

Health Psychology: The Psychological Impact of Managing and Treating Type-I
Diabetes for Children

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Abstract

Type-1 Diabetes Mellitus (T1DM) is a complex chronic illness which requires intensive insulin replacement treatment via Multiple Daily needle Injections (MDI) or Continuous Subcutaneous Insulin Injections (CSII). Both treatment options cause significant disruptions to the lives of diagnosed children and their families, and are difficult to integrate with everyday life. To improve one's quality of life and minimise treatment disruptions as well as medical outcomes, consideration of the psychosocial functioning of children with T1DM becomes an important issue.

This thesis is presented in the form of two stand-alone pieces of work. The first is a systematic review of quantitative research investigating the psychosocial impact of transitioning to CSII for children. Studies that met the inclusion criteria investigated a range of constructs, indicative of a diverse area of research. Such constructs included child cognitive and emotional functioning, quality of life, impact of treatment, eating patterns, as well as parental and family functioning. Overall published research indicated a trend toward a neutral or positive psychosocial impact of transitioning to CSII for children. In summary, the use of CSII in children appears to be supported by improvements in psychosocial factors in addition to small yet significant medical benefits.

The second study used a qualitative approach to understanding the impact of T1DM and its treatment from the child's own perspective. This approach sought to expand the range of issues addressed and build on current quantitative findings that typically investigate specific variables of interest selected by the researcher. Qualitative interviews, with 17 children (aged 7 to 15) at two different time points in their treatment, sought to holistically understand the child's experience of T1DM and the experience of the transition from MDI to CSII. Interviews were analysed using Grounded Theory coding (Glaser, 1979; Strauss & Corbin, 1990), leading to the development of the *Transitional Stages Model of Treatment and Coping*. This model describes key stages of transition and adaptation for children starting with the onset of undiagnosed, vague symptoms. Of particular interest within this model were shifts in the embodiment and interpretation of one's own bodily cues at each of these stages. Further, children did not seem to strive toward 'normality' or autonomy as treatment goals. Instead it was important for children with T1DM to feel supported in a network termed the *distributed system of management*, involving parents, teachers, peers and technology. Implications for clinical practice and opportunities for psychological intervention are also discussed.

Statement of Candidate

I certify that the research described in this dissertation has not already been submitted for any other degree.

I certify that this submission is my own work and that to the best of my knowledge all sources used and any help received in the preparation of this dissertation have been acknowledged.

Signature _____

Madeleine I. Fraser

Date _____

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General Introduction

Type-1 Diabetes Mellitus (T1DM) is a complex and demanding chronic illness typically diagnosed in early childhood. There is currently no cure for T1DM and incidence rates in children continue to rise (Haynes, Bower, Bulsara, Jones, & Davis, 2004; Patterson, Dahlquist, Gyurus, Green & Solte, 2009). T1DM is an autoimmune disease characterised by a loss of insulin production in the pancreas. Insulin directly moderates the glucose levels of the blood, and large fluctuations in levels have been linked with serious complications and hypoglycaemic events involving seizures, unconsciousness or even death (Misso et al., 2010). Treatment strives to maintain a stable blood-glucose balance and reduce these risks (American Diabetes Association, 2004).

Traditionally T1DM treatment is based on the use of Multiple Daily Injections (MDI), which uses up to 6 needles daily to administer insulin injections according to a strict routine. Recently Continuous Subcutaneous Insulin Infusion (CSII), also known as insulin pump therapy, has become increasingly recognised as a preferred treatment option for children with T1DM. This is in part due to the increased lifestyle flexibility it offers (Walsh & Roberts, 1994). CSII continuously delivers basal insulin to the individual through a portable electronic device, with user activated bolus doses for food and glucose corrections. As a result, CSII more accurately mimics the insulin release of the normal pancreas. Whilst both treatment options can be highly effective at managing the medical features of the condition for diagnosed children, both cause significant disruptions to everyday life and can be difficult for families to adjust to. Thus the behavioural and psychological functioning of the child and family directly influences the effectiveness of such intensive and demanding treatment.

Psychological research has an important role in identifying factors that may contribute to minimising the impact of intensive treatment plans and thus improving the quality of children's lives. This thesis seeks to contribute to a growing body of research that investigates links between T1DM and psychological functioning and wellbeing. This thesis also sought to examine children's lived experience of their illness in more detail and from their perspective. Of specific interest is their experience of the psychological impact of CSII treatment in comparison to MDI. Thus this thesis begins with a systematic review of relevant literature.

In Australia, approximately 10% of people with T1DM use an insulin pump, and almost half of all insulin pump users are under 25 years old (Australian Institute of Health and Welfare 2012). The newer CSII technology has been linked with small yet significant improvements in medical outcomes (Jeha, et al., 2005; O'Connell, et al, 2009; Pickup & Sutton, 2002; Retnakaran et al., 2004). Importantly, emerging research from endocrinologists, diabetes nurse educators and diagnosed children themselves, suggests that one significant

feature of CSII technology is its beneficial impact on psychosocial factors. Current research investigating psychosocial factors associated with CSII treatment is new and starting to expand, addressing mental health, quality of life, treatment satisfaction and even parental psychological functioning.

Such research is important as psychological factors have an instrumental role in the management of chronic illnesses. Psychological wellbeing has been linked with improved self-care management, reduced stress and reduced strain on the physical body (Redmer, Longmier & Wedel, 2013; Surwit et al., 2002). Better understanding the role of psychological and behavioural factors for those living with chronic illness may lead to both improved quality of life and medical outcomes. Furthermore, children are an important population whose voices are often overlooked. Children present unique challenges to the management of illnesses as they have needs regarding continuing emotional and physical development (Woodgate, 1998). This means research should focus on child and adult populations in ways that are alive to the possible differences, rather than attempting to generalise results from adult findings that may not be applicable and that may miss crucial concerns for the younger age group. Also, research investigating the psychological functioning of children with T1DM is important given that such factors may have long term impacts on physical and psychological health. Identifying such factors and targeting them with early psychologically orientated interventions may lead to positive shifts in the lifespan trajectory of that child's physical illness, ability to manage the illness and overall psychological wellbeing.

As it stands, currently there is no review of literature summarising and drawing together these recent studies that investigate the impact that CSII has on the psychosocial functioning of the child and their immediate family. Furthermore, there is also a lack of research that adopts qualitative methods to gain insight into the lives of children living with this disease. Research acknowledging children's perspective is limited, and may fail to capture what is important or meaningful, particularly in relation to managing their illness day-to-day and transitioning to CSII.

Thus this thesis had two research aims. Firstly, to systematically review published studies investigating the psychological impacts of using CSII for children in comparison to MDI. This review also aimed to identify which psychological factors current research focuses on, and the psychometric tools used to ascertain this information. Secondly, this thesis was interested in better understanding the lived experience of T1DM and the process of transitioning to CSII, from the perspective of the children themselves. This thesis explored these research aims in two stand-alone, yet inter-linked, studies - a systematic review and a qualitative study.

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STUDY 1

Target journal: Psychoneuroendocrinology

Title: The Psychosocial Impact of Transitioning to CSII for Children with Type-1 Diabetes: A Systematic Review
(Original Research)

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Key words: *Systematic review, CSII, insulin pump therapy, psychological outcomes, children, type 1 diabetes*

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Abstract

Continuous Subcutaneous Insulin Infusion (CSII) offers increased lifestyle flexibility and improved blood-glucose control for children with Type-1 Diabetes Mellitus (T1DM). Clinically significant yet small improvements in medical outcomes have been found for children who transition to CSII compared to Multiple Daily needle Injections (MDI). An emerging body of research has begun to recognise that CSII also influences the psychosocial functioning of children with T1DM. However a critical synthesis of research in this area is notably lacking. The present study conducted a systematic review and quality analysis of existing publications that investigate a psychosocial construct in relation to CSII use for children. The findings support CSII as a treatment option for children with T1DM. CSII does not appear to diminish psychological or behavioural functioning, but rather is linked with a maintenance or even improvement in functioning across a range of psychological, emotional and behavioural scales. This review contributes to a holistic understanding of CSII use in children.

Key words: *Systematic review, CSII, insulin pump therapy, psychological outcomes, children, type 1 diabetes*

1. Introduction

Children diagnosed with type-1 diabetes mellitus (T1DM) and their families are required to implement and maintain a treatment regimen that influences every aspect of daily life (Bierschbach, Cooper & Liedl, 2004). Traditionally treatment has depended on the use of Multiple Daily Injections (MDI), which requires multiple daily needle injections to administer insulin according to a strict routine. Recently Continuous Subcutaneous Insulin Infusion (CSII), also known as insulin pump therapy, is increasingly recognised as a preferred treatment option for children with T1DM given the increased lifestyle flexibility it offers (Walsh & Roberts, 1994). CSII continuously delivers basal insulin to the child through a portable electronic device, with user activated bolus doses for food and glucose corrections. As a result, CSII more accurately mimics the insulin release of the normal pancreas. CSII has been linked with a small but significant improvement in medical outcomes by a large body of research (Misso, Egberts, Page, O'Connor, & Shaw, 2010; Pickup & Sutton, 2008; Pańkowska Blazik, Dziechciarz, Szypowska, & Szajewska, 2009). In contrast, addressing what might be the psychosocial outcomes of CSII remain a relatively new area of research. Due to the high financial cost and small improvement in medical outcomes, the overall cost effectiveness of CSII has been raised as an important issue.

1.1. Medical Benefits of CSII

CSII offers a higher precision of insulin replacement than MDI (O'Connell & Cameron, 2008). In children and adolescents, CSII has been linked to decreased blood glucose variability, (Jeha, et al., 2005; O'Connell, et al, 2009; Pickup et al., 2002) and a reduced risk of hypoglycemic episodes (Fredheim et al., 2013; Hoogma et al., 2006; Nimri et al., 2006; Pickup et al., 2002; Retnakaran et al., 2004). Hypoglycemia is a medical emergency defined by a diminished level of glucose in the blood. Its effects range from mild dysphoria to more serious complications such as seizures, unconsciousness or even death. A Cochrane review (Misso et al., 2010) found that CSII was linked with a reduction in non-severe hypoglycaemic events compared to MDI, however there was no difference for severe hypoglycaemic events. Overall there are mixed findings regarding the extent to which CSII improves medical outcomes.

Greater stability of blood glucose levels fostered by CSII has also been linked with a decreased risk of other complications; however research in this area also remains inconclusive. The Diabetes Control and Complications Trial Research Group (2006) found that the risk of microvascular complications extends over the entire range of blood glucose levels and fluctuations. This means that for people with diabetes, there is no threshold (short

of normal glycaemia patterns) below which there is no risk. Yet larger fluctuations in blood glucose levels have been linked with a greater risk of long-term health complications such as peripheral neuropathy, blindness, heart disease, kidney failure and limb amputation (Bragd et al., 2008; The Diabetes Control and Complications Trial Research Group, 1993; Hirsch, 2005). Studies focusing on pediatric hospital in-patient populations have also found that increased glucose variability is associated with increased morbidity and mortality rates (Rake, Srinivasan, Nadkarni, Kaptan, & Newth, 2010; Wintergerst et al., 2006). These findings emphasise the importance of implementing treatment programs that are able to maintain the most stable blood-glucose levels possible. This means that even small improvements in blood-glucose levels associated with CSII may have a large impact on the risk of developing later complications.

CSII has also been linked to a small but clinically significant reduction in HbA1c levels (Bruttomesso, Costa & Baritussio, 2009; Litton et al., 2002; Monami, Lamanna, Marchionni & Mannucci, 2010). HbA1c laboratory tests measure the average level of glucose in the blood over the three-month period and are often used as an indicator of diabetes management efficacy. Colquitt, Green, Sidhu, Hartwell and Waugh's (2004) systematic review reported an overall 0.5% reduction in HbA1c for children using CSII compared to MDI. Despite this reduction, HbA1c levels whilst using CSII remain higher than the value recommended by international consensus guidelines of 7.5% (Rewers et al., 2009). A multi-centre matched-pair cohort analysis ($N = 434$ pairs) found that HbA1c results were significantly lower for the first year after commencing CSII compared to MDI. HbA1c readings tended to rise, however, to the same level as in the MDI group during the third year of treatment (Jakisch, et al., 2008). Therefore while medical improvements have been linked with CSII, these improvements are somewhat temporally limited.

Having established the important but limited medical benefits of CSII, the high financial cost must be acknowledged. Colquitt, Green, Sidhu, Hartwell and Waugh (2004) estimated the additional cost of CSII compared to MDI was between £1,091 to £1,680 per annum, depending on the make of the pump and life of the device. In most Western countries, private health insurance covers the costs of the pump. For example, approximately 80% of Australian CSII users obtain a private health insurance rebate for the purchase of their pump (Australian Institute of Health and Welfare, 2012). These expenses raise the issue of the overall cost effectiveness of CSII as a critical question for insurance companies and government healthcare funding. This is likely to become more important given the increasing rate of diagnosis of T1DM in children, and reluctance for insurance companies to cover the

cost of more expensive CSII treatment when there is a cheaper alternative, MDI, with similar medical outcomes (Patterson, Dahlquist, Gyurus, Green & Soltez, 2009).

1.2. A Holistic Approach

In response to the question of cost effectiveness, it is important to understand holistically the psychological and social impact of CSII for children and their families in addition to medical outcomes. This is particularly the case as T1DM is a self-managed condition whereby outcomes are closely linked to specific and intensive self-care behaviours. The Biopsychosocial model of health (Engel, 1977) argues that patient wellbeing is contingent on not only physical health outcomes, but also social, psychological and behavioural factors. A key component of the Biopsychosocial model is the child's overall quality of life, defined as the overall state of physical, mental and social wellbeing rather than merely the absence of disease (WHO, 1947). The impact of such factors unavoidably influence the extent to which daily treatment requirements can be followed, which in turn encourages normal growth and development (American Diabetes Association, 2004).

The consideration of psychological factors are of particular importance because children with diabetes have an increased risk of adverse mental health outcomes (Northam, Lin, Finch, Werther, & Cameron, 2010; Northam, Matthews, Anderson, & Cameron, 2005), with prior research finding rates two to three times higher than in the general population (Blanz, Rensch-Riemann, Fritz-Sigmund, & Schmidt, 1993; Kovacs, Goldstron, Obrosky, & Bonar, 1997). A more recent meta-analytic review (Reynolds & Helgeson, 2011) found that compared to controls, children with diabetes had a slighted elevated risk for psychological difficulties such as depression, anxiety and behavioural problems. Furthermore, children with T1DM are a population with unique physiological and psychological characteristics compared to adults. Illustratively, recent research has highlighted a link between an onset of T1DM during puberty and an accelerated risk of developing medical complications (Cho, Craig, & Donaghue, 2014). Further differences between children and adults can include difficulties understanding the complex endocrine system, stigma concerns arising from their sensitivity to how they are viewed by their peers (Battista, Hart, Greco, & Gloizer, 2009) and the involvement of multiple parties in the child's care including family, parents and teachers (Dantzer, Swendsen, Maurice-Tison, & Salamon, 2003; Compas, Connor-Smith, Saltzman, Thomsen, & Wadsworth, 2001).

1.3. Previous Literature Reviews

While a number of reviews focusing on CSII and psychological outcomes currently exist, they often focus exclusively on quality of life measures and restrict their inclusion

criteria to randomized control trials (RCT). This is problematic given there is a large number of more recent and informative studies that do not conform to these criteria. Barnard, Lloyd and Skinner (2006) conducted a systematic review focusing exclusively on quality of life outcomes associated with CSII use for both child and adult populations. Specifically, the authors reviewed nine paediatric articles and found mixed support for quality of life outcomes related to CSII use. They argue that the lack of a robust outcome is primarily due to the inconsistent use of measurement tools, the questionable sensitivity of these tools in detecting meaningful differences and poor methodologies utilized (Barnard et al., 2006). Focusing on child populations, Pańkowska et al.'s (2009) systematic review commented on four RCTs investigating the psychological impact of CSII compared to MDI. Whilst treatment satisfaction and quality of life scores tended to be higher for children using CSII, the use of different quality of life scales led Pańkowska et al. (2009) also to argue that no firm conclusions could be drawn.

Churchill, Ruppe and Smaldone (2009) conducted a systematic review on parental quality of life and satisfaction outcomes for children aged less than seven years. Seven RCTs were included in their review and found high variability in the assessment tools used across the studies. The authors conclude that CSII was consistently associated with improved parental quality of life, particularly for fathers. To date, existing systematic reviews tend to report an improvement in quality of life after transferring to CSII, or remain inconclusive. This body of work emphasises the importance of acknowledging psychological factors in relation to the care of T1DM for children, particularly in relation to newer technologies and treatments.

An important limitation of the applicability of these reviews to current clinical practice is the dated publications included. Many insulin pumps used in the 1990s or earlier are now considered obsolete and are no longer in circulation. CSII technology has rapidly progressed and newer pump models are more advanced. For example, newer pumps include features such as a bolus calculator that considerably increases the utility of these devices (Ziegler, et al., 2013). Thus it is important that current clinical practice is based on the most recent and relevant research that evaluates current treatments. Pańkowska et al. (2009) searched for articles published between 1966 and 2007, including a study published in 1982. Similarly, Barnard, Lloyd and Skinner (2006) searched for any articles prior to 2005, including articles published in 1988. Given data are often collected years prior to publication date, these timeframes suggest the conclusions of previous reviews may not generalise to current clinical practice and technology.

There is no current systematic review that examines the broad, holistic psychological impact of CSII in paediatric populations. Accordingly, the primary objective of the current review is to systematically evaluate published studies investigating the psychological impacts of using CSII for children in comparison to MDI. Psychological factors are broadly defined as emotional, socio-cultural, cognitive or behavioural functioning and studies are included which use any validated measure of these parameters. It is hypothesised that CSII is associated with improved psychological outcomes (relative to MDI), potentially including factors such as quality of life, treatment satisfaction, emotional regulation and cognitive functioning for children. Of secondary interest is identifying which psychological factors current research focuses on, and the psychometric tools used to ascertain this information. This paper seeks to extend earlier reviews by including research designs such as cross-sectional and correlational studies, in addition to RCTs, and also to broadly examine any variables related to a psychological outcome, beyond quality of life measures.

2. Method

2.1. Literature Search Strategy

Electronic literature searches were conducted in April 2013 using the following databases; PsycInfo, Ovid Medline, Embase, Cinhal and Scopus. The search terms used across the five databases are listed in Table 1. In addition, reference lists from selected studies were searched for relevant titles.

Table 1: Search terms

Search	Search Terms
1	((insulin-dependent diabetes mellitus or IDDM or type 1 diabetes or childhood onset diabetes) not type 2).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
2	(insulin pump or CSII or continuous subcutaneous insulin infusion).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
3	(psycholog\$ or mental or distress or self-care or satisfaction or emotion or cognition or well-being or social\$ or outcome).mp. [mp=title, original title, abstract, name of substance word, subject heading word, unique identifier]
4	1 and 2 and 3
5	limit 4 to ("infant <to one year>" or "child <unspecified age>" or "preschool child <1 to 6 years>" or "school child <7 to 12 years>" or "adolescent <13 to 17 years>") and to (English language and yr="1993 -Current")

2.2. Inclusion and Exclusion Criteria

The inclusion and exclusion criteria of the current review, established a priori, are summarised in Table 2. Given advances in CSII technology and the requirement of up-to-date

data on contemporary technology, the current review was limited to peer-reviewed publications since 1993 (Neylon, O'Connell, Skinner & Cameron, 2013). The most pertinent inclusion criterion was the use of a validated psychological measurement scale. Psychological outcomes were intentionally broadly defined given that a goal of this review was to ascertain the focus of current research in this area. Hence they cover emotional, cognitive, behavioural or subjective experiences. Measurement scales used to assess these parameters of psychological functioning could be assessed independently or alongside biophysical or medical measures. Studies that investigated psychological outcomes but did not utilise a validated scale were not included in the current review. These include, for example, open-ended questions about patient experiences of CSII. Such studies are addressed in a separate paper outlining qualitative indices of young patient's experiences (Fraser, McIlwain, & Ambler, 2014).

Table 2: Inclusion and Exclusion Criteria

Criterion	Inclusion Criteria	Exclusion Criteria
Type of Participants	Children aged 0 - 20 years	Adults aged > 20 years
	Diagnosis of type 1 diabetes	Diagnosis of type 2 or gestational diabetes
	≥ 10 participants	≤ 9 participants
Type of Intervention	CSII, Insulin Pump Therapy	Daily insulin injections
Type of Outcome	At least one outcome related to a psychological outcome is measured using a validated scale	No reference to psychological outcomes using a validated scale
Type of Studies	Randomized control trials, Cohort studies and Non-randomized studies	Anecdotal, Expert opinion, Manual, Case reports or Case studies
	Written in English language	Not written in English
	Published studies	Incomplete or unpublished research projects
	Within subjects or between subjects design	No comparative group
	Published between January 1993 and April 2013	Published before January 1993 or later than April 2013

2.3. Methodological Quality

It is crucial to assess the methodological quality of published papers to avoid undue weight being allocated to studies that are not as strong in methodological rigour (Jüni, Altman & Egger, 2001; Valentine & Cooper, 2008). All articles were rated by Kennelly's (2011) modified version of the Methodological Quality Checklist, originally developed by Downs and Black (1998). This checklist was selected given its capacity to assess the quality of both

randomised and non-randomised studies, specifically related to health care interventions (Jarde, Losilla & Vives, 2012). The quality appraisal was not done in a blinded fashion, given such practice has not been found to affect the ultimate results of a systematic review (Jadad et al., 1996). Small modifications and points of clarification were added to the original checklist by the authors to increase the relevancy for the present research question (see Appendix A).

2.4. Data Extraction

Publications identified by the database searches were exported into and managed by EndNote (V5) software. Publication selection for the current review involved a multi-step process, outlined in the flow chart displayed in Figure 1. Titles and abstracts were scanned for relevance against the inclusion and exclusion criteria by one author (MF). The full text of an article was examined when an abstract would not be rejected with certainty. From the initial 756 articles identified by the database search, 29 publications met eligibility criteria and were included in the current review. One author (MF) completed data extraction and quality assessment scoring. A second author (TA) independently extracted and quality scored 40% of the articles. Discrepancies between the reviewers were resolved by discussion, and following this an interrater reliability analysis using the Kappa statistic was performed to determine consistency among raters.

