

UNIVERSITY OF SOUTHERN QUEENSLAND

What are the experiences of children aged 2–12 years with type 1 diabetes, adolescents aged 13–17 years with type 1 diabetes, and that of their parents when making the transition to insulin pump therapy?

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ABSTRACT

Whilst researchers have identified an improvement in quality of life for families using insulin pump therapy there is little information about the experiences of children and/or adolescents and their parents when making the transition to insulin pump therapy. To gain an understanding of children and adolescents with type 1 diabetes and their parents' experiences making the transition to insulin pump therapy data were collected from families (n = 11 parents and n = 12 children/adolescents) making the transition to insulin pump therapy from the Mater Children's Hospital diabetes clinics (n = 50 starting insulin pump therapy) in 2008. Parents and their child/adolescent were interviewed and completed questionnaires before and approximately three months after starting insulin pump therapy. Families also recorded their thoughts and feelings about insulin pump therapy in diaries during the three months. The data were analysed using NVivo software Version 8. Three categories were identified with eleven themes emerging: 'The meaning of diabetes,' encompassed planning and constancy of diabetes care; worries and concerns which included hypoglycaemia, and long term health. 'Transition to insulin pump therapy,' related to 'starting over,' and effort required to manage insulin pump therapy. 'The meaning of insulin pump therapy,' included fewer needles, freedom, better control of blood glucose levels and being attached, which was related to feeling 'normal'. The findings suggest continuing insulin pump therapy depends on whether the child/ adolescent feels more or less normal being attached to a machine. The data suggest children/adolescents using the pump find they have more freedom and the pump is easier than using injections to manage their diabetes and they were happier. The findings can be used to make recommendations to improve the education process.

CERTIFICATION OF DISSERTATION

I certify that the ideas, experimental work, results, analyses, software and conclusions reported in this dissertation are entirely my own effort, except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.

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## DEFINITION OF TERMS

Basal – Small amount of insulin which is infused continuously

Bolus – Insulin, which is given immediately

Correction bolus – Insulin given when the blood glucose level is high

Meal bolus – Insulin, which is given to cover carbohydrate food

Hyperglycaemia – High blood glucose levels

Hypoglycaemia – Low blood glucose levels

Infusion cannula – Small plastic cannula inserted into subcutaneous fat

Ketones – Develop when insufficient insulin is available to move glucose into the cells to be used for energy. Fat is broken down to be used for energy and the by product of fat breakdown is ketones

## CHAPTER 1: INTRODUCTION

Type 1 diabetes is a chronic illness requiring insulin injections, blood glucose monitoring, meal planning and exercise. Insulin pump therapy offers an alternative to insulin injections when managing type 1 diabetes and has many benefits including fewer needles, freedom with timing of meals, choice of food and better control of blood glucose levels.

Being diagnosed with type 1 diabetes for a child/adolescent leads to many changes in the daily routine as diabetes is integrated into their lives. Diabetes can be disruptive for the child/adolescent as they often have to stop what they are doing to attend to diabetes management (Wennick & Hallstram, 2007). Insulin pump therapy offers another option which children/adolescents see as an easier alternative than having needles.

Families must be prepared to make the transition to insulin pump therapy as parents have compared it to the time when their child/adolescent was diagnosed with diabetes. Extra work, night time monitoring of blood glucose levels and trying to work out insulin doses for the pump can cause extra stress.

### Background

Past research indicates that insulin pump therapy, also called continuous subcutaneous insulin infusion, improves quality of life (Fox, Buckloh, Smith, Wysocki, & Mauras, 2005; Sullivan-Bolyai, Knafl, Tamborlane, & Grey, 2004). There are both benefits and disadvantages to insulin pump therapy (Rodgers, 2008). Some families have less trouble making the transition to insulin pump therapy and do not take long to feel comfortable using an insulin pump. Other families take longer to get used to it and find the transition more difficult.

### Aims of the Study

The aims of the study were to:

1. Describe the experiences of children and adolescents with type 1 diabetes and their parents when making the transition to insulin pump therapy.
2. Identify the significant issues that children with type 1 diabetes, adolescents with type 1 diabetes and their parents face when making the transition to insulin pump therapy.
3. Use the findings to make recommendations to improve the education program for children with type 1 diabetes, adolescents with type 1 diabetes and their parents.
4. Psychological interventions may also be developed to improve the transition to insulin pump therapy.

### Research Question

The research question was: To describe the experiences of children with type 1 diabetes, adolescents with type 1 diabetes, and their parents when making the transition to insulin pump therapy. Families who find the transition easier can be identified and that information can be used to help those families finding the transition more difficult.

### Study Parameters

This study involved children, adolescents and their parents from the diabetes clinics at the Mater Children's Hospital in Brisbane who made the decision to manage type 1 diabetes with insulin pump therapy. Describing the experiences of children, adolescents and their parents making the transition to insulin pump therapy was the focus of the study. Children and adolescents were included in the study as focusing on either group would have made it difficult to recruit enough participants for the research study in a timely manner.

### Significance of the Research

Some families find the transition to insulin pump therapy overwhelming, taking approximately two to three months to adjust to this form of treatment.

- It is anticipated that any information collected during the course of this research study will be used to improve education for families transitioning to insulin pump therapy.
- Children and adolescents with type 1 diabetes and their families may therefore have a more positive experience.
- Concerns and aspects of insulin pump therapy that families find difficult may be identified.
- Education and interventions can be developed to target those aspects that families find difficult.
- A smoother transition to insulin pump therapy for families may take place in the first three months, while they are becoming accustomed to insulin pump therapy so that families are less stressed.
- Families who are going to find the transition more difficult may be identified.

## CHAPTER 2: LITERATURE REVIEW

Type 1 diabetes is a chronic illness, which has become increasingly more complex to manage and requires initial and ongoing diabetes self-management education for the necessary behavioural changes to occur (Funnell, Brown, Childs, Haas, Hosey, & Jensen, 2008). Diabetes management includes a complicated treatment regimen including insulin injections, blood glucose monitoring, nutritional management, and physical activity (Funnell et al., 2008). It is therefore imperative that patients receive education on self management to enable them to maintain blood glucose levels close to the normal range. Achieving blood glucose levels close to the normal range is believed to prevent or delay the development of long-term complications including neuropathy, retinopathy and nephropathy (The Diabetes Control and Complications Trial Research Group, 1993).

The Diabetes Control and Complications Trial was a multicentre, randomized clinical trial which compared intensive therapy with conventional therapy to examine the development and progression of the effects of early vascular and neurologic complications. The primary goal was to determine whether intensive therapy including insulin pump therapy and multiple daily injections, with the aim of achieving glucose levels as close to the normal range as possible, would either prevent or delay the development or slow the progression of the long-term complications of type 1 diabetes (The Diabetes Control and Complications Trial Research Group, 1993). The results of the Diabetes Control and Complications Trial demonstrated that normoglycaemia would prevent or delay the long-term complications of diabetes mellitus. Intensive therapy in the form of multiple daily insulin injections improves glycaemic control, however the risk of hypoglycaemia occurring is increased. In contrast, insulin pump therapy

improves glycaemic control by mimicking more closely the action of the pancreas with minimal risk of increasing hypoglycaemia (Boland, 1999).

An insulin pump is a small device (see figure 1) programmed to deliver rapid acting insulin (<http://www.medtronic.com>; <http://www.diabetesnet.com>). A small amount of insulin is infused continuously (basal rate) via a small plastic cannula inserted into the subcutaneous fat, usually in the abdomen or buttock. The pump is programmed to deliver a bolus dose of insulin when the person eats any carbohydrate food or has a blood glucose level above the target range.



*Figure 1.* Paradigm insulin pump, Deltec Cozmo insulin pump and Animas insulin pump

Insulin pump therapy is not suitable for all families and not all families are able to afford an insulin pump because the initial outlay is high and the cost of consumables (infusion sets and syringes) is ongoing. However, insulin pump consumables have been available on the National Diabetes Services Scheme (NDSS) since September 2004 making them more affordable for families. Health funds cover the cost of the pump if the family has private hospital health insurance. Alternatively the family can buy the pump, which is approximately \$8000.00. Now families can also apply for the government subsidy. The subsidy is means tested and the amount of the subsidy is based

on family income. A minimum subsidy of \$500 is available to approved applicants and an additional means-tested component brings the maximum subsidy to \$2,500.

The most common reasons for initiating insulin pump therapy are to achieve:

- Better glycaemic control.
- Fewer fluctuations in blood glucose levels
- An alternative to insulin injections, which many children and their parents find to be a burden
- Increased flexibility in daily living

There are both benefits and disadvantages (see Table 1) of insulin pump therapy which families need to be aware of (Rodgers, 2008).

Table 1

*Benefits and Disadvantages of Insulin Pump Therapy*

Benefits	Disadvantages
Better glycaemic control	Increased risk of ketoacidosis
Fewer episodes of hypoglycaemia	More frequent blood glucose monitoring
Flexible eating and sleeping patterns resulting in increased freedom of lifestyle	Psychological lifestyle issues related to being attached to an external device
Fewer injections	Risk of infection

*Patient selection criteria for insulin pump therapy*

There are not any criteria that will predict which families will do well with insulin pump therapy. Few data are available concerning the factors that predict which children will benefit from insulin pump therapy (Maniatis, Toig, Klingensmith, Fay-Itzkowitz, &

Chase, 2001). Maniatis et al. (2001) suggested that the determinants of successful paediatric insulin pump therapy are considered to be commitment to insulin pump therapy and commitment to improving diabetes control.

The study by Maniatis et al. (2001) was initiated to examine whether these factors would predict metabolic control with insulin pump therapy. The study included 52 participants, aged 7.6 years to 23.6 years who were followed for six months. Thirty-seven participants reported initiating insulin pump therapy for a combination of reasons including wanting to achieve better metabolic control, dislike of injections and/or increased flexibility. All other participants wanted the pump for a single reason including six participants who wanted the pump to improve metabolic control. There was no difference in HbA<sub>1c</sub> for those wanting to improve metabolic control compared to those wanting increased flexibility.

One of the main criteria for determining whether the pump is an appropriate choice is whether both the family and the child or adolescent are interested (Owen, 2006). Insulin pump therapy is not recommended if the child or adolescent does not want to use a pump. Bode, Tamborlane, and Davidson (2002) suggested that the best candidates for insulin pump therapy are those who are already monitoring their blood glucose levels frequently and recording the results and insulin doses in a diary, attending a diabetes clinic on a regular basis, and counting carbohydrates. They are more likely to continue these behaviours when starting insulin pump therapy.

Cogen, Streisand, and Sarin (2002) suggested that it is imperative that children and adolescents are already undertaking most of the necessary diabetes tasks and making relevant self-care decisions before starting insulin pump therapy. The family must remain involved in the child's care when starting insulin pump therapy. Giving children

and adolescents full responsibility too soon often leads to reduced adherence to the diabetes management regimen. Rather than encouraging full independence, a continued child/parent relationship should be maintained while insulin pump therapy is initiated. Williams, Storch, Lewin, Geffken and Silverstein (2004) suggested that diabetes-specific family factors as well as past adherence to behaviours are important predictors of success when using an insulin pump. Optimal characteristics for insulin pump candidates (see table 2) include both motivational and treatment factors (Fisher, 2006).

Table 2

*Optimal Characteristics for Insulin Pump Candidates*

Motivational factors	Treatment factors
Wanting to lower BGLs and HbA1c levels	Good management skills and follow up
Wanting to reduce the risk of hypoglycaemia	Able to count carbohydrates
Wanting improved lifestyle	Checking BGLs four or more times per day
Interested in trying insulin pump therapy	Adequate control using insulin injections
Realistic expectations	Reliable adult supervision
	Able to master technical aspects of a pump
	Communication with the diabetes team

*Further education*

There is a need to prepare the parents of children and adolescents with diabetes for the transition to insulin pump therapy and give them enough time to adjust to the different diabetes management process. The family must adjust to a variety of new tasks

including more frequent blood glucose monitoring, adjusting the basal and bolus insulin doses, counting carbohydrates, and managing exercise, which can have a psychosocial impact (Fox et al., 2005). Families must therefore be motivated to learn these new tasks when insulin pump therapy is initiated.

Adults who could recall the time their diabetes was diagnosed achieved better glycaemic control when they started insulin pump therapy (Ritholz, Smaldone, Lee, Castillo, Wolpert, & Weinger, 2007). Some parents also described their child starting insulin pump therapy was like being diagnosed all over again. Cogan et al. (2002) and Sullivan-Bolyai et al. (2004) also found similarities between starting on an insulin pump and initial diagnosis of diabetes. However, starting insulin pump therapy is accompanied by a sense of excitement, which is associated with the possibility of greater control over their lives and anticipating improved quality of life (Cogan et al., 2002).

People using insulin pump therapy need to be active participants in their diabetes management (Klingensmith, Temple-Trujillo, & Johnson, 2001). Young children are not able to program the pump and rely on parents and other caregivers to manage it. A parent or adult must be willing and able to learn to manage the pump and all the associated tasks. Unlike young children, adults transitioning to insulin pump therapy are able to actively participate in their diabetes self-care. Table 3 illustrates the education program required when making the transition to insulin pump therapy (Fisher, 2006).

Table 3

*Education Program for Initiation to Insulin Pump Therapy*

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Education required when children initiate insulin pump therapy

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Programming the insulin pump

Drawing up insulin into the syringe and loading it into the pump

Insertion of the infusion cannula

Principles of basal and bolus insulin therapy

Management of insulin dosage

Counting carbohydrates

Preventing, treating and detecting hyperglycaemia

Preventing, treating and detecting hypoglycaemia

Adjustment of insulin in relation to physical activity and exercise

Managing sick days

Integrating insulin pump therapy into everyday life including school

---

*Parent's expectations of insulin pump therapy*

Parents are not always adequately prepared for the challenges of using an insulin pump (Low, Massa, Lehman, and Olsham, 2005). Adolescents and families who anticipated that insulin pump therapy would improve glycaemic control and increase flexibility did better than those with unrealistic expectations (Low et al., 2005). Parents who have unrealistic expectations regard the pump as a 'cure' rather than a tool to achieve better glycaemic control and flexibility.

Parents had more difficulties adjusting to the insulin pump if they were not prepared for the demands of checking blood glucose levels frequently including overnight, site changes, programming and pump problem solving (Low et al., 2005). Parents experienced nervousness, stress, and fatigue while they were getting used to the insulin pump (Low et al., 2005). Parents had more difficulty learning pump technology than adolescents. Adolescents had little difficulty with the transition to pump therapy and took more responsibility for their diabetes management.

### *Transition to insulin pump therapy*

Most parents reported feeling comfortable with the pump two to three months after using it (Sullivan-Bolyai et al., 2004). Parents and children were equally well prepared for the transition to insulin pump therapy and using the pump was rated from easy to very easy by parents and children (Mednick, Cogan & Streisand, 2004). Parents and children responded that there was more flexibility and they had fewer worries about caring for their diabetes. Nearly half the children in the study by Mednick et al. (2004) had improved glycaemic control and one third of the parents said their child was better able to manage their diabetes.

