.6 Time one and two parental protectiveness and separation anxiety

Hypothesis 6: For children under eight years of age, parental protectiveness as measured by the Parent Protection Scale (PPS) and separation anxiety as measured by the Maternal Separation Anxiety Scale (MSAS) at 12 months post-diagnosis will be greater than parental protectiveness and separation anxiety within two months following diagnosis.

Contrary to expectations, the sixth hypothesis was not supported. Levels of parental protectiveness (PPS) and maternal separation anxiety (MSAS) at 12 months post-diagnosis were not greater than protectiveness and separation anxiety following diagnosis of Type 1 diabetes. There was no significant difference between parental self-reported ratings on the PPS and MSAS at Time one and two.

### 3.9.7 Time one and two quality of life, self-efficacy and metabolic control

Hypothesis 7: For adolescents between ten and eighteen years of age, quality of life, self-efficacy and diabetes health status will be poorer at 12 months post-diagnosis than two months following diagnosis.

The seventh hypothesis was supported. Self-efficacy on adherence for adolescents between ten and 18 years decreased over time. Metabolic control also decreased (as shown by increased HbAc1 levels) over time. Self-efficacy and metabolic control were both poorer at 12 months post-diagnosis than self-efficacy and metabolic control following diagnosis.

Contrary to expectations in the same hypothesis on diabetes-specific variables, quality of life for adolescents between 12 and 18 years of age did not change, as there was no significant difference between DQOL-Y reports at Time one and two.

## 4 DISCUSSION

Research on psychological adjustment in children and adolescents with Type 1 diabetes has focused on depression (Dantzer et al., 2003), social factors such as peer support (La Greca & Bearman, 2002), and medical factors such as treatment adherence (Littlefield et al., 1992; Pendley et al., 2002; Stewart et al., 2003). Yet research on young patients has less often considered psychological factors across time. The question of whether clinical problems were present before the onset of diabetes is of course not easily addressed but only a few studies (e.g., Grey et al., 1995; Northam et al., 1999) have observed adjustment both *soon after diagnosis* and then followed up at later time points.

The current study found that poor psychological adjustment in children and adolescents with diabetes were influenced by factors such as maternal psychological adjustment both at the time point following diagnosis and 12-months post-diagnosis. The influence of maternal adjustment on quality of life and diabetes health status of adolescents was also evident in the results from the study.

This section provides a brief overview of the factors identified in the current study that may contribute to poor psychological adjustment in young patients with Type 1 diabetes.

#### **4.1 Review of Main Research Aims and Findings**

The primary aim of this research was to examine maternal and child/adolescent factors in relation to the time point two months after diagnosis and 12 months post-diagnosis of Type 1 diabetes in young patients. The research provided a profile of the psychological adjustment of children and adolescents following a diagnosis of diabetes. The profile in this early period after diagnosis also included mothers' psychological adjustment and parenting characteristics in the mother-child relationship for very young children, and diabetes-specific outcomes such as quality of life, self-efficacy on adherence to treatment in older children together with metabolic control.

Psychological adjustment of children and adolescents with diabetes was measured using parent, teacher and adolescent self-report ratings. Based on previous research findings (Dantzer et al., 2003; Berg et al., 2007), the current study proposed that the psychological adjustment of children and adolescents with diabetes would be influenced by maternal psychological adjustment.

As adolescent patients assume greater responsibility for treatment tasks, the effect of diabetes on quality of life and self-efficacy on adherence was expected to influence psychological adjustment in this age group.

The second aim of this research was to examine change in psychological adjustment and medical status across time, from soon after diagnosis of Type 1 diabetes to 12 months post-diagnosis; and third, to determine if factors measured soon after diagnosis could predict adjustment and management of diabetes 12 months later. The data analyses examined several associations among the broad range of variables including adjustment in patient children, adolescents and parents, parenting characteristics, self-efficacy, quality of life and metabolic control.

1. Maternal psychological adjustment (i.e., symptoms of depression, anxiety and stress) was a small but influential factor in the

psychological adjustment of children and adolescents newly diagnosed with diabetes. The findings from the current study were consistent with previous findings of an association between the psychological adjustment of children and adolescents with diabetes and their mothers (Berg et al., 2007; McDonnell et al., 2007; Schmidt, 2007; Whittemore et al., 2003). Consistent with findings from an earlier study (Whittemore et al., 2003), the current results for mothers showed that this sample had poorer psychological adjustment compared to Australian (Lovibond & Lovibond, 1995) and U.K. (Crawford & Henry, 2003) normative data for samples of healthy adults.

2. Contrary to the second hypothesis, at 12 months post-diagnosis the psychological adjustment of children and adolescents was not poorer than it had been soon after diagnosis. However, consistent with expectations, diabetes health status (i.e., metabolic control) in the current sample ( $n=52$ ) decreased over time. Metabolic control following diagnosis was similar to that reported in a previous Australian sample (Northam et al., 1999) of young patients (3-14 years) but in contrast to results from that study there was a decrease in metabolic control at 12 months post-diagnosis for the current sample. An important finding of the current study was that psychological adjustment in mothers of newly diagnosed adolescent patients (12-18 years) influenced their adolescent's metabolic control at 12 months post-diagnosis. Earlier research had failed to reveal an association between parental factors and metabolic control (Kovacs et al., 1989). This study is one of the few studies (see also Berg et al., 2007) to report an association between young patients' metabolic control and the psychological adjustment of their mothers.

3. The effect of diabetes on quality of life for adolescents between 12 and 18 years of age did not change over the two time points. Reported quality of life in the current study was however greater than that reported for the same measure in the original sample of adolescents between 10 and 21 years of age (Ingersoll & Marrero,

1991). For patients aged 10 to 18 years old in the current study, self-efficacy in regard to adherence decreased during the 12-month period. Levels were lower over time than normative data for a sample of adolescents between 13 and 18 years of age (Littlefield et al., 1992). However it is important to note that in the current study despite the significant difference in SE mean scores from Time 1 to Time 2 the decrease was extremely small and unlikely to be regarded as clinically significant. Maternal psychological adjustment and self-reported adolescent psychological adjustment were together strong contributing factors to the effect of diabetes on quality of life for adolescents between 12 and 18 years of age at 12 months post-diagnosis.

4. In mothers of children eight years of age and under, parental protectiveness and separation anxiety were relatively high soon after diagnosis compared to normative data on non-patient samples (Thomasgard et al., 1995; Hock et al., 1989) but the expected change in these parenting characteristics did not occur. The current results may have been influenced by the high initial impact on parents of receiving their child's diagnosis of diabetes in spite of the assumption of a 'honeymoon' effect on diabetes symptoms and metabolic control produced by initial professional support and intervention. Only one other study (Mullins et al., 2007) has examined parental protectiveness in a very young patient sample. The current scores for parental protectiveness were much higher than those reported in this previous study of children aged between eight and 12 years (Mullins et al., 2007). These discrepant findings may be explained by the different age of the patient samples and consequent differences in developmental expectations of the parents of these patients. Where previously maternal separation anxiety had been examined in the context of parental stress and marital status (Kelley et al., 1994), this study is the first to examine maternal separation anxiety in very young patients with Type 1 diabetes.

