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Whittaker, J A (2012) *The effect of Insulin Pump Therapy on children and adolescents' quality of life: A qualitative study*. D Clin Psy thesis.

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VOLUME I

**THE EFFECT OF INSULIN PUMP THERAPY ON CHILDREN AND
ADOLESCENTS' QUALITY OF LIFE: A QUALITATIVE STUDY AND CLINICAL
RESEARCH PORTFOLIO**

(Volume II bound separately)

Jennifer A. Whittaker

MSC (Distinction)

Submitted in partial fulfilment of the requirements for the degree of Doctorate
in Clinical Psychology (DClinPsy)

Mental Health and Wellbeing
University of Glasgow

July 2012



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Acknowledgements

I would like to give a heartfelt thank you to all the wonderful young people who participated in my research; they gave up their personal time to tell me their story, in order to help better the lives of others in similar situations. For that I thank you.

I would also like to thank my supervisors Sarah Wilson and Liz Hunter for all their advice, support and encouragement throughout the past two years. In addition, thank you to the team at The Royal Hospital for Sick Children, Glasgow, whose support and involvement made this research possible.

On a more personal note, I would like to thank my AMAZING year group and friends, who provided constant support, motivation and kept me on track! I think we have developed our 'coping tool kit' to whole new levels, but my particular favourite has definitely been laughing with friends, whilst drinking red wine, eating good food and listening to power ballads (with dance-moves of course)! I would like to specifically mention Leah, Ally, Fiona, Vanessa and Sinead for being there for me come rain or shine and helping me through the last stages of write-up.

As for my family, well its difficult to know where to start. I honestly could not have got through the past three years without your constant love and encouragement. Your support in everything I have done has made me the person I am today. A further thank you goes to my brother Duncan for being a great proof-reader and my sister Lynne for her amazing layout and table skills despite being in Oz!

Finally, an extra special thank you goes to my fiance Lewis who has put up with me for the past eleven years and hopefully forever more. It is impossible to describe all he has done for me and I look forward to finishing this course with a bang - our wedding!

VOLUME I - TABLE OF CONTENTS	Page Numbers
-------------------------------------	---------------------

CHAPTER ONE: SYSTEMATIC LITERATURE REVIEW	5 - 30
--	--------

The impact of parenting style on young people's adherence to their diabetes self-management treatment regime and glycaemic control: A systematic review

CHAPTER TWO: MAJOR RESEARCH PROJECT	31 - 66
--	---------

The effect of Insulin Pump Therapy on children and adolescents' quality of life: A qualitative study

CHAPTER THREE: ADVANCED CLINICAL PRACTISE I CRITICAL REFLECTIVE ACCOUNT (Abstract Only)	67 - 68
--	---------

Multidisciplinary team working: A reflective account of the roles and limitations of a Clinical Psychologist

CHAPTER FOUR: ADVANCED CLINICAL PRACTISE II CRITICAL REFLECTIVE ACCOUNT (Abstract Only)	69 - 70
--	---------

The wider influences on the role of a Clinical Psychologist: A reflection on my experiences in adult services

APPENDICES

Systematic Review	71 - 76
--------------------------	---------

Appendix 1.1 Author guidelines for publication

Appendix 1.2 Quality criteria assessment tool

Appendix 1.3 Quality rating of studies included in systematic review

Appendix 1.4 Psychometric properties of measures

Major Research Project	77 - 112
-------------------------------	----------

Appendix 2.1 Author publication guidelines

Appendix 2.2 Ethics approval letter

Appendix 2.3 Hospital criteria to determine eligibility for Insulin Pump Therapy

Appendix 2.4 Information pack: information sheets (parent and participants versions), participant and parent consent form.

Appendix 2.5 Interview topic guide

Appendix 2.6 Transcript from interview

Appendix 2.7 Major research project proposal

CHAPTER ONE: SYSTEMATIC REVIEW

The impact of parenting style on young people's adherence to their diabetes self-management treatment regime and glycaemic control: A systematic review

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KEYWORDS: type one diabetes, parenting, adherence, glycaemic control, systematic review

Submitted in part fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy). Written in accordance with the requirements for submission to British Journal of Health Psychology (Appendix 1.1).

Abstract

Introduction: The management of type one diabetes mellitus (T1D) in children and adolescents involves a complex and intensive daily self-management treatment regime (SMTR) in order to achieve optimal glycaemic control and prevent associated long-term complications (World Health Organisation, 2006). Recent research has highlighted the importance of parenting style in promoting young people's adherence to their diabetes SMTR. In particular, an 'authoritative' parenting style is thought to correlate with better glycaemic control and adherence to a SMTR in adolescence, but as yet there are no systematic reviews to encapsulate the findings (Shorer et al., 2011).

Objectives: This review aims to evaluate the current evidence base, which explores the impact of parenting style on young peoples' glycaemic control and/or adherence to their diabetes SMTR and to establish whether a specific parenting style is optimal for improved adherence and glycaemic control.

Method: A systematic search strategy was employed to identify relevant articles, which report the effects of parenting style on young peoples' glycaemic control and/or adherence to their diabetes SMTR. The articles were then screened using a priori inclusion criteria, which resulted in the inclusion of ten studies in this review.

Results: In order to achieve optimal glycaemic control and improved adherence to the SMTR, the findings support the use of an authoritative parenting style when parenting adolescents with T1D. The evidence remains inconclusive in relation to children/pre-adolescents due to the paucity of research in this population.

Conclusion: Further research is required to develop effective parenting education programs which encourage the use of an authoritative parenting style, to help promote self-management adherence behaviours in young people with T1D.

Introduction

Children and adolescents with type one diabetes mellitus (T1D) have a lifelong dependence on insulin in order to circumvent the severe and long-term consequences of hypoglycaemia (World Health Organisation, 2006). The management of this chronic illness is both complex and intensive; it involves a daily self-management treatment regime (SMTR) incorporating meal planning, repeated blood glucose testing, insulin injections and exercise (Seiffge-Krenke, 2001). It can thus represent a substantial challenge for the individual and their family. Consequently, it is vital that the potential impact of the family context on a young person's adherence to their diabetes SMTR is addressed and recognised.

Research indicates that young people benefit from a cohesive family environment in which the parenting style is supportive and emotionally warm (Butler et al., 2007), whilst flexibly adaptive to the needs of the developing child (Beveridge & Berg, 2007). The original parenting research conducted by Baumrind (1966) depicted three different parenting styles which were intended to influence, teach and control a child's behaviour: *authoritarian* (telling their children exactly what to do), *permissive* (allowing their children to do whatever they wish) or *authoritative* (providing rules and guidance without being overbearing). This model was later extended to include *negligent* parents (disregarding their children and focusing on other interests). The literature suggests that authoritative parenting styles are most often associated with the highest achievement levels in young people and positive health outcomes, whereas the authoritarian parenting style is most often associated with poorer academic and health outcomes (Spera, 2005). This generic parenting model has been applied to chronic illnesses such as T1D and suggests that of all the family variables investigated to-date, parenting style is the optimum predictor of diabetes outcome (Davis et al., 2001).

In the past ten years, research investigating parenting styles for young people with T1D has expanded to include both mothers and fathers parenting styles and has utilised a variety of measures. The most recent study by Shorer and colleagues (2011) examined the parental styles for Israeli adolescents who have T1D. The study reported that an authoritative parenting style of fathers was related to better glycaemic control and adherence to their SMTR in the adolescent, whereas a permissive parenting style of mothers was related to worse glycaemic control and lower adherence to their SMTR in adolescents. It appears that

parents who help their child or adolescent with their blood glucose levels but who have an authoritative parenting style (high levels of warmth, sensitivity and expectation for adherence) are likely to facilitate increased blood glucose monitoring and/or to support them to make sensible food choices. In contrast, parents who are involved in their child or adolescent's blood glucose monitoring within the context of an authoritarian parenting style (high levels of expectation for adherence and low levels of sensitivity and warmth) will likely inhibit their child's adherence to blood glucose monitoring or healthy food choices (Anderson, 2011).

Rationale and Objectives

There have been numerous studies published recently which have investigated the effect of parenting style on young peoples' adherence to their SMTR and glycaemic control; yet a systematic review has not been conducted to encapsulate the findings. Hence, this review aims to determine whether parenting style has an effect on young peoples' glycaemic control and/or adherence to their diabetes SMTR and to establish whether a specific parenting style is optimal for improved adherence and glycaemic control levels.

Method

Search Strategy

The following electronic databases were searched: MEDLINE, EMBASE, PsychInfo and CINAHL. Additional searches utilising the Web of Science and Google Scholar were also included, alongside a review of the reference section of the final ten articles. The databases were limited to years 2001-2011, English language and humans. The following search terms and boolean operators were used:

[type one diabetes or type one diabetes mellitus or diabetes]

AND

[adherence or non-adherence or compliance or non-compliance or management]

AND

[parent or parenting]

AND

[child or children or adolescent or paediatric or youth or young people or teen or teenager or teenagers]

The search generated a total of 71 studies; screening titles led to the removal of duplicated and irrelevant studies, leaving 24 potentially relevant papers (see Figure 1). The following inclusion/exclusion criteria were applied to the abstracts from these studies to screen for suitability.

Inclusion Criteria;

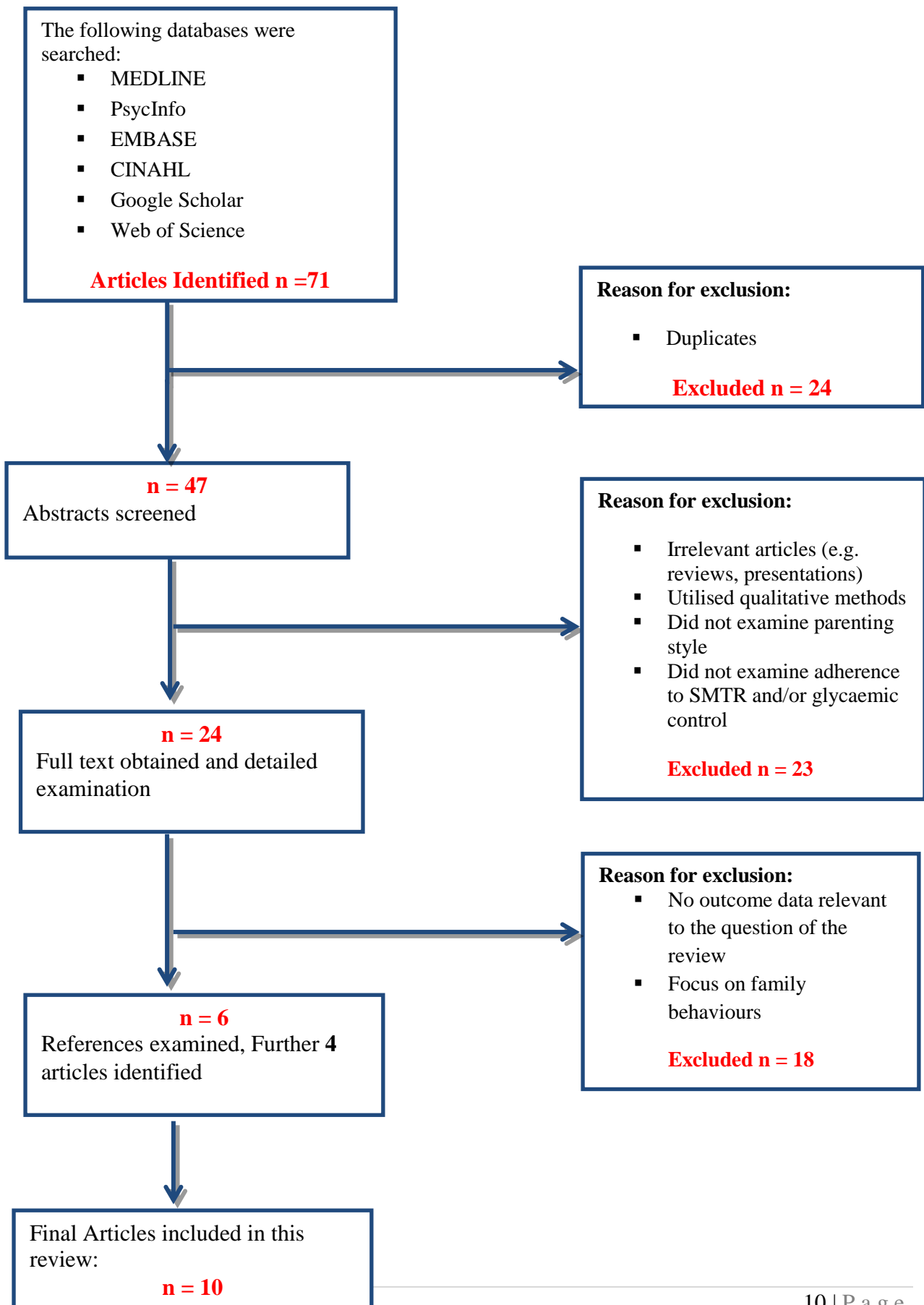
- Published in a peer reviewed journal
- Published in English language
- Participants must include children or adolescents with T1D (up to age 18)
- Parenting style must be identified, measured and reported.
- Young peoples' glycaemic control and/or adherence to SMTR (e.g. diet, exercise) must be measured and reported.

Exclusion Criteria;

- Reviews, dissertations and single case studies.
- Qualitative methods.

Studies which failed to meet these requirements were excluded from the study, resulting in six studies being identified as suitable for inclusion in this review. To ensure the validity of the results, the reference lists from these final six studies were screened, generating a further four studies. Finally, the reference lists of these four studies were also hand-searched but did not yield any further studies which met the above inclusion and exclusion criteria. Ten articles were reviewed in total.

Figure 1: Flow diagram of review selection process



Procedure

The final ten studies were evaluated using a quality assessment tool which was developed by the researcher following consultation of the Scottish Intercollegiate Guideline Network methodology (2011), the CONSORT Statement on the review of Randomized Trials of Non-pharmacological Treatments (Schulz et al., 2010) and Downs and Black's (1998) checklist. The quality assessment tool is detailed in Appendix 1.2. Each study was awarded points in accordance with the following areas: internal validity, introduction, method, assessment, confounding variables, statistical analysis and discussion. A maximum of 36 points could be awarded, with (A) representing a percentage score of 80% or above (*good quality*), (B) representing a percentage score of 55-79% (*acceptable quality*) and (C) representing a percentage score of 0-54% achieving a *poor quality* score.

Each paper was rated independently by an experienced researcher in order to ensure the validity and reliability of the quality assessment tool and discussion took place in order to reach agreement on all items.

Results

Quality rating of studies

An overview of the final ten studies included in the review is presented in Table 1. Table 1 presents the following information: primary aims, participants, adherence/glycaemic control measure, parenting measures, data analyses and main findings. For the sake of brevity, the studies will be referred to by the first author's surname from here on.

Overall, five studies (50%) were rated as 'good' quality (Armstrong, Greene, Duke, Lewin, Davis) and five studies (50%) were rated as 'acceptable quality' (Shorer, Jaser, Sherifali, Faulkner, Butler). See Appendix 1.3 for details.

Table 1: Overview of reviewed studies¹

Study (Country and Quality Rating %)	Primary Aim	Participants	Adherence/Glycaemic Control Measures	Parenting Measures	Data Analysis	Main Findings
Shorer et al., 2011 Israel 55.6%	To determine the parental factors that predict adherence and glycaemic control	100 adolescents (aged 11-18years) with T1D and their parents Diagnosed at least 1 year previously	Adherence to Diabetes Treatment Regimen Questionnaire HbA1c	Parental Authority Questionnaire	Correlation and multiple regression	Authoritative parenting style was associated with better adherence and glycaemic control in adolescents, whereas authoritarian and permissive parenting styles predicted poorer outcomes.
Armstrong et al., 2011 USA 86.1%	To elucidate the relationship of critical parenting behaviours, child depressive symptoms, child self-efficacy for diabetes care and self-care behaviour in preadolescents	84 pre-adolescents (aged 9-11 years) with T1D and their parents 55% on insulin injections 43% on insulin pump or MDI	Self-Care Inventory (Child and Parent Version) A1c	Diabetes Family Behaviour Checklist	Correlation and hierarchical linear regression	Critical parenting behaviours were significantly associated with depressive symptoms and self-efficacy. No relation between self-care behaviours and glycaemic control. No significant correlation between critical parenting behaviour and self-care behaviour.
Greene et al., 2010 USA 88.8%	To explore the relationship among glycaemic control, self-care behaviours and parenting in adolescents with T1Ds.	29 adolescents (aged 10-18 years) with T1D and their parents. Diagnosed with diabetes for at least two years	The Diabetes Self-Care instrument A1c	62-item Parenting Practices report	Correlation and regression analyses	Self-care behaviours did not significantly correlate with A1C values Authoritative parenting was positively correlated with glycaemic control and overall scores on self-care. Of this, authoritative mothering was the strongest predictor of glycaemic control.