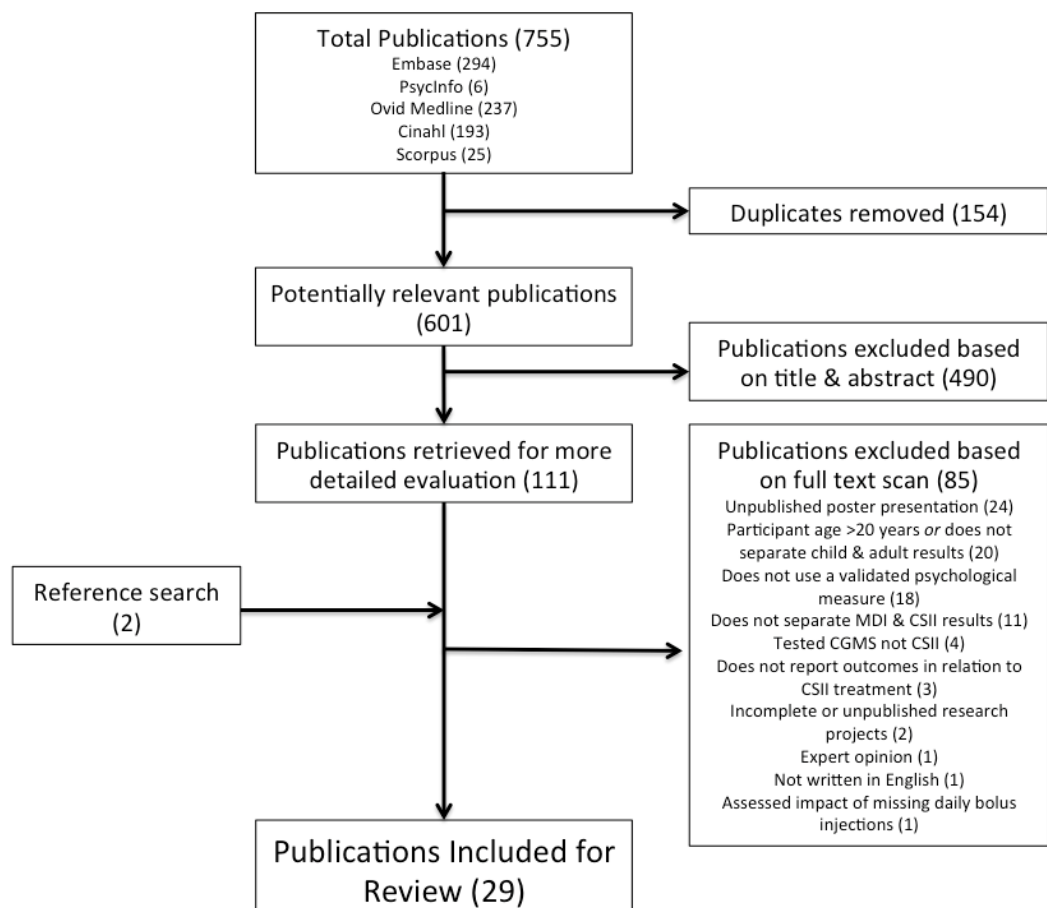


Figure 1: Flowchart outlining selection process of relevant articles

3. Results

3.1. *Characteristics of the Selected Studies*

A total of 29 studies met inclusion criteria. The aim of most studies ($N = 22$) was directly relevant to the current research question of investigating the impact of CSII on psychological functioning. Of the seven studies that examined different hypotheses, enough detail was provided to extract data relevant to the current review. Given that variables of interest can yield different patterns of effects across within and between-subject experiments (Greene, 1996), the type of experimental design used was also acknowledged (see Table 4, Column 10).

Two studies reported on the same data set. The first reported participant data at baseline, six and eight weeks later (Knight et al., 2009), the second reported on the same participants 24 months later (Knight, Northman, Cameron & Ambler, 2011), with an 84 percent retention rate of participants from the initial study. To avoid unduly inflating the influence of this sample, these two studies were treated as one in the current analysis (reported as Knight et al., 2011), with relevant results extracted from each.

Of these 29 studies, participant numbers varied from 16 to 300 ($M = 78.2$, $SD = 71.6$). 19 of the studies included a control group, and an additional three studies referenced a previously published control group from a separate study (Mednick, Cogen & Streissand, 2004; Markowitz, Alleyn, Phillips, Muir, Young-Hyman & Laffel, 2013; Patton, Williams, Dolan, Chen & Powers, 2009).

Overall, four studies focused on participants who were developmentally aged between infancy and toddlerhood (birth- three years), 10 studies focused on early childhood and school age (three - 11 years), and 15 studies focused on adolescence (12 - 20 years). The majority of the studies were conducted in the United States (62%).

3.2. *Quality Assessment of Selected Studies*

According to Kennelly's (2011) quality checklist, 18 studies were rated as good quality (score above 20), nine rated as fair quality (score between 11 and 20), and two rated as poor quality (score below 11; see Table 3). Of a possible total score of 47, the range of total quality scores was 7 – 28 ($M = 20.6$, $SD = 4.8$). The five main subscales of the quality assessment included Reporting, Internal Validity- Confounding, Internal Validity- Bias, External Validity and Power. The included publications tended to perform best on Reporting ($M = 9.5$, $SD = 2.5$ of a possible total score 13), indicating that information reported in the publications was generally sufficient to allow a reader to make an unbiased assessment of the

findings. The Power subscale overall had the lowest average score. Many studies did not conduct a power analysis ($N = 22$), which is important when considering the type-II error rate, that is, whether negative findings were due to chance. Given that sample sizes across studies remained substantial, future research would benefit from including power analyses.

In Table 3, publications have been arranged in their ranking on the quality assessment (see column 1), and also according to whether psychological functioning outcomes showed an improvement, decline or no change (neutral) for children using CSII (see column 2). Publications that were scored at the three different levels of quality tended to be evenly distributed across the main findings of psychological outcomes. Of the publications that received the highest quality score, for example, seven found a neutral impact of CSII on psychological outcomes, seven found mixed results (predominantly neutral and improvement in functioning) and four found an improvement in psychological functioning. It would be problematic, for example, to conclude that CSII causes a decline in psychological functioning if a large number of low-quality studies reported this, compared to a smaller number of higher quality studies reporting an alternative outcome. The relatively even distribution of quality across the main findings strengthens the conclusions of the current review, as results are more likely to be an accurate reflection of a genuine phenomenon rather than the artefact of methodological discrepancies (Gough, Thomas, & Oliver, 2012).

A second author (TA) extracted data from 12 of the publications and scored the publications according to the quality assessment measure. Areas of disagreement were resolved through discussion, and the inter-rater reliability was calculated for the final overall quality assessment score awarded to each paper. The inter-rater reliability for the raters was strong with Kappa = 0.84 ($p < 0.001$), 95% CI (1.35, 1.95).

Table 3: Description of Selected Studies & Quality Assessment

Quality Assessment	Quality Score	Impact of CSII ^a	Primary Author	Year	Country	Type of Study ^b	Sample Size ^c	Age Range (years)	T1DM Duration <i>M ± SD or 25 & 75th percentile^d</i>
Good	28	No Effect	Weintrob	2003	Israel	Randomised Trial	23	9.4 - 13.9	5.8 ± 2.3
Good	25	No Effect	Nabhan	2009	USA	Randomised Trial	35	0 - 5	1.6 ± 0.6
Good	25	No Effect	Nuboer	2008	Netherlands	Randomised Trial	39	4 - 16	(CSII: 5.6 ± 3.3; MDI: 4.7 ± 2.9)
Good	24	No Effect	Wiebe	2010	USA	Randomised Trial	252	10 - 14	4.2 ± 3.0
Good	23	No Effect	Valenzuela	2005	USA	Cross Sectional	160	5 - 17	4.6 ± 3.0
Good	22	No Effect	Wilson	2005	USA	Randomised Trial	19	1.7 - 6.1	1.4 ± 0.6
Good	21	No Effect	Hanberger	2009	Sweden	Cross Sectional	400	2.6 - 19.6	5.1 ± 3.8
Good	25	↑/ No Effect	Fox	2005	USA	Randomised Trial	22	3.6 - 4.1	(CSII: 15.3 ± 3.4; MDI: 19.7 ± 4.1)
Good	25	↑/ No Effect	Cortina	2010	USA	Cross Sectional	150	13 - 18	6.0 ± 3.9
Good	25	↑/ No Effect	Hilliard	2009	USA	Time Series Study	53	8 - 17	4.4 ± 3.3
Good	22	↑/ No Effect	Moreland	2004	USA	Cross Sectional	153	8 - 16	6.3 ± 3.5
Good	21	↑/ No Effect	Knight	2011	Australia	Time Series Study	(32) 27	6.2 - 15.9	3.3 (0.2 - 12.7)
Good	21	↑/ No Effect	McMahon	2004	Australia	Prospective Cohort Study	105	3.9 - 19.6	5.1 ± 3.8
Good	20	↑/ No Effect	Opipari-Arrigan	2007	USA	Randomised Trial	16	3.1 - 5.3	> 1
Good	26	↑	Battaglia	2005	USA	Cross Sectional	69	12 - 18	(CSII: 6.8 ± 3.37; MDI: 7.48 ± 3.66)
Good	24	↑	Boland	1999	USA	Prospective Cohort Study	75	12 - 20	(CSII: 7.7 ± 3.8; MDI: 9.5 ± 3.7)
Good	24	↑	Muller-Godeffroy	2009	Germany	Before-After	117	4 - 16	3.8 ± 2.9
Good	22	↑	Haugstvedt	2009	Norway	Cross Sectional	115	1.6 - 15.9	3.9 ± 2.9
Fair	18	↑/ No Effect	Kawamura	2008	Japan	Time Series Study	26	6 - 18	7.5 ± 3.8
Fair	18	↑/ No Effect	O'Neil	2005	USA	Cross Sectional	103	9 - 17	5.6 ± 3.1
Fair	18	↑/ No Effect	Patton	2009	USA	Cross Sectional	31	5.0 ± 1.3	> 1
Fair	16	↑/ No Effect	Wu	2010	USA	Cross Sectional	62	12 - 17	4.2 ± 3.2
Fair	16	No Effect	Ingerski	2010	USA	Cross Sectional	261	13 - 18	7.0 ± 3.9
Fair	18	↑	Cogen	2007	USA	Prospective Cohort Study	52	9.3 - 15.5	(CONV: 4.9 ± 3.7; GLARG: 4.1 ± 3.0)
Fair	18	↑	Markowitz	2013	USA	Time Series Study	37	10 - 17	2.1 (1.2 - 6.3; 25 th - 27 th percentile)
Fair	17	↑	Pańkowska	2010	Poland	Non-Randomised Trial	61	0 - 7	(CSII: 2.5 ± 1.4; MDI: 2 ± 1)
Fair	12	↑	Shehadeh	2004	Israel & Slovenia	Cross Sectional	15	1.3 - 5.7	NR
Poor	10	↑/ No Effect / ↓	Mednick	2004	USA	Cross Sectional	22	10 - 18	6.8 ± 4.0
Poor	7	↑/ No Effect / ↓	Barczykowska	2011	Poland	Cross Sectional	98	8 - 12	NR

^a ↑ = improvement in functioning; **No Effect** = no measured change; ↓ = decline; Some findings reflect different scales or subscales used within a study (see Table 4 for further detail)

^b Coded according to Kennelly's (2011) Study design algorithm

^c Child sample size used to analyse the results of the study; not including samples referenced from prior publications

^d Duration of T1D diagnosis (in years) for whole sample if reported or within groups; to 1 decimal place; NR = not reported in article; >1 = inclusion criteria specified great than 1 year

3.3. *Psychological variables addressed by current research*

There was considerable variation between studies as to which psychological variables were investigated. In total, 51 validated scales across the 29 studies measured some form of psychological outcome. Overwhelmingly, the results of these studies suggest that transitioning to CSII has either a positive or neutral impact across several broad areas of psychosocial functioning.

A significant decline in functioning associated with CSII was found in only two studies for specific subscales of the questionnaires used: the Restriction scale of the Child Feeding Questionnaire (CFQ; Patton, Williams, Dolan, Chen & Powers, 2009), and the Satisfaction scale of the Diabetes Quality of Life for Youth Scale (DQOL-Y; Mednick et al., 2004). Both studies used a between-subjects design, comparing children who used CSII to those who used MDI. No other study examined by the current review applied the CFQ, however the 12 other studies that also applied the DQOL-Y found either a non-significant change or improvement for the satisfaction subscale. Furthermore Patton et al. (2009) received a quality assessment score in the 'fair' range, and Mednick et al. (2004) was one of only two studies to receive a 'poor' rating. This suggests that the limited negative results for the psychological impact of CSII for children may reflect the experimental design of the study rather than a genuine decline in functioning.

The content of included scales meaningfully clustered into seven key domains: Family Functioning, Parent Functioning, Child Emotional Functioning, Quality of Life, Treatment of Diabetes, Eating Patterns and Cognitive Function (See Table 2). The first author's surname and year of publication are listed in Table 2, with the full bibliographic details of each article listed in the references section. A discussion of each domain cluster follows.

Table 4: Psychological Outcomes of CSII Summary of findings

Construct Measured	Scale	Scale full title	Specificity ^a	Length ^b	Subscales ^c	P ^d	C ^e	Author	Design ^f	CSII Impact ^g
1) Child Emotional Functioning										
Behaviour	BASC 2	Behaviour Assessment System for Children; 2 nd Edition	Generic	134-160 i	Internalising (Int) & Externalising (Ext) Behaviours	✓	✓	Knight	W	↑ Parent ↑ Teacher (Int) 6wks No Effect Teacher (Ext) 6wks & Child
	CBCL	Child Behaviour Checklist	Generic	100-120 i	DSM diagnoses, Internalising & Externalising Behaviours	✓		Nabhan	Both	↑ 6 [] [] [] [] [] \$ No Effect 12 [] [] [] [] [] [] \$
								Opipari-Arrigan	Both	No Effect
Depression	CDI	Children's Depression Inventory	Generic	27 i	Total score, Emotional & Functional Problems		✓	Boland	Both	↑ Within No Effect Between
								Cortina	B	No Effect
								Ingerski	B	No Effect
	CDI: P	Children's Depression Inventory	Generic	17 i	Total score, Emotional & Functional Problems	✓		Cortina	B	No Effect
2) Cognitive Functioning										
Attention	TEA-Ch	Test of Everyday Attention for Children	Generic	9 t	Sustained, Selective and Divided Attention		✓	Knight	W	No Effect Sustained ↑ Selective & Divided
Cognitive Flexibility	CNT	Contingency Naming Test	Generic	4 t	Cognitive flexibility score for each trial		✓	Knight	W	↑

^a Generics = broad scale developed for all populations, Health = scale developed for chronic health conditions, Diabetes = scale developed for populations with diabetes

^b On each questionnaire, the number of i = items or t = tests or tasks is reported

^c All subscales of the questionnaire (in some instances not all subscales were used by each study)

^d P = Questionnaire developed for parents to complete

^e C = Questionnaire developed for a child (aged 0 – 18) to complete

^f B = Between Subjects design; W = Within Subjects design; Both = Both Between and Within Subjects Design

^g Results are presented overall, or for each subscale when results are conflicting; ↑ = improvement in functioning; No Effect = no measured change; ↓ = decline; *(MR) = only means are reported (no statistical analysis presented)

Construct Measured	Scale	Scale full title	Specificity ^a	Length ^b	Subscales ^c	P ^d	C ^e	Author	Design ^f	CSII Impact ^g
Executive Function	DKEFS	Delis–Kaplan Executive Function System	Generic	9 t	16 main achievement scores		✓	Knight	W	No Effect Letter Fluency ↑ Semantic Fluency
Intelligence	SB: FE	Stanford-Binet Intelligence Scale: 4 th Edition	Generic	15 t	Verbal, Quantitative, Abstract/Visual Reasoning & Short-term Memory		✓	Nabhan	Both	No Effect
	WISC-IV	Wechsler Intelligence Scale for Children; 4 th Edition	Generic	15 t	Verbal Comprehension VC, Perceptual Reasoning PR, Letter-Number Sequencing LN, Digit Span DS		✓	Knight	W	↑ LN & PR No Effect DS & VC
Learning	PAL	Paired Associative Learning	Generic	4 t	Immediate & Delayed recall		✓	Knight	W	No Effect
Memory	ROCFT	Rey-Osterrieth Complex Figure Test	Generic	2 t	Delayed and Immediate recall		✓	Knight	W	No Effect
Visual & Motor Skills	VMI	Developmental Test of Visual-Motor Integration	Generic	2 t	Visual Perception & Motor Coordination		✓	Nabhan	Both	No Effect
3) Eating Behaviours										
At-risk Feeding	BPFAS	Behavioural Paediatrics Feeding Assessment Scale	Generic	35 i	Frequency and Problem scores for Parent and Child	✓		Muller-Godeffroy	W	↑
								Patton	B	↑
Disordered Eating	DEPS-R	Diabetes-Specific Eating Problems Survey Revised	Diabetes	16 i	Total score		✓	Markowitz	W	↑
	EAT-26	Eating Attitudes Test	Generic	26 i	Dietary Restraint, Bulimia, Oral Control & Total score		✓	Battaglia	B	No Effect
	EDI-2	Eating Disorder Inventory	Generic	64 i	8 subscales assessing Anorexia & Bulimia		✓	Battaglia	B	No Effect
Parent Feeding Practices	CFQ	Child Feeding Questionnaire	Generic	12 i	Restriction & Pressure to Eat		✓	Patton	B	↓ (Greater) Restriction No Effect Pressure to Eat

4) Family Functioning										
Family Conflict	DFCS	Diabetes Family Conflict Scale	Diabetes	19 i	Total Score, Direct & Indirect Management	✓	✓	Cortina	B	No Effect Parent & Child
								Ingerski	1TP	↑Parent
								Moreland	B	No Effect Parent & Child
								Muller-Godeffroy	W	No Effect Parent & Child
Impact of Disease	IFS	Impact on Family Scale	Health	27 i	Financial Impact; Familial-Social Impact, Personal Strain, Mastery	✓		Fox	B	No Effect
Responsibility	DFRQ	Diabetes Family Responsibility Questionnaire	Diabetes	17 i	Regimen Task Responsibility, General Health Maintenance & Social Presentation of Diabetes	✓	✓	Cortina	B	↑
								Moreland	B	↑
	DRCS	Diabetes Responsibility & Conflict Scale	Diabetes	23 i	Total Score	✓	✓	Wiebe	Both	↑
Traumatic Events	LEC	Life Events Checklist	Generic	25 i	Total Score	✓		Cortina	B	No Effect
5) Parental Functioning										
Depression	BDI-II	Beck Depression Inventory – 2 nd Edition	Generic	21 i	Total Score	✓		Opipari-Arrigan	Both	No Effect
	CES-D	The Centre for Epidemiological Studies – Depression	Generic	20 i	Total Score	✓		Ingerski	1TP	No Effect
Distress	BSI	Brief Symptom Inventory	Generic	53 i	9 Symptom Scales & 3 Global Scales	✓		Fox	Both	No Effect
								Opipari-Arrigan	Both	No Effect
Fear of Hypos	HFS-P	Hypoglycaemia Fear Survey	Diabetes	25 i	Behaviour & Worry	✓		Haugstvedt	B	↑ Behaviour No Effect Worry
								Muller-Godeffroy	W	↑ Worry No Effect Behaviour
Marital Function	DAS	Dyadic Adjustment Scale	Generic	32 i	Total Score	✓		Opipari-Arrigan	Both	No Effect
Stress	PSI	Parenting Stress Index	Generic	120 i	Child Functioning & Parent	✓		Fox	Both	No Effect

					Functioning		Nabhan	Both	No Effect
	SIPA	Stress Index for Parents of Adolescents	Generic	112 i	4 scales to measure child & parent characteristics	✓	Wu	B	No Effect
Stressors	PIP	Paediatric Inventory For Parents	Health	42 i	Frequency and Difficulty of Stressors	✓	Opipari-Arrigan	Both	↑ Frequency No Effect Difficulty
6) Quality of Life									
Diabetes-Specific	DQOL-Y	Diabetes Quality of Life for Youth Scale	Diabetes	52 i	Satisfaction, Impact & Worry	✓	Battaglia	B	↑
							Boland	Both	↑ Within No Effect Between
							Cogen	W	↑ (Greater improvement for Conven. treatment pre-CSII)
							Hillard	W	↑ Satisfaction & Worry No Effect Total & Impact
							McMahon	W	↑ Impact No Effect Satisfaction & Worry
							Mednick	B	↑ Worry ↓ Satisfaction No Effect Impact
							Nuboer	Both	↑ Within Impact No Effect Between Impact (Modified For Parents)
							O'Neil	B	No Effect
							Shehadeh	W	↑ Impact & Worry (Modified)
							Weintrob	Both	No Effect
							Wilson	Both	↑ Within No Effect Between
							Wiebe	Both	No Effect
							Wu	B	No Effect

	DiHRQOL	DISABKIDS - Diabetes Module	Diabetes	10 i	Impact & Treatment	✓	✓	Hanberger	B	No Effect
	ITR-QOL	Insulin Therapy Satisfaction Questionnaire	Diabetes	23 i	Social Activity, Physical Condition, Daily Activity, Emotional Domain, Current Status Domain & Total Score	✓	✓	Kawamura	W	No Effect
	KINDL-R-DM	KINDL-R-Diabetes Module ages 8 – 11	Diabetes	21 i	Total Score	✓	✓	Muller-Godeffroy	W	↑
	KINDL-R-DM	KINDL-R-Diabetes Module ages 12 – 16	Diabetes	21 i	Total Score	✓	✓	Muller-Godeffroy	W	↑
	PedsQL 3.0	PedsQL-Questionnaire Diabetes Module 3.0 ages 8 - 12	Generic	23 i	Physical Functioning, Treatment Barriers, Treatment Adherence, Treatment Worries & Communication Problems	✓	✓	Barczykowska	B	No Effect Child similar rating to Parent for Communication ↑ Child > Parent rating for all other subscales (Polish version) *(MR)
								Ingerski	B	No Effect Worries, Treatment Barriers & Adherence (Child)
								Opipari-Arrigan	Both	↑ Worries (Parent)
								Valenzuela	B	No Effect
Global Measures	EQ-5D	EQ-5D	Generic	5 i	Mobility, Self-Care, Usual Activities, Pain/Discomfort & Anxiety/Depression	✓	✓	Hanberger	B	No Effect
	KINDL-R	KIDSCREEN-10 Index	Generic	10 i	Total Score	✓	✓	Muller-Godeffroy	W	No Effect
	PedsQL 4.0	Paediatric Quality of Life Inventory – Generic Core 4.0	Generic	23 i	Total Score, Physical, Emotional, Social & School Functioning	✓		Barczykowska	B	↑ Total & 3 Subscales ↑ Physical (Polish) *(MR)
								Valenzuela	B	No Effect
	PedsQL 4.0	Paediatric Quality of Life Inventory	Generic	23 i	Physical, Emotional, Social & School Functioning	✓		Barczykowska	B	↑ Physical & Emotional No Effect Social & School (Polish) *(MR)

								Fox	Both	↑ Fathers No Effect Mothers
								Nuboer	Both	↑ Within No Effect Between (Dutch)
	PedsQL 4.0	Paediatric Quality of Life Inventory	Generic	23 i	Physical, Emotional, Social & School Functioning	✓		Barczykowska	B	↑
								Fox	Both	No Effect
								Nuboer	Both	↑ Within No Effect Between (Dutch)
								Valenzuela	B	No Effect
Health Specific	GeHRQOL	DISABKIDS - Chronic Generic Module	Health	19 i	Independence, Emotion, Social Inclusion & Exclusion, Limitation & Medication	✓	✓	Hanberger	B	↑ Child aged 8 – 12 years No Effect Adolesc. & Parents
7) Diabetes Treatment										
Blood-Glucose	BGMC	Blood Glucose Monitoring Communication Questionnaire	Diabetes	8 i	Total Score	✓	✓	Cortina	B	↑
Coping		Issues in Coping with IDDM scale	Diabetes	14 i	How Hard Activities Are & How Upsetting Tasks Are	✓		Boland	Both	↑
Knowledge	DKT	Diabetes Knowledge Test Modified	Diabetes	16 i	Total Score	✓		O'Neil	B	No Effect (Modified)
Satisfaction	DTSQ	World Health Organisation Diabetes Treatment Satisfaction Questionnaire	Diabetes	8 i	Total Score	✓	✓	Pańkowska	Both	↑ Parent (Modified)
								Shehadeh	W	↑ Parent <input type="checkbox"/>
								Weintrob	Both	↑ Child
	IPTSQ	Insulin Pump Therapy Satisfaction Questionnaire	Diabetes	13 i	Satisfaction, Life Change & Qualitative Items	✓	✓	Mednick	Both	↑
Self-Efficacy	SED	Self-Efficacy for Diabetes Scale	Diabetes	35 i	Diabetes-Specific & Medical Situations Self-Efficacy & General Situations	✓		McMahon	W	↑
								Boland	Both	↑ Within No Effect Between

3.3.1 Child Emotional Functioning

In relation to emotional functioning, three studies measured symptoms of depression and two studies screened for internalising and externalising behaviours. Given the intense and demanding nature of T1DM management, it is unsurprising that depression is a focus of current research. Illustratively, in an American sample Hood (2006) found one in seven children with diabetes, regardless of treatment type, met clinical criteria for depression. The Children's Depression Inventory (CDI) was applied in three studies (Boland, Grey, Oesterle, Fredrickson, & Tamborlane, 1999; Cortina, Repaske & Hood, 2010; Hillard, Goeke-Morey, Cogen, Henderson, & Streisand, 2009; Ingerski, Laffel, Drotar, Repaske, & Hood, 2010). Despite the intensive nature of CSII, these studies consistently found no significant difference for children using CSII across both within and between-group study designs. Cortina et al. (2010) also found no significant difference between CSII and MDI on children's depressive symptoms as reported by parents.