Overall, the results from statistical analyses provided mixed support for the several hypotheses. The inter-relations between adjustment in patient children, adolescents and parents, parenting characteristics, adolescent self-efficacy, quality of life and metabolic control highlight the importance of considering the developmental stages of children and adolescents with diabetes. The current study revealed associations between maternal psychological adjustment and child/adolescent psychological adjustment, and demonstrated the influence of maternal adjustment on metabolic control and adolescent quality of life. Also revealed was the decrease in both self-efficacy and metabolic control over the 12-month study period. Some prominent themes are worthy of discussion.

## **4.2 Psychological functioning of children and adolescents**

### **4.2.1 Adjustment across time**

The hypothesis (H2) that there would be a decrease in child/adolescent adjustment from Time 1 to Time 2 was not confirmed. Current levels of child/adolescent psychological adjustment were only slightly lower than norms (Reynolds & Kamphaus, 1992) and these levels did not change across time. Therefore it might seem that young patients were not affected by their condition in the first 12 months post-diagnosis. Indeed, this conclusion is consistent with those from previous longitudinal studies (Kovacs et al., 1989; Chaney et al., 1997; Grey et al., 1995). However, it does raise the question as to whether psychological functioning actually remains the same over the first year of diagnosis, or whether there are both positive and negative aspects to the experience of diabetes for the young person that balance the ostensible normality of their levels of adjustment. A further explanation could be related to the assessment measure. The BASC was not designed for young patients with diabetes and so it is possible that the BASC may not be sensitive to the impact of diabetes.

Part of the problem in interpreting the results from this and similar studies is the difficulty in discerning possible secondary effects of diabetes from psychological problems that may have been present prior to the diagnosis of diabetes. If there was any change in adjustment due to the secondary effects of diabetes, it may have already occurred when the young person became ill prior to diagnosis and treatment. On the other hand, what may appear to be a secondary effect could have derived from an earlier condition. Obviously prospective studies are not possible and the validity of retrospectively examining adjustment is questionable. Nevertheless, it must be kept in mind that the premorbid psychological adjustment of these young patients is likely to influence their adaptation to diabetes.

There is also the fact that a child is not only learning to live with diabetes, he or she is in an ongoing process of development. According to Grey and colleagues (1995), research had not yet determined periods of risk

for poor psychological adjustment in children with diabetes that were not due to age and developmental expectations. Even the psychological symptoms seen in patients and families soon after diagnosis tended to dissipate in Kovacs and colleagues' six-year study (1989). It has been argued that some symptoms will decrease with maturity and adaptation (Northam et al., 1999).

Later research (Kovacs, Ho, & Pollock, 1995) did obtain evidence of depressive symptoms in 8 to 13 year old children with diabetes, but unlike the current study, the time period was not controlled. The question still remains, however, as to whether there are no effects in this first year following diagnosis or instead whether processes are occurring, for example, disruptions to developmental tasks, that are later manifest as psychological problems.

Similarly to the current study, Grey and colleagues (1995) had found no deterioration in adjustment of children (8-14 years) with diabetes at 12 months post-diagnosis, but after 24 months levels of depression, dependency and withdrawal had risen significantly. Northam and colleagues (1999) had found deterioration in cognitive functioning of children and adolescents (3-14 years) with diabetes at two years post-diagnosis. The current findings of relatively stable psychological functioning could mean that possible secondary effects of diabetes are not yet apparent in the first year post-diagnosis. An alternative explanation is that other situational changes to the everyday life of a young patient after receiving the diagnosis have provided a positive influence, at least in the first year.

Indeed, it appears that most young patients cope well (see Whittemore et al., 2003). Perhaps children that have been at risk for poor adjustment actually benefit by the attention of medical services at the time of treatment and diagnosis. Because of the importance of the medical regimen, schoolteachers and other significant figures outside of the family are usually made aware, which increases awareness of the care of the child. This may have a positive effect on the young patient's adjustment for an initial period after diagnosis. Grey and colleagues (1995) explain the absence of

psychological symptoms in the first year as due to the 'honeymoon' period for children in their adaptation to diabetes.

#### 4.2.2 The honeymoon period

The positive management of diabetes associated with a stage of relative remission following a new diagnosis may have offset the potentially negative aspects of the condition. As mentioned, levels of psychological adjustment in children and adolescents were neither above normal nor changed over the 12-month study period. It also is important to acknowledge the physiological effect of continued insulin secretion on one hand, and the assistance of medication on the other for a young patient that may have been ill for some time prior to diagnosis and treatment. Due to the 'honeymoon' effect, relatively normal levels of psychological functioning were anticipated soon after diagnosis because of the expected balance between initial support and the impact of receiving a diagnosis. This balance was also apparent on all other Time one patient variable results, including the diabetes-specific factors of effect on quality of life (DQOL-Y), self-efficacy (SE) and metabolic control (HbA1c). As hypothesised (H6) there was a decline in adolescent's self-efficacy (12-18 years) and metabolic control from Time one to Time two but there was no significant change in quality of life over time. It could be argued that the honeymoon period continued in psychological terms for most young patients at 12 months post-diagnosis.

Chaney and colleagues (1997) had also found relatively stable levels of adjustment in parents of young patients over the first year after diagnosis. However in the current study, higher than expected levels were shown on all of the maternal factors at Time one, including the mother's general health, parental protectiveness, separation anxiety and psychological adjustment. The reported levels of distress may be due at least in part to the difficulties that arise with a new diagnosis, and the demands of the new medical regimen. Maternal general health and psychological adjustment tended to improve slightly at Time two. Other research (Dolgin, Phipps, Fairclough, Sahler, Askins, Noll, Butler, Varni & Katz, 2007) on mothers of young cancer patients, found that maternal adjustment was slightly poorer than the normal population

following their child's diagnosis, but then showed steady improvement at three and six-month follow-up. These researchers concluded that in spite of the distress experienced by mothers, they showed resilience over time (Dolgin et al., 2007). Similarly, it appears that adjustment in mothers in the current sample was slightly lower than the normal adult population soon after diagnosis, although maternal adjustment did not quite return to normal levels at 12 months post-diagnosis.

These results might suggest that there is a greater impact on mothers when their child receives a diagnosis of diabetes than on the young patients themselves. Hence, it could be argued that the parents of these young people experienced an earlier ending to the so-called honeymoon period, or that for mothers in particular, there was no honeymoon period.

