

THE UNIVERSITY OF HULL

An exploration of type 1 paediatric diabetes: Child and parental perspectives

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By

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Overview

This thesis portfolio is comprised of three distinct sections: a narrative synthesis of qualitative research findings, an empirical study and the appendices.

Systematic literature review: Narrative synthesis

A qualitative review of studies examining the parental experiences of having a child with type 1 diabetes. This topic was chosen for its significant links to the empirical project, and to provide insight into the lived experiences of parents supporting children to live with a chronic health condition. This is of particular relevance for professionals supporting such families. Three superordinate themes were derived from nine articles.

The Empirical Project

An empirical study examining the experiences and opinions of children with type 1 diabetes using insulin pumps. Six children were interviewed and the data was analysed using the qualitative framework, Interpretative Phenomenological Analysis (IPA). Three superordinate themes were emerged from the interviews, and the implications of such are discussed.

Appendices

The appendices support both the narrative synthesis and the empirical project. There is an accompanying reflective statement commenting upon the research process.

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(Including tables, figures and References; excluding Appendices)

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Part One
Systematic Literature Review
A narrative synthesis study

This paper is written in the format ready for submission to the *Journal of Qualitative Health Research*.

Please see Appendix A for the author guidelines.

Parental experiences of caring for a child with type 1 diabetes: A review

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Abstract

Objective

Parents and caregivers of children with diabetes experience a range of emotions and face various challenges when managing the condition. This review investigated the experiences of being a parent or caregiver of a child with type 1 diabetes to see which themes appeared from the literature.

Method

A narrative synthesis approach was selected. The themes from 9 qualitative papers exploring parental experiences were synthesised and discussed.

Results

Parents and caregivers were found to experience significant distress in their care-giving roles. The primary themes which emerged were (1) the psychological impact of diabetes (impact of diagnosis; grief and loss; guilt; immediate and future concerns), (2) adaptation and learning (confidence and competency; coping; normality) and (3) relationships (family; friends; professionals).

Conclusions

Caring for a child with type 1 diabetes requires many adjustments and influences different areas of caregivers' lives. Often it impacts upon psychological wellbeing and social networks. Continued professional support and visible access to such is crucial to help families with their journeys.

Introduction

Diabetes Mellitus is a chronic disorder characterised by inadequate activity of the hormone insulin, produced within the pancreas (NICE, 2008). When blood glucose levels are high, insulin is released to regulate the metabolism of carbohydrates, proteins and fats, providing the body with energy (NICE, 2008). In type 1 diabetes (T1DM), the insulin producing-cells in the body are destroyed, leading to an absence of the hormone (NICE, 2008). This serious condition can result in both short and long term metabolic complications, with life expectancy adversely affected. Short-term conditions include diabetic ketoacidosis, resulting from high blood glucose levels, and hypoglycaemia caused by low blood glucose levels (NICE, 2008). Mild hypoglycaemia is treatable with oral sugar ingestion (NICE, 2008), however, more severe hypoglycaemia can be life-threatening and results in comas, convulsions, and in those younger than five, cognitive impairments (NICE, 2008). Longer term vascular conditions resulting from chronically elevated blood glucose levels can include blindness, kidney failure, heart disease, stroke, and in severe cases, amputation (NICE, 2008).

T1DM is principally observed in children and young adults, with an approximate prevalence of 6.57% (International Diabetes Foundation, 2013). Management programmes designed to promote good diabetic control are important not only for the child, but also for family members. Given that it is the responsibility of the parent to ensure that their child is following a good maintenance regime, it is unsurprising that children with diabetes have been referred to as a source of “*intense parental anxiety*” (NICE, 2008, p.6). For parents of younger children, the first year following diagnosis is markedly challenging as the child is susceptible to hypoglycaemia accompanied by convulsions (Hatton, Canam, Thorne & Hughes, 1995). Furthermore, it is common for younger children to present with ketoacidosis, dehydration and significantly high blood glucose readings (Hatton, *et al.*, 1995). The parental role therefore requires acquisition of technical knowledge and skill. With the assumption that the caregiver has the potential to effectively manage the child’s condition (Hatton, 1992), parents are often required to perform emotionally distressing acts including injections.

The parental role is not static, and the needs of the child evolve with age. Parents therefore need to adapt their roles to successfully support the child’s journey towards independence (Silverstein *et al.*, 2005). Parents of adolescents

eventually face the challenge of relinquishing control to their developing child (e.g. Marshall, Carter, Rose & Brotherton, 2009). In a study conducted by Scholes *et al.*, (2012), interviews with young people aged 11 to 22 years revealed that parents were perceived to be “*stressed and worried*” (p. 1238) about their child’s ability to manage the disease. Older children welcome the move towards autonomy, whereas parents can interpret this “*moving on*” as “*moving away*” (Marshall *et al.*, 2009, p.1708). In order to compensate, parents may resort to measures which conflict with the needs of the emerging young person (e.g. Weinger, O’Donnell & Ritholz, 2001), giving rise to potential rifts in the parent-child dyad. Naturally, as the child assumes more responsibility, the dynamics in the parent-child relationship change. The way in which parents respond to this can impact upon the behaviour of the child, and ultimately, their self-care (Marshall *et al.*, 2009). There is a growing literature exploring the experience of diabetes from a family perspective. Wennick & Hallstrom (2006) described the family experience of adaptation as “*an ongoing learning process*” (p. 368), and as Schur, Gamsu and Barley (1999) note, parents who are more attuned to the meaning of diabetes for their child are better positioned to offer consolation. Child and parent struggles are not dissimilar. Marshall *et al.*, (2009) identified four themes interlacing child and parent accounts of living with diabetes; namely attachment, transition, loss and meaning. Whilst the themes were shared by parents and children alike, the implications were different. For example, where transition represented a ‘normal’ part of becoming an adult for the child, it implied a loss of control for the parent.

With such responsibility and an evolving role, it is unsurprising that parents can become susceptible to psychological distress (e.g. Williams, Laffel & Hood, 2009). Further stress can occur when the goals of the parents are incongruent with those of the medical team. Parental objectives primarily revolve around avoidance of short-term difficulties (i.e. hypoglycaemia), whereas professional targets concern longitudinal management and avoidance of complications (Hatton, 1992). A qualitative study conducted by Leonard, Garwick and Adwan (2005) examining youth perspectives suggested that young people are aware of their parents’ “*frustration and concern*” (p. 412). Leonard *et al.*, (2005) proposed that the emotive and potentially conflictual nature of shared diabetes management necessitates adequate service support for parents. Owing to the shift in locus of control, the authors recommended that there be specific

interventions for parents of pubescent children. Overall, the literature suggests that a holistic approach to diabetes management is agreeable. The ability of a young person to live well with diabetes is often influenced by the surrounding systems. As such, it is likely that the same is true for parents.

The aim of this review was to identify which themes emerge most commonly from the literature base examining parental experiences. It is hoped that the findings can inform care teams responsible for the wellbeing of families living with diabetes, to help to meet the parental needs implied by existing research.

Methodology

Research question

What are the common themes pertaining to parental experiences of having a type 1 diabetic child as described by qualitative methodologies?

Literature search protocol

Using the search engine, EBSCO, a complete database search was conducted up to and including February, 2016. Databases identified were CINAHL, Medline, Academic Search Premier, PsycInfo, Education Research Complete, Business Source Alumni Edition, Business Source Premier, ERIC, Library, Information Science & Technology Abstracts (LISTA), PsycARTICLES, and SPORTDiscus. Databases were not limited to ensure that the maximum number of articles would be retrieved from a number of different clinical disciplines. The following broad terms were used for searching the online databases:

(type 1 diabetes mellitus OR T1DM OR type 1 diabet*)

AND (famil* OR parent* OR caregiver*)

AND qualit*

Inclusion and exclusion criteria

Inclusion:

- Participants are parents or main care-givers of a child/children with type 1 diabetes
- Qualitative studies

- English language studies (to minimise translation errors/misinterpretation)
- Journal articles

Exclusion:

- Participants are not restricted to parents or main care-givers of a child/children with type 1 diabetes
- Papers examining co-morbid chronic disorders or psychological disorders
- Quantitative or mixed-methods studies
- Focus group studies
- Papers examining experiences of specific interventions/studies or diabetes-management experiences
- Non-English or translated studies
- Review, discussion or case study papers
- Non-journal articles

Final selection

The aim of the literature search was to provide a selection of qualitative English-language journal articles examining the experiences of caregivers of type 1 diabetic children. Based on the abstracts, papers which did not meet one or more of the exclusion criteria were retrieved in full. The papers were then reviewed and reassessed against the inclusion/exclusion criteria. Owing to the small pool of papers meeting inclusion criteria, age restrictions were not applied. Papers examining parental experiences of caring for children on insulin pumps specifically were excluded owing to an existing review (Alsaleh, Smith & Taylor, 2012). Two papers were written by the same authors using the same data set. A study by Lowes, Lyne & Gregory (2004) was later re-written from psychosocial perspective resulting in a second publication (Lowes, Gregory & Lyne, 2005). The first of the papers was included in the review because of its chronological placement and broader title. A further paper by Dashiff, Riley, Abdullatif & Moreland (2011) initially appeared to fit the criteria, however it was part of a larger mixed-methods study involving children and caregivers and was therefore excluded from the final selection. A total of 7 papers remained. From the final selection, reference lists were examined for further papers meeting inclusion criteria. Two further papers were identified generating a total of 9 for review. The final selection process is shown in Figure 1.

Quality review

In order to appraise each article, the National Institute for Health and Clinical Excellence (NICE) methodology checklist for qualitative research was used (NICE, 2009). This measure is suitable for assessing the robustness of qualitative research across 6 domains (theoretical approach; study design; data collection; validity; analysis; ethics; Appendix B). Each section is rated by making a selection from 1 of 3 boxes with varying responses (e.g. appropriate; inappropriate; not sure). Domains considered to be of good quality (e.g. appropriate) scored 1 point. Those in the latter categories scored 0 as it was not consistently clear which response merited more or less points. Each article could score a maximum of 14 points (Appendix C). In order to determine inter-rater reliability, a subset of papers was reviewed by a Clinical Psychologist. Where discrepancies occurred, differences were discussed and a mutual consensus reached. Quality assessment (QA) values were considered in relation to study conclusions, for example, whether poor QA scores influenced the robustness of findings.

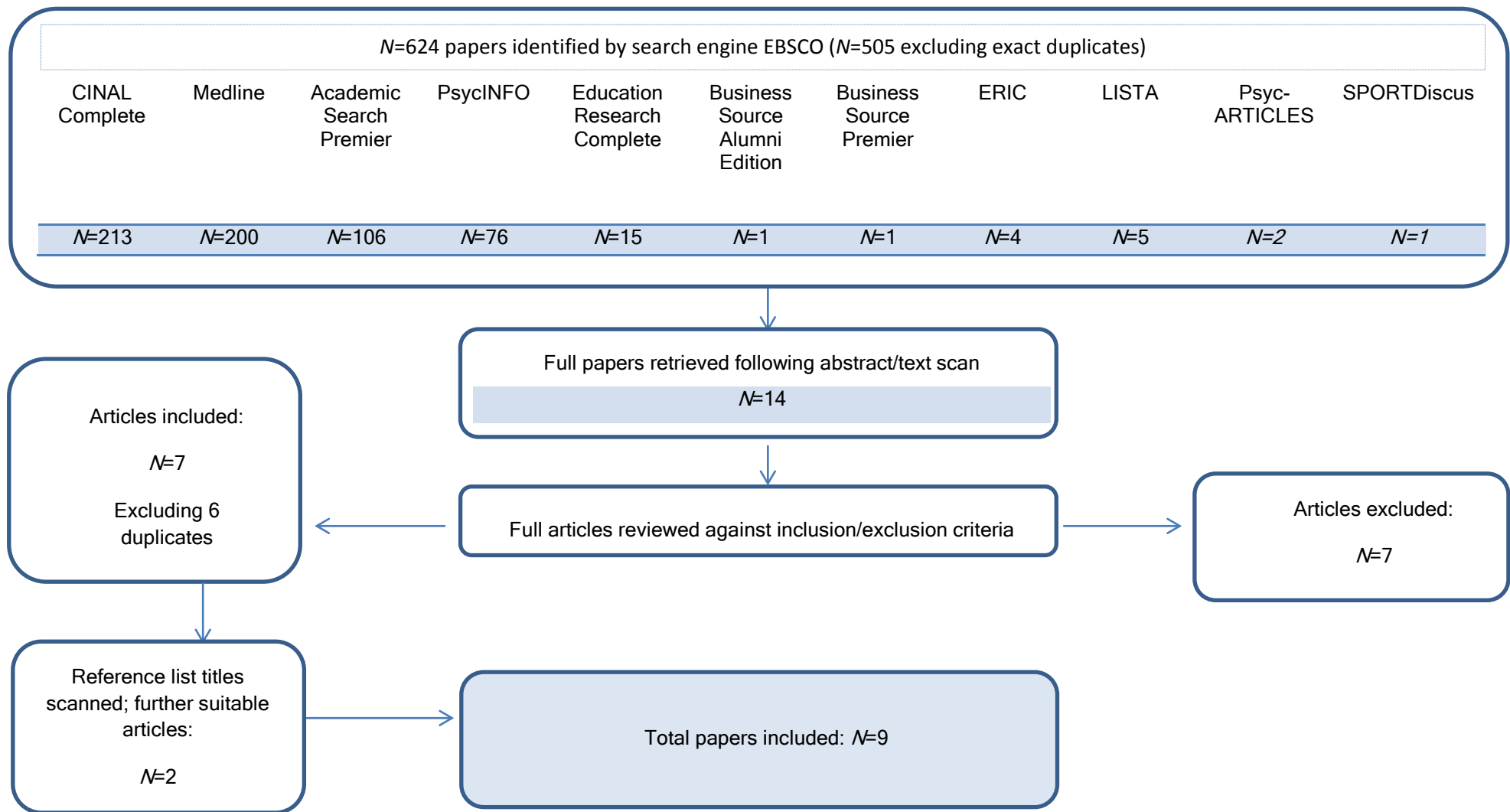


Figure 1: Flow-chart illustrating the final article selection protocol

Synthesis

A narrative synthesis approach was utilised to analyse the final papers. Objectives of a narrative synthesis, as described by Popay *et al.*, (2008; PowerPoint slides, PDF) are to: (i) consider a theory, (ii) develop a subsequent synthesis, (iii) examine the data for relationships/patterns, and (iv) critically appraise the robustness of findings. As there is no definitive method for conducting a narrative synthesis (Popay *et al.*, 2008), the authors' guidance and further methodological materials (Arai *et al.*, 2007) were used as a framework for conducting the review. A qualitative methodology was chosen to capture the lived experiences of parents and allow for examination of reoccurring themes. The synthesis type was selected to enable the findings to be presented as a comprehensive narrative.