Both the Behaviour Assessment System for Children; 2nd Edition (BASC-2) and Child Behaviour Checklist (CBCL) report an overall score for externalising (e.g. behaviours such as hyperactivity and conduct problems) and internalising behaviours (e.g. emotional functioning such as anxiety and depression). Reports from children, parents and teachers were mixed. Knight et al. (2011) found parents but not children reported a significant improvement on both scales. Teachers reported an improvement in children's internalising, but not externalising behaviours (Knight et al., 2011). In contrast, Nabhan et al. (2009) found a significant improvement in children, as reported by parents at six months, was not maintained at follow-up 12 months later. This discrepancy may be partially explained by the placebo effect. Parents are required to invest great time, effort and financial cost to allow their child to commence CSII. Nabhan et al.'s (2009) finding that short term improvements were not maintained at follow-up may reflect the parent's high investment in CSII fostering a need for validation that such effort was worth it. Further research in relation to parental expectations and testing of this hypothesis would be of clinical interest.

Summary: Child depressive symptoms do not differ when using CSII compared to MDI. In the short term (six months) parents report an improvement in internalising and externalising behaviours for children using CSII, however there are mixed findings over the long term (12 months).

3.3.2 Cognitive Functioning

A number of different standardized tests of cognitive functioning were assessed ($N = 8$); yet these were only conducted in two studies (Nabhan et al., 2009; Knight et al., 2011).

This may suggest that investigating CSII and cognitive functioning remains a new area of research. Knight et al. (2011) found no effect for CSII on simpler tasks such as repeating a string of numbers (WISC-IV; DS), recalling a word pair (PAL), or copying and recalling a detailed picture (ROCF). Comparatively, tests requiring higher cognitive demands showed a significant improvement in performance after transitioning to CSII. These included tests of semantic fluency (DKEFS), cognitive flexibility (CNT), selective and divided attention (TEA-Ch), working memory (WISC-IV; LN) and abstract reasoning (WISC; BD), each reported by Knight et al. (2011). Comparatively, Nabhan et al.'s (2009) assessment of general ability and visual-spatial and motor skills showed no significant difference when conducting between and within-group analyses. Although consistently there was no negative impact of CSII on any domain of cognitive functioning, positive results may have limited generalisability given all results demonstrating an improvement with CSII use were determined by one study (Knight et al., 2011).

Summary: Performance tends to improve on tasks that require a higher cognitive demand for children using CSII. However positive results are limited to one study and thus may not generalise. Overall across most other cognitive domains, functioning does not significantly differ between CSII and MDI use.

3.3.3 Eating Behaviours

Across four studies, eating behaviours were measured using five psychometric scales. Battaglia, Alemzadeh, Katte, Hall, and Perlmutter (2005) found no significant differences between CSII and MDI using the Eating Attitudes Test (EAT-26) and the Eating Disorder Inventory (EDI-2). However Battaglia et al.'s (2005) sample size was 69, and power analyses required a sample of 120 to detect meaningful differences, thus potentially explaining the null result. In contrast a scale specifically developed for children with diabetes, The Diabetes-Specific Eating Problems Survey Revised (DEPS-R; Markowitz et al., 2013), found an improvement in adaptive eating habits for those using CSII.

The Behavioural Paediatrics Feeding Scale (BPFAS) identified an improvement in the frequency and severity of parental at-risk feeding behaviours for CSII users. Such parental behaviours include feeling anxious, frustrated or angry when feeding their child, lacking confidence in their ability to manage their child's feeding, or placing food in the child's mouth by force. This finding was consistent across both within-subjects (Müller-Godeffroy, Treichel, & Wagner, 2009) and between-subjects studies (Patton et al., 2009). Patton et al. (2009) however also found that scores for the subscale Restriction from the CFQ were poorer for CSII users. This suggests that parents of CSII users were more likely to attempt to restrict

their child's eating during meals than the parents of children using MDI. Research has shown that CSII facilitates greater lifestyle and eating flexibility as insulin can be titrated to suit children's carbohydrate intake (Silverstein et al., 2005; Shalitin & Phillip, 2008).

Summary: CSII is linked with an improvement of most 'at-risk' feeding behaviours of parents; however one study found that CSII encouraged greater food restrictive behaviours in parents. Children themselves reported either a neutral or beneficial impact of CSII on disordered eating behaviours.

3.3.4 Family Functioning

Managing T1DM has a large impact on not only the diagnosed child, but also on the family functioning and routine (Rickert & Drotar, 2000). In a cyclical pattern, the quality of family relationships has been linked with the overall management of T1DM and vice versa (Klemp & La Greca, 1987; Jacobson et al., 1994). Of the six studies that examined family functioning in the current review, none reported a decline in quality of family functioning associated with CSII use. In general, CSII did not significantly differ to MDI use in relation to the characteristics of the family (Hillard et al., 2009; Valenzuela et al., 2005) or experience of traumatic events (Cortina et al., 2010). Most studies found no difference in the level of family conflict between CSII and MDI users (Cortina et al., 2010; Moreland et al., 2004; Müller-Godeffroy et al., 2009), however Ingerski et al. (2010) did find that parents of children using CSII reported less conflict. Encouragingly, caregivers and adolescents favourably reported a greater sharing of treatment responsibilities when using CSII compared to MDI (Cortina et al., 2010; Moreland et al., 2004).

Summary: CSII does not appear to negatively impact family functioning. CSII is linked with an increase in the sharing of treatment responsibility between adolescents and parents.

3.3.5 Parental Functioning

Given the high demands of T1DM treatment, parental functioning has an important role in the care of a child, particularly for children of a younger age. Eight different scales were used across seven studies, indicating that research has identified a diverse range of constructs relevant to parental functioning. Depressive symptoms (Ingerski et al., 2010; Opipari-Arrigan et al., 2007), distress (Fox et al., 2005; Opipari-Arrigan et al., 2007), stress (Fox et al., 2005; Nabhan et al., 2009; Wu et al., 2010) and quality of marital functioning (Opipari-Arrigan et al., 2007) did not significantly differ between the parents of CSII and MDI users. Opipari-Arrigan et al. (2007) did find however that the *frequency* of stressors associated with caring for a chronically ill child was significantly lower for children using

CSII compared with MDI. Haugstvedt Wentzel-Larsen, Graue, Søvik, and Rokne (2009) and Müller-Godeffroy et al. (2009) both found an improvement in the parents' fears of hypoglycaemia when their child used CSII, demonstrated by a reduction in such fear. Interestingly Haugstvedt et al. (2009) found an improvement in fear-related behaviour for parents but no change for worrying, whilst Müller-Godeffroy et al. (2009) found the reverse.

Summary: CSII does not influence parental psychological functioning in relation to stress, depression and marital functioning. CSII is linked with a reduction in parental fears of hypoglycaemia and fewer perceived stressors.

3.3.6 Quality of Life

This review found a diverse range of scales measuring quality of life were used across 20 studies, indicative of a robust area of research. T1DM requires intensive treatment that disrupts the routines and relationships of the entire family (Ricket & Drostar, 2000; Laffel et al., 2003). Given there is currently no cure for T1DM, it is important to understand impacts on quality of life to better minimise the disruption caused by this illness. Thus it is not surprising that this concept is well researched. Interestingly, quality of life measures have also been found to act as a proxy of general wellbeing in paediatric populations that can predict health behaviours and outcomes such as glycaemic control (Hillard, Mann, Peugh & Hood, 2012).

The current review found that 19 studies applied a diabetes-specific measure of quality of life, one study used a health specific measure, and six used a global measure. The Diabetes Quality of Life for Youth Scale (DQOL-Y) was the most commonly used measure, included in 13 studies. The DQOL-Y includes three scales, Satisfaction, Impact and Worry, which focus on disease-related behaviours and functioning, rather than normal socio-emotional and physical development. Nine of these 13 studies found an improvement in at least one subscale when the child transferred to CSII. Only one study found a decrease in one subscale measuring satisfaction with treatment after the child transitioned to CSII (Mednick et al., 2010).

Comparatively, the health specific measure (DISABKIDS- Chronic Generic Module) and three global measures (EQ-5, KIDSCREEN-10 Index, and Paediatric Quality of Life Inventory) found mixed results across different subscales and different respondents (i.e. child compared to adult reports). Based on these studies, the specificity of the scale (i.e. diabetes specific compared to a global measure) seemed to be related to the consistency in the findings. This may suggest that diabetes-specific measures are more accurate in detecting

subtle changes in the quality of life construct and are more applicable for this paediatric population.

Of note, using a health specific measure Hanberger et al. (2009) found an increased quality of life score for children aged eight to 12 who used CSII, while finding no difference for adolescents' or adults' reports. This suggests that quality of life outcomes may be affected by CSII differently for different age cohorts. More research comparing the quality of life effects on different age cohorts is required given that current studies primarily focused on middle childhood and adolescent age-ranges (approximately 6 – 18 years).

Summary: There is a substantial body of research examining the influence of CSII on quality of life, spanning a diverse range of measures. Transitioning to CSII does not appear to have a negative impact on quality of life outcomes, and often has a positive impact. Diabetes-specific measures may be more sensitive to subtle changes in children than global measures.

3.3.7 Self-management of Diabetes

In the current review, eight studies investigated a diverse range of procedures and qualities related to managing the demands of T1DM treatment for children and their families. Such constructs included blood-glucose monitoring, coping, knowledge about diabetes, satisfaction with current treatment and feelings of self-efficacy. The current review found that self-efficacy (McMahon et al., 2004) and affective responses to blood glucose monitoring (Cortina et al., 2010) both improved when using CSII. Accuracy of knowledge of diabetes remained consistent between MDI and CSII users (O'Neil, Jonnalagadda, Hopkins, & Kicklighter 2005). Child and parent satisfaction with the pump was measured with the Insulin Therapy Satisfaction Questionnaire (ITR-QOL) and the Diabetes Treatment Satisfaction Questionnaire (DTSQ). Overall satisfaction, as measured by these scales, consistently improved following CSII transition for studies conducted in Poland (Pańkowska, Nazim, Szalecki, & Urban, 2010), the United States (Mednick et al., 2004), Israel (Shehadeh et al., 2004; Weintrob et al., 2003) and Slovenia (Shehadeh et al., 2004).

Summary: Whilst knowledge about diabetes does not differ between children using CSII and MDI, overall coping, satisfaction, self-efficacy and blood-glucose monitoring each improved for CSII users.

4. Discussion

This review identified 29 studies examining the psychological impact of transitioning to CSII for children with T1D. Given the studies reported in the current review were very heterogeneous in their selection of variables and psychometric scales used, the current review could not use a meta-analytic approach to compare statistical findings (Littell, Corcoran & Pillai, 2008). In light of this, Valentine (as cited in Littell et al., 2012) proposes that a conclusion can instead be based on a vote count of the findings concerning the direction of effects in the primary studies.

The principal conclusion from this review is that compared to MDI use, transitioning to CSII is linked with either the maintenance of, or a general improvement in psychological functioning. This conclusion reflects the findings of 26 of the 29 included studies, suggesting a maintenance of or improvement in psychological functioning occurs across a diverse range of psychometric scales. Very limited data reported a negative impact of CSII on psychological functioning. Three studies reported a decline in functioning for a specific subscale of measures for parental feeding practices (Patton et al., 2004) and quality of life (Barczykowska et al., 2011; Mednick et al., 2004). However the decline in functioning measured by the quality of life subscale (Mednick et al., 2004) was not replicated in the 11 other studies using the same scale (see Table 2). All three studies that reported a decline in functioning received a low quality rating. This may suggest that design factors inherent in these studies may have also contributed to their negative results.

Currently, research into the psychological functioning of children who use CSII appears to be diverse in focus and continuing to expand. The current review identified six dominant areas of psychological factors which current research focuses on including: Family Functioning, Parent Functioning, Child Emotional Functioning, Quality of Life, Treatment of Diabetes, Eating Patterns and Cognitive Functioning. These key domains link with the central components of Engel's (1977) Biopsychosocial Model, including psychological, social and behavioural factors in addition to medical factors (See Figure 2). These links suggest that current research is acknowledging the need for a holistic approach to treatment.

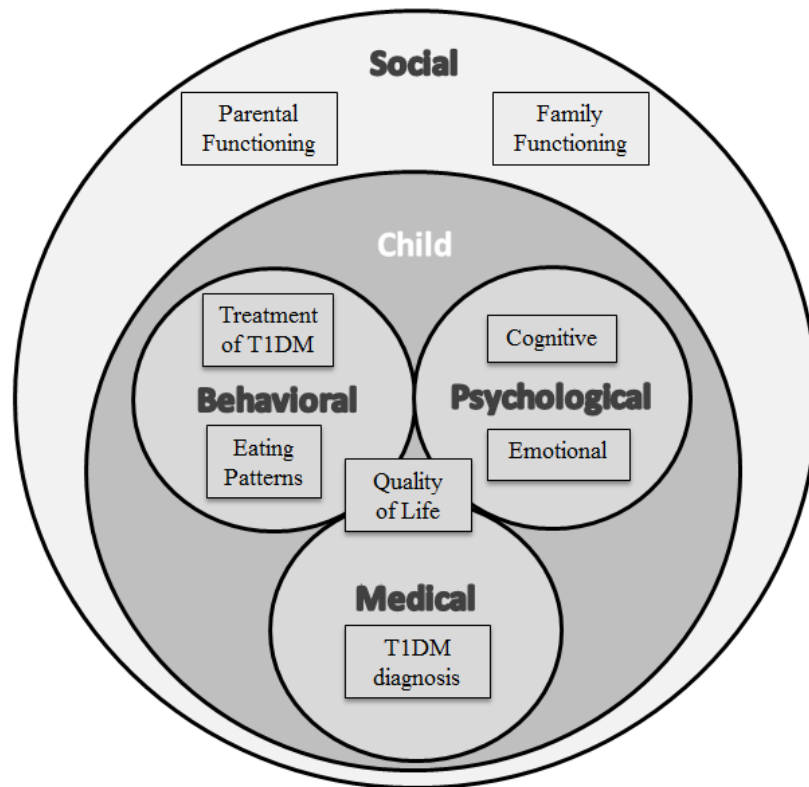


Figure 2: Diagrammatic representation of the key areas of current CSII research applied to the Biopsychosocial Model of Health

There was a great degree of variability and very little consistency in the scales used to measure these six areas of functioning. The child psychological variables that reported an improvement for CSII users included child externalizing behaviors and symptoms of depression, cognitive flexibility, attention and executive functioning, at-risk feeding and disordered eating behaviours, and quality of life (general, health-specific and diabetes specific). Improvement in parental functioning was seen in relation to improved family conflict, shared responsibility for treatment, parental fear of hypoglycemia and stressors. Finally both parents and children reported improved treatment satisfaction, self-efficacy, blood-glucose monitoring behaviors and coping for CSII users. It was interesting to note that scales specific to the disease seemed to detect shifts in more nuanced issues related to the lived experience of managing T1DM, such as disordered eating, fear of hypoglycemia or treatment satisfaction over and above more generic scales.

4.1. Limitations

It was outside of the scope of this review to determine whether different scales claiming to measure the same variable are indeed tapping into a uniform underlying construct.

Two scales which both claim to measure quality of life specifically for children with T1DM, for example the DQOL-Y and PedsQL 3.0, may actually focus on different symptoms and thus be measuring different constructs. Despite this, almost all results across all studies presented in this review converge to communicate a consistent trend for either a positive or neutral impact on psychosocial functioning for children who transition to CSII.

It also is important to acknowledge that an inherent bias may exist in the sample populations used across all studies. Most studies reported their selection criteria for participants and adequately reported demographic information, however the participants approached were generally already on CSII waitlists. Current clinical practice when selecting pump candidates is to screen for prevailing good medical routine adherence and ample family support (Fisher, 2006). The high financial cost of the insulin pump may also contribute to an international demographic of CSII candidates who are from families in a higher socio-economic status. Consequently, the studies included in the current review may be biased. Participants may tend to have overall higher wellbeing and higher capacity to adapt to the demands and change in treatment requirements that CSII requires. It would be of interest to observe if these positive results in psychological functioning generalize to children of other, more diverse backgrounds.

Although the current review utilised a broad inclusion criteria in an attempt to capture a diverse range of studies, as with most systematic reviews, this review was unable to account for potential publication bias in clinical research given that null results are less likely to be published (Hopewell, Loudon, Clarke, Oxman, & Dickersin, 2009). Consequently there may be evaluations of CSII outside published literature that may have altered or tempered current findings. The 24 poster presentations that were excluded from the current review (see Figure 1) due to a lack of data reported and no related publication provide support for the likelihood of a publication bias.

4.2. *Research Implications*

Overall the current review identifies a broad range of psychological factors that are affected by CSII use in children. It is important to conduct further qualitative research to identify the additional benefits for the child's overall wellbeing that may have been missed by the administration of specifically validated scales.

Barnard, Lloyd and Skinner (2007) observed the significant lack of published qualitative studies that attempt to identify quality of life issues that may occur as a result of CSII use. The authors addressed this gap by using qualitative phone interviews to identify quality of life issues for adults using CSII. The authors found adults identified several key

areas of improvement not identified by current quality of life measures, such as greater control, flexibility, freedom, effects on the broader family, convenience and independence. Several studies have qualitatively investigated adult's experiences of transitioning to CSII (Garmo, Hornsten & Leksell, 2013; Berg & Sparud-Lundin, 2009); however there remains a lack of qualitative studies examining the child's perspective.

Also of interest would be to further assess how children themselves feel about transitioning to CSII, and whether it changes their view of their chronic illness or personal identity. Many of the psychometric scales reported in this review appeared sensitive enough to detect shifts associated with CSII treatment. Thus it is possible that CSII may also have an impact on more abstract areas of functioning such as a child's view of themselves, their illness and their abilities.

4.3. *Practice Implications*

The present review suggests that across a diverse range of scales, the psychological functioning of the child and their parent does not decline following a transition to CSII. Instead, children seem to maintain their current level of functioning or in some areas actually improve with CSII use. Most consistently, an improvement was seen in scales measuring quality of life and treatment satisfaction. Overall the current review supports prior research highlighting CSII as a safe and effective form of diabetes management (Misso et al., 2010; Pickup & Sutton, 2008; Pańkowska et al., 2009). The current review suggests that CSII generally has a positive or neutral impact on psychological functioning in addition to the established medical benefits

Rates of T1DM diagnosis in children continue to increase, establishing diabetes as one of the most common chronic illnesses worldwide (Gillespie, 2006; Patterson, Dahlquist, Gyurus, Green & Soltez, 2009). The provision of accessible and efficacious treatments that improve the medical management of T1DM for children is vital. Given the chronic nature of T1DM, and the impact of treatment management on almost every aspect of daily functioning, it is important to also consider the psychological impact of current treatment options. A growing body of research supports the positive psychological, social and emotional impact of transitioning to CSII. The current review supports CSII as a safe and efficacious treatment option for children with T1DM.

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6. Appendices

Appendix A: Quality Control Checklist used in the Current Review

Quality Checklist for RCTs and Observational Studies

Kennelly's (in Handler, Kennelly & Peacock, 2011) adaption based on a Methodological Quality checklist originally developed by Downs and Black (1998).