#### 4.2.3 Multiple informants

Mothers inevitably play an important role in the daily life of their child or adolescent. The hypothesised associations between child/adolescent adjustment and maternal adjustment at Time 1 (H1) and maternal adjustment at Time 1 with child/adolescent adjustment at Time 2 (H3) were confirmed. While this study demonstrated that mothers had an influence on patient psychological adjustment they were also used as a source of information about adjustment. It is possible that the finding of an association between parental ratings of patient adjustment and maternal psychological adjustment occurred because of their close involvement with their own child, which had allowed them to have a good understanding of how their child was functioning. Alternatively, the closeness of the relationship may have meant that mothers' opinions about their children were more a reflection of their own functioning.

Authors such as Reynolds & Kamphaus (1998) have recommended the use of multiple informants to allow for issues of bias. However, differences between informants are not necessarily due to bias, but instead may reflect accurate perspectives of the young patient in different settings. Except for slightly raised parental ratings in the current analyses, consistency and

temporal stability of the adjustment variables showed similarities as well as differences between informants.

An important contribution of this study was the collection of information from teachers. While parent and teacher reports are commonly accessed in studies of children without chronic medical conditions, this has not occurred in studies of childhood diabetes. Teachers completed the BASC at both time points of this study. The hypothesised decrease in teacher-ratings of adjustment from Time 1 to Time 2 (H2) was not confirmed. Although consistency of teacher ratings has been previously reported (Merydith, 2000; Verhulst & Akkerhuis, 1989), it was interesting that in the current study teachers provided surprisingly stable reports even though pupils usually changed teachers by graduating to the next grade level over the 12-month study period.

It is possible that the behaviour of children and adolescents remains more consistent, or less erratic, over time in the context of larger group settings and public places than it does in the privacy of home. Compared to a home environment in which all family members may be struggling to come to terms with a diagnosis of a serious condition, the more structured setting of schools may serve to increase stable behaviour.

Consistent with findings from previous studies (Verhulst & Akkerhuis, 1989), teachers' ratings of psychological symptoms in children and adolescents were lower than parents' ratings of the same children. While parents may be exaggerating the profile of their child or adolescent's adjustment for various reasons such as projections of their own adjustment, it is also possible that teachers under-rate psychological symptoms in their pupils, particularly if they are ambivalent about completing a questionnaire for a third party other than the pupil's parent. An alternative explanation is that the discrepancy between parent and teacher ratings reflects a true difference in children's behaviour in different settings. As suggested above, school may provide a less emotionally charged environment and greater consistency that lead to better adjustment in the child.

A third source of information for adolescent patients between 12-18 years of age was self-report ratings. From these three informants (parents, teachers, adolescents) of adolescent psychological adjustment, it was notable that only adolescents' self-reports contributed to the effect of diabetes on quality of life (i.e., an association of adolescent self-reports of adjustment with DQOL-Y at Time 2; H5 was confirmed). As a time for focussing on personal identity and peer relations, adolescence emphasises developmental separation from the family. This is represented appropriately in the content of the DQOL-Y measure (See Appendix D12), which is largely school and peer-related. It is therefore not surprising that an adolescent patient's perspective of their own adjustment predicted the effect diabetes has had on their quality of life. Perhaps understandably, a parent's perspective of adjustment in their adolescent child would differ relatively from their adolescent child's own perspective, and this was evident in the descriptive analyses.

On the other hand, a comparison between group means of adolescent self-reports and teacher adjustment ratings showed almost no difference, yet both were lower than parental adjustment ratings (see section 3.1.2, Table 3). Such agreement between teachers and adolescents regarding psychological adjustment suggests that the discrepancy between mothers and their adolescent child cannot be attributed to generational differences. Due to their affiliation with peers and models outside the family, adolescents are likely to identify themselves more with their experience of school than of home, and this could be why their self-reports and their teachers' reports of adjustment were similar.

### **4.3 The importance of mothers**

#### **4.3.1 Maternal psychological functioning**

Previous findings of increased psychological symptoms in mothers (Berg et al., 2007; Schmidt, 2007) having an effect on child patients' adjustment were confirmed in the current study. It is understandable that signs of distress may result from a parent's heightened awareness and perception of their child's vulnerability due to their diagnosis. Managing a chronic medical condition is potentially difficult and stressful for families (Whittemore et al., 2003). If psychological symptoms persist in the mother as primary carer of the patient, then there may be an increase of risk for poor adjustment in the patient in the long term.

There are three principal reasons why the psychological functioning of mothers of children with diabetes is so important. The first is that their level of adjustment is likely to affect their child's adjustment (Crawford & Henry, 2003). A mother's adjustment also influences the effect of diabetes on quality of life for her adolescent child (12-18 years), as confirmed here and in a previous study (Whittemore et al., 2003). It could be argued that even children and adolescents, who may not have been at risk of poor adjustment predating the condition, might become more vulnerable in the care of a mother suffering from psychological problems who is confronted by a stressor which is potentially traumatic in nature (Landolt, Vollrath, Laimbacher, Gnehm, & Sennhauser, 2005).

Second is the effect psychological functioning may have on parenting characteristics and the subsequent parent-child relationship. These aspects were considered in the mothers of the very young patients of the current study with results showing slightly higher levels of parental protectiveness (0-8 years) and maternal separation anxiety (0-6 years). Given the correspondence between current results of the relatively poor level of maternal adjustment and poor levels on these two parenting characteristics of patient mothers, the parent-child relationship could be altered after the onset of diabetes. Some

support for this idea has been provided by previous studies of mothers of children with chronic conditions (e.g., Mullins et al., 2004; Berg et al., 2007).

A further related reason is that parenting needs to change in order to facilitate the child's growth across developmental stages. For example, the normal expected struggles of adolescence (Ingersoll, 1989; Lewandowski & Drotar, 2007) may be expressed in conflict between mothers and their adolescents around diabetes management. Current results of both the somewhat poor adjustment of mothers and the influence of this variable on patient adjustment may be indicative of maternal stress in relation to a difficulty coping (Kelley et al., 1994) with the situational changes involved in managing diabetes. Psychological distress in mothers is likely to lead to some vulnerability in the adolescent's normal psychological development due to the difficulty the parent may have in adapting to the changes expected to occur as the child matures.

#### 4.3.2 Possible effects on parenting

Previous studies have demonstrated a link between maternal psychological adjustment and collaborative involvement between mothers and young adolescents (Berg et al., 2007) and greater autonomy and reduced conflict in the mother/adolescent (13-18 years) relationship (Lewandowski & Drotar, 2007). Mothers may have more difficulty in adjusting to normal developmental changes, leading to an exacerbation of the normal conflict that can be typical of this stage. The prediction of an effect of diabetes quality of life by adolescents' and mothers' adjustment at 12 months post-diagnosis indicates a link between mother/adolescent functioning and the impact of diabetes, which could be reflecting a maladaptive coping style in the relationship.