Results

Overview of the literature

A summary of the final 9 articles can be seen in Table 1. The studies were carried out between 1993 and 2015 across the United Kingdom, United States, Canada and New Zealand. There were 254 participants total across the 9 selected studies. Forty-four percent of the studies omitted parental ages (Dashiff, 1993; Hatton *et al.*, 1995; Bowes *et al.*, 2009; Symons *et al.*, 2015), however of the remaining selection, the mean age of the caregivers ranged from 33 to 42.1. Lowes *et al.*, (2004) reported an alternative score; a median age of 39. Many of the studies reported incomplete data sets. For example, ethnicity was not routinely reported and was discussed in only 4 studies, 2 of which reported Caucasian participant pools. Means of recruitment was sometimes under-reported (e.g. Sullivan-Bolyai *et al.*, 2006) meaning that many of the studies would not be replicable based upon their descriptions. In some cases, the method of diabetes management was unclear (e.g. Lowes *et al.*, 2004). The studies varied in their explorations; some titles suggested a broader overview of parental experiences (Lowes *et al.*, 2004; Sullivan-Bolyai *et al.*, 2006; Symons *et al.*, 2015), whereas others utilised specific age groups of children (e.g. Dashiff, 1993; Hatton *et al.*, 1995; Sullivan-Bolyai *et al.*, 2003; Smaldone & Ritholz, 2011). Two studies addressed a more specific area of interest; Lawton *et al.*, (2015) examined parental experiences of optimising glycaemic control,

and Bowes *et al.*, (2009) researched chronic sorrow. The majority of papers interviewed both parents. The methodology reported in the studies was varied and sometimes vague (e.g. “guided by”) however the majority of the studies used either content analysis (Dashiff, 1993; Sullivan-Bolyai *et al.*, 2006; Smaldone & Ritholz, 2011) or phenomenological principles (Lowes *et al.*, 2004; Hatton *et al.*, 1995). Of the selection, 100% of the articles were peer reviewed and were featured in a variety of journals, most of which were nursing publications.

Quality assessment

The maximum achievable quality score was 14 points. The papers reported in this review earned scores of 5 ($N=1$), 8 ($N=3$), 9 ($N=1$), 10 ($N=2$), 11 ($N=1$) and 12 ($N=1$). For the purposes of synthesis, no studies were excluded based upon their quality ratings. The majority of the papers scored above 50%; papers achieving lower scores generally lost points based upon validity ratings. This included consideration of the role of the researcher, the context and methodology of research. In addition, the paper scoring 5 was not explicit about the ethical approval of the study and how the data collection was carried out. However, despite the range of quality scores, each paper contributed to the themes elucidated by the review.

Table 1: Data extraction of articles

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<i>Parents' perceptions of diabetes in adolescent daughters and its impact on the family</i> Dashiff (1993) USA	"Parents' perceptions of diabetes in adolescent daughters and its impact on the family was examined."	Qualitative Content Analysis	Numbers: 12 parent couples of daughters (aged 11 - 15) with a diagnosis ≥ 1 year Ages (yrs): Parental age: Unknown Child mean age = 12.8 Ethnicity: Unknown Occupation: 7 mothers were employed outside of the home environment; fathers were employed in a variety of occupations (9 = "white-collar"; 1 = disability; 2 = "blue-collar")	A clinical nurse specialist from the diabetes clinic identified and approached potential participants from a clinic roster Families were sent consent letters by the principal investigator, who initiated telephone contact to arrange an interview time Management techniques: Unclear	Interviews were conducted at the principal investigator's office or the participants' homes averaging 90 minutes - 2.5 hours Both parties partook in all interviews	8

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<p><i>Parents' perceptions of caring for an infant or toddler with diabetes</i></p> <p>Hatton, Canam, Thorne & Hughes (1995)</p> <p>Canada</p>	<p>"...The purpose of this phenomenological study was to gain knowledge and understanding of the parents' experiences so that appropriate interventions could be developed and implemented to support parental care for this unique population."</p>	<p>Use of phenomenological principles</p>	<p>Numbers: 28 two-parent families with an "infant or toddler" (aged 2-3 years) who had been managing the diabetes for ≥ 2 months. <i>Only 8 child ages reported</i></p> <p>Mean ages: Unknown</p> <p>Ethnicity: Unknown</p> <p>Occupation: Mothers:</p> <p>1x teacher, receptionist, nurse, librarian and 4x homemakers</p> <p>Fathers': accountant, librarian, printer, dentist, shipping, bus driver, boat builder/designer, advertising</p>	<p>A computer-generated list of families meeting criteria was reviewed by the Medical Director</p> <p>During clinic appointments, families were given information pertaining to the study by members of the clinic</p> <p>Staff and invited to call a number if interested</p> <p>Management techniques: Unclear</p>	<p>N= 14 interviews conducted over 5 months in participants' homes averaging 2-3 hours</p> <p>Mothers and fathers were interviewed jointly</p>	<p>5</p>

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<p><i>Constant vigilance: Mothers' work parenting young children with type 1 diabetes</i></p> <p>Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane & Grey (2003)</p> <p>USA</p>	<p>"The purpose of this study was to describe the day-to-day experiences of mothers (N= 28) raising young children under 4 years of age with type 1 diabetes."</p>	<p>Descriptive Naturalistic Enquiry</p>	<p>Numbers: 28 English-speaking mothers of children (18 boys and 10 girls) under 4 years of age (with a diagnosis of ≥ 3 months</p> <p>Ages (yrs): Mothers' mean age = 33 Child mean age = 2.9</p> <p>Ethnicity: 25 mothers (89%) were white</p> <p>Occupation: 15 mothers were not working outside of the home</p>	<p>Participants were recruited from 2 diabetes clinics following advice from staff (consent forms completed prior to interview)</p> <p>Management techniques: Unknown</p>	<p>N= 28 interviews were conducted in participants' homes averaging 1.5-3 hours</p>	<p>12</p>

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<p><i>Childhood diabetes: Parents' experience of home management and the first year following diagnosis</i></p> <p>Lowes, Lyne & Gregory (2004)</p> <p>Wales, UK</p>	<p>"To explore parents' experience of having a child diagnosed with Type 1 diabetes, managed at home, and their first year following diagnosis."</p>	<p>Longitudinal "guided by theories from the social sciences and interpretative phenomenology"</p>	<p>Numbers: 38 parents of $N = 20$ newly diagnosed children (11 boys; 9 girls aged 2-15) who were clinically well at presentation and treated at home following referral</p> <p>*There were two single-parent households</p> <p>Age (yrs): Parental median age = 39 (aged 23-49); children's median age = 9</p> <p>Ethnicity: All white English-speaking parents</p> <p>Occupations ranged teaching, office-administration, engineering, cleaning and journalism; 5 mothers were not employed outside the home; 2 fathers were unemployed</p>	<p>All parents meeting criteria from March 1998-October 1999 were invited and consented - it is unclear who recruited and how</p> <p>Management techniques: Unclear</p>	<p>$N = 40$ interviews were conducted in parents' homes, averaging 30-90 minutes (children were not present)</p> <p>$N = 19$ parents had 3 interviews (within 10 days of diagnosis; 4 months after; 12 months after)</p> <p>$N = 7$ parents had 1 interview (4 months after diagnosis)</p> <p>$N = 12$ parents had 1 interview (12 months after diagnosis)</p> <p>Unclear if interviews were with both parents each time</p>	<p>11</p>

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<i>Fathers' reflections on parenting young children with type 1 diabetes</i>	"To describe fathers' experiences in parenting and managing the care of their young children with type 1 diabetes."	Fundamental Qualitative Description	Numbers: 14 fathers of N= 15 children (9 boys; 6 girls aged 2-8) with type 1 diabetes *Two children were siblings	Fathers were contacted after they agreed to receive more information regarding the study - it is unclear who recruited and how	N= 16 interviews were conducted (at home or in clinic) averaging 60-90 minutes	10
Sullivan-Bolyai, Rosenberg & Bayard (2006)		Based upon principles of naturalistic enquiry and content analysis	Age (yrs): Fathers' mean age = 36; child mean age = 5 Ethnicity: White Occupation: "All...married...well educated"	Data collection conducted over >12 month period Management techniques: MDIs & CSII	N= 14 fathers were interviewed once, and 2 fathers were interviewed twice	

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<p><i>Chronic sorrow in parents of children with type 1 diabetes</i></p> <p>Bowes, Lowes, Warner & Gregory (2009)</p> <p>Wales, UK</p>	<p>“This paper reports on a study exploring parents’ longer-term experiences of having a child with type 1 diabetes.”</p>	<p>Based upon a theoretical framework of grief, loss, adaptation and change</p>	<p>Numbers: 17 parents (10 mothers and 7 fathers); of children (gender ratio unknown) diagnosed 7-10 years prior to the study</p>	<p>Recruitment by Paediatric Diabetes Specialist Nurses (Information Sheet and Consent Form posted to families for return)</p>	<p>N= 15 interviews were conducted (2 at hospital; 13 at home) between January and May 2007; average time unknown</p>	<p>8</p>
	<p>Further aim: to explore whether “emotional adjustment differs between fathers and mothers.”</p>		<p>Age/ethnicity/occupations: Unknown</p>	<p>Management techniques: MDIs (CSII not reported)</p>	<p>Parents were interviewed separately with the exception of 2 families</p>	

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<i>Perceptions of parenting children with type 1 diabetes diagnosed in early childhood</i>	"The purpose of this study was to explore perceptions of psychosocial adaptations in parenting young children with type 1 diabetes (T1DM) from diagnosis through childhood."	Content analysis	Numbers: 14 parents (3 mothers, 3 fathers and 4 couples) of <i>N</i> = 11 children diagnosed ≤5 years of age Ages (yrs): Parental mean age 41.7 Ethnicity: 13 white parents; 1 Hispanic	Children recruited from a diabetes day camp and through word-of-mouth from a participant Demographic questionnaire completed prior to study	Parents were interviewed independently of one another in their own homes	9
Smaldone & Ritholz (2011) USA			*1 mother had 2 diabetic children Occupation: 7 fathers and 2 mothers worked full-time; 2 mothers worked part-time and 3 mothers were not employed outside of the home	Management techniques: MDIs and CSII	Length of interviews: Unknown	

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<p><i>Challenges of optimizing glycaemic control in children with type 1 diabetes: A qualitative study of parents' experiences and views</i></p> <p>Lawton, Waugh, Barnard, Noyes, Harden, Stephen, McDowell & Rankin (2015)</p> <p>Scotland, UK</p>	<p>"To explore the difficulties parents encounter in trying to achieve clinically recommended blood glucose levels and how they could be better supported to optimize their child's glycaemic control."</p>	<p>Based upon Grounded Theory principles</p>	<p>Numbers: 38 mothers and 16 fathers of <i>N</i> = 41 children (gender ratio unknown) with a diagnosis of at least 6 months</p> <p>*1 set of parents had 2 diabetic children</p> <p>Age (yrs): Mothers mean age = 40</p> <p>Fathers mean age = 42.1</p> <p>Children: Girls = 9</p> <p>Boys = 8</p> <p>Ethnicity = Not stated</p> <p>Occupations: Mixed (full-time = 19, part-time = 18, full-time carer = 7, unemployed = 9, in education = 1)</p>	<p>Recruitment by health professionals from 4 Scottish paediatric departments</p> <p>Management techniques: MDIs and CSII</p>	<p><i>N</i> = 40 interviews were conducted in parents' homes between November 2012 and June 2013 (averaging 2 hours)</p> <p><i>N</i> = 24 interviews with mothers, 2 with fathers and 14 with mother and father</p>	<p>10</p>

Title of Study/Authors/ Country	Aim(s)	Qualitative Method	Participants (caregivers)	Recruitment	Data Collection	Quality Score (14)
<p><i>"The whole day revolves around it": Families' experiences of living with a child with type 1 diabetes – A descriptive study</i></p> <p>Symons, Crawford, Isaac & Thompson (2015)</p> <p>New Zealand</p>	<p>"In this study, parents' experiences of living with a child with Type 1 diabetes (T1D) were explored."</p>	<p>Inductive approach to Thematic Analysis</p>	<p>Numbers: 9 parents (5 mothers and 4 fathers from 6 families) of children (aged 4-14) diagnosed ≥ 1 year</p> <p>*1 family was single-parent</p> <p>Mean ages, ethnicity and occupation: Unknown</p>	<p>Participants were from the catchment area of Regional District Health Board</p> <p>Management techniques: MDIs (CSII not mentioned)</p>	<p>Total number of interviews unknown (each averaging 50 minutes) were conducted in 2012 with the majority occurring in the homes</p> <p>Some parents were interviewed jointly, whereas others opted to be interviewed separately - no further information supplied</p>	8

Table 2: Themes from the literature

Initial consideration of themes	Condensed themes	Relevant papers
After diagnosis: Diagnostic experience; grief and loss (e.g. healthy child/freedom); present concerns (e.g. injections and hypos); future implications	<u>Psychological impact of diabetes</u> Experience of diagnosis; grief and loss; feelings of guilt; immediate concerns; concerns for the future	Dashiff (1993); Hatton <i>et al.</i> , (1995); Sullivan-Bolyai <i>et al.</i> , (2003); <i>Lowes et al.</i> , (2004); Sullivan-Bolyai <i>et al.</i> , (2006); Bowes <i>et al.</i> , (2009); Smaldone & Ritholz (2011); Lawton <i>et al.</i> , (2015); Symons <i>et al.</i> , (2015)
Competency and confidence: Of parent; of the child; of responsible other; quest for normality	<u>Adaptation and learning</u> Developing confidence and competency; forming coping strategies; striving for normality	Dashiff (1993); Hatton <i>et al.</i> , (1995), Sullivan-Bolyai <i>et al.</i> , (2003); <i>Lowes et al.</i> , (2004); Sullivan-Bolyai <i>et al.</i> , (2006); Bowes <i>et al.</i> , (2009); Smaldone & Ritholz (2011); Lawton <i>et al.</i> , (2015)
Relationships: Marital; father/mother roles; child developing into adult (desire for autonomy); professionals (validation; support)	<u>Relationships</u> Family and friends; the child, parent and autonomy; professional support	Dashiff (1993); Hatton <i>et al.</i> , (1995) Sullivan-Bolyai <i>et al.</i> ,(2003); <i>Lowes et al.</i> , (2004); Sullivan-Bolyai <i>et al.</i> , (2006); Bowes <i>et al.</i> , (2009); Smaldone & Ritholz (2011)

Theme 1: Psychological impact of diabetes

Subtheme: Experience of diagnosis

Diagnosis was generally a shocking time for parents, with many in denial (e.g. Hatton *et al.*, 1995). Whilst some suspected diabetes, they looked for more common explanations. For some, it was only when the child's symptoms persisted that they sought advice. The professional response was one of urgency (*Lowes et al.*, 2004). Whilst the majority of parents were shocked, some were consoled: *"I think it was relief, as well, that we had found out what was wrong..."* (*Lowes et al.*, 2004, p.533). Some parents were confused and doubted by staff (Smaldone & Ritholz, 2011). Many accounts described ongoing feelings of anxiety, which continued into the child's adolescence (e.g. Dashiff, 1993). Mothers described the impact of constant anxiety on their physical selves which included migraines, weight loss/gain, and for some, hospitalisation (Sullivan-Bolyai *et al.*, 2003).