KEY:	
Bolded Text	– Quality assessment variable
<i>Italicised text</i>	– Kennelly's (2011) dictionary to increase specificity
<u>Underlined text</u>	– Adaptations for the current systematic review to increase relevancy and scoring consistency. Modifications developed by two authors (MF & TA)

REPORTING		Y	N	U/D
1. Is the hypothesis/aim/objective of the study clearly described?		1	0	0
2. Is the underlying theory described? <i>If the authors describe the formative research, theoretical basis(es) or constructs upon which the intervention was developed the question should be answered yes.</i> <ul style="list-style-type: none"> <u>Needs to provide a summary of past research in the area to justify current study to be awarded one point</u> 		1	0	0
3. Are the main outcomes to be measured clearly described in the Introduction or Methods section? <i>If the main outcomes are first mentioned in the Results section, the question should be answered no.</i>		1	0	0
4. Are the characteristics of the study population included in the study clearly described? <i>In cohort studies and trials, inclusion and/or exclusion criteria should be given. In case control studies, a case-definition and the source for controls should be given.</i>		1	0	0
5. Are the interventions under study clearly described? <i>Interventions and placebo (where relevant) that are to be compared should be clearly described.</i> <ul style="list-style-type: none"> <u>Intervention is defined as using an insulin pump (CSII) and control group is typically children with diabetes using injections (MDI) or a similar comparison group.</u> <u>Description of CSII should include reference to at least one of the following: number of blood-glucose readings per day, Total Daily Dose of insulin (TDD), type of insulin used, brand of insulin pump, etc</u> 		1	0	0
6. Was exposure to the intervention measured? <ul style="list-style-type: none"> <u>Interpreted as the duration each child used CSII</u> 		1	0	0
7. Are the distributions of principal confounders in each group of study participants to be compared clearly described? <i>Give one point if some confounders are described and two only if most of these principal confounders are described.</i> <ul style="list-style-type: none"> <u>Principal confounders include:</u> <ul style="list-style-type: none"> <u>Gender</u> <u>Age</u> <u>Duration of diagnosis</u> <u>Family Socio-economic status</u> <u>Ethnicity</u> <u>HbA1c prior to the study</u> 	Y2	P 1	N0	U/D0

<ul style="list-style-type: none"> • <u>2 confounding variables mentioned = 1 point</u> • <u>>2 confounding variables mentioned = 2 point</u> 				
8. Are the main findings of the study clearly described? <i>Simple outcome data (including denominators and numerators) should be reported for all major findings so that the reader can check the major analyses and conclusions. (This question does not cover statistical tests that are considered below).</i>		1	0	0
9. Does the study provide estimates of the random variability (e.g., standard error, standard deviation, confidence intervals, interquartile range) in the data for the main outcomes? <i>In non-normally distributed data the inter-quartile range of results should be reported. In normally distributed data the standard error, standard deviation or confidence intervals should be reported. If the distribution of the data is not described, it must be assumed that the estimates used were appropriate and the question should be answered yes.</i>		1	0	0
10. Have all important adverse events/negative outcomes that may be a consequence of the intervention been reported? <i>This should be answered yes if the study demonstrates that there was a comprehensive attempt to measure adverse events/negative outcomes of the intervention.</i> <ul style="list-style-type: none"> • <u>Possible adverse events/ negative outcomes:</u> <ul style="list-style-type: none"> ○ <u>Hypoglycaemia or hyperglycaemia</u> ○ <u>DKA events</u> ○ <u>Hospitalisations</u> ○ <u>Drop-outs (discontinued using the pump)</u> ○ <u>Insulin omissions</u> 	0	1	0	0
11. Have the characteristics of study participants lost to follow up been described? <i>This should be answered yes where there were no losses to follow-up or where losses to followup were so small that findings would be unaffected by their inclusion. This should be answered no where a study does not report the number of patients lost to follow-up.</i>		1	0	0
12. Have actual probability values been reported (e.g., 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?		1	0	0
EXTERNAL VALIDITY		Y	N	U/D
13. Were the study participants asked to participate representative of the entire population from which they were recruited? <i>The study must identify the source population for study participants and describe how the study participants were selected. Study participants would be representative if they comprised the entire source population, an unselected sample of consecutive participants, or a random sample.</i> <i>Random sampling is only feasible where a list of all members of the relevant population exists.</i> <i>Where a study does not report the proportion of the source population from which the study participants are derived, the question should be answered as unable to determine.</i>		1	0	0
14. Were study participants who agreed to participate representative of the entire population from which they were recruited? <i>The proportion of those asked who agreed should be stated. Validation that the sample was representative would include demonstrating that the distribution of the main confounding factors was the same in the study sample and the source population.</i>		1	0	0
15. Were the staff, places, and facilities where the study participants received the intervention representative of the intervention the majority of subjects receive? <i>For the question to be answered yes, the study should demonstrate that the intervention was representative of that in use in the source population. The question should be answered no if, for example, the intervention was undertaken in a clinically located site in which only subjects participating in clinical care might have participated in the intervention. For randomized studies where the subjects would have no way of knowing which intervention they received, this should be answered yes.</i>		1	0	0
16. Were the screening criteria for study eligibility specified?		1	0	0

INTERNAL VALIDITY - BIAS		Y	N	U/D
17. Was an attempt made to blind study participants to the intervention they received? • Generally impossible as the child must learn how to use CSII (all coded as NO)		1	0	0
18. Was an attempt made to blind those measuring the main outcomes of the intervention? <i>For randomized studies where the researchers would have no way of knowing which intervention subjects received, this should be answered yes.</i>		1	0	0
19. Were appropriate methods used to adjust for the differences between groups with and without the intervention (to control for selection bias)? <i>For non-randomized studies, if methods were used to adjust for initial differences between groups, the answer should be yes.</i>		1	0	0
20. Were appropriate methods used to account for any biases related to differential ascertainment of the outcome in groups with or without the intervention? <i>For non-randomized studies, if the same methods were used for ascertainment of the outcome in both groups, the answer should be yes.</i>		1	0	0
21. If any of the results of the study were based on “data dredging,” was this made clear? <i>Any analyses that had not been planned at the outset of the study should be clearly indicated. If no retrospective unplanned subgroup analyses were reported, then answer yes.</i>		1	0	0
22. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of study participants, or in case-control studies, is the time period between the intervention and outcome the same for cases and controls? <i>Where follow-up was the same for all study subjects the answer should be yes. If different lengths of follow-up were adjusted for by, for example, survival analysis the answer should be yes. Studies where differences in follow-up are ignored should be answered no.</i>		1	0	0
23. Were the statistical tests used to assess the main outcomes appropriate? <i>The statistical techniques used must be appropriate to the data. For example, nonparametric methods should be used for small sample sizes. Where little statistical analysis has been undertaken but where there is no evidence of bias, the question should be answered yes. If the distribution of the data (normal or not) is not described it must be assumed that the estimates used were appropriate and the question should be answered yes.</i>		1	0	0
24. Was compliance with the intervention reliable? <i>Where there was non-compliance with the allocated treatment or where there was contamination of one group, the question should be answered no. For studies where the effect of any misclassification was likely to bias any association to the null, the question should be answered yes.</i>		1	0	0
25. Were the main outcome measures used accurate (valid and reliable)? <i>For studies where the outcome measures are clearly described, the question should be answered yes.</i> <i>For studies which refer to other work or that demonstrates the outcome measures are accurate, the question should be answered as yes.</i> • <u>In instances of citing other work, need to provide detail about accuracy of scale, or the content of the scale - not just author</u>		1	0	0
INTERNAL VALIDITY - CONFOUNDING		Y	N	U/D
26. Were the study participants in the different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited from the same population? <i>For example, subjects for all comparison groups should be selected from the same population. The question should be answered unable to determine for cohort and case control studies where there is no information concerning the source of subjects s included in the study.</i>		1	0	0

• <u>In the case of “within-subject” study design, a point is awarded.</u>				
27. Were study participants in the different intervention groups (trials and cohort studies) or were the cases and controls (case-control studies) recruited over the same period of time? <i>For a study which does not specify the time period over which subjects were recruited, the question should be answered as unable to determine.</i>		1	0	0
28. Were study participants randomized to intervention groups? <i>Studies which state that subjects were randomized should be answered as yes except where method of randomization would not ensure random allocation. For example, alternate allocation would score no because it is predictable.</i>		1	0	0
29. Answer this Q.27, if randomization occurred: was the randomized intervention assignment concealed from both study participants and intervention staff until recruitment was complete and irrecoverable? <i>If randomization occurred, and assignment was concealed from subjects but not from staff, it should be answered no.</i>		1	0	0
30. Answer this Q.27, if randomization did not occur: were study participants in the research or evaluation, unaware of the study hypotheses? <i>If randomization did not occur and if methods used ensure that those in the intervention group and those in the comparison group were unaware of the study hypotheses, then the answer should be yes.</i>		1	0	0
31. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn? <i>This question should be answered no for trials if: the main conclusions of the study were based on analyses of treatment rather than intention to treat; the distribution of known confounders in the different treatment groups was not described; or the distribution of known confounders differed between the treatment groups but was not taken into account in the analyses. In nonrandomized studies if the effect of the main confounders was not investigated or confounding was demonstrated but no adjustment was made in the final analyses the question should be answered as no.</i>		1	0	0
32. Were losses of study participants to follow-up taken into account? <i>If the numbers of patients lost to follow-up are not reported, the question should be answered as unable to determine. If the proportion lost to follow-up was too small to affect the main findings, the question should be answered yes.</i>		1	0	0
POWER		Y	N	U/D
33. Did the study mention having conducted a power analysis to determine the sample size needed to detect a significant difference in effect size for one or more outcome measures?		1	0	0

STUDY 2

Target journal: Qualitative Health Research

Title: Normality is Shifting – A Child’s Perspective of Living with Type-1 Diabetes
(Original Research)

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Key words: *Qualitative Research, CSII, insulin pump therapy, psychological outcomes, children, type-1 diabetes, transition*

Abstract

Introduction: Learning to manage Type-1 Diabetes Mellitus (T1DM) holds important implications for medical outcomes (Silverstein et al., 2005), psychological wellbeing (Kongkaew, Jampachaisri, Chaturongkul, & Scholfield, 2014), and identity formation (Charmaz, 1983). How children understand and learn to cope with T1DM is of great clinical interest, yet historically children's views tend to be overlooked.

Purpose: We sought to investigate the child's lived experience of managing T1DM and how this may differ across treatment regimens. The two primary forms of insulin replacement for T1DM include Multiple Daily Injections (MDI) or Continuous Subcutaneous Insulin Infusion (CSII), also known as Insulin Pump therapy.

Materials & Methods: We used a qualitative approach to conduct semi-structured interviews with 17 children (aged 7 – 15 years). The children were interviewed twice, four months apart and the transcribed interviews were analysed using Grounded Theory coding (Charmaz, 1990; Glaser, 1978; Strauss & Corbin, 1990). Half the children transitioned to using CSII ($N = 8$) immediately after the first interview, and the other half continued their usual MDI treatment ($N = 9$). Demographic and basic medical information, including current blood-glucose level (measured by HbA1c), was also collected at both time points.

Results & Discussion: One primary model with several key components emerged from the data representing the lived experience of children diagnosed with T1DM. The Transitional Stages Model of Treatment and Coping [henceforth called the Transitional Stages Model] identified key stages of transition and adaptation that all children experienced. Of particular interest were shifts in the sense of embodiment and interpretation of one's own bodily cues within these stages, and the meanings children attributed to their chronic illness. Adaptation involved children navigating a system of distributed management involving technology, parents, peers and school.

Conclusions: Implications for clinical practice and opportunities for psychological intervention are discussed, specifically for children with T1DM experiencing distress or coping with a key transitional phase.

Key words: *Children, type-1 diabetes, chronic illness, coping, CSII, insulin pump therapy, mixed methods*

1. Introduction

Type 1 Diabetes Mellitus (T1DM) is a complex metabolic disorder typically diagnosed in childhood and characterised by insufficient insulin production (ADA, 2014). Treatment for T1DM is life-long and intensive, influencing almost every aspect of daily life for diagnosed children and their families (Moreira, Frontini, Bullingger, & Canavarro, 2013). As a result, this chronic illness may hold important implications for a child's psychological wellbeing (Lawrence et al., 2006; Kongkaew, Jampachaisri, Chaturongkul, & Scholfield, 2014), and identity formation (Charmaz, 1983; 1995). Understanding the psychological functioning of children with chronic illness is important for researchers and clinicians, as mental and physical health are closely intertwined (Purdy, 2013; Weiss, Haber, Horowitz, Stuart & Wolfe, 2009). Specific emotional factors such as stress (Boardway, Delamater, Tomakowsky, & Gutai, 1993), depression (Grey, Boland, Davidson, Yu, Sullivan-Bolyai, & Tamborlane, 1993; Hilliard, Herzer, Dolan, & Hood, 2011; Johnson, Eiser, Young, Brierley, & Heller, 2013) and low self-efficacy (Forsander et al., 1998; Stupiansky, Hanna, Slaven, Weaver, & Fortenberry, 2013) have been linked with poor medical outcomes for children with T1DM. Chronic emotional arousal caused by different forms of stress may contribute to poor medical outcomes; either directly by exacerbating metabolic processes, or indirectly by disrupting the child's ability to implement their treatment regimen (Moran, Fonagy, Kurtz, Bolton, & Brook, 1991). Such research emphasises the importance of optimising psychological wellbeing, however prior studies tend to focus on demographic predictors which are not easily modified, or use quantitative scales which may not capture the nuances of children's experiences.

In the present study we sought to better understand the complexities of the lived experiences of children with T1DM and identify what is most relevant from their perspective. Whether differing views or interpretations of T1DM in children are linked with improved medical outcomes and overall wellbeing is also of clinical interest. In the present study we used qualitative methods to investigate the impact of T1DM on children's sense of personal identity and to understand whether this differed between common insulin replacement treatments.

1.1. Medical Treatment and Management of T1DM

As insulin is instrumental in converting glucose into energy, children with T1DM are at risk of serious microvascular (e.g., retinopathy, neuropathy) and macrovascular (e.g., cardiovascular disease) complications, and even fatality (De Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Drotar, 2006; Orchard et al., 1990). Poor blood glucose control and hypoglycemia have been linked with a decline in neurocognitive processing, specifically a

decrease in overall full-scale intelligence quotient scores (Northam, Anderson, Jacobs, Hughes, Warne, & Werther, 2001) and executive functioning (Tonoli et al., 2014). To minimise these risks, children and their families are required to integrate complex self-care management into their daily lives. Management of T1DM is difficult as the insulin replacement needs of children constantly vary according to a myriad of lifestyle factors including diet, exercise and sleep (Ellenberg & Rifkin, 1983). Treatment involves multiple tasks (see Schilling, Grey & Knafl, 2002), including regular blood-glucose monitoring to inform exogenous insulin replacement via Multiple Daily Injections (MDI) or Continuous Subcutaneous Insulin infusion (CSII). CSII is a small electronic device otherwise referred to as an ‘insulin pump’, which is worn externally to the body and can be programmed to deliver insulin, as required, via a catheter. This is an alternative to MDI and is commonly recognised as a more flexible form of treatment (Lenhard & Reeves, 2001). CSII use is gradually becoming more common; in 2011 approximately 10% of Australians diagnosed with T1DM used CSII and almost half were aged under 25 (Australian Institute of Health and Welfare, 2012). In a systematic review of research investigating the psychological impact of CSII as measured by quantitative scales, Fraser, McIlwain, Ambler and Attuquayefio (2014), found CSII was linked with improvements in quality of life, parent and child emotional functioning, and lifestyle flexibility. Given these trends, children with T1DM may hold different beliefs and interpretations of their illness based on their treatment.

Children and their families struggle to integrate treatment regimens with their daily lives for a number of reasons. First, T1DM is a difficult illness to understand. It is hard to interpret and predict the link between the momentary fluctuations of blood glucose levels with food, exercise and replacement insulin. Children typically lack the cognitive capacity to completely understand the complex endocrine system. This may partially explain the presence of ‘folk’ understandings of T1DM in adult populations; that is, understandings based on personal experiences or misinformation rather than medical knowledge (Williams, Baker, Parker, & Nurss, 1998). Second, diabetes management takes place within the context of a child’s continuing cognitive, psychosocial and pubertal development. Woodgate (1998) termed this a “dual crisis”, as children not only need to deal with complex normative developmental tasks, but must also manage the treatment of a life-threatening illness. Furthermore, children are unable to take full responsibility for their treatment, and often rely on a network of adults including parents and teachers to complete daily self-care tasks (Anderson, Ho, Bracket, Finklestein & Laffel, 1997). Much research explores the lived experience of diabetes for adults (Barnard, Skinner, & Peveler, 2006; Garmo, Hornsten & Leksell, 2013; Grigsby, Anderson, Freedland, Clouse, & Lustman, 2002; Compeán-Ortiz,

Gallegos, Gonzalez-Gonzalez, Gomez-Meza, Therrien, & Salazar, 2010). However children with T1DM are a unique population whose self-care is influenced by a diverse range of factors differing from adult populations, and therefore requires research specific to their needs and experiences to guide clinical practice and intervention.

1.2. Prior Quantitative Research for Children with T1DM

Specific demographic factors of children with T1DM have been linked with metabolic control including: gender (Helgeson, Siminerio, Escobar, & Becker, 2009), socioeconomic status (Rosenbaur, Dost, Karges, Hungelle, Stahl, Bachle, Gerstle, Kastendieck, Hofer & Hall, 2012; Haugstvedt, Wentzel-Larsen, Rokne & Graue, 2011), duration of T1DM diagnosis (Rosenbaur et al., 2012; Johnson, Kelly, Henretta, Cunningham, Tomer, & Silverstein 1992), and parental family status (Helgeson et al., 2009; Urbach, La Franchi, Lambert, Lapidus, Daneman, & Becker, 2005). Interestingly, a series of psychological factors measured with quantifiable self-report measures have also been linked with improved metabolic control including; high self control and emotional processing (Hughes, Berg, & Wiebe, 2012), as well as self-regulation and executive control (Berg et al., 2014). The link between parental stress and the child's metabolic control has also been widely supported (Gilbertson, Brand-Miller, Thorburn, Evans, Chondros, & Werther, 2001; Landolt et al., 2002; Streisand, Swift, Wickmark, Chen, & Holmes, 2005).

Recently, Blicke et al. (2014) found that children's (age range 11-17 years) personal resources such as body awareness and an open-minded attitude were associated with improved metabolic control. This is an exciting finding. These personal resources have the potential to be malleable and modifiable with appropriate treatment, which may in turn lead to improved psychological and medical outcomes. However, Blicke et al. (2014) used very brief measures of both constructs that may not capture the full complexity of child experiences. Body awareness as a construct was measured using an unpublished scale, the Essen Resource Inventory for Children and Adolescents. This scale contained 8 broad items, such as "I feel content with my body", and may not genuinely reflect the bodily experiences of children themselves. The open-minded attitude score was coded in the child's responses to a single question "I would give the following advice to other children suffering from diabetes". Although such an open-ended question may provide more opportunity for children to express their opinions, the notion of 'advice' may encourage children to reflect on their ideal rather than actual state, and the terminology "suffering" may have implicitly primed a sympathetic answer and to some degree instantiated a victim perspective.

Similarly, McGrady, Peugh and Hood (2014) found that illness representations of adolescents (age range 15–20 years) predicted adherence to T1DM management plans, measured as frequency of blood-glucose monitoring. Illness representations were measured using two scales of the Diabetes Illness Representations Questionnaire (Skinner, Hampson, & Fife-Schaw, 2002). These scales measured children's perceived effectiveness of treatment to control diabetes and prevent complications, as well as perceived consequences of the disease. Overall, quantitative research has highlighted the significant relationships that exist between psychological variables and metabolic outcomes. These relationships highlight the importance of understanding psychological factors for children with chronic illnesses. However such studies use a pre-existing scale or questionnaire to investigate a specific aspect of the child's psychological functioning. As a result, these methodologies may not capture the diversity of psychological factors that are likely to be relevant for children. Issues that are important from the child's perspective may also remain unacknowledged. For example, an overreliance on quantitative data may overlook information about the feelings, worries, hopes and goals of children themselves (Woodgate, 1998) that have not been anticipated by adult researchers. Furthermore such quantitative research implicitly positions psychological wellbeing and adjustment to T1DM as final outcomes rather than ongoing processes. Given both child development and T1DM management plans are constantly changing, it is likely that psychological wellbeing and adaptation to the illness are also continually changing processes involving dynamic adaptation.

1.3. Theoretical Foundation of Qualitative Research

Alternatively, qualitative research takes seriously the experiences of the individual being studied to determine what is salient or important about a phenomenon, rather than a predetermined research hypothesis based on theory. Darbyshire, MacDougall and Schiller (2005) argue that researching the perspectives of children offers unique insights which may be difficult to access through use of a single method of data collection. Symbolic interactionism is a theoretical approach to qualitative research which encourages a view of the individuals being studied as being considered experts in their experiences. This approach emphasises that people do not respond directly toward events, people or objects. Rather, they react to the meanings they attribute to such things, and are continuously in the process of interpretation and meaning-making (Benzies & Allen, 2001). Adopting the symbolic interactionist approach, Charmaz (1983; 1995; 1999; 2002) has written extensively on the process of identity change and adaptation as a result of chronic illness. This framework informed and underpinned our current study. Most chronic illnesses cause physical changes and diminish

bodily functions, leading to the experience of an altered sense of oneself. Charmaz's (1983) early work highlighted four key factors determining the suffering of those with chronic illness: experiencing restricted lives, social isolation, being discredited and burdening others.

Charmaz (1991) went on to hypothesise that adapting to the suffering or impairment caused by chronic illness promotes an 'odyssey of self'. Adaptation is a reactive process in response to a radical disruption of body and self, accepting bodily losses, and resolving this disruption (Charmaz, 1995). Whilst Charmaz's (1983; 1995; 1999; 2002) work predominantly focuses on adult populations, this body of research emphasises the value of a qualitative approach to provide insight into the idiosyncratic and personalised experience of chronic illness. It also encouraged the researchers in the current study to adopt an open-minded approach, sensitive to the potential biasing role of their own 'hunches' and preconceptions, as well as to the complexities of experiences felt by children diagnosed with T1DM.

1.4. Prior Qualitative Research for Children with T1DM

Existing qualitative research exploring the lived experience of T1DM typically focuses on older adolescents, parents, caregivers, teachers, and clinicians on behalf of the child (Jaser, Linsky, & Grey, 2014; Jönsson, Hallström & Lundqvist, 2012; Weinger, O'Donnell, & Ritholz, 2001; Whittemore, Jaser, Chao, Jang, & Grey, 2012). Whilst valuable, such research offers insight into adult perceptions of their own, or their child's experiences of T1DM, rather than the direct views of the children themselves. This may be a result of traditional medical approaches to care which tend not to consult children, judging them to be incapable of complex thought (Amer, 1999; Guell, 2007). A newer area of qualitative research has begun to investigate the perspective and experiences of younger children directly. However, results are often conflicting and focus predominantly on treatment compliance and practical difficulties rather than psychological factors that potentially motivate such measured behaviours.

Spencer, Cooper and Milton (2009) conducted a systematic review of qualitative studies focusing on child populations with T1DM. The authors summarised the findings of 20 papers published between 1988 and 2008 into four key areas: independence and autonomy in children managing their diabetes, living with diabetes, family relationships and diabetes self-care. The authors identified an overarching theme across these studies: that social relationships with parents, peers and teachers were fundamental to the effective management of diabetes. A more recent systematic review specifically examined the relation of peer influence to medical outcomes for adolescents with T1DM in both qualitative and quantitative research (Palladino & Helgeson, 2012). In contrast, the authors found a weak relationship

between peer support and self-care, and mixed evidence relating peer support to glycemic control. Interestingly, two longitudinal studies identified by Palladino and Helgeson (2011) to be of high quality found peer conflict related to poor diabetes outcomes – confirming peer influences to be important, though not necessarily playing a positive role. Thus the role of peer relationships for children with T1DM remains inconclusive; and whether the impact of peer relationships differed across treatment type (MDI or CSII) was not discussed in either review. This may be relevant given the benefits of CSII discussed previously.

One study focused on the adolescent's understanding and personal feelings toward diabetes. Using qualitative interviews, Schur, Gamsu and Barley (1999) found that adolescents (aged 16 – 22 years) overcame the shock of diagnosis to develop a relationship with diabetes involving acceptance of the illness, and finding a balance between self-care tasks and daily life. A number of strategies were utilised to achieve this balance including sharing ideas and frustrations with family and others who also had diabetes, adaptive denial to diminish the anxiety around possible complications and downward social comparisons to those in a worse-off situation. One aim of the current study is to better understand how children under 16 years interpret and understand their illness, and whether different meanings or coping strategies for T1DM occur in this younger population. An additional aim is to determine whether these perceptions change according to treatment regimen.

1.5. *Prior CSII research*

Specific to CSII, Berlin et al. (2006) interviewed 20 adolescents (mean age 14.04 years) and their parents who had recently transferred to CSII. The authors used a behavioural and family-systems framework to explore problematic situations related to CSII and the context in which the problems occurred. Data was collected using a structured interview with several open-ended questions. They found that parents and adolescents most frequently experienced difficulty with self-management tasks such as meal planning, insulin administration and carbohydrate counting. This was over and above other common problems such as site infections, CSII technical malfunctions and managing hypoglycemia. When rating the difficulty of possible situations, adolescents rated social situations (i.e. parent not allowing child to sleepover at a friend's house due to hypoglycemia risk) as the most difficult. Perhaps validating the basis of the frustrations of adolescents, parents were most concerned about hypoglycemia and also CSII malfunctions, which may have led to their concerns regarding social situations. However the survey's focus on asking adolescents about a range of problem areas may have primed a negatively weighted view of managing T1DM.