For younger children mothers may inadvertently prolong the child's dependence on the parent. The hypothesised increase in PPS and MSAS scores from Time 1 to Time 2 (H7) was not confirmed. The mother's difficulty in being separated from her child with diabetes and the need to protect this child did not increase over the study period. However the levels of parental

characteristics soon after diagnosis were already higher than normal and stayed above normal 12 months later. It seems reasonable to suggest that the onset of the child's condition may have resulted in a change to the mother's parenting with implications for the continuing development of the child in terms of delaying autonomy and individuation (Thomasgard & Metz, 1999).

The parenting characteristics of overprotective behaviour and maternal separation anxiety share similar qualities in that highly anxious mothers are reported to be enmeshed with or 'overprotective' of their own children, limiting their child's growth toward independence (Hock & Schirtzinger, 1992). The stability of the current results on levels of parental protectiveness and maternal separation anxiety over time raises a question about enduring styles of parenting. Thomasgard and Metz (1999) described the construct of parental protectiveness as a stable pattern of specific parenting behaviours variously associated with factors in the history of the parent.

Hock and colleagues (1989) explain that maternal separation anxiety is neither a trait nor a state, but a parenting disposition affecting the parent-child relationship. It could be that some parents are predisposed to separation anxiety or overprotective behaviours without them becoming problematic, until there is a precipitating circumstance such as coping with the onset of their very young child's diabetes.

Mothers of children with diabetes must undertake medical tasks for their child frequently throughout each day, often requiring the assistance of others, including kindergarten and schoolteachers. Some mothers may have more difficulty in negotiating the daily management of their child's diabetes in the context of their child's activities away from home, leading to parenting issues of overprotection and separation anxiety. The mother's worry about her child and the subsequent separation anxiety they may experience could impact upon their child's experience of dealing with normal events in the absence of their mother.

It is reasonable to assume that mothers may be more protective of their child when they perceive them to be more vulnerable than a child without the same condition, however the effect of the mother's 'extra' concern on the parenting of her child may lead to long-term patterns of separation anxiety that impairs the normal development of the young patient. While these issues have been examined in very young children (Thomasgard & Metz, 1999; Mullins et al., 2004) it might be expected that parenting by an overprotective and anxious mother will affect older children in the long-term.

## **4.4 Age and development**

### **4.4.1 Self-care and diabetes responsibility**

As the young person with diabetes develops from dependence on parents toward maturity and independence, the transfer of responsibility for diabetes management means less parental involvement over time, yet the adjustment of both parent and young person are likely to shape this process. The struggle between parents and children around the transfer of treatment tasks is a well-known issue that can negatively affect the management of diabetes (Ingersoll, 1989). For this reason, the sharing of responsibility for the management of diabetes between parents and their adolescent child has been given increased attention in recent research (Palmer et al., 2004; Lewandowski & Drotar, 2007).

Conflict arising from the transfer of responsibility is known to be expressed in poor treatment adherence and poor metabolic control (Lewandowski & Drotar, 2007). Results from the current study show that the mother's level of adjustment has an effect on the quality of life and metabolic control of her adolescent child (aged 12-18 years). The hypothesised associations between maternal adjustment at Time 1 and DQOL-Y at Time 2 (H5) and maternal adjustment at Time 1 and HbA1c at Time 2 (H4) were confirmed for adolescents aged 12-18 years. There is previous evidence (Palmer et al., 2004) that too much or too little maternal involvement in diabetes responsibility can result in poorer metabolic control and issues of non-compliance. Normal issues of self-care, self-worth, independence and identity for adolescents with diabetes may be amplified by mother's own psychological distress and developmental expectations.

In the current study, the associations between adjustment in mothers, their adolescent children, adolescent self-efficacy and adolescent quality of life might suggest a pattern of factors affecting diabetes management. Similar findings were reported by Skinner and Hampson (1998) from their research on family predictors of adolescent adjustment, where the efficacy in diabetes

management and perceived impact of diabetes were associated with poor adjustment in young patients.

Developmental struggles in adolescence can become conflictual if anxiety around managing diabetes is heightened, particularly in the adolescent's mother. It could be argued that the current associations between maternal adjustment, adolescent adjustment, self-efficacy and quality of life for adolescents are an expression of increased levels of mother-adolescent conflict, as reported elsewhere (Lewandowski & Drotar, 2007). If a mother and an adolescent with diabetes are both experiencing psychological distress, they may act out their difficulties in the negotiation and transfer of treatment tasks. This in turn may lead to poorer health in the adolescent with diabetes, consistent with the increase in HbA1c levels at 12 months post-diagnosis in this age group and the association with the mother's adjustment soon after diagnosis.

#### 4.4.2 Younger and older adolescents

In the broad age range of the current sample (1-18 years) factors specific to young adolescents coping with diabetes have been identified. Following diagnosis mothers rated poorer psychological adjustment in younger adolescents than those in their later teens. It would appear that for older adolescents, parents perceived either better psychological adjustment or fewer symptoms. Alternatively, parents may be less aware of problems in older children or assume a greater coping capacity for managing diabetes in their adolescent child, as found by Schmidt (2007). Skinner and Hampson (1998) found that older adolescents reported less diabetes-specific family support, which could mean their strategies for coping are more removed from the home.

As hypothesised an association between adolescent self-reports of adjustment and DQOL-Y at Time 2 (H5) was confirmed. However while adolescent psychological adjustment and quality of life were associated at both time points in the first year after diagnosis, age was inversely associated with adolescent quality of life following diagnosis, so that the younger

participants in the adolescent subgroup (12-18 years) reported a greater effect of diabetes on their quality of life. As found in a recent study (Schmidt, 2007), this result may be further evidence of an increased capacity to cope with diabetes in the older patient participants of the current study with the younger adolescents most vulnerable. It is understandable that a child in the early stages of puberty may have particular difficulties because of the normal physical and psychological changes that accompany this developmental period, which can affect Glycosylated haemoglobin levels.

The developmental aspect of diabetes management is further indicated by the current results in terms of an adolescent's growing sense of confidence in managing their medical tasks. This study found that self-efficacy played a role in adolescent adjustment and quality of life, which can be considered with the above-mentioned effect of age on parental ratings of adjustment and quality of life. Perhaps poor adjustment and quality of life leads to reduced confidence in adherence for the young adolescent. The lower level of self-efficacy of patients (aged 10-18 years) at the second time point compared to norms (Littlefield et al., 1992) could be due to the inclusion of younger adolescents (10-13 years) in the current study. Together these factors resemble Schmidt's profile of a developmental coping capacity (2007) that increased with age in children and adolescents (aged 6-18 years) with diabetes.

Age and development, and related concerns of responsibility and coping with diabetes management appear in the current findings as a pattern in which adolescents' psychological adjustment tended to be influenced by mothers' self-reported adjustment, the effect diabetes has on their quality of life, self-efficacy and metabolic control by 12 months post-diagnosis.