Subtheme: Grief and loss

Following diagnosis, parents experienced grief at the loss of their healthy child. Some parents expressed suicidal ideation; one mother reported the desire to drive into oncoming traffic (Hatton *et al.*, 1995). Such feelings were not gender exclusive; one male described wanting to walk into a bonfire (Hatton *et al.*,

1995). For others, grief evoked anger: *"...when my husband tried to comfort me I just let into him"* (Hatton *et al.*, 1995, p. 572). Another parent noted: *"It was difficult for me to come to terms with...the anger will always be with me"* (Bowes *et al.*, 2009, p. 995). Such feelings were sometimes projected towards the medical staff. Many parents also expressed a loss of freedom following diagnosis (e.g. Hatton *et al.*, 1995; Symons *et al.*, 2015) which extended into work. Some mothers relinquished their careers for lack of available babysitters, whilst some fathers were required to change their work schedules (e.g. Hatton *et al.*, 1995, p. 573). Some parents viewed diabetes as a life-sentence: *"Never be free again. Like a prisoner, only the prison is diabetes and the chains are insulin and blood tests"* (Hatton *et al.*, 1995, p. 573).

Subtheme: Feelings of guilt

Underlying the grief reaction was a sense of guilt which was felt by both mothers and fathers. Some felt it was assigned by others, namely the medical staff: *"...I know they blamed me...Of course the nurses and doctors told us it was no one's fault but then they couldn't fully explain how our son got his diabetes either so I still blame myself. I think I always will"* (Hatton *et al.*, 1995, p. 572). The hereditary aspect of the condition caused further guilt: *"I blamed myself because it came through my mother's side of the family..."* (Bowes *et al.*, 2009, p. 995). Locus of guilt was not limited to genetics. Some parents perceived themselves to have failed the child and assigned themselves blame (e.g. Bowes *et al.*, 2009).

Subtheme: Immediate concerns

Diagnosis imposed new responsibilities. One of the most pertinent causes for concern was injections: *"...we would lie her on the floor and pin her down then just give it. I was dying inside..."* (Hatton *et al.*, 1995, p. 573). For fathers, the health-related implications of injections and administering too much insulin were concerning: *"You make a mistake and you can kill your child!"* (Sullivan-Bolyai *et al.*, 2006, p.27). One mother expressed distress at observing injections: *"We haven't given any injections but it still hurts me when I see him inject himself"* (Bowes *et al.*, 2009, p. 995). This topic was sensitive for mothers and fathers alike, and the task often required challenging their own needle fears (e.g. Hatton *et al.*, 1995; Sullivan-Bolyai *et al.*, 2006). In the study conducted by Sullivan-

Bolyai *et al.*, (2006), 29% of fathers reported becoming the main injection-giver, with the remainder assigned this responsibility after work and/or at weekends. Hypoglycaemia was a further source of distress. For some parents, extreme measures were taken to ensure that blood sugar levels did not fall too low (Hatton *et al.*, 1995). Night-time was a particular source of worry, which led to sleep deprivation (e.g. Sullivan-Bolyai *et al.*, 2003). In contrast to findings reported by Hatton *et al.*, (1995), some mothers felt anxious about maintaining their child's blood sugar levels in the lower range for protracted periods. Lawton *et al.*, (2015) revealed each parent had expressed fear about finding their child unconscious or dead in the morning: "*You're scared to go into her room in the morning, every morning*" (p. 1066).

Subtheme: Concerns for the future

For fathers, diabetes related to a lifetime of finger-calluses, limited opportunities and unsuitability for marriage (Sullivan-Bolyai *et al.*, 2006). Similarly, one mother was concerned about the implications for her daughter's future: "*...it will have an impact on her future as a wife, mother, and a person*" (Dashiff, 1993, p. 367). The implications for the child's physical health were also reasons to remain focussed. One parent commented: "*...there's a person...who has had his leg amputated...That kind of thing is quite a worry...That's quite upsetting even now*" (Bowes *et al.*, 2009, p. 996). One parent asserted that they were doing all that they could to ease their worries: "*That's my focus at the moment. Getting good control for later life...*" (Lowes *et al.*, 2004, p. 535).

Theme 2: Adaptation and learning

Subtheme: Developing confidence and competency

In order to deal effectively with the new diagnosis, parents were required to gain knowledge (e.g. when to conduct blood tests) and learn new skills. For many, leaving the security of the hospital was a realisation that they were newly responsible (e.g. Hatton, *et al.*, 1995). Learning generally took time. For some, this was felt particularly during the first 6 months following diagnosis, leading to seclusion and feelings of ineptitude. Many perceived their competence to be reflected by the child's blood sugar levels (e.g. Lowes *et al.*, 2004). The study by Lowes *et al.*, (2004) examined confidence over a period of one week to a year following diagnosis. Twelve months following diagnosis, all but one parent felt

that they were coping the majority of the time; however nocturnal episodes of hypoglycaemia remained a concern. Once the initial fear subsided, some mothers reported that they had become skilled at daily management and interpretation of their child's physical presentation (Sullivan-Bolyai *et al.*, 2003). For others, the adaptation occurred more quickly, with 53% of parents in one study experiencing an increase in confidence after just one week (Lowes *et al.*, 2004) whilst others described change occurring at 6-8 weeks. Fathers gained confidence by taking an active approach (e.g. Sullivan-Bolyai *et al.*, 2006, p.28) and some felt that they were more suited to performing invasive procedures (Hatton *et al.*,1995).

Parents also expressed concern regarding the competency of others. For mothers (Sullivan-Bolyai *et al.*, 2003), worries about leaving the child at day-care provoked anxiety. Many parents reported a lack of babysitters who were willing to take on the responsibility with a few parents relying upon grandparents (Smaldone & Ritholz, 2011). Separated fathers were also cited as a source of worry (Lawton *et al.*, 2015). One mother described placing restrictions upon her child's activities to manage risk: "*Because what if she goes hypo, will the other parent know what to do...*" (Lawton *et al.*, 2015, p. 1066). Parents were also concerned about the child's ability to monitor themselves (e.g. Lawton *et al.*, 2015), and for adolescents, expectations were sometimes negative: "*I think we've seen the best. I believe it's going to get worse as time goes by*" (Dashiff, 1993, p. 364). For mothers, this anxiety extended to thoughts about the child moving out, and how well they would be able to manage independently (Dashiff, 1993).

Subtheme: Forming coping strategies

Dashiff (1993) described four ways in which parents coped with their emotional distress: (1) overseeing the routine; (2) distancing themselves; (3) communicating and (4) accessing support. The desire to oversee events was reflected in the account of one mother: "*When I was managing the diabetes I had 'control', I made it live with us and not live with it, you have to adapt*" (Bowes *et al.*, 2009, p. 996). A father of an adolescent daughter expressed his need to acquire physical proof that she was managing effectively (Dashiff, 1993, p. 366). For parents in this study, monitoring was most concentrated for the 11-14 year old girls, and included reminders about blood checks and injections.

Fathers often adopted positions inside children's sports teams (Sullivan-Bolyai *et al.*, 2006), whilst some parents elevated their child's blood sugar levels (Lawton *et al.*, 2015). This strategy was also employed to deal with night-time fears about hypoglycaemia (Lawton *et al.*, 2015). A common complaint amongst parents was sleep deprivation due to anxiety. To combat this, some mothers elected to have the child sleep in their bed to ensure close proximity (Sullivan-Bolyai *et al.*, 2003). This method of coping was discordant with the distancing techniques of some parents: "*Sometimes I just have to get out and get away from it for a while*" (Dashiff, 1993, p. 366).

For some there was a desire to communicate with support services that were not there. One father commented: "*...it would have helped to have talked about it*" (Bowes *et al.*, 2009, p. 996). Of those who did receive support via groups, the response was mixed. For mothers of children under 4, age appropriate support groups were viewed as being particularly consoling (Sullivan-Bolyai *et al.*, 2003). This was not the case for all, however. One mother commented: "*I went to a parents' group, but I actually stopped going to it as I didn't find it beneficial*" (Bowes *et al.*, 2009, p. 996). Some of the fathers reported that they attended purely to support their partners, and how others' stories had the potential to increase their anxiety (Smaldone & Ritholz, 2011).

Subtheme: Striving for normality

Diabetes presented a challenge for parents who often worked to maintain normality, whilst acknowledging that their child had different, life-saving requirements. The subject of normality traversed many parental accounts, and for some, diabetes eventually became part of their 'normal' routine. Systemic factors often contributed; a few mothers described difficulties securing their child a space at school (Sullivan-Bolyai *et al.*, 2003). One parent felt they had adapted to a routine 4 months after diagnosis (Lowes *et al.*, 2004). Fathers took practical approaches to ensuring that their child remained involved in activities, (Sullivan-Bolyai *et al.*, 2006), and likened their child's condition to that of common complaints (e.g. the need to wear glasses). Many parents struggled to decipher bad behaviour from shifts in blood glucose levels (e.g. Sullivan Bolyai *et al.*, 2003) and worried about the psychosocial impact of the disease for their children. One mother commented that she felt diabetes to be "*taking (her daughter's) childhood away from her*" (Lawton *et al.*, 2015, p. 1067). Parents

often set aside some 'normal' time, namely letting their children eat what they desired, in an attempt to assuage their feelings of abnormality: "...I just said to her 'eat what you want and then I'll correct it later'. And now we do just the same if there's a birthday party" (Lawton *et al.*, 2015, p. 1067). Some implied that they let blood sugar levels run high in order to ensure that other parents were not deterred from inviting their child to events (Lawton *et al.*, 2015).

Theme 3: Relationships

Subtheme: Family and friends

The findings of Dashiff (1993) suggested that the impact of having a diabetic child negatively influenced the spousal relationship. Some parents implied that there was not as much time for one another because diabetes commanded a lot of their resources. One couple stated that their daughter "*got the best of both*" of them (p. 364). Another father described feeling alienated by his wife's emotional wall (Hatton *et al.*, 1995). For those who were unable to communicate their feelings effectively, arguments and periods of silence ensued (Hatton *et al.*, 1995). One mother described feeling unable to share her worries (Boyes *et al.*, 2009), and some fathers reflected a similar difficulty: "*I feel that I can't say to them (family) that I find it a struggle*" (Bowes *et al.*, 2009, p. 997). For some, the disease was seen as the glue holding the relationship together: "*...we would have gone our separate ways*" (Dashiff, 1993, p. 364). Some were unsure about their ability to remain together once their daughter left home. For many mothers, supportive fathers were cherished (Dashiff, 1993). One commented: "*...we were a team, so that was huge...we did everything together...*" (Smaldone & Ritholz, 2011, p. 90). Fathers too reported feeling comforted by their spouse (Sullivan-Bolyai *et al.*, 2006). Task division often resulted in mothers providing meals and overseeing care, whilst both parents discussed the important decisions; only a few fathers expressed dissatisfaction with the division of responsibility (Sullivan-Bolyai *et al.*, 2006).

For some parents of adolescent daughters with T1DM, the disease was perceived to bring the family together (Dashiff, 1993). The impact was thought to affect family members more than the individual. Family dynamics were influential on the relationship trajectories; as Dashiff (1993) reported, some families were too frightened to express their feelings in case their daughter got

"the edge" (p. 366). Some families benefitted from spending time in parent-child dyads, whereas for others *"nobody (talked) about it (diabetes)"* (Dashiff, 1993, p. 366). Some children were socially affected by their parents' decisions. One mother explained that she had not enrolled her younger child in nursery owing to her concerns (Smaldone & Ritholz, 2011, p. 91). Mothers of younger-age children reported bonding issues, which they attributed to injections and dietary limitations, whilst fathers reported the opposite (Hatton *et al.*, 1995). Some fathers described a less positive impact of being involved however, describing themselves as assuming the role of the *"food and time police"* (Sullivan-Bolyai *et al.*, 2006, p. 28).

Some parents expressed anger towards family members who could not be counted upon during periods of distress (Dashiff, 1995). One couple felt that relatives were simply uninterested (Dashiff, 1993). For some grandparents, the new responsibility was too much, resulting in an emotional withdrawal (Hatton *et al.*, 1995). This was not true of all however. Sullivan-Bolyai *et al.*, (2003) found that members of the immediate family provided reassurance. In some instances, older siblings of the diabetic child assisted and were attuned to indicators of hypoglycaemia (Sullivan-Bolyai, *et al.*, 2003). For some, friends were the most reliable source of support. In the study by Dashiff, (1993), only two parents cited people who could be relied upon; their friends. For many however, friendships suffered when their friends became 'phobic' about diabetes (Dashiff, 1993). Some would garner initial offers of support that were later withdrawn (Sullivan-Bolyai *et al.*, 2003). The impact of limited babysitters was felt by mothers who had little opportunity to socialise with their friends (Sullivan-Bolyai *et al.*, 2003).

Subtheme: The child, parent and autonomy

Parents alluded to the fact that it was difficult to balance the medical needs of the child with their developing autonomy (Dashiff, 1993; Lowes *et al.*, 2004). For some, there was a need to maintain close physical proximity at all times: *"We don't let her out of the care of one of us. Where we go we carry the kids"* (Dashiff, 1993, p. 366). This was not always the case. A father of an 8 year old girl was more relaxed: *"Let her figure it out for herself for a little bit and she knows...I just don't want to limit her..."* (Smaldone & Ritholz, 2011, p. 91).

Subtheme: Professional support

For some, the relationship with their healthcare provider was one of utmost importance. As Hatton *et al.*, (1995) found, the needs of parents of younger children were only met with professional support. For some, the relationships with care-providers strengthened following diagnosis. One mother described how the hospital had helped her to feel more reassured (Hatton *et al.*, 1995). Another commented: “*You were there when we needed you...*” (Lowes *et al.*, 2004, p.534). Services perceived to be sympathetic to the parental position engendered better relationships with families (Dashiff, 1993). Some mothers reported feeling well-supported by staff members who were “*always available for phone consultation and problem-solving assistance*” (Sullivan-Bolyai *et al.*, 2003, p. 26), whilst others felt judged and misunderstood (Sullivan-Bolyai, *et al.*, 2003). Relationships with schools improved when parents felt staff members were keen to help. As one mother described: “*He went on the (insulin) pump (prior to kindergarten). The (school) nurse...came to pump training with us...she wanted to help and she wanted to learn...*” (Ritholz & Smaldone, 2011, p.91). The move from paediatric to adult services also induced feelings of sadness and anxiety (Bowes *et al.*, 2009).