Low et al. (2005) found that parental involvement in their child's diabetes management and anxiety about their child having diabetes stayed the same or decreased following transition to insulin pump therapy. Parents were less anxious about their child's diabetes once they commenced on the insulin pump because they were less concerned about hypoglycaemia if meals or snacks were delayed, high blood glucose levels could be corrected easily, and there was more choice and flexibility with food (Klingensmith et al., 2001).

*Insertion of the infusion cannula*

Parents need to learn how to draw up the insulin into the syringe, load it into the pump and insert the infusion cannula, which is usually changed every three days.

Mednick et al. (2004) found that inserting the infusion cannula was a challenge for most children. Likewise, Hanas (2002) found slightly more than half of the children and one-third of parents found the most challenging aspect was inserting the infusion set.

Insertion sites and mechanics of pumping can present challenges for families (Low et al., 2005). Adolescents are often more comfortable with pump technology than their parents but they rely on parents for assistance with set changes and programming (Low et al., 2005).

*Needle phobia*

Children often do not like having injections. Maniatis et al. (2001) conducted a study involving 52 participants, 25% of the participants reported being afraid of needles. Of the 52 participants four were children, 25 adolescents and 23 young adults. Being needle fearful predicted less satisfactory glycaemic control (Klingensmith et al., 2001; Maniatis et al., 2001). In a previous study involving adults with type 1 diabetes, participants who were afraid of injections had a higher HbA<sub>1c</sub> (>8%) compared with adults who did not fear injections (HbA<sub>1c</sub> <8%).

Children often want to use an insulin pump to avoid injections. Maniatis et al. (2001) hypothesised that with one insertion of the infusion cannula every three days, using an anaesthetic cream would be particularly helpful for children. This was not the case. Evaluation of needle fearfulness was indicated prior to initiating insulin pump therapy. Behavioural techniques could then be taught prior to initiating insulin pump therapy.

*Preventing, treating and detecting hypoglycaemia*

Managing young children can be difficult because insulin absorption is unpredictable due to their erratic eating patterns and activity levels, increased sensitivity to small amounts of insulin, parental fear of hypoglycaemia and the difficulty of treating hypoglycaemia when the child refuses to eat or drink (Fox et al., 2005).

Fear of hypoglycaemia is known to be a major concern for people with type 1 diabetes (Barnard & Skinner, 2007). Fear of hypoglycaemia is common in adolescents and families of children with type 1 diabetes and often poses a barrier to good diabetes control (Phillip, Battelino, Rodriguez, Danne, & Kaufman., 2007). Parents and adolescents who fear hypoglycaemia tend to maintain blood glucose levels at a higher level than the target range of 4mmol/l – 8mmol/l (Juliussen, Graue, Wentzel-Larsen, & Sovik, 2006). Insulin pump therapy has been found to lower the risk of hypoglycaemia. Hypoglycaemia will still occur intermittently, and parents need to learn how to prevent, treat and detect hypoglycaemia when using an insulin pump.

*Preventing, treating and detecting hyperglycaemia*

Parents also need to learn how to prevent, treat and detect hyperglycaemia. Because only rapid acting insulin is used in the pump there is a greater risk of diabetic ketoacidosis (DKA) occurring compared with children on insulin injections (Bode et al., 2002). DKA can also occur more rapidly in patients using an insulin pump. Children using insulin injections have a combination of rapid acting insulin and longer acting insulin. The longer acting insulin delays the onset of DKA.

Unexplained high blood glucose levels can indicate a problem with insulin delivery such as an occlusion with the infusion set (Boland, Ahern, & Grey, 1998). An occlusion can occur if the cannula is bent. The pump may not detect an interruption in

insulin delivery for several hours (Torrance, Franklin, & Greene, 2003). The infusion set should be replaced and a correction bolus (extra insulin to lower the blood glucose level) given. Education regarding the need to monitor blood glucose levels at least four times per day and how to treat high blood glucose levels can help prevent DKA. Bode et al. (2002) observed fewer episodes of DKA in adolescents and adults using insulin pump therapy. Likewise, Hanas & Adolfsson (2006) found that recurrent admissions for DKA were reduced when using insulin pump therapy.

*Adjustment of insulin in relation to physical activity and exercise*

Parents need to learn how to manage their child/adolescent's exercise using an insulin pump. The appropriate adjustment of the insulin pump during exercise among children and adolescents is not yet clear (Admon et al., 2005; Low et al., 2005). Children often participate in unplanned physical activity. Admon et al. (2005) found that hypoglycaemia during exercise could be prevented only when the meal bolus was reduced by 50% and basal insulin discontinued during exercise. Reducing the meal bolus requires planning the activity. Reducing the basal insulin rate by 25% during the hours following exercise reduced late hypoglycemia. A bedtime snack was also recommended to prevent hypoglycaemia. The study by Admon et al. (2005) included ten participants and used a randomized crossover design. Trial and error remains the principal method of regulating blood glucose levels during exercise (The Diabetes Research in Children Network Study, 2006).

*Integrating insulin pump therapy into everyday life including school*

Berlin et al. (2006) interviewed 20 adolescents with type 1 diabetes and 34 parents. For adolescents the most frequently reported problematic situations were type 1 diabetes self-care relating to social and peer contexts (Berlin et al., 2006). Parents had

more family related problems. A limitation of the Berlin et al. (2006) study was that all patients using insulin pump therapy were deemed “well suited” for insulin pump therapy. Nevertheless, numerous other difficulties were identified in this group of patients (Berlin et al., 2006). For example adherence difficulties were experienced in specific social contexts creating challenges with communication by the family and/or professionals with the youth.

Psychosocial studies by Fox et al. (2005) suggest children and adolescents with diabetes are not as well adjusted at home as they are at school. In the study by Fox et al. (2005) children/adolescents were chosen for insulin pump therapy indicating they were expected to do well as they had better compliance, control and understanding. The pump appears to facilitate social interaction for adolescents because of flexibility (Low et al., 2005).

Low et al. (2005) found that 50% of participants in their study reported concerns about the pump at school. These issues related to checking blood glucose levels, bolusing, and pump management while at school. Education and training for school personnel was one of the most frequent concerns mentioned (Low et al., 2005). Older primary school aged children may be able to program the pump themselves but are cognitively unable to troubleshoot when problems occur (Klingensmith et al., 2001).

Darby (2006) used a phenomenological approach to examine the experiences of eleven school nurses caring for students using an insulin pump. Several themes emerged. School nurses were initially scared when they encountered insulin pump therapy due to a lack of education and experience. Significant factors which assisted the school nurses to become competent providers of care in the school setting included: learning and

teaching, trust, knowing the students with pumps, communicating by knowing the language, dealing with problems and carbohydrate counting.

*Transferring responsibility for diabetes management from parent to child*

More responsibility for the management of diabetes is often placed on children by their parents when they reach adolescence (Boland et al., 1998). The gradual transition of responsibility for diabetes self-care, when the adolescent learns appropriate problem-solving skills is a better option. Expecting younger adolescents to perform specific problem-solving skills such as making insulin adjustments based on planned exercise, blood glucose monitoring and food intake may be unrealistic (Boland et al., 1998). If too much responsibility is given too soon the adolescent may not adhere to diabetes self-management tasks, which can result in the deterioration of glycaemic control, reduced self-esteem and family conflict (Boland et al., 1998).

When adolescents transitioned to insulin pump therapy parental involvement stayed the same or decreased (Mednick et al., 2004). Even among children with poor glycaemic control parental involvement did not increase. Parental involvement should be encouraged especially if glycaemic control is less than optimal or deteriorating. None of the children in the study by Mednick et al. (2004) reported increased anxiety. Parents whose children had a HbA1c > 8.1 reported less anxiety.

Williams et al. (2004) examined the relationship between family factors and glycaemic control in 109 adolescents with type 1 diabetes. Poorer glycaemic control was associated with critical or unsupported parental behaviours and the child or parent unable or unwilling to take responsibility for diabetes tasks whereas better glycaemic control was associated with higher rates of parental warmth and caring.

*Psychosocial factors*

Low et al. (2005) explored the psychosocial issues related to insulin pump therapy in adolescents and their parents. Both groups reported high levels of satisfaction with insulin pump therapy. Few issues were reported in relation to body image, appearance or the social aspects of relying on an insulin pump. Concerns included the demands of initiating pump therapy, pump alarms and pump malfunctions, potential for regimen non-compliance with insulin pump therapy and school related issues. Parents were surprised about the demands of the pump and about the potential for problems (Low et al., 2005).

Ritholz et al. (2007) used focus groups and content analysis to identify the psychosocial issues related to having diabetes, approaches to self-care, self-perceptions and social interactions among 30 adult insulin pump users with long term diabetes. Active participation in self-care, realistic expectations of pump use and emotional recall of diabetes diagnosis were associated with better glycaemic control (Ritholz et al., 2007).

Ritholz et al. (2007) identified differences between people with high HbA<sub>1c</sub> levels ( $9.1\% \pm 0.5\%$ ) and those with and low HbA<sub>1c</sub> levels ( $6.8\% \pm 0.4\%$ ). Mid HbA<sub>1c</sub> ( $7.8 \pm 0.3\%$ ) groups sometimes could be categorised with the high HbA<sub>1c</sub> group and sometimes with the low HbA<sub>1c</sub> group. People in the high HbA<sub>1c</sub> groups believed that the pump would make the diabetes disappear, were reluctant to perform the necessary self-care behaviours and had difficulty understanding the need to limit their behaviours (Ritholz et al., 2007).

In contrast people in the low HbA<sub>1c</sub> group recognised the pump as a tool that required them to check their blood glucose levels, count carbohydrates and use bolus

insulin (Ritholz et al., 2007). They remained actively involved in their diabetes care, used self-reflection and had insight into the limitations and benefits of using the pump. In addition, they described feeling more normal and found it easier to talk about their diabetes, since using the pump. Their perception of initiating pump therapy was reminiscent of how they felt when they were initially diagnosed (Ritholz et al., 2007).

### *Quality of life*

Quality of life issues are extremely important because they may be significant in predicting an individual's capacity to manage their disease and maintain long-term health and well being. Some psychosocial factors including health related beliefs, social support, coping style, and personality type might have a significant effect on quality of life. Hoogma et al. (2004) compared quality of life and metabolic control in patients with type 1 diabetes treated with insulin pump therapy and those treated with multiple daily injections. Changing to insulin pump therapy did not reduce quality of life.

Although several studies into insulin pump therapy have been conducted few address the psychosocial aspects or quality of life issues in the paediatric population (Fox et al., 2005). Fox et al. (2005) concluded that insulin pump therapy is safe and well tolerated in young children, and enhances their quality of life, although it may not improve glycaemic control.

Likewise Hanas and Adolfsson (2006) suggested quality of life issues are becoming increasingly important when deciding to use insulin pump therapy to manage diabetes. Daily insulin requirements are usually lower than those needed for injection therapy, the HbA<sub>1c</sub> can be lowered, the risk of severe hypoglycaemia is reduced and recurrent admissions for diabetic ketoacidosis are reduced. In addition insulin pump therapy resulted in adolescents having greater independence and taking more

responsibility for their diabetes. According to Hanas (2002) an adolescent who forgets many injections will do much better on a pump because basal insulin is infused regularly.

### Chapter Summary

Literature relevant to this research study was reviewed. Search strategies involved searching for studies relating to children and/or adolescents using insulin pump therapy or making the transition to insulin pump therapy. Journals and databases used included PubMed, Cinahl and PsycINFO. Key words such as insulin pumps and type 1 diabetes were used. A study using qualitative methods to identify psychosocial issues relating to adults with type 1 diabetes using insulin pump therapy was also used. Literature from 2000 was used where possible; the use of older literature was kept to a minimum.

Research has contributed to the knowledge on children and adolescents transitioning to insulin pump therapy. Research in this area is limited and further research is needed to expand on this knowledge. Making the transition to insulin pump therapy is a challenge for families. Families need to be motivated to commence insulin pump therapy, they have to attend education sessions to enable them to manage insulin pump therapy, and they have to adjust to this change. Further research will identify specific psychosocial issues relevant to children, adolescents and their families when they make the transition to insulin pump therapy. Education to target the specific needs of the family can be developed.

## CHAPTER 3: METHODOLOGY

The current research study aimed to describe the experiences of children/adolescents and their parents when making the transition to insulin pump therapy. To gain a better understanding of the experiences of families making the transition to insulin pump therapy both children/adolescents and their parents were interviewed before and after starting insulin pump therapy. They were also asked to complete a questionnaire and record thoughts in a diary.

To explore the experiences of children/adolescents and their parents when making the transition to insulin pump therapy it was necessary to develop an interview schedule and questionnaire. To improve the education process it was necessary to describe families' experiences regarding diabetes. Consequently it was necessary to interview the families before starting the pump and again three months after starting the pump. Sullivan-Bolyai et al. (2004) found that families were comfortable using a pump after two to three months. Three months allowed most families to become accustomed to the pump and therefore this time frame was used for the interviews in the present study.

### Research Design

A mixed method design was used in the present study. A mixed method design consists of one complete method with supplementary strategies drawn from a second method (Munhall, 2007). In the present study the qualitative approach was the primary method used and strategies from the quantitative approach were supplementary. A questionnaire was designed which supplemented the interviews and diaries.

A descriptive analysis is used to summarise data with the purpose of detecting trends and patterns (Teddlie & Tashakkori, 2009). A descriptive analysis was used to analyse the questionnaires and a thematic analysis identified emerging themes from the

interviews and diaries. Data was collected to describe the experiences of children, adolescents and parents making the transition to insulin pump therapy.

In a cross sectional design one or more samples are taken from the population at one time (Shaughnessy, Zechmeister, Zechmeister, 2003). A cross sectional study was used in the present study. Families were recruited for the study before starting an insulin pump. This represented the transition to insulin pump therapy which occurred at one specific point in time. Families were invited to participate in the study until saturation of the data occurred. The decision to stop inviting participants into the study was determined by data saturation i.e. no new data was coming out of the interviews.

This study was divided into three phases. The first phase consisted of the time period from when the families made the decision to start insulin pump therapy until they started, the second phase covered the three months following the start of insulin pump therapy, and the third phase will cover the next three to six months after starting insulin pump therapy. The third phase was not included in this thesis because time restraints did not allow this to be feasible.

Eleven families making the transition to insulin pump therapy were included in the study. Data was collected from families, including both parents and the child when old enough to be interviewed or adolescents using taped interviews and self-complete questionnaires before starting insulin pump therapy and again approximately three months after starting the pump. Ultimately parents decided if the child should be interviewed so consequently preschool children were not interviewed. Parents and children/adolescents were also given diaries to record their thoughts and feelings about insulin pump therapy during the three months after they started on the insulin pump.

The study participants were aged 3-16 years of age (mean = 10.5 years) living in Brisbane (n = 11 families which included in the study, 11 parents and 12 children/adolescents). There were not any single parent families in this study. In 2008 at the Mater Children's Hospital 50 children/adolescents started on insulin pump therapy. Of the 12 children/adolescents included in the study there were six females and six males. Duration of diabetes ranged from 9 months to 10 years (mean = 4 years).