## **4.5 Factors of mental and physical health**

### **4.5.1 Metabolic control**

Glycosylated haemoglobin percentage levels or metabolic control is an important indicator that diabetes is being managed adequately (Stewart et al., 2003). As a measure of diabetes health status, metabolic control has been associated with various factors in previous research from parental reports of diabetes management (Palmer et al., 2004; Lewandowski & Drotar, 2007) to patients' perceptions of support (Pendley et al., 2002). On the other hand, results from other studies (e.g., Ingersoll & Marrero, 1991) that show diabetes-specific factors such as quality of life in adolescents were not associated with metabolic control remind researchers of the intricate relationship between factors of mental and physical health.

Previous research examining HbA1c values over time has shown mixed results (Pendley et al., 2002; Dantzer et al., 2003). For example, two similarly aged samples in one to two year longitudinal studies found no significant change in metabolic control over time (Grey et al., 1995; Northam et al., 1999). The use of self-report measures in conjunction with medical outcomes has been questioned by Blanz and colleagues (1993), who preferred to assess adjustment via clinical interviews. Other researchers (Chaney et al., 1997) combined interviews with self-report measures. Variability in findings between studies has raised questions regarding research methodology (Stewart et al., 2003) including differences in the age of the samples used.

A clear link between maternal psychological functioning and metabolic control has not been established (Rodrigues & Patterson, 2007). The hypothesised association of maternal adjustment at Time 1 with HbA1c at Time 2 (H4) was confirmed. The current finding that maternal psychological adjustment soon after diagnosis was associated with subsequent metabolic control is consistent with results from some previously published studies (e.g., Berg et al., 2007), but other studies have not found such associations (Lavigne et al., 1982). Time one levels of metabolic control in the current study

(7.4%) were similar to those reported by Whittemore and colleagues (2003), who reported psychological adjustment in children with diabetes as within the normal range. These researchers did find that the mothers of these young patients reported a relatively high rate of psychological symptoms, particularly depression (Whittemore et al., 2003), but their cross-sectional study could not assess the influence of maternal adjustment on metabolic control over time.

Davis and colleagues' (2001) study of children with diabetes and their mothers showed that characteristics such as restrictiveness were associated with poor metabolic control. Restrictive parenting may be a defence against the difficulty in coping with diabetes management for the mother, which affects the parent-child relationship and the development of the young person by causing stress (Davis et al., 2001). The circular problem of poor coping and stress is similar to the issue of parental protectiveness. In the effort to cope the patient's mother may be inadvertently producing stress for her child, leading to a deleterious effect on metabolic control.

While the current study did not find a direct association between quality of life and metabolic control for adolescents the hypothesised associations between maternal adjustment at Time 1 and HbA1c at Time 2 (H4) and between maternal adjustment and DQOL-Y at Time 2 (H5) were confirmed. The results suggest that the interactions between diabetes health status, quality of life and the psychological adjustment of adolescent patients are complex, as Dantzer and colleagues (2003) concluded in their review of 20 years of psychological research on young patients with diabetes.

#### 4.5.2 Discrepancy between quality of life and metabolic control

It is noteworthy that the effect on diabetes quality of life for adolescents was significantly predicted by adolescent self-reports of adjustment, but neither predicted metabolic control. This outcome is similar to Schmidt's results (2007); in her sample (patients aged 6-18 years) the older children were found to manage treatment tasks better than the younger children, but expressed negative attitudes about their diabetes. Adolescent patients may have managed their condition well in the current study, thereby achieving

adequate metabolic control, but at the same time experienced dysphoric feelings reported as signs of poor adjustment. Conversely, those adolescents with poorer metabolic control, who reported a minimal effect on their quality of life and adjustment, may have been less concerned by the physiological aspects of their quality of life.

The current findings were consistent with Ingersoll and Marrero's original study (1991), which also did not find a link between the DQOL-Y and HbA1c. These results may suggest that while quality of life and health status are important to adolescents, these factors may vary in the interpretation of their meaning on the DQOL-Y measure. As pointed out by Ingersoll and Marrero (1991), an adolescent's perception of their quality of life may appear to contradict their experience of managing diabetes. Compliance to treatment tasks may be less important than conforming to peer-group expectations and independent or risk-taking behaviours. The discrepancy between physical health and self-reported mental health in the current findings may be interpreted as an effect of the diverse and independent concerns adolescents have as they move into adulthood, and these may be different from medical or societal expectations.

Differences in the meaning of mental and physical health explain to an extent why research on psychological factors in adolescents with diabetes has produced such varied findings (Littlefield et al., 1992; Pendley et al., 2002; Stewart et al., 2003). This may also explain why there was a link between adjustment in mothers and adolescent metabolic control to the exclusion of adolescent adjustment in the current study. That is, a mother's concern or worry about their adolescent's diabetes health status may emanate from the mother's own psychological adjustment in relation to the actual level of metabolic control. Representations of the meaning of emotional distress and health status may be more congruent for the patient mother than her adolescent child.

#### 4.5.3 Directions of influence

Psychological adjustment in children and adolescents was associated with maternal and diabetes-specific factors at two independent time points with stronger associations found at 12 months post-diagnosis. While the hypothesised associations of maternal adjustment at Time 1 with HbA1c at Time 2 (H4) and maternal adjustment at Time 1 with child/adolescent adjustment at Time 2 (H3) were confirmed no conclusions can be drawn about the direction of influence in these associations. The stronger association at 12 months could be due to the close involvement of mothers with their children in managing the diabetes. However, the complex associations between psychological variables and metabolic control in other studies (Pendley et al., 2002) were also apparent in the current study.

For example, the hypothesised associations of maternal adjustment and self-reported adolescent adjustment with DQOL-Y at Time 2 (H5) were confirmed but the hypothesised associations between DQOL-Y, Self Efficacy on adherence and HbA1c at Time 2 (H5) were not supported. On the other hand, the association of maternal adjustment at Time 1 with HbA1c at Time 2 was supported (H4) and this association was moderately substantial. There was also support for the hypothesised poorer diabetes health status (an increased HbA1c) at Time 2 compared to Time 1 (H7). Like other models that have tested psychological factors and metabolic control, a fixed direction of effect of mental health on physical health was expected (Pendley et al., 2002; Stewart et al., 2003). Different expectations of both the adolescent patient and their mother have been discussed as a possible explanation for these mixed findings.