Similarly, Low, Massa, Lehman and Olshan (2005) used content analysis to interpret

interviews with 18 adolescents (age range 11-18 years) and their parents in the United States. A series of 25 open-ended questions were used to gather data about CSII experiences. This study reported both benefits, such as greater treatment and diet flexibility, as well as practical difficulties or challenges such as CSII alarms and malfunctions and positioning the CSII device during exercise and sleep. Low et al. (2005) commented that families who anticipated CSII would be a 'cure', or who held other unrealistic expectations, generally had poorer medical outcomes. However underlying themes of how the child understood diabetes or how it shaped their self-concept were not further explored. Other qualitative research has also linked CSII use with shifts in responsibility for blousing – an injection of fast-acting insulin – between adolescents and their parents (age range 12-19 years; Olinder, Nyhlin & Smide, 2011), and a feeling of greater freedom in terms of sleeping in and more choice in diet (age range 3-16 years; Pay, 2011).

1.6. A focus on 'Normalcy'

Normalcy tended to be raised by many researchers as a core, underlying goal of children living with T1DM. Davidson, Penney, Muller and Grey (2004) used content analysis to interpret interviews conducted with 34 adolescents (age 12 - 20 years) after a coping skills intervention. Davidson et al. (2004, p.76) described the adolescents as feeling a "sense of difference in their lives, despite their concerted efforts to maintain a sense of normalcy". Similarly, Dovey-Pearce, Doherty and May (2007) describe the impact of a T1DM diagnosis on personal identity as establishing a sense of difference, being 'not normal' and 'unwell'. Freeborn, Dyches, Roper and Mandleco (2012) conducted focus groups with 16 children (age range 6-18 years) and found that self-care tasks such as blood-glucose checking contributed to strong feelings of being different from their peers, often resulting in children not performing these tasks. Similarly, Marshall, Carter, Rose and Brotherton (2009) concluded that all children interviewed in their sample ($N = 10$, age range 4-17 years) aspired to 'being normal' and 'having a normal life'. Whilst identifying being 'normal' as a central unifying theme for these children, Marshall et al. (2009) acknowledged there was great variability in how each child and their parent defined a sense of 'normalcy' and recommended future research further explore "what children and their parents mean by 'normal' and how they frame normal in respect of their lives, their family, peers and society" (p.1709). Although such definitions were often notably absent, across these studies 'normalcy' tended to be used as a term of social comparison with children who were not diagnosed with a chronic illness, positioning a child with T1DM to lie outside 'normality' and thereby reinforcing ideas of being different or abnormal. It is precisely the singularity of the view of normalcy that this paper opens up for

consideration.

1.7. *The Present Study*

In the present study, we sought to extend on prior work detailing issues around behavioural compliance and the difficulties of managing T1DM to focus on the lived experience of children and the possible impact on their sense of self concept and identity. We also sought to better understand these experiences in the context of different treatment modalities, particularly MDI and CSII. To accomplish this, we conducted semi-structured interviews with children using MDI or CSII at two time points, four months apart (Charmaz, 1990; Glaser, 1979; Strauss & Corbin, 1990). Analysis of the interviews used a Grounded Theory approach, which positions children as the experts of their own experiences.

2. Method

2.1. *Participants and Recruitment*

Participants ($N = 17$) were all patients of the Department of Endocrinology at The Children's Hospital Westmead, Sydney. The procedures of this study were implemented as part of a larger randomised control trial investigating the effect of CSII on attention, concentration and behaviour. The procedure and results of the larger study are reported elsewhere (O'Connell et al., manuscript in preparation).

Eligible patients were identified using CSII waiting lists from the Department of Endocrinology at The Children's Hospital at Westmead in Sydney. Eligibility criteria included children who were aged seven to 15 years, naive to CSII and using MDI for at least one month's duration. Children also needed to speak a sufficient level of English to participate in an interview, and to not have been diagnosed with a comorbid pervasive developmental delay or neurological disorder. There are currently no formal guidelines for selecting patients suitable for CSII, and diabetes teams often base their recommendations on the stability of the family environment and the requests of the child and family. Families are generally required to have demonstrated satisfactory treatment adherence whilst on MDI, expressed an interest in CSII and have access to funding (through private health insurance, a donated pump or private funding).

Prior research has suggested that children aged below 7 years of age experience difficulties in interview situations and tend to limit their responses to 'yes' or 'no' answers (Hetherington & Parke, 1986). Comparatively, children above the age of 7 are more likely to have developed the cognitive and verbal capacity to participate in the interview process. Rebok, et al. (2001) studied the capacity of children aged 5 to 11 years to understand and

report on their own health condition. The authors found that children under 5 years were unable to adequately describe or understand their own health condition. Six and 7 year olds had difficulty with some health-related terms. They were more likely to endorse middle and extreme scores on a Likert scale, yet overall were able to meaningfully describe their experiences. The current study included participants aged 7 to 15 years, and included both open-ended and Likert-scale questions. This age group was selected as we wished to sample younger children's views, which historically, have been less likely to be acknowledged by qualitative research, and we were interested in the understanding of diabetes for younger children.

All eligible participants were invited to take part in the study. Potential participants were approached by the first author either in person (for example, when attending a routine diabetes outpatient appointment) or by telephone. The project was verbally explained to the primary caregiver and child, and a detailed consent form was provided. Of the 25 families approached, 17 gave their consent to participate in the study. The most commonly cited reasons for non-involvement of participants were a lack of time, and limited flexibility to attend research appointments in addition to medical appointments at the hospital.

2.2. *Ethical considerations*

Given the participants were outpatients of the Department of Endocrinology, ethical approval for the current study was gained from the NSW Health Human Research Ethics Committee based in Children's Hospital at Westmead (11/CHW/11), in addition to the Macquarie University Ethics Review Committee (Human Research: 5201300012). Written consent was gained from both the parents and the child prior to the interview. The study was also described in detail over the phone to the Principals of each school attended by the child. Both the principal and teacher who had most contact with the child also completed consent forms to participate in the study. Interviews were conducted after the children had completed the cognitive study (approximate duration 2 hours) and had taken a lunch break. The participants were interviewed on site at the hospital in a quiet room with minimal distractions whilst parents remained in the waiting room. Given the age range, we tried to keep interviews to average duration of 10 - 25 minutes to prevent the interview from becoming tedious or disengaging (actual interview times ranged from 8 to 45 minutes). Each child had met with the interviewer prior to the actual interview, and was familiar with the outpatient rooms in which the interviews took place. It was explained to the children and families that the interviewer was not linked with the medical team, and that the interview would not affect their current medical treatment. Participation was entirely voluntary and participants did not

receive any form of reimbursement for their involvement.

2.3. Design

This qualitative, exploratory study investigated the lived experience of children with T1DM, with a particular interest in how this may shift with different treatments. Children were interviewed at two time-points after transitioning to CSII, and also compared to children using MDI. The data for the 17 participants were collected between September 2012 and January 2014.

Upon entering the study, children were randomly allocated to a group that started CSII immediately after the baseline appointment (treatment group, $N = 8$) or a group that continued their usual treatment regimen of MDI (control group, $N = 9$). Both groups were interviewed again after four months. The purpose of the second interview was to detect any changes in the individual's experience of diabetes after transitioning to CSII in comparison to the group that maintained MDI treatment, as well as identifying how transitory or stable the child's views were across time. At both time points, the children were interviewed using an open-ended questionnaire in a conversational style. At the baseline appointment, parents also completed a demographics questionnaire, and at both time points an HbA1c analysis was conducted. HbA1c is a laboratory test conducted on a small sample of blood that provides an average blood-glucose level for the month. It is widely used as an indication of treatment management and overall blood glucose control (Rohlfing, Wiedmeyer, Little, England, Tennill, & Goldstein, 2002).

2.4. Questionnaires

2.4.1 Demographics

Demographic information was collected, via parent questionnaire, regarding the child's age, gender, ethnicity, treatment received at the hospital, date of type-1 diabetes diagnosis and duration of illness as well as screening for any developmental or learning difficulties. Socioeconomic status (SES) was assessed based on the primary income earner of the family, and coded according to the Australian and New Zealand Standard Classification of Occupations (ANZSCO; Daniel, 1983) using a 1–8 rating scale (high SES 1 – 2.5, medium SES 2.6 – 5.4, low SES 5.5 – 8).

2.4.2 Qualitative Interviews

A series of broad questions, specifically focusing on the influence of diabetes on one's character and capacity, were developed for the current study and administered in a semi-structured interview format (see Appendix A and B). The questions were broad and language

that was likely to be leading was excluded from the questions. For example, children were asked: “is there anything that you would like to do, or anything you would like to be when you grow up, that will be a little bit tricky because of diabetes?” The use of the term ‘tricky’ sought to investigate the child’s view of the long-term impact of their illness in a more neutral and child-friendly tone than referring to ‘problems’ or ‘difficulties’. The aim was to encourage the children to reflect on their experiences and what these experiences meant to them, thus interviews were conducted in a conversational manner. In addition, early in the interviewing process similar prompts were often noted to naturally follow the semi-structured questions in the course of the interview. These prompts were identified and included in future interviews when needed – for example, to encourage further elaboration (see Appendix C). The focus of the interviews, however, was on encouraging the children to further elaborate on themes or topics that they themselves had raised. Whenever possible, the interviewer tried to encourage further elaboration on new ideas or themes by asking open-ended questions which used terminology introduced by the children themselves. To optimise consistency, all interviews were conducted by one author (MF), who had experience working with children in clinical and medical settings.

2.5. *Qualitative Data analysis*

2.5.1 *Grounded Theory Approach*

The Grounded Theory approach (Strauss, & Corbin, 1990) to qualitative research seeks to develop an understanding of human behaviour based on the lived experience and point of view of those being studied. This approach is an alternative to characterising an individual’s experience according to predetermined categories defined by theory or existing hypotheses. Grounded Theory begins with broad, open-ended questions, encouraging participants to be positioned as experts of their experiences. In accordance with Grounded Theory, the data collected in the present study was analysed closely, line-by-line, to identify key themes. We developed a clearer description of these themes and drew links between similar themes, describing them at higher levels of abstraction whilst retaining their complexity and wholeness (Patton, 2002). Rigorous procedures, detailed in the data analysis section, were used to identify, test and validate these themes, building toward a theoretical understanding of the phenomenon under investigation (Fassinger, 2005).

This systematic methodology is often applied in health psychology research, and was selected for the present study for its ability to generate, rather than test, hypotheses and develop theory based on the viewpoint of the children themselves (Strauss & Corbin, 1998;

Strauss & Corbin, 1990). The suitability of this approach has previously been supported in populations suffering from chronic illness (Charmaz, 1990).

2.5.2 Author Frameworks

It is important to acknowledge that all researchers carry with them implicit schemas, conceptual frameworks and theoretical orientations. These personal qualities inevitably influence the research process and characterise interpretations of the data. A co-constructivist approach acknowledges the subjectivity inherent in analysing qualitative data (Charmaz, 2006), and accepts that interpreted data also reflects the researchers' views despite seeking to focus solely on the person being studied. Grounded theory attempts to address this issue by recommending the framework and approach of the researchers are explicitly stated.

Madeleine Fraser is interested in how children conceptualise and interpret their world. She is a doctorate of clinical psychology candidate whose training has predominantly been grounded in Cognitive-Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT), with an emerging interest in psychodynamic psychotherapy. Her clinical interests include working with children and adolescents with chronic physical health conditions and comorbid psychological distress. She has experience working with such populations in private practices, research-based treatment clinics and both public and private hospitals.

A/Prof Doris McIlwain is a psychoanalytically-influenced researcher in the experience of emotion and embodiment and a psychodynamic psychotherapist. She has supervised and published with many doctoral and masters students whose interests lead them to adopt a qualitative research framework spanning: children's experience of repeated painful medical treatments, women's resilience in the face of domestic violence in Sri Lanka, the handling of sexual attraction in psychotherapy, the interpretations of metrosexuality among young people, and social and personality-level contributions to resilience and peak experiences in elite cricketers, psychotherapists and yoga practitioners. As a personality researcher, in addition to exploring empathy, morality and charisma, she is interested in how individual differences shape forms of coping and the meanings accorded to experiences past, present and future.

2.5.3 Transcript Preparation

To optimise objectivity, all 34 interviews were transcribed verbatim using an independent transcription service. All recorded interviews were listened to again by MF, and the independently transcribed written interviews were checked for accuracy. Minimal changes to the original documents were required.

Interview scripts were transferred to a transcript file (Browne & Sullivan, 1998). The file contained three columns, the verbatim script was placed in the middle column, surrounded by memos (the author's thoughts about the content) and coding columns to facilitate word-by-word and line-by-line analysis of each interview. These files were later uploaded and coded in Nvivo10, qualitative coding software, as the large number of interviews and data quantity became difficult to manage.

2.5.4 Transcript Analysis

We simultaneously collected and analysed data until saturation was reached. Saturation is defined as the point at which no new concepts or relationships are identified, indicating a substantial theory about the behaviour of investigation has formed (Fassinger, 2005). Simultaneous data collection and analysis also allowed the interview and coding process to inform each other. Transcripts were re-read several times in their entirety before coding took place to enhance overall understanding. The transcripts were then open-coded line by line whilst digital recordings were concurrently listened to. Listening to the recorded interviews allowed more subtle verbal cues such as tone, expression and expressed emotion to also be acknowledged and coded. To improve internal reliability and consistency, a second researcher, (DM) also conducted open coding on all interviews. Areas of difference or dispute between the two researchers were reconciled through discussion.

Beyond a broad interest in how children understand their illness, particularly in relation to their identity and physical capacities, no pre-existing themes had been developed for the coding process. Thus during open coding, interesting concepts were labeled as nodes as they arose. We clustered similar nodes into themes and subthemes, and memos (the researcher's interpretive thoughts and side comments) were also recorded. Axial coding is recommended by Strauss and Corbin's (1990) method to identify connections between nodes, reconnecting the coded data in new ways. The broader themes, which arose from the open and axial coding, led to the development of explanatory models. During this process, we adopted several rigorous procedures to improve the accuracy of the interpretation (Fassinger, 2005). Constant comparative analysis (Henwood & Pidgeon, 1992) was used to draw comparisons between provisional hypotheses and different participants at each stage of the interpretative process to improve clarity and acknowledge complexity. In addition, negative case analysis involves actively seeking cases or examples that may disprove the theory as it is forming. The final models were validated through their application to individual cases, measuring their idiosyncratic applicability (Strauss & Corbin, 1990).

To report the current results, quotations were used to illustrate themes. Participant

quotations were edited subtly to improve readability, however care was taken to ensure original meaning was preserved. All data has been de-identified to protect confidentiality. Specifically, each child was given a pseudonym to protect their identity, and that pseudonym remained consistent through the paper to enable readers to track comments made by the same children. The pseudonyms selected were common names in English-speaking countries, and did not reflect the nationalities of the children interviewed but did reflect their identified gender. To optimise clarity, and consistent with qualitative research practice, the results and discussion sections are reported together.

3. Results and Discussion

The current findings are presented in three sections. Firstly the demographic characteristics of the sample will be described. Secondly, the qualitative results will outline the Transitional Stages Model of Treatment and Coping – henceforth referred to as the Transitional Stages Model – that was developed from the data. Within this model, particular attention will be paid to two key sub-models which reflect the children’s experience; the embodiment of bodily cues and distributed system of management. Finally, the methodology of the current study will be critiqued and clinical implications and areas for future research discussed. To improve clarity of expression, the results and discussion sections shall be combined.

3.1. *Participant Characteristics*

The participants ($N = 17$) ranged in age from 7.3 – 15.5 years ($M = 11.8$, $SD = 2.4$). 10 of the children were female, and 7 were male. The average duration of each child’s T1DM diagnosis was 1.5 years ($SD = 1.8$). One child had comorbid diagnosis of coeliac, two were also diagnosed with thyroid disease, and two were also diagnosed with asthma. The average HbA1c result at baseline was 8.3% ($SD = 1.4$), and 7.9% ($SD = 1.0$) at the follow up time point. Specifically at the four month follow up, the average HbA1c for CSII users was 7.6% ($N = 9$; $SD = 0.9$) and for MDI users 8.4% ($N = 8$; $SD = 1.3$). Over three-quarters of this sample (76.5% at baseline and 64.7% at follow-up) exhibited HbA1c levels higher than the recommended threshold of 7.5% (Silverstein, et al. 2005). Pen and paper recordings of blood-glucose monitoring over a six-day period averaged 5.1 ($SD = 1.1$) readings per day at the baseline time point. The American Diabetes Association (2014) recommends 6 - 8 readings per day for optimal blood-glucose control, and on average the children in the current sample met this criterion. At the baseline appointment, 15 children using MDI were treated with four insulin needle injections per day, and two were treated with three injections. Average Body Mass Index of the current sample was 20.16 at baseline ($SD = 3.8$), broadly classified as a

healthy weight range (CDC, 2014). At baseline, correlational analyses found a moderate, positive relationship between the duration of the child's T1DM diagnosis and their HbA1c ($r = .66$; $P < 0.01$), and no relationship between BMI and HbA1c ($r = -0.02$).

All children lived in New South Wales Australia and the average ANZSCO rating of SES was 2.7 ($SD = 1.1$) for mothers and 2.9 ($SD = 1.4$) for fathers out of a total score of five. Occupations classified within a score range of 1 – 2.5 out of 8 are defined as 'high socio-economic status'. In the present study, five of the nine children had been approved for a pump provided by state government health funding. In Australia the government each year funds a limited number of insulin pumps.

3.2. *Transitional Stages Model of Treatment and Coping*

All children, with and without diabetes, experience important and often complicated periods of change and adjustment (Schlossberg, 1981). These periods of change can be triggered by specific events such as starting school or high school, or through 'non-events', which can be instances when the individual's assumptions about the world are challenged or confronted. Schlossberg (1981) suggests these triggers produce disequilibrium, as the usual pattern of daily living is disrupted. This in turn facilitates the acquisition of new skills and behaviours to overcome challenges posed by the transitional event. Ultimately a transition is both an outcome and a process, and may involve both growth and deterioration (Brennan, 2001; Schlossberg, 1981), forming key markers for life span development. Children diagnosed with diabetes appear to experience a complex and challenging series of medical treatment transitional phases in addition to these general life transitions.

As children described their experiences of living with T1DM, a chronological set of phases in T1DM treatment and management emerged. While there was variance in the duration of each stage and processes of adaptation used within each stage, commonalities to all the children's experiences were found. These commonalities were combined to create the Transitional Stages Model of Treatment and Coping [henceforth Transitional Stages Model], including three key stages as follows (see Figure 1):

1. Transitional Stage 1: transitioning from an absence of symptoms to the presence of untreated T1DM symptoms
2. Transitional Stage 2: transitioning from an undiagnosed experience of T1DM to receiving a medical diagnosis and commencing MDI
3. Transitional Stage 3: transitioning from MDI to CSII treatment

The individual variability between children within each stage highlights the

importance of adopting an idiographic approach to understanding chronic illness in children. These transitions involve a dynamic and interactive process of adjustment for both the child and their family; however the focus of this study was the child. While the end of each stage overlapped with the commencement of the next, the key focus of each stage was the transitional event. Each of the three key stages is described in more detail below.

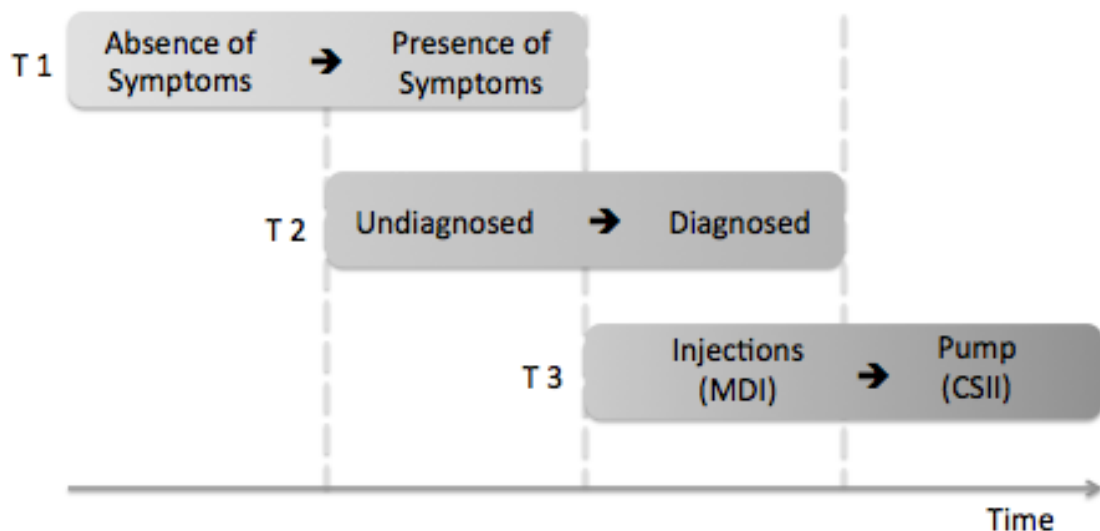


Figure 1: Diagrammatic representation of the Transitional Stages Model of Treatment and Coping

3.3. *Embodiment of Bodily Cues*

In addition to the Transitional Stages Model, a reoccurring theme that arose from the interviews were the ways the children understood, interpreted and responded to their own bodily signals. We labeled the relationship children had with their own embodiment as a ‘mind-body connection’. After identifying this common theme, we re-read the interviews with sensitivity toward noting how the child described their own bodily functioning and their relationship with their physical body. This mind-body connection included several elements such as an attunement to one’s bodily cues and the level of attention paid to the body and these cues. As a result of this attunement, children subsequently differed in their interpretation of these cues and their subsequent cognitive, emotional and behavioural reactions.

Much emotion literature suggests that felt activation of physiological arousal and bodily sensations contribute to mental experiences of emotion (Barrett, Mesquita, Ochsner & Gross, 2007). A physiological process underlies the experience of arousal, whereby the brain and muscles are supplied with increased glucose, and both adrenaline and noradrenaline are released into the systemic blood circulation (Binder, Barry & Kaiser, 2005; Cannon, 1932).

The presence of this physiological arousal is thought to give rise to 'evaluative needs' (Festinger, 1954), triggering a sense-making process of searching for causal explanations. Indeed, many cognitive-behavioural approaches to the treatment of affective disorders focus on encouraging an awareness and acceptance of one's physiological state when experiencing anxiety (Beck & Emery, 1985). For example, a child with severe social phobia who arrives at a birthday party may feel their heart racing, sweatiness and quickened breath. Such physiological feedback may heighten their experience of anxiety and may act as confirmatory evidence that they are in danger. Humans are notoriously poor at attuning to and accurately interpreting and engaging with their own bodily experiences and emotions (Zillmann, 1971). This complexity is perhaps reflected by the diversity of research in this area. For children with T1DM, this process of experiencing and understanding one's own bodily cues and physiology seems to be further complicated by underlying shifts in the mind-body connection triggered by changes in medical treatment.

Although complicated by the presence of a chronic illness, a body of research has identified that the mind-body connection is important for people diagnosed with diabetes. Redmer, Longmier and Wedel (2013) provide a brief systematic review of mind-body stress reliever treatments for adults with Type-2 diabetes. Interestingly, biofeedback treatments, yoga, mediation and Qigong were each found to have a significant and beneficial influence on measurable medical outcomes. For example, one study found progressive muscle relaxation, deep breathing and mental imagery decreased HbA1c levels by 0.5 over a one-year period compared with a control group (Surwit et al., 2002). Such research suggests that one's emotional state, physiological reactions and medical outcomes are causally intertwined.