### Study Participants

Children aged 2-12 years with type 1 diabetes, adolescents 13-17 years with type 1 diabetes and their parents making the transition to insulin pump therapy at the Mater Children's Hospital (MCH) in Brisbane from October, 2008 to January, 2009 were invited to participate in the research study. Between October 2008 and January 2009, a convenience sample of participants was recruited from the diabetes clinics at the Mater Children's Hospital in Brisbane, six families from the paediatric clinic, three families from the adolescent clinic and two families from a private clinic.

A convenience sample was used to recruit participants. This method allowed participants to be recruited depending on their availability and their willingness to be included in the study (Shaughnessy et al., 2003). Families were invited to participate in the study when they decided to start insulin pump therapy. From October 2008 to January, 2009 17 children/adolescents started insulin pump therapy. Families living outside of Brisbane were not included in the study. In some cases the whole family was not available to be interviewed prior to starting insulin pump therapy and therefore the decision was made not to include them in the study.

## Informed Consent

Information sheets described the research study in language appropriate to the younger child 7-12 years of age and the older child 13-17 years of age (see information sheets in appendix A). The child/adolescent had the opportunity to ask questions which were then answered to their satisfaction, making sure they understood what the study meant and what was expected of them. Written informed consent was obtained from parents of children/adolescents prior to their participation in the study. Written informed consent was also obtained from parents prior to their inclusion in the study. Children 7-12 years and adolescents 13-17 years who agreed to participate in the research study signed assent forms. Assent forms varied for the two groups as the forms were set out using age appropriate language. Assent forms are used for children/adolescents to say they are willing to participate in the study. However it is up to the parents to consent on their behalf thus the need for both consent and assent forms.

At the time of the research study there were not any criteria for children/adolescents starting on an insulin pump. Inclusion and exclusion criteria for the research study are set out below. Although coeliac disease is a chronic illness, children/adolescents with coeliac disease were included in the study. This is because having coeliac disease does not preclude these children/adolescents from getting an insulin pump.

Inclusion criteria:

- Children with type 1 diabetes commencing insulin pump therapy at MCH during the recruitment period were eligible to participate.
- Children on medication for hypothyroidism were included in the study if

thyroid function tests were within normal levels.

- Children with coeliac disease were included in the study.

Exclusion criteria:

- Children with cystic fibrosis related diabetes
- Children with type 1 diabetes who also had another chronic illness not related to diabetes
- Children taking cortisone medication

Ethical clearance was gained from the Mater Health Services Ethics Committee on 17 December, 2007 and from the University of Southern Queensland's Ethics Committee on 5 June, 2008. The dissertation proposal was endorsed on 28 August, 2008. Anonymity of participants was maintained by not including identities in the research study. Audiotapes have been kept in a locked cupboard and will subsequently be disposed of.

#### Data Collection

Data was collected using interviews, questionnaires and diaries. Interviews were conducted before starting insulin pump therapy and approximately three months after starting on the insulin pump. Questionnaires were distributed at the same time as the interviews. Diaries were also given to families to record information during the transition to insulin pump therapy.

Demographic variables were recorded for all participants. This included age of the child, gender, and duration of diabetes. Glycated haemoglobin (HbA<sub>1c</sub>) was also collected before starting the pump and three months after starting on the pump. HbA<sub>1c</sub> was measured using Ames DCA 2000 HbA<sub>1c</sub> analyser.

*Initial interview*

Participants, including parents and children/adolescents were interviewed before commencing insulin pump therapy. Both structured and semi-structured questions were used and where possible questions were open ended. Specific questions were used in the interview. However, questions were adjusted slightly to suit the needs of the person being interviewed. Open ended questions were used where possible as they allowed the respondent to reply in some detail.

Interview schedules were developed specifically for this study. This included an interview schedule for parents and an interview schedule for children and adolescents prior to commencing insulin pump therapy. The interview schedule for parents differed to the interview schedule for children and adolescents. See appendix B for questions for parents and appendix C for questions for children/adolescents. A structured standardised interview in which the questions were asked in a specific order was used to get responses to the same questions from participants in the research study. The purpose of the interview was to get an understanding of the meaning of diabetes, and the impact it had on their lives before starting on the insulin pump. The interview schedule was designed to elicit this information. When designing the interview schedule previous research was considered and the knowledge of the principle investigator who was experienced in initiating insulin pump therapy.

The principal investigator conducted all the interviews. The same interview techniques were used in all interviews. It was anticipated that the interview for parents before starting on the pump would take approximately one hour, however most of the interviews did not take this amount of time. Parents were interviewed separately. Children/adolescents were interviewed in the presence of their parents. All interviews

except one took place in the participant's home as it made it possible to recruit both parents and child/adolescent into the study. It would have been more difficult to recruit fathers into the study if the interviews were conducted at the Mater Children's Hospital rather than in their homes. Interviews were recorded with the participants' permission to facilitate an accurate record of what was said.

### *Questionnaire*

A questionnaire was developed to be used in conjunction with the pre pump interview. The questionnaire was the same for parents and children and adolescents. Another questionnaire was developed to be used in conjunction with the interview three months after transition to insulin pump therapy. Again it was the same for parents and children and adolescents. Questionnaires were not validated for this study as they were used in conjunction with the interview rather than only using a questionnaire to collect data.

The questionnaire was used for questions that required a simple answer such as yes or no. By doing this, the time required from participants was reduced as it would have taken longer if the questions had been included in the interview. An example of the questions on the questionnaire includes "Are you worried about hypoglycaemia?" See appendix D for a copy of the questionnaires.

### *Diary*

Parents and children were given a diary to record further information in relation to insulin pump therapy. The diary had an open format, allowing participants to record activities and events in their own words. The type of information they were asked to record in the diary was how they managed, problems with insulin pump therapy, their feelings about insulin pump therapy, and any other information they wanted to record in

their diary. Diaries provided further information in addition to the interview. In some cases events may be difficult to recall accurately or may be easily forgotten so writing in a diary was able to supplement the interview data and provided further information on participant's behaviour and experiences on a daily basis (Corti, 1993).

*Follow up interview*

Three months after commencing insulin pump therapy families were interviewed again. This was a semi-structured interview. The questions differed from the first interview. Sessions were taped and then transcribed. It was anticipated that interviews would take approximately one hour and 30 minutes for parents, one hour for older children and adolescents and from a few minutes to 30 minutes for younger children. Interviews did not usually take this long; only one person exceeded this amount of time with the rest taking less than the allocated time. Once transcribed, parents were given an opportunity to read the transcriptions and make changes to ensure an accurate interpretation of the interview. Only minor changes were made which did not impact on the meaning of the transcriptions. Children/adolescents were interviewed in the presence of parents. Again the interviews took place in the home of the participants. One post pump interview took place at the Endocrine Unit, Mater Children's Hospital. It was not possible to interview one father following transition to insulin pump therapy. This was due to his busy work schedule.

Interview schedules were also developed for parents and children and adolescents to be used three months after starting insulin pump therapy. Again the interview schedule for parents was different than the interview guide for children and adolescents. The purpose of the interview schedules was to get an understanding of the experience of families when changing to the insulin pump and becoming accustomed to it.

## Data Analysis

NVivo version 8, a qualitative research analysis tool was used to manage and code the data. The software was used to carry out a thematic content analysis to identify, analyse and report emerging patterns and themes from the interviews and diaries. This was done by formatting the interviews using consistent paragraph styles and then using auto coding to group all the answers to each question. It was then possible to gather together all the material related to a topic. Patterns came from direct quotes or by paraphrasing common ideas (Aronson, 1994). Thematic analysis focused on identifiable themes and patterns of living and/or behaviour.

SPSS 11.0 student version is a computer program that provides statistical analysis of data and was used to conduct a descriptive analysis of the questionnaires. Descriptive analysis was used to compare the questionnaire results from children/adolescents, mothers and fathers before starting insulin pump therapy and again three months after starting the insulin pump and used to determine whether there were any significant differences between the groups.

## CHAPTER 4: RESULTS

The findings of the study will be presented. A number of main themes and sub themes were identified from the interview transcripts and diaries. Themes will be described and examples of statements made by participants that exemplified that theme will also be presented. See table 4 below for a list of themes.

Table 4

*Themes Identified from Interviews and Diaries*

Categories	Themes
The meaning of having diabetes	<ol style="list-style-type: none"> <li>1. Planning</li> <li>2. Constancy of diabetes care</li> <li>3. Worries/concerns               <ol style="list-style-type: none"> <li>3.1 Hypoglycaemia</li> </ol> </li> <li>4. Long term health</li> </ol>
Transition to insulin pump therapy	<ol style="list-style-type: none"> <li>5. Starting over</li> <li>6. Effort</li> </ol>
The meaning of insulin pump therapy	<ol style="list-style-type: none"> <li>7. Fewer needles</li> <li>8. Freedom and flexibility</li> <li>9. Better control of blood glucose levels</li> <li>10. Being attached</li> <li>11. Feeling normal</li> </ol>

Elements of insulin pump therapy which families found difficult will be discussed. Those elements which families found easy will also be discussed. Topics include infusion cannulas, bolusing, carbohydrate counting, exercise, hyperglycaemia and ketones, school, baby sitting, and blood glucose levels. The education program and HbA<sub>1c</sub> before and after starting insulin pump therapy will also be discussed. Results from the quantitative data will be presented. Table 5 illustrates the demographic variables of children/adolescents included in the study.

Table 5

*Demographic Variables of Children/Adolescents Recruited for the Research Study**(N = 12)*

Age of child/adolescent	Gender	Duration of diabetes
3	Male	9 months
5	Male	2 ½ years
8	Male	6 years
8	Female	1 ½ years
10	Male	3 ½ years
11	Male	3 years
12	Female	10 years
13	Female	2 ½ years
13	Female	1 ½ years
13	Female	7 ½ years
14	Female	7 years
16	Male	3years

## Interviews and Diaries

A thematic analysis of the interviews and diaries identified emerging themes. Not all participants recorded information in their diaries. Eight mothers, five fathers and

eight children/adolescents recorded information in their diaries. The information which was recorded in the diaries confirmed what the families said in the interviews. Themes were categorised according to the meaning of having diabetes before initiating insulin pump therapy, transition to insulin pump therapy and the meaning of insulin pump therapy.

Having diabetes meant planning, constancy of diabetes care, concerns and worries including hypoglycaemia and the long term health of the child/adolescent. Mothers said that making the transition to insulin pump therapy was like starting over again and involved extra work. Most of the children/adolescents using the pump to manage diabetes were happy and said the pump was easier than having needles. Benefits of the pump included fewer needles, freedom, and better control of blood glucose levels.

Being attached to a machine was cited as a disadvantage by most of the parents and children/adolescents. Despite being attached most children/adolescents felt more normal. However one adolescent did not feel normal; she was not happy using the pump and subsequently went back to using pens.

#### *The Meaning of Diabetes*

The meaning of diabetes describes the impact of diabetes on the lives of children/adolescents with type 1 diabetes and their parents. Having diabetes for children/adolescents meant having injections, doing finger pricks, and a lack of freedom regarding food choices. For mothers it meant having more worries, lack of freedom regarding timing of meals and food choice and constantly checking. Fathers also had more worries, were more planned and organised, felt they had more responsibility and were constantly aware or conscious of diabetes. The long term health of their child/adolescent was a concern for most parents.

*1. Planning/lack of spontaneity/lack of freedom*

This theme represented planning, lack of spontaneity and lack of freedom regarding food choice and timing of meals which parents and children/adolescents discovered. Some children/adolescents said that diabetes made no difference or had minimal impact on their lives; they mentioned meal planning, not having food choices, injections, blood glucose monitoring, and extra attention when talking about the affect diabetes had on their lives.

*Freedom with food, and you have to time meals and everything (child/adolescent).*

*Eating has changed a lot, like having to eat at certain times, not really having a choice, whether I'm hungry or not and stuff (child/adolescent).*

*Very minimal, probably just having to change my routine (child/adolescent).*

*No difference (child/adolescent).*

*Nothing much has changed (child/adolescent).*

*Sometimes you get extra attention because you are doing all of everything (child/adolescent).*

One of the biggest adjustments children/adolescents had to make since being diagnosed with diabetes was freedom regarding food choices and freedom regarding the amounts of food they liked to eat. They also had to eat at set times, whether they wanted to or not; often food was refused to prevent high blood glucose levels or to avoid having another needle.

*I think it has made us more aware about what they're eating and the meal times in particular, not being able to just go out, I mean he needs his snack, morning tea, in case we are not near a shop. It has probably made me more organised in terms of food and planning. That's the biggest change (parent).*

Parents said having a child/adolescent with diabetes resulted in a lack of spontaneity in their lives, they had to be more organised, there was a lack of freedom especially with timing of meals, and they had to do a bit more work.

*We can still be spontaneous to a certain extent but its planned spontaneity if you know what I mean by that. So we can still wake up and say lets go to the coast today but we can't be out the door in five minute (parent).*

*It's the going out I suppose. We don't just get up and go (parent).*

*It has probably made me more organised in terms of food and planning (parent).*

Fathers also said they were more planned and organised.

*We are a lot more planned and organised with life in general (parent).*

*We can't do anything without a plan (parent).*

## *2. Constancy of diabetes care*

This theme represented the constant thinking about diabetes management which was necessary. It impacted on the lives of parents in that it was continuous. Mothers said that diabetes was constant in that it was always present. They could not have a break from it. There was constant testing, and constant needles. Children/adolescents have to monitor blood glucose levels at least four times a day and have two or more needles each day. Diabetes was there all the time for the families, it did not go away.

*Always constantly checking to make sure we have enough supplies when we go anywhere. Making sure she has enough food (parent).*

*There's always that constant reminder that it's there all the time (parent).*

*But it's still a constant worry to me still (parent).*

*I think the fact it doesn't go away that's probably the hardest thing (parent).*

*It's a constant, constant testing, constant needles (parent).*

*I guess that's the biggest restriction, the constancy (parent).*

*Blood tester, all her diabetes stuff with us at all times (parent).*

*Always constantly checking to make sure we have enough supplies when we go anywhere (parent).*

They always had to be thinking about and dealing with diabetes.

*Just always having to think about it, always making sure we have food and water.*

*That's the thing I always use to worry about (parent).*

*So there's always something that you've got to deal with it (parent).*

*That's something that's always there (parent).*

### 3. Worries/concerns

This theme was about the concerns and worries of parents; hypoglycaemia was identified as one of the main concerns for mothers. Having a child/adolescent with diabetes affected the mothers more, making them worry more, more sad, and more protective. Parents spoke about the impact of diabetes on their lives and they had more worries since their child/adolescent was diagnosed with diabetes. Mothers were more worried about hypoglycaemia than were fathers or children/adolescents.

Children/adolescents were more concerned about high levels than low levels. Fathers were also more concerned about hyperglycaemia than hypoglycaemia. Most parents said the long term health of their child/adolescent was their biggest concern.

*I seem to worry a bit more about day to day care (parent).*

As a result of the worry parents become more protective or sad.

*It has probably made us more protective (parent).*

*Other than it makes me sad it hasn't really affected my life (parent).*

Fathers said there was a bit more responsibility.

*It does obviously add a bit more responsibility (parent)*

Some fathers said they just get on with life and deal with the fact that their child has diabetes.