If the effect of diabetes on an adolescent's quality of life increases and self-efficacy on adherence decreases, then this might affect their own adjustment and/or their mother's adjustment. The opposite is also apparent, that adjustment in patient and mother influences quality of life. Perhaps the trend will later influence the patient's metabolic control via a change in their adjustment, or perhaps variable metabolic control can trigger the trend. A period of risk for poor adjustment in the patient is nevertheless evident in the

first year after diagnosis; that is, if the mother is suffering psychological symptoms, there could be an effect on quality of life and/or metabolic control for the adolescent. The direction of influence may be reciprocal or nonlinear with regard to patient adjustment and diabetes-specific factors, and this may explain why research (Littlefield et al., 1992; Ingersoll & Marrero, 1991; Stewart et al., 2003) has shown mixed results regarding the associations between these factors of mental and physical health.

## **4.6 Design and Measurement Issues**

Design issues for the current study that have been previously identified include the absence of a control group and the inclusion of broad age ranges (Grey et al., 1995). While cross-sectional studies have managed these aspects through cohort sample comparisons (Lernmark et al., 1996), longitudinal studies have needed to be limited in their research samples due in part to the long-term involvement of participants. In the current study the measures were suited to a number of different age ranges. The broad age range was managed by conducting some analyses on sub-samples. For example, the examination of the association between adjustment predictors and metabolic control was restricted to the adolescent subgroup (12-18 years).

The rest of this section considers the application and performance of measures such as the DASS and MSAS that have not been used previously in diabetes research on young patients and their families. The other nondiabetes-specific measures in the current study, the BASC, GHQ and PPS have been used in previous studies (Cameron et al., 2003; McDonnell et al., 2007; Mullins et al., 2004; Northam et al., 1996;). The three diabetes-specific measures; DQOL-Y, SE and metabolic control are also examined (Pendley et al., 2002; Stewart et al., 2003; Palmer et al., 2004).

### **4.6.1 Ratings on child/adolescent adjustment**

Child/adolescent adjustment in the current study was found to be similar to U.S. norms (Reynolds & Kamphaus, 1992); however there was broad variation in scores. Only recently has the BASC been tested on patient populations, and recommended as a screening tool for the adjustment of children and adolescents with diabetes (Cameron et al., 2003). This study is the second known (McDonnell et al., 2007) to have applied the BASC to longitudinal diabetes research on child/adolescent psychological adjustment.

As a measure of psychological adjustment in children, the BASC was found to be robust in the analyses, obtaining similar adjustment levels to norms (Reynolds & Kamphaus, 1992), and was significantly correlated with

several other diabetes-specific variables. These findings were consistent with a recent Australian longitudinal study (McDonnell et al., 2007) on pre-pubertal children with diabetes, which found an association between parental ratings on the BASC and diabetes health status.

There are two general issues for consideration. First is the question of consistency between multiple informants of child/adolescent adjustment. Reynolds and Kamphaus (1998) claimed that an advantage of the multimethod system of assessment of the BASC was that it provided different perspectives that could enhance the interpretation of data in individual assessment. However, in the current group analyses, means for teacher ratings of child/adolescent psychological adjustment were similar, although slightly lower than those for parental ratings. The small difference between parents' and teachers' reports reflects some agreement between these informants, as previously found (Verhulst & Akkerhuis, 1989). It would seem that there was general consistency of reporting between informants.

However, teachers rated 16% of cases as in the at-risk to clinical range compared to the 25% of parent-rated cases that were in the at-risk to clinical range. The wider variance of parental adjustment ratings meant that some respondents provided particularly high or low scores. Verhulst and Akkerhuis' study (1989) also demonstrated a tendency for parents to rate more psychological problems in their child than the teacher of the same child.

The second issue for consideration is the cultural difference between Australia and the U.S., where items pertaining to location were found to be irrelevant to the current sample, particularly in the adolescent self-report version. For example, item 137: "I take a plane trip from New York to Chicago at least twice a week" often elicited questions by respondents, as an authentic answer was inevitably "false". Another item was similarly non-discriminating; that is, item 68: "I would rather work for the FBI than be a teacher". Because of the frequent American references, 'false' responses may have been made more often by Australian respondents than by American respondents. False negative responses may have deflated scores on some of the BASC versions,

which otherwise might have shown higher scores on the Behavioural Symptoms Index.

#### 4.6.2 Maternal psychological adjustment

Levels of maternal psychological adjustment and the influence of maternal functioning on child/adolescent functioning were prominent in the current analyses, which used nondiabetes-specific measures of adjustment, including the DASS and BASC. Another instrument that measured mental health was the GHQ, which was not associated with the other variables in the current study. These tools are well-established measures of psychological adjustment (Goldberg, 1978; Reynolds & Kamphaus, 1992; Lovibond & Lovibond, 1995) and, except for the DASS, have been used in previous diabetes research, including recent Australian studies (Cameron et al., 2003; McDonnell et al., 2007; Northam et al., 1996; Lawlor et al., 2005). As tools of measurement in the current study, the DASS and the GHQ were used in different ways.

An issue for concern in the assessment of maternal general health was participant feedback, which included criticisms of the statements in GHQ. Some items were probably outdated as, for example, item A2: “-been feeling in need of a good tonic?” which elicited several comments from respondents regarding the meaning of the old-fashioned term, ‘tonic’. Although the measure is well established in psychological research and has been applied to populations with diabetes (e.g., Northam et al., 1996), it was found to produce negative reactions from some participants.

#### 4.6.3 Parenting characteristics in mothers of very young patients

Due to the low number of participants within the age range for administration of the PPS (2-8 years) and MSAS (0-6 years), subgroup sample sizes were too small to conduct the regression analyses necessary to test the hypotheses. There have been relatively few studies (Thomasgard & Metz, 1999; Blunk & Williams, 1999) on clinical populations that have utilised these measures. As noted, the PPS had very low internal consistency (Cronbach’s  $\alpha = .43$ ,  $n=25$ ), perhaps due to the broad age-range (0-8 years) of

participants in the current subgroup. Conversely, the MSAS showed excellent internal consistency (Cronbach's  $\alpha = .89$ ) given the small number of respondents ( $n=19$ ) in this study.

Neither of the measures correlated significantly with age, although it was apparent in bivariate correlations that higher PPS scores related to younger patient age. The PPS may be sensitive to age, where mothers are more protective in their own parenting style when their children are young. Perhaps the MSAS was more age-appropriate than the PPS, which has been used in other research for parents of children up to ten years of age (Thomasgard & Metz, 1999). Limiting administration of the PPS to a younger age range (e.g., preschool) may increase reliability and construct validity. Also, the maternal separation anxiety scales could be the more useful measure for research on diabetes, as it includes references to the patient mother's fear of their child's hospitalisation (Mullins et al., 2007).

#### 4.6.4 Quality of life and self-efficacy in adolescents

The age range and the study time period in the current study may explain why some of the hypotheses involving measures of adolescent variables were supported and others were not confirmed. Although the age range of this study replicated recent research (Stewart et al., 2003), it may have influenced the overall poorer level of self-efficacy by the inclusion of adolescent patients (10-13 years) younger than those in the original study (Littlefield et al., 1992). It was further noted that the nine-year-old participants at the first time point completed the SE at 12 months post-diagnosis only, and this may have contributed to overall poorer self-efficacy for the same reasons.