¹ The references for adherence and parenting measures can be found in the relevant sections in the review on pages 17 – 18.

Jaser and Grey, 2010 USA 75%	<p>To provide effect sizes of the relationships between specific observed parenting variables with maternal anxiety and depression, and adolescents' depressive symptoms, quality of life and glycaemic control.</p>	<p>30 adolescents (aged 10-16 years) with T1D and their mothers.</p> <p>Diagnosed with diabetes for at least 6 months</p>	<p>The Pediatric Quality of Life Inventory</p> <p>HbA1c</p>	<p>The Iowa Family Interaction Rating Scale</p>	<p>Correlation</p>	<p>Higher levels of observed maternal hostility was related to poorer glycaemic control. Whereas, higher levels of child-centered parenting were related to better glycaemic control.</p> <p>Intrusive parenting was related to adolescents' quality of life and depressive symptoms.</p>
Sherifali et al., 2009 Canada 77.8%	<p>Exploratory approach examining possible relationships among diabetes control, quality of life and parenting styles.</p>	<p>216 children and adolescents (aged 5-12 years) and their parents</p> <p>Diagnosed with diabetes for at least 1 year</p>	<p>The Pediatric Quality of Life Inventory</p> <p>A1c</p>	<p>The Parenting Dimension Inventory</p>	<p>Correlation</p>	<p>Most parents exhibited an authoritative parenting style for nurture, consistency, and control, but also exhibited a permissive parenting style with respect to maturity demands.</p> <p>Parenting style did not correlate with glycaemic control, or the child's report of quality of life.</p>
Duke et al., 2008 USA 83.3%	<p>1. To examine if diabetes-specific measures of family functioning accounted for significant variance in HbA1c.</p> <p>2. To examine if the relationship between critical parenting and HbA1c was mediated by adherence.</p>	<p>120 children and adolescents (aged 8.25 – 18.75 years) and their caregivers</p> <p>Diagnosed with diabetes for at least 6 months</p>	<p>Diabetes Self-Management Profile</p> <p>HbA1c</p>	<p>Diabetes Family Behaviour Scale</p> <p>Diabetes Family Behaviour Checklist</p>	<p>Correlation and hierarchical linear regression</p>	<p>Young people reported that critical parenting significantly predicted HbA1c.</p> <p>Critical parenting was associated significantly with HbA1c and adherence</p>
Faulkner and Chang, 2007 USA	<p>1. Do age, sex, race, parental education, family behaviour and duration of diabetes predict participation in self-care</p>	<p>99 children and adolescents (aged 10-18 years) with T1D.</p>	<p>Self-Care Questionnaire</p>	<p>Diabetes Family Behaviour Scale</p>	<p>Independent t-tests, correlations, and stepwise regression</p>	<p>Families that exhibited more positive emotional support, and communication had children or adolescents who had higher levels of self-care participation, experienced a lower impact of diabetes, had fewer worries</p>

77.8%	activities? 2. Do age, sex, race, parental education, family behaviour and duration of diabetes predict QoL or glycaemic control of glucose levels?	Diagnosed with diabetes for at least 1 year. All insulin treatments included	The Diabetes Quality of Life Instrument HbA1c			about diabetes and experienced greater life satisfaction. The fathers' educational levels was the only significant predictor of HbA1c.
Butler et al., 2007 USA 75%	To examine aspects of adolescent well-being and the associations with adolescent and mothers' perceptions of three dimensions of maternal parenting style.	78 adolescents (aged 11.58 - 17.42) with T1D and their mothers. Diagnosed with diabetes for at least 1 year.	Self-Care Inventory	Child Report of Parent Behaviour Inventory Parent Report of Parent Behaviour Inventory	Correlation and regression analyses	Adolescent reports of psychological control or firm control were unrelated to adherence. Adolescent reports of acceptance were unrelated to adherence.
Lewin et al., 2006 USA 86.1%	To test the relation between a combination of diabetes family functioning constructs and glycaemic control	109 children and adolescents (aged 8 – 18years) with T1D and their parents. Diagnosed with diabetes for at least 1 year.	Diabetes Self-Management Profile HbA1c	Diabetes Family Behaviour scale Diabetes Family Behaviour Checklist	Correlation and hierarchical multiple linear regression	Negative family functioning has a negative impact on children's adherence behaviours and subsequent glycaemic control. Overall, children who reported more negative and critical relationships with their parents were in worse glycaemic control.
Davis et al., 2001 USA 80.6%	Examine the relationship among parenting style, regimen adherence, and glycaemic control.	55 children (aged 4-10years) with T1D and their parent/guardian. About one fourth had been diagnosed with T1D in the past year.	Self-Care Inventory GHb Assay	The Parenting Dimension Inventory	Correlation and hierarchical regression	Parenting style was related to diabetes regimen adherence: more parental warmth was associated with better adherence. Whereas parental restrictiveness was associated with worse glycaemic control.

Demographic Information

Overall, a combined total of 920 children and adolescents participated in the ten studies included in this review. Of these young people, 468 were females (50.9%) and 452 were males (49.1%), equating to an almost equal gender distribution. Five studies focused purely on adolescents (Shorer, Faulkner, Jaser, Butler, Greene), three studies on children (Armstrong, Davis, Sherifali) and two studies examined both children and adolescents (Duke, Lewin). The young peoples' age ranged from 4 years to 18 years old. Ethnicity was reported by eight of the ten studies (Armstrong, Duke, Davis, Faulkner, Lewin, Jaser, Butler, Greene); on average, 77.3% of young people were Caucasian, resulting in the final 22.7% to be from either African-American, Hispanic or other ethnic background.

Five of the ten studies reported the length of time the young people had been living with T1D, which averaged out as 5.6 years (Shorer, Faulkner, Lewin, Jaser, Greene). Three studies only reported a minimum duration; six months (Duke) and one year (Butler, Sherifali), one did not report these statistics (Armstrong) and one study revealed that 27% of their participants' had been diagnosed in the past year, but this was not explored further (Davis).

Two studies (Jaser, Butler) singularly investigated maternal parenting style, with the remaining eight studies measuring both paternal and maternal parenting styles. However, only nine studies directly examined parents (fathers and/or mothers) in their study (Shorer, Armstrong, Duke, Davis, Lewin, Jaser, Sherifali, Butler, Greene), resulting in one study collecting their parental data from the perspective of the child/adolescent (Faulkner). Of the final ten studies, only four reported the average parental age; working out as 42.2 years across the studies (Jaser, Butler, Sherifali, Greene) and six did not report any results regarding the age of parents (Shorer, Duke, Faulkner, Davis, Lewin, Armstrong). In addition, it appeared that parents' education level varied markedly between the studies; one study reported that the majority of their sample had achieved approximately 14 years of education (Faulkner); three studies indicated their parent sample had mostly attained between 14 to 18 years of education (Jaser, Sherifali, Greene); one study stated that the majority of its sample had achieved 18 plus years of education (Butler) and the remaining five studies did not report these statistics (Shorer, Duke, Davis, Lewin, Armstrong).

Family income and socio-economic status was not reported in two studies (Faulkner, Butler) and in the remaining eight studies it was reported in many different formats which could not be grouped together (Shorer, Armstrong, Duke, Davis, Lewin, Jaser, Sherifali, Greene).

Of the ten studies reviewed, six excluded young people with co-morbidities and mental health difficulties (Shorer, Armstrong, Davis, Faulkner, Jaser, Sherifali) and four did not mention this factor (Duke, Lewin, Butler, Greene). Eight studies excluded young people with intellectual disabilities (Shorer, Armstrong, Duke, Davis, Faulkner, Lewin, Jaser, Sherifali) and two made no mention of this variable (Butler, Greene).

Research Design

Nine studies employed a cross-sectional design and employed self-report data collection methods (Shorer, Armstrong, Duke, Davis, Faulkner, Lewin, Jaser, Sherifali, Butler). The tenth study used a retrospective correlational design, whilst also utilising self-report data (Greene). One study used an additional observational method (Jaser) and two studies utilised an additional structured interview (Duke, Lewin). It should be noted that although of cross-sectional nature, one study (Armstrong) made use of participants from the baseline of a larger randomised control trial, which is currently unpublished. Furthermore, readers must be aware that only two of the studies used a power calculation to determine sample size (Sherifali, Faulkner); hence, the results from the eight remaining studies may be unreliable due to lack of power.

Treatment Modality

Only four of the final ten studies reported the type of T1D treatment that participants were receiving (Shorer, Armstrong, Faulkner, Jaser), for example, Insulin Pump Therapy or Multiple Daily Injections. This was a concerning finding, as research indicates that the form of treatment a young person receives can have a substantial difference on both their level of adherence and quality of life (Huang et al., 2007). Hence, we must be cautious in our interpretation of the generalizability of these findings to all young people on various forms of T1D treatment.

Measures Assessing Glycaemic Control

Objective measures of glycaemic control were utilised in nine studies; five used HbA1c (Shorer, Duke, Faulkner, Lewin, Jaser), three used A1c (Armstrong, Sherifali, Greene), one used GHb assay (Davis) and one did not use an objective measure (Butler). Due to the nature of the measures, the values could not be collated.

Measures Assessing Adherence to SMTR

Seven studies utilised one self-report measure of SMTR adherence (Shorer, Armstrong, Davis, Jaser, Butler, Sherifali, Greene), one study used two self-report measures (Faulkner), and the final two studies applied structured interviews (Duke, Lewin). Within the studies, a variety of self-report measures were employed and one structured interview, as revealed in Table 1 and described below. For information regarding the psychometric properties of the described measures, please refer to appendix 1.4.

The Self-Care Inventory (La Greca et al., 1990) was employed by three separate studies (Armstrong, Butler, Davis), due to its excellent validity and reliability scores for this population. It focuses on items such as blood glucose monitoring, insulin and food regulation, exercise and emergency precautions (e.g. carrying sugar to treat reactions). In addition, two studies (Jaser, Sherifali) employed The Pediatric Quality of Life Inventory (Varni et al., 2003), which assesses five main areas: diabetic symptoms, treatment barriers, treatment adherence, worry and communication. Two further self-report measures were utilised; Faulkner employed the Self-Care Questionnaire (Saucier and Clark, 1993) and Greene developed their own measure called The Diabetes Self-Care Instrument. Largely, all the self-report measures referred to in this review reported good internal consistency and validity, with the exception of the Adherence to Diabetes Treatment Regime Questionnaire (Tom-Katzav, 2007) used by Shorer. Little is known about this measure as it appears to be unpublished and no description accompanies it in the study. Hence, caution should be taken when interpreting the results from this study.

The Diabetes Self-Management Profile (Harris et al., 2000) is a structured interview, which assesses five areas of diabetes management, including: insulin administration/dose adjustment, blood glucose monitoring, exercise, diet and management of hypoglycaemia. This measure was used in two studies (Duke, Lewin) and appears to have good internal consistency and inter-observer agreement, lending credence to its use in this population.

Parenting Measures

Nine of the studies utilised self-report measures to determine parenting style and one study adopted an observational measure (Jaser). These self-report measures varied greatly, however three studies (Armstrong, Duke, Lewin), used the ‘negative parenting’ subscale of the Diabetes Family Behaviour Checklist (Schafer et al., 1986). Furthermore, the sub-scales ‘warmth and caring’ and ‘guidance and control’ of the Diabetes Family Behaviour Scale (Waller et al., 1986) was employed in three studies (Duke, Faulkner, Lewin). In addition, Butler adopted the Child/Parent Report of the Parent Behaviour Inventory (Schaefer, 1965a, 1965b) which is a long-standing measure of parenting. These three scales also appear to show good internal consistency and reliability levels. It should be noted, however, that these measures were not developed specifically to map onto Baumrind’s (1966) concept of parenting styles, but do nevertheless measure aspects of parenting styles which relate to these labels (Anderson, 2011).

Four studies (Shorer, Greene, Sherifali, Davis) used three different self-report measures which directly modelled on Baumrind’s typology of parenting style. Shorer and colleagues (2011) used the Parental Authority Questionnaire (Buri, 1991), Greene and colleagues (2010) used the 62-item Parenting Practices Report (Robinson et al., 1995), and Sherifali and colleagues (2009), along with Davis and colleagues (2001) used The Parenting Dimensions Inventory (Power, 1993). All of these measures reported high internal consistency, reliability and validity.

Jaser and Grey (2010) utilised an observational measure; The Iowa Family Interaction Rating Scale (Melby and Conger, 2001). This is a well-established and widely used global coding

system which is applicable across different cultures, ethnicities and paediatric populations, whilst retaining good inter-rater reliability (Alderfer et al., 2008). For further information regarding the psychometric properties of the above measures, please refer to appendix 1.4.

Findings

Each of the ten studies included in this review addressed the influence of parenting style on adherence to young people's SMTR, with nine investigating the influence of parenting style on young peoples' glycaemic control (Shorer, Armstrong, Duke, Davis, Faulkner, Lewin, Jaser, Sherifali, Greene).

Parenting style and glycaemic control

Of the nine studies (Shorer, Armstrong, Duke, Davis, Faulkner, Lewin, Jaser, Sherifali, Greene) which investigated the influence of parenting style on glycaemic control, seven stated that an authoritative parenting style was related to better glycaemic control (Shorer, Duke, Davis, Faulkner, Lewin, Jaser, Greene). They also reported that authoritarian and/or permissive parenting styles were related to poorer glycaemic control. Conversely, two studies (Armstrong, Sherifali) found that parenting style had no impact on glycaemic control within their population. It is of interest that both of the studies which did not report a correlation between parenting style and glycaemic control were within child populations. In addition, no difference was found between paternal and maternal parenting styles and glycaemic control.

Parenting Style and Adherence

All of the ten studies investigated the influence of parenting style on adherence to the SMTR. Of these, seven studies found that an authoritative parenting style improved adherence behaviours, whereas an authoritarian or permissive style decreased adherence behaviours (Shorer, Duke, Davis, Faulkner, Lewin, Jaser, Greene). This finding stood for both paternal and maternal parenting. It should be noted, however, that Lewin and colleagues (2006) only

found this association in older children. Three studies found that parenting styles had no impact on adherence behaviours (Armstrong, Sherifali, Butler).

Discussion

This is the first systematic review to examine the relationship between parental style and adherence and glycaemic control in young people with T1D. Ten studies have been reviewed and the findings will now be discussed in relation to the objectives of this review.

Parenting Adolescents with T1Ds

Overall, the evidence appears to support the use of an authoritative parenting style when parenting adolescents with T1D (Shorer, Duke, Davis, Faulkner, Lewin, Jaser, Greene). This form of parenting seems to result in superior glycaemic control and improved adherence to their SMTR. One hypothesis is that parents who employ an authoritative parenting style engage in certain behaviours, such as providing rewards, giving regular positive feedback and planning self-care activities with the adolescent; these parenting behaviours are thought to promote increased glycaemic control and improved adherence behaviours. This form of parenting appears to work particularly well with adolescents who are beginning to take responsibility for their own diabetes management, but still need a degree of support (Palmer et al., 2009). This is in contrast to parents who are perceived as critical and authoritarian, these parenting behaviours appear to lead to a decrease in adherence behaviours and poorer glycaemic control. One explanation for this influence is harmonious with Patterson's coercion model (Patterson, 1982). This suggests that if parents are perceived as critical then young people may resist parental control by engaging in non-adherent behaviour, which has a subsequent impact on glycaemic control (Borus and Laffel, 2010). This results in families feeling trapped in a power struggle, which subsequently influences family functioning and diabetes-related behaviours.

Parenting Children with T1Ds

Despite the clear evidence supporting the link between parenting style and adolescents' glycaemic control and adherence behaviours, the evidence remains inconclusive in relation to younger children/pre-adolescents. The dominant explanation for the lack of relationship between parenting style and glycaemic control/adherence behaviours, is that for younger, pre-adolescent children, parents are still responsible for the majority of diabetes-related tasks and so children are not expected to take on the self-management of their treatment regime (Patton et al., 2011). Hence, critical parenting has less of a direct impact on the child's diabetes. However, there is some evidence to support the relationship between an authoritative warm parenting style and improved adherence behaviours in children as young as four years old (Davis). Despite this, the evidence for younger children remains inconclusive due to the paucity of research in this population.