*It has affected us but we just move on, deal with it, that's the way it is (parent).*

*Not a burden for us, just something we deal with I guess (parent).*

*Just deal with it. That's the cards, you've got to play them (parent).*

Parents were concerned about leaving their child/adolescent with someone because other people do not have the knowledge regarding diabetes that they have.

*Just trying to impart the knowledge to them I suppose (parent).*

*That they don't have the knowledge that we have (parent).*

*I certainly didn't know what it was and I just don't think people quite understand the seriousness of what it actually is (parent).*

*That they don't understand, I mean we don't leave him with anybody. They don't understand it, don't understand the disease, don't understand how to manage it, don't understand the tell tale signs (parent).*

Some families also had problems with the school managing their child/adolescent's diabetes.

*Oh, we have had big problems with school people managing his diabetes (parent).*

*Lack of knowledge, whether they want to be responsible (parent).*

*Just unfortunately being at a school where they had no idea how to deal with it and were not prepared to learn about the right thing to do (parent).*

*They have no idea so nobody ever does or has [managed her diabetes at school] (parent).*

Parents did not usually have support outside of the family except for the clinic and were happy they had the after hours doctors on call service.

*I see you guys as our main support (parent).*

*Clinics [are the main support] (parent).*

Parents said clinics were supportive because outside of clinic visits they could phone the diabetes educator or endocrinologist on call for information. Mothers usually took on more of the diabetes management than the fathers. Fathers were more involved and helped more with the younger children.

### *3.1 Hypoglycaemia*

Hypoglycaemia was identified as a sub theme under concerns and worries because it caused considerable concern for mothers. It impacted significantly on their lives in terms of worry and affected the management of diabetes for their children/adolescents.

*My concern more at the moment he has quite a few of them [hypoglycaemia] (parent).*

*I probably worry more, at night time if I'm not 100% confident that she's eaten enough (parent).*

*Sometimes it takes a little while for him to register that he is actually low (parent).*

*That she's not going to wake up to them (parent).*

*I just get scared at night if she has a low (parent).*

*"I'm worried she might go low in the night, you know what I do, I automatically now get up in the night and get into her bed. I don't take her blood every time. I make sure she's still moving. One thing I remember, and I think it was Liz that said to me, I think it was Liz, at one of the clinics at the very beginning, the night time does scare me a little bit, if I just go in there and check on her and go to bed,*

*is there any way you can tell if you've gone too low or something and she said no you just look like you're sleeping so I just don't know, unless you check the blood do you? She doesn't generally have a low very often, I make sure she doesn't"*  
(parent).

Mothers in particular were more concerned about night time hypos. Two mothers admitted to running blood glucose levels high to prevent hypoglycaemia.

*There have been occasions when I have done that [run BGLs high] for sleepovers particularly, yes. I'd rather give them 1 unit less than, especially at night. They wake up but you never know* (parent).

*I don't worry about night time hypos because we don't really let him go low, very rarely would he go low at night* (parent).

#### 4. Long term health

This theme was about the long term health of children/adolescents. It represented a major concern for parents because they worried about the complications of diabetes.

*And I worry long term; you know the damage having the highs is doing to her body* (parent).

*The long term effects, just the, I suppose long term effects* (parent).

*I do worry about the long term thing* (parent).

*I don't think I really have any worries really other than her long term health*  
(parent).

*Long term [referring to long term health]* (parent).

*Ongoing future health issues really, more so* (parent).

*I had initial worries about long term you know, bad* (parent).

*The complications later on* (parent).

Long term health remained a major concern for parents of a child/adolescent with diabetes following the transition to an insulin pump even though with insulin pump therapy better glycaemic control can be achieved.

#### *Transition to Insulin Pump Therapy*

Transition to insulin pump therapy was identified as another category because it represented a new beginning in the management of diabetes. It was the time when families became familiar with using an insulin pump. Mothers said that making the transition to insulin pump therapy was like starting over and they recognised that it involved extra work. Parents found the sleep deprivation due to night time monitoring of blood glucose levels difficult.

#### *5. Starting over*

This theme represented starting over, the change from injections to using the insulin pump to manage diabetes. Some mothers said that it was like starting over (like being diagnosed again). It made parents remember back to when their child was diagnosed with diabetes and some recalled their stories. It was an emotional time. Some parents talked about when their child/adolescent was diagnosed with diabetes during the interviews.

*For me when you go on the pump it's like when you are first diagnosed (parent).*

*That it's like starting over again was true (parent).*

*I have heard from other people that it's like going back to square one, when you first start, and I'm nervous about that because that was a challenge (parent).*

*Just the first two weeks, loss of sleep and brought up a lot of the stuff with the first diagnosis (parent).*

*Starting all over again, felt very clumsy doing the set site change for the first time today, reminded me of day one with the needle (parent).*

*It's a bit like starting all over again. Lots to learn, my mind is spinning (parent).*

Most children heard about the insulin pump when they attended diabetes camp and decided they wanted a pump after seeing other children/adolescents use it. Parents heard about it by reading diabetes magazines, from the clinic or by attending information sessions. Mostly, the child/adolescent and the mother decided they wanted the pump and the fathers went along with it. Children/adolescents felt excited and at the same time nervous about starting on the pump. However, most children/adolescents said the transition was easy.

*Nervous feeling not knowing what tomorrow brings and the excitement of going onto a much easier, more natural control of diabetes mix together to create a strange excited yet anxious feeling (child/adolescent).*

*I'm not too sure how I feel about getting the pump. I feel kind of excited but nervous and unsure at the same time (child/adolescent).*

*I'm really excited for getting the pump and a little bit nervous (child/adolescent).*

*I am feeling excited and nervous (child/adolescent).*

Fathers were a little more sceptical regarding the pump

*I've got no great expectations of it (parent).*

*I am not 100% sure if this is the right thing or not but will just have to wait and see (parent).*

Starting on an insulin pump meant less stress for mothers. One mother had less stress, while some mothers did not have any stress and some mothers were stressed in the

beginning while they were getting used to the pump. Fathers also had less stress, no stress or some stress initially due to interruption to night time sleep.

*6. Effort required to manage insulin pump therapy*

Effort represented extra work for parents but children/adolescents thought using an insulin pump was easier. Parents and children had differing opinions on what insulin pump therapy meant in terms of effort needed to use the pump. Parents spoke about the extra work involved while children talked about the pump being easier compared to having needles. Parents found the night time monitoring was particularly difficult because of the sleep deprivation.

*Getting up at night time and stuff, like that's not been much fun (parent).*

*Probably really only the night time hassle, the interruption to night time sleep (parent).*

*I don't know mostly the biggest stresses are the night time (parent).*

*I was more worried about the overnight stuff when we were still juggling with rates (parent).*

Prior to starting on the pump both parents and children said the pump would make life easier, although parents realised it would mean extra work while making the transition to insulin pump therapy.

*If he thinks it will make his life easier or better then I am all for it (parent).*

*It might be easier (child/adolescent).*

*It will be a lot easier (child/adolescent).*

Children reported using the pump was easier because all they had to do was press a few buttons rather than having a needle. Pressing a few buttons meant giving a meal bolus

which involved working out how much carbohydrate was in the food they were going to eat and then programming that into the pump.

*When I go to my friends it is much easier because now I can just press a few buttons and my insulin is done (child/adolescent)!*

*It's a lot easier than having to guess and check and everything (child/adolescent).*

*Easy to use (child/adolescent).*

*It's a lot easier to use (child/adolescent).*

However getting used to bolusing (pressing a few buttons) because it was something new they had to do was one of the harder things to get used to when they started using the pump.

*In some ways I prefer the needles, because with needles all you have to do is one in the morning and one at night. With the pump, after every meal you have to figure out how many carbs are in the food you ate (child/adolescent).*

*At first I used to struggle to remember to bolus. I got used to that part (child/adolescent).*

*Bolusing. It's just when you're on needles, I mean you don't have to do a needle every time you eat (child/adolescent).*

*Having to inject the bolus before you eat. You only had to test yourself before and now you have to put stuff in (child/adolescent).*

#### *The Meaning of Insulin Pump Therapy*

This theme was about what insulin pump therapy meant to families. Using an insulin pump had a positive impact on the lives of most families. Children/adolescents liked the pump, including one adolescent who stopped using the pump. All but one mother were satisfied or very satisfied with the pump.

Parents cited freedom, better blood glucose levels, making life easier and long term health as the main reasons for wanting the pump. Children/adolescents also said the pump would give them better blood glucose levels but the main reason for wanting a pump was to avoid needles. They also said the pump would give them freedom and allow flexibility regarding timing and choices of food and flexibility of sleeping patterns. Being attached but feeling normal was integral to continued use of the pump. Most parents took approximately two months to become accustomed to the pump. Some took less time, from straight away, three or four days, or two to three weeks, and others took longer, from three months to still learning.

#### *7. Fewer needles*

This theme represented fewer needles as children/adolescents cited fewer needles as the main reason for wanting to use an insulin pump. Children/adolescents did not like having injections although the children/adolescents in this study tolerated injections.

*So I don't have to get more needles. I just want needles every 3 days instead of having a needle more than once (child/adolescent).*

*Tired of injections (child/adolescent).*

*Instead of like having a shot, if I want something after dinner I can dial up some more insulin (child/adolescent).*

*It looks easier than syringes (child/adolescent).*

*I won't have to inject myself (child/adolescent).*

*It will lower the amount of needles needed (child/adolescent).*

*Not having to give injections, I hate it (child/adolescent).*

*Nice to not draw up, give injections (child/adolescent).*

After they started on the pump, children reported that the biggest benefit for them was having fewer needles.

*Easier than having a needle (child/adolescent).*

*You don't have to get needles and it doesn't hurt as much (child/adolescent).*

*In a way it's easier than doing needles because what I mean, needles sometimes hurt, but with the pump you only have to do a needle every three days (child/adolescent).*

*Well it's very easy because there are a lot less needles (child/adolescent).*

#### *8. Freedom and flexibility*

This theme represented freedom and flexibility which improved the quality of life for children/adolescents with type 1 diabetes and their parents. Children/adolescents saw getting the pump as getting their freedom back; freedom from needles, and freedom in terms of food, being able to eat when they wanted and more choice in the foods they could eat. Parents are often restrictive in food choices and amount of food their child/adolescent can eat because they are worried that high blood glucose levels will occur if they eat certain foods or eat more food. The pump allowed flexibility of eating times and amounts they could eat which allowed them to eat when they were hungry. Parents also said freedom was a benefit of insulin pump therapy.

*I've had a lot more freedom with it (child/adolescent).*

*It gives you more freedom (child/adolescent).*

*It's like a lot freer (child/adolescent).*

*A bit more freedom (child/adolescent).*

*I feel the insulin pump has given us more freedom (parent).*

*We are enjoying the freedom of not having to eat as regularly (parent).*

*Eat a little bit more freely (parent).*

*Allowing him more freedom in what to eat (parent).*

*Have seen the extra freedom it affords the children in their eating habits and lifestyle (parent).*

Some of the families spoke about being able to sleep in as well. Previously, prior to having the pump they were not able to sleep in.

*It gives him more freedom to sleep in too (child/adolescent).*

Freedom for the children also meant freedom from needles.

*I like the freedom of not having to do five injections every day (child/adolescent).*

#### *9. Better control of blood glucose levels*

This theme was about having better blood glucose levels. Parents wanted more stable blood glucose levels which were in the target range of 4 mmol/l to 8 mmol/l as this is related to long term health. Children/adolescents also wanted better blood glucose levels. Both parents and children and adolescents talked about having better, more stable blood glucose levels.

*The levels, they're a lot easier to keep good (child/adolescent).*

*My levels are a lot better. They're not up and down and there staying pretty much the same (child/adolescent).*

*Just the levels, keeping it at a good level instead of having highs and lows and going all over the place (child/adolescent)*

*It's got more control of glucose levels (child/adolescent).*

*I'm really happy with it and I like it because my levels don't change as often (child/adolescent).*

*Just from his glucose readings and results, his averages that we see on the meter, I think it's coming down (parent).*

*I think it's helped her get her levels a lot better (parent).*

Some parents reported that the behaviour of their child/adolescent had improved because there were fewer fluctuations in the blood glucose levels. Parents also observed a change in emotions.

*He's not going from low, the over-correcting and then he was going really high, therefore his behaviour at school is much better (parent).*

*She started concentrating better and I thought perhaps she's a little bit, she's happier, she's more confident a bit more grown up (parent).*

*Yes happier (parent).*

*Yes, there was a stage where he'd get really frustrated and angry which is usually when he was high so obviously he's not going as high, because his levels have come down (parent).*

*He's certainly a lot better [talking about behaviour] (parent).*

#### *10. Being attached*

This theme was about being attached to the insulin pump. Both parents and children said that being attached to a machine was a disadvantage.

*The practical fact that he's got an attachment (parent).*

*I suppose from my perspective being tied to a machine again I've asked A about that and she said its fine. That's it having to lug this little metal box around with you and things like that. It's a very expensive plastic box (parent).*

*For her to carry it around probably (parent).*

*It could be annoying just having an attachment, a cling on wherever you go  
(parent).*

Parents were not sure how the children would sleep with an insulin pump.

*Even I thought how the hell could she sleep with that hanging off her (parent)?  
I suppose it's going to be a little bit cumbersome maybe. It's attached to him. I  
don't know how he's going to go with sleeping because he's a restless sleeper so I  
don't know how that's going to be (parent).*

However, the children did not have any problems sleeping with the pump.

*That night, just before bed, I thought of something – where was I going to keep my  
pump while I was sleeping? I didn't know whether to hold it in my hand, keep it on  
my pillow, or clip it to my front! In the end, I decided to clip it on my front because  
I mostly sleep on my back (child/adolescent).*

*It was my first night and when I rolled over and it stung a bit. And then I seemed to  
get used to it (child/adolescent).*

*It wasn't really hard sleeping with the pump to be honest I didn't even know it was  
there (child/adolescent)*

### *11. Feeling normal*

This theme was about feeling normal which was related to being attached to a machine. Despite being attached to a machine most children/adolescents felt more normal after getting a pump. Children/adolescents talked about not feeling normal before getting the pump. Parents also used the term 'normal' in their conversations.

*So like you're not normal (child/adolescent).*

*Before, with a normal child you did not have to (parent).*

*We can't do anything like normal people (parent)*

*A flat day for me was I wasn't myself I was just really sluggish. I'd get out of bed in the morning and like just be I wasn't my normal happy self (child/adolescent).*

After getting the pump they said they felt more normal.

*It just makes me feel more normal (child/adolescent).*

*They just sort of treat you normal (child/adolescent).*

One adolescent stopped using the pump after six weeks because being hooked up to a machine did not make her feel normal.

*For the last couple of days people started to treat me differently they were always worried about me, checking to see if I did my test and asking tons of questions about the pump (child/adolescent).*

*K has told us that she no longer wants the pump because she feels that she is hooked up to a machine and does not feel like a normal kid (parent).*

She was happy once again when she stopped using the pump and went back to using pens to manage her diabetes.

*It's been a couple of days since I went off the pump, my mood lifted and people stopped asking questions, to be honest I felt normal again, the old me (child/adolescent).*

The adolescent who stopped using the pump said that prior to starting on the pump the hardest part of having diabetes was that people saw her as having a disease.