The second possible reason for higher mean scores on quality of life compared to normative data (Ingersoll & Marrero, 1991) is in the timing of the DQOL-Y administration following diagnosis. Adolescents may have identified particularly with the diabetes impact subscale, which included questions such as item 13: "How often do you find yourself explaining what it means to have diabetes?" and item 19: "How often do you find that your diabetes prevents you participating in school activities?" (Ingersoll & Marrero, 1991)

Being questioned about diabetes in the context of new compromises to lifestyle and a new understanding of the health risks involved may be more difficult soon after diagnosis than 12 months later. The recency of receiving a diagnosis of Type 1 diabetes is likely to enhance the importance of these questions, and lead to scores on the DQOL-Y being elevated soon after diagnosis rather than normal or minimised during the 'honeymoon period' following diagnosis. The similarity of results at both time points may have appeared as stability of effect on quality of life over time through development of more negative attitudes in adolescents as shown by Schmidt (2007).

## **4.7 Research limitations and implications**

### **4.7.1 Limitations**

There were several methodological limitations of the study. A longitudinal design was used to examine the links between family functioning, and the effect of diabetes on children's and adolescent's health and self-care. Although findings supported several associations between diabetes-specific factors, maternal adjustment and child/adolescent adjustment, this study did not include cohort comparisons. While control groups have been included in cross-sectional studies (e.g., Whittemore et al., 2003), inclusion of control groups of peer-selected children without diabetes in longitudinal studies could assess the influence of factors that have been suggested in the current study.

Age and developmental aspects need to be taken into account in the administration of repeated measures over time. As individual participants graduated to older age categories, their ratings on measures for the first time may have altered results. The SE is a case in point as mentioned; the current study had followed the recommendations of recent research (Stewart et al., 2003) by including adolescents younger than the 13 to 18 year age range of the sample used in the original study (Littlefield et al., 1992). Current results of SE on adherence could have been weakened by the responses from younger adolescents who are likely to be less competent with treatment tasks than older adolescents (Schmidt, 2007). The SE may be an age-sensitive measure.

The size of the current sample ( $N=62$ ) was similar to that used in previously published studies (Grey et al., 1995; Davis et al., 2001; Lewandowski & Drotar, 2007); however the age range of participants in these previously cited studies was narrower. The inclusion of a broad age of children and adolescents, from birth to 18 years, in the current study meant a variety of age-appropriate measures were required, including three age categories of the BASC. Except for this measure of adjustment, tests on other measures had to be performed on specific age subgroups. With a relatively small sample that covered a broad age range, it is not possible to determine whether the effects observed would be less than what may be found in a large sample

using the same quantitative approach. For this reason, the findings on subgroup samples of 30 or less participants are best characterised as exploratory in nature.

Homogeneous characteristics that limit generalisation of the current research findings include the conditions of medical care, diabetes education, regular attendance to and location of services at the clinic from which participants were recruited. The Diabetes Ambulatory Care Service (DACs) model of care for the current sample of young patients is based on an outpatient service approach, which aims to avoid hospital admission as a requirement for a diagnosis of diabetes, but does include an initial inpatient stay if the child is very ill or very young.

This sample may differ from the general population of child and adolescents with diabetes due to the implications of ambulatory care for the adjustment of the young person and their family at the time of diagnosis. An example may be in the level of professional support that allows the young patient to be at home during the initial period of condition at diagnosis, and the difference this may have on levels of emotional distress in the family.

A prospective study in Switzerland which identified high levels of Post Traumatic Stress Disorder (PTSD) symptoms in parents of children newly diagnosed with diabetes reported that the average inpatient admission following diagnosis was two weeks (Landolt et al., 2005). In Landolt and colleagues' study, a moderate but significant association was found between PTSD symptom severity in fathers (but not mothers) and the number of days the child spent in hospital. The results of the current study can therefore only be generalised to a limited population, given the sample was not random but determined by characteristics of patient and family's utilisation of health services at one medical centre.

Using self-report measures to gain information from participants has its own limitations in the form of test bias such as resistance or response anxiety; repeated measures practice effect and social desirability. Because most

participants were responding to more than one measure, reporter bias may have led to some overlapping of results, for example, in the relation of a parent rating of psychological adjustment (BASC-PRS) to the mother's self-reports of psychological adjustment. Similarly adolescents completed multiple measures - BASC-SRP-A, SE and the DQOL-Y so that the question of reporter bias must be considered in interpreting results. Repeated measures practice effect may have slightly altered results on those measures that produced similar results at the two time points. The self-report ratings by parents including parenting characteristics and maternal psychological adjustment were relatively high and they did not change over time. However the time period between administrations of the measures was usually between ten and fourteen months making a practice effect less likely.

There were several limitations to the procedural aspect of the study, particularly recruitment. Issues of social desirability, confidentiality and the extension of time commitments by the patient family are considered next.

Approaching patient participants in the clinic waiting room required negotiation with the reception staff, who on occasion became involved in the introduction between researcher and participants. Confidentiality therefore needed to be carefully managed in the exchange of patient family contact details. This care extended to the wording of letters to teachers (See Appendix C5). Some teachers were aware of the medical condition of their pupil, while those who were not expressed concern as to the purpose of the study in which they were required to answer questions about a child's behaviour to an organisation outside of the school. Although confidentiality of all participants was maintained to research standards, fear of disclosure, social desirability and resistance may have led to under-reporting by school teachers.

Participation in the research required a separate meeting time after the patient families' first clinic consultation. Arranging a suitable meeting for the questionnaire administration was often difficult for families, particularly for mothers who were working part or fulltime in addition to their family care commitments. Most of the potential participants that declined to be involved in

the study stated their reason as lack of time. For those who did participate, the reasons for volunteering included interest in the study, and belief in the long-term benefit of providing information to support future programs. It is important to consider the motive for the family of a patient in accepting or refusing an invitation to participate in research. Participant factors may determine inclusion and exclusion, and the subsequent representativeness of the sample. There may be issues of participant anxiety raising scores or, on the other hand, social desirability lowering scores on parental measures.

#### 4.7.2 Research implications

This section considers further issues on methodology, group analyses, reporting and the implications of the current study for future research.

Further empirical research is needed to clarify some of the associations between the psychological and physiological variables found in the current study. The complexities of diabetes management and responsibility of care (Palmer et al., 2004; Lewandowski & Drotar, 2007) for the developing adolescent have already been noted. Parenting characteristics are also implicated in families of very young patients, and should be investigated in all patient families in relation to adjustment over time.