Methodological limitations and Future research

The studies in this review all received overall ratings of moderate to high quality but this does not mean they did not have methodological shortcomings. Firstly, all the studies were of a correlational design and so directional causation was only hypothesised, not determined. For example, the reviewed studies lead the reader to believe that authoritative parenting leads to better T1D self-management and glycaemic control. Whereas it could be the converse that is true; better glycaemic control and optimal adherence behaviours may be associated with higher levels of compliance in the adolescent, which in turn could make it easier for parents to employ an authoritative parenting style. Furthermore, the parent-child attachment style was not investigated in any of the included studies. Hence, it would be of interest for future research to examine attachment style to investigate whether authoritative parenting is a reflection of an attuned attachment relationship.

The generalizability of the studies was questionable as all but one of the studies (Shorer) were carried out in Western Societies, limiting their relevance to other cultures and ethnicities. Furthermore, the majority of studies indicated that their small sample size was of concern as this unveiled the possibility that they did not have the power to support their findings, especially given that only two of the studies conducted a power analysis. The

information gained here provides a starting point for a larger multi-site study with a more diverse sample of ethnic and socioeconomic statuses.

The type of T1D treatment participants were receiving was not controlled for, or even reported in most studies. This was despite the evidence which indicates that certain treatment regimes are easier to adhere to and achieve greater glycaemic control than others (Huang et al., 2007). To accurately reflect the relationship between glycaemic control, adherence behaviours and parenting style, future studies should control for the type of T1D treatment. In particular, future research should consider investigating the parenting styles of families with children/adolescents on a low number of injections and comparing this to those families with children/adolescents on multiple daily injections.

Additionally, it should be noted that no restrictions were applied to the included studies regarding the length of time since diagnosis of T1D. This is an important caveat to consider as we cannot ascertain if the results may have been influenced by the ‘honeymoon phase’ phenomenon, which states that patients may experience a period of time in which they are in partial remission and have good glycaemic control shortly after diagnosis (Abdul-Rasoul et al, 2006). Hence, future studies need to control for the time since diagnosis in order to reduce confounding factors.

The studies reviewed included young people ranging in age from four years old to eighteen years old. Hence, this review tried to collate the results of all the young people, whilst taking into consideration the studies which only examined children or adolescents. Consequently, this review spanned two developmental periods which authors have suggested are separate and distinct from one another and as such should not be classified together (Ross et al., 2011). Hence, future reviews should take this into consideration and should consider comparing young people by developmental stage.

The majority of studies utilised self-report measures, which are inherently associated with biases, primarily due to socially desirable responding. Consequently, future studies should look to include a range of measures including an observational measure and measures with multiple informants, specifically investigating both maternal and paternal parental styles in order to increase the reliability of the results.

The three studies which did not find a relationship between parenting style and adherence and/or glycaemic control, indicated that this may be due to most of their sample rating themselves as authoritative and so it is possible that the lack of extremes in parenting may have influenced their lack of findings (Armstrong, Sherifali, Butler). Once again, this suggests a socially desirable bias in respondents, and/or a homogenous sample, which may not be representative of the population as a whole.

Clinical implications

The generic parenting literature supports an authoritative parenting style in order for children to develop appropriate autonomy and mastery over tasks (Spera, 2005). This review further examines the importance of applying this parenting style to chronic illnesses such as T1D in order to achieve optimal health. The findings demonstrate the importance of helping parents to be involved with their children's diabetes care in a non-critical way, to increase adherence to their SMTR and improve glycaemic control. It seems it is the quality of these interactions and support that is of vital importance to young people with T1D. Hence, the evidence suggest that it may be beneficial to devise a brief preventative approach aimed at providing parents with information on how to stay involved using authoritative, supportive parenting and reduced critical parenting behaviours. These prevention programs must be introduced at an early age in order to minimise difficulties in adolescence and could be included as part of the current structured education program which is delivered to all children and adolescents with T1D alongside their parents, as recommended by the Scottish Intercollegiate Guidelines Network (2010) and National Institute for Clinical Excellence (2004) guidelines.

Currently the research is unclear regarding which theoretical approach to apply. Some studies have recommended utilising a Behavioural Family Systems Therapy (Wysocki et al., 2007) approach with a focus on specific diabetes family functioning such as communication and overcoming conflict (Butler, Lewin, Duke). Evidence is limited, however, indicating the need for prospective, randomised controlled trials to test these interventions. Furthermore, the introduction of targeted individual strategies for improving shared responsibilities in daily routines for insulin administration, diet and exercise would be beneficial, especially when

children are maturing and reaching adolescence. However, it would be beneficial to consult patients and their parents to investigate which approaches are most acceptable.

Conclusions

Overall, the findings from this review highlight the importance of parental style. The use of an authoritative parenting style when parenting adolescents' with T1D is vital, in order to encourage adherence to their diabetes SMTR and to achieve optimal glycaemic control. The evidence in regards to children/pre-adolescents is inconclusive, but it would seem prudent to assess parenting practices and if required, teach parents how to use authoritative parenting as a part of their repertoire. Further research is required to develop effective parenting education programs, which focus on promoting self-management adherence behaviours with young people.

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CHAPTER TWO: MAJOR RESEARCH PROJECT

The effect of Insulin Pump Therapy on children and adolescents' quality of life: a qualitative study

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KEYWORDS: type one diabetes, insulin pump therapy, children, adolescents, quality of life

Submitted in part fulfilment of the requirements for the degree of Doctorate in Clinical Psychology (D.Clin.Psy). Written in accordance with the requirements for submission to British Journal of Health Psychology (Appendix 1.1).

Lay Summary

Type 1 diabetes (T1D) is a long-term condition which requires daily treatment with insulin in order to prevent severe health problems and even death. In the past, T1D was treated with insulin injections; however, recent advances in technology have resulted in insulin being able to be given via a pump. Some research shows that the insulin pump has many benefits such as improving people's quality of life (QoL) and their control over their condition, however, other research does not find this. The aim of this study was to explore the impact of Insulin Pump Therapy on the QoL of young people. Interviews were carried out with eight young people (aged 8-13) with T1D, at the Royal Hospital for Sick Children, NHS Greater Glasgow & Clyde. The interviews were recorded and typed out word for word. They were then read over a number of times and themes searched for. Six themes were found: 'Physical Impact', 'Mood and Behaviour', 'Lifestyle Flexibility', 'Practicalities', 'Peer Reactions', and 'Support'. Together, these themes showed that most of the participants found that switching to Insulin Pump Therapy resulted in improvements to their QoL and so they were happy to be using the pump. A number of recommendations have been made and areas for future research have been outlined.

Abstract

Introduction: Insulin Pump Therapy has gained worldwide acceptance for the treatment of Type 1 diabetes mellitus (T1D), offering a new method of insulin delivery, which circumvents the need for Multiple Daily Injections (MDI). It is thought to improve quality of life (QoL) by facilitating an increase in lifestyle flexibility, independence and glycaemic control (Scottish Intercollegiate Guidelines Network, 2010; National Institute for Clinical Excellence, 2008). These benefits have resulted in the National Health Service (NHS) Scotland pledging funding of at least £1million to deliver insulin pumps to under 18s (Scottish Government, 2012). Currently, investigations regarding the impact of Insulin Pump Therapy on QoL have resulted in conflicting findings (Barnard et al., 2007). This study aims to explore the impact of Insulin Pump Therapy on the QoL of children and adolescents, using Interpretative Phenomenological Analysis.

Method: Eight participants with T1D, aged between 8 and 13 years and using an insulin pump, were recruited from the Glasgow Royal Hospital for Sick Children Diabetes Clinic. Each participant completed an in-depth interview, which explored their beliefs and attitudes towards Insulin Pump Therapy including its impact on their QoL.

Results: Analysis of the transcripts led to the identification of six super-ordinate themes: ‘Physical Impact’, ‘Mood and Behaviour’, ‘Lifestyle Flexibility’, ‘Practicalities’, ‘Peer Reactions’, and ‘Support’. It is suggested that these six factors are not mutually exclusive and together inform the complexity of individuals’ experiences and the impact that the insulin pump has had on many aspects of their lives. These findings suggest a framework to help clinicians understand how young people with T1D perceive and conceptualise their treatment regimes.

Conclusions: There was general agreement amongst participants that switching to Insulin Pump Therapy resulted in improvements to their QoL. Additional concerns were outlined but reportedly none of the participants regretted switching to an insulin pump.

Introduction

Background

Insulin Pump Therapy, also known as Continuous Subcutaneous Insulin Infusion (CSII), has gained worldwide acceptance in the treatment of Type 1 diabetes mellitus (T1D). It offers a new method of insulin delivery, which omits the need for Multiple Daily Injections (MDI). Current national recommendations advise the use of Insulin Pump Therapy for those with very low insulin requirements (such as infants and very young children) and for all patients who experience recurring episodes of severe hypoglycaemia (Scottish Intercollegiate Guidelines Network, SIGN, 2010). It has also been endorsed by the National Institute for Clinical Excellence (NICE, 2008), who report that it has the potential to improve quality of life (QoL) by increasing lifestyle flexibility and offering greater independence, as well as improving patients' glycaemic control. Given the rising incidence of T1D in Scottish children over the last 30 years and the apparent QoL benefits the insulin pump can offer, the Scottish Government has pledged funding totalling one million pounds to help provide Insulin Pump Therapy to under 18s with T1D (NHS Scotland, 2009; SIGN, 2010; Scottish Government, 2012).

Insulin Pump Therapy

Conflicting findings have been identified in relation to the impact of Insulin Pump Therapy on patients' QoL with regard to adult and child/adolescent populations. The authors of a recent systematic review tentatively suggested that these conflicting findings were the result of variations in study quality and the QoL assessments used (Barnard et al., 2007).

It is only in recent years that qualitative approaches have been utilised to explore the impact of Insulin Pump Therapy on QoL (Barnard and Skinner, 2007). Qualitative approaches address certain methodological flaws, such as reduced measure sensitivity, as demonstrated in the Diabetes QoL questionnaire (Jacobsen et al., 1988), yet they are underrepresented and to date, have not focused exclusively on young people (Barnard and Skinner, 2007). The accumulating qualitative evidence appears to indicate that changing from MDI to Insulin Pump Therapy in adulthood can present challenges in the short-term but over an extended period, it is associated with a significant improvement in QoL for the users (Todres et al., 2010).

Children and adolescents

Late childhood to early adolescence is known to be a complex transitional period in which a variety of physiological and psychosocial changes are occurring; this can result in a decrease in the body's sensitivity to insulin (Silverstein et al., 2005). Concurrently, developmental needs such as the desire for social acceptability, independence and identity formation can interfere with diabetes treatment adherence (Hamilton and Daneman, 2002). These adolescent changes are of vital importance and merit exploration. Hence, this study focuses on young people in the developmental period that occurs between ages 8-13 years old.

Quality of Life

Quality of life is a multifaceted dynamic concept and as such, there is currently no uniform definition. Many authors have tried to conceptualise QoL and after much discussion within the research team, for the purpose of this study, we look to Joyce (1994) who stated that QoL is "what the patient says it is". This view emphasises the subjective nature of this psychological outcome and tries to capture what is important to the individual, as opposed to what others think is important. Further, it was felt that the broadness of this definition was helpful when working with children and adolescents, unlike many other specific terms such as that defined by the World Health Organisation (1997), which target an adult population with differing needs and desires to obtain a good QoL. In addition, this person-centred definition reflects the form of analysis employed; Interpretative Phenomenological Analysis (IPA) as it puts the individual at the centre of the question and allows them to define what make for a good QoL.

Aim

This study will use IPA to explore young peoples' perspectives regarding the impact that Insulin Pump Therapy has on their QoL. It is hoped that this study will address some of the gaps within the current research and provide a framework for future investigation and analysis.

Method

Ethics

Prior to the study commencing, ethical approval was granted by the West of Scotland Research Ethics Committee (Appendix 2.2) and the Clinical Governance body within NHS Ayrshire and Arran. Data was handled in accordance with the Data Protection Act (1998), the Freedom of Information (Scotland) Act (2002) and the NHS Confidentiality Code of Practice Guidelines (2003). Practice was informed by the British Psychological Society Code of Ethics & Conduct (2009).

Design

This study utilised a retrospective qualitative design with in-depth interviews. Concerns regarding the reliability of retrospective memory were noted, with particular emphasis on recall bias (Moss & Goldstein, 1979). Accumulating evidence, however, suggests that retrospective reporting is typically factually accurate, especially when an individual is recalling a salient experience such as changing treatment regime (e.g. Blane, 1996; Norris et al., 1992).

Recruitment and Participants

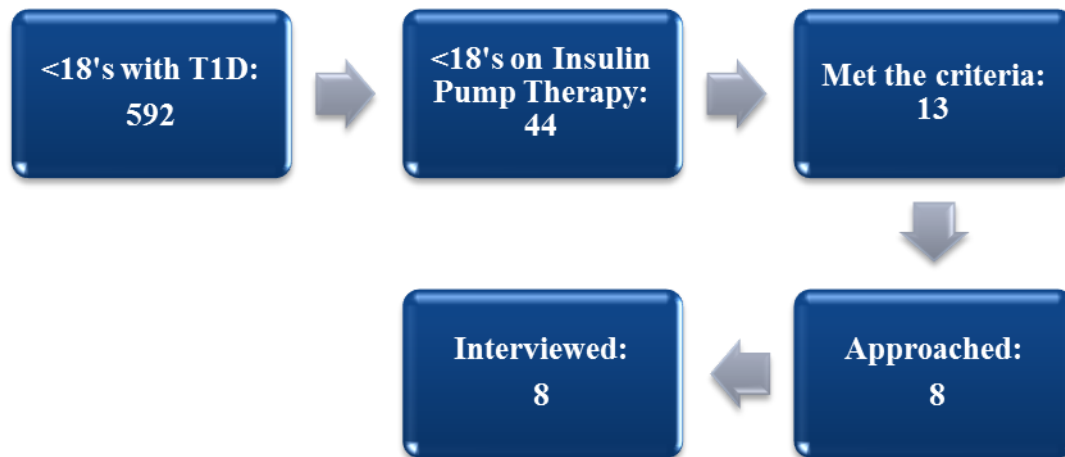
Purposive sampling was used to recruit young people from a regional children's hospital between October 2011 and February 2012. The Clinical Nurse Specialist identified patients who fully met the inclusion criteria and none of the exclusion criteria (see Table 1). For information on the hospital criteria to determine eligibility for Insulin Pump Therapy please see Appendix 2.3.

Table 1: Inclusion and Exclusion Criteria

Inclusion	Exclusion
<ul style="list-style-type: none">• Diagnosis of T1D as specified by their Consultant and in line with the WHO (2006) criteria• Between the age of 8 and 15• Duration on Insulin Pump Therapy: between 6 months to 3 years.• Prior to starting Insulin Pump Therapy must have been on MDI for a minimum of 6 months• Attend the diabetes clinic at a regional children's hospital.	<ul style="list-style-type: none">• Non-English speaker• Presence of a learning disability• Any additional medical illness (mental or physical)

The Clinical Nurse Specialist contacted the first eight participants on the clinic list (and their parent/guardian) via telephone, inviting them to participate in the research study. All eight participants gave permission for their contact details to be passed on to the principal researcher. An information sheet was sent to participants and their parents/guardians and an appointment was subsequently arranged at a mutually agreeable time. A flow diagram outlining recruitment is detailed in Figure 1. Prior to the interview, all participants and their parent/guardian were asked to provide written informed consent and had the opportunity to ask further questions. The information sheets and consent forms can be viewed in Appendix 2.4.

Figure 1: Flow diagram for participant recruitment



The final sample of eight participants achieved data saturation. This is in line with Guest and colleagues (2006) who report that a minimum of six to a maximum of twelve interviews are required to facilitate data saturation and allow the researcher to explore participants' narratives in depth and gain a greater understanding of their experiences. Furthermore, as recommended by Smith and Osborn (2003), the participants in this study represented a reasonably homogenous, purposive sample. Hence, six females and two males were interviewed, all White Scottish, aged between 8 - 13 years old. It should be noted that there was a wide-range of deprivation scores, indicating a range of socioeconomic statuses amongst participants. Participant characteristics can be found in Table 2. In order to protect their anonymity, participants will be referred to by numbers.