Discussion

This review sought to identify the common themes pertaining to parental experience of caring for a child with T1DM. A few broad themes appeared: (1) the psychosocial implications of the disease for parents, (2) the adaptation to diabetes, and (3) how T1DM impacts relationships. The findings of this review highlight the importance of ongoing support for parents beginning at diagnosis until the termination of paediatric service support.

An overwhelming sense of loss permeated the literature with some grieving for the loss of ‘the healthy child’ whilst others mourned their former freedom. It would be useful to investigate whether this theme is reflective of purely first world narratives which suggest entitlement to a ‘healthy’ child. A process similar to the grieving cycle occurred, whereby parents moved through stages as described by the Kübler-Ross grief model (1969): denial, anger, bargaining, depression and acceptance. Denial was seen particularly during the early stages wherein action was only taken when symptoms of diabetes persisted

and/or worsened. Many managed their feelings by bargaining and doing the best that they could. Depression was a natural progression for those who struggled more, leading to suicidal ideation for a couple of parents who simply felt too overwhelmed. The suggestion that those with fewer resources have more difficulty coping is supported by studies such as that of Eiser *et al.*, (1993) who highlighted the importance of support systems. Some parents eventually reached an acceptance whereas others continued to grapple with their situation. Kovacs *et al.*, (1985) suggests that the initial 'settling in' period of the disease resolves itself within the first 6 months, and that marriages are not adversely affected. This contrasts with the findings of the current review which suggests that, for some families, diabetes placed too high a demand on parental relationships (e.g. Dashiff, 1993). Furthermore, Lowes *et al.*, (2004) found that many resolved their situation after 12 months, suggesting that the experience is individual and will depend upon a variety of factors. The majority of parental concerns revolved around injections and hypoglycaemia. Many had to inflict pain for the greater good; a concept more difficult for younger-age children to comprehend. The significance of the fear of hypoglycaemia has been reflected in other studies (e.g. Haugstvedt *et al.*, 2010).

Regardless of whether parents fully accepted the diagnosis, there was a need for adaptation and learning. For many, inexperience led to feelings of incompetency. Overall, parents appeared to be more satisfied with their own abilities when compared with schools and grandparents. This led to some becoming highly involved in diabetes care, sometimes resulting in dissatisfied partners and difficulty allowing children to become autonomous. In terms of the family life cycle, adolescence requires a shifting of roles in the child-parent relationship (Montemayor, 1983). Silverberg and Steinberg (1987) found a strong correlation between parents' crisis and the degree of autonomy felt by their children. Diminished confidence was felt not only by parents, but by people in the parental networks. Accounts were often permeated by feelings of frustration with others' unwillingness to take responsibility, sometimes leading to isolation. The lack of shared responsibility is a reflection of individualist ideology. Others thrived due to the involvement in their child's care. Some turned to support services, with many of the appraisals mixed. The desire to maintain normality was apparent amongst many parents and caused considerable concern and anxiety. Some perceived their lives with diabetes to

be the 'new normal' whereas for others, there was a marked sadness and dissatisfaction.

Whilst each parents' journey is individual, accounts of the experience of caring for a diabetic child are largely influenced by systemic factors. The main points are summarised in Figure 2. It is useful to note that current research suggests no correlation between the prevalence of T1DM and socioeconomic status (Connolly *et al.*, 2000). The African philosophy, 'it takes a whole village to raise a child' teaches that a child's care is communal and requires input from multiple sources. For modern first world societies, this is often not the case, influencing narratives around adversity and management. A review by Bronfenbrenner (1986) investigated the degree to which "*intrafamilial processes [are] affected by extrafamilial conditions*" (p.723), highlighting the significance of different systems. Many online forums suggest a 'blame game' is occurring (e.g. Diabetes Health, 2012) which is supported by the findings of this review. Continued education is vital to remove some of the stigma associated with diabetes. NICE guidance (2004) recognises the need for families to have access to support because of their vulnerability to anxiety and depression. Recently updated NICE guidance (2015) describes a package of care via a multi-disciplinary team, 24-hour access to advice and regular liaison between schools and diabetes teams. The American Diabetes Association (2016) also explores some of the themes highlighted within this review on its help page; information is provided for parents on keeping children safe at school, maintaining a normal life and striking a healthy balance between being vigilant and intrusive. Whilst resources are available, it remains unclear whether they are visible enough. Given that parents have the potential to be isolated, support groups should encourage friends and family members to become involved. Currently, Diabetes UK (2016) runs such groups and continued visibility of support networks is crucial. The importance of liaison with schools was also evident within this review. Diabetes UK (2016) recognises the important role that teachers play in the care of children and also supplies some information via the website. It remains unclear whether support groups are available for teachers; school nurses may provide a valuable source of support where available.

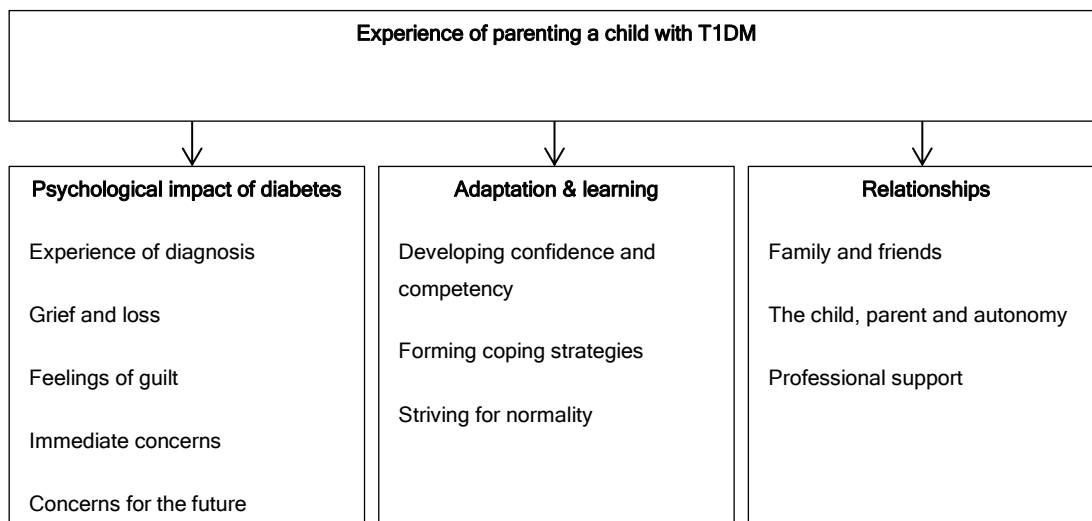


Figure 2: Findings from the synthesis

The findings of this review should be considered in parallel with the limitations of the papers (also see *overview of the literature*). It is acknowledged that the papers varied in terms of quality and topic-focus. It is therefore difficult to comment on generalisability; however this is not the aim of qualitative literature. This review has therefore provided insight into a range of unique and individual experiences. There are two main limitations of the review. Firstly, only qualitative accounts of parental experiences were examined (quantitative papers would likely contribute further to the findings). Secondly, the review addressed only English-language papers, meaning that there is limited cultural diversity. This decision was considered justified owing to the significance of language in qualitative literature, and the risk of important elements becoming lost during the translation process.

Future reviews could incorporate the effect of T1DM on siblings (e.g. Loos & Kelly, 2006). Such a review might make for a more robust examination of the influence of the condition on the family as a whole. Further research into support groups for parents of younger children is also recommended. If parents feel well-supported and more confident, they feel better able to help children live 'normal' lives, fostering healthy autonomy. Whilst it is encouraging that literature is available for review, further work is clearly required. This review has contributed to the current understanding of parental experiences of caring for a child with T1DM by assembling themes from the current qualitative literature

base. The results suggest that systemic approaches to treatment and continued professional involvement is crucial.

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Part Two

Paediatric diabetes: Children's experiences of the insulin pump

This paper is written in the format ready for submission to the *Journal of Qualitative Health Research*.

Please see Appendix A for the author guidelines.

Paediatric diabetes: Children's experiences of the insulin pump

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Abstract

Objective

Paediatric diabetes is a chronic condition. Statistics suggest that more and more children are being diagnosed each year. Children with type 1 diabetes manage their condition using either multiple daily injections, or an insulin pump. The decision to transition to a pump is guided by different factors including age, national guidance and the views of the individual. Despite the need for more research, there remains little qualitative data examining paediatric experiences of using the pump.

Method

Semi-structured interviews were used to explore the experiences of six children (aged 7 - 11) with T1DM, who had either transitioned to the pump, or were considering this move. The study was conducted using Interpretative Phenomenological Analysis.

Results

Three superordinate themes emerged from the findings:

- (1) The decision to get a pump: *(Who makes the decision? How was it decided?)*
- (2) Using the pump: *(The cannula; Learning the technical aspects; Wearing the pump; Pump safety)*
- (3) Do I benefit more from the pump?: *(The need for fewer injections; Time saved or required?; Do I feel better on a pump?)*

Results

The insulin pump was viewed as having advantages and disadvantages. The main disadvantage was the cannula changes which caused pain and the pump was viewed as being difficult to master. However, the pump offered benefits such as easier mealtimes and overall left participants feeling less ill. The study also highlighted important aspects of diabetes more generally, including the propensity for children with diabetes to feel different when compared with peers. The need for contact between children with diabetes is discussed.

Introduction

Type 1 diabetes (T1DM) is an autoimmune disorder which destroys insulin-producing cells. Diabetes figures continue to rise, most notably in children under the age of five (NICE, 2008). Approximately 10% of the annual National Health Service (NHS) budget is utilised for diabetes treatment totalling £9 billion each year (Costs of diabetes, 2012). T1DM has the potential to reduce life-expectancy by an average of 23 years (DoH, 2007), and as a chronic condition, necessitates lifelong insulin treatment. Multiple daily injections (MDIs) of the hormone are therefore administered dependent on what is required for the individual. An alternative method for the delivery of insulin is continuous subcutaneous insulin infusion (CSII), or 'insulin pump' therapy. This method utilises an external pump that infuses insulin via a medical tube inserted under the skin (NICE, 2008). This method of self-management is suggested for use in children with T1DM, of 12 years and over, and is now widely considered for children under 12 if MDIs are considered unsuitable (NICE, 2008).

Treatment and ongoing management of T1DM is essential for maintaining good health and healthy blood glucose (HbA1c) levels to avoid dangers such as hypoglycaemia. Current target ranges for short-term plasma glucose control are (i) a fasting plasma glucose level of 4-7 mmol/litre upon waking; (ii) a plasma glucose level of 4-7 mmol/litre prior to meals at other times of the day; (iii) a plasma glucose level of 5-9 mmol/litre following meals and (iv) a plasma glucose level of at least 5 mmol/litre when driving (NICE, 2015). It is a large responsibility, not only for the parents to ensure that their child is following a regime, but also for the child who will need to adjust their lifestyle accordingly. Those with greater management reap short-term benefits including greater academic performance, reduction in hospital admissions and improved satisfaction with service providers (DoH, 2007).

Management

As outlined by Plotnick *et al.*, (2003) there are a number of advantages to pump therapy comparable to daily injections. Pump therapy allows for the separate maintenance of basal (background) and bolus (surplus) insulin, and is more adaptable in terms of both food intake and physical exertion. CSII has been found to be effective in the treatment of diabetes for young children, perhaps

more so than MDIs for reducing the risk of hypoglycaemia (Weinzimer *et al.*, 2004). The literature supports systemic approaches to diabetes management; there is a plethora of papers examining the diabetic experience from both the child and family perspective (e.g. Newbould, Smith & Francis, 2008; Marshall, Carter, Rose & Brotherton, 2009).

Current Research

The literature examining the lived experiences of young people with T1DM is growing and reveals important findings. One recurring theme is the potential impact T1DM has on youth perspectives of normality. Multiple studies have noted the tendency for young people to feel abnormal when compared with peers (e.g. Huus & Enskär, 2007; Freeborn, Dyches, Roper & Mandelco, 2013; Hapunda, Abubakar, van de Vijver & Pouwer, 2015). Significant stressors for young people include insulin induced weight-gain, dietary restrictions and pain associated with injections (Hapunda *et al.*, 2015). There is a more modest research base relating to child experiences of CSII therapy, and the findings from paediatric studies suggest that HbA1c levels are improved after transition (e.g. Olinder, Kernell & Smide, 2007; de Bock *et al.*, 2012). A two-year follow-up study for girls identified improved quality of life as the main benefit of CSII therapy, for example, the ability to eat “*almost anything*” at “*flexible times*” (Olinder *et al.*, 2007, p. 36). Parental experiences have also been investigated. Lowes (2005) and Sullivan-Bolyai, Knafl, Tamborlane and Grey (2004) revealed similar findings with quality of life and more flexibility being persuasive arguments for CSII. Further research examining both child and parental experiences (e.g. Mednick, Cogen & Streisand, 2004; Hilliard *et al.*, 2009) reports an overall satisfaction with CSII. A meta-review conducted by Alsaleh, Smith and Taylor (2012) examining parent and/or child perspectives, yielded a small pool of six papers. Children included in the studies ranged from 6 to 23 (and as young as one in a parental experience paper). Two of the studies, whose participants were girls, collectively aged 7 to 18 (Low *et al.*, 2005; Olinder *et al.*, 2007) were particularly forthcoming with regards to the negative impact of CSII therapy, including pump appearance and its impact on clothing choices.

A more recent study by Alsaleh, Smith, Thompson and Taylor (2013) examined family experiences of an insulin pump therapy programme facilitated by a London hospital. The programme included ‘pre-pump education’, the ‘pump

school' itself and 'post-pump education'. Prior to pump training, parents spoke of their worries about the cannula, operating the pump, and how wearing such a device might interfere with their child's daily life. Each child reported fearing insertion of the cannula. Following the training, one of the main benefits of pump school for parents was getting to experience wearing a pump themselves. However, in one child's opinion, "*too much of the talking and the vocabulary used was aimed at parents, rather than at them*" (Alsaleh *et al.*, 2013, p.29).

There is a paucity of research relating to family experiences of CSII, in particular, younger age children (Alsaleh *et al.*, 2012). As researchers in this field note, the perspectives of children (including those as young as 5) using insulin pumps are required to enhance the current understanding of their needs and requirements (Alsaleh *et al.*, 2012). This study therefore sought to examine the experiences of younger children using insulin pumps and explore their perspectives on this type of management system.

Methodology

Research question:

What are the experiences and opinions of children with T1DM using insulin pumps?

The research question changed over the course of the study. The original research design sought to explore children's experiences of the *transition* between MDIs and CSII. Therefore it was structured using transitional theory (Schlossberg, 1981) and the interview questions were guided by such. During the interviews however, participants revealed more about their experiences of using the pump itself as opposed to the transitional period. The study therefore evolved accordingly and the research question changed to address children's experiences of using the insulin pump.