*People seeing you as having a disease (child/adolescent).*

#### Transition to Insulin Pump Therapy: What is or isn't Difficult?

The aspects of insulin pump therapy families found difficult and/or easy will be presented to illustrate the significant issues which children and adolescents with type 1 diabetes and their parents faced when making the transition to insulin pump therapy. To

identify significant issues parents and children/adolescents were asked what they found more difficult when getting used to the pump and what was easy. Other information relating to significant issues will also be presented.

For children/adolescents the hardest things to get used to when starting the pump were the cannula changes, carbohydrate counting and remembering to bolus. However they reported that other aspects of the pump, such as programming the pump was easy.

For parents, adjusting the basal and bolus rates was more difficult. Other things mentioned as being more difficult included changing the cannula, programming the pump, carbohydrate counting, learning the new language, remembering to change the site every three days and trusting the pump. Parents found dosing the insulin was easy. Families did not have any difficulties in readjusting to how they thought about managing diabetes.

The families described what they thought would be the benefits and disadvantages of insulin pump therapy. See table 6 for a list of benefits and disadvantages as cited by the families. Benefits included fewer injections, freedom and flexibility of eating and sleeping patterns and better blood glucose levels. Disadvantages included being attached, the pump not working, taking the pump off for sport, resiting and problems with the cannula and sites, and getting used to the pump. Parents found the overnight monitoring of blood glucose levels was difficult because the interrupted sleep caused exhaustion.

Table 6

*Benefits and Disadvantages of Insulin Pump Therapy Cited by Families*

Benefits	Disadvantages
Better control of blood glucose levels	Being attached to a machine
Easier lifestyle	Possibility of the pump not working
Less highs and lows	Taking pump off for sport and swimming
Less injections/less painful	More frequent blood glucose monitoring
Freedom/flexibility of eating and sleeping	(including overnight) resulting in
Long term benefits	disturbed sleeping pattern
Will not stop child/adolescent from doing things	Resiting and problems with the sites
	Cannula being pulled out
	Getting used to the pump

*Infusion cannulas*

Some children/adolescents had problems initially with the infusion cannulas. Problems included skin irritation to the adhesive, adhesion, air bubbles in the line and kinked cannulas. Only one adolescent had a site infection which was treated with topical antibiotic cream. Most families had resolved these problems during the three months. Inserting the infusion cannula was cited by the children/adolescents as one of the harder things to get used to because it was different than needles. Some children/adolescents found the sensation of inserting the Cleo infusion set unpleasant. Not all children/adolescents had problems with the cannula.

Inserting the cannula the first time was not easy for some children/adolescents.

*Mum put it in and it stung. I went as white as a sheet. I felt like I was going to be sick (child/adolescent).*

*After putting the cannula thing in I felt a bit funny, really wobbly and yea I can't really explain it but it was something I had never felt before (child/adolescent).*

Changing the infusion set was not always easy for children/adolescents.

*My first time at changing my set was a bit difficult as it did not stick to me a few times but eventually it did (child/adolescent).*

*Did not enjoy set changes at all. I don't find it hurts, but the feeling as it goes in bothers me (child/adolescent).*

Mothers found it difficult also.

*Probably inserting the cannula, every time we did it cried just the first few times (parent).*

*Remembering to bolus*

Some children/adolescents found it difficult to remember to bolus.

Children/adolescents who did not forget to bolus said it had become a habit. Parents also reminded them to bolus.

*Mum and Dad are always reminding me. It's just like getting automatic as you eat something, you bolus for it, part of the routine (child/adolescent).*

*When I eat, or about to eat I just do it (child/adolescent).*

*I've just got into the habit now (child/adolescent).*

*Just eating (child/adolescent).*

*Carbohydrate counting*

Some parents and children/adolescents found carbohydrate counting a little challenging. The most difficult part of carbohydrate counting was when they bought

food from the bakery or had food at other people's places. They did not know the carbohydrate content of these foods and had to guess.

*When we go out (parent).*

*I don't know, I guess it brought it home to me that not all carbs are created equal.*

*It's good that it's on the packages but then you have to convert the serving sizes, 100 grams into whatever he has. It has been a bit of extra work. At the end one day*

*when we get to the end figure of 45 or 50 I just wonder how close we are, because obviously the more food the more likelihood of error (parent).*

*I didn't have a clue really what to bolus for something from the bakery like that that's what the dietitian said, I remember the dietitian saying have a guess if it's something like a sweet desert, have a guess and you can correct, more on the lower side than the higher side. When I do that, when I correct the next time the correction doesn't seem to count up for what it should have been and so then he'll go high again after that (parent).*

Guessing the carbohydrate content of food was not easy as the blood glucose levels will go high if the carbohydrate content of food is underestimated. Another issue occurred when the carbohydrate content of food was programmed into the pump and the child/adolescent decided they did not like that food. Then they had to substitute it with another food.

*Probably just, really like counting the carb thing. I should eat, if I don't know what the food is. I should try it first in case I don't like it. A lot of the time I read the packet and put it into my pump and I had the first bite and I didn't like it and it was too much (child/adolescent).*

*We had that a couple of times and at dinner time you'd work out how much the carbs were for dinner and then she wouldn't eat all the dinner and then you'd have to make toast afterwards so that she had enough carbs to cover the insulin she put in (parent).*

#### *Exercise*

Most children/adolescents took the pump off while they exercised and often this was all they needed to prevent hypoglycaemia following exercise. Children/adolescents who were doing a lot of exercise also set a temporary basal rate afterwards so they had less insulin after exercise to prevent hypoglycaemia.

#### *Hyperglycaemia and ketones*

A few families reported their child as having a sick day as a result of hyperglycaemia and ketones since starting on the pump. It came as a surprise to one mother how fast ketones could develop.

*However ketones is a whole other story!! Never having had to deal with ketones in the past, it came as a shock to me to see how quickly it can happen (parent).*

Another mother also commented on high blood glucose levels.

*Obviously when something goes wrong with it, it goes more wrong so like quite quick (parent).*

Prior to starting the pump half the families did not check for ketones when blood glucose levels were high. More families checked for ketones after starting on the pump when blood glucose levels were high.

#### *School*

Children from eight years of age bolused for meals at school without any assistance from the teacher. Parents wrote the carbohydrate amount on stickers which

they put on the food in the school lunch box. Most of the children kept their blood glucose meter and hypo kit in their school bag and did their blood glucose level where their school bag was or wherever they were. One child did the blood glucose level in the classroom and one at the school office. Prior to starting on the pump the children/adolescents who gave injections at school did them wherever they were. There was not anywhere they could go to do their injection unless they went to the toilets or the office. After getting the pump it was easier for the children/adolescents who had previously been doing injections at school.

*At school it's a whole lot easier instead of like having kids huddle around you, like watching you do your needles and stuff. They just sort of treat you normal, like you don't have big crowds anymore because you take it out of your pocket and dial everything up and slip it back so yeah that's really good (child/adolescent).*

#### *Baby sitting*

Parents of the two younger children had previously been able to leave their child with grandparents but since starting the pump they had found they could no longer leave their child with them. All other children/adolescents were able to be looked after by someone else if necessary because they could do their own meal bolusing.

#### *Blood glucose levels*

Prior to starting on the pump, the average number of blood glucose levels the children/adolescents did was five. While the number of blood glucose levels increased immediately after starting the pump, most of them were again doing five blood glucose levels per day by the end of the three months. Parents continued to do more blood glucose levels on the two younger children, including night time monitoring. Most of the older children/adolescents no longer had overnight monitoring of blood glucose levels.

### The Education Program

Questions regarding the education program were included in the interview following transition to insulin pump therapy and responses may help determine recommendations to improve the education program. Psychological interventions may also be developed to aid the educational process thereby improving the transition to insulin pump therapy.

Families often did their own research on the insulin pump and made an appointment with the diabetes educator to discuss insulin pump therapy. When they made the final decision to start using a pump, a commencement date was organised. Dietary education was provided prior to starting on the pump. An appointment of approximately one hour's duration was made with the dietitian in the time leading up to starting on the pump.

The child/adolescent was admitted to hospital for an overnight stay when starting on the pump. Usually the education started early on day one and finished at lunch time the following day. Two families attended education sessions at the same time. Not all fathers were able to attend the education when their child/adolescent started on the pump. However they said they had enough education.

Families were encouraged to ring twice weekly for help with basal and bolus insulin adjustment and to help with problem solving. Ten mothers rang the diabetes educator for help with insulin adjustment on a regular basis for the first few weeks after starting the pump. One family did not ring for help with insulin adjustment. Families were invited back to the pump clinic at one month, three months and six months after starting on the pump. They will attend their usual clinic, i.e. paediatric diabetes clinic, adolescent diabetes clinic, or the private diabetes clinic after six months. All families

attended clinic, again not all fathers were able to attend. There is also an after hours endocrinologist on call service for families to ring if needing advice and two families rang the after hours phone for advice when their child/adolescent was unwell.

Some parents thought that there was a lack of awareness among parents of children/adolescents with diabetes regarding insulin pumps and that it should be promoted more as an alternative way to manage type 1 diabetes.

*It's an awareness thing. Most people would not know you can have an insulin pump (parent).*

*I think if people knew more about it (parent)*

*I think more information before they actually decide to do it, probably more promotion of the fact that if it doesn't work out, you can stop so it's not something that's going to be implanted and have to use forever so if on the off chance you don't like it, you can always go back to what you already know so you've really lost nothing except a bit of your time (parent).*

Promotion of practical tips was suggested.

*So maybe even promotion of the practical things that are going to make your life easier (parent).*

Making people more aware of the overnight blood glucose monitoring which leads to sleep deprivation was another suggestion.

*And knowing the sleep deprivation hasn't been much fun (parent).*

Children/adolescents recommended getting the pump saying it is better than injections and suggested that children/adolescent contemplating using the pump talk to other children/adolescents already using pumps.

*It will be better because you don't have to get needles and it doesn't hurt as much and it will make life easier (child/adolescent).*

*Have a one on one session with someone who recently used the pump and who's coping really well (parent).*

*Meet other children with it on (child/adolescent).*

*Education, one on one is better. It's up to the person isn't it (parent)?*

*I think that staying in overnight and having that practice pump was fabulous (parent).*

The adolescent who stopped using the pump also suggested children/adolescents try it as she thought it was a good device.

*I'd say get it because it does make your levels better and see how you go. I thought*

*I would like it because other people liked it (child/adolescent).*

### Questionnaires

Quantitative data was also analysed to understand the experiences of families making the transition to insulin pump therapy, to identify significant issues, and the findings could be used to improve the education program. Data from questionnaires were analysed by doing a descriptive analysis. See table 7 for a comparison of what children/adolescents, mothers and fathers reported before starting on the pump. There were some differences between the groups.

Table 7

*Comparison of Questionnaire Results for Children/Adolescents, Mothers, and Fathers before Starting the Pump (N = 10 children/adolescents, 11 mothers, and 11 fathers)*

Questions	Frequency of yes replies		
	Child	Mother	Father
Do you adjust insulin doses?	6	10	6
Do you have any concerns about hypos?	3	9	3
Do you have any concerns about high BGLs?	5	11	5
Do you check ketones?	4	6	4
Have there been ketones at any time?	3	5	4
Are there any problems with giving the insulin injections?	3	1	3
Are there problems with baby sitting?	8	11	8
Do you have any problems managing diabetes?	0	3	0
Is there conflict regarding diabetes care?	0	1	0

Questionnaire results from children/adolescents; mothers and fathers were compared before starting the insulin pump. Children/adolescents had similar results to fathers. Mothers were usually responsible for the diabetes management.

All families were adjusting insulin doses; all except one mother were adjusting insulin doses in which case the older adolescent was adjusting doses. Mothers had more concerns about hypoglycaemia and hyperglycaemia compared to fathers and children/adolescents. Half of the families checked for ketones when blood glucose levels were high. Some families did not check for ketones, however they did not leave the blood glucose levels high for any length of time, making it unlikely that ketones would develop.

Two children/adolescents, one mother and three fathers reported having a

problem with the insulin injections. Adolescents were giving their own injections; older children often gave their own injections, otherwise mothers gave the injections; fathers helped with giving the preschool children injections. Usually the child/adolescent could be left with other people, mainly family. Three mothers said there was a problem managing their child/adolescent's diabetes and one mother said there was conflict with her child/adolescent regarding diabetes care. This group of families did not report any major problems.

Data from questionnaires were analysed after children/adolescents started on the pump. See table 8 for a comparison of the groups.

Table 8

*Comparison of Questionnaire Results for Children/Adolescents, Mothers, and Fathers after Starting the Pump (N = 10 children/adolescents, 11 mothers, and 10 fathers)*

Questions	Frequency of yes replies		
	Child	Mother	Father
Have there been ketones since starting the insulin pump?	5	6	5
Have there been any sick days since starting the insulin pump?	3	4	4
Have there been any problems with:			
• cannulas kinking	3	4	2
• skin irritation	2	6	4
• air bubbles	2	8	4
• infections	1	1	1
Do you make adjustments to basal/bolus insulin doses?	7	10	7
Have you had any problems with carbohydrate counting?	3	4	3
Do you sometimes forget to bolus for meals?	5	4	2
Are there any problems with baby sitting?	10	11	8
Do you have enough knowledge about insulin pump therapy?	10	9	6
Have you purchased special belts or cases or other pump-wear?	5	7	4
Are there any problems related to wearing an insulin pump?	1	1	2
Is there conflict regarding diabetes care?	1	1	0

Families were asked how well prepared they were for insulin pump therapy. A likert scale was used to determine how well prepared parents and children/adolescents were for transition to the insulin pump. Options included not prepared, slightly prepared or well prepared. Seven children/adolescents said they were well prepared and three children/adolescents said they were slightly prepared for the transition to insulin pump therapy. There were not any children/adolescents who reported not being prepared. Two

fathers were well prepared, six slightly prepared and one not prepared. Five mothers were well prepared, five slightly prepared and one not prepared.

Families were also asked how difficult they found the transition to insulin pump therapy. A likert scale was also used to determine how difficult parents and children/adolescents found the pump compared to what they expected. Options were not difficult, slightly difficult and very difficult. Nine children/adolescents said the transition was not difficult, and one said it was slightly difficult. One mother said the transition was very difficult, one mother said it was slightly to very difficult, four mothers found it slightly difficult and five mothers found it not difficult. Five fathers said the transition was not difficult and four fathers said it was slightly difficult.

Half of the 12 children/adolescents had developed ketones since starting on the pump. More families were found to be checking for ketones when blood glucose levels were above 15 mmol/l compared to previously. One third of the parents said they had managed sick days since getting the pump. None of these children/adolescents were admitted to hospital, they were managed at home.

Various problems with cannulas kinking, skin irritation and air bubbles occurred. Only one infection of the site was reported. Most families were adjusting insulin doses. One third of the families had some problems with carbohydrate counting. Five children reported forgetting to bolus. Fewer parents reported their child/adolescent forgetting to bolus. All children said they had enough information about insulin pump therapy, a few of the parents felt they could have had more information.

Half the families bought special pump wear such as belts and pouches. There were some problems for girls regarding wearing of the pump. There was little conflict between parents and children/adolescents regarding diabetes care.