Table 2: Participant Characteristics

Participant	Age at Interview (year & month)	Gender	Scottish Index of Multiple Deprivation Decile (2009/10)²	Age at T1D diagnosis (years)	MDI Experience (years)	Insulin Pump Experience (years)
1	11.1	Female	3	5	3.5	2.5
2	13	Male	9	7	5	1
3	8.8	Female	7	4	3	1.5
4	8.1	Female	5	5	1.5	1.5
5	12.2	Male	7	6	4	2
6	13.4	Female	8	9	1	3
7	13.7	Female	8	7	5	1.5
8	8.6	Female	1	2.5	4.5	2

Interview Procedure

Individual, semi-structured interviews were conducted with young people, utilising open-ended and non-directive questioning. This was to encourage participants to reflect on their thoughts, feelings and experiences regarding the impact Insulin Pump Therapy has had on their lives compared to their previous treatment (MDI). Areas to be explored were identified within the interview schedule. This schedule was developed through discussion with the research team using the Common Sense Model of Self-regulation of Health and Illness as a theoretical framework to support participants' reflective engagement (Leventhal et al., 1984) (see Appendix 2.5). This model was used in order to provide a structure and fluidity to the interview, which the QoL literature was unable to achieve. This schedule was not prescriptive in its nature, its main purpose was to guide the interviewer and provide prompts, without explicitly controlling the direction of the interview. The topic guide was piloted with a subset of the sample (n=3) to assess the appropriateness of the topic areas.

² The Scottish Index of Multiple Deprivation (SIMD) provides a relative ranking of the deprivation data zones in Scotland, based on a weighted combination of data in the domains of Current Income, Housing, Health, Education, Skills and Training, Employment and Geographic Access and Crime (no Crime data available for SIMD 2004). An overall relative ranking score can be assigned; decile 1 is the most deprived 10% of Data Zones and decile 10 is the least deprived 10% of Data Zones.

Following analysis of the pilot interview transcripts, revision of the topic guide was not deemed necessary and the three pilot participants were included in the main study sample. Interviews were conducted in a private room within the hospital grounds. The interviews lasted between 30 and 50 minutes, were audio recorded, transcribed verbatim and anonymised for reference to person or place. The recordings were stored on an encrypted laptop and when transcription was completed and checked, each recording was destroyed.

Data Analysis

Interpretative Phenomenological Analysis was employed to analyse these data. The six phase process as described by Smith and colleagues (pp. 82-103, 2009) was followed (summarised in Table 3). This enabled the researcher to gain an ‘insider’s perspective’ of the participants’ individual experiences, whilst taking into consideration the principal researcher’s own thoughts and feelings (Smith and Osborn, 2003). A sample transcript and initial coding can be seen in Appendix 2.6.

Table 3: Six-stage analytical procedure

Stage	Description
1	<i>Reading and re-reading</i> Each transcript was reviewed a number of times in order to gain a contextual and holistic understanding of the entire narrative.
2	<i>Initial coding</i> Each interview was explored and examined for semantic content and language.
3	<i>Developing emergent themes</i> Exploratory comments and coding were analysed to identify emerging themes.
4	<i>Searching for connections across emergent themes</i> Charting or mapping how the themes fit together.
5	<i>Moving to the next case</i> Repeating steps 1-4 for the rest of the transcripts.
6	<i>Looking for patterns across cases</i> Identifying the most illuminating themes and how they inter-connect across participants’ transcripts.

Reflexivity

A vital aspect of IPA is the researcher's awareness of their own experiences, bias, attitudes and beliefs, and recognising how this may influence their data interpretation (Reid et al, 2005). This is referred to as reflexivity and it is important to acknowledge these influences within this study. The principal researcher is a 27-year-old female who does not have T1D, nor does she have any close family members or friends with T1D. She has, however, worked within a medical paediatric setting and worked individually with young people who have T1D. Consequently, she had some prior knowledge and insight into some of the challenges and barriers that this client group face. In recognition of the potential for bias in interpretation, a random sample of three transcripts were independently analysed by a second researcher; a Psychologist, aged over fifty, experienced in the use of IPA, who had no prior interaction with the members of this patient group, either professionally or personally. A high level of agreement between analysts was found for the themes identified, which supports the reliability and validity of this research.

Results

Of the eight potential participants approached, all agreed to take part and there were no concerns regarding retrospective memory, suggesting that the topic under investigation is particularly salient for them all. Throughout the interviews, the participants did not appear distressed by the content; in fact, many of them commented that they had enjoyed the experience. It seemed that partaking in this research study activated a process of reflection for most participants, where they seemed to be developing their own personal story about their experiences. This led to the emergence of a number of themes, many of which were recounted by multiple participants.

Six super-ordinate themes were identified which aligned themselves alongside participant experiences with both the pre- multiple daily injections (MDI) and their current insulin pump treatment regime. The themes are identified in Table 4.

Table 4: Table of emergent themes

Super-ordinate Themes	MDI Themes and Sub-themes	Insulin Pump Themes and Sub-themes
1. Physical Impact	Negative physical impact: <ul style="list-style-type: none"> i. Pain ii. Visible scarring iii. Distressing iv. Poor glycaemic control 	Reduced physical impact: <ul style="list-style-type: none"> i. Less Pain ii. Hidden scarring iii. Cannula iv. Improved glycaemic control
2. Mood and Behaviour	Negative impact: <ul style="list-style-type: none"> i. High frequency of injections ii. Uncontrolled blood glucose levels iii. Negative feelings towards injections 	Positive impact: <ul style="list-style-type: none"> i. Less frequent injections ii. Controlled blood glucose levels iii. No need for injections
3. Lifestyle Flexibility	Negative impact on: <ul style="list-style-type: none"> i. Eating ii. Exercise iii. Social life iv. Sleep v. Routine 	Positive impact on: <ul style="list-style-type: none"> i. Eating ii. Exercise iii. Social life iv. Sleep v. Routine
4. Practicalities	<ul style="list-style-type: none"> i. Convenience ii. Practical problems 	<ul style="list-style-type: none"> i. Convenience ii. Practical problems iii. Visibility
5. Peer Reactions	N/A	<ul style="list-style-type: none"> i. Positive reactions ii. Negative reactions
6. Parental Support	Parental burden	Parental support

SUPER-ORDINATE THEME 1: ‘PHYSICAL IMPACT’

The majority of participants’ identified the physical impact of their treatment regime as having a significant impact on their QoL. This gave rise to two sub-themes: (i) the negative physical impact from MDI and (ii) the reduced physical impact from Insulin Pump Therapy.

MDI - Negative physical impact

i. Pain

It appeared that the MDI's were aversive due to four reasons. Firstly, participants reported that the injections caused a lot of pain:

"I don't know, maybe just cause I was getting so much of it at a time I was just getting really sore".

[Participant 7, P2: L52]

Although some participants remarked that they got used to the pain:

"Well, when you get diabetes you have to get injections first, but then it's quite sore at first but when you get used to all the finger pricks and all the injections that you get, it's not as sore".

[Participant 4, P1: L8]

ii. Visible scarring

Secondly, participants described in detail the visible affect it had on their bodies:

"You had bruises all over and I didn't really like seeing blood all over it".

[Participant 4, P15: L312]

"I got big red marks and they were itchy and sore and having loads of them on your legs was just a pain".

[Participant 6, P9: L156]

iii. Distressing

Thirdly, a few participants also commented that they found the thought of injecting themselves on multiple occasions throughout the day distressing:

"Yeah, it's just like the thought of like a needle going into me. I've never liked needles".

[Participant 1, P2: L42]

iv. Poor glycaemic control

Fourthly, participants stated that they struggled to gain control over their blood glucose levels and experienced many more hypoglycaemic and hyperglycaemic events:

“It was high and then it went to low. It was only, em, and when I had that at school I had loads of hypo’s”.

[Participant 4, P3: L60]

Insulin Pump Therapy – Reduced physical impact

i and ii. Less pain and Hidden scarring

As described above, all participants remarked on the negative affect of MDI on their bodies and frequently compared this with the lesser impact from their insulin pump. This perceived physical improvement appears to mirror the previous MDI factors of pain and the visibility of the scarring:

“Yeah, my legs are fine and you just need to put your cannula in, you just need to give alternative, I put my cannula in my stomach so I just need to move about and it’s definitely not as sore cause I mean in three days when I was on injections I was doing all my injections on my stomach. I was doing fifteen, all of them tiny, tiny holes, but fifteen in me. Now I’ve only got one compared to fifteen. So, my stomach can, it’s much better”.

[Participant 2, P7: L120]

iii. Cannula

It should not be overlooked, however, that the insulin pump can also cause physical difficulties. Primarily it seems due to cannula insertion and the positioning of the pump:

“Em, well when you’re on injections it makes your legs all lumpy and bruised, and it does the same to your stomach when you are on cannula changes”.

[Participant 1, P2: L24]

“Well, it nips me.... Like a dog. Well not my dog cause it doesn’t nip, but like a Jack Russell cause every time you move it, it nips you and there’s a big mark on your hip... It’s sore”.

[Participant 4, P13: L270]

iv. Improved glycaemic control

Furthermore, participants revealed the insulin pump had improved their glycaemic control to a more manageable level, although it was still not perfect:

“And the pump, I can live a, two days or more of maybe having perfect blood sugars and then the odd high maybe and then come back down...But it’s, I don’t get as many highs on the pump”.

[Participant 2, P3: L64]

SUPER-ORDINATE THEME 2: ‘MOOD AND BEHAVIOUR’

A common theme which arose was the impact that treatment regime can have on participants mood and subsequent behaviour. All of the participants divulged that they struggled to maintain a positive mood whilst on MDI, primarily due to three reasons: (i) frequency of injections, (ii) uncontrolled blood glucose levels and (iii) not wanting an injection. It appears that when these factors were removed via Insulin Pump Therapy, participants observed an improvement in their mood and behaviour.

i. High vs. Low Frequency of Injections

The frequency of the injections was often cited as a major influencing factor on participants mood. Within this theme, participants reflected that it was the quantity of injections when using MDI which had the most significant impact on their mood. Conversely, it was the removal of this factor on the Insulin Pump Therapy which improved their mood:

“Yeah, yeah. I probably felt more angry when I was on injections cause it was harder then cause we had to do loads of injections instead of just once every two days. And so I was probably angrier then but now it’s more relaxed I think having the pump”.

[Participant 3, P14: L316]

ii. Uncontrolled vs. Controlled blood glucose levels

Secondly when their blood glucose levels were uncontrolled on MDI, participants commented that their mood was more negative. In contrast, on the insulin pump, their blood glucose levels were more controlled which resulted in their mood improving:

“When I’ve been on injections and that I used to get really moody if my blood sugars were high and get in a mood or really angry, and I’ve only had that once since I’ve been on the pump and I used to have that once a month when I was on the injections, and now it’s been only once since I’ve been on the pump.... I’ve just never”.

[Participant 2, P4: L74]

iii. Feelings towards injections

Thirdly, participants reported that they simply did not want to have an injection and described behaviours such as hiding and pushing their parents away:

“I’d run and hide in the bathroom and lock the door. Like there was one time when I stayed in there for like half an hour, an hour”.

[Participant 1, P3: L70]

“Well, I was kinda pushing them away cause I didn’t really want... Well I wasn’t like pushing them, I was just like, I didn’t, didn’t want the injections”.

[Participant 4, P6: L116]

Whereas participants reported that their behaviour and mood on the insulin pump had significantly improved:

“Em, just really, you know, happy, cause it’s more, it allows you to do more things that you couldn’t do”.

[Participant 5, P12: L338]

It should also be noted that two of the participants described concurrently struggling with feelings of frustration with both the MDI and Insulin Pump Therapy:

“Yeah it does, but there have been times that I’ve wanted to go back to injections because it does get annoying having to keep having it on, and there have been times that I’ve just ended up really angry at it because it is really good in general but I’ve, like the fact when I do then do an injection and it doesn’t hurt, and I don’t really, I forget why I went onto it. I’m just like I want to go back, just for a week, but then I think no because it would be fine but no, not if it was in school. I’d hate that. It would just take up too much time and I don’t like school or anyone getting too involved. I don’t like people getting too involved, it just annoys me”.

[Participant 6, P11: L204]

SUPER-ORDINATE THEME 3: ‘LIFESTYLE FLEXIBILITY’

Participants described a number of factors vital to helping them live a more flexible lifestyle and fundamentally cope better with their diabetes. These included the impact on: (i) Eating, (ii) Exercise, (iii) Social life, (iv) Sleep and (v) Routine.

i. Eating

The majority of participants indicated that on the MDI their lives were often restricted by when and what they ate:

“So when suddenly like the feeling knowing you can’t eat, like you can’t eat even if you are absolutely starving, is horrible, but then when you’re being forced to eat, you’re being forced to sit at the breakfast table and you have to eat it, unless you’re gonna go. I didn’t like it”.

[Participant 6, P3: L52]

This is in stark comparison to their food intake whilst on the insulin pump, which seems to allow for greater lifestyle flexibility, as participants have more control over when and what they eat:

“On the pump, I would maybe eat what I’m not supposed to eat, I could still control it like I would if I would eat something else, like chocolaty or something”.

[Participant 5, P8: L214]

ii. Exercise

Participants suggested that neither the MDI nor the insulin pump constrained them from taking part in activities, but that the increased control over their blood glucose levels when on Insulin Pump Therapy allowed them to participate more fully in activities. They attributed this to improved energy levels:

“I feel a lot healthier cause I can, now I can, I feel as if I can run faster anyway. I can do more activities. It’s not as if it was restricting me but I can do more now, I feel as if I can do more now cause I’ve got more energy to do it”.

[Participant 2, P3: L52]

iii. Social life

The majority of participants reported experiencing a negative impact upon their social lives whilst on MDI. This extended to school, extracurricular activities and parties:

“There was one point where my mum said that she asked all my friends mums not to invite me to their parties cause I’d just get so upset”.

[Participant 1, P4: L84]

“Yeah, and it takes up a lot of time at school, cause you wait in the line, then you have to eat your lunch, then you have to go, do an injection, pack it all away, and by the time you’ve done that you don’t really have time to see people and say hey and stuff. And then I feel bad, cause my friends are obviously gonna come with me but I don’t want them to have like, have to wait around with me”.

[Participant 6, P11: L202]

Whereas participants described having better social lives now on the insulin pump:

“Yeah, like going to parties. I can go to parties and I can do what I want now”.

[Participant 1, P14: L368]

“It’s made it easier cause obviously if we’re out and about and we’re doing something fun, I don’t have to be taken to the side to do it. So it has made a difference cause it’s not so much hassle, it’s much easier to control”.

[Participant 6, P18: L334]

iv. Sleep

Participants described frequently being woken up at night when on their MDI in order for their parents to adjust their insulin levels. Using the insulin pump, however, if adjustment is required, parents can enter the units into the meter without the need for an injection or waking their child up:

“I check my blood in the middle of the night.... Yeah, well it’s not actually me who does it, it’s mum. She actually gets up and checks it while I’m still asleep... She just checks my blood and if it needs corrected she just gets my pump and puts it in”.

[Participant 7, P12: L356]

v. Routine

Participants reflected on the difference that their treatment regime has made to their diabetes routines. They unanimously voiced that on the MDI they had a long and often tedious routine, which revolved around the frequency of their injections:

“Em, well sometimes it could be around five or six times a day. If it was a day say like Christmas Day or New Years Day say when I would be eating a lot, maybe about eight injections a day”.

[Participant 5, P2: L26]

This is in contrast to participants’ view of their current routine on Insulin Pump Therapy, which can be encapsulated by the following quote:

“Like it’s not, it’s not a routine. That’s what’s good about it”.

[Participant 1, P11: L274]

SUPER-ORDINATE THEME 4: ‘PRACTICALITIES’

One of the dominant themes to arise from the interviews was the practicalities of the different treatment regimes and the degree to which participants found these distressing. There were three sub-themes: (i) convenience, (ii) practical problems and (iii) visibility.

i. Convenience

The idea that Insulin Pump Therapy was more convenient than MDI was mirrored throughout most of the interviews. All of the participants said it was ‘easier’ to administer their insulin via the pump, which in turn made their lives easier in general:

“Well, it was just, when you are on the pump it’s just so much easier cause for me it was just.. unless anything went wrong with your cannula or the site or anything. Em, but it was just one injection compared to fifteen which basically means you’re taking away fourteen injections from me, if everything goes well”.