Design

This qualitative study was designed using an Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) framework. Given that the research was rooted in the child's personal experience, a research method

which could effectively capture and explore the data was required, making IPA the most suitable choice. This “dynamic” research method is used to examine individual experiences, whilst acknowledging the influence of the researcher (Tebbet & Kennedy, 2012). IPA is primarily concerned with “*how people make sense of their major life experiences*” (Smith *et al.*, 2009, p.1). To complement the process, a picture-drawing activity was included. Pictures were used as a warm-up interview activity and were considered during analysis.

Ethical approval for the study was given by the University of Hull Faculty of Health and Social Care and NHS East Midlands: Nottingham 1 Research Ethics Committee, with further approval provided by participating research and development departments.

Participants

Opportunity sampling was used to recruit children with a diagnosis of T1DM, aged between 6 and 11 years (to reflect recommendations that CSII should be considered for those younger than 12). Children were fluent in English and described as being in the transitional phase by the service provider. Children had been using CSII for no more than 6 months. Children who were using MDIs were included; i.e. participants were not required to have fully transitioned, and could still be in the stages where they were undecided. Other than having T1DM, children were physically well and were not considered if they met the following criteria: (1) were in physical discomfort, (2) were terminally ill or (3) had difficulties communicating.

Field supervisors from 5 NHS trusts identified suitable participants, which resulted in six children being recruited across three. All participants who wished to take part were eligible (Table 1). The families’ demographic questionnaires described various processes of preparation for a pump which included pump trials, home visits by nurses; pump evenings and psychology assessments. One of the families in the study did not have a pump trial, but did try the cannula. A couple of families described being directed to websites to aid their decision. The final sample consisted of 2 males and 4 females, aged between 7 and 11 years. All participants were white with an average age of 7 years at diagnosis.

Table 1: Participant demographics

*At the time of interview

Pseudonym	Age*	Gender	Ethnicity	Age at diagnosis	Time on CSII*
Maisy	7	Female	White	5	N/A
Elena	8	Female	White	7	Unsure
Tamzin	9	Female	White	5	Within 1 month
Andy	9	Male	White	7	5 months
Todd	9	Male	White	7	6 months
Keira	11	Female	White	9	Unsure

Recruitment Procedure

Field supervisors identified potential participants. The researcher sent each supervisor stamped envelopes containing information packs which contained a child information sheet (Appendix D), an adult information sheet (Appendix E), a consent form (Appendix F) and a demographic questionnaire (Appendix G). A stamped addressed envelope was included for return of the forms. Envelopes were posted back to the field supervisors who collated replies for the researcher. If no reply was received, a participant reminder sheet (Appendix H) was posted by field supervisors three weeks after the initial packs. For those who did reply, the researcher followed-up with a phone call to arrange a suitable day and time for interview. One family contacted the researcher via email to enquire about the study. Having subsequently consented to the study, this family was then phoned to arrange an interview. As the family elected to be interviewed in the home, there was no requirement for them to post the reply back to site (this was retrieved in person on the day). The researcher was also working on placement within one of the trusts at the time of the study meaning that recruitment was adapted for this site. During a clinic day, the researcher met with potential families to talk about the research in person. (The researcher

did not work with any of the families clinically). Each of the 3 families asked to receive an information pack which was posted to them. One family agreed to participate on the day, and after the researcher followed-up with a telephone call, the family was told that they could bring their forms to the interview (it was unnecessary to post it given the time between contact). The family forgot the forms on the interview day and therefore the parental consent form was completed in the room and the demographic questionnaire was completed over the telephone. The researcher was invited to attend two pump days held by the London-based trusts in November 2015 and February 2016 to maximise recruitment potential.

Interviews

The finalised interview was based upon Schlossberg's transition theory (1981; Appendix I). Interviews were conducted in the home or the local hospital. Half of the interviews took place in the home. Prior to each, the researcher completed a child assent form with each participant. Assent forms were simplified versions of the consent forms, designed for children (Appendix J). Each participant was assured about confidentiality, asked about the use of the tape recorder and reassured that they could stop the interview at any time. In most cases one parent remained in the room, however, during one home-based interview, two parents remained present. During another, the child wanted to be seen alone.

To begin each interview, the child was asked to think about what it is like to have diabetes and draw a picture based upon what came to mind. If this proved too difficult, or the child wanted to draw something different, this was encouraged. Picture-drawing enabled the researcher and child to get to know one another, and served as an interview aid should the child become anxious. After the picture-drawing, the interview commenced. Children were offered comfort breaks during interview sessions, which lasted 46 minutes on average. Following the interview, each participant had the opportunity to add to their picture, and parents were provided with a sources of support sheet (Appendix K) to direct them to further agencies if required.

Participant books

As a gesture of appreciation, and an optional resource to share with diabetes staff, each child received a private, personalised A4-sized book with three

distinct parts 'About Me', 'About My Diabetes' and 'My Picture'. Participants were asked to select fonts from a list of options. At the end of the study, participants' books were bound and sent to the family homes. Forms detailing the study findings/requesting feedback were also posted.

Data analysis

The IPA approach to data analysis was used, following the guidance of Smith *et al.*, (2009). Each transcript was considered individually (Appendix L) before being compared against others to identify themes. Themes were assembled into superordinate and subordinate categories. To enhance the validity of the findings, a selection of the transcripts were reviewed by a Clinical Psychologist. Participant quotations were used to support the themes.

Results

The following themes emerged from the interviews. A summary is presented in Table 2.

Table 2: Themes generated by the interviews

Superordinate theme	Subordinate themes
The decision to get a pump	Who makes the decision? How was it decided?
Using the pump	The cannula Learning the technical aspects Wearing the pump Pump safety
Do I benefit more from the pump?	The need for fewer injections Time saved or required? Do I feel better on a pump?

Superordinate theme: The decision to get a pump

(Subordinate themes: Who makes the decision? How was it decided?)

Of the participant pool, 5 of the 6 children had decided to transition to a pump. Andy could not remember who showed him a pump until his Mum prompted his memory. He said that he was “*not really*” interested in how the pumps worked when they were brought to his house, but expressed some frustration with others:

“It was alright, but I, but all I remember is [other people] always butting in. . .for their own opinions, which is quite annoying.” (760-61)

Andy spoke about how his Mum decided on his model of pump, whereas for Tamzin, the decision was split between herself and her parents. Tamzin explained that her parents opted for the waterproof model, and that she got to select the colour as a compromise. Elena could not remember the period when the family were considering the pump at all. Todd did however, and recalled “*a man*” showing him two models to help him decide which was preferable. Todd conceded that his parents made the ultimate decision, and struggled to verbalise his own opinion, stating:

“ . . .I’ll just say I was happy with the pump that was chosen. I don’t wanna get any more confused than I already am.” (710-11)

Tamzin and Keira both spoke about peers using pumps which influenced their decision. Tamzin saw the pump at a diabetes camp:

“ . . .I saw they had pumps and I thought ‘well I could try one’ so when I got back from diabetes camp I di-, started doing injections for myself, then I told Mummy I wanted to get a pump and I have got one.” (630-32)

For Keira, school peers were influential:

“ . . .I saw how cool it looks. . .and I thought it was really easy for them because. . . that person was in year three.” (186-88)

Keira explained that part of the reason for getting a pump was because she believed it would be simpler:

“ . . .because I think if I started the year with a pump I ...wouldn't have of um so much complication because people in my last like months I had a needle and had to go through all those things. . .” (93-95)

Tamzin admitted to feeling excited and nervous about trialling a pump:

“Well the first time I ever had it on, it was not this one I'm wearing but it didn't have anything in it. . .No salt water or anything. . .we were just practising how to put it in and take it out. . .then you put the salt water in you learn how to control it then we got used to controlling it then we just um put insulin in. . .” (661-66)

For Maisy, the prospect of a pump was not at all appealing. At the time of interview, Maisy did not feel she wanted to make the transition. When asked about a pump, she described “*everything*” about it as ‘bad’. Though she had trialled the pump for a day, it was enough for her to conclude that she “*didn't like it*”.

Superordinate theme: Using the pump

(Subordinate themes: The cannula; Learning the technical aspects; Wearing the pump; Pump safety)

The cannula and cannula changes featured prominently in many of the participants' accounts. For Keira, despite the fact that the cannula was “*gummy*”, it remained painful and could “*spike you*”. Andy found the cannula changes to be so frightening that he sometimes ran away.

“Well I hate the cannula changes. . . 'cause they hurt. They're annoying. I normally end up running into the cellar and hiding. . .” (444-455)

Andy explained that he was yet to administer a cannula change:

“ . . .Mum tried to make me do it, but I still wouldn't do it. . .because I normally push things down a lot.” (501-504)

Andy added that his family had a rotation “*system*” for placement of the cannula, and that the injection was more painful if it was in his leg. The anticipation of cannula changes was enough to lead Todd to be unsure of the transition to a pump. When he was asked what was particularly worrying about the prospect of a pump he replied:

“ . . .Just the cannulas...but everything. . .putting it in. Sometimes I wish could, I had a...don't know, a clock, stop-watch and I could skip from five minutes, ten minutes, fifteen minutes. . .” (258-60)

He later became self-conscious about cannula changes, preferring this activity to happen at home to limit the people who could watch him. Todd remembered using cannulas in the hospital, explaining:

“Well...it was quite, I don't know if nerve-wracking's the word, but...um, yeah.”
(295-96)

Todd explained that normally he would be assisted with this task:

“Normally I have an adult with me, um...that depends where I put it. . .” (594)

Elena used imaginative thinking to help with her cannula changes:

“Well...it's not...I don't really like it but I don't cry much anymore. I just go (breathes) and then I would sometimes maybe close my eyes and hold tight t-, to my wand. . .And to say a spell with it before Mum and Dad pr-, presses the elephant's nose to put the cannula in me.” (645-651)

In contrast, Tamzin said that her cannula hurt “*only a little bit*”, and that it was done with her parents present:

“ . . . it makes me feel better because I know I've got somebody with me.” (485)

Learning to use the pump itself was not always easy or interesting. Andy remembered his parents trying to teach him:

“Well for Mum I think learning it...was like a bit easy and then teaching it to me was the hard bit because I would keep on wandering off. . .Bye!” (825-29)

Andy felt his Dad struggled more, explaining that he had experienced difficulties with the software:

“ . . .when he first tried to upload, it crashed, then he had a tantrum about it.”
(854-55)

Learning to operate the pump was also daunting for Keira:

“Because you have to like press um really complicated buttons and if you press the wrong thing, like it might...I don’t know, do the wrong thing like fill tubing and you’re actually trying to live to change that. . .” (85-87)

When she was asked how she could be helped, Keira described wanting to be given very clear instructions by staff on how to use it and to be closely observed doing so:

“For let’s say if I forgot how to change my...cartridge, I have really accurate instructions to say how to do it.” (325-26)

Todd also seemed ambivalent about his ability to work a pump. Initially he said that he felt okay with operating it:

“I think, a bit, but when I know how to do things it’s normally wrong, but, I go with it anyway.” (679-80)

The physical presence of the pump was also troublesome. Kiera described her difficulty when she adjusted her tights and knocked her pump free. The sticker almost came off leading to anxiety about how to change it and a desire to return to the safety of home:

“I was walking home, and that was really frustrating to change coz I didn’t know how. . . I was trying to get home a lot quicker and trying to see what was wrong with it.” (143-51)

Keira’s struggles were echoed in Tamzin’s account; whilst she appreciated the water-proof nature of her pump, she expressed concerns about going swimming with it, fearing that it would “*look weird*”. She later conceded that “*nobody asked*” her about it despite her anxieties. Tamzin dismissed the idea of her pump impacting upon sports, commenting that as long as her pump was on tight enough, it would not make a beeping sound. Andy also commented upon the sound of his pump, saying:

“. . . I don’t like the buttons ‘cause when I bend over, all you can hear is that “beep, beep, boo-de-beep.” (610-11)

For Keira, there was still ambiguity about what might happen should the pump fail. She expressed concern that she would fall during play and cause the pump to “*break*”, “*smash*” and ultimately “*explode*”. Even though staff had attempted to

assuage her fears, Keira still felt anxious. When asked if the clinic staff had talked to her about those things, Keira said she had been advised that such activity would not “*hurt the pump*”.

Superordinate theme: Do I benefit more from the pump?

(Subordinate themes: The need for fewer injections; Time saved or required?; Do I feel better on a pump?)

Whilst the pain associated with cannula changes was negative, the requirement to do this less often than injections was positive. As Elena explained:

“Well I feel...it’s a bit hard to explain but, I feel much better because I-, er, it’s better than injections, to have it four times a day. . .” (630-31)

Tamzin too liked the fact that her cannula only had to be changed every few days, and said that both of her parents were usually present for this. Todd agreed with the need for fewer injections, stating that cannula changes meant:

“. . . a longer time and you don’t have to have an injection.” (148)

For Todd, one of the pump’s advantages was that it made things faster at meal times:

“. . . I’ve tested my blood, oh it’s...6.4, um, have an injection, [count] one, two, three, four, five, six, seven, eight, nine, ten, while my sister’s already eating, I could be eating, Mum’s eating. . . But, when with a pump...all you have to do is test my blood, 6.4, um go start eating. . .” (247-254)

Andy made similar comments, namely the need to count to ten when using injections. In contrast, Kiera felt that she lost time preparing the pump:

“That takes a lot more time to do it. . . You know like...changing the cartridge and the sticker...that takes a lot of time. . . complicated still. . . like not being able to- sometimes getting confused of what-, how to turn it on and off. . .” (120-31)

Andy too admitted that sometimes it could take “*ages*” when the pump performed various technical operations, such as filling tubing. However, he did mention that he felt the pump was simpler for his parents to manage:

“It’s easier about Mum and Dad not having to work out the insulin. . . It’s just the carbs now.” (794-97)

The influence of the pump on improved blood glucose levels was less clear. Tamzin explicitly stated that she felt that her levels had improved, albeit marginally, since making the transition. She said that she felt “*lots better*” when she was asked how she felt about her pump. Elena said that her diabetes was “*not as bad*” and felt “*better*” with a pump. Andy too concluded that he did not feel as “*ill*” using this treatment. In contrast, Keira mentioned that whilst the move to the pump was “*exciting*”, she felt she had less “*control*” than when using “*the needle*”. Todd explained that, whilst the prospect of the pump was daunting because of the “*scary*” cannulas:

“ . . . it’s been better. . . I’ve liked having a pump, it’s been easier.” (240)

Discussion

There is a growing recognition that wider diabetes research is vital given the psychosocial implications of the condition and the influence of such on metabolic control (e.g. Nardi *et al.*, 2008). National guidance (NICE, 2015) acknowledges the requirement to consider psychological aspects of diabetes care recommending (i) tailored emotional support which addresses social, cultural and age requirements (ii) the availability of psychosocial support systems, and (iii) contact with psychological services for both the child and family. The increasing move towards CSII treatment for children younger than twelve (NICE, 2008) highlights a need for new research; yet literature examining youth perspectives remains in its infancy. If CSII therapy is to be provided for younger children, it is of paramount importance that providers remain informed about the complexities of this treatment from the perspective of the child.