Existing research suggests the effectiveness of such self-awareness programs may be explained by 'body listening' (Hernandez, Bradish, Laschinger, Rodger & Rybansky, 1997; Thorne, Paterson & Russell, 2003). For people diagnosed with diabetes, body listening involves a process of tuning into one's own body cues and sensations, and using this body knowledge to make appropriate insulin regimen changes to achieve glycemic control (Hernandez, 1991; Hernandez, 1996). Hernandez (1996) used a Grounded Theory approach to understand the lived experience of learning body listening skills in adults with T1DM. Following diagnosis, adults seemed to engage in a process of integration between their personal identity and the newly emerged diabetes identity. Through a gradual process of trial and error, adults became experts in understanding their own diabetes by tuning in to bodily sensations, and learning experientially. This was often triggered by a motivating 'turning point', for instance when the adult experienced a severe physiological event such as a severe

hypoglycemia, or a referral to a specialist whose more intrusive treatment recommendations led to a notable improvement in health.

Hernandez's (1996) theoretical explanation of adults navigating the mind-body connection was found to be relevant to the children in the present study. The children continuously used a trial-and-error process to make sense of their physiological experiences and when determining an appropriate course of action. Important differences in the mind-body connection between adults and children were also identified. Such differences include a greater emphasis (on the part of the children) on the involvement of additional external entities and people in the treatment and care of children, such as parents, peers, teachers and technology. Furthermore, there were notable developmental differences in children's cognitive capacity to understand their own bodily states compared to adults. In addition, each phase in the Transitional Stages Model were characterised by to the children dynamic changes in the manner of the children's engagement with bodily cues; a process which each child seemed to move through in similar ways. These processes seemed to be common to each child at that particular transition phase, perhaps suggesting the mind-body connection changes as a result of adapting to different stages of managing T1DM. This differs to Hernandez's (1996) finding that adults linearly strove toward more accurate interpretations of one's bodily state through trial and error. Shifts in the mind-body connection will be discussed within the Transitional Stages Model.

3.3.1 Stage One: Transitioning to the Presence of Symptoms

Initially the symptoms of T1DM are difficult to identify and interpret. These symptoms include: excessive urination, dehydration and acute vomiting, sometimes resulting in initial delayed diagnosis or misdiagnosis (Anderson, & Brackett, 2005). These symptoms are largely generalised, not specific to one area of the body, and could easily be mistakenly understood as a symptom of a different disease or condition. Most children found it difficult to recall the onset of T1DM symptoms, which is likely due to the symptom's gradual and generalised nature. This may perhaps explain the distinct trend for children to compare themselves to others when describing life with T1DM, particularly siblings and peers, rather than comparing their current state and lifestyle compared to pre-diagnosis. Whilst it was difficult to recall the onset of symptoms, many children vividly recalled a period of feeling very unwell. Uncertainty regarding the explanation for these illness symptoms seemed to heighten the child's emotional reactions, particularly anxiety.

"I'm aware of what to do now, and I know why - because I used to be sick, like, all the time, and now we know why." Chloe (age 13 years)

Chloe's emphasis and repetition of 'why' suggest the diagnosis of T1DM brought relief and clarity, enabling her to make sense of her bodily symptoms which would have been previously unexplained. Further, her shift from the personal pronoun "I" to a collective "we" indicates a communal sense of confusion and meaning-making for both herself and family. This highlights the importance of the close network of support which surrounds a child with T1DM, which will be later discussed at length as the Distributed System of Management.

3.3.1.1. Stage One: Embodiment of Bodily Cues

As previously discussed, the symptoms of undiagnosed diabetes are vague and generalised. Because of the difficulty in accurately labelling these symptoms as diabetes, particularly for families without medical training, often the child's symptoms were exacerbated by a continuous lack of insulin over time. For most children this resulted in a hospital presentation. This crisis suggests an indefinite period of time during which the child noticed uncomfortable sensations, which they none-the-less needed to override or even ignore as an unexplained presence in order to continue with daily life. Attempting to cope with these untreated symptoms is likely to have promoted a disconnect between mind and body, which remains unresolved until later in the Transitional Stages Model as children seemed to develop body listening skills. Jack (age 11) found it difficult to reflect on his experiences during the early phase of present yet undiagnosed T1DM symptoms. Instead of placing 13th in a running race as he had the week before the interview, he recalled that in the past he had run much more slowly;

"I used to come, like 30-something [Interviewer: why is that?] I don't know. I couldn't run. I don't know. I didn't have enough energy." Jack (age 11)

Jack seemed to find it difficult to label the non-specific symptoms of untreated T1DM, generally describing an all-encompassing feeling of not having enough energy. Despite this, he still completed running events, but noticed a significant impact on his performance. Thus the undiagnosed presence of symptoms triggered a disconnect between the mind and the body in these children during this phase.

3.3.2. Stage Two: Transitioning to a Diagnosis

3.3.2.1. Diagnosis – "it was just shocking"

Being diagnosed with diabetes was a powerful experience vividly recounted by most children. Often the children were critically ill at the time of their diagnosis and were admitted to hospital in response to severe symptoms. Such hospital visits were described as confusing and overwhelming experiences.

“But, like, at the hospital, there were, like, five people there that were asking questions, so that was a bit, like... scary. It was okay. I also got really tired” Cathie (age 11)

Here Cathie appeared to use a ‘positive seal’ as an emotional coping strategy. After describing her hospital admission in concrete terms, referring to her interaction with multiple medical staff members, she pauses before labeling the experience as “scary”. Cathie quickly follows with a positive statement “it was okay” perhaps as a way to mitigate and re-construct the extremely powerful and overwhelming memory of her experience as a situation she was able to manage and cope with. She finishes with the description of “tired”, perhaps capturing the overall drain on her physical and emotion resources.

Similarly, for 12-year old Patrick, hospitals were linked with negative and anxious feelings. He used smell and colour to describe the sterile environment’s assault on his senses.

“[Interviewee: What do you think when you think of hospital?] Like something bad happened or is happening, yeah something like that... it kind of just reminds me of the smell of hospital and like, white. I think of white. [Interviewee: What does it smell like?] I’m not sure. It smells like – kind of like medicine or something like that” Patrick (age 12)

Patrick’s sensory description of the hospital can be better understood in the context of Van der Kolk’s (2002) work with neuropsychology and trauma. Van der Kolk (2002) proposes that when people are frightened or aroused, the frontal areas of the brain responsible for cognitive analysis and interpretation of a situation deactivate. As a result, highly stressful situations prevent people from processing and rationally understanding what is occurring to them. In addition, high levels of emotional arousal also interfere with the brain’s ability, specifically Broca’s area, to put emotions and feelings into words. Instead of linguistically processing the event, people focus on and later recall, sensory-perceptual elements such as sounds or smells. The stress and emotional arousal associated with visiting hospital seems to have reduced Patrick’s capacity to rationally describe his experiences, instead relying on emotional memories based on particular sensations, sounds and smells experienced in that moment.

The trauma of a diabetes diagnosis for children and their families was often heightened by uncertainty and a lack of agency. Children keenly felt their lack of control over their circumstances at this time. A lack of understanding and knowledge of the condition seemed to often feed into anxiety and catastrophic reactions where fear of death was present for a child. Rebecca (age 12) vividly recounts a spiral of anxious thoughts and worries she experienced at this time.

“I was at school and then I got pulled out of class, my parents told me and we had to go to the doctor’s straight away. [Interviewer: What was that like?] It was just shocking. I was fairly creeped out. Everything was rushing through my head. [Interviewer: What sorts of things were rushing through your head?] Oh my God, am I going to die? What’s going to happen to me now?” Rebecca (age 12)

3.3.2.2. “Gives me more energy”

An interesting and seemingly contradictory pattern emerged when children were asked to reflect on whether diabetes had changed any of their physical capacities. Several children immediately answered positively, citing an improvement in their physical ability, better performance in sport and higher energy levels.

“Run longer, because I’ve got more energy in me, so I can run longer... I can do stuff better and everything.” Jack (age 11)

“Now it gives me more energy to run around. [Interviewer: What gives you more energy?] Now that I have stable levels so I don’t feel weak when I feel high or low.” Nicholas (age 10)

Jack (age 11) and Nicholas (age 10) linked an improvement in their physical health and ability with the label ‘diabetes’. Presumably this reflects the monumental impact of receiving a T1DM diagnosis and commencing insulin replacement treatment. Diagnosis provided the children with a medical, rational explanation for their generalized and confusing symptoms. Providing a label for experiences that were previously shrouded in uncertainty and mystery seemed to alleviate catastrophic thoughts and fears. As a result of this diagnosis, children commenced an insulin replacement therapy. This treatment seemed to dramatically improve bodily functioning, providing stability for the child’s blood glucose levels. The impact of somewhat alleviating these T1DM symptoms was surmised by children broadly in agentic and self-efficacy-inspiring terms such as *“I can do stuff better...”*.

3.3.2.3. Learnt Medical Knowledge and the Distributed System of Management

Given the complex nature of this chronic illness, children recently diagnosed as having it, and their families, are provided with extensive education and support from medical teams involving endocrinologists, diabetes nurse educators, dieticians and social workers. Children and their families learn a myriad of complex tasks to manage their specialised insulin replacement treatment. It is common clinical practice to initially place children on an MDI regimen according to their body’s idiosyncratic insulin replacement requirements. MDI involves a diverse range of tasks including carbohydrate counting, meal planning and a degree

of dieting, administration of insulin, and checking blood sugar levels (Berlin, et al., 2006). Interestingly, when children described these tasks, it was within the context of a network of supports and resources. We termed this the ‘distributed system of management’ (see Figure 2).

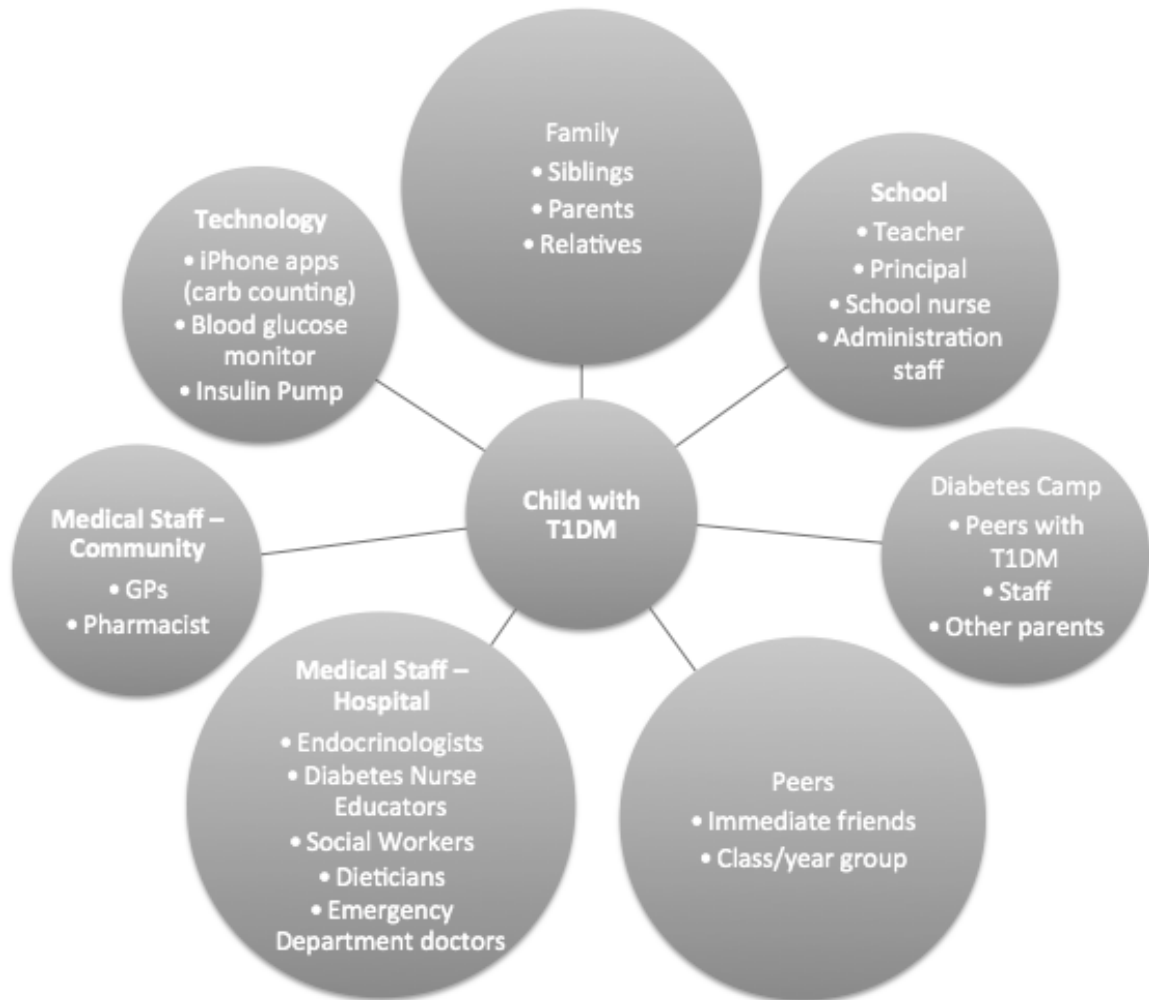


Figure 2: Diagrammatic Representation of the Distributed System of Management

The child is at the centre of this system, requiring varying levels of input and support from every major sphere of life including at home with family, in social settings with friends, and in the school environment with teachers and peers. Feeling supported within this system seemed to be of great importance for children. The distributed system seemed to provide both emotional and practical assistance, enabling children to navigate the complexities of T1DM treatment. Comparatively, social support has been found to be less significant and unrelated to metabolic outcomes in adults (Chlebowy & Garvin, 2006), presumably due to their increased capacity to accept full responsibility for their treatment. This system involved social resources such as family and peers, medical resources in hospital, community and diabetes camp

settings, the school environment (see Figure 2). These findings relate to those of Blicke (2014) who found that children and adolescents valued personal, social and structural resources in relation to their diabetes care. In addition the present study found that children spoke of technology as a source of support, including blood glucose monitors, pumps and iPhone apps to help with carbohydrate counting and alarm reminders. Blicke (2014) found that social support and attachments with others were a key part of children's ability to cope with T1DM, yet we found that peer friendships in addition to aiding coping in some cases, fulfilled diverse roles for children managing their diabetes.

Some children with T1DM used their friendships as an escape and deliberately tried to avoid discussing their condition with their friends, wanting to not be treated differently. For example, when talking about friendships with peers, Patrick (age 12) seemed to treat these friendships as an escape from diabetes. He resented his peers when they attempted to adopt a 'checking' role within his distributed system of management. Furthermore, his own anxieties regarding possible complications of diabetes such as low blood sugar levels seem to be so overwhelming that he projects these worries onto those around him, suggesting his friends are scared of his condition, rather than he himself.

"The thing with diabetes is I wish people wouldn't talk about it so much so I'd kind of forget, but they keep reminding me that I have it and it's kind of annoying... Yeah, even though they don't specifically say 'is your diabetes okay?', I know they're asking about that... It's because - I don't know, maybe they're scared if I'll have low blood sugar, really low, might have to call the hospital or something. They don't want that to happen." Patrick (age 12)

Similarly, when returning to the classroom after an insulin injection in the school administration office, Sarah (age 14) expressed irritation at unwanted intrusions by peers in her year group. Interestingly, she had a clear idea of which peers she openly confided in, and which she politely refrained from confiding in. Here Sarah demonstrated strong boundary-setting skills in controlling the disclosure of her condition. The perceived intention behind peers asking questions related to T1DM appeared to determine the level of disclosure.

"It's a bit annoying, because then I have to go back, and then I get questioned by the students, because they're all nosey. Then I have to catch up on what I've missed. [Interviewer: What do you say to the nosey people?] I was just like - it depends on their question. If it's just like, 'are you okay?' Then I'll be like, 'yeah, I'm fine, thanks, don't worry about it.' But if it's like, 'oh, what's happened? What did you have to do? Why did you have to leave? Why did you just get up and walk out?' I'll just be like, um - it depends on the person. Because if I like them, then I'll tell them. If I don't, then I'm just like 'go away.' Well I'm not like, 'go away', I'll be like,

'thank you for worrying, but it's personal and I don't really feel like sharing it with you, if that's okay.'" Sarah (age 14)

While Sarah was discerning in regards to whom she confided in about her illness, others relied more broadly on their friendship networks as an integral part of their diabetes management plan. For Chloe (age 13), friends adopted a monitoring, checking and assisting role. She appeared confident allowing her friends to better understand diabetes and welcomed their 'checking in'. For many children, friendships were integrated within the distributed system of management informally; relying on medical knowledge received from the children with T1DM themselves.

"All my friends know, so they know - and they ask me, 'oh, did you check your blood?'" Chloe (age 13)

While everyone knew about her illness, Chloe went on to describe a select number of close friends who also played, in addition, an active role in her T1DM management.

"I always have a friend who's there to come with me to the office or to wherever I have to go, so it's good... she comes with me to the office everyday... she already knows that I have to wash my hands and take it. She writes down the date and the time and the score. She knows what's high and what's low, and what's good and what's bad. Yeah, she's good". Chloe (age 13)

In this example, Chloe's friend shares a degree of responsibility for checking her blood glucose levels. This friend also demonstrates learnt knowledge and expertise, when interpreting blood glucose fluctuations. Chloe's friend has been formally allocated a specified role within Chloe's distributed system of management, a process encouraged by many schools including Joseph's (age 14).

"They [school teachers] were like, okay, if you need to leave, just go. Choose one person in the class that will go with you all the time, and then if they're away, have a backup. So I have two people, and that's in all my classes." Joseph (age 14)

An important distinction, which often seemed linked to the role accorded to friendships, was the degree of shame or embarrassment the child with T1DM felt toward their condition. For example, Patrick (age 12), who resisted allowing friends to enter the distributed system of management, described embarrassment and an urge to maintain secrecy concerning management tasks for T1DM.

“Sometimes when I go out and eat at a restaurant or something I have to do it [blood glucose checking], every time I have to excuse my family, go to the toilet and do it or something... sometimes we go to a restaurant and order and then sit at a table and the toilet's not near, so I kind of just hide behind the table or something, or my mum tries to cover me or something... it's just like, kind of embarrassing, having to do the injections with family near...” Patrick (age 12)

The results of the present study suggest a possible explanation for the inconclusive effect of peer relationships found in previous research (Palladino & Helgeson, 2011; Spencer, Cooper & Milton, 2010). No notable differences were found in perceived support role of peers within the distributed system of management for children using CSII and MDI, despite large differences in the treatment requirements.

The level of shame the child felt about their illness and the need for secrecy or to hide it appeared linked the child's willingness to accept peer support and benefit from this support. This pattern holds important implications for psychosocial interventions. Common psychosocial interventions include attending diabetes camps with other children who are also diagnosed with T1DM, or the potential for ‘buddy systems’ in schools where a child more experienced at managing T1DM is linked with a newly diagnosed child. These interventions appear likely to be effective if the child diagnosed with T1DM does not feel ashamed about their illness, otherwise this underlying distress and discomfort may need to be targeted first to maximise the effectiveness of such interventions. Our findings here about the role of shame and friendships open up future avenues for future research, and require verification in other research modalities.

Illustratively, Rebecca (aged 12), who very openly shared her experiences with her peers and welcomed their support, found it invaluablely helpful when her teacher introduced her to an older peer at school who also had T1DM and adopted a mentoring role in her life. Recounting his advice in detail emphasises his shared wisdom has been understood and integrated into Rebecca's interpretation of T1DM and self-concept.

“He's had it his whole life. He was - from when he was a toddler, and he's now 17-ish, maybe. He just said, if you're worried, if you are scared about someone, talk to me or James. We'll help you through it. If it's anything - if someone has said that you've changed or are making fun of you because of diabetes. Then just - and then he said something like a lion doesn't fraternise with the lambs. So he's like if they're doing that, then they're the lamb, you are the lion, just walk away.” Rebecca (age 12)

Hernandez's (1996) qualitative finding from interviews with 12 adults with T1DM found that adults viewed themselves as experts in diabetes management. This was an important pattern as Hernandez (1996) points out, they were impatient with educators or clinicians who tried to tell them what they could or could not do, and the best collaborative relationships were those that acknowledged the adults expertise. In contrast, children viewed their connections within the Distributed System of Management as an integral part of their diabetes care. Whilst a collaborative relationship and acknowledgement of children's expertise would be likely to contribute to their sense of self-efficacy, children seem to rely on this system far greater than their adult counterparts.

3.3.2.4. Interruption from Life

Children described self-management tasks as an interruption, requiring a temporary pause from normal daily activities. This was the case particularly for frequent blood-glucose checking, requiring a finger prick and testing of blood using a monitor to detect the child's exact blood-glucose level. This interruption continued to be a hassle across time, however Patrick (age 12) also alluded to a process of gradual adaption and habituation from feeling 'overwhelmed' to getting 'used to it'.

"First then I felt like why me and I have to do all this stuff and remember all this stuff and it was so overwhelming. But like now, it's kind of like - I don't mind it so much anymore. I've gotten used to it. I just do it and return to my life, so, yeah." Patrick (age 12)

"[Interviewer: What's that like, having to do finger pricks?] Boring. [Interviewer: Boring?] Yes. [Interviewer: How come?] Because you need to get up and go over to it and do it and then go back and then it just bothers me. ... the beeping and it's just annoying that I need to get up and stop doing what everyone's doing, yeah." Nicholas (age 10)

Patrick views self-management tasks as separate; they are framed as interruptions that have not been integrated into 'life'. Nicholas (age 10) also mentions the impact of this disruption on others around him as they also "stop doing" their usual tasks. This suggests Nicholas is sensitive to the disruption of these activities, on not only on his own life, but also on the lives of those around him.

3.3.2.5. Stage Two: Embodiment of Bodily Cues

3.3.2.5.1. Interpret Bodily Cues

This phase in the Transitional Stages Model is characterised by a conflict between the child's perceived bodily sensations and the demands of their treatment regimen. An important part of education provided by clinical teams focuses on enabling children and their families to

detect and accurately interpret certain bodily cues, particularly as markers of dangerous fluctuations in blood-glucose levels. Previous bodily sensations need to be interpreted differently in light of the medical knowledge taught to children. Children are required to notice and attune to their bodily cues. In order to interpret such cues accurately, children are also required to recall and apply learnt medical knowledge about T1DM symptoms and consider external environmental factors that may be misleadingly contributing to their psychological cues. This shifts the mind-body connection to be orientated by ‘top down intrusions’ meaning children must cognitively override natural body rhythms and psychological sensations to comply with T1DM treatment demands.

Accurately understanding one’s bodily state in the context of T1DM required children to use advanced problem-solving skills and flexibility. The complexity of this process is emphasised by the broad range of influences on blood glucose levels, including diet, sleep and exercise. Children continuously engaged in this problem-solving process; on an ad hoc basis when trying to make sense of a high blood glucose pattern to be avoided in the future, consistently throughout the day and also preventively when planning future events. In many children, interpretations appeared to create a high number of ‘false positives’; meaning bodily sensations were often incorrectly interpreted as indicators of hypoglycaemia. However this approach makes practical sense given the urgency and high risk of hypoglycaemic events which can be life threatening.