[Participant 2, P2: L48]

More specifically, some of the participants said this was due to greater technical control with the insulin pump:

“Also the pump is more accurate, than the insulin, em, sorry the pens. Em, say for instance the pens can only dial half units, so its half, one, one and a half, two. Instead with the pump, you can get 0.1 of a unit”.

[Participant 5, P9: L248]

“Yeah, cause it’s not like just your head working it out, it’s also like a computer working it out for you. So its em, obviously you estimate what it’s gonna be and then it will tell you exactly, the exact amounts so it’s usually spot on”.

[Participant 6, P15: L266]

Participants also indicated that they found it easier to learn how to use the insulin pump and to maintain this knowledge long-term:

“Well, it took a wee while to get used to it but once you’ve got the hang of it it’s really easy”.

[Participant 7, P4: L112]

Hence, this ease of use was in turn supporting participants’ desire to become more independent. In fact, we saw from two participants that they found the insulin pump made their lives feel more ‘normal’ to the point they could forget about their diabetes; this was not experienced whilst on MDI:

“Cause it just allows to do, allows to do what you want to do. With the insulin, you would have to follow the rules of the insulin pen, but with the pump you do just whatever you like. You take your insulin. You just live a normal life”.

[Participant 5, P17: L472]

Although, it is important to note that this increase in independent diabetes control can be hard for parents to come to terms with:

“Yes because sometimes when I want to try and do some of it myself my mum and dad always step in and say ‘no participant 5, let me do it’... So I would maybe let them do it sometimes, and sometimes I would say, I want to try it this time... And then they would let me try it”.

[Participant 5, P5: L124]

ii. Practical problems

Regarding the MDI, practical problems such as finding a private place to inject oneself and the awkwardness of carrying the injections around, was mentioned by most participants:

“I could always do injections whenever I wanted but it wasn’t really always accessible. If you’re out you can’t just be fiddling about with your trousers and doing an injection if you’re out with your friends”.

[Participant 6, P15, L260]

“I don’t think you can forget the injections, you’ve got to carry them about with you. You’ve got to carry a pump as well but the pump goes in your pocket, the injections stick out your pocket”.

[Participant 2, P11, L202]

We must also not overlook the inconvenient factors associated with the insulin pump, which were explicitly mentioned by nearly all of the participants. These included the consequences of the insulin pump tubing getting caught and/or falling and the inconvenience of tucking the tubing in:

“The worst thing is when you’re running up the stairs and getting the cable or tubing caught on the door handle or something. I’ve done that...three times... it comes back out of you and it’s painful. I’ve done that once coming up the stairs, once on the bathroom door handle and once when I was playing sport³... I went up for the ball and pulled it with my pinky”.

[Participant 2, P10: L188]

“Yeah sometimes, sometimes it just falls out my pocket and pulls. It’s quite sore... It doesn’t happen often though”.

[Participant 7, P10: L300]

Some participants also commented that the insulin pump can come loose when exercising, which can be both irritating and embarrassing:

“The only thing I don’t like about it is if you’re on a trampoline and like running and you can, it does like move up and down. That’s a bit annoying, sometimes it’s unclipped and I’ve not realised, and its dangling and you are just like what, and people tell you and it’s so embarrassing”.

[Participant 6, P13: L234]

Yet, it seems despite these inconvenient factors, participants appear to prefer the insulin pump over the MDI due to the ease of use, increase in independence and the low frequency of the insulin pump tubing getting caught.

iii. Visibility

This sub-theme reflects how aware some of the participants were of the size and shape of their insulin pump. There was a split between participants’ viewpoints; some participants were unaffected about the visibility of their pump, whereas others were concerned about this and said they felt embarrassed and annoyed. Participants did not comment on the visibility of their MDI.

³ Wording altered to prevent identification of participants.

Visibility: not bothered

“No I don’t really bother about it... I don’t know, I’m just used to it”.

[Participant 7, P9: L278]

“Um, no I don’t really mind people seeing my pump... No, normally when I am just wearing a dress I just stick it under my pants or something”.

[Participant 8, P6:L134]

Visibility: unhappy

“I hate wearing, em, I hate people noticing it cause everybody notices it. Even people who don’t even know me ask what it is. It annoys me cause I hate having to, cause I walk through school and stuff and they stare at me like, they stare, they don’t look away. I can feel they are staring, I can tell they are staring at me. So I just try, sometimes I’ve been in the lunch queue and I just try to hide it, just standing in line with someone so they don’t see it. Sometimes my friends lend me their cardigans cause I’ve just forgotten to bring one and then I’m like no I can’t, I don’t want people to see this”.

[Participant 6, P12: L204]

SUPER-ORDINATE THEME 5: ‘PEER REACTIONS’

This theme addresses the reactions that the participants experienced from their peers in relation to their insulin pumps. The majority of participants alluded to this theme during their interview and both positive and negative reactions were reported. It is noteworthy that none of the participants described their peer’s reactions to their MDI.

i. Positive reactions

“Well, like my close friends, like, like, the ones I’ve known for a long time, they know that I have a pump and all that, and they know a little bit about diabetes, but probably not as much as you know, as some people would... But, em, they are fine with it”.

[Participant 3, P9: L198]

ii. Negative reactions

“..there were times when I wish that nobody knew because at the end of last year, em, this really horrible boy in the other class, em stuffed paper towels down his trousers and pretended that it was my pump”.

[Participant 1, P7: L164]

“When I’m at clubs they always pull up my t-shirt and they say what’s that and I don’t really like it, and they always say that...”.

[Participant 4, P8: L182]

SUPER-ORDINATE THEME 6: ‘PARENTAL SUPPORT’

Within the interviews, parental support emerged as a significant theme in shaping participants’ ability to maintain a good QoL. It appeared that whilst on MDI, participants described being a burden to their supportive parents:

Parental burden

“Yeah, I would like, my mum would have to hold me down if my dad did it... Like I’d have to be held down...and sometimes I had to be held down even when my mum was doing it”.

[Participant 1, P3: L74]

“Well since my mum, when I had diabetes, when I got it, she, before she was in work⁴, but because I had diabetes she couldn’t go to work because she had to look after me. But she said she would rather look after you than go to work⁴”.

[Participant 4, P2: L34]

Yet, when speaking about the insulin pump, this burden was not reported; participants appeared able to simply accept parental input as positive support.

⁴ Wording altered to prevent identification of participants

Parental support

“It does yeah, cause now I feel that I’ve got more support and I realise that support is good cause I’m not always in a bad mood.... I can let them support me”.

[Participant 2, P8: L152]

In addition, multiple participants revealed that they now argued less about diabetes with their parents since the insulin pump:

“Well actually there are more arguments but fewer about diabetes”.

[Participant 1, P15: L382]

Discussion

This study is an exploration of the impact that Insulin Pump Therapy can have on young peoples’ QoL. The results convey an overarching message that participants’ QoL had changed for the better since commencing Insulin Pump Therapy. Six super-ordinate themes were identified: ‘Physical Impact’, ‘Mood and Behaviour’, ‘Lifestyle Flexibility’, ‘Practicalities’, ‘Peer Reactions’, and ‘Parental Support’. Taken together, the final themes inform us of the complexity of the individuals’ experiences and the impact that the insulin pump has had on many aspects of their lives. These themes suggest a framework for clinicians to conceptualise how young people with T1D perceive their treatment regimes; recognising the more positive aspects of Insulin Pump Therapy, but taking care not to overlook the downsides of this treatment. Furthermore, it should be recognised that the themes do not stand alone, but interact with one another, as indicated in Barnard and Skinner’s (2007) findings.

Similar to previous studies (e.g. Weintrob et al., 2003; Litton et al., 2002; Bruttomesso et al, 2008), the first theme suggests that Insulin Pump Therapy has a positive influence on glycaemic control for young people. This was perceived to be a QoL benefit in both the short and long-term, as research indicates that better glycaemic control means fewer complications associated with T1D (SIGN, 2010). This was also evident throughout some of the other themes, which revealed that an improvement in glycaemic control has a positive influence on participants’ mood, behaviour and flexibility of their lifestyle.

Consequently, by improving glycaemic control through the use of insulin pumps, improvements in young peoples' QoL can be facilitated in the short and long-term. This acknowledgment is of great importance as it underpins the provision of insulin pumps in the UK, providing further support for the Scottish Government's initiative to fund optimal T1D treatment delivery (Scottish Government, 2012). In addition, these findings concur with the national guidelines in reporting the success of Insulin Pump Therapy within this age group (SIGN, 2010; NICE, 2008).

Super-ordinate theme one can be further explored in relation to the impact that the different treatment regimes had on participants' bodies. Participants revealed that in the past, when on MDI, they experienced a great deal of pain and discomfort and were often left with visible bruising and scars. In contrast, participants reported less pain when using the insulin pump. Furthermore, any scarring or bruising was reported to be easier to hide as it was situated on areas that are normally clothed. This appears to have had a significant impact upon young people's self-image and ability to cope with their diabetes, factors which are seen to promote an optimal QoL. This concurs with past research by Weintrob and colleagues (2003) whom also indicated that the decrease in pain levels was associated with improved QoL amongst children. Nevertheless, we should not overlook the fact that multiple participants disclosed that although the insulin pump was not as painful as MDI, it caused its own physical difficulties. The majority of these difficulties focussed on the cannula insertion, despite the use of Lidocaine Hydrochloride cream to numb the area. Hence, improvements to the process of cannula changes could be addressed by the manufacturers in order to reduce this particular downside.

The dominant mediating factor on the young peoples' mood and behaviour seems to be the decrease in frequency of injections (super-ordinate theme two). Several participants stated that the decrease from an average of fifteen injections over three days, to one cannula change in three days, made them feel more 'normal' and improved their mood. Thus the reported difficulties of cannula insertion appear to be tempered by the apparent benefits to their mood and behaviour and associated QoL. Furthermore, participants commented that their glycaemic control improved on Insulin Pump Therapy, which had a knock-on, positive impact upon their mood. This finding is in line with a meta-analytical review by Lustman and colleagues (2000) who revealed that depression is associated with hyperglycaemia.

Recent research suggests that lifestyle flexibility is a major influencing factor on the QoL of people with T1D (Todres et al., 2010). These findings were supported by this study which identified that young people reported a positive improvement in the flexibility of their lifestyle as a consequence of starting Insulin Pump Therapy (super-ordinate theme three). In accordance with past research, such as Hoogma and colleagues (2005), participants indicated an improvement in the flexibility of their eating, exercise, social life, sleep and daily routines. Furthermore, when describing these changes, they seemed noticeably more animated; possibly indicating lifestyle flexibility makes the biggest difference to their QoL.

An interesting theme to arise from these data was the day-to-day practicalities of the treatment regime (super-ordinate theme four). Specifically, the insulin pump was reported to be more convenient and easier to use than MDI. This can be attributed to the insulin pump allowing for greater technical control and ease of learning. However, it must also be considered that this may be attributable to participants increase in age and the fact that they have had more time to adjust to having diabetes. Nevertheless, nearly all the participants were in agreement that the insulin pump was more convenient, but this came with caveats.

Some participants reported that, occasionally, the insulin pump tubing could get caught, resulting in the cannula falling out and/or the pump falling to the floor. Furthermore, some participants described issues when they were exercising and the pump moving. Whereas, practical concerns regarding the MDI was captured by reports of the awkwardness of carrying the injections and issues regarding privacy when having to inject oneself.

The MDI concerns have been recognised in past research (E.g. Peyrot et al., 2010), however, the insulin pump concerns have not fully been explored, except for by Barnard and Skinner (2007) who highlighted a few technical issues such as “when things go wrong”. The question therefore arises; are these insulin pump concerns more relevant to young people? One tentative hypothesis may be that young people tend to engage in more risk taking behaviours which have the potential to cause things to go amiss, such as with their insulin pumps (Jackson et al., 2010; Suris et al., 2008). Furthermore, the young people interviewed traverse a range of developmental stages which can impact upon their self-esteem levels. For example, some of the participants were at an age when they are more aware of others judgements and so may find situations where they feel embarrassed to be highly aversive (Robins et al., 2002). Alternatively, it is possible that this factor has not been found in adult

literature due to the dearth of qualitative studies which would permit wider exploration of patients' experiences. These tentative hypotheses require further examination in order to fully understand the limitations of the insulin pumps within a younger age group.

Similar to Barnard and Skinner's (2007) study, some of the young people reported visibility of the insulin pump to be a key weakness of this treatment regime. However, others did not seem to mind that it could be easily seen (continuation of super-ordinate theme four). Additionally, participants also described peers' reaction to their insulin pump, which suggests that there are two opposing camps (super-ordinate theme five). On one side you have young people who have encountered negative reactions from their peers, which in turn appears to make them feel embarrassed and annoyed. In contrast, we have the alternative view, where participants reported positive reactions from their peers and felt 'fine'. This leads us to question, what is the difference between those who mind and those who don't and those who experience negative reactions from peers and those who don't? The characteristics of our participants do not appear to give us any clue and so this leads one to wonder what the underlying mechanisms are. Unfortunately, this study is currently unable to answer this question, but it may prove useful to bear in mind for future research and when working clinically with young people.

In the final super-ordinate theme, participants described feeling they were a burden to their parents when on MDI, whereas now on their insulin pump, they revealed that they are able to accept this as positive support. This is an interesting concept and one which appears to be partially unique to this study. Barnard and Skinner (2007) revealed that participants felt they now had greater independence for both themselves and for their family members, which is reflected in these findings. This theme, however, goes one step further and looks at the impact not only on their independence, but also on young people's perception of their illness as a 'burden' or 'normal'. This increased sense of normalisation suggests a positive impact on young people's QoL. It is also of interest to note that some parents commented in passing to the researchers that they found transitioning to Insulin Pump Therapy a greater burden. Hence, it would be interesting to conduct a follow-up study investigating parental attitudes and beliefs towards Insulin Pump Therapy.

Strengths and Limitations

There are a multitude of strengths within this study, which add validity to the findings, such as the homogeneity in the sample and the fact that the participants were interviewed individually. The gender balance was 75% female; 25% male which reflected the overall gender balance of young people on insulin pumps within this regional hospital (Lamb, 2012). Furthermore, the ease of recruitment reflects the salience of this topic to the participants. Nevertheless, limitations must be recognised.

One such shortcoming is that only three children were interviewed resulting in a mix of developmental stages which may have confounded the results. In addition, it is not known if age and/or duration at commencement of Insulin Pump Therapy, and/or the number of injections per day prior to Insulin Pump Therapy may have affected participants' answers. However, McMahon and colleagues (2005) conducted a large scale quantitative study and reported no significant impact of these factors on glycaemic control or QoL measures. It should also be noted that the inclusion criteria specifically stated that participants must have been on Insulin Pump Therapy for a minimum of six months. This was to allow for any novelty effect of a new treatment to wear off and for most patients to be established on Insulin Pump Therapy. Further, young people with co-morbid medical conditions were excluded from this study to prevent cross-contamination of the results. Hence, these parameters may impact the generalisability of the results for those young people who have just initiated Insulin Pump Therapy and/or suffer with an additional medical condition.

Implications for clinical practise

The findings from this study provide some unique insights into the personal experiences of young people with T1D. It is from this that we can extrapolate and consider both the clinical implications and recommendations for healthcare professionals involved in their care. The expectations of young people preparing to start Insulin Pump Therapy need to be addressed, with professionals providing clear and concise information about the benefits, but also the potential problems with this treatment. The present service currently offers this information to young people via contact with a dedicated Clinical Psychologist and the Clinical Nurse Specialist, but this study indicates that we need to ensure this information is also being conveyed to parents in order to optimise their support throughout this challenging time. Greater understanding of the concerns of this population may facilitate guidance

opportunities within schools and thus identify appropriate support. In addition, the provision of a brief group psychoeducational intervention to increase young peoples' self-esteem prior to and during the commencement of Insulin Pump Therapy may be beneficial. Finally, it may also be of use for the insulin pump product designers to consider the potential pitfalls which our participants have encountered, such as the tubing getting caught and look to an alternative solution to minimise this risk factor.