The decision to get a pump

The decision to transition to a pump is complex, and requires the consideration of many factors, including when to transition and which pump is most suitable. Families are supported to make this decision in different ways, for example using pump assessments, and with input from different members of their care teams. Many of the participants struggled to recall who was involved in the decision from a service perspective, however they were able to name their parents as being largely influential. Given that the transitional period has the potential to be overwhelming for children, it is important that parental guidance is offered to enable families to better support the child. The professionals more

commonly cited in the process of preparing for pump were the diabetes nurses. This was true of a study conducted by Forsner *et al.*, (2014) examining parental experiences of CSII therapy, and suggests the importance of nursing involvement. For the females in particular, peers contributed to their decision to trial a pump, suggesting a desire to be like others. Feelings of abnormality abound in the literature on diabetes more generally (e.g. Huus & Enskär, 2007; Freeborn *et al.*, 2013; Hapunda *et al.*, 2015) and it therefore remains an important issue.

Using the pump

Learning to use the pump was challenging not only for the participants, but their families too. Cannula changes are commonly cited as a concern for parents and children alike (Alsaleh *et al.*, 2013). When faced with the prospect of such, participants' strategies were varied, and ranged from using imaginative thinking to running away and hiding. Mastering the software presented a further challenge for many, and a distinct lack of confidence permeated the accounts. Erikson's (1968) psychosocial 'industry versus inferiority' stage teaches that from their sixth year, children develop a sense of industry; adopting more responsible roles and preparing to contribute as an adult. However if children feel underprepared for such demands, they are vulnerable to feelings of inferiority which challenges their sense of identity. At times, participants did suggest that it was preferable to be "*the baby at home rather than the big child in school*" (Erikson, 1968, p. 124) with regards to diabetes management. However, whilst many relied on their parents for cannula assistance, they also wanted to establish their position as the expert on diabetes. For example, Andy elected to demonstrate how he used to prime his injections during his interview.

Do I benefit more from a pump?

Though the participants cited concerns about cannula changes, software noises and appearance, there was an element of cost-benefit analysis regarding pump usage. For many, having one painful and frightening cannula change was preferable to having four daily injections. The pump was also viewed positively at mealtimes because it was considered to save time and afforded more feelings of normality. The literature suggests that the prospect of improved HbA1c levels using a pump is a persuasive argument for parents (Sullivan-

Bolyai *et al.*, 2004; Alsaleh *et al.*, 2014); however the findings of this study suggest that for children, the gains are more immediate. Such thinking is representative of the developmental age of the participants, largely defined as the 'concrete operational' stage of development by Piaget (1952). Future progression to 'formal operational' stages will likely facilitate an appreciation of longitudinal gains including health benefits.

A recent systematic review (Churchill, Ruppe & Smaldone, 2009) examined the use of CSII therapy in young children with T1DM. The results suggested CSII improved HbA1c levels, parental satisfaction and decreased hypoglycaemia. The general benefits of the pump reported by participants supported current literature, including more flexibility at meal times (e.g. Olinder *et al.*, 2007), fewer injections (e.g. Wilson, 2008) and feeling less "ill" (e.g. Olinder *et al.*, 2007). Not all of the advantages were supported however and one participant revealed she felt she had less "control". Other disadvantages included concerns about pump breakage and sounds, and interference with clothing choices (Low *et al.*, 2005).

Suggestions

The findings of the study suggest that whilst the pump offers some benefits, there are other psychosocial issues linked to diabetes that require consideration, including feelings of loneliness, isolation and difference. Given the movement into adolescence, it is likely that the physical aspects of the pump may also become more significant for the participants in this study in coming years. A recent qualitative review of CSII therapy revealed that girls in particular named issues with the visibility of the pump (Alsaleh *et al.*, 2012). This further highlights the need for peer support and normalisation which might be addressed in various ways; currently diabetes camps appear to be helpful, but contact between children is limited. It may be that other psycho-social interventions could be useful, such as group or individual psychological interventions, or consultancy to groups/schools to aid education among peers and teachers.

Limitations

There are several limitations to the current study. The participants involved were all Caucasian and therefore did not represent a culturally diverse sample. Half of

the participants were interviewed in a hospital setting as opposed to their home. A neutral location was favoured by the researcher as this limited disruption to interviews. Whilst the influence of setting cannot be overlooked it is worth noting that some of the longer interviews were gathered from hospital-based interviews. Some of the parents added to interviews, e.g. prompting participants' memories. Given the developmental age of the participants, a number of interview questions needed rephrasing into simpler language to aid understanding of the question. The depth of meaning from interviews required consideration, particularly for younger-age children who were sometimes unable to explain their thinking, or understanding the links between topics. Furthermore, if the research reflects an inability for children to understand their thinking processes, it implies a need for specialist services to be involved in the transition decision; to support, educate and advocate on their behalf.

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Part Three

Appendices

Appendix A

Journal guidance

Top Reasons to Publish with SAGE

As the world's leading international academic publisher, we pride ourselves on playing a creative role in society by disseminating teaching and research on a global scale. Publishing your article with SAGE means that you will benefit from:

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Manuscript Submission Guidelines: Qualitative Health Research (QHR)

Qualitative Health Research (QHR) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

QHR is a member of the Committee on Publication Ethics.

This Journal recommends that authors follow the Uniform Requirements for Manuscripts Submitted to Biomedical Journals formulated by the International Committee of Medical Journal Editors (ICMJE)

1. Article types

Please read the guidelines below then visit the Journal's submission site <http://mc.manuscriptcentral.com/qhr> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are

submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types

Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:

Description and analysis of the illness experience

Experiences of caregivers

Health and health-seeking behaviors

Health care policy

Sociocultural organization of health care

A Variety of Perspectives

QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

In-Depth Timely Coverage

Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTeX templates are available on the Manuscript Submission Guidelines page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's Manuscript Submission Guidelines. Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our Manuscript Submission Guidelines page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association [“APA”], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for “APA format.”

4.5 Reference style

QHR adheres to the APA reference style. Click [here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal’s specifications should consider using SAGE Language Services. Visit SAGE Language Services on our Journal Author Gateway for further information.

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/qhr> to login and submit your article online.

IMPORTANT: Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne.

5.2 Title, keywords and abstracts

Please supply a title, short title, an abstract and keywords to accompany your article. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and

guidance on how best to title your article, write your abstract and select your keywords by visiting the SAGE Journal Author Gateway for guidelines on How to Help Readers Find Your Article Online

5.3 Corresponding author contact details

Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

Appendix B

NICE Checklist

The guidelines manual (appendices)

Appendix I: Methodology checklist: qualitative studies¹

Study Identification <i>Include author, title, reference, year of publication</i>	
Guidance topic:	Key research question/aim:
Checklist completed by:	

Section 1: theoretical approach		
1.1 Is a qualitative approach appropriate? For example: <ul style="list-style-type: none"> • Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings? • Could a quantitative approach better have addressed the research question? 	<input type="checkbox"/> Appropriate <input type="checkbox"/> Inappropriate <input type="checkbox"/> Not sure	Comments:
1.2 Is the study clear in what it seeks to do? For example: <ul style="list-style-type: none"> • Is the purpose of the study discussed – aims/objectives/research question(s)? • Is there adequate/appropriate reference to the literature? • Are underpinning values/assumptions/theory discussed? 	<input type="checkbox"/> Clear <input type="checkbox"/> Unclear <input type="checkbox"/> Mixed	Comments:

¹ This checklist is based on checklists in:

Spencer L, Ritchie J, Lewis J, Dillon L (2003) Quality in qualitative evaluation: a framework for assessing research evidence. London: Government Chief Social Researcher's Office. Available from: www.strategy.gov.uk/downloads/su/qual/downloads/ogc_rep.pdf

Public Health Resource Unit England (2006) Critical Appraisal Skills Programme (CASP) – making sense of evidence: 10 questions to help you make sense of qualitative research. Available from: www.phru.nhs.uk/Doc_Links/Qualitative%20Appraisal%20Tool.pdf

National Training and Research Appraisal Group (NTRAG); contact: www.ntrag.co.uk

British Sociological Association (BSA); contact: www.britsoc.co.uk

The guidelines manual (appendices)

Section 2: study design		
<p>2.1 How defensible/rigorous is the research design/methodology?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Is the design appropriate to the research question? • Is a rationale given for using a qualitative approach? • Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used? • Is the selection of cases/sampling strategy theoretically justified? 	<input type="checkbox"/> Defensible <input type="checkbox"/> Not defensible <input type="checkbox"/> Not sure	<p>Comments:</p>
Section 3: data collection		
<p>3.1 How well was the data collection carried out?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Are the data collection methods clearly described? • Were the appropriate data collected to address the research question? • Was the data collection and record keeping systematic? 	<input type="checkbox"/> Appropriate <input type="checkbox"/> Inappropriate <input type="checkbox"/> Not sure/ inadequately reported	<p>Comments:</p>

The guidelines manual (appendices)

Section 4: validity		
<p>4.1 Is the role of the researcher clearly described?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Has the relationship between the researcher and the participants been adequately considered? • Does the paper describe how the research was explained and presented to the participants? 	<p><input type="checkbox"/> Clear</p> <p><input type="checkbox"/> Unclear</p> <p><input type="checkbox"/> Not described</p>	<p>Comments:</p>
<p>4.2 Is the context clearly described?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Are the characteristics of the participants and settings clearly defined? • Were observations made in a sufficient variety of circumstances? • Was context bias considered? 	<p><input type="checkbox"/> Clear</p> <p><input type="checkbox"/> Unclear</p> <p><input type="checkbox"/> Not sure</p>	<p>Comments:</p>
<p>4.3 Were the methods reliable?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Were data collected by more than one method? • Is there justification for triangulation, or for not triangulating? • Do the methods investigate what they claim to? 	<p><input type="checkbox"/> Reliable</p> <p><input type="checkbox"/> Unreliable</p> <p><input type="checkbox"/> Not sure</p>	<p>Comments:</p>

Section 5: analysis		
<p>5.1 Is the data analysis sufficiently rigorous?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Is the procedure explicit – Is it clear how the data were analysed to arrive at the results? • How systematic is the analysis – Is the procedure reliable/dependable? • Is it clear how the themes and concepts were derived from the data? 	<input type="checkbox"/> Rigorous <input type="checkbox"/> Not rigorous <input type="checkbox"/> Not sure/not reported	Comments:
<p>5.2 Are the data 'rich'?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • How well are the contexts of the data described? • Has the diversity of perspective and content been explored? • How well have the detail and depth been demonstrated? • Are responses compared and contrasted across groups/sites? 	<input type="checkbox"/> Rich <input type="checkbox"/> Poor <input type="checkbox"/> Not sure/not reported	Comments:
<p>5.3 Is the analysis reliable?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Did more than one researcher theme and code transcripts/data? • If so, how were differences resolved? • Did participants feed back on the transcripts/data? (if possible and relevant) • Were negative/discrepant results addressed or ignored? 	<input type="checkbox"/> Reliable <input type="checkbox"/> Unreliable <input type="checkbox"/> Not sure/not reported	Comments:
<p>5.4 Are the findings convincing?</p> <p><i>For example:</i></p> <ul style="list-style-type: none"> • Are the findings clearly presented? • Are the findings internally coherent? • Are extracts from the original data included? • Are the data appropriately referenced? • Is the reporting clear and coherent? 	<input type="checkbox"/> Convincing <input type="checkbox"/> Not convincing <input type="checkbox"/> Not sure	Comments:
<p>5.5 Are the findings relevant to the aims of the study?</p>	<input type="checkbox"/> Relevant <input type="checkbox"/> Irrelevant <input type="checkbox"/> Partially relevant	Comments:
<p>5.6 Are the conclusions adequate?</p>	<input type="checkbox"/> Adequate	Comments:

The guidelines manual (appendices)

<p><i>For example:</i></p> <ul style="list-style-type: none"> • How clear are the links between data, interpretation and conclusions? • Are the conclusions plausible and coherent? • Have alternative explanations been explored and discounted? • Does this study enhance understanding of the research subject? • Are the implications of the research clearly defined? • Is there adequate discussion of any limitations encountered? 	<input type="checkbox"/> Inadequate <input type="checkbox"/> Not sure	
Section 6: ethics		
<p>6.1 How clear and coherent is the reporting of ethical considerations?</p> <p><i>For example,</i></p> <ul style="list-style-type: none"> • Have ethical issues been taken into consideration? • Are ethical issues discussed adequately – do they address consent and anonymity? • Have the consequences of the research been considered; for example, raising expectations, changing behaviour? • Was the study approved by an ethics committee? 	<input type="checkbox"/> Clear <input type="checkbox"/> Not clear <input type="checkbox"/> Not sure/not reported	<p>Comments:</p>

Appendix C

Researcher quality ratings

<i>Paper title</i>	<i>Approach</i>		<i>Design</i>	<i>Data collection</i>	<i>Validity</i>			<i>Analysis</i>						<i>Ethics</i>
	1.1	1.2	2.1	3.1	4.1	4.2	4.3	5.1	5.2	5.3	5.4	5.5	5.6	6.1
Challenges of optimizing glycaemic control in children with type 1 diabetes: A qualitative study of parents' experiences and views	1	1	1	1	1	0	1	0	1	0	1	1	1	0
Childhood diabetes: Parents' experience of home management and the first year following diagnosis	1	1	1	1	0	0	1	1	1	1	1	1	1	1
Chronic sorrow in parents of children with	1	1	0	1	0	0	0	0	1	0	1	1	1	1

type 1 diabetes														
Fathers' reflections on parenting young children with type 1 diabetes	1	1	0	0	0	1	1	1	1	1	1	1	1	0
Parents' perceptions of diabetes in adolescent daughters and its impact on the family	1	1	1	1	0	0	0	1	1	0	1	1	0	0
Perceptions of parenting children with type 1 diabetes diagnosed in early childhood	1	1	0	0	0	0	1	1	1	1	1	1	1	0
"The whole day revolves around it": Families'	1	1	0	0	0	0	1	0	1	1	1	1	1	0

experiences of living with a child with type 1 diabetes – A descriptive study														
Constant vigilance: Mothers' work parenting young children with type 1 diabetes	1	1	1	1	0	0	1	1	1	1	1	1	1	1
Parents' perceptions of caring for an infant or toddler with diabetes	1	1	0	0	0	0	0	0	1	0	1	1	0	0

Appendix D

CHILD INFORMATION SHEET

Title of the study: Paediatric Diabetes: Children's experiences of the transition from multiple daily injections to the pump.

Information sheet for children. Guardians are asked to please guide your child through this information sheet before making any decisions.

Hello,

I would like to invite you to take part in my work looking at children's diabetes.