HbA<sub>1c</sub>

Of the 11 children/adolescents still using the pump, 10 children/adolescents had lower HbA<sub>1c</sub>'s three months after starting the pump (mean HbA<sub>1c</sub> 7.6%, SD .67) compared to before the pump (mean HbA<sub>1c</sub> 8.4%, SD .64). Only one child had a higher HbA<sub>1c</sub> three months after starting the pump. This was because he forgot to bolus for food and forgot to put his pump back on after having it off for swimming. HbA<sub>1c</sub> readings for children/adolescents before and after starting the pump are illustrated in figure 2. Figure 3 illustrates mean HbA<sub>1c</sub> before and after starting the pump.

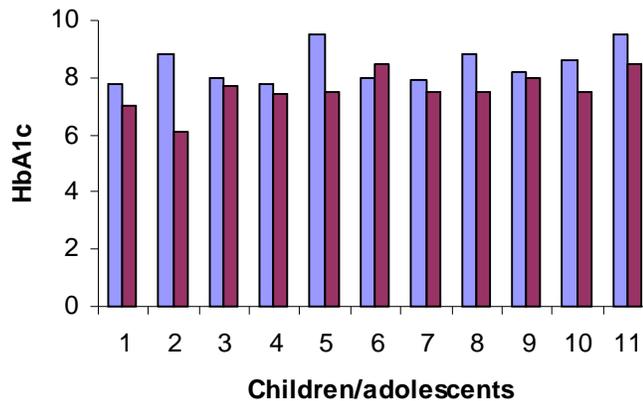
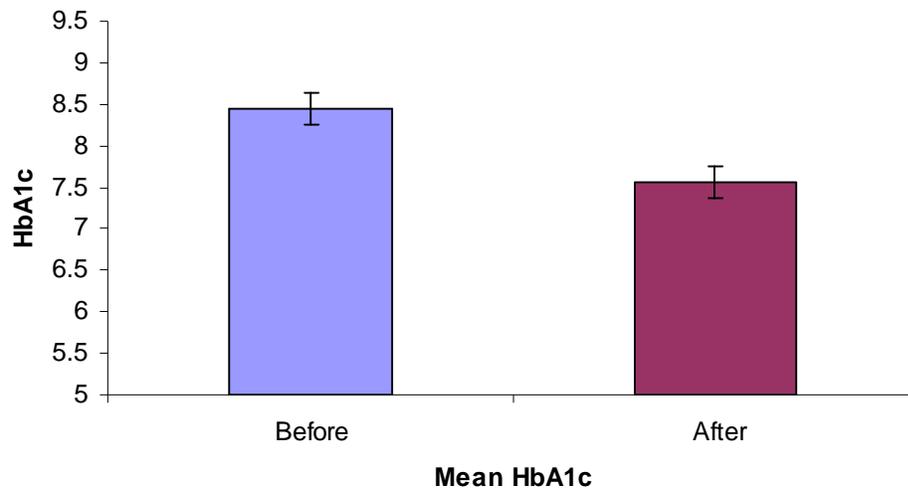


Figure 2. HbA<sub>1c</sub> before and after insulin pump therapy

Transition to insulin pump therapy



*Figure 3.* Mean HbA<sub>1c</sub> before and after insulin pump therapy.

## CHAPTER 5: DISCUSSION OF RESULTS

The findings illustrate families' experience of living with diabetes and their subsequent transition to insulin pump therapy.

The aims of the study were to:

1. Understand the experiences of children/adolescents with type 1 diabetes and their parents when making the transition to insulin pump therapy.
2. Identify the significant issues that children with type 1 diabetes, adolescents with type 1 diabetes and their parents face when making the transition to insulin pump therapy.
3. Use the findings to make recommendations to improve the education program for children with type 1 diabetes, adolescents with type 1 diabetes and their parents
4. Develop psychological interventions to improve the transition to insulin pump therapy.

### New Findings in the Present Study

The results suggest that feeling normal for children/adolescents was an important attribute for insulin pump therapy to be successful. When children/adolescents felt more normal they continued to use the insulin pump. Past research has not determined why insulin pump therapy is discontinued. One adolescent stopped using the pump in the present study and was interviewed three months after starting the pump, as were the other research participants. The adolescent was not happy wearing the pump, even though she felt better. Also she felt like she wasn't normal and that people treated her like she wasn't normal. When she stopped using the pump she felt like her normal self. Feeling normal seemed to be an important attribute for children/adolescents in the present study.

Other findings demonstrate the experience families have of diabetes and their transition to insulin pump therapy. Families who have a child or an adolescent with type 1 diabetes have to plan, especially meal times, and there was a lack of freedom particularly with food. They had set eating times and food choice was limited. Diabetes was constant; they always had to be thinking about it. Parents were more stressed and worried as a result of having a child or adolescent with diabetes. The main concern for parents was the long term health of their child/adolescent. Families thought using an insulin pump would offer a better alternative compared to injections.

While most children/adolescents wanted the pump to avoid needles, parents wanted the pump for a variety of reasons, one of the main reasons being freedom and flexibility. Low et al. (2005) also reported that adolescents wanted a pump to avoid needles.

Insulin pump therapy is considered to be an intensive therapy regime improving metabolic control (The Diabetes Control and Complications Trial Research, 1993) and while some parents mentioned better control of blood glucose levels, improved diabetes management was not the main reason for wanting insulin pump therapy. These findings are consistent with Mednick et al (2004) who found that better lifestyle and quality of life was more important than improved metabolic control for children/adolescents making the transition to insulin pump therapy.

Previous research (Sullivan-Bolyai et al., 2004; Maniatis et al., 2001) found that a combination of improved metabolic control and easier lifestyle were the main reasons for making the transition to insulin pump therapy. Overall the findings of the present study and previous research reported the main reasons for wanting an insulin pump were to avoid needles, to allow freedom and flexibility, and better control of blood glucose

levels. The studies differ only in the order of importance, with some studies finding lifestyle more important and some finding improved metabolic control more important.

Most families said having a machine attached all the time was a disadvantage; some families mentioned that a machine could break down. One disadvantage of insulin pump therapy which parents did not mention was the increased risk of ketoacidosis. There is an increased risk of ketoacidosis because only rapid acting insulin is used in the pump. Ketones usually develop after three or four hours if there is an interruption to insulin delivery. Prior to getting the pump parents often are not aware that only rapid acting insulin is used in the pump.

Parents in the present study gave extra insulin if blood glucose levels were high because they were concerned about the effect of high blood glucose levels on their child/adolescent and the long term complications of diabetes. Not all families checked for ketones when blood glucose levels were high, they did not seem to fully understand the importance of checking for ketones and were unaware that ketones can cause vomiting.

When using a pump it is important to check for ketones if blood glucose levels are high. Families were urged by the diabetes educator to check for blood ketones if the blood glucose level was above 15 mmol/l; knowing the level of ketones helps decide the insulin dose, which parents do not seem to comprehend.

Parents in the present study were surprised how quickly blood glucose levels rose when there was a problem with insulin delivery using the pump. Parents may need to experience this phenomenon to realise just how quickly blood glucose levels do rise when insulin is not being delivered. There are times when parents delay changing the cannula or using an injection to give insulin when there are high blood glucose levels

and/or ketones present. More time discussing hyperglycaemia and ketones may be extremely important in increasing parents' knowledge.

There is conflicting reports about how difficult the transition to insulin pump therapy is. Mednick et al. (2004) found that families found the transition easy. Sullivan-Bolyai et al. 2004 reported that all parents emphasised that insulin pump therapy required work. The present study found that most families thought the transition was relatively easy.

Children/adolescents reported that the pump was easy to use. Only one mother found the transition to insulin pump therapy very difficult. All other parents and children/adolescents found the transition not difficult or slightly difficult.

Most parents and children/adolescents reported being slightly or well prepared for insulin pump therapy. Most parents and children/adolescents were satisfied; some very satisfied with insulin pump therapy. Only one mother was not happy. Results from Mednick et al. (2004) were slightly more positive and found that parents and children were extremely satisfied and well prepared for insulin pump therapy. Low et al. (2005) also found that families had high levels of satisfaction with the pump.

Ritholz et al. (2007) found that adults with low HbA<sub>1c</sub> levels ( $6.8\% \pm 0.4\%$ ) described feeling more normal. The current study found that feeling more normal was associated with continued use of the pump to manage diabetes despite being attached to a machine. The study by Ritholz et al. (2007) included adults whereas the present study included children and adolescents which may explain the difference in results.

### Significant Issues

The study explored significant issues that children/adolescents and their parents face when making the transition to insulin pump therapy. Children/adolescents

said set changes, remembering to bolus, and carbohydrate counting were harder to become accustomed to although most of it was easy. For mothers the most difficult task was adjusting insulin doses, set changes and programming the pump. Night time monitoring of blood glucose levels was difficult because of the ensuing sleep deprivation.

*Infusion set changes*

Inserting the cannula was more difficult for children/adolescents to become accustomed to when starting on the pump. Previous research (Sullivan-Bolyai, 2004) also identified that parents and children found learning to insert the cannula was a difficult process. In the present study insertion of the infusion cannula was a bit daunting for children/adolescents and parents to begin with. Some children did not like inserting the cannula so having early psychological intervention may be advantageous. When children have difficulties inserting the set they are more likely to prolong changing the set, leaving the old set in longer than the recommended three days. Blood glucose levels are then likely to be higher than usual after three days thus compromising metabolic control. Parents sometimes use anaesthetic cream prior to inserting the infusion cannula. However this does not always resolve the problem. Psychological intervention is often beneficial.

There were some problems with the sets initially, including adherence of the tape, skin irritation and kinked or blocked cannulas. Heat can make it harder for the tape to adhere to the skin and keeping the skin cool was found to help with adherence. There are also many different types of cannulas and some children did not like the pushing sensation of the Cleo set even though it was relatively easy to insert. The Cleo infusion

set is inserted into the subcutaneous fat by pressing the set until the needle retracts. See figure 4 below (<http://www.cleoinfusionsets.com>).



*Figure 4. Cleo infusion set*

Some families had problems with skin irritation which settled by changing to a different set with a different tape or barrier wipes were used which provided protection to the skin from the tape. Longer cannulas which are inserted at a 45 degree angle do not seem to kink as much as the smaller cannulas which are inserted straight in at 90 degrees. One child changed to using these cannulas and was having fewer problems with kinked cannulas. Parents and children/adolescents often do not want to use the longer cannulas as they think insertion will cause more discomfort.

#### *Remembering to bolus*

Burdick et al. (2004) revealed that missed meal boluses were the main reason for suboptimal metabolic control when using the pump. Forty-eight youths with a mean age of 15.3 who had received insulin pump therapy for six months or longer were included in the study by Burdick et al. (2004). Thirty patients were found to forget to bolus one or more times per week. Forgetting to bolus four times per week represented a 1% increase in HbA<sub>1c</sub> (Burdick et al., 2004).

One third of children/adolescents in the present study said remembering to bolus was one of the more difficult things to get used to and half of the children/adolescents reported forgetting to bolus. This may be because they did not previously have to bolus. Children/adolescents who did not have an injection at lunch time were more likely to have trouble remembering to bolus. Children/adolescents who remembered to bolus said it was a habit. One adolescent set alarms to help her remember. An alternative to bolusing is to increase the basal rate at lunch time. Parents often do not like this alternative because the child/adolescent then has to eat at that time or risk hypoglycaemia. Parents are often fearful of hypoglycaemia and do not want to rely on the teachers to making sure the child eats.

### *Carbohydrate counting*

Families need to learn carbohydrate counting prior to starting insulin pump therapy. Insulin is given to cover the carbohydrate content of food. Families need to be fairly accurate in counting the carbohydrate food or the correct insulin dose is not given resulting in hyperglycaemia or hypoglycaemia. Parents have difficulty making an accurate assessment of carbohydrate foods when they eat out. Previous research has not identified concerns with carbohydrate counting.

### *Adjusting insulin doses*

While the pump allows for more flexible sleeping patterns for children/adolescents, in the beginning parents need to monitor blood glucose levels more frequently, including overnight. This leads to disruptive sleeping patterns for parents and some children/adolescents. Some children/adolescents sleep through while others are disturbed by having their blood glucose levels monitored. Parents, especially those of

the younger children continued to monitor blood glucose levels and were still doing overnight blood glucose levels when interviewed at three months.

Monitoring of blood glucose levels is necessary to make adjustments to the insulin doses, including basal rates and bolus doses. Parents are often concerned about hypoglycaemia, particularly at night. These parents are more likely to continue to monitor blood glucose levels overnight.

#### *Programming the pump*

Mothers in the present study found programming the pump more difficult than adolescents. This is consistent with previous research (Low et al., 2005) whereby adolescents were more comfortable with pump technology than were parents.

#### The Education Program

Significant issues for families when making the transition to insulin pump therapy have been identified. Findings from the present study can be used to make recommendations to improve the education program for families making the transition to insulin pump therapy. When starting on an insulin pump, families need further education and it is necessary to modify behaviour because managing diabetes with a pump is different than managing diabetes with injections.

Group education seems to be becoming more popular for educating families starting insulin pump therapy (Rodgers, 2008). Individual education may be more time consuming but could be better suited to some families. Some families learn better in a group whereas some prefer one on one education. Additional education on carbohydrate counting, especially estimating carbohydrates when eating out, adjustment of basal and bolus insulin and more practice with cannula insertion is recommended to reduce stress when starting insulin pump therapy.

*Adjustment of insulin in relation to physical activity and exercise.*

Insulin pump therapy made it easier for parents to manage sport. The Diabetes Research in Children Network Study (2006) suggested trial and error is the principal method of managing blood glucose levels during exercise. Considering there are no guidelines it might be expected that families have some hassles managing sport. The families in this study did not have any major concerns working out whether the child/adolescent should have less insulin, more food or a combination of less insulin and more food for sport.

*Integrating insulin pump therapy into everyday life including school*

In this group of children/adolescents, children/adolescents from eight years of age looked after the pump at school themselves. Day care and schools need to take on more responsibility for children less than eight years of age. This is because children are not able to manage the pump themselves, they cannot bolus for carbohydrate food or problem solve. An eight year old child can bolus for food if the food is labelled with the carbohydrate content, however they are not able to problem solve if the blood glucose levels are high. They may even be able to program a high reading into the pump so that they have extra insulin. There is a risk that high blood glucose levels may indicate that the infusion cannula is kinked and if not changed levels will increase and ketones develop. Parents need to develop a school plan and ask to be contacted if the blood glucose level is above 15 mmol/l. Some parents get permission for their older child/adolescent to have a mobile phone at school so they can contact their parents for problem solving. School personnel often are not adequately prepared to manage an insulin pump.

### Psychological Interventions

The findings can be used to develop psychological interventions to improve the transition to insulin pump therapy. Psychological factors include behaviour and mental processes which involve cognition, emotion, and motivation (Caltabiano, Byrne, Martin & Sarafino, 2002). Strategies may include awareness of insulin pump therapy and to encompass information from families already using insulin pump therapy. Tip sheets such as a guide to help parents of children/adolescents having difficulty with inserting infusion sets may be developed.