Implications for future research

Perhaps one of the key strengths of this study is that it fills a gap in the research and highlights the remarkable value a qualitative study can provide. The richness of this data has conveyed important insights into the lives of young people with T1D. It has portrayed areas of interest which, in the past, quantitative studies have only been able to allude to and tentatively hypothesise about. Further studies are needed to focus more on the generalisability of these QoL benefits among different population groups, including those with co-morbidities and in terms of long-term usage, as the longest duration of insulin pump use in this study was only two and a half years. It would also be beneficial to conduct further research, which focuses on how to reduce the impact of the reported downsides to Insulin Pump Therapy. Lastly, qualitative research exploring the wider impact of Insulin Pump Therapy from a parent perspective would be particularly worthwhile.

Conclusions

Improvements in QoL mean different things to different people, but what this study suggests is that there is a general agreement amongst the sample of young people interviewed that switching to Insulin Pump Therapy has resulted in improvements to their QoL. This study reflects the participants' enthusiasm for Insulin Pump Therapy, while simultaneously recognising the potential problems of this treatment regime.

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CHAPTER THREE: ADVANCED CLINICAL PRACTICE I

Critical Reflective Account

Multidisciplinary team working: A reflective account of the roles and limitations of a

Clinical Psychologist

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*Submitted in part fulfilment of the requirements for the degree of Doctorate in
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Abstract

Reflective practice aims to facilitate Clinical Psychologists to engage in continuous learning by reflecting on their own work. This can be considered of vital importance for both professional and self-development. This critical reflective account describes my experiences of working within a multi-disciplinary team, and the limitations and roles which this entails. It is structured around Gibb's (1988) reflective model to analyse my thoughts, feelings and behaviours that occurred in response to two specific experiences of Multidisciplinary Team (MDT) working which highlighted my changing role, and my exploration of specific issues such as resistance, and limitations within a team. I also draw upon the National Occupational Standards for Psychology (BPS, 2006), the Code of Ethics and Conduct (BPS, 2009) and the policy New Ways of Working for Applied Psychologists (BPS, 2007) to guide my thoughts, and reflect on these experiences in the wider context. I draw on two specific examples, firstly one which illustrates the change in my skills and confidence over the past three years at MDT meetings, with particular emphasis on my changing role within these meetings. Secondly, I demonstrate the importance of knowing my own limitations within a MDT, and being able to communicate this to my colleagues effectively. The learning experiences from these reflections are discussed, and my enhanced awareness of the evolving role of a Clinical Psychologist is reflected upon.

CHAPTER FOUR: ADVANCED CLINICAL PRACTISE II

Critical Reflective Account

The wider influences on the role of a Clinical Psychologist: A reflection on my experiences in adult services

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Clinical Psychology (D.Clin.Psy)*

Abstract

Reflective practice and Clinical Psychology are synonymous terms, as it is through the process of critical reflection that a clinician's learning and subsequent continuous professional development is facilitated. In this account, I have reflected on how the role I have fulfilled in my placements has largely been determined by the specific skills set required by the service itself. The reflections contained in this account are based on the experiences I accrued in my current placement within adult health (Oncology and Cardiology) and in my first year placement in a Primary Care Mental Health (PCMH) team. This account is broadly structured around Johns and Graham's (1996) five-stage model to support reflections on four primary themes which relate to how the individuality of services impacted upon my role: 1) multidisciplinary team requirements, 2) local and national policies, 3) crisis management, and 4) supervision needs. This account has encouraged me to reflect upon my experiences throughout training and consider how I will use these reflections in my future life as a qualified Clinical Psychologist.

Appendix 1.1 – Author Publication Guidelines

British Journal of Health Psychology

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
- review papers, which should aim to provide systematic overviews, evaluations and interpretations of research in a given field of health psychology; and
- methodological papers dealing with methodological issues of particular relevance to health psychology.

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers should normally be no more than 5000 words (excluding the abstract, reference list, tables and figures), although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i.e. 5000 words)

For full details see: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8287/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8287/homepage/ForAuthors.html)

Appendix 1.2: Quality Assessment Tool

<u>The impact of Parenting style on young people's adherence to their diabetes self-management treatment regime and glycaemic control: A systematic review</u>	
Authors	
Title of Article	
Title of Journal	
Date of publication	
Completed by	
Completed on	

1. INTERNAL VALIDITY		
1.1	Does the study have a clear aim and hypothesis?	2 Well covered 1 Adequately covered 0 Poorly/not covered
2. INTRODUCTION		
2.1	Has the scientific background and explanation of rationale been provided?	2 Well covered 1 Adequately covered 0 Poorly/not covered
3. METHOD		
3.1	Is the population and how it is recruited is clearly stated?	2 Well covered 1 Adequately covered 0 Poorly/not covered
3.2	Are details provided of participant characteristics and are they representative of the target group (e.g. gender, age, ethnicity, socio-economic status, disease duration)?	2 Well covered and representative sample 1 Adequately covered but unrepresentative of the target group 0 Poorly/not covered
3.3	Is the inclusion and exclusion criteria clearly stated?	2 Well covered

		1 Adequately covered 0 Poorly/not covered
3.4	Was a power calculation used?	1 Yes 0 No
3.5	Does the article outline the flow of participant's through each stage?	2 Well covered 1 Adequately covered 0 Poorly/not covered
4. ASSESSMENT		
4.1	Were the outcome measures clearly defined?	2 Well covered 1 Adequately covered 0 Poorly/not covered
4.2	Is adherence to diabetes treatment regime measured appropriately? E.g. HbA1c and validated questionnaire	3 Observational and self-report methods 2 Observational or Standardised self report measure – good validity 1 Standardised self-report measure – poor/unknown validity 0 Non-standardised tools
4.3	Is parenting style measured appropriately?	3 Observational and self-report methods 2 Observational or Standardised self report measure – good validity 1 Standardised self-report measure – poor/unknown validity 0 Non-standardised tools
5. CONFOUNDING VARIABLES		
5.1	Are the main potential confounders identified and taken into account in the design and analysis?	2 Well covered 1 Adequately covered 0 Poorly/not covered
6. STATISTICAL ANALYSIS		
6.1	Is the analysis conducted appropriate to the design?	1 Yes

		0 No
6.3	Are the results clearly reported?	2 Well covered 1 Adequately covered 0 Poorly/not covered
6.4	Are confidence intervals, effect sizes, p-values etc. provided where appropriate?	2 Well covered 1 Adequately covered 0 Poorly/not covered
7. DISCUSSION		
7.1	Are the limitations of the research study described?	2 Well covered 1 Adequately covered 0 Poorly/not covered
7.2	Is the generalizability of the research discussed?	2 Well covered 1 Adequately covered 0 Poorly/not covered
7.3	Do the authors provide recommendations for clinical practice or future research in relation to the findings?	2 Well covered 1 Adequately covered 0 Poorly/not covered
7.4	Do the conclusions drawn directly link to the results achieved?	2 Well covered 1 Adequately covered 0 Poorly/not covered
Total Score (out of 36):		
Percentage (%):		
Overall Quality Rating:		

***Overall Quality Rating Key**

(80% + Good)

(55-79% Moderate)

(<54% Poor)

Appendix 1.3: Quality rating of studies included in systematic review

Study	Quality Score (max = 36)	Percentage Quality Rating	Descriptive Quality Rating
Shorer et al., 2011	20	55.6%	Acceptable
Armstrong et al., 2011	31	86.1%	Good
Greene et al., 2010	32	88.8%	Good
Jaser and Grey, 2010	27	75%	Acceptable
Sherifali et al., 2009	28	77.8%	Acceptable
Duke et al., 2008	30	83.3%	Good
Faulkner and Chang, 2007	28	77.8%	Acceptable
Butler et al., 2007	27	75%	Acceptable
Lewin et al., 2006	31	86.1%	Good
Davis et al., 2001	29	80.6%	Good

- (A) representing a percentage score of 80% (*good quality*)
(B) representing a percentage score of 55-79% (*acceptable quality*)
(C) representing a percentage score of 0-54% (*poor quality*)

Appendix 1.4: Psychometric Values of Measures

Adherence Measure	Reference	Psychometric Values (Internal consistency)
Adherence to Diabetes Treatment Regimen Questionnaire	Tom-Katzav, 2007	Not stated
The Self-Care Inventory (Child and Parent Version)	La Greca et al., 1990	0.73 – 0.84
The Diabetes Self-Care instrument	Greene et al., 2010	0.79
The Pediatric Quality of Life Inventory	Varni et al., 2003	0.84
Diabetes Self-Management Profile	Harris et al., 2000	0.65 – 0.86
Self-Care Questionnaire	Saucier and Clark, 1993	0.78

Parenting Measures	Reference	Psychometric Values (Internal consistency)
Parental Authority Questionnaire	Buri, 1991	Not stated
Diabetes Family Behaviour Checklist	Schafer et al., 1986	0.60 – 0.82.
62-item Parenting Practices report	Robinson et al., 1995	0.75 – 0.91
The Iowa Family Interaction Rating Scale	Melby and Conger, 2001	0.61 – 0.79
The Parenting Dimension Inventory	Power, 1993	0.55 – 0.85
Diabetes Family Behaviour Scale	Waller et al., 1986	0.69 – 0.83
Child/Parent Report of Parent Behaviour Inventory	Schaefer, 1965a/1965b	0.81 – 0.90

Appendix 2.1 – Author Publication Guidelines

British Journal of Health Psychology

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology across the life span, ranging from experimental and clinical research on aetiology and the management of acute and chronic illness, responses to ill-health, screening and medical procedures, to research on health behaviour and psychological aspects of prevention. Research carried out at the individual, group and community levels is welcome, and submissions concerning clinical applications and interventions are particularly encouraged.

The types of paper invited are:

- papers reporting original empirical investigations;
- theoretical papers which may be analyses or commentaries on established theories in health psychology, or presentations of theoretical innovations;
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For full details see: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)2044-8287/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)2044-8287/homepage/ForAuthors.html)

Appendix 2.2. Ethics Approval Letters

WoSRES **West of Scotland Research Ethics Service**

Miss Jennifer Whittaker
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www.nhsggc.org.uk

Date 31 October 2011
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail evelyn.jackson@ggc.scot.nhs.uk



Dear Miss Whittaker

Full title of study:	An interpretative phenomenological analysis of the effects of continuous subcutaneous insulin infusion (CSII) therapy on children and adolescent's quality of life
REC reference number:	11/WS/0047
Protocol number:	1

Thank you for your e-mail of 18 October 2011. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 20 September 2011. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Participant Information Sheet: 8-12 yrs old	1	11 October 2011
Participant Information Sheet: 12-16 yrs old	2	11 October 2011

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

11/WS/0047	Please quote this number on all correspondence
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Yours sincerely

Ms Evelyn Jackson
Committee Co-ordinator

Copy to: Dr Sarah Wilson, Gartnavel Royal Hospital
Dr Michael Barber, R&D Office, Tennent Building, Western Infirmary

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www.nhsggc.org.uk

WoSRES

West of Scotland Research Ethics Service



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Miss Jennifer Audrey Whittaker
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Date 29 September 2011
Direct line 0141-211-1722
Fax 0141-211-1847
e-mail Andrea.torrie@ggc.scot.nhs.uk

Dear Miss Whittaker

Study title:	An interpretative phenomenological analysis of the effects of continuous subcutaneous insulin infusion (CSII) therapy on children and adolescent's quality of life
REC reference:	11/WS/0047
Protocol number:	1

The Research Ethics Committee reviewed the above application at the meeting held on 20 September 2011. Thank you for attending to discuss the study.

Ethical opinion

The committee reviewed the above study.

In discussion, the committee noted the following ethical issues which were put to the researcher for clarification and which were answered to their satisfaction namely:

Study Design:

- The committee were concerned that you would be interviewing 8 year olds in isolation. You confirmed that this would be the case but this would be done sensitively and if either the children or the parent expressed a wish to be included, then this would be done - firmly stipulating to the parent that they should not have any input.
- Clarification is sought by committee as to the numbers being recruited? There appeared to be a discrepancy in the submission i.e. 4 > 12 patients/ 6 > 12 patients? You confirmed that 4 > 12 is the main number with 12 being the maximum.
- According to the references provided it looked as if some of this work might have been done already and the committee wondered what is "new" about this? You confirmed that this type of thing has been done in adult diabetics but has never been looked at in children before.
- The committee sought clarification about the involvement of the two sites i.e. RHSC and RAH? You explained that the RAH was a satellite clinic of the Department in RHSC - same people, patients are patients of RHSC.
- The committee wondered if RHSC had signed up for this as there was no correspondence to confirm this? You replied that "Yes they are indeed signed up for this with agreement from the Clinical Psychologist and a Diabetes Nurse".

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- f) The committee sought re-assurance that data stored on the University laptop would have i) back-up and ii) have NHS encryption on it? You confirmed that this was the case for both.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Other Conditions Specified by the REC

The committee wish the undernoted minor amendments to be made to the Patient Information Sheets.

The committee felt that you should draw up a specific Information sheet for 8 > 12 year olds simplifying the wording accordingly.

The existing Participant Information Sheet should be used for 12 > 16 year olds with the undernoted amendments:

- a) A further sentence should be added to indicate that this study is being done for an educational qualification.
- b) Dr Ken Mullen's name should be added to this as an "independent person".

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview Schedules/Topic Guides	1	29 August 2011
Investigator CV	-	29 August 2011
Other: CV Supervisor - Dr S Wilson	-	26 August 2011
Other: CV - Co-Investigator - E Hunter	-	22 August 2011
Participant Consent Form: Parent/Guardian	1	17 August 2011
Participant Consent Form	1	17 August 2011
Participant Information Sheet	1	17 August 2011
Participant Information Sheet: Parent/Guardian	1	17 August 2011
Protocol	1	29 August 2011
REC application	-	29 August 2011

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

There were no declarations of interest.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

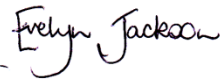
Further information is available at National Research Ethics Service website > After Review

11/WS/0047

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



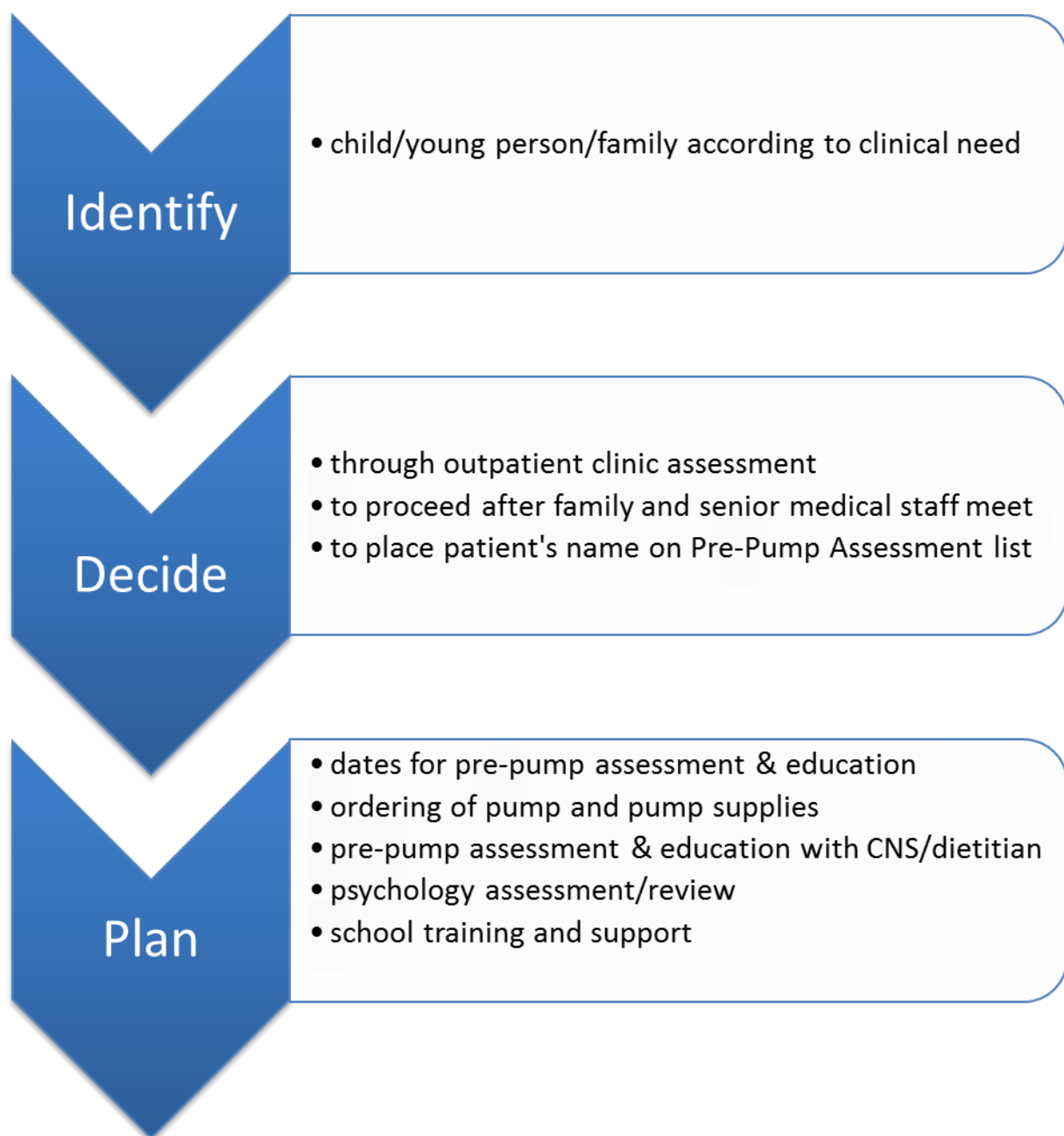
 **Dr Sue Langridge**
Chair

Enclosures: List of names and professions of members who were present at the meeting
"After ethical review – guidance for researchers"

Copy to: Dr Sarah Wilson, Gartnavel Royal Hospital
Dr Michael Barber, R&D Office, Tennent Building, Western Infirmary

Children's Diabetes Service Insulin Pump Pathway

Planning Pump Therapy



Appendix 2.4 – Information Pack

University of Glasgow
Department of Mental Health and Wellbeing
Gartnavel Royal Hospital
Administration Building
1055 Great Western Road
Glasgow, G12 0XH

Participant Information Sheet: 8 > 12 years olds

Title: The effects of insulin pump therapy on young people's quality of life

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what you would need to do. Please take time to read this information and talk to your parent/guardian about it.