I would like to know what it is like for children to change from having injections to having an insulin pump.

What is the study for?

This study is to help people understand what it is like for children to stop having injections and start using a pump.



Why have I been asked?

You have been invited because you aged between 6 and 11, have Type 1 diabetes and are changing from injections to a pump.

Do I have to take part?

No, it is your choice.

If you say yes, you can change your mind later, as long as you tell me before I start to write about our work together.

What will happen if I do decide to take part?

If you say yes, your parent/guardian will give me some information and we will make a plan for you to meet me.



When we meet, you will talk with me.

You can have breaks, and one of your parents/guardians can be in the room with you.

I will be asking you about you, what it is like to have diabetes, and what it is like moving from your injections to a pump.

You will also be asked to draw a picture to tell me what it is like to have diabetes.

What you say will be put on a tape to help me to remember what you told me.



What is bad about taking part?

Talking to me will take some time.

You might feel sad when you talk - your parent/guardian and I will be with you to help.



If you say something that makes me feel worried about you, I will talk to your parent/guardian and a doctor.

What is good about taking part?

What you tell me is important and it will help me to know how you are feeling.

It might make you feel good to talk.



You will get a special book about you when I have written about our meeting.

What if there is a problem?

If you or your parent/guardian has any worries, you can talk to me or the people I work with.

We will do our best to answer your questions.

Will my information be safe?

Yes. I will be writing about what we talk about but I will not use your name.

You will also be asked to think of a superhero or a princess name which can be written on your drawing to keep your name private.



You will be asked not to write the full names of people on the drawing, but you can write things such as "mummy" and "daddy" if you like.

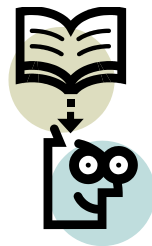
The only time that I might have to tell somebody about what we have talked about is if I feel worried about you.

What will happen when I have written about our chat?

When I have finished talking to you and I have written about what you have said, your book will be posted to you.

You will be asked if you would like to know what other children have said too.

You will be asked if you would like to tell me what you thought of our meeting and your book.



Who is looking after this work?

This work is being done for a course I am doing (a little bit like school). This course is helping me to learn about people and it is run by the University of Hull.

Who has ensured that the study is suitable and as safe as possible?

Prior to starting, this work was looked at by some people to make sure it is safe This study has been looked at by..... and got some good feedback.



Thank you for considering working with me and looking at this information sheet.

If you have any questions, your parent or guardian can contact me.

Yours sincerely,

Felicity Roberts

Trainee Clinical Psychologist

Jointly supervised by:

Dr Dorothy Frizelle,

Consultant Clinical Health Psychologist
Psychologist

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Appendix E

PARTICIPANT INFORMATION SHEET

Title of the study: Paediatric Diabetes: Children's experiences of the transition from multiple daily injections to the pump.

Information sheet for guardians. Guardians are asked to please read this information sheet before making any decisions.

We would like to invite you to take part in our research study looking at children's diabetes. We are interested in what it is like for children to move from multiple daily injections to an insulin pump. Before you decide if you would like to help us with our study, we would like to give you some more information so that you know what to expect. You can talk to other people and you can also talk to the researcher before you decide.

What is the purpose of the study?

We know little about what it is like for children with Type 1 diabetes to move between injections and the pump. This study is designed to help services understand what it is like to make this change and what can be done to support children going through it.

Why have I been invited?

This information sheet is given to families of children who are attending services that help them with their diabetes care. The children we are inviting are aged between 6 and 11, have Type 1 diabetes and are moving between injections and a pump. The staff from diabetes services will be giving this sheet to families who might be interested in helping with the study.

Do I have to take part?

No, it is your choice. If you would like to take part, you will be asked to sign a consent form (and each child an assent form). Later on, you might decide that you no longer want to be part of the study. That is okay and you can withdraw up until the point where your answers are analysed. You do not need to give a reason for withdrawing. Your decision does not affect your legal or medical rights.

What will happen if I do decide to take part?

If you agree to take part, please complete the contact details at the end of this form and leave it with a member of staff (in its envelope), or send it back to your service provider, addressed to:

You will then be contacted by the researcher to arrange a convenient time and place for a talk between the researcher and your child. They will have a chat with the researcher for between 30 minutes and 1 hour. Each child will be allowed to have breaks and you can be in the room too (one guardian is preferred). The researcher, who is training to be a psychologist, will be asking questions about what it is like to have diabetes, and what it is like moving from injections to a pump. This talk will be audio recorded. It is not a test and there are no right or wrong answers. We are only interested in what it is like for each child. Each child will also be asked to draw a picture to tell us what it is like to have diabetes. The researcher will provide the materials they will need for this.

What are the possible risks of taking part?

Participating in the study will require your time which might be inconvenient. Some children might become sad or upset when talking about their diabetes. The researcher and/or guardian will support them. The researcher can also talk to you about further support services to help you. If something that the child say causes the researcher to feel worried about them or their safety, they will inform you and a member of staff.

What are the benefits of taking part?

We cannot promise that children will benefit personally from the study. However, by helping us to understand what it is like to move from injections to a pump, they may help other children with their move. It might also help children to feel better when they talk about their experience. At the end of the study, when the answers have been analysed, the child's book will be sent to your house. This will include some of the things they said in the talk, such as what they like/don't like about their injections or pump. A copy of their picture will be in their book to show that it is theirs.

What will happen if I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and written up.

What if there is a problem?

If you have any worries, you can contact the researcher or their supervisor. We will do our best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through Dr Nick Hutchinson, Director of the Doctorate Programme in Clinical Psychology in the Faculty of Health and Social Care, University of Hull, on 01482 464804 or email n.hutchinson@hull.ac.uk. You may also contact the Patient Advice and Liaison Service: PALS@ulh.nhs.uk.

Will my information be kept confidential and safe?

Yes; all of the personal information provided will be kept confidential. Any information that might identify individuals will not be used in the study. Each child will be given a code to keep their names secret, and after the study is finished, all audio recordings will be destroyed. Each child will also be asked to think of a superhero or a princess name which can be written on their drawing. Children will be asked not to write the full names of people on the picture, but they can write things such as “mummy” and “daddy” if they wish. The only time that something they say might have to be shared is if they tell the researcher something that makes the researcher think that there might be a risk to the child or someone else. This risk might be physical or mental. If the researcher is worried, they will share this worry with you and the appropriate people.

What will happen to the results of the study?

After the study is completed, if you would like to know more about the results generally, these will be shared with you in a written format. You will also have the child’s book posted to you. Children will be invited to give feedback on the study and book, and this is completely voluntary. Some direct quotes and the picture and book (without any personal details) may be used in the write-up and sharing of results.

Who is funding and organising the study?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and overseen by the University of Hull. Some relevant sections of data collected during the study may be examined by responsible individuals from the University of Hull, your diabetes service, or from regulatory authorities to ensure that appropriate procedures were followed by the researcher.

Who has ensured that the study is suitable and as safe as possible?

Prior to starting, the study is reviewed by an independent organisation called a Research Ethics Committee. The Committee protects the interest of people who participate in research. This study has been reviewed by NRES Committee East Midlands - Nottingham 1, and has received a favourable review.

Thank you for considering the study and taking the time to read this information sheet. If you have any further questions or queries, please do not hesitate to contact the researcher, Felicity Roberts.

Yours sincerely,

Felicity Roberts, Trainee Clinical Psychologist

Jointly supervised by:

Dr Dorothy Frizelle,

Consultant Clinical Health Psychologist

Dr Annette Schlosser,

Clinical Child Psychologist

Further information and contact details

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Participant details

If you are interested in taking part in the study, please complete the following details and pass this information to a staff member at your diabetes clinic, or send it onto the service at the address on Page 1. You will be contacted by the researcher to arrange a meeting at a convenient place and time. Participation is voluntary, and in 2-3 weeks a reminder letter will be sent to all participants from whom we have not received a reply, just in case you would still like to take part.

Name:

Address:

Telephone Number:

Preferred contact times:

Signature:

Date:

Please tick this box if you would like to receive written information regarding the findings of the study after its completion.

Appendix F

Consent form

Project Title: Paediatric Diabetes: Children’s experiences of the transition from multiple daily injections to the insulin pump.

Centre Number:

Study Number:

Patient Identification Number for this trial:

Version number: 2 (14.04.15)

CONSENT FORM FOR PARENTS/GUARDIANS ON BEHALF OF THE CHILD

Name of Researcher: *Felicity Roberts*

Please initial all boxes

(child)

1. I confirm that I have read and understand the information sheet dated 08/05/15 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that participation is voluntary and that withdrawal is allowed at any time before data analysis, without giving any reason, and without subsequent medical care or legal rights being affected.
3. I understand that relevant sections of medical notes and data collected during the study, may be looked at by individuals from my child’s service, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the records.
4. I agree to the audio taping of interviews and transcription. I confirm that direct quotes from the interview may be used in future publications and understand that they will be anonymised.
5. I understand that the researcher would have to break confidentiality if they felt there was a risk to the participant or to others.
6. I give permission for the (anonymous) child story book (including picture) to be shared with those involved in the research process (services; the University of Hull; research examiners) and in the final study write-up and future publications.
7. I acknowledge that one guardian is welcome to attend the interview, on the understanding that it is the participant who will be answering the questions.

Name of Participant

Date

Signature

Name of Legal Guardian

Date

Signature

Name of Person Taking Consent

Date

Signature

Consent form date of issue:
Consent form version number:

Page 1 of 1

Appendix G

Demographic Questionnaire

Please complete this form and either pass it back to a member of staff at the clinic (in its envelope), or send it back to the service as detailed on Page 1 of the Information Sheet.

If you are not sure about the answers please write “unsure”. When the form is received at the clinic, the researcher will ask staff to help to complete this form by accessing relevant records for you.

If you do not wish to answer a question, please write “prefer not to answer”.

If the question does not apply, please write “N/A” for not applicable.

1. Name of participant (child)							
2. Participant date of birth	(..../..../....)						
3. Gender of child							
4. Ethnicity of the child <i>(please circle)</i>	White Black Asian Hispanic Other (please specify:						
5. Name of parent(s)/guardian(s)	<table style="width: 100%; border: none;"> <thead> <tr> <th style="text-align: left; border: none;">Name</th> <th style="text-align: left; border: none;">Relationship</th> </tr> </thead> <tbody> <tr> <td style="border: none;">1.....</td> <td style="border: none;">.....</td> </tr> <tr> <td style="border: none;">2.....</td> <td style="border: none;">.....</td> </tr> </tbody> </table>	Name	Relationship	1.....	2.....
Name	Relationship						
1.....						
2.....						

<p>6. Are there any other children in the household?</p>	<p>Number:</p> <p>Age(s):</p>
<p>7. If you are working, please write down your job title.</p>	<p>Person 1.....</p> <p>.....</p> <p>Person 2.....</p> <p>.....</p>
<p><u>Diabetes</u></p> <p>8. How old was the child when Type 1 diabetes was first diagnosed?</p>	
<p>6. When did the child begin having multiple daily injections?</p>	<p>Date.... / /</p>
<p>7. When was the decision made for the child to transition to a pump?</p>	<p>Date.... / /</p>
<p>8. Please provide details on how this decision happened (How did the service advise you? Did you request a transition? Did the service recommend a transition? What sort of things have been done with you?)</p>	

<p>Please provide an approximate date that transition was first discussed</p>	<p>Month.....Year.....</p>
<p>9. What has been the process for preparing the child for pump?</p> <p>(Did you attend pump clinics? Did a member of staff demonstrate the pump? Is/has the child had to trial the pump prior to transition?)</p>	
<p>10. When did the child get their pump? OR when is the child due to get their pump?</p>	<p>Month.....Year.....</p>

Thank you for completing this form.

Print guardian name(s).....

Signature of guardian(s).....

Appendix H

PARTICIPANT REMINDER SHEET

Title of the study: Paediatric Diabetes: Children's experiences of the transition from multiple daily injections to the pump.

This is a generic reminder letter regarding a study you received an information sheet for 2-3 weeks ago. The opportunity to participate in the study is still open if you would like to take part. A further copy of the Information Sheet is below.

PARTICIPANT INFORMATION SHEET

Title of the study: Paediatric Diabetes: Children's experiences of the transition from multiple daily injections to the pump.

Information sheet for guardians. Guardians are asked to please read this information sheet before making any decisions.

We would like to invite you to take part in our research study looking at children's diabetes. We are interested in what it is like for children to move from multiple daily injections to an insulin pump. Before you decide if you would like to help us with our study, we would like to give you some more information so that you know what to expect. You can talk to other people and you can also talk to the researcher before you decide.

What is the purpose of the study?

We know little about what it is like for children with Type 1 diabetes to move between injections and the pump. This study is designed to help services understand what it is like to make this change and what can be done to support children going through it.

Why have I been invited?

This information sheet is given to families of children who are attending services that help them with their diabetes care. The children we are inviting are aged between 6 and 11, have Type 1 diabetes and are moving between injections and a pump. The staff from diabetes services will be giving this sheet to families who might be interested in helping with the study.

Do I have to take part?

No, it is your choice. If you would like to take part, you will be asked to sign a consent form (and each child an assent form). Later on, you might decide that you no longer want to be part of the study. That is okay and you can withdraw up until the point where your answers are analysed. You do not need to give a reason for withdrawing. Your decision does not affect your legal or medical rights.

What will happen if I do decide to take part?

If you agree to take part, please complete the contact details sent to you in the Information Pack 2-3 weeks ago, and leave it with a member of staff (in its envelope), or send it back to your service provider, addressed to:

You will then be contacted by the researcher to arrange a convenient time and place for a talk between the researcher and your child. They will have a chat with the researcher for between 30 minutes and 1 hour. Each child will be allowed to have breaks and you can be in the room too (one guardian is preferred). The researcher, who is training to be a psychologist, will be asking questions about what it is like to have diabetes, and what it is like moving from injections to a pump. This talk will be audio recorded. It is not a test and there are no right or wrong answers. We are only interested in what it is like for each child. Each child will also be asked to draw a picture to tell us what it is like to have diabetes. The researcher will provide the materials they will need for this.

What are the possible risks of taking part?

Participating in the study will require your time which might be inconvenient. Some children might become sad or upset when talking about their diabetes. The researcher and/or guardian will support them. The researcher can also talk to you about further support services to help you. If something that the child say causes the researcher to feel worried about them or their safety, they will inform you and a member of staff.

What are the benefits of taking part?

We cannot promise that children will benefit personally from the study. However, by helping us to understand what it is like to move from injections to a pump, they may help other children with their move. It might also help children to feel better when they talk about their experience. At the end of the study, when the answers have been analysed, the child's book will be sent to your house. This will include some of the things they said in the talk, such as what they like/don't like about their injections or pump. A copy of their picture will be in their book to show that it is theirs.

What will happen if I no longer wish to take part?