#### *Patient selection for insulin pump therapy*

At the time of the study there were not any set criteria for children/adolescents starting on a pump and self-referral was the method used by families.

Children/adolescents often heard about the pump from diabetes camps and parents had either read about it in diabetes magazines, heard about it at clinic or at pump information sessions. Parents do not always understand what insulin pump therapy is and how it works. Further discussion with families prior to making the decision to use a pump would be advantageous. Talking to other families who have recently changed to an insulin pump would also be beneficial.

According to Owen (2006) criteria for determining whether the pump is an appropriate choice is that both the child and family need to be interested, they should be checking blood glucose levels at least four times per day, and be unable to achieve HbA<sub>1c</sub> goals with conventional therapy. The group of families in the present study were suitable for insulin pump therapy according to these criteria. Nearly all of the children/adolescents had improved glycaemic control three months after starting on the pump.

*Parent's expectations of insulin pump therapy*

Some of the reasons children/adolescents and parents cited for wanting a pump were fewer needles, better control, more flexibility, and to manage exercise. These expectations could be considered realistic as fewer needles, better blood glucose levels, freedom and flexibility and managing exercise can be achieved using an insulin pump. From the conversations it was understood that the families were expecting the pump would make their life easier. Families need to be aware of the extra work required.

Better control of blood glucose levels was not the most common reason for wanting the pump despite long term health of their child/adolescent being the main concern of parents. Over time some families seem to neglect trying to achieve better control of blood glucose levels in favour of improved lifestyle factors.

It is an observation of the diabetes clinic at the Mater Children's Hospital that changing to insulin pump therapy is often delayed because fathers are not convinced that it might be a better alternative to managing diabetes. Fathers in the present study were also sceptical about the benefits of insulin pump therapy. Discussion regarding patient's expectations of insulin pump therapy would be beneficial to ensure they know the benefits and disadvantages of using an insulin pump. Talking to other families who have recently started to use a pump would also be beneficial.

*Transferring responsibility for diabetes management from parent to child*

The adolescents in this study became more independent when they changed to insulin pump therapy. Parents were available for support if required but adolescents seemed to take on more responsibility for diabetes management. Williams et al. (2004) suggest that a child/parent relationship be maintained while insulin pump therapy is initiated. If a child/adolescent is given too much independence before they are ready for

the responsibility of diabetes management glycaemic control is likely to diminish. To encourage adolescents and older children to use the pump appropriately they need continued support from parents.

### *Hypoglycaemia*

It is necessary to monitor overnight blood glucose levels so that adjustment to the basal rate can be made. Parents are often worried about hypoglycaemia, especially at night and therefore continue night time monitoring of blood glucose levels. Older children often wake at night when they are low. However younger children are not always able to communicate when they are low. With more glucose monitoring systems coming onto the market it might be possible to monitor younger children. An alarm would then alert the parents that the blood glucose level was low.

It is apparent that some mothers purposely run blood glucose levels high to avoid hypoglycaemia. Two mothers in the present study admitted to this and other mothers were worried about hypoglycaemia, particularly at night. Fear of hypoglycaemia is a deterrent to good glycaemic control (Phillip, Battelino, Rodriguez, Danne, & Kaufman, 2007). The hypoglycaemia fear scale could be distributed to families at a predetermined time before they start insulin pump therapy. If mothers are found to be fearful about hypoglycaemia they could benefit from further counselling prior to starting on the pump.

Parents in the present study were a little less concerned about hypoglycaemia after starting the pump. Still it can take time for families to feel comfortable with lower blood glucose levels, particularly at night time.

### Implications of the Findings

Findings suggest children/adolescents felt more normal using an insulin pump despite being attached to a machine which they cited as a disadvantage. Benefits

included improved lifestyle factors and fewer needles. While families wanted better control of blood glucose levels it was less important. This information can be discussed with families contemplating insulin pump therapy. They should be advised that it is also important to maintain blood glucose levels close to the normal range.

Children/adolescents found set changes, remembering to bolus and carbohydrate counting more challenging when starting a pump. Mothers found insulin adjustment, set changes and programming the pump as most challenging. Additional education can be delivered to target these specific areas to improve the transition to insulin pump therapy.

### Chapter Summary

For most families in the present study insulin pump therapy was a better alternative than needles. The children/adolescents were happier not having needles and enjoyed the extra freedom in terms of eating and sleeping patterns. Parents were happy that there were fewer variations in their child/adolescent's blood glucose levels which resulted in improved behaviour. Using an insulin pump meant some extra work. Parents found that the sleep disturbance which occurred because they needed to monitor blood glucose levels overnight was exhausting. Most families were accustomed to the pump after approximately two months. Changing the cannula, carbohydrate counting and remembering to bolus was a little challenging for children/adolescents in the beginning but families were able to overcome any problems.

Children/adolescents were more likely to continue using an insulin pump if they perceived they felt more normal despite being attached to a machine. One adolescent did not feel normal being attached to a machine which resulted in the discontinuation of the

pump. This was despite the pump allowing fewer needles, better blood glucose levels and freedom.

## CHAPTER 6: CONCLUSION

The current research study explored the experiences of children and adolescents with type 1 diabetes and their parents when making the transition to insulin pump therapy. This group of families, who participated in the present research study, did quite well in terms of making a smooth transition to insulin pump therapy. There was one mother who found it very difficult compared to what she expected. Ironically she was the one who did the most preparation prior to starting her child on the pump. She had many frustrations about the whole process. Only one mother reported not being prepared for the transition to insulin pump therapy. The reason this group of families did well may be the opportunity they had of talking about diabetes and the insulin pump in more detail with the diabetes educator prior to starting insulin pump therapy. This may have made a difference to the education because the investigator also did the insulin pump education and therefore had additional information about the families when they started on the insulin pump.

Being attached to a pump was identified as a disadvantage by most children/adolescents and parents. However being attached for most children/adolescents made them feel more normal as it allowed them freedom with timing of meals and choice of food and it was easier than injections. One adolescent stopped using the pump because she did not feel normal using the pump. In the interview prior to starting insulin pump therapy she said that the hardest thing about having diabetes was people seeing her as 'having a disease' whereas other children/adolescents found having diabetes not hard; some said the most difficult thing about having diabetes was having needles, the eating, correcting, and not having control. The comment about 'having a disease' may

reflect the adolescents' feelings about having diabetes indicating that she was not as well adjusted to having diabetes as the other children/adolescents.

This research study identified issues which children with type 1 diabetes, adolescents with type 1 diabetes and their parents faced when making the transition to insulin pump therapy. Inserting the cannula, carbohydrate counting and remembering to bolus were the harder things for children to become accustomed to. Adjusting basal and bolus insulin doses were more difficult for parents. Sleep deprivation as a result of night time blood glucose monitoring was also difficult for parents. Set changes and programming the pump were harder for mothers to get used to.

#### Recommendations

Recommendations to improve the education program for children/adolescents with type 1 diabetes and their parents can be developed. The research findings which have been presented can be used to guide this process. This would include educational material including brochures, tip sheets and booklets.

A number of strategies that could be developed include:

- Interviews conducted by the diabetes educator for families prior to starting on an insulin pump to find what concerns they have about using an insulin pump and again three months after starting on the pump to determine the specific difficulties families are having. In the present study interviewing this group of families before starting the pump and three months after starting the pump revealed more information regarding what they thought was difficult and what was easy than otherwise would have been known from a single interview.
- Targeting of education more specifically to the individual needs of families.

- Psychological interventions may also be developed to improve the transition to insulin pump therapy. Strategies could include:
  - Tools, such as stickers on lunch boxes to encourage children/adolescents to remember to bolus.
  - Children/adolescents often do not like insertion of the cannula. Relaxation techniques and behavioural modification to help make cannula insertion easier would be beneficial.

#### Areas for Further Research

This research could be extended by including participants from several hospitals to compare results. The results of the present study suggested that feeling more normal is important for insulin pump therapy to be successful. Further research may clarify if not feeling normal results in discontinuation of insulin pump therapy. Further research could also focus on whether being well adjusted to type 1 diabetes means that transition to insulin pump therapy will be more successful. Success in this situation is measured by improved glycaemic control and improved quality of life. Further research looking at group versus individual education for families starting on a pump may be warranted in the future.

#### Limitations

Only a small number of participants were recruited for this study from one hospital in Brisbane and may not be representative of the whole population. The population includes all children/adolescents making the transition to insulin pump therapy. Therefore the findings may not be generalised to the rest of the population. The families in this study were also considered good candidates to start on insulin pump

therapy so the results cannot be generalised to families who may not meet the criteria as well.

A limitation of the methodology was that the qualitative data was not coded by a second person. It was anticipated that a focus group held at approximately six months after starting insulin pump therapy might add more information to the study. However the focus group was not included in the thesis due to time constraints. All information regarding the study therefore was not reported.

### Chapter Summary

This study explored the experiences of children/adolescents and their parents when making the transition to insulin pump therapy. Before starting on an insulin pump their lives were ruled by planning, lack of freedom and injections. The main reason children/adolescents wanted to use a pump was so they would have fewer injections. Parents thought the pump would achieve freedom in timing of meals and choice of food, and better blood glucose levels. The most common concern of parents was long term health of their children/adolescents. Starting on an insulin pump represented freedom, yet being attached. The results of this study differed from previous studies as it identifies why a child/adolescent may not be happy using an insulin pump. Feeling more normal or not feeling normal meant the difference between using the pump and not using the pump. One adolescent stopped using the pump because she did not feel normal. Children/adolescents using the pump felt happier. The adolescent not using the pump was moody while using the pump and felt happier when she stopped using the pump.

Children found inserting the infusion set, carbohydrate counting and remembering to bolus was the hardest when getting used to insulin pump therapy. They said that giving the bolus was easy. Programming of the pump was not difficult for adolescents.

For mothers the most difficult task was adjusting insulin doses, set changes and programming the pump. Parents of the adolescents did not have much to do with programming of the pump and did not know much about it. Most families in this study were managing diabetes using the insulin pump well with an improvement in HbA<sub>1c</sub>.

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Appendix A

**INFORMATION SHEET FOR OLDER CHILDREN**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their Parents making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children's Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

**What is this information about?**

You are invited to take part in the research project because you have type 1 diabetes and changing to the insulin pump. The purpose of the research is to understand the experiences of children with type 1 diabetes and their parents when changing to the insulin pump.

If you agree to take part in the research project you will answer a survey and be interviewed before you start the insulin pump. You can be interviewed with your parents present. The interview will take about ½ hour. All care will be taken in the interview to make you feel comfortable. You will answer a survey and be interviewed again three months after you start the insulin pump. This interview will be longer and take about 1 hour. The interviews will be audio taped. Once transcribed, you and your parents can read what is written to make sure it is accurate. Tapes will be kept in a locked filing cabinet until the dissertation is passed and then will be disposed of in hospital medical waste and incinerated. You will be asked to keep a diary recording your experiences about the insulin pump. Your HbA1c will be recorded before you start the insulin pump and again in three months.

**What will happen to the information?**

The information will be analysed and reported as part of my Master of Health thesis.

**What are the possible risks in taking part?**

There are no known risks. However it is possible that you could become upset when remembering an unhappy incident with the pump. If this happens the interview will be stopped.

**What are the possible benefits of taking part?**

There may be no benefit from taking part in the research project. The only benefit is the knowledge that you will be helping us understand the experiences of children with type 1 diabetes and their parents when they change to an insulin pump.

**Are my details confidential?**

At the time of consent all information is confidential. Your identity will not be reported in the research results. The Mater Health Services Human Research Ethics Committee has approved this research project and may wish to check the data collected. Participants' identities, but not individual research results may be disclosed.

**Do I have a choice?**

Participation is voluntary and if you do not wish to take part you do not have to. Your care in the clinic or your relationship with the staff will not be changed in any way. You may withdraw at any time if you change your mind.

**Who do I contact for further information or if I have any problems**

If you need more information or have any problems about this project, you can contact the principle researcher, Roslyn Pay (Phone: 3163 8937) or Dr Andrew Cotterill (Phone: 3163 1741).

**Who do I contact if I have a complaint?**

You may contact the Research Secretariat 3163 1585 if you have any complaints about the way the research is carried out or if you have any concerns. The Research Secretariat may contact the Patient Representative or Hospital Ethicist at its discretion.

**Is there any feedback about the research results?**

The results of this research project will be reported to parents in a focus group. Results also will be published in scientific journals. You will not be identified in any way.

**What are the costs, compensation and treatment?**

Your parents are responsible for all medical costs including admission to Mater Children's Private Hospital to start the insulin pump. Your health fund will cover the cost of the pump or you can buy or rent the pump. There will be no extra costs for participants in the project.

**ASSENT FORM FOR OLDER CHILDREN**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children’s Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

I have:

- read or have had read to me in my first language, and I understand the Participant Information Sheet dated.....
- freely agreed to participate in this project according to the conditions in the Participant Information Sheet;
- been informed I will be given a copy of the Participant Information and Assent Form to keep;
- My doctor has agreed not to reveal my identity and personal details in any publication;
- I agree to the collection of information as described in the Information Sheet.

Participant’s Name:.....

Signature:.....Date.....

Name of Witness:.....

Signature:..... Date.....

Researcher’s Name:.....

Signature:..... Date.....

## **INFORMATION SHEET FOR YOUNGER CHILDREN**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents when making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children's Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

### **What is this information about?**

I am asking you to take part in a research project, and I want to tell you about it. You have decided to get an insulin pump. I would like you to help me by telling me what you think about having diabetes and changing to the insulin pump.

I would like to talk to you and ask some questions before you start using the insulin pump. The time taken to ask these questions would be from a few minutes to ½ hour. I would like to talk to you again in three months after you have been using the insulin pump and ask some more questions. Again the time taken to ask these questions would be from a few minutes to ½ hour. I would also like you to write or draw pictures in a diary.

I hope my research study will help us to learn more about children with type 1 diabetes changing to the insulin pump. What we learn might help us teach children about the pump so they understand it better. Being in this research study is a free choice. You do not have to be in it and, if you do, you can change your mind and stop. There is not anyone who will not be happy with you if you do not want to be in the study. Please ask any questions you might have.

**ASSENT FORM FOR YOUNGER CHILDREN**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents when making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children's Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

Please tick 1 box

I agree to participate in this research study

OR

I do not agree to participate this research study

This has been explained to me by \_\_\_\_\_

\_\_\_\_\_  
Signature of Minor (Participant) Date of signing

\_\_\_\_\_

\_\_\_\_\_  
Print Name of Minor (Participant)

\_\_\_\_\_  
Date of Birth

\_\_\_\_\_  
Signature of consenting Parent/Guardian

\_\_\_\_\_  
Date of signing

\_\_\_\_\_  
Signature of investigator

\_\_\_\_\_  
Date of signing

## ADULT INFORMATION SHEET

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents when making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children's Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

### **What is this information about?**

You are invited to take part in the research project because your child has type 1 diabetes and is changing to the insulin pump. The purpose for the research is to understand the experiences of children with type 1 diabetes and their parents when changing to the insulin pump.

If you agree to take part in the research you will answer some survey questions and be interviewed before your child starts the insulin pump. The interview will take approximately 1 hour. The interview will be audio taped.