Who is carrying out the research?

The research is being carried out by Jennifer Whittaker and Dr Sarah Wilson from Glasgow University's Academic Unit for Mental Health and Well Being, alongside Dr Liz Hunter from the Department of Clinical Psychology at Yorkhill.

Why are we doing this study?

We want to know what effect using an insulin pump has on the lives of the young people who use them. We are hoping that with this information, we will be able to help the hospital to improve their service to young people like you and make using an insulin pump easier for both you and other children.

Why have I been invited to take part?

All young people who have changed from injections to insulin pump therapy over the past three years; attend the diabetes clinic; and are aged 8 – 15 years old have been invited to take part in this study.

Do I have to take part?

No – it is up to you and your parent/guardian to decide. If you do decide to take part, you will be given a copy of this information sheet to keep and be asked to sign a form to show you have agreed to take part. Your parent/guardian will also be asked to do this. You are free to stop at any time and without giving a reason. This will not affect your care or treatment.

What will happen if you take part?

You will meet with Jennifer for about 30 - 45minutes to talk about the effect that insulin pump therapy has had on your life. This will be recorded, and will be kept completely private. The recordings will be destroyed once we have taken the information from them.

What happens to the information?

The recordings will be typed up with all personal information such as your name removed. This will be kept on a safe computer, and then the recordings will be destroyed. We will not share this information with other people, without you, and your parent/guardians permission. We may use information you have given us in writing a report on this study but we will make sure that no one can tell who gave it to us.

What are the possible risks of taking part?

There are no direct risks from taking part, although some people may feel uncomfortable talking about their experiences. If we are worried then we would ask you if you would like extra help from the Diabetes Team. This would be discussed with you and your parent/guardian. You could also choose to speak with someone from the psychology service attached to the Diabetes Clinic.

Who has reviewed the study?

This study has been reviewed by NHS West of Scotland Research Ethics Committee 2.

If you are interested in taking part?

If you would like to take part, please ask your parent/guardian to complete the tear-off slip on their information sheet and return it in the envelope provided (***no stamp required***), or to pass this on to a member of the diabetes team.

Or, please ask them to contact Jennifer Whittaker or Sarah Wilson on 0141 211 3921.

If you would like some more information about the study, please do not hesitate to contact us. Or, if you would prefer to talk to someone not involved in the research, please contact Dr Ken Mullen Lecturer, School of Medicine University of Glasgow, on 0141 211 3932.

Thank You for Reading this Information Sheet

University of Glasgow
Department of Mental Health and Wellbeing
Gartnavel Royal Hospital
Administration Building
1055 Great Western Road
Glasgow, G12 0XH

Participant Information Sheet: 12 > 16 years olds

Study Title: The effects of insulin pump therapy on young people's quality of life

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with your parent/guardian. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being conducted by Jennifer Whittaker and Dr Sarah Wilson from Glasgow University's Academic Unit for Mental Health and Well Being, alongside Dr Liz Hunter from the Medical Paediatric Department of Clinical Psychology. This research is part of the Doctorate in Clinical Psychology qualification.

Why are we doing this study?

We want to know what effect using an insulin pump has on the lives of the young people who use them. We are hoping that with this information, we will be able to help the hospital to improve their service to young people like you and make using an insulin pump easier for both you and other children.

Why have I been invited to take part?

All young people who have changed from multiple daily injections to insulin pump therapy over the past three years, attend the diabetes clinic, and are aged 8 – 15 years old have been invited to take part in this study.

Do I have to take part?

No – it is up to you and your parent/guardian to decide. If you do decide to take part, you will be given a copy of this information sheet to keep and be asked to sign a consent form to show you have agreed to take part. Your parent/guardian will also be asked to read an information sheet and sign a consent form. You are still free to stop at any time and without giving a reason. A decision to stop, or a decision not to take part, will not affect the care that you receive or any future treatment.

What will happen if you take part?

The research involves meeting you to talk about the effect that insulin pump therapy has had on your life. Taking part will take about 30-45 minutes and will be recorded. The recording will only be used for this research study, and all the information will be kept

completely private, and then the recordings will be destroyed once we have taken the information from them.

What happens to the information?

Your personal information will be kept completely private and known only to the researchers. The recordings will be typed up with all personal information removed. These typed records will be kept on a secure computer, and then the recordings will be destroyed. We will not share this information with other people, without you, and your parent/guardians permission.

What are the possible risks of taking part?

There are no direct risks from taking part, although some people may feel uncomfortable talking about their experiences. If we are worried about your wellbeing, we would ask you if you want the Diabetes team to offer some extra help. This would be discussed with you and your parent/guardian and the option of being referred to the dedicated psychology service attached to the Diabetes clinic would be available.

Who has reviewed the study?

This study has been reviewed by NHS West of Scotland Research Ethics Committee 2.

If you are interested in taking part?

If you would like to take part, please ask your parent/guardian to complete the tear-off slip on their information sheet and return it in the envelope provided (***no stamp required***), or to pass this on to a member of the diabetes team.

Alternatively, please ask them to contact Jennifer Whittaker or Sarah Wilson on 0141 211 3921.

If you would like some further information about the study, please do not hesitate to contact us. Alternatively, if you would prefer to talk to an independent person, out-with the research team, please contact Dr Ken Mullen Lecturer, School of Medicine University of Glasgow, on 0141 211 3932.

Thank You for Reading this Information Sheet

University of Glasgow
Department of Mental Health and Wellbeing
Gartnavel Royal Hospital
Administration Building
1055 Great Western Road
Glasgow, G12 0XH

Parent/Guardian Information Sheet

Study Title: The effects of insulin pump therapy on children's quality of life

We would like to invite your child to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for them. Please take time to read the following information carefully. Talk to others about the study if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is conducting the research?

The research is being conducted by Jennifer Whittaker and Dr Sarah Wilson from Glasgow University's Academic Unit for Mental Health and Well-being alongside Dr Liz Hunter from the Medical Paediatric Department of Clinical Psychology.

What is the purpose of this study?

We want to find out what effect insulin pump therapy has on children's quality of life. This information will help the hospital services by identifying the types of support that are required to make the use of insulin pumps as successful as possible for every child that uses one.

Why has my child been invited to take part?

All children who have changed from multiple daily injections to insulin pump therapy over the past three years, attend the diabetes clinic, and are aged 8 – 15 years old have been invited to participate in this study.

Does my child have to take part?

Participation is completely voluntary and confidential. It is up to you and your child whether or not to take part. If your child does decide to take part you will be given this information sheet to keep and be asked to sign a consent form to show you have agreed to your child taking part. Your child will also be asked to read an information sheet and sign a consent form. Even if you decide that your child will take part, they are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care that your child receives or their future treatment.

What will happen if your child takes part?

The researcher will meet with your child to talk about how using an insulin pump affects their life. This interview will take approximately 30-45 minutes and will be voice recorded. This recording will only be used for the purposes of this research, all the information will be completely anonymised before it is analysed, and the recordings will then be erased.

What happens to the information?

Your child's identity and personal information will be completely confidential and known only to the researchers. The voice recordings will be written out word-for-word (transcribed) and will be anonymised during transcription. Transcriptions will be kept on an encrypted computer so that only the research team will be able to access them. Once the transcription has been checked, the recording will be erased. The data will be held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people, without your permission.

What are the possible risks of taking part?

There are no direct risks from taking part, although some children might feel uncomfortable talking about their experiences. If any concerns arose about your child's wellbeing, the researcher would ask your child if they would like the Diabetes team to provide extra support. If we felt your child was in need of psychological input, this would be discussed with both you and your child and the option of requesting a referral to the dedicated psychology service attached to the Diabetes clinic would be available.

Who has reviewed the study?

This study has been reviewed by the NHS West of Scotland Research Ethics Committee 2.

If you are interested in taking part?

If you would like to take part, please complete the tear-off slip below and return it either in the stamped addressed envelope provided (*no stamp required*), or pass this on to a member of the diabetes team.

Alternatively, please contact Jennifer Whittaker or Sarah Wilson on 0141 211 3921.

If you would like some further information about the study, please do not hesitate to contact us. Alternatively, if you would prefer to talk to an independent person, out-with the research team, please contact Dr Ken Mullen Lecturer, School of Medicine University of Glasgow, on 0141 211 3932.

If you have a complaint about any aspect of the study? If you are unhappy about any aspect of the study and wish to make a complaint, please contact the researcher in the first instance, but the normal NHS complaint procedure is also available to you.

Thank you for your time and co-operation.
(Tear off Slip)

Research Study: **The effects of insulin pump therapy on children's quality of life**

Chief Investigator: Jennifer Whittaker

Trainee Clinical Psychologist (University of Glasgow / NHS Ayrshire and Arran)

Participant Name Signature

Telephone

For office use: *An interpretative phenomenological analysis on the effects of continuous subcutaneous insulin infusion (CSII) therapy on children and adolescent's quality of life.*

Participant number:

University of Glasgow
Department of Mental Health and Wellbeing
Gartnavel Royal Hospital
Administration Building
1055 Great Western Road
Glasgow, G12 0XH

Subject number:

The effects of insulin pump therapy on young people's quality of life

Participant Consent Form

Please initial the BOX

I confirm that I have read and understand the information sheet dated 29/08/2011 (version 1) for the above study and have had the opportunity to ask questions

☐

I understand that I do not have to take part in this study. It is my choice and I can stop at any time, without giving a reason and that this will not affect any part of my care.

☐

I am aware that the interview will be recorded by the researcher, Jennifer Whittaker, and only used for the purposes of the research study, as described in the information sheet.

☐

I understand that all names, places and anything that could identify me will be removed and nothing that identifies me will appear for others to see.

☐

I agree to take part in the above study

☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

1 copy to the patient, 1 copy to the researcher, 1 Original for the patients' notes

University of Glasgow
Department of Mental Health and Wellbeing
Gartnavel Royal Hospital
Administration Building
1055 Great Western Road
Glasgow, G12 0XH

Subject number:

The effects of insulin pump therapy on young people's quality of life

Parent/Guardian Consent Form

Please initial the BOX

I confirm that I have read and understand the information sheet dated 29/08/2011 (version 1) for the above study and have had the opportunity to ask questions

☐

I understand that this is voluntary and my child can withdraw at any time, without giving a reason and that this will not affect any aspect of their care.

☐

I am aware that the interview will be recorded by the researcher, Jennifer Whittaker, and only used for the purposes of the research study, as described in the information sheet.

☐

I understand that all names, places and anything that could identify my child or me will be removed and nothing that identifies my child will appear for others to see.

☐

I agree to my child taking part in the above study

Name of Participant

Date

Parent/Guardian Signature

Name of Researcher

Date

Signature

1 copy to the patient, 1 copy to the researcher, 1 Original for the patients' notes

Appendix 2.5 – Interview Schedule

Interview Schedule (Version 1, 29/08/11)

The below questions will be used as a guide only to initiate discussion. Prior to commencing interviews, participants will be reminded that they can have a break at any point and that there are no right or wrong answers. They will also be reminded that the information will be anonymous.

A. Type 1 Diabetes

Q: If you imagine you have been asked to explain type 1 diabetes to someone who knows nothing about it what would you say?

Prompt: How is it caused? What are the symptoms? How does it affect your body?
How much control do you have over it? How does it affect you on a day-to-day basis?

Q: What do you think about having Diabetes?

Prompt: How do you feel about having Diabetes?

B. Multiple Daily Injections (MDI)

Q: What did you call it when you were taking MDIs?

Prompt: Injections?

Q: Can you remember what your MDI regime was like?

Prompt: Number of injections, Glycaemic control – particularly in the evenings:
HbA1c levels, Weight, Pain.

Q: When on MDI, did you feel in control of your diabetes?

Prompt: Did you feel like you could manage your diabetes without any help?

Q: Did you have any difficulties with your diabetes when you were on MDI?

Prompt: What did the health professionals tell you? What did your parents and family say? What did your friends say? How did you feel? Did it cause arguments within the family?

Q: Were there many visits to hospital when you were on MDI?

Prompt: If you are not sure, take a guess. More variable blood sugar results?

Q: Did the MDI affect your body?

Prompt: physical side-effects? (e.g. lumpy/marked legs), Physical complaints or restrictions?

Q: Did the MDI affect you socially?

Prompt: Was it difficult/embarrassing to inject yourself? Did having to inject yourself affect your friendships/restrict your life?

Q: Did the MDI have an impact on your feelings?

Prompt: Did you worry about having to inject yourself?

Q: How did you cope with your diabetes when on MDI?

Prompt: Did you alter your eating, exercise, sleeping habits, frequency of blood glucose monitoring?

Q: Did you speak with anyone to help you manage your diabetes?

Prompt: Who supported you at that time – parents, friends, diabetes nurse?

Q: Can you remember how you felt when on MDI?

Prompt: what was your mood like and was it affected by your diabetes? Were you confident about doing your part in controlling your diabetes?

Q: Do you think that you used to cope well with the MDIs?

Prompt: If not, what was it that was difficult for you to cope with?

C. Insulin Pump

Q: What was your regime like now?

Prompt: Glycaemic control – particularly in the evenings: HbA1c levels, Weight, Pain.

Q: Do you feel more in control of your diabetes now you are on an insulin pump?

Prompt: Do you feel like you could manage your diabetes independently?

Q: Is the insulin pump causing any difficulties with your diabetes?

Prompt: What do the health professionals tell you? What do your parents and family say? What do your friends say? How do you feel? Does it cause arguments within the family?

Q: Do you go to hospital more or less since you have been on the insulin pump?

Prompt: If you are not sure, take a guess. More variable blood sugar results?

Q: What effect does the insulin pump have on your body?

Prompt: side-effects? Physical complaints or restrictions?

Q: What effect does the insulin pump have on you socially?

Prompt: Is it difficult/embarrassing to have an external device on yourself – does this restrict your lifestyle?

Q: What effect does the insulin pump have on you emotionally?

Prompt: Did you worry about your diabetes more than you used too?

Q: Do you have to change things in order to cope with having diabetes now you are on an insulin pump?

Prompt: Do you alter your eating, exercise, sleeping habits, frequency of blood glucose monitoring?

Q: Do you speak with anyone to help you manage it?

Prompt: Who supports you? – parents, friends, diabetes nurse.

Q: How are you feeling now?

Prompt: what is your mood like and is it affected by your diabetes? Are you more confident about doing your part in controlling your diabetes?

Q: Do you think that you cope well, being on the insulin pump?

Prompt: Can you tell me more about that?

D. Overall

Q: Which treatment made you feel more in control of your diabetes?