Because the intricate relationship between psychological problems and diabetes health has been difficult to determine (Stewart et al., 2003), findings that do demonstrate these associations (McDonnell et al., 2007) highlight the need for future research in this area. Mixed findings from other research (Ingersoll & Marrero, 1991; Grey et al., 1995) suggest that linear models have been limited in providing an understanding of the influence of psychological factors on this physiological variable.

In designing future studies other more complex models such as a reversed or circular direction of factors could be considered. For example, poor metabolic control may confer a risk to psychological adjustment, resulting in low self-efficacy, poor adherence and even poorer metabolic control. Nonlinear models of the association between these variables may provide

further understanding of their interaction effects (Stewart et al., 2003). Future studies based on larger samples would allow the use of structural equation modelling in order to further assess the multiple associations indicated in the current study. The specific symptoms of such conditions as anxiety and depression could be included.

Although the strength of quantitative research is in the application of standardised measures to large groups, its weakness lies in the inattention to individual cases. The mild association between maternal and child/adolescent psychological adjustment following diagnosis that strengthened 12 months later to a moderate association implicated the cases in the 'at risk' and clinical categories. Modelling individual trajectories over time may provide further understanding of those families at risk for changes in adjustment. Qualitative and quantitative studies may identify more specific links through retrospective assessment between an individual's premorbid and post-diagnosis psychological functioning.

The current results add to the growing body of research on diabetes and the mental health of this age group (Skinner & Hampson, 1998; Pendley et al., 2002; Whittemore et al., 2003; Stewart et al., 2003; Palmer et al., 2004). The influence of factors of adjustment, self-efficacy and effect on quality of life, particularly on the young adolescent is clearly demonstrated in the this study, but future research should consider closer examination of this particular patient population (10-14 years) because the discrepant findings between quality of life and metabolic control. It is important to note that adolescence is the time in which the onset of diabetes is most likely to occur (Seiffe-Krenke, 2001; Taplin et al., 2005) and will be most challenging to the individuation of the developing person (Ingersoll & Marrero, 1991).

Maternal psychological adjustment was found to be the most important factor influencing the adjustment of young patients in the current study, confirming other recent studies (e.g., Schmidt, 2007). Parental protection and maternal separation anxiety were higher than normal for very young patients, and metabolic control increased for all young patients over the 12-month

period. The implications of these results for future research are in clarifying the associations between parental adjustment and parenting characteristics in larger samples of mothers of very young patients aged from birth to eight years.

Questions for future research may include the following:

- Is there an association between adjustment and parenting in parents of young patients?
- What is the relationship between diabetes-specific factors and metabolic control for young adolescents in particular (10-14 years)?
- How does psychological functioning at 12 months post-diagnosis compare with psychological functioning at two-five years post-diagnosis?
- Are specific psychological problems such as anxiety associated in young patients and their mothers?
- Which specific psychological symptoms of poor adjustment are associated with metabolic control?
- Do parental characteristics such as parental protectiveness and maternal separation anxiety predict the adjustment of children with diabetes?
- Does the adjustment of fathers predict the adjustment of children with diabetes in the first year after diagnosis?

#### 4.7.3 Theoretical and clinical implications

This section considers screening assessment tools and support services for families and young patients with Type 1 diabetes in the light of the findings from the current study.

Theoretical understanding has been gained from current and past research (Palmer et al., 2004; McDonnell et al., 2007; Schmidt, 2007) by examination of psychological functioning in relation to parents, and mothers in

particular, and their role in the adjustment of young patients with diabetes. Although research has considered the mother-child relationship important in the early development of the individual (Lavigne et al., 1982; Whittemore et al., 2003), it is now apparent that the interaction between young adolescents and their mothers is also crucial to the overall health of the young person with diabetes.

Awareness of the influence of parental adjustment and characteristics on newly diagnosed children will be crucial to their adjustment in the long term. Negotiation of daily treatment tasks between parents and children is important to the child's development toward self-care. In the gradual transfer of responsibility, the parent-child relationship is central to this process (Palmer et al., 2004). The application of the DASS, PPS and MSAS to the screening of mothers of young patients with diabetes would appear to be an appropriate step toward understanding the experience of receiving their child's diagnosis, and coping with the ongoing management of diabetes.

As shown recently in Australia (McDonnell et al., 2007), the BASC is a useful screening tool for assessing behavioural symptoms in children with diabetes. The screening of psychological adjustment through the use of the BASC could be undertaken in the diabetes outpatient clinic alongside other consultations. Children or adolescents identified as having 'at-risk' or 'clinically significant' levels on the symptom indices may require further psychological assessment. Early identification of psychological problems in children with diabetes and their parents is therefore essential, as failure to do so may result in 'double jeopardy' for adverse physical and mental health outcomes (NHMRC, 2005).

Raised scores on some of the other measures, including the PPS, MSAS, DASS and DQOL-Y following diagnosis was an important finding in the current study. A multifarious assessment of the current psychological status of the patient family that includes psychological and diabetes-specific tools could assist the clinician in the planning of preventative measures where there is risk to adjustment, or where interventions are required immediately.

The current study highlights the importance of psychological work in paediatric health settings. The implementation of psychological screening procedures, assessment and interventions can contribute to the multidisciplinary approach to diabetes outpatient care. Psychologists could consult with medical specialists and school teachers on the adjustment of children and adolescents with diabetes and their families through education and group programs. Families may be more amenable to psychological services in a health setting compared to a separate mental health service.

Results from the current study provide support for the routine screening and treatment of psychological symptoms among children and adolescents with diabetes. Factors including the diabetes health, quality of life and parental psychological adjustment were influential to the child and adolescent adjustment of young patients, which means that early intervention is feasible. Improving family adjustment through the provision of supportive services could reduce the secondary psychological effects of diabetes for young patients in general and adolescents in particular.

#### **4.8 Concluding statement**

This thesis investigated psychological adjustment in children and adolescents with Type 1 diabetes. Adjustment in young patients involves a complex relationship between physical and mental health. Metabolic control over the first year after diagnosis was influenced by the adjustment of young patients and their mothers. In particular, maternal adjustment, adolescent adjustment and metabolic control need to be explored further.

A significant minority of children and adolescents with diabetes are likely to have psychological symptoms, which may lead to long-term clinical disorders. For parents of young patients, caring for their developing child and negotiating diabetes management involves a potentially challenging task. The transfer of responsibility for treatment with increasing age of the child may lead to conflict as the young patient enters adolescence and consequently poorer diabetes management.

Research needs to take a developmental perspective, focusing on the mutual associations and influences of psychological factors in relation to age-appropriate expectations. Maternal psychological adjustment and diabetes-specific factors influenced adolescent adjustment in the current study. Parental protectiveness and maternal separation anxiety may also be influential factors in children's psychological adjustment.

Greater awareness of psychological factors in children and adolescents with diabetes may lead to the provision of professional services with appropriate care for the family and facilitation of the healthy development of the young patient.

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## APPENDICES