You are free to withdraw from the study before the results are analysed and written up.

What if there is a problem?

If you have any worries, you can contact the researcher or their supervisor. We will do our best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through Dr Nick Hutchinson, Director of the Doctorate Programme in Clinical Psychology in the Faculty of Health and Social Care, University of Hull, on 01482 464804 or email n.hutchinson@hull.ac.uk. You may also contact the Patient Advice and Liaison Service: PALS@ulh.nhs.uk.

Will my information be kept confidential and safe?

Yes; all of the personal information provided will be kept confidential. Any information that might identify individuals will not be used in the study. Each child will be given a code to keep their names secret, and after the study is finished, all audio recordings will be destroyed. Each child will also be asked to think of a superhero or a princess name which can be written on their drawing. Children will be asked not to write the full names of people on the picture, but they can write things such as “mummy” and “daddy” if they wish. The only time that something they say might have to be shared is if they tell the researcher something that makes the researcher think that there might be a risk to the child or someone else. This risk might be physical or mental. If the researcher is worried, they will share this worry with you and the appropriate people.

What will happen to the results of the study?

After the study is completed, if you would like to know more about the results generally, these will be shared with you in a written format. You will also have the child’s book posted to you. Children will be invited to give feedback on the study and book, and this is completely voluntary. Some direct quotes and the picture and book (without any personal details) may be used in the write-up and sharing of results.

Who is funding and organising the study?

This research is being undertaken as part of a doctoral research project in Clinical Psychology. The research is funded and overseen by the University of Hull. Some relevant sections of data collected during the study may be examined by responsible individuals from the University of Hull, your diabetes service, or from regulatory authorities to ensure that appropriate procedures were followed by the researcher.

Who has ensured that the study is suitable and as safe as possible?

Prior to starting, the study is reviewed by an independent organisation called a Research Ethics Committee. The Committee protects the interest of people who participate in research. This study has been reviewed by NRES Committee East Midlands - Nottingham 1, and has received a favourable review.

Thank you for considering the study and taking the time to read this information sheet. If you have any further questions or queries, please do not hesitate to contact the researcher, Felicity Roberts.

Yours sincerely,

Felicity Roberts, Trainee Clinical Psychologist

Jointly supervised by:

Dr Dorothy Frizelle,

Consultant Clinical Health Psychologist

Dr Annette Schlosser,

Clinical Child Psychologist

Further information and contact details

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d.frizelle@hull.ac.uk

Annette: +44 (0) 1482 464094
a.schlosser@hull.ac.uk

Participant details

If you are interested in taking part in the study, please complete the following details (including those in your Information Pack) and pass this information to a staff member at your diabetes clinic, or send it onto the service at the address on Page 2.

Name:

Address:

Telephone Number:

Preferred contact times:

Signature:

Date:

Please tick this box if you would like to receive written information regarding the findings of the study after its completion.

Appendix I

Interview Proposal (Version 2: 14.04.15)

- PERCEPTION OF THE TRANSITION

1. Can you tell me about what it is like having diabetes?

Prompts: How does it make you feel?

2. Can you tell me what it is like to move/be moving from your injections to a pump?

Prompts: Do you feel ready? What has helped you? What has not helped you?

3. How do you feel about this change?

Prompts: What is good about it? What is bad about it?

4. How was it decided that you would be moving from injections to a pump?

Prompts: Who was involved in the decision? How do you feel about it?

- ENVIRONMENT

4. Please tell me more about your family

Prompts: Who lives with you? What are they like?

5. Please tell me more about your friends

Prompts: What are they like? What do your friends say about you having diabetes?

6. Please tell me more about where you live

Prompts: What is your home like? What do you like/dislike about it?

7. Please tell me about the doctors and nurses at the clinic

Prompts: Who helps you? How do they help you? Who is the most helpful & why?

8. Tell me what it is like at the clinic/hospital

What do you like about it? What do you dislike about it?

- INDIVIDUAL CHARACTERISTICS

9. Please tell me about your diabetes

Prompts: How does it make you feel? What do you like/dislike about it?

10. How do you feel about your health?

Are there times when you feel poorly? Are there times when you feel better?
What do you think made you feel poorly/better?

11. How do/did you feel about your injections?

What is/was good about them? What is/was bad about them?

12. How do you feel about your pump/a pump?

What is/could be good about it? What is/could be bad about it? What are the things you feel worried/happy about & why?

Appendix J

Project Title: Paediatric Diabetes: Children's experiences of the transition from multiple daily injections to the insulin pump.

Centre Number:

Study Number:

Patient Identification Number for this trial:
(14.04.15)

Version number: 2

ASSENT FORM

Name of Researcher: Felicity (Fliss) Roberts

Please tick the box



1. I am happy to talk to Fliss:

YES



NO



2. I would like someone to be with me whilst I talk to Fliss:

YES



NO



3. I understand the work we will be doing:

YES



NO



4. I understand that I can stop the work if I don't like it:

YES 

NO 

5. I am happy to be recorded on a tape:

YES 

NO 

6. I understand that Fliss would have to talk to other people if she thought I was in danger:

YES 

NO 

7. I understand that the people involved in this work might have to look at my doctor's notes:

YES 

NO 

Child name:.....Child signature:.....

Appendix K

Sources of Support

If you feel that you were affected by the discussion today, and would like any further support or guidance, please contact the following:

- Your advisor at the clinic/hospital who is overseeing your care
- Your general practitioner

Or for further support:

Diabetes UK (www.diabetes.org.uk)

Central Office

Macleod House,

10 Parkway, London NW1 7AA

Tel: 0345 123 2399*

Fax: 020 7424 1001

Email: info@diabetes.org.uk

Diabetes Careline

Call: 0345 123 2399

Monday to Friday (9am-7pm)

Email: careline@diabetes.org.uk

“What is Careline? The Diabetes UK Careline is a dedicated diabetes helpline for all people with diabetes, their friends, family, carers and healthcare professionals. The confidential helpline is staffed by professional counsellors who have extensive knowledge of diabetes. They can provide information about the condition, take the time to talk things through and explore emotional, social, psychological or practical difficulties.”

-www.diabetes.org.uk

Appendix L

Transcript segment

I: Okay, and so what's good about having diabetes?

*I'm a kid
Different from being older
Learning happens
Help from friends*

P: Hm, well then, as you're a kid, you learn things, or when you're older, you know more things, so it's, so like you learn things that other people don't learn, so then you can tell them and...you can have like friends and they can help you with it and all that

Responsibilities are different for adults/children

Privilege to share knowledge?

Expert position implied

I need/would like help with this

I: Yeah, that's a good point, and so do your friends help you with your diabetes?

P: Mm, hm

I: And how do they help you?

*Hypo is significant
Teacher let me to pick friends
I chose the people I liked to be with me*

P: ...Well, um...when I went in Year, when I was in Year 4, and we went to (...) and um, one, um we, coz I was had a hypo before we left to go to (...), and...um, the teacher told me to pick some friends. So I picked some friends but, only one of them stayed and they talked with me...and um, when I-, you know I said I-, they help me...

Only one stayed – I expected more to (disappointed)

I felt helped when they talked to me; talking helps

I: Yeah

*They protect me
They want to see if I'm okay
Bloods are significant for friends too*

P: ...um, what I basically mean is like...they...they like stick up for me and they, when something's, like I test my blood before I go out for break, they come and say, "oh, what's your blood? Are you alright?"

Basically – does it feel more complex?

When something's... 'wrong'? i.e. it could be

They may have left me before, but they are there for me in other ways

They actively seek me out to see if I'm okay

I: Okay, wow. And are there any other ways that they help you as well?

P: Well...not really

I: No, okay. And is there something bad about having diabetes do you think?

Exhales = effort

4 is worse than 1

'At least'

P: (Exhales), well...can be-, I suppose you have to but um, four in-, the *four injections a day and cannula every*, well, when you put your cannula in, it's, that's at least that's you've got a...think you may say delay - I don't know - but a longer time and you don't have to have an injection...

'At least' suggests some kind of reward/it's not all bad

Weighing up here; it could be this, but it's this...

I: Okay

As a kid...

Not everyone is the same

Activity is important – gets interrupted by hypos

P: ...And...well yeah, that's um, and when you're a kid you've, you like to be quite active - or some people anyway - like to be quite active, and um when you have a hypo and you're about to p-, so say you're doing PE, and you're playing a r-, your favourite game in PE, and you have a hypo, you're like, "aw"

Implied roles here – I'm supposed to be

'About to' – it's interrupted the flow; stopped me

'Aw' – as in now I have to face the consequences of this

I: Yeah, and what's it like having a hypo?

P: Bad.

I: Ye-

Home is better though

Immediate benefits

This is preferable

P: It's not too bad at home because you do get to sit down on the sofa and watch telly or play with your tablet and do anything that's relaxing

When this happens elsewhere it's different

Home=saf(er)?

Parents are better able to cope than teachers for example? Or, now my parents will assume responsibility?

I: (Laughs)

Appendix M

Epistemological statement

When I first decided to use a qualitative method of research, it was both exciting and daunting, being as I had not formally conducted a piece of qualitative research before. I learned about IPA via previous trainees and decided that this methodology was the right fit for me. Not only did I like the central concept, that it is the lived experience of the individual which is crucial, I was encouraged by the significance of the researcher in the process. As the authors note, IPA is concerned with three central strands of philosophy: phenomenology, hermeneutics and idiography (Smith, Flowers & Larkin, 2009). Phenomenology centres around the human experience itself, i.e. what it is "*like*" to be human and how we make sense of our experiences (Smith *et al.*, 2009). Hermeneutics refers to the interpretation of an event (Smith *et al.*, 2009) and idiography "*is an argument for a focus on the particular, which also leads to a re-evaluation of the importance of the single case study*" (Smith *et al.*, 2009, p. 32). It is a challenge to engage in a double hermeneutic; i.e. "*trying to make sense of the participant trying to make sense of what is happening to them*" (Smith *et al.*, 2009, p. 3). This is of particular importance for children, who in many cases are spoken for by parents and guardians owing to legalities. I was interested in how children would express their views on their experiences and whether I could sensitively interpret such to communicate the experience "*in its own terms, rather than according to predefined category systems*" (Smith *et al.*, 2009, p.32). IPA also appealed to me as I feel that it is always important to acknowledge why a particular piece of research appeals to an individual. I am aware that when I began researching the topic, I was unsure about how much children would want to talk about their very private and sometimes difficult experiences. Hearing the accounts helped me to realise that sharing was very therapeutic. I have always been a positive person, and as such, was aware of my potential need to seek out positives. I was delighted to learn that there were some very uplifting and humorous accounts. I hope that this study was as therapeutic for the participants as it was for me. Not only did I learn to reflect upon my own motivations and positioning during this piece of work, I feel that I better understand the personal, rather than purely medical, implications of diabetes for young children and their families.

Reflective statement

When my research began two years ago, I was nervous and excited. I am by no means 'statistically-minded' and knew straight away that a qualitative approach was going to be the best option. The big question was what to research. I've always been interested in child psychology, and have been fortunate enough to be accommodated by two paediatric health placements over the duration of the course. On the departmental research day I met with Dr Dorothy Frizelle, excited to hear more about health psychology. This has always been a significant interest of mine. I am a believer in the link between the mind and body, and continue to be touched by the strength and resilience that people with chronic conditions demonstrate. The prospect of child health study piqued my interest. I met with Dr Annette Schlösser to discuss this further and knew that I wanted to make this dream a reality. I was fortunate that both Dorothy and Annette agreed to supervise me. Dorothy suggested a diabetes study, specifically the use of insulin pumps. At this time I had very little knowledge of diabetes, and I was eager to learn more. I was also interested in hearing from younger children. I was told on occasion that it might be difficult to interview younger children, and I became determined to prove otherwise. Paediatric research is generally based upon smaller sample sizes, and I wanted to contribute something to this area. I was interested in how candid children would be, and what might motivate their worlds (i.e. did they have the same views as adults and were they comfortable talking about serious subjects). I grappled with the fact that potentially, diabetes was a sensitive topic. I did not want to unduly upset children. However, I began to realise that not talking about something does not make it any less painful. I conducted further research and narrowed down the age of participants to six to eleven year olds. I knew that parents would likely want to be involved in interviews, and this was both comforting (should the child become distressed) and a little daunting (almost like having an audience). I would later discover that my fears were unfounded.

In order to conduct a specialised study, I widened the recruitment pool as far as I could geographically. I travel long distances regularly and this did not worry me. When I was faced with the reality that I was going to have to gain access to five different NHS trusts, my enthusiasm started to waver. I needed to be extremely organised and patient, and with the help of my academic and field

supervisors, I finally made it. The task was then to distribute information packs to all of the sites and keep track of where I was with each. I did not manage to recruit from two trusts in the south of England which was disappointing. It was not for lack of trying, and the teams worked hard to help me. Recruitment appeared to happen fairly quickly at the beginning of the study, between November 2015 and January 2016. Things then slowed down, and with five participants, I began to wonder if I would recruit anyone further. A few months before the conclusion of the project I was contacted by a family interested in the research. This family was not only very enthusiastic about the research topic, but from a trust I had not managed to recruit from. The interview happened quickly afterwards and I started to feel prepared to the write up.

The process of transcribing was something that I stalled for a long time. This was due to my anxiety about my ability as an interviewer, and because I had been warned by previous trainees about the length of time it required. I sat down to do this within a fairly small time scale and soon found myself immersed in another world. Why had I not started this sooner? I was truly touched by what I heard. Not only was there sadness, there was resilience. I giggled at some moments and almost cried at others. There were times when I wanted to wave a magic wand and make it all go away. Humour was a large part of many of the interviews and the stories were heart-warming. I began to wonder if this wave of emotion was what the families experienced during the interviews. I also wondered if my reluctance to start the transcription process was an avoidance of painful subject matter. I am aware that when I entered this project I thought that it would be overwhelmingly positive given the way pumps are portrayed in the literature.

The next stage was the designing of the personal books for each child. This process was thoroughly enjoyable. Whilst I know that the children are currently too young to read this study, I wanted to give each something that reflected the value of their time and input. I hope that they have as much fun reading their books as I did making them.

When I began the data analysis stage, I made myself mind maps which I stuck to the walls of the study. I remember standing amongst the words; the fears, pain, hope and resilience and feeling emotionally overwhelmed. It was at this point that I truly connected to what I was doing and the importance of delivering

a piece of work which did these families proud. The writing of the project still remains a mystery to me, it feels like time stopped for a while and everything just happened. I soon realised that whilst a quantitative project was daunting, a qualitative project truly did speak to me. It has been a steep learning curve using a qualitative methodology. It fits with my personal preference for research. Whilst I appreciate and remain in awe of quantitative methods, I do believe that there are some topics that do not lend themselves well to mathematics. I enjoy talking with people; I believe that every experience is personal. I believe that this project was valuable, and it is my hope that it will make a difference.