Prompt: Insulin pump or MDI? Can you tell me more about that?

Q: What differences has being on an insulin pump made to your family?

Prompt: More independence? Control? Fewer arguments?

Q: Have your feelings towards your diabetes changed since starting on the insulin pump?

Prompt: Can you tell me more about that?

Q: Has the insulin pump had any impact on your life?

Prompt: has it changed your future?

Q: What is the best and worst thing about insulin pump versus MDI?

Prompt: Can you tell me more about that?

Q: Are you going to stay on insulin pump long-term?

Prompt: Yes, Maybe, No.

Q: Would you recommend the insulin pump over MDI to other children your age?

Prompt: Yes, Maybe, No.

Q: What advice would you give to someone who is going to start insulin pump now?

Prompt: Can you tell me more about that?

Q: Is there anything else you would like to tell me?

Appendix 2.6 – Transcript and Coding Example (P6, pp 7- 8)

I = Interviewer

P = Participant

	Interview	Notes/Codes
I	Very good, so when you were on the injections, what was your control, what was your control of your blood sugars like? Was it ok or?	
P	They were really, really, I think they were really good, I think I got it down to 7.	Glycaemic control good on jags
I	Wow	
P	With my injections, 6.9, I don't know whether that was on the pump on not. It was really good control, and em, its really easy now if I do, If there is something wrong with my Cannula, I like at school, I can still get my pump, type it in, and it tells me and I just type that into the injections and I know exactly what to give, I don't have to work it out on paper or anything.	Glycaemic control good on jags Pump easier to use Cannula problems Pump more automatic – helps to work out amounts of insulin required.
I	Oh that's really good so the pumps, been quite advantageous in that way cause it tells you exactly what you need to do and its less work in a way.	
P	Well there has been, there is a thing. My tube got caught on a bag and the person kept walking and they didn't realise and it snapped.	Tubing getting caught
I	Oh my goodness.	
P	And they didn't realise it was half snapped, and I was just walking along and it was really embarrassing but yeah it was like really, you couldn't use it, and it was about to be lunch so I just typed it in and I had to do injections that day but I didn't feel them and it was fine.	Tubing getting caught – embarrassment Pump not working so having to rely on injections
I	Ok, so you said that it kinda, it got caught cause some people have said that because the tube falls out of your pocket or comes out of wherever you've put it, cause it can be quite long at times that it can actually get caught quite easily. Has that happened a lot or is it just the once?	
P	Em, its got caught a few times, um, it sometimes gets caught, I think it once got caught on a desk, but nothing happened like it wasn't damaged badly. It got caught on the side of the desk and I remember walking and getting pulled back by it, but it wasn't damaged enough to do anything, it still worked.	Tubing catching - frequency
I	It still worked.	
P	Yeah it was fine.	

I	That must be a pain though having to be aware of this cord sometimes?	
P	Yeah. It's got caught in doors, it's got caught in quite a lot of things.	Tubing catching
I	Yeah, like things like door handles and things like that?	
P	Yeah, it's been caught in a door handle and it just ripped right off.	Tubing catching and cannula coming out
I	That sounds painful?	
P	It's so fast though it's less painful than taking it out normally. It just feels, it just feels like a sudden release. I did have it off cause when it came off in school I had it off for the whole day, it felt really good to have, cause it does feel weird to have, to, and especially when you're like walking and you feel it rubbing, it does feel weird. It felt so good not to have something heavy on me, not to have, and I was glad I'd gone through the injections cause it felt so good just to be able to walk knowing there's nothing there.	Pump not working – release from the heaviness of pump Pump rubbing Pump heavy Pump permanently with you/attached to you
I	So that's one of the disadvantages of the pump?	
P	Yeah	
I	It is a little bit heavy, it's always there and you can't take it off. It's permanently with you.	
P	Mmmm.	

Appendix 2.7 – Research Proposal

Title: An interpretative phenomenological analysis on the effects of continuous subcutaneous insulin infusion (CSII) therapy on children and adolescent's quality of life

Abstract

Background: Continuous subcutaneous insulin infusion (CSII) therapy has been endorsed by the National Institute for Clinical Excellence (NICE, 2008), who state that it has the ability to improve quality of life as it allows for an increase in lifestyle flexibility and greater independence as well as improving patients' blood glucose control. However, investigations regarding the impact of CSII therapy on quality of life has utilised a variety of methods, which have resulted in conflicting results (Barnard et al., 2007).

Aims: The primary aim of this study is to investigate the impact CSII therapy can have on paediatric and adolescent's quality of life, using interpretative phenomenological analysis.

Methods: 6-12 participants aged between 8 and 14 years with type 1 diabetes, and utilising CSII therapy, will be recruited from the Glasgow Royal Hospital for Sick Children diabetes' clinic. Each participant will complete an in-depth interview, exploring their beliefs and attitudes towards CSII therapy, and its impact on their quality of life.

Applications: The findings of this study can be used to help to direct resources to help young patients with type 1 diabetes achieve optimal quality of life.

1.0 Introduction

1.1 Background

The World Health Organisation (2006) classify diabetes as “a condition primarily defined by the level of hyperglycaemia giving rise to risk of microvascular damage”, and it is reportedly associated with complications such as myocardial infarction, cardiac revascularisation, stroke, kidney disease, diabetic eye disease, and foot complications (Scottish Diabetes Survey, 2009). There is also evidence that indicates that diabetic patients often have a reduced life expectancy and diminished quality of life (Scottish Intercollegiate Guidelines Network (SIGN), 2010). There are two forms of diabetes, type 1 and type 2. Type 1 diabetes is characterised by deficient insulin production, whose causation is unknown and therefore unpreventable, whereas as the more common form, type 2 diabetes, results from the body’s ineffective use of insulin and is usually accredited to excess body weight and physical inactivity (WHO), 2006).

The rising incidence of type 1 diabetes in Scottish children over the last 30 years has resulted in Scotland achieving the status of the “most common metabolic disease in the young” (Scottish Diabetes Survey, 2009; SIGN, 2010). Currently, 6.4% of people with type 1 diabetes in Scotland are aged between 5-14years old (Scottish Diabetes Survey, 2009), putting Scotland in the lead position for the highest diabetes incidence in the world (SIGN, 2010). Consequently, the SIGN Guidelines (2010) have produced recommendations regarding the treatment of type 1 diabetes. They recommend the use of continuous subcutaneous insulin infusion (CSII) for those with very low insulin requirements (such as infants and very young children), for whom even small doses of insulin may result in hypoglycaemia, and also state that it should be considered in all patients who experience

recurring episodes of severe hypoglycaemia. CSII therapy has also been endorsed by the National Institute for Clinical Excellence (NICE, 2008), who state that it has the ability to improve quality of life as it allows for an increase in lifestyle flexibility and greater independence as well as improving patients' blood glucose control.

1.2 Late Childhood and Type 1 Diabetes

Within paediatric/adolescent populations, late childhood to early adolescence is known to be a complex transitional period. Erikson (1956) stated that there were a multitude of tasks which adolescent's must undertake in order to progress through the lifecycle; for example, establishing an identity, developing peer and romantic relationships and establishing greater independence and autonomy. Research has indicated that these developmental stages can be adversely affected by the presence of a chronic disease such as type 1 diabetes (Suris et al., 2004).

Barnard, Lloyd and Skinner (2007) conducted a systematic review of studies addressing the impact that CSII could have on a patient's quality of life with regard to adult and paediatric/adolescent populations, and concluded that there were conflicting findings; these they considered were possibly due to variations in study quality and quality of life assessments used. They included three uncontrolled observational studies in a paediatric/adolescent population in which all three reported significant improvements in quality of life (McMahon et al., 2005; Mednick et al., 2004; Litton et al., 2002). However, one non-randomised controlled study and three randomised controlled trials reported no significant difference in quality of life between patients on CSII or Multiple Daily Injections (MDI) (Boland et al., 1999; Wilson et al., 2005; Weintrob et al., 2003; Fox et al., 2005).

Despite this, the most robust study cited, conducted by Hoogma and colleagues (2005), suggested that CSII does have a significant positive impact on quality of life. Nevertheless, Barnard and colleagues (2007) were forced to conclude that there was no robust evidence to support or oppose the view that quality of life benefits are associated with CSII.

1.3 Quality of Life

Despite the multitude of studies investigating quality of life, and wide recognition that chronic health conditions which require self-management places greater demands on the individual (Speight, 2009), there is currently no agreed definition. For the purpose of this study, Gill and Feinsteins (1995) definition of quality of life has been adopted. They state that quality of life is an “individual’s appraisal of the degree to which their lives contain features that they find satisfying or meaningful”. Further, they state that generally, individuals define quality of life in terms of fulfilment or purpose, personal control, interpersonal relationships, participation in pleasant activities, personal and intellectual growth and material possessions” (Barnard et al., 2007; Gill and Feinstein, 1995).

2.0 Aims

To date, investigations regarding the impact of CSII therapy on quality of life has utilised a variety of methods, which have resulted in conflicting results. Additionally, many studies have not focused exclusively on children and adolescents, or utilised qualitative methodology. Therefore, this study aims to explore the impact an insulin pump can have on the quality of life of children and adolescents’ age 8 – 14 years old, using qualitative analysis.

3.0 Plan of Investigation

3.1 Participants

Participants will be recruited from the Glasgow Royal Hospital for Sick Children's diabetes clinic. They must have a diagnosis of type 1 diabetes as specified by their consultant and which is in line with the World Health Organisation (2006) criteria. They must have been on an insulin pump for a minimum of 1 year, up to 2 years, in order for sufficient time to pass to have an effect participant's quality of life. Further, they must be aged 8 – 14 years old.

3.2 Inclusion Criteria

- 1) Have a diagnosis of type 1 diabetes as specified by their consultant and which is in line with the World Health Organisation (2006) criteria
- 2) Participants must have been on CSII therapy for a minimum of 1 year, up to 2 years, and prior to starting this treatment must have been on Multiple Daily Injections for a minimum of six months
- 3) Age 8 – 14 years old
- 4) Attend the diabetes clinic the Glasgow Royal Hospital for Sick Children
- 5) No known learning disability
- 6) No additional medical illness (mental or physical)
- 7) English must be their first language
- 8) Written consent by both participant and their parents/guardians must be obtained

3.3 Recruitment Procedure

A member of the diabetes team will approach patients who match the inclusion criteria (and their parent/guardian) either in the diabetes clinic or by telephone, inviting them to participate

in the research study. If patients express interest, both the participant and their parent/guardian will be provided with an information sheet, and an indication of how they wish to be contacted will be passed onto the principle researcher. An appointment will subsequently be arranged with interested patients, either at the time of their next diabetes clinic appointment or at another more suitable time. Participating patients and their parent/guardian will be asked to provide written informed consent. The opportunity to ask further questions will be available prior to the acquisition of consent. Participants will be recruited on a first come basis and recruitment will continue until the required number of participants has been met, or saturation of themes has been achieved.

3.4 Interview

A semi-structured interview, lasting approximately 30 – 45 minutes, will be conducted on an individual basis. This interview will be recorded using a digital voice recorder. The interviews will be structured using an interview schedule developed through discussion with the principal researcher and supervisors, and using ‘The Common Sense Model of Self-regulation of Health and Illness’ as a theoretical framework (Leventhal et al., 1984). For the purpose of the interview, the term ‘insulin pump therapy’ will be used instead of CSII as this is the term the participants are more familiar with. The interview schedule will be piloted with a subset of the sample ($n = 3$) in order to practice interview technique and to assess the appropriateness of the topic areas. Subsequently, the interview topics will be revised according to the emerging themes in the pilot interviews. Further, to ensure reliability of the analysis, a second experienced researcher will independently analyse a sample of the transcripts.

3.5 Design

The study will use a retrospective qualitative design with in-depth interviews. Concerns regarding the reliability of retrospective memory were noted, with particular emphasis on recall bias (Moss & Goldstein, 1979). There is however, accumulating research evidence that suggests that retrospective reporting is usually accurate and stable, especially when an individual is recalling a salient experience (e.g. Blane, 1996; Norris et al., 1992) and changing method of medication delivery would be a highly salient event. However, if it proved difficult to elicit and compare participant's beliefs and expectations regarding changing to CSII, a greater exploration of how type 1 diabetes can affect participant's quality of life would be carried out.

3.6 Justification of Sample Size

Between 6 – 12 participants will be recruited, dependent on respondent rates. This is in accordance with Guest and colleagues (2006) who suggest that is the number of participants required to reach data saturation. Further, Smith and Eatough (2006) indicate that this will allow the researcher to explore the participants' narratives in depth and allow a greater understanding of the participants' experiences. Data collection will be deemed completed when either when saturation of themes is reached or 12 participants have been interviewed.

3.7 Settings and Equipment

Interviews will be conducted by the principle researcher, within a private room in the Glasgow Royal Hospital for Sick Children. The interview will be conducted on an individual basis, lasting approximately 30 – 45 minutes and will be audio recorded using a digital voice recorder. They will be transcribed verbatim by the principle researcher, and all identifiable information will be removed to preserve anonymity. The recordings will be stored on an

encrypted laptop and when transcription is completed and checked, each recording will be destroyed.

3.8 Data Analysis

The use of the qualitative methodology Interpretative Phenomenological Analysis (IPA) will be employed to analyse this data. This dynamic process allows the researcher to gain a deeper understanding of the participants' individual experiences by attempting to gain an 'insider's perspective', whilst taking into consideration the principle researchers own thoughts and theoretical concepts of such experiences (Smith and Osborn, 2008).

Interpretation is both empathetic and critical, exploring the area of concern, with no attempt to test a predetermined hypothesis.

The analysis involves verbatim transcription of the interviews and requires the principal researcher to transcribe, code and then identify themes within the transcripts by following a six phase process (Smith and Eatough, 2006). Themes will be identified as recurrent when referred to by at least half of the participants. A sample of transcripts will be independently analysed by a second researcher and reliability checked by comparison of the identified themes.

4.0 Health and Safety Issues

4.1 Researcher Safety Issues

The interviews will be conducted on an individual basis, and thus the safety of both the researcher and participant will be ensured by conducting all interviews within normal working hours and will comply with standard safety procedures. When participants are being

interviewed, hospital staff will be nearby and available if required, and a panic alarm will be situated in the room. No domiciliary visits will be conducted.

4.2 Participant Safety Issues

Written consent will be obtained from both from the participant and their parent/guardian, and the opportunity to opt-out (with no repercussions) at any time will be made clear.

Confidentiality will be explained to participants at the outset and an opportunity will be given for the participant or their parent/guardian to ask questions. If any participant discloses information which indicates that they or others are at risk, those involved will act professionally and appropriately, respecting the limits of confidentiality. If psychological difficulties are apparent, this will be discussed with the participant and their parent/guardian, and they will have the option of requesting a referral to the dedicated psychology service attached to the Diabetes clinic.

5.0 Ethical issues

Ethical approval will be sought from Greater Glasgow NHS Trust Ethics Committee as well as the local Research and Development department at the Royal Hospital for Sick Children.

Participants and their parent/guardian will be asked to provide written informed consent to participate in this study. They will have the opportunity to opt-out (with no repercussions) at any time from the study, and will receive written information sheets explaining that their responses are confidential and will not influence their future treatment in any way.

Data will be handled in accordance with The Data Protection Act (1998), the Freedom of Information Act (2000) and the NHS Confidentiality Code of Practice Guidelines (2003). All identifying information will be removed to preserve anonymity. Audio recordings will be stored on an encrypted laptop and when transcription has been completed, each recording will be destroyed.

6.0 Financial Issues

Equipment costs will amount to one digital voice recorder and transcribing kit (to be borrowed from the University of Glasgow), and photocopying costs. Travel expenses for the primary researcher to and from appointments at the Glasgow Royal Hospital for Sick Children will also be required.

7.0 Timetable

May 2011:	Submit proposal to University
June/July 2011:	Proposal assessed
Aug/Sept 2011:	Apply for ethical approval
October 2011:	Begin recruitment
Feb/March 2012:	Analysis
April-June 2012:	Write up research
July 2012:	Submit research to University
September 2012:	Viva

8.0 Practical Applications

The Diabetes team at the Glasgow Royal Hospital for Sick Children are providing a greater number of insulin pumps for children and adolescents' and thus are developing their service in accordance with this. Hence, the team is supportive of this research as they may be able to utilise the findings of this study to direct resources to help young patients with type 1 diabetes achieve optimal quality of life.

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