To further complicate this process of interpretation, bodily cues were often contradictory. Paradoxically, a feeling of greater energy, described by Cathie as a feeling of being ‘brighter’, could be a symptom of dangerously high blood-glucose levels. Thus positive bodily sensations needed to be interpreted as dangerous rather than enjoyable or as a sign of energy. The uncertainty and difficulty of accurately interpreting such states is reflected by her pauses and repetition of “I don’t know”.

“[Interviewer: How do you know when you're feeling unwell? What happens in your body?] I just get a bit of a headache, feel a bit dizzy. That's about it... but when it's low, you feel it. But when it's high, you feel better than what it was, if it's around seven. So when it's high, you feel a lot better. [Interviewer: Oh, that's tricky. How do you know you're high then?] You can't really tell, but when you know it - when you do it and you know it's high, you just feel better... I don't know. You just feel - you feel like you have more energy. I just notice I can do a lot more. Play the Wii, play with the dogs. So yeah so - I don't know, you just feel more brighter.” Cathie (age 11)

After detecting potentially harmful fluctuations in blood glucose levels, children reported they needed to conduct a finger-prick blood test to identify their actual blood glucose level. Based on the results the child then followed learnt “if – then” contingencies, based on their learned medical knowledge.

“Check blood sugar levels, give insulin. So many things to do, if I have a hypo I have to have juice or water, I have to take injections, have to check my blood glucose levels” Graeme (age 7)

“I feel like lightheaded and then I do the prick and then find out and then ... I need to get a hypo kit from there which is juice and Tiny Teddies.” Nicholas (age 10)

Children seemed to rely heavily on these ‘if-then’ contingencies. These contingencies seemed to bring a degree of predictability to situations of medical uncertainty and reinforce the child’s own capacity to handle the situation appropriately.

The process of interpreting one’s own bodily cues also relied on the distributed system of management. In addition to the child themselves noticing a sensation linked with blood-glucose fluctuations, parents were often required to adopt the role of being an additional ‘checker’ and observer, monitoring the child’s state and acting as a source of knowledge and advice for the child. Friends who had acquired knowledge from the child themselves also adopted a ‘back up’ role within the system.

“All my friends know, so they know - and they ask me ‘oh, did you check your blood?’” Ellen (age 13)

“If I am hungry, then I’ll say, mum I’m hungry. She’ll be like ‘do a check’. Because last time I was hungry, that’s when I had a seizure when I was really hungry. So that’s why she always gets me to check. Then if it’s normal then I can just eat a sandwich or something - something small.” Sarah (age 14)

3.3.2.5.2. Understanding the Body through a Medical Lens

As a potential by-product of the medical focus of interpreting bodily cues, many children who were using MDI explained their bodily states quantitatively through reference to their blood glucose level. Interestingly, the child’s focus on blood glucose levels and specific numbers seemed to dominate other alternatives to understanding one’s bodily state. For example, the child learns to reinterpret hunger as a sign of hypoglycemia instead of a body demand for nourishment.

“Now I'm very careful. I just randomly get shaky and my level could be 9.8, which has happened before, and I'm just shaky. Or - there aren't really - because I can get heat flushes and it could just be because I'm hot in my uniform or something. It's only just set in that I need to take off a layer. But I don't - the - I think a warning sign for it being really low is, when I'm sweating and it's not hot - because it was really cold that day, but I don't think I was sweating. I don't actually remember. Or if I'm ridiculously hungry that I don't think that it - a sandwich will take away that hunger.” Sarah (age 14)

In this extract, Sarah applied a complex algorithm to interpret her current physical state, focusing on her blood-glucose level and whether she needs to take action. Her mind-body connection, that is her cognitive interpretation of the physical sensations in her body, seems to be mediated by consideration of possible environmental factors. Such factors include the weather, warmth of her clothing, and possible signs of low blood sugar. She provides multiple potential causes for her current physical state in quick succession and without hesitation, potentially reflecting the high cognitive demands of this moment-by-moment problem solving.

3.3.2.5.3. Override Bodily Cues

After considering a complex algorithm of competing factors, often children are required to override natural body sensations such as hunger and sleepiness to comply with their treatment requirements. Overriding such cues is a process that is likely to reinforce the disconnect between mind and body.

“You have to eat more than what you would without it. So if it goes low, you have to have a Poppa or jellybeans or something like that. You just get sick of it... it's just the constant taste of jellybeans and Poppas, it just - I don't know. It's just not - you just get sick of it after a certain time.” Jane (age 14)

“If you're not that hungry you still have to - you can't - I can't skip a meal” Sarah (age 14)

“Sometimes in the morning, I'm moody because I have to get up early, because if I leave it too late, my blood will be higher and then I have to take lunch later, because it's not five hours in between. So, yes, I'm moody in the mornings.” Chloe (age 13)

3.3.3. Stage Three: Transitioning to CSII

3.3.3.1. Needles (MDI)

During the interviews, needles required for insulin replacement were almost unanimously described as the most painful and disliked component of MDI treatment.

Needles were described as gross and disgusting, with violent terminology emphasising how intrusive the needles felt, a direct assault on the child's body. Chloe's (age 14) feelings of overwhelming discomfort and disgust at self-inflicting such an experience are reflected by her difficulty in verbally labelling her experience. Her speech was punctuated with long pauses and a disgusted facial expression.

"To think that it's going in you and you have to stab yourself. It's - you - I hate needles... When I first saw them, I was really scared, but then I got used to it. But it was still yuck, like - yeah." Chloe (age 14)

In one case, the child's dislike of needles was to such a strong extent she experienced a mild form of bodily dissociation. Michelle's (age 14) actions physically manifested her level of distress related to giving herself an injection with her hand refusing to move.

"I don't know, it was more like this mental thing how I just - I tried giving injections but my hand just wouldn't move any more...I kept on telling myself it won't hurt because I knew it wouldn't but it was just the fact that I hate you know, like pain sort of thing. I'm just one of those people that hate pain and yeah, prefer not to experience pain." Michelle (age 14)

The three most common coping strategies that children seemed to utilise to manage their needle injections were gradual habituation, rationalization and adaptive denial. Many children spoke of a process of habituation over time, as initial anxiety and discomfort reduced and became easier to manage as a result of greater exposure. As an example of habituation, one child metaphorically compared insulin needles to immunization injections, linking T1DM treatment with a commonly and widely used medical procedure experienced by the general community.

"When I first saw them, I was really scared, but then I got used to it. But it was still yuck, like - yeah." Chloe (age 14)

"[Interviewer: what do you think of when you think of needles?] I'm used to them now, so I think it would be either diabetes or blood tests or something - immunisations and stuff." Jane (age 15)

Rationalisation was also a powerful tool to enable children to endure injections. For example, at the follow-up interview after using the CSII for 4 months, Michelle (age 14) reflected on her experiences using needles. In a pattern that perhaps only became clear in hindsight, her body felt the direct impact and efficacy of an insulin injection, providing the energy required for the morning. This was followed by a subsequent 'drop off' in energy as the injection 'wore off'. Such a notable bodily reaction linked with injections in a time-

accurate manner seemed to help children adaptively rationalise their importance.

“When I was on the injection needles I would eat - like I would give like this certain amount of insulin and it would last for up until lunch time to dinner and I would give the dose and I'd eat a little, like my breakfast, what I would usually have. Then around the third period, the second period that I'd have what I have, my sugar will get really low and I wouldn't really concentrate well in class because it's hard to when I have a headache or I feel dizzy and my hands are shaking. Now that I'm on the pump, that never happens to me any more.” Michelle (age 14)

Related to habituation, several children also seemed to balance the knowledge of dangerous complications associated with T1DM with a degree of adaptive denial. For example, Jack (age 11) distanced himself from T1DM risks through a shift in linguistics between first-person (when describing his blood-glucose levels) to second or third person (when speaking of negative consequences). This adaptive form of mild and adaptive denial enables Jack to acknowledge the importance of monitoring and treating his condition whilst avoiding being consumed by anxiety and fears as to possible highly negative outcomes of which he is nonetheless completely cognizant.

If I'm really high, like, for like two months and I'm high and I stay high for two months, you can lose your eyesight and stuff like that.” Jack (age 11)

3.3.3.2. Transitioning to CSII

3.3.3.2.1. Expectations prior to starting the CSII

For the 8 children who received CSII treatment within four weeks of their initial interview, expectations of their upcoming treatment change could be broadly categorised as emotional or practical in content.

Firstly, in terms of expressed emotions and feelings toward CSII, children's descriptions generally involved a combination of conflicting emotions. These emotions seemed to be heightened by both anxiety at the uncertainty of treatment changes, and excitement anticipating the benefits CSII would bring.

"[Interviewer: How are you feeling about going on the pump?] Excited and a bit nervous."

Rebecca (age 12)

"[Interviewer: what are you thinking about going on the pump?] I don't know. I'm a bit unsure about it now. But I reckon once I get it, I'll be a lot better. I think just because now - because I haven't gotten it yet, I'm not fully sure of it. But once I know like more about it, I'll be good I reckon. [Interviewer: What might be making you feel unsure?] I don't know. I'm just unsure about the whole thing, whether I want it. I know I want it, I'm just not completely sure about it. But I reckon once I get it, it'll be a lot better." Jane (age 15)

It is important for clinicians to recognise the presence of these conflicting emotions prior to pump start, particularly anxiety. Research has shown that anxiety disrupts information encoding, processing and memory recall during cognitive tasks (Ashcraft & Kirk, 2001), which could hold important implications for education training, and teaching the child how to use CSII. Should this anxiousness escalate on the day that CSII is commenced, children may struggle to understand and retain technical information about entering information into the pump and how to respond to alerts or unexpected problems. Concerns about starting CSII, which could guide the focus of future educational interventions, and anticipated benefits of CSII are outlined in Table 1. Overall, children tended to report more anticipated benefits than concerns. The children's responses to questions about what they thought it would be like using the pump provided insight to the issues they prioritised and felt were important in daily life:

Anxieties and Concerns		Anticipated Benefits	
1.	Fear of the insertion site including worries about the catheter detaching unexpectedly or hurting when being inserted or knocked	1.	Significantly less needles
2.	Overwhelmed at knowledge demands and the need to constantly consider and manage the pump	2.	Saving their parents' money on daily expendables required for MDI
3.	Concerns about being permanently attached to an electronic device 24 hours a day.	3.	Data on blood-glucose levels being saved, and able to be downloaded for both the family and clinical staff to see and interpret
4.	Uncertainty about how to calculate and enter carbohydrate intake into the pump	4.	Increased flexibility around meal time and diet
		5.	Easier to travel with
		6.	Ability to sleep-in on weekends
		7.	Less medical uncertainty

Table 1: Common Anxieties and Anticipated Benefits of Transitioning to CSII

3.3.3.2.2. *Experiences following transition to the CSII*

At the second, 4-month interview, all 8 children who had transitioned to CSII were still using this form of treatment. Overall, children reported a greater number of benefits after transitioning to CSII in comparison to detrimental experiences or limitations. Both benefits and shortcomings could be grouped into four categories; medical, psychological, lifestyle or dietary, and are listed in Table 2.

Benefits	Shortcomings/ Challenges
Medical	
<ul style="list-style-type: none">• Sustained energy throughout the day• Improved blood-glucose levels• Fewer incidences of hypoglycaemia• Less anxiety around possible hypoglycaemia• Significantly fewer needle injections	<ul style="list-style-type: none">• Need to double check insulin is released correctly down the cannula (no air bubbles or “kinks”)
Psychological	
<ul style="list-style-type: none">• Peace of mind, sense of security in managing diabetes• Do not feel anything/ forget the pump is present• Better concentration at school as less worrying about needles• Less disruption at lunchtime: do not need to go to the office to administer an insulin injection using needles	<ul style="list-style-type: none">• Sense of greater responsibility• Greater cognitive effort; counting carbohydrate intake and entering information into the pump• Sense of being permanently attached to technological device
Lifestyle	
<ul style="list-style-type: none">• Easier and less extraneous equipment involved when programming carbohydrate intake (compared to a needle injection)• Easier to travel on planes and cruise ships with CSII• Chance to be able to sleep in on weekends• More easily able to focus on activities of daily living	<ul style="list-style-type: none">• Annoying to manage during sport: often need to disconnect during a match to avoid damage• Feeling the pump and cord when lying down• Noticing the feel of the cannula attached to the skin, described as a ‘tiny needle’
Dietary	
<ul style="list-style-type: none">• Increased flexibility with meal times• Increased food variety• Increased flexibility in amount of food consumed in one sitting	<ul style="list-style-type: none">• Difficulty knowing carbohydrate content of foods

Table 2: Common Experiences after Transitioning to CSII

One prominent psychological theme, which was common for many children, was the sense of security provided by CSII treatment. The sense of trust children placed in this

technology is captured by Chloe's (age 13) appreciative tone. The insulin pump seems to be fulfilling its designated role within Chloe's Distributed System of Management, and actively contributing to improved medical outcomes, including a reduction in the number of hypoglycemic events. Michelle (age 14) echoes this sense of security and confidence in the insulin pump.

"[Interviewer: What's changed, since going on the pump?] I get - I haven't had a hypo in like three months. So it's really good for hypos and for if I'm out. I don't have to go somewhere and do my needle separately. I can just put it in and then I'm done. It's so much easier. ... It makes me feel like the pump's working. It's doing a good job... I feel grateful, yeah, that it's working. " Chloe (age 13)

"Not much really, just besides the fact that you feel a lot more secure about your blood glucose levels. You don't feel - because whenever I was on injections I was always worrying about what if it gets too high or what if it goes too low. With the pump if I calculate the right amount of carbohydrates I know that I'll be fine, yeah." Michelle (age 14)

Rebecca (age 12) further normalises the insulin pump by drawing a metaphorical comparison to an iPod music device. This also seemed to partially mitigate an issue which several children experienced difficult with; the permanency of being attached to an electronic device.

Having an electronic device on me 24/7... it's like it's my battery - it's almost like I have my iPod on me all the time but it's just attached to me literally" Rebecca (age 12)

Here Rebecca seems to be cognitively reconstructing how she views the sense of being permanently attached to the insulin pump. This remarkable insight suggests that likening the pump to a special and culturally valued device advertised as popular and desirable normalises the pump and its permanency. Viewing the pump in this way seemed to also emphasise that the CSII treatment is valued and enhances one's quality of life, like an iPod, rather than fostering a negative view of being chained to an unwanted burden. This process of cognitively restructuring the meaning children attribute to CSII technology could direct future interventions to target the identified problems such as a sense of being 'permanently attached' or discomfort when noticing the cannula. Overall the benefits of transitioning to CSII seemed to outweigh the shortcomings or detrimental features for this sample.

3.3.3.3. Stage Three: Embodiment of Bodily Cues

Interestingly, children who commenced CSII treatment seemed to experience a shift in their mind-body connection. As a result of this change in treatment, the children re-learnt how

to listen, attune to and interpret their bodily cues. Children using CSII began to reconnect with a bottom-up method of interpreting bodily cues. This differed to being guided by top-down cognitive intrusions mediated by problem-solving and medical learnt knowledge whilst on MDI. Children began to attune to their basic bodily sensations with greater trust when using CSII. These sensations included signals of hunger or tiredness, and children reacted to such signals in accordance with these bodily needs rather than overrule them. Sarah (age 14) described the impact of CSII treatment as ‘putting her back’ before diabetes, this broad statement potentially capturing a return to her usual mind-body connection prior to the onset of diabetes symptoms.

“I don't really think it's a big change. I think the change was having to start doing injections. I think this just puts me back before I had to think about all this in a way if that makes sense. [Interviewer: When you say back before, before what?] Before being diagnosed. I could just eat when I wanted and not really have to worry about much but now I can eat when I want and just make sure I put it in this pump and that's - yeah.” Sarah (age 14)

Illustratively, the most commonly mentioned impact of transitioning to CSII was increased flexibility in diet, and the ability to respond to sensations of hunger. After 4 months of treating diabetes with CSII, all children reported a shift in their relationship with food and bodily sensations of hunger or satiation. The insulin pump allowed Sarah to engage in more desire-based eating and allowed children to listen to and satisfy their bodily states. This related to quantity of food, timing of meals and food types. Eating was often forced while on MDI, and food was treated as ‘fuel’, necessary to consume for energy, whereas for CSII users food and eating tended to be perceived as pleasurable activity again.

“You can be more flexible with it. You don't have to have breakfast at eight o'clock. You can get till 9:00 and it'll be fine. Breakfast - dinner doesn't have to be at 6:00. It could be 8:00.” Jane (age 15)

“It's changed - I have more variety of foods and I'm not worried about what I eat as much. When I'm on the insulin I have to have more. I don't have to panic about how many carbs because it will give me the amount of insulin that I need.” Rebecca (age 12)

“Well if I was given a candy cane I had to trade it with mum and dad for a toy and not have it, or I'd trade for something not so sweet like a chocolate and it wasn't good because I didn't like it as much. Now I can eat when I want and just bolus. I like it much better now as I can have the candy cane. I prefer the pump ... there are no injections and I only need to take 1 needle every 3 days instead of like 5 needles a day” Charlotte (age 7)

“[Interviewer: Are there any changes since going on the insulin pump that you've noticed?] Yes, a lot less hypos and it's like, for me to eat and all that. It's a lot more flexible because sometimes on the injection needles I feel like I have to eat or I don't want to eat at all sometimes. Like sometimes at breakfast I don't feel like eating but I have to give an injection or else my sugar will rise.” Michelle (age 14)

Thus after transitioning to CSII, children seemed to reconnect with their natural bodily cues and rhythms, and were able to interpret and act on these cues more accurately as signs of hunger or tiredness rather than sensations to be ignored. This reconnection between the mind and body also seemed to be related to the action required for insulin administration. When using MDI, an ability to ‘switch off’ and ignore one’s pain or bodily sensations was a skill likely to be useful when constantly administering needles, which has a number of consequences. As vividly depicted by Penelope (age 10);

“Because the pump is easier than the injection because the injection - you have to jab it in your stomach, but the pump it's automatic - gives you insulin in your body and that.” Penelope (age 10)

Penelope’s use of the verb “jab” emphasises the physicality of the motion required to administer MDI needles. It suggests a perceived sense of bodily attack and antagonism toward oneself. In comparison CSII pumps require an action far more removed from the body, pushing buttons to enter carbohydrate intake or adjust insulin injections. The technology seems to act as a mediator between the action required of the child, and the actual administration of the insulin. The sense of hurting ones own body is removed, in addition to a significant reduction in the experience of pain. Penelope emphasises automaticity of this process as an advantage. The present study was unable to identify how shifts in the child’s mind-body connection as a result of their treatment regimen may influence larger concepts such as one’s sense of identity or self-concept. However such influences are arguably likely given that the way we notice, interpret and interact with our bodily sensations and emotions forms an important part of who we are. Future research in this area may deepen our understanding of the experiences of these children and inform our broader understanding of our relationships with our bodies.

3.4. Revisiting Normalcy

As previously discussed, much prior research into populations with T1DM placed an emphasis on an underlying theme of ‘normalcy’ (Davidson et al., 2004; Dovey-Pearce et al, 2007; Freeborn et al., 2012; Marshall et al., 2009). Such research proposed that children

diagnosed with T1DM felt they were outside of ‘normality’ and that their treatment goal was to strive toward an ill-defined benchmark of ‘normal’. In the present study however, children did not seem to hold this view of themselves. The interviews were carefully read with sensitivity toward detecting references to a sense of normality. In an attempt to further reduce coder bias, a ‘Query’ word search for derivatives of ‘normal’ was conducted using the Nvivo qualitative data package as an impartial way of identifying all uses of the term.

References to normality were rare, either implicitly or explicitly. The few instances in which a reference to normality was made generally used the term as a medical descriptor to interpret fluctuations in blood glucose levels. For example, Sarah (age 14) used the term ‘normality’ as a marker of her current blood-glucose level. Whether or not her current blood-glucose level could be described as ‘normal’ determined the required course of action.

“If I am hungry, then I’ll say, mum I’m hungry. She’ll be like do a check. Because last time I was hungry, that’s when I had a seizure when I was really hungry. So that’s why she always gets me to check. Then if it’s normal then I can just eat a sandwich or something - something small.” Sarah (age 14)

When Ellen (age 13) described her lived experience of CSII, she appeared to be firmly emerged in the process of meaning making (Benzies & Allen, 2001; Himelfarb & Richardson, 1983), possibly articulating her experiences for the first time in such detail. Ellen initially described her experience of CSII as a return to ‘normality’. However she quickly retracted this terminology, possibly because verbalising the word ‘normal’ highlighted its lack of fit with the personal meaning she attributed to her experiences. This resistance to using the term ‘normality’ is interesting as it may suggest it is a general term that typically comes to mind, but does not accurately capture the child’s interpretation of events, and requires correction.

“[Interviewer: can you tell me more about the insulin pump?] It feels like I don’t have diabetes, like back before when I was normal, well not normal but before I had diabetes. When I didn’t have diabetes and I didn’t know much about it I thought there were only injections, but like, now I know there’s a pump too. It’s much better than injections everyday” Ellen (age 13)

In accordance with methods entailing negative case analysis (Strauss & Corbin, 1990), we explicitly sought examples that contrasted this medical description of normality. We found that one child did use normality as a reference point to make sense of their experiences. Interestingly, Patrick (age 12) seems to demarcate between himself who is ‘normal’, and the required T1DM treatment that is viewed as outside of normal. Treatment tasks are viewed as

an interruption to life, after which Patrick returns to his status quo of ‘normality’. The only time he seemed to feel that he himself was outside of ‘normal’ was when he felt others were judging him socially. Thus even when a child felt a perceived social judgment of ‘abnormality’ they were understandably upset and resistant to this, but they themselves did not internalise this view of their being ‘abnormal’.

“I know I have school and I need to get these injections quickly done and my finger pricks so I can't be late for school... it's part of me now. It almost feels normal, yeah, so. Now I don't like really mind it really... First then [after diagnosis] I felt like ‘why me’ and I have to do all this stuff and remember all this stuff and it was so overwhelming. But like now, it's kind of like - I don't mind it so much anymore. I've gotten used to it. I just do it and return to my life, so, yeah.” Patrick (age 12)

“I know they think I'm different. I don't want to feel odd or something, I just want to fit in with everyone else.” Patrick (age 12)

In general, instead of using normality as a reference point for understanding oneself and their chronic illness, children seemed to have a relationship with diabetes that characterised the disorder as either an externalised object outside of one’s self, or a more internalised view of the illness as apart of their identity. Axial coding during the data analysis identified a trend for children to fall on a continuum within these two categories (see Table 3).

<p style="text-align: center;">Externalise Medical</p> <p>“Diabetes is a disease, which comes when you're born or - and in diabetes, your pancreas doesn't work and it doesn't give you any insulin.” Graeme (age 7)</p>	<p style="text-align: center;">Externalise Pest</p> <p>“Like a disease or something that you don't want to have and yeah, you just want it to go away.... Like a sickness or a pest something like that. Like, you don't want it, yeah.” Michael (age 8)</p>
<p style="text-align: center;">Internalise Acceptance</p> <p>“I don't think it's really changed what I'm able to do because I do the same things apart from eat sugar but I didn't really do that a lot anyway... I don't really think it's changed what I'm able to do because I'm still able to participate in PE even though I hate it. Still able to play music and sing and I'm still able to go out so it hasn't changed anything.” Sarah (age 14)</p> <p>“Annoying, but you get over it. So it's not like a major hassle, but it's still annoying.” Jane (age 15)</p>	<p style="text-align: center;">Internalise the ‘Sick Child’</p> <p>“I've been - I'm always sick, even before I got diabetes. I was always sick. I had had about three operations - four operations on my ears, before that. So I was always the problem kid... Nothing ever happens to my brother. Ever.... It's always me... Always sick or - but something broken or hurt something.” Cathie (age 11)</p>

Table 3: Internalising and Externalising Views of T1DM

Some children who viewed T1DM as an externalized object adopted a medicalised description of the illness. This involved repeating knowledge learnt from clinicians explaining the body's functioning, rather than a genuinely understood and personalised understanding of T1DM. Other externalised views of T1DM classified the illness as a 'pest' or something that maintained an annoying presence in their lives. In contrast, an Internalised view of T1DM tended to be framed as a form of acceptance and integration of the illness with one's life, or T1DM was internalised as a perception of being the 'sick' child who continuously experienced poor health.