Three months after your child starts the insulin pump you will answer survey questions and be interviewed. The interview will take approximately 1½ hours. The interview will be audio taped. All care will be taken in the interviews to make you feel comfortable. Once transcribed you can read what is written to make sure it is accurate. Tapes will be kept in a locked filing cabinet until the dissertation is passed and then disposed of in hospital medical waste and incinerated. You will be asked to keep a diary recording your experiences about the insulin pump.

You will be invited to take part in a focus group approximately six months after your child has started the insulin pump. Research results will be given to you and discussed. Focus groups will be video taped.

### **What will happen to the information?**

The information will be analysed and reported as part of my Master of Health thesis.

### **What are the possible risks in taking part?**

There are no known risks. However, it is possible you could become upset when remembering an unhappy incident with the insulin pump. If this should happen the interview will be stopped.

### **What are the possible benefits of taking part?**

There may be no benefit from taking part in the research. The only benefit is the knowledge that you will be helping us understand the experiences of children with type 1 diabetes and their parents when they change to an insulin pump.

### **Are my details confidential?**

At the time of consent all information is confidential. Your identity will not be reported in the research results. The Mater Health Services Human Research Ethics Committee has approved this research project and may wish to check the data collected. Participants' identities, but not individual research results may be disclosed.

**Do I have a choice?**

Participation is voluntary and if you do not wish to take part you do not have to. Your care in the clinic or your relationship with the staff will not be changed in any way. You may withdraw at any time if you change your mind.

**Who do I contact for further information or if I have any problems?**

If you need more information or if you have any problems concerning the research, you can contact the principal researcher, Roslyn Pay (Phone: 3163 8937), or you can contact Dr Andrew Cotterill (Phone: 3163 1741).

**Who do I contact if I have a complaint?**

You may contact the Research Secretariat 3163 1585 if you have any complaints about the way the research is carried out or if you have any concerns. The Research Secretariat may contact the Patient Representative or Hospital Ethicist at its discretion.

**Is there any feedback about the research results?**

The results of the research will be available and will be reported to parents in a focus group. Results will be published in scientific journals. You will not be identified.

**What are the costs, compensation and treatment?**

You are responsible for all medical costs including admission to Mater Children's Private Hospital for your child to start the insulin pump. Your health fund will cover the cost of the pump or you can buy or rent the pump. There will be no extra costs for participants in the project.

**ADULT CONSENT FORM**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents when making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children’s Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

**Statement of Consent:**

I have read the information sheet (above) and have had the opportunity to ask questions and have had them answered to my satisfaction. I understand that the information will NOT be used for any purpose other than that associated with this project. I understand that I will not benefit directly from this research, and no reimbursement will be provided. I understand I am free to withdraw at any time without penalty. I hereby give consent to participate in the study “ What are the experiences of children with type 1 diabetes and their parents making the transition to insulin pump therapy?” according to the conditions in the information sheet. I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Signatures: .....

Participant Date

.....

Witness Date

.....

Investigator (if applicable) Date

**(NB A copy of the signed statement needs to be given to the participant(s))**

## **PARENT/GUARDIAN INFORMATION SHEET**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents when making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children's Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

### **What is this information about?**

Your child is being invited to take part in the research project because he/she has type 1 diabetes and is changing to the insulin pump. The purpose of the research project is to understand the experiences of children with type 1 diabetes and their parents changing to the insulin pump. If you agree for your child to take part in the project your child will answer some survey questions and be interviewed before starting the insulin pump. It will depend on the age of your child if the survey questions will be answered and how long the interview takes. He/she can be interviewed with you present.

Three months after your child starts the insulin pump he/she will answer survey questions and be interviewed. The interviews will be audio taped. All care will be taken in the interviews to make your child feel comfortable. Once the interviews have been transcribed you and your child can read what is written to make sure it is accurate. Tapes will be kept in a locked filing cabinet until the dissertation is passed and then disposed of in hospital medical waste. Your child will be asked to keep a diary recording his/her experiences about the insulin pump. Younger children who are not able to write can draw pictures.

### **What will happen to the information?**

The information will be analysed and reported as part of my Master of Health thesis.

### **What are the possible risks in taking part?**

There are no known risks. There is the possibility that your child may become upset when remembering an unhappy incident with the insulin pump. If this happens the interview will be stopped.

### **What are the possible benefits of taking part?**

There may be no benefit from taking part in the study. The only benefit is the knowledge that your child will be helping us understand the experiences of children with type 1 diabetes when they change to the insulin pump.

### **Are my details confidential?**

At the time of consent all information is confidential. Your child's identity will not be reported in the research results. The Mater Health Services Human Research Ethics Committee has approved this research project and may wish to check the data collected. Participants' identities, but not individual research results may be disclosed.

**Do I have a choice?**

Participation is voluntary and if you do not wish to take part you do not have to. Your care in the clinic or your relationship with the staff will not be changed in any way. You may withdraw at any time if you change your mind.

**Who do I contact for further information or if I have any problems?**

If you need more information or if you have any problems concerning the research, you can contact the principal researcher, Roslyn Pay (Phone: 3163 8937), or you can contact Dr Andrew Cotterill (Phone: 3163 1741).

**Who do I contact if I have a complaint?**

You may contact the Research Secretariat 3163 1585 should you have any complaints about the way the research is carried out or if you have any concerns. The Research Secretariat may contact the Patient Representative or Hospital Ethicist at its discretion.

**Is there any feedback about the research results?**

The results of this research project will be reported to parents in a focus group. Results also will be published in scientific journals. You will not be identified.

**What are the costs, compensation and treatment?**

You are responsible for all medical costs including admission to Mater Children's Private Hospital for your child to start the insulin pump. Your health fund will cover the cost of the pump or you can buy or rent the pump. There will be no extra costs for participants in the project.

**PARENT/GUARDIAN CONSENT FORM**

**PROJECT TITLE:** What are the experiences of children with type 1 diabetes and their parents when making the transition to insulin pump therapy?

**INVESTIGATOR:** Roslyn Pay RN (Credentialled Diabetes Educator)  
Mater Children’s Hospital  
Phone 3163 8937  
Postgraduate student Master of Health  
University of Southern Queensland

**Statement of Consent:**

I have read the information sheet (above) and have had the opportunity to ask questions and have had them answered to my satisfaction. I understand that the information will NOT be used for any purpose other than that associated with this project. I understand that I will not benefit directly from this research, and no reimbursement will be provided. I understand I am free to withdraw at any time without penalty. I hereby give consent to participate in the study “ What are the experiences of children with type 1 diabetes and their parents making the transition to insulin pump therapy?” according to the conditions in the information sheet. I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Signatures: .....

Participant Date

.....

Witness Date

.....

Investigator (if applicable) Date

**(NB A copy of the signed statement needs to be given to the participant(s))**

Appendix B

*Interview schedule for parents*

**Date**.....**Age of child**.....

**Duration of diabetes**..... **Gender**.....

**HbA1c** (prior to commencing insulin pump therapy).....

*Questions to be asked prior to commencing insulin pump therapy.*

1. How do you think having a child with diabetes has affected your life?
2. Where did you first hear about the insulin pump?
3. Why did you decide to use the insulin pump?
4. How do you think the insulin pump will change your life?
5. What do you think the benefits of using an insulin pump will be?
6. What do you think the disadvantages will be?
7. Please say what concerns you have about hypoglycaemia.
8. Please say what concerns you have about high blood glucose levels.
9. If your child has had ketones at any time how unwell was your child?
10. Please say what problems you have had with giving your child insulin injections?
11. What concerns do you have about other people managing your child's diabetes?
12. What concerns do you have about school personnel managing your child's diabetes?
13. What supports do you have to help manage your child's diabetes?
14. How do you cope with managing your child's diabetes?
15. What concerns/worries do you have about your child's diabetes?
16. What do you find most difficult about the diabetes regime?
17. Who is responsible for the diabetes management?
18. What are your expectations of your child regarding diabetes care?
19. Please say what conflict there is between you and your child regarding diabetes care if there is any?
20. What are your biggest concerns/challenges at present?
21. Is there anything else you would like to add about your experience with diabetes?
22. If you have any concerns about changing to an insulin pump please say what they are.

*Questions to be asked after commencing insulin pump therapy.*

**HbA1C** (after commencing insulin pump therapy).....

**Insulin Pump**.....

1. How would you describe the experience of changing over to the insulin pump?
2. How satisfied are you with the insulin pump?
3. What are the benefits of using an insulin pump?
4. What are the disadvantages of using an insulin pump?
5. What did you find most difficult when getting used to the insulin pump?
6. What was easy about getting use to the pump?
7. What features of the pump do you use?
8. How has your child's behaviour changed?
9. How does diabetes affect your life now that your child is using an insulin pump?
10. How long did it take you to get used to the insulin pump?
11. How have you managed high BGLs?
12. When do you check for ketones?
13. If there have been ketones since starting the insulin pump, how did you manage?
14. If your child has had any sick days since starting the insulin pump, how did you manage?
15. How have you managed exercise with the insulin pump?
16. If you have had problems with cannulas kinking, skin irritation, air bubbles or infection what did you do to overcome the problem?
17. Can you please say what problems, if any you have had with carbohydrate counting?
18. How do you manage your child's pump at school?
19. Please say what problems are related to your child wearing an insulin pump if there are any.
20. Was suitable education provided for you?
21. What suggestions can you make that would improve the education process?
22. What strategies do you think would help people contemplating using the insulin pump?
23. Who looks after the management of diabetes?

24. If not bolusing for meals has been a problem what have you done to overcome the problem?
25. What worries do you have about your child's diabetes?
26. What stress has the insulin pump caused for you?
27. What support have you got?
28. What difficulties have you had in getting used to thinking differently about diabetes now that your child is using a pump?
29. What are your biggest concerns/challenges at present?
30. Is there anything you would like to add about your experience with insulin pump therapy so far?
31. What help or advice would you offer to other children and families considering the insulin pump?

Appendix C

*Interview schedule for children*

**Date**.....**Age**.....**Duration of diabetes**.....

**HbA1c** (prior to commencing insulin pump therapy).....

*Questions to be asked prior to commencing insulin pump therapy.*

1. How do you think having diabetes has affected your life?
2. Who told you about the insulin pump?
3. Why do you want an insulin pump?
4. How will things be different with the pump?
5. What do you think will be good about having an insulin pump?
6. What do you think will not be so good about an insulin pump?
7. How many blood glucose levels (BGLs) do you do each day?
8. How does hypoglycaemia affect you?
9. Who gives the injections?
10. What questions do you have about the insulin pump?
11. Can you sleep over at your friend's place?
12. Where do you do your finger prick at school?
13. Where is your meter kept at school?
14. Where is your hypo pack kept at school?
15. What do you find the hardest part about having diabetes?
16. Which pump have you chosen?
17. Why do you like that pump?

*Questions for children to be asked after commencing insulin pump therapy.*

**HbA1C** (after commencing insulin pump therapy).....

**Pump**.....

1. Tell me about the insulin pump?
2. Do you like the pump? No  Yes
3. Why do you like the pump or why don't you like the pump?
4. What did you find the hardest about getting used to the insulin pump?
5. What was easy?
6. How do you feel now?
7. What is different now with the pump than before you had the pump?
8. How often do you do finger pricks?
9. What is good about using an insulin pump?
10. What is not so good about using an insulin pump?
11. Where do you wear your insulin pump?
12. Where do you put it when you go to bed?
13. Do you press the buttons on the pump?
14. Who looks after the pump when you are at school?
15. Who changes the sets?
16. Are there any problems changing the set?
17. Do you sometimes forget to bolus?
18. What helps you remember to bolus?
19. Can you go on sleepovers with your friends?
20. Can you disconnect the pump yourself?
21. What do you do with the pump when you take it off?
22. Is there anything else you would like to tell me about the pump?
23. What would you say to other children thinking about using a pump?

Appendix D

**Survey Questions**

*Question for parents to be asked prior to commencing insulin pump therapy.*

**Date**..... **Age of child**.....

**Gender** ..... **Duration of diabetes**.....

**HbA1c** (prior to commencing insulin pump therapy).....

1. How many times a day do you check the blood glucose at present?	
2. Do you adjust insulin doses?	Yes <input type="checkbox"/> No <input type="checkbox"/>
3. Do you have any concerns about hypos?	Yes <input type="checkbox"/> No <input type="checkbox"/>
4. Do you have any concerns about high BGLs?	Yes <input type="checkbox"/> No <input type="checkbox"/>
5. Do you check ketones?	Yes <input type="checkbox"/> No <input type="checkbox"/>
6. Do you check for blood or urine ketones?	Blood <input type="checkbox"/> Urine <input type="checkbox"/>
7. Has your child had ketones at any time?	Yes <input type="checkbox"/> No <input type="checkbox"/>
8. Are there any problems with giving the insulin injections?	Yes <input type="checkbox"/> No <input type="checkbox"/>
9. Who gives the insulin injections?	
10. Are you able to get someone to baby sit your child if needed?	Yes <input type="checkbox"/> No <input type="checkbox"/>
11. Do you have any problems managing your child's diabetes?	Yes <input type="checkbox"/> No <input type="checkbox"/>
12. Is there conflict between you and your child regarding diabetes care?	Yes <input type="checkbox"/> No <input type="checkbox"/>

Transition to insulin pump therapy

*Questions for parents to be asked after commencing insulin pump therapy.*

**HbA1c** (3 months after commencing insulin pump therapy).....

**Insulin pump**.....

1. How prepared were you for your child's transition to the insulin pump?	Not prepared <input type="checkbox"/> Slightly prepared <input type="checkbox"/> Well prepared <input type="checkbox"/>
2. How difficult is the pump compared to what you expected?	Not difficult <input type="checkbox"/> Slightly difficult <input type="checkbox"/> Very difficult <input type="checkbox"/>
3. Has your child had ketones since starting the insulin pump?	Yes <input type="checkbox"/> No <input type="checkbox"/>
4. Has your child had any sick days since starting the insulin pump?	Yes <input type="checkbox"/> No <input type="checkbox"/>
5. Have you had any problems with: <ul style="list-style-type: none"> <li>• cannulas kinking</li> <li>• skin irritation</li> <li>• air bubbles</li> <li>• infections</li> </ul>	Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/>
6. Do you make adjustments to basal rates and bolus insulin doses?	Yes <input type="checkbox"/> No <input type="checkbox"/>
7. How often do you check BGLs?	
8. Have you had any problems with carbohydrate counting?	Yes <input type="checkbox"/> No <input type="checkbox"/>
9. Does your child sometimes forget to bolus for meals?	Yes <input type="checkbox"/> No <input type="checkbox"/>
10. How many times per week does your child forget to bolus?	
11. Can you leave your child with other people?	Yes <input type="checkbox"/> No <input type="checkbox"/>
12. Do you think you have enough knowledge about insulin pump therapy?	Yes <input type="checkbox"/> No <input type="checkbox"/>
13. Have you purchased special belts or cases or other pump-wear?	Yes <input type="checkbox"/> No <input type="checkbox"/>
14. Are there any problems related to your child wearing an insulin pump?	Yes <input type="checkbox"/> No <input type="checkbox"/>
15. Is there conflict between you and your child regarding diabetes care?	Yes <input type="checkbox"/> No <input type="checkbox"/>