In the present study we were unable to categorise individual children into one discrete and static category. We had intended to investigate links between such categories and treatment outcomes or treatment types. However these categories seemed to be highly transitory, and children displayed shifts in their views of T1DM from moment to moment, even mid-sentence. It may be useful for future research to investigate the nature of these categories further. It would also be of interest to examine whether general patterns of interpreting T1DM within the framework of a particular category relate to better medical outcomes. Should future research find potential patterns between medical outcomes and a tendency to view T1DM in a particular way, psychological interventions could target the less adaptive meanings attributed to T1DM. Interventions may work to shift maladaptive views to be replaced with more positive views of T1DM.

In addition, the description of continual shifts in the children's experience of the embodiment of their own bodily cues that mapped onto the Transitional Stages Model suggests that normality is a shifting relationship for children with T1DM rather than a static goal. The distributed system of management model emphasises that children are constantly coupled to a broader network of support. This ongoing relationship, involving parents, medical practitioners, teacher and peers in the management of T1DM, is vital for children, particularly given the low predictability and unexpected nature of this illness. Thus positing 'normalcy' and autonomy to be a goal for children with T1DM is an unachievable and unrealistic goal. Just as all humans are coupled to a broad social network of co-workers, friends and family, so too do children with T1DM require the support of others.

3.5. *Methodological Critique and Areas for Future Research*

Several features of the methodology used in the present study could be considered strengths which future research may benefit from replicating. Firstly, meeting with each child on two separate occasions may have provided greater opportunity to capture rich accounts of each child's lived experiences. The interviewer was aware of her position as a stranger to the

children, and meeting on multiple occasions assisted in the development of rapport, encouraging the children to feel more at ease and willing to share their experiences. Also, conducting the interviews at various time points during significant changes to treatment, particularly initiating CSII, allowed children to describe their experiences with a greater sense of immediacy rather than retrospectively which may have encouraged a hindsight bias.

Another consideration is the setting in which the interviews took place. Children seemed comfortable completing the interviews within a quiet room in the Department of Endocrinology, and with awareness that parents or their usual medical clinicians could not hear their responses. This may have encouraged more honest responses. We were aware that conducting the interviews in a setting that the children associated with their regular clinical care, and possibly associated with upsetting or even painful procedures, might have influenced their responses. Indeed, Patrick's descriptions of the hospital being a place '*where bad things happen*' suggest some children may have had strong memories triggered by the location. However, overall children were happy to be interviewed alone with the interviewer and did not appear outwardly distressed or uncomfortable.

Interviewing children about their lived experiences posed several methodological difficulties. One child, Graeme (age 7), was less engaged and forthcoming in his responses than other children. He tended to answer questions very briefly and needed encouragement to further elaborate on his responses, which is understandable given his developmental age. His brief answers may also possibly due to a lack of interest or perhaps a lack of insight into his own experiences. In attempting to encourage the child to further clarify and elaborate, at times the interviewer in had difficulty remaining impartial.

"[Interviewer: What do you like better, the needles or the pump?] The pump... [Interviewer: What's it like wearing the pump?] Nothing. [Interviewer: Nothing? What do you mean, nothing?] Doesn't feel like anything. [Interviewer: So when you say, it doesn't feel like anything, is that because you don't notice it?] Yes." Graeme (age 7)

In asking, "*is that because you don't notice it?*" it was the interviewer's intent to offer an interpretation of Graeme's meaning and providing the opportunity for him to correct this interpretation. However it must be acknowledged that here the interviewer injected their own interpretation of the child's experience into their line of questioning. It is unclear whether Graeme was confirming the accuracy of this interpretation or merely displaying an acquiescence bias. Graeme's was one of the earlier interviews conducted, and this error was identified during qualitative coding that was conducted simultaneously. This process of continual critique and assessment allowed the interviewer to develop their interview

technique, be sensitive to such intrusions and avoid similar issues in future interviews. Such an example illustrates the intrusion of the interviewer's bias in an explicit way, underscoring the need for rigorous methodologies, co-coding as the interviews progressed, and transparency when conducting qualitative research.

An important limitation of the present study is the potential selection bias of the sample interviewed. A key criterion was a prior assessment of suitability to join the CSII waitlist. No strict guidelines are currently followed when selecting CSII candidates, and the decision to commence CSII is made as a collaborative agreement between the clinicians, parents and child themselves. Families must have access to funding to be placed on the waitlist, however the inclusion of many children who transitioned to CSII through applying for government funding partially mitigates this bias towards families in a higher socio-economic status. Clinicians also consider the child and family's existing capacity to follow treatment requirements on MDI, given that CSII technology does require more intensive cognitive effort. Thus the current participants may reflect a subgroup of children with T1DM who are better able to manage their condition and integrate treatment demands in everyday life. This bias is potentially reinforced by the positive experiences of all children in the sample, as no child discontinued CSII during the fourth-month period. Discontinuing CSII treatment may have been indicative of a different group of children who had difficulty caring for their diabetes. Some prior research has found discontinuation rates for CSII in children vary from 5 to 20 per cent (de Vries, Grushka, Lebenthal, Shalitin, & Phillip, 2011; McMahon et al., 2005; Wood, Moreland, Volkening, Svoren, Butler, & Laffel, 2006). The most common reasons for discontinuation included major clinical problems (e.g., diabetic ketoacidosis), diabetes burnout, and infusion site issues (Wood et al., 2006) and in some cases psychiatric conditions (McMahon et al., 2005). Whilst we were unable to assess which factors may explain or even predict discontinuation rates in the present study, it is still valuable to understand the experiences of children who are able to successfully manage their diabetes. Investigating the impact of CSII for children who are not coping well as well as those who are would be an important area for future research, particularly understanding what specific factors contribute to such difficulties. In particular, this study found the mind-body connection and how the children were able to adapt to shifts in this connection across treatment phases may contribute some understanding as to why other children are unsuccessful and could be an area for future research.

3.6. Implications for Clinical Practice

Throughout the discussion section, several important areas that could be targeted by

future intervention programs have been mentioned. Several constructs have been identified by the current study as relevant to children and currently under-researched, such as the embodiment of bodily cues, the role of shame in friendship and the distributed system of management. Although these constructs require further replication in other diverse samples and with other methods, these raise interesting issues for psychological treatment and early intervention. Some possible directions for psychological intervention may include:

- Leaning on Narrative Therapy traditions, the ‘Tree of Life’ exercise (Ncube, 2006) may present an opportunity to build a child’s self esteem and strong self-concept, placing T1DM as a small component over their overall identity. The ‘Tree of Life’ exercise encourages children to draw a tree, with the components of a tree metaphorically representing a part of their identity. For example, the roots of the tree reflect their family origins and cultural background, whilst the trunk reflects their core skills and strengths and fruit represents important people in their lives. The presence of diabetes could be symbolically presented as different coloured leaves; acknowledging that T1DM causes parts of the body to work differently, but not reinforcing the idea of being ‘damaged’ or ‘impaired’. Such a symbolic representation of T1DM may also suggest this disease is apart of one’s identity, however is not the key dominating feature. This may be important given the high management demands placed on children, and the concerns some children had about peers asking questions about T1DM. For a fictional example of such a drawing, see Appendix D.
- Metaphors for CSII use appeared to be helpful when normalising the feeling of being permanently attached to an electronic device. Such metaphors could be encouraged by drawing comparison to multiple devices that are carried on one’s person and are of great benefit such as iPhones, pedometers, portable radios and pagers. Encouraging positive meanings attributed to CSII technology, in addition to vital medical education, may assist a child’s overall adjustment. For an example of a worksheet that may promote this normalisation, see Appendix E.
- An extreme dislike of needle injections on MDI and a fear of the associated pain and physicality of this treatment arose as a key concern. Further development of needle-phobia treatments targeting sub-clinical fears of needles would be of great benefit. This may take the form of including a psycho-educational component as a part of clinical medical education when teaching

children and their families how to implement MDI treatment. Common anxiety treatment tools such as graded exposure hierarchies for using needles could be included in standard medical education (Barlow, Rapee & Brown, 1992). This would particularly be beneficial for sub-clinical participants who are able to comply with MDI demands and did not present with a psychological disorder, but who nonetheless found this process disconcerting.

- Future psychological interventions for children could also target shame and embarrassment in relation to managing T1DM. Specific interventions would ideally target unhelpful cognitive thoughts such as “they don’t think I’m normal”, or a felt need to hide self-care behaviours. Cognitive-Behavioural Therapy approaches could encourage children to become ‘detectives’ of their own thoughts and challenge the unhelpful, inhibiting thoughts (Barlow et al., 1992). In addition, exercises focusing on diffusing from unhelpful thoughts within an Acceptance and Commitment Therapy approach may help reduce the potency of these social concerns (Masuda, Hayes, Sackett & Twohig, 2004).
- Following on from increasing self-acceptance and challenging feelings of embarrassment, and depending on the child’s receptiveness, formal positions for peers to fill within the distributed system of management could be established. At school this could take the form of a buddy system, nominating a peer to accompany the child when they are feeling unwell or need to attend sickbay. However the present study emphasises that this is perhaps most effective for children who are receptive to involving their peers. Forcing child to accept their peer before they are ready for this could be potentially counter-productive.
- The continual shifts in children’s mind-body connections and changes in the experience of the embodiment of their bodily cues were important underlying features of the present study. This opens a new avenue for research, as very limited research exists on this mind-body connection in children with T1DM. This mind-body connection suggests that at different points in their treatment, involvement in yoga, body scanning, body listening, mindfulness or similar body concentration exercises would be of great benefit for children with T1DM. In particular, after transitioning to CSII children re-learnt how to listen to their bodily cues and were able to respond to them without cognitively overriding sensations such as hunger or sleepiness. Yoga exercises leading up

to CSII transition may assist this re-establishment of the child's mind-body connection.

3.7. Conclusion

The present study highlights the idiosyncratic complexities of the lived experience for a child with T1DM. Extending on prior research, this study emphasises that 'normality' for these children is continually shifting. It was also suggested that children who are sensitive to social judgment might feel others judge them to be 'not normal', however they themselves do not hold a view of being abnormal. Normality and autonomy were not seen as the goal for children managing T1DM. Instead, increased agency and an understanding of shifts in their mind-body connection and embodiment of their own bodily cues were goals of importance and value. The present study also further supports the growing acknowledgement of the value of qualitative research into children's personal experiences of medical care and treatment, and underscores the role for psychologists within health psychology. The children interviewed were articulate and insightful, reflecting their capacity to be experts of their own experiences. Recommendations for potential psychological interventions have been proposed, and would benefit from empirical validation and testing.

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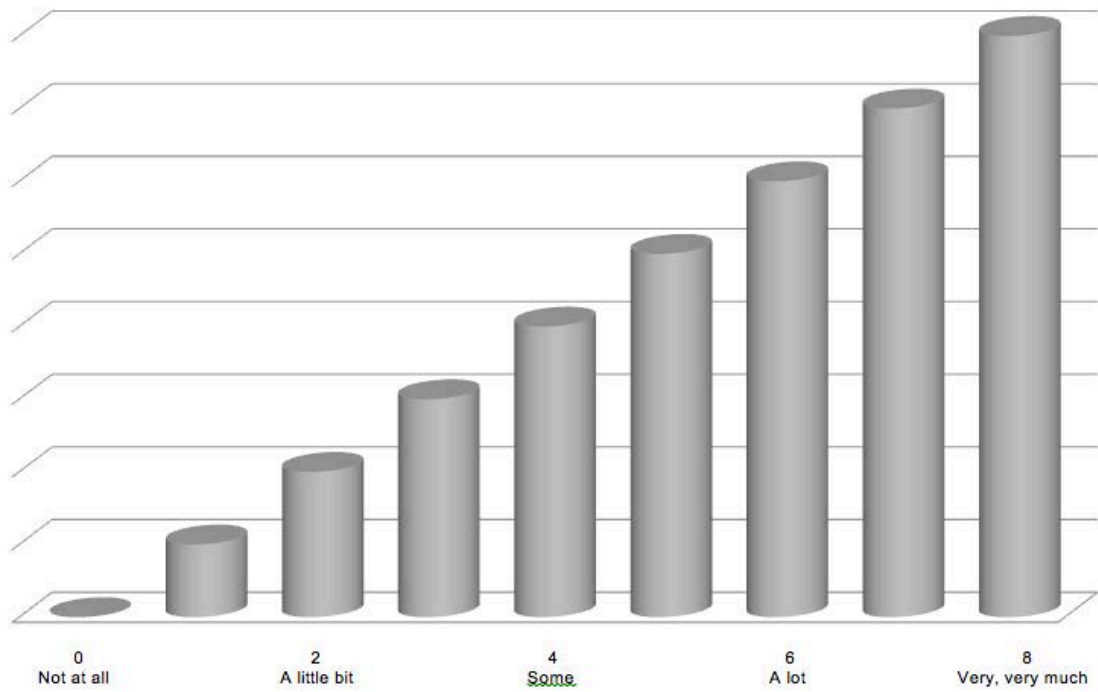
5. Appendices

Appendix A: Original questions for the semi-structured interview

1. What's the first thing that you think of, now, when I say the word "Diabetes"?
2. How (if at all) has diabetes changed what you are able to do?
3. On a scale of 0 (not at all) - 8 (very, very much), overall, how much has diabetes changed what you are able to do?
4. How (if at all) has diabetes changed who you are - your character?
5. On a scale of 0 (not at all) - 8 (very, very much), overall, how much has diabetes changed who you are - your character?
6. Is there anything that you would like to do, or anything you would like to be when you grow up, that will be a little bit tricky because of diabetes?

Appendix B: Scale used for Questions 3 and 5

Feelings Chart



**Appendix C: Questions which naturally evolved during the semi-structured interview
including prompts**

1. What's the first thing that you think of, now, when I say the word "Diabetes"?
2. How (if at all) has diabetes changed what you are able to do?

PROMPTS:

- a. It sounds like you really enjoy [activity], are there any moments in the day when you feel like you can't do this?
- b. When were you diagnosed with diabetes? Can you remember a time before you had diabetes?... what's different between that time and now?
3. On a scale of 0 (not at all) - 8 (very, very much), overall, how much has diabetes changed what you are able to do?

FOLLOW UP QUESTIONS:

- a. On this same scale, how good is this change?
- b. What about this change is better?
- c. What about this change is worse?
4. How (if at all) has diabetes changed who you are - your character?

PROMPTS:

- a. Do you feel like the same person?
- b. Has diabetes changed any of your thoughts?
- c. Has diabetes changed any of your feelings?
- d. Has diabetes changed any of your bodily sensations?
5. On a scale of 0 (not at all) - 8 (very, very much), overall, how much has diabetes changed who you are - your character?

FOLLOW UP QUESTIONS:

- a. On this same scale, how good is this change?
- b. What about this change is better?
- c. What about this change is worse?
6. Is there anything that you would like to do, or anything you would like to be when you grow up, that will be a little bit tricky because of diabetes?

PROMPTS:

- a. Do you know what you would like to do when you are older?
 - b. Is there any way diabetes might make that a bit trickier to do?
7. How are you feeling about going on the pump? (When applicable)

PROMPTS:

- a. Will there be any good things about the pump?
 - b. Is there anything about the pump which you are uncertain about, or which worries you?
8. What's changed since going on the pump? (When applicable)

PROMPTS:

- a. What's the best thing about going on the pump?
 - b. What's the worst thing about going on the pump?
9. Is there anything else you'd like to tell me about diabetes that we haven't talked about?

Appendix D: Sample drawing of the 'Tree of Life' for children with T1DM (labels in black boxes)



Appendix E: Sample worksheet seeking to normalise the feeling of being permanently attached to a piece of technology

**We all rely on different types of technology to make life easier.
Circle some forms of technology that you keep with you and
often use...**



Mobile phone or iPhone



iPod or Walkman or music device

Wrist watch



Pedometer



Pager

Can you think of any others? List them here...

All images sourced from www.freedigitalphotos.com

An insulin pump is another form of technology that you keep with you at all times to make your insulin administration easier. List some good things and some tricky things about carrying an insulin pump with you. You can brainstorm ideas with your diabetes nurse educator about how to overcome some of the tricky things

Good things	Tricky things	Ways to overcome the tricky things
*	*	*
*	*	*
*	*	*
*	*	*

General Discussion

The current findings highlight the fundamental role of health psychology research within the field of paediatric T1DM management. Such research contributes to a better understanding of how children with T1DM manage and make sense of their illness and its required treatment. This thesis was interested in further developing existing knowledge about the psychosocial impact of managing T1DM and available treatments, namely CSII. Taken together, the results of both studies converge to suggest that the experience of CSII is very positive for children. This is a promising result given the vastly different methods used by the two stand-alone, yet inter-linked studies; a systematic review of quantitative publications, and qualitative study investigating the child's perspective.

Study 1: The Psychosocial Impact of Transitioning to CSII for Children with Type-1 Diabetes: A Systematic Review

The first study was a systematic review of quantitative research investigating the psychosocial impact of transitioning to CSII for children with T1DM. Small improvements in *medical* outcomes, which are clinically significant, have been found for children who transition to CSII compared to Multiple Daily Injections (MDI). An emerging body of research suggests that CSII also influences the *psychosocial functioning* of children with T1DM, however a critical synthesis of research in this area is notably lacking. The current systematic review searched five relevant data bases for publications which met the study criteria, the most stringent being inclusion of a validated scale measuring at least one aspect of psychosocial functioning. The inclusion criteria for psychosocial variables and the study methodology were kept broad because a secondary aim of the review was to surmise which psychosocial variables are currently the focus of current literature.

Overall the 29 studies reported in the systematic review used a diverse range of scales, variables and statistical methods to interpret the data. This meant a meta-analysis could not be conducted. Instead the results were grouped into similar constructs and a count-method was used to compare main findings. These constructs included; Family Functioning, Parent Functioning, Child Emotional Functioning, Quality of Life, Treatment of Diabetes, Eating Patterns and Cognitive Functioning. Despite such variety in studies and psychological constructs, a fairly consistent pattern emerged linking CSII with a neutral and, in some cases, improvement in functioning for each of these constructs. Very limited research found a decline in functioning linked with CSII, however these findings were afforded little weight as they were also rated poorly by the quality assessment measure. This review supports the use of CSII in children and links CSII use with an improvement or neutral effect on psychosocial

functioning, quantifiably strengthening the cost effectiveness argument for CSII. Thus whilst medical improvements continue to be significant yet small, the psychosocial benefits of transitioning to CSII appear to be well supported by current research, perhaps better mitigating the high financial costs of such equipment.

Study 2: Normality is Shifting – A Child’s Perspective of Living with Type-1 Diabetes

The second study used a qualitative approach to understanding the impact of T1DM and its treatment from the child’s own perspective. This approach sought to build on current quantitative findings reported in the first study that suggested transitioning to CSII positively influenced a diverse range of specific psychosocial variables. It was of interest to further investigate whether these independent variables were related to an underlying psychological construct such as the child’s understanding of their illness. The second study also sought to identify whether any psychosocial factors, unaccounted for by current quantitative research, were identified as important from a child’s perspective.

Qualitative interviews with 17 children (aged 7 to 15) across two different time points in their treatment sought to holistically understanding the child’s experience of T1DM and transition from MDI to CSII. Interviews were analysed using a Grounded Theory approach, which positions children to be the experts of their own experiences. Grounded Theory, as a qualitative research methodology, allows themes and models to develop from the data rather than being determined by a specific set of hypotheses based on existing knowledge. A line-by-line, meticulous analysis of the interviews lent to the development of the *Transitional Stages Model of Treatment and Coping*. This model described key stages of transition and adaptation for children starting with the onset of undiagnosed, vague symptoms. The model also progressively captured the experience of a T1DM diagnosis, learning to use MDI and finally transitioning to CSII.

Of particular interest were shifts in the embodiment and interpretation of one’s own bodily cues within these stages. This mind-body connection appeared to be fundamental to the lived experience of children’s management of T1DM. Interesting, prior to diagnosis children seemed to be required to ignore and override their general, vague and undiagnosed T1DM symptoms to get on with tasks of everyday life. This disconnect between the mind and body often led to a worsening of symptoms and hospitalisation before being formally diagnosed. On MDI, children were taught through formal educational processes to re-interpret their bodily cues in a top-down manner. Here they used problem-solving and learnt knowledge to interpret their physiological sensations through a medical lens. For example, child learnt to interpret feelings of energy or motivation as potentially high blood-glucose

levels, and relied on learnt ‘if-then’ contingencies to test and correct their blood-glucose levels. Most importantly, after transitioning to CSII, children began to re-connect with their bodily cues such as hunger, thirst and tiredness and were less often required to override such physiological cues. Instead CSII provided the flexibility to eat a wider range and amount of food when hungry, and to sleep in when desired rather than wake up to administer a required insulin needle injection. The child’s experience of embodiment, of their physiological body cues was a concept which was unaddressed by previous quantitative research, and future research and clinical practice may benefit from acknowledging and further researching this construct.

In addition, children did not seem to strive toward ‘normality’ or autonomy as treatment goals. Instead it was important to feel supported in a network termed the *distributed system of management*, involving parents, teachers, peers and technology. Implications for clinical practice and possible opportunities for psychological intervention were also discussed. Specifically, the present results provide theoretical support for mind-body interventions such as yoga and mindfulness that focus on developing the child’s attention toward their physiological sensations and acceptance of these sensations. Such interventions may be particularly helpful during the transitional phase from MDI to CSII as children reconnect with their natural physiological sensations and are able to respond to such sensations or cues as required. Overall this thesis emphasises the complexities of managing T1DM for children, and demonstrate the importance of psychological research in this area.

Thesis Appendix: Final ethics approval letter – Macquarie University

From: Ethics Secretariat <ethics.secretariat@mq.edu.au>

Date: Wed, Jan 30, 2013 at 2:13 PM

Subject: External Approval Accepted- McIlwain (5201300012)

To: Dr Doris McIlwain <doris.mcilwain@mq.edu.au>

Dear Dr McIlwain

Re: "The character/capacity distinction; a clinical application to childhood diabetes"

The above application was considered by the Executive of the Human Research Ethics Committee. In accordance with section 5.3 of the National Statement on Ethical Conduct in Human Research (2007) the Executive has accepted the final approval from the Children's Hospital at Westmead and your right to proceed under their authority.

Please do not hesitate to contact the Ethics Secretariat if you have any questions or concerns.

Please retain a copy of this email as this is your official notification of external approval being accepted.

Yours sincerely

Dr Karolyn White
Director of Research Ethics
Chair, Human Research Ethics Committee

Office of the Deputy Vice Chancellor (Research)

Ethics Secretariat

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http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval