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PARENTS' EXPERIENCES DURING THE TRANSITION FROM
CHILDHOOD TO ADOLESCENCE WITH TYPE 1 DIABETES: PARENT-
CHILD RELATIONSHIPS AND SUPPORT RECEIVED DURING THIS TIME
AND CLINICAL RESEARCH PORTFOLIO

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

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CHAPTER 1 – SYSTEMATIC REVIEW

A systematic review of the relationship between family conflict and adherence to diabetes management regime, and glycaemic control in adolescents with Type 1 Diabetes.

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Abstract

Background: Glycaemic control in Type 1 Diabetes is important in reducing the chance of future complications related to the condition. In adolescence glycaemic control and adherence to a diabetes management regimen often decreases. It is also a time when conflicts with their parents' increases as adolescents seek independence from their caregivers.

Objectives: To carry out a systematic review of the link between family conflict and adherence to the diabetes management regime.

Methods: A systematic search of relevant databases was carried out and papers were checked using predefined inclusion/exclusion criteria. Eight papers were included in this review.

Results: Higher levels of family conflict correlated with higher HbA1c levels and less frequent blood glucose monitoring (BGM). Differences between maternal and paternal report of family conflict were found as well as differences between parent and adolescent report. Adolescent-reported conflict with their father was directly related to frequency of BGM while adolescent-reported conflict with their mother was indirectly related to frequency of BGM through adolescent externalizing symptoms. Factors that mediate the relationship between family conflict and glycaemic control included adolescent anxiety and aggression. Family conflict mediated the relationship between caregiver negative affect about BGM and glycaemic control.

Conclusions: Further research is required to add to this evidence base. There is a relationship between level of family conflict and adherence to diabetes management regimen and glycaemic control. Consideration should be taken of which parent performs the main diabetes caregiver role. Individual factors should be considered when choosing appropriate interventions for adolescents struggling with glycaemic control.

Key Words

Type 1 Diabetes, Adolescents, Family conflict, Adherence

Introduction

Type 1 Diabetes (T1D) is a chronic condition characterized by a deficiency in the body's insulin production, with onset typically occurring in childhood or adolescence. The cause of T1D is not known and there is currently no known way of preventing it. People with T1D need insulin, administered daily, to regulate their blood glucose levels (1).

As children reach adolescence they seek to become more independent of their parents and they find more affiliation with their peers (2). Adolescents use a number of strategies to gain this independence, ranging from more obvious behavioural tactics, to less evident cognitive strategies (3). As this desire to be independent of their parents becomes stronger in adolescence, the level of conflict with their parents increases (4).

Adolescence is a particularly important time for young people with Type 1 Diabetes for a number of reasons. It is often the time when young people take on more responsibility for their diabetes management from their parents (5), and it is also a time when neurohormonal changes can affect endocrine pathways, which in turn influence metabolic control (6). As a result of these neurohormonal changes, good diabetes management is integral to reducing the possibility of future diabetes related complications (7). Although this need for good control to prevent future complications is well documented, adolescence is typically a time when adherence to the diabetes management regime becomes a problem (8).

A number of studies have looked at the relationship between levels of family conflict and glycaemic control/adherence to diabetes management across the age range of paediatric populations (9, 10, 11). Family conflict is measured in varying detail depending on which assessment tool is used. Some assessment tools concentrate solely on conflict and all questions in the tool relate to this whereas others contain conflict as a subscale within a broader relationship assessment. The measures of family conflict, or the subscales relating to family conflict concentrate on arguments or disagreements that occur between family members. Questionnaire items ask

the completer to rate how often they argue or disagree with their parent/child either generally or in relation to specific tasks such as diabetes management tasks. The studies found that an increased level of family conflict is related to less glycaemic control, however, one study only found this effect in upper-class families (10). One study found that more advanced pubertal status in young people also predicted less glycaemic control (9) and another found that higher levels of psychological distress were associated with more family conflict (11). This suggests that it is important to consider other factors that may impact on the relationship between family conflict and adherence/glycaemic control. Given that in adolescence there are a number of additional factors that make diabetes control more difficult and increase the risk of family conflict, it is important to examine this group of young people independent of younger children to establish whether there are any lessons to be learned about this particular cohort.

Rationale and Objectives

Research into the link between family conflict and adherence to diabetes management regime, specifically in adolescence, is being conducted, but a systematic review of the research has not yet been carried out. The aim of this systematic review is to determine whether level of family conflict has an effect on adherence to diabetes management regime in adolescents and, if a link is found, whether there are any factors that mediate this relationship.

Method

Search Strategy

Searches of the databases MEDLINE, EMBASE and PsycINFO were carried out. An additional search of Web of Science was completed and the reference sections of the final eight articles were hand searched. The databases were searched individually with limits of English language and age [13-17 for PsycINFO and EMBASE, 10-18 for MEDLINE]. The searches were also limited to articles published from 2000 to present in order to ensure the review captured more recent literature. The following search terms show the exact terms used for the search of PsycINFO. Searches in other databases were adjusted to fit with the database search strategies:

Family conflict OR Family n3 conflict

AND

Diabetes OR Diabetes Mellitus OR Diabetes n3 ('type 1' OR 'type one')

The search was initially carried out on 15th April 2016 and was repeated on 6th May 2016. The search resulted in 167 articles; screening article titles led to the exclusion of 46 duplicates; 121 abstracts were screened using the following suitability criteria;

Inclusion Criteria

- Published in a peer reviewed journal
- Published in English Language
- Participants must be adolescents (aged 12-18) with a diagnosis of T1D
- Must measure and report level of family conflict
- Must measure and report adherence to treatment and/or glycaemic control

Exclusion Criteria

- Reviews, dissertations and single case studies
- Qualitative methods

Studies that failed to meet these criteria were excluded from the review, resulting in 13 articles that appeared suitable for inclusion. These 13 articles were obtained and the full text was checked using the same inclusion/exclusion criteria. This resulted in five studies being removed leaving eight articles that were suitable for inclusion. The reference sections of these eight articles were also searched for further suitable articles. Two abstracts were obtained and examined, however, they did not meet criteria for the review. No further articles were identified. In total, eight articles were included in this review. Figure I details the flow of studies through the identification process.

Figure I: Procedure of identifying papers included in the review.



Procedure

The final eight articles were reviewed using a quality rating scale developed by the researcher following consultation of the CONSORT 2010 guidelines (12), the Scottish Intercollegiate Guideline Network methodology (13), and the Downs and Black checklist for non-randomised studies (14). Items included in the rating scale were chosen to reflect the methodological aspects that were important in the studies to be examined. As the target articles were not treatment studies, questions relating to treatment or adverse events, control groups, randomisation and blinding procedures were excluded. Items were added to assess the presence and quality of measures relating to family conflict and glycaemic control. The quality rating scale was discussed with an experienced researcher to ensure all relevant areas were covered. The quality rating scale is detailed in Appendix 2.1. Each study was awarded points in relation to the following areas: aims, participants, recruitment, outcomes, measures, statistical analysis, confounding variables and discussion. A maximum of 36 points could be awarded. Studies were categorized as (A) representing a percentage score between 80% and 100% (good quality), (B) representing a percentage score between 55% and 79% (moderate quality), or (C) representing a percentage score of between 0% and 54% (poor quality).

In order to ensure the validity and reliability of the quality rating scale, and to control for bias, a second researcher rated 50% of the articles independently. Discussion between the two researchers took place to reach agreement on all items.

Results

Quality rating of studies

An overview of the final eight studies is shown in Table I. Table I presents information on the primary aim, participants, measure of adherence/glycaemic control, measure of family conflict, method of statistical analysis, main findings and quality rating percentage score of the studies.

Six of the studies were rated as 'Good' quality (75%) and two were rated as 'Moderate' quality (25%). A breakdown of the study ratings can be found in Appendix 2.2.

Table I. Overview of studies

Study [Reference number] (Country and Quality rating %)	Primary Aim	Participants	Adherence/ Glycaemic control measures	Family conflict measures	Data Analysis	Main Findings
Gray <i>et al.</i>, 2013 [17] USA 80.56%	To examine the associations among adolescent and caregiver Negative BGM affect, diabetes-specific family conflict, and A1c.	150 adolescents (age 13-18) and one of their caregivers. Participants had a diagnosis of T1D and were receiving treatment at a paediatric tertiary medical centre.	A1c	Diabetes Family Conflict Scale - revised	Correlation and regression analysis	Greater negative BGM affect predicts more conflict, which in turn results in higher A1c. In adolescents, only conflict about direct diabetes management tasks mediates the relationship between negative BGM affect and A1c.
Hilliard <i>et al.</i>, 2013 [18] USA 80.56%	To examine the patterns and predictions of BGM frequency and glycaemic control.	150 adolescent (age 13-18) – parent pairs. Participants had T1D and were receiving multidisciplinary care at a tertiary	BGM frequency. A1c	Diabetes Family Conflict Scale - revised	Latent group-based trajectory monitoring.	3 subgroups were identified – ‘meeting targets’, ‘not meeting targets – normatively similar’ and ‘not meeting targets – high risk’. More diabetes specific family conflict predicted membership of a subgroup with poorer

		paediatric medical centre.				diabetes management and control.
Luyckx <i>et al.</i>, 2013 [16] Germany 69.44%	To investigate how parent-adolescent conflict, treatment adherence, and glycaemic control are interrelated over time, and whether externalizing and internalizing symptoms function as mediators.	109 adolescents with T1D. Participants were recruited from 17 paediatric healthcare services.	Physician-report HbA1c	Network of Relationships Inventory	Cross-lagged path analysis from a structural equation modeling approach.	Father-adolescent conflict positively influenced treatment non-adherence over time leading to higher HbA1c mediated by externalizing, but not internalizing, symptoms. Mother-adolescent conflict was indirectly related to non-adherence through its relationship with externalizing symptoms.
Moore <i>et al.</i>, 2013 [22] Australia 77.78%	To examine the interaction between adolescent disease control in T1D and family functioning.	76 parent-adolescent dyads with adolescents aged 12 to 18. Participants were recruited from diabetes clinics at the Royal Children's Hospital (Melbourne).	Diabetes Self-Care Inventory HbA1c	Child Health Questionnaire Parent Report	T-test and correlation	Higher HbA1c and worse adolescent self-care were associated with lower family functioning, poorer adolescent mental health and more behavioural difficulties. Parent-rated family conflict, and disease impact on family dynamics and parental stress were all rated as high.

Hilliard <i>et al.</i>, 2011 [19] USA 86.11%	<p>To investigate the impact of BGM frequency on the relationship between diabetes-specific family conflict and glycaemic control for one year.</p>	<p>145 adolescent (13-18)-parent pairs.</p> <p>Adolescents had a diagnosis of T1D.</p> <p>Participants were recruited from diabetes clinics in a large tertiary care children's hospital.</p>	<p>HbA1c</p> <p>Frequency of BGM</p>	<p>Diabetes Family Conflict Scale - revised</p>	<p>Correlation , ANOVA and multivariate linear models.</p>	<p>Higher adolescent-rated family conflict predicted less frequent BGM and higher HbA1c levels with BGM frequency accounting for 24% of the variance in the link between family conflict and HbA1c.</p> <p>Caregiver marital status and method of insulin administration at baseline were both associated with glycaemic control one year later.</p>
Herzer <i>et al.</i>, 2011 [20] USA 80.56%	<p>To examine whether anxiety or depressive symptoms, or diabetes-specific worry mediate the family conflict-glycaemic control link.</p>	<p>147 adolescents (aged 13-18) and one of their caregivers.</p> <p>Participants were recruited from diabetes clinics at a paediatric tertiary care centre.</p>	<p>A1c</p> <p>Frequency of BGM</p>	<p>Diabetes Family Conflict Scale - revised</p>	<p>Bivariate correlation and mediator analysis.</p>	<p>Caregiver-reported family conflict was correlated with A1c, anxiety scores, depressive scores and diabetes-specific worry.</p> <p>Anxiety symptoms accounted for 20% of the family conflict-glycaemic control link.</p> <p>Depressive symptoms and diabetes-specific worry did not mediate the family</p>

						<p>conflict-glycaemic control link.</p> <p>More frequent BGM correlated with lower A1c.</p>
<p>Ingerski et al., 2010 [21]</p> <p>USA</p> <p>83.33%</p>	<p>To examine changes in responsibility for diabetes management tasks and diabetes-specific family conflict, and their relationship to frequency of BGM and blood glucose control in relation to age and time.</p>	<p>147 adolescents with T1D and their primary caregiver.</p> <p>All participants were receiving care from a multidisciplinary team at a paediatric diabetes centre.</p>	<p>HbA1c</p> <p>Frequency of BGM</p>	<p>Diabetes Family Conflict Scale - revised</p>	<p>ANOVA and hierarchical regression analysis</p>	<p>As age increased, responsibility for diabetes management tasks shifted from caregiver to adolescent.</p> <p>Diabetes specific conflict did not change with age or time.</p> <p>Higher HbA1c and less frequent BGM was seen with increasing age.</p> <p>Greater adolescent responsibility and more family conflict predicted less frequent BGM at 6 months.</p>
<p>Anderson et al., 2009 [15]</p> <p>USA</p>	<p>To identify aspects of family behaviour that are associated with glycaemic</p>	<p>64 adolescents (age 12-14) and their primary caregiver in relation to their diabetes management.</p> <p>Participants were</p>	<p>HbA1c</p>	<p>Diabetes Family Conflict Scale</p>	<p>Correlation and regression models</p>	<p>Greater parent-reported family conflict was correlated with less glycaemic control.</p> <p>Adolescent-reported family conflict was not correlated with glycaemic control.</p>

83.33%	control in adolescents with a diagnosis of T1D.	recruited from four large paediatric tertiary care diabetes centre's.				Level of dyadic agreement was not correlated with HbA1c levels.
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Key

A1c = Shortening of HbA1c = Glycated haemoglobin

ANOVA = Analysis of variance

BGM = Blood Glucose Monitoring

HbA1c = Glycated haemoglobin

T1D = Type 1 Diabetes

Demographic information

In total, 399 adolescents and their parent(s)/caregiver(s) participated in the eight studies included in this review. 200 (50.13%) of the adolescents were female and 199 (49.87%) were male. The age range was 12 to 18. One study included a younger age group of 9 to 11 year olds (15). This study separated the age groups so it was possible to obtain data for the older age group of 12 to 14 year olds and the younger participants were excluded from all analyses including the overview of studies (Table I). Of the parents/caregivers: 187 were mothers, 39 were fathers, 64 were unspecified by the study, and one study (16) used only the adolescents but examined their views on both parents for each adolescent (n adolescents in that study = 109). Five of the studies used the same participant cohort (17, 18, 19, 20, 21) and four of these studies reported the ethnicity of the participants. One other study also reported the ethnicity of its participants (15). 216 of the adolescents were Caucasian, 14 were African-American, 12 were Hispanic, 9 reported other or mixed ethnicity, and 20 of the adolescents ethnicity was not specified. Two studies did not report on the ethnicity of their participants (16, 22). All of the studies reported the mean duration of participants T1D. The pooled mean duration of T1D, in years, was 5.59 (pooled SD= 3.68).

Research Design

Five of the papers included in this systematic review used data from the same longitudinal research study (17, 18, 19, 20, 21). One of the three remaining studies also used a longitudinal design (16) while the other two used a cross-sectional design (15, 22). All of the studies employed self-report methods of data collection.

One study specified that it was a pilot and feasibility study and therefore had not used a power calculation to select the sample size for the study (15). None of the other studies reported power calculations and therefore all eight papers reviewed may be unreliable due to a lack of power.

Treatment Modality

Six of the final eight studies reported the method of treatment participants were receiving (17, 18, 19, 20, 21, 22). This means that method of treatment data was only gathered in two of the cohorts. One cohort had 22 participants receiving their insulin via pump, one participant who did not report the method of insulin administration and the rest ($n=53$) receiving insulin via multiple daily injections (22). The cohort from the other five studies included 95 participants who received their insulin via a pump and the remaining 55 received multiple daily injections. It is useful to know the treatment modality of the participants in the studies, however, none of the studies separated participants receiving multiple daily injections and participants using an insulin pump in their analysis. This is an important factor to consider as method of insulin administration has been shown to have an effect on adherence to diabetes management regime (23).

Assessment of glycaemic control/diabetes management

All eight of the studies measured HbA1c levels using data collected from blood samples obtained at diabetes clinic visits.

Four studies used frequency of blood glucose monitoring (BGM) to measure adherence to the diabetes management regimen (18, 19, 20, 21). This data was obtained from meter readings or clinician notes taken at clinic visits and the frequency of daily checks was averaged from the previous two weeks. Where meter readings were not available, self-report or clinician report (based on clinical interactions) of frequency was used. One study used a physician-report questionnaire to assess adherence to diabetes management regimen (16). One study used an adolescent self-report questionnaire called the Diabetes Self Care Inventory (24) to measure diabetes management (22). Two studies did not measure adherence to diabetes management regimen (15, 17).

Measures assessing family conflict

Six studies used the revised Diabetes Family Conflict Scale (25) to assess the level of family conflict (15, 17, 18, 19, 20, 21). Five studies used both the

parent and adolescent reporting on this scale while one only used caregiver report on this scale (18). One study used the Network of Relationships Inventory (26) to assess family conflict (16). The adolescents, but not the parents/caregivers completed this. One study used the Child Health Questionnaire (27) Parent report (CHQ-PF50) to assess levels of family conflict (22).

Findings

The eight studies in this review examined the relationship between levels of family conflict and glycaemic control. Six studies measured diabetes-specific conflict and two measured more general levels of family conflict (16, 22). Three studies measured the effect of mediating factors on the relationship between family conflict and glycaemic control (16, 19, 20) while one study tested family conflict as a potential mediating factor in the relationship between glycaemic control and negative affect about BGM (17).

Family conflict

Six of the studies examined diabetes specific family conflict. Five of these studies used the same cohort but measured the relationship between diabetes specific family conflict and glycaemic control/adherence at different time points. These five studies found that level of diabetes specific family conflict was significantly correlated with HbA1c levels at baseline (17, 18), and predicted HbA1c levels at 6 months (21), 9 months (20) and 12 months (19). The sixth study (15) also found that diabetes specific family conflict was significantly related to HbA1c levels. Two studies (16, 22) measured general levels of family conflict. Both found that higher levels of general family conflict were associated with higher levels of HbA1c.

Maternal conflict vs. paternal conflict

One study (16) separated maternal-adolescent and paternal-adolescent conflict, as reported by the adolescents. This study found that level of paternal conflict positively predicted frequency of BGM, which, in turn, positively predicted higher levels of HbA1c. The study found that level of maternal conflict did not directly influence frequency of BGM but was related

indirectly through the influence that conflict had on the adolescents externalizing symptoms. A separate study reported that the level of maternal-reported family conflict was higher than paternal-reported family conflict (19).

Adolescent report vs. parental report

Five of the papers (15, 17, 19, 20, 21) explored both adolescent and parental report of family conflict, two (18, 22) only explored parental rating of family conflict and one (16) only measured adolescents experience of family conflict. The studies that relied on parental report alone found a significant relationship between the level of family conflict and diabetes control. More family conflict was correlated with poorer HbA1c and less frequent BGM. The study that relied on adolescent report alone separated the adolescents' experience of conflict with each individual parent. The findings of this study can be found in the paragraph previous to this. One study found that caregiver reported conflict was correlated with A1c values at 9 months whereas adolescent reported caregiver conflict did not correlate with A1c values at 9 months (20).

Mediators

A number of the papers examined factors that mediate the relationship between family conflict and glycaemic control, and one study used family conflict as a mediating factor between glycaemic control and negative affect about BGM. One study found that the frequency of blood glucose monitoring accounted for 24% of the variance in the family conflict-glycaemic control link when family conflict was rated by adolescents. It found a smaller but still significant mediation effect when caregiver reported family conflict was used (19). One study found that anxiety accounted for 20% of the family conflict-glycaemic control link. This study also found that neither depression or diabetes-specific worry acted as significant mediators in the family conflict-glycaemic control link (20). One study found that adolescent externalizing symptoms (aggression and delinquency) mediated the link between family conflict and glycaemic control but found that adolescent internalizing symptoms (anxious/depressed, withdrawn, and somatic complaints) did not mediate this link (16). This finding is in line with the previous study, which

found no mediating effect of depression but is in contrast to the previous studies finding that anxiety was a mediator in the conflict-glycaemic control link. Finally, one study found that level of family conflict, as reported by caregivers, accounted for 39% of the variance in the link between caregiver negative affect about BGM and adolescent glycaemic control. It also found that adolescent reported family conflict accounted for 30.6% of the variance between caregiver negative BGM affect and adolescent glycaemic control (17).

Discussion

A number of the papers in this study point out that their data relies on the patients attending clinic to complete the research measures. This means that the results may have a bias towards families who are more engaged in medical care for their diabetes and possibly, therefore, better at managing their diabetes than the overall T1D population. That said, the results show a relationship between family conflict and poor control and therefore it seems that reduction of family conflict is an important area for intervention. The results found that higher levels of family conflict are correlated with higher HbA1c levels and less frequent BGM. There appears to be a difference between mothers and fathers, both on how much conflict they have with their adolescent, based on adolescent ratings, and in how much conflict they themselves report with their adolescent. This could be important in helping families to decide who takes on the role of main caregiver in relation to the child's T1D, however, the findings may also be a result of the tendency for mothers to be the main carers in relation to disease treatment responsibility in paediatric populations (28). It may be that mothers are involved in more conflict because they are the parent who most often enforces the diabetes treatment regimen, and therefore, changing the main caregiver to the father, in relation to T1D, would simply result in a shift to greater conflict being reported in relation to the father than the mother. There also appears to be a discrepancy between the views of adolescents and their caregivers on level of family conflict. This shows that it is important to remember that adolescents and parents may view conflict differently. Where parents may find conflict frustrating, and may place more focus on conflict related to diabetes, adolescents may view diabetes related conflict as part of the normal levels of family conflict that occur during adolescence. They may also be less affected by family conflict as their focus is moving more towards their relationships with their peers (2). Finally, it is apparent that the link between levels of family conflict and glycaemic control does not occur in isolation. Anxiety, aggression and delinquency, and frequency of BGM all mediate the link between family conflict and glycaemic control. Individual characteristics of adolescents play an important role in the link between family conflict and glycaemic control.

Methodological Limitations and future research

One of the major limitations of this research is that five of the eight studies examined used data from the same research study. This means that the review was taking information from only four separate participant cohorts, which limits the application of the findings. Due to time limitation, it was not possible to contact authors to try to extract specific data from the papers. As a result of this, some studies were excluded as they analysed children outwith the inclusion age range as well as children within the acceptable range, and therefore, a far smaller number of papers were included in the review. All of the studies involved populations from Western societies. This limits the generalisability of the findings to other cultures with T1D. Finally, as none of the studies used a power calculation to determine sample size it is possible that the results reviewed in this paper are not reliable.

It is clear that this area of research requires more investigation in order to build on the evidence presented in this review. Preliminary findings appear to show a relationship between levels of family conflict and glycaemic control making it a possible area for targeted intervention, however, with such a small number of studies it is difficult to generalise the findings. Future research should seek to replicate the findings of this review by looking specifically at the adolescent population with T1D. The lack of differentiation between methods of insulin administration is an important consideration for future research. Research carried out without controlling for treatment modality may not be generalisable to the T1D population.

Clinical Implications

The results of this systematic review indicate that level of family conflict is related to HbA1c levels and frequency of BGM. Interventions that help families to resolve conflict should be implemented where family conflict is high and research into HbA1c levels and frequency of BGM before and after these interventions would be beneficial in building on the relationship observed in this review. The results of this review suggest that consideration of which parent takes on the role of caregiver in relation to T1D may have an effect on family conflict and in turn glycaemic control, although this requires

further research. When considering interventions targeted at family conflict, clinicians should consider individual characteristics such as anxiety and delinquent behaviour as alternative areas for intervention.

Conclusion

Overall, the results of this review show that level of conflict in families with T1D is correlated with glycaemic control and adherence to diabetes management regime. Further research is needed to build on this evidence base and to explore other factors (such as choice of caregiver in relation to T1D, adolescent anxiety and aggression) that may mediate the relationship between family conflict and glycaemic control.

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CHAPTER 2 – MAJOR RESEARCH PROJECT

Parents' experiences during the transition from childhood to adolescence
with Type 1 Diabetes: parent-child relationships and support received during
this time

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Plain English Summary

Title – Parents' experiences during the transition from childhood to adolescence with Type 1 Diabetes.

Background – Type 1 Diabetes is a chronic condition that requires daily treatment to control. When young children have Type 1 Diabetes their parents are often very involved with this treatment. When they become teenagers, parents may take a step back from being involved in their child's treatment. This can cause worry for parents and can cause difficulties in the parent-child relationship.

Aims and Questions – The aim of the study is to find out about parents experiences during the change from childhood to adolescence. The study aims to find out how the parent-child relationship changes and how supported parents feel to be able to cope with these changes.

Methods – Parents of children with Type 1 Diabetes were recruited from the NHS Highland Paediatric Diabetes Service. The child had to be aged between 13 and 17, to have been diagnosed with Type 1 Diabetes before the age of 13, and they must have had Type 1 Diabetes for at least two years. Eligible parents were sent an information pack about the study, they were told about the study through a newsletter and a poster, and they were given a reminder about the study when they attended their clinic appointment with the Paediatric Diabetes Team. Participants took part in one semi-structured interview with the researcher. This was recorded and then transcribed and the

researcher removed any information, which may have identified the participant or anyone that they talked about during the interview. The transcripts were analysed using Interpretative Phenomenological Analysis. This is a qualitative method, which aims to explore people's experience of significant events.

Main findings – Three people consented to take part in the study. Six main themes were identified from the interviews. These were practicalities, emotional impact, other peoples understanding, conflict, control, and support. Participants talked about the amount of new equipment and learning involved when their child was diagnosed with Type 1 Diabetes. They said that there was an emotional impact on the whole family and talked about how difficult it was to see their child in distress. Parents talked about how they always worry about their child and spoke about the difficulties of getting other people to understand the seriousness of diabetes. Participants said that they preferred when they were in control of their child's diabetes care but said that trying to be involved often caused conflict with their teenager. Participants said that the support from the Paediatric Diabetes team was very good as they were always available, however, they said that there was a long wait before the first clinic appointment and said that facilitated groups to discuss worries may be helpful. More research into these suggestions would be helpful.

Conclusions – Participants experienced worry relating to aspects of their adolescents Type 1 Diabetes that they could not control, but were aware that trying to keep control caused arguments with their adolescent. Areas of future research were identified.

Scientific Abstract

Background: Type 1 Diabetes (T1D) management often worsens as children become adolescents. This can be a difficult time for parents as they hand over responsibility of diabetes management to their adolescent.

Objectives: To look at the experiences of parents with a child with T1D as they move to adolescence and take more responsibility for their diabetes management. To find out about parents' experience of support during this transition.

Subjects: Three parents of adolescents with T1D. Participants were recruited from the NHS Highland Paediatric Diabetes Service.

Methods: Participants took part in a one-to-one semi-structured interview with a researcher. Interpretative Phenomenological Analysis was used to analyse the interviews and find common themes across the interviews.

Results: Participants experienced worry throughout their child's transition to adolescence. They found it difficult to let their child take responsibility for their diabetes but acknowledged that their involvement caused tensions with their adolescent. Participants' experience was that there were a number of practical adjustments to be made with a diagnosis of T1D and educating the network around their child was important. The participants reported that the diagnosis of T1D had an impact on the whole family and not just the child with the diagnosis. The parents felt well supported medically but said that the amount of time before their first clinic appointment felt too long. All participants had concerns about their adolescent moving to the adult diabetic service.

Conclusions: Participants experienced worry relating to aspects of their adolescents T1D that they could not control, but were aware of the tensions caused by trying to keep elements of control. Areas of future research were identified.

Key Words

Type 1 Diabetes, Adolescence, Parents' experience, Relationships, Support

Introduction

Type 1 Diabetes Mellitus (T1D) is one of the most common chronic illnesses in childhood (1). If not managed effectively, it can cause serious short and long-term consequences (2). T1D is characterized by raised blood sugar levels (3) and can be detrimental to both life expectancy and quality of life (4).

A diagnosis of T1D results in the need for a strict routine of managing diet, exercise, and insulin levels to avoid high blood sugar levels (5). For young children, they must rely on their parents to manage these factors due to the complexity of the tasks involved. This can lead to difficulties when they enter school, as the parent will not be present during the school day (1). A systematic review examined the impact on parents of having a child with a diagnosis of T1D, and found that anxiety and depression is common (6). A further study found that parents of children with T1D experience increased stress in relation to parenting tasks in comparison to parents of healthy children (7).

As children with a diagnosis of T1D transition from childhood to adolescence they are faced with new challenges relating to their chronic illness. Adolescents go through major changes as they develop both physically and mentally, making the regulation of blood sugar levels more difficult (4). At this time, responsibility of diabetes management begins to be passed from the parent to the adolescent as they learn to become more autonomous in controlling their blood sugar levels. Studies have found that control of diabetes during adolescence worsens (8), and there is a decline in self-care behaviours for disease management during this time (9).

As well as the consequences for the adolescent, the transition from childhood to adolescence has repercussions for parents of children with T1D. Studies have shown that parents 'letting go' and gradually allowing their child to become more independent with their diabetes management find this stressful (10), and experience feelings of worry and frustration in relation to their teenager self-managing their diabetes (11).

Evidence suggests that the most successful adolescent management of T1D occurs when the right balance of adolescent autonomy and parental assistance and monitoring is established (12,13). This is a difficult equilibrium to find, as many adolescents do not adhere to their treatment regime (14) but well-intentioned efforts, by parents, to assist with diabetes management can be perceived by adolescents as controlling and intrusive (15).

Research by Dashiff *et al.*, (16), of 131 families with an adolescent, aged 11-15, found that mothers will have more difficulty in encouraging autonomy in adolescents if they are anxious about separation from their child. A study by Luyckx *et al.*, (17) found that more father-adolescent conflict resulted in higher treatment non-adherence in T1D. In contrast, persuasive strategies used by mothers have been shown to lead to improvements in next-day blood glucose management (18). Parents using an autonomy supportive approach will have an increased chance of their adolescent sharing their diabetes tasks with them (19).

Previous research has focused on the emotional impact of T1D on parents and adolescents. There is also some research into interventions to reduce conflict between parent-adolescent dyads, but there is limited research into how supported parents feel during the transition of their child from childhood to adolescence. The aim of this study is to examine the experiences of parents with children who have transitioned from childhood to adolescence with a diagnosis of T1D. Specifically, the study will explore how their relationship with their child changes and how supported they feel during the transition of their child into adolescence.

Ethics

Ethical approval was given by the Cambridgeshire and Hertfordshire Ethics Committee (study number – 16/EE/0082). The project was initially approved on 15th March 2016 (Appendix 3.1). After seeking NHS Highland Research and Development approval which was granted on 31st March 2016 permission for a major amendment was sought. This was due to the NHS

Highland Paediatric Diabetes team having concerns that the wording of the study title and sections of the participant information sheet would result in the study becoming an evaluation of their service rather than a study of parent experiences. During discussion it was also decided that the inclusion criteria should be more explicit in stating the length of time participants should have had diabetes and the maximum age they should have been when diagnosed. This was to ensure parents had experienced a change in the level of involvement in their child's diabetes management. The major amendment was permitted by the Cambridgeshire and Hertfordshire Ethics Committee on 20th May 2016 (Appendix 3.2).

Methods

Subjects

Participants were parents of adolescents (aged 13-17) who had a diagnosis of Type 1 Diabetes Mellitus. Participants were recruited from the NHS Highland Paediatric Diabetes Service. The study aimed to recruit between 4 and 10 participants and to interview each of them once. This is the number of interviews that Smith, Flowers and Larkin (20, pp 52) recommend for a practitioner doctorate level research project. In line with Smith, Flowers and Larkin's (20, pp 49-51) guidance, the sample interviewed was selected purposively so as to be homogeneous for being the parent of a child with Type 1 Diabetes.

Inclusion Criteria

- Participants must be the parent of an adolescent (aged 13-17) with Type 1 Diabetes Mellitus.
- The child must have been diagnosed before the age of 13
- The child must have had a diagnosis of Type 1 Diabetes Mellitus for at least two years.
- Participants must speak English fluently and have the capacity to consent to the study.

Exclusion Criteria

- Participants will be excluded if they are deaf, as the project does not have sufficient funds for an interpreter.
- Participants will be excluded if their child has Type 1 Diabetes Mellitus but is aged 12 or under.
- Participants will be excluded if they are a parent to the same child as an individual who is already a participant in the study.

There were 21 families that met eligibility criteria for the study.

Protocol

Potential participants were informed about the study in four separate ways. Firstly, the study was mentioned in a newsletter sent out by the paediatric diabetes team to all parents of children in the service. Secondly, the 21 eligible parents were sent a recruitment pack containing a covering letter from the paediatric consultant of the diabetes team introducing the study (Appendix 3.3), a participant information sheet (Appendix 3.4), and an opt-in form (Appendix 3.5), along with a stamped addressed envelope to return the opt-in form should they wish to participate. Thirdly, eligible parents were given a flyer advertising the study (Appendix 3.6), a participant information sheet and an opt-in form when they attended the diabetes clinic. This was done in order to serve as a prompt for any parents who might have wanted to participate when the information pack was sent to them but did not return the opt-in form at the time. The opt-in form could be given to any member of the diabetes team, or if the parent still had the stamped addressed envelope they had been sent they could use that to send the opt-in form to the researcher without involving the diabetes team. The opt-in form also had an email address and a telephone number that the researcher could be contacted on. Finally, a poster for the study (Appendix 3.6) was displayed in the waiting room of the paediatric diabetes clinic. The poster contained contact details on which the researcher could be reached.

Participants took part in a semi-structured, one-to-one interview with the researcher. An interview schedule (Appendix 3.7) was developed to cover the key areas to be explored and appropriate prompts to encourage participants to fully participate in the interview. Interviews took place at Raigmore Hospital in Inverness and were arranged for a time that was convenient for the participant. Before the interview began, participants were given an opportunity to ask any questions they had about the study. They then completed a consent form (Appendix 3.8) before the recorded interview took place. After the interview, the researcher transcribed the recording and anonymised any identifiable information. This included person and place names, and any identifiable hobbies. Transcripts were then double checked by the researcher by reading the transcript whilst listening to the recording for a second time.

Data Analysis

Data were analysed using Interpretative Phenomenological Analysis (IPA). This is a qualitative method, which focuses on the way in which people make sense of their significant life experiences (20, pp 1). Analysis using IPA follows six steps, as set out by Smith, Flowers and Larkin (20, pp 82-102). These steps are;

1. Reading and re-reading – *each transcript is reviewed multiple times to gain a contextual and holistic understanding of the entire narrative.*
2. Initial noting – *each interview is studied to examine semantic content and language.*
3. Developing emergent themes – *exploratory comments were analysed to identify emergent themes.*
4. Searching for connections across emergent themes – *mapping how themes fit together.*
5. Moving to the next case – *repeat steps 1-4 for each transcript.*
6. Looking for patterns across cases – *identifying the most illuminating themes and how they interconnect across participant transcripts.*

Following the researcher's analysis, extracts from the interviews were analysed by a second researcher with experience of IPA to check the identification of themes. An extract from the analysis document identifying themes can be found in Appendix 3.9.

Results

Of the 21 eligible parents approached to take part in the study, three people took part. All three were mothers, two had sons and one had a daughter with Type 1 Diabetes. Due to the small number of participants, all references to the gender of the child with T1D have been anonymised in any interview quotations used in this report.

During analysis, six super-ordinate themes were identified with a total of 19 emergent themes. The themes and super-ordinate themes are listed in Table I. Some sections of the quotations used have been left out as they were either not relevant or would potentially identify the participant. The excluded sections are indicated by the symbol [...]. An example of the type of section that has been excluded can be found in Appendix 3.10.

Table I – Super-ordinate and emergent themes identified during analysis.

Super-ordinate themes	Emergent themes
1. Practicalities	I. Equipment II. Calculations III. Communication
2. Emotional Impact	I. Impact on whole family II. Possibility of child's death III. Parental anxiety IV. Seeing child's distress
3. Other peoples understanding	I. Educating the network around the child II. Understanding seriousness of condition
4. Conflict	I. Nagging parent II. Parents feelings of frustration III. Child's anger IV. Trying to find solutions to conflict

5. Control	I. Parents need for control II. Continued support when leaving home
6. Support	I. Support from diabetes team II. Support from parents group III. Routine emotional support IV. Fear about adult services

1. Practicalities

Participants all spoke about the practicalities of having a child with Type 1 Diabetes. Three themes were identified within the super-ordinate theme of practicalities.

I.

Firstly, participants spoke about the amount of equipment that is required to manage T1D.

“...you get loads of stuff, you know, eh you know, you need a whole cupboard for all the diabetic stuff, you need to clear space in your house for it. There’s a big box under my bed and then there’s a cupboard in the hall that has all [child]’s diabetic stuff, emm, so you get you know, pump, eh not pumps, eh meters and ketone meters and glucose sticks and ketone sticks and lancets emm, spare meters and [...] finger prickers, and eh you know umm... kits and urine testing things and, quite a lot of paraphernalia that you get emm, all of a sudden. I mean a, big, box.”

[Participant 2, Page 4]

II.

Secondly, they mentioned the complicated calculations that need to be done each time insulin is given.

“So then we had to do a lot of carb counting, so you have to work out how much carbohydrates is in [child’s] food and then do a calculation, and it’s quite complicated for parents cause you have to work out how much carbs there is, then you have to work out according to a carb ratio how much insulin you give [child], then you have to adjust it depending on what [child’s] sugar is, so there’s an adjustment factor depending on what [child’s] sugar is, before [child’s] dinner, and then you have to do another adjustment depending on what [child’s] about to do. [...] So there’s quite a lot to kind of calculate.”

[Participant 2, Page 5]

Participants also talked about the calculations in the context of the child having to do them without assistance.

“...and the problem then was that [child] was gonna have to work out [child’s] ratios, and [child’s] injection, and do that [themselves] at school, [...] [Child] would be screaming and, crying, and we didn’t understand why [...] [child] says it was because [child] was frightened, with [child] having to control it [themselves],”

[Participant 3, Page 3]

III.

Finally, participants talked about needing to be able to contact their child and vice versa at any time.

“[Child] actually had a mobile phone quite early on because I wanted [child] to be able to contact me, umm, if [child] needed to ask, “mum I’m eating this and I need to know what my, umm, insulin should be”, so [child] had a mobile phone very early on. So I had constant contact.”

[Participant 3, Page 3]

2. Emotional Impact

Participants talked about a number of issues relating to the emotional impact of having a child with T1D.

I.

One theme that was evident in all three interviews was the impact of T1D on the entire family.

“...[husband] would have dreams of [child] falling off a cliff and not being able to catch [child]...”

[Participant 3, Page 4]

“...but it’s completely devastating for a family, and that’s, that’s the really big difficulty [...] [Siblings] didn’t know very much about it but you know, when you see your [sibling] having to get injections and emm you know your mum and dad are quite stressed so they can’t spend as much time with you, then they get all stressed about it...”

[Participant 2, Page 2]

II.

Two of the participants spoke about specific worries relating to the possible fatal consequences of having T1D.

“...because I was frustrated and worried to death that I couldn’t take it anymore, you know, I thought I don’t know how we’re gonna get [child] to live through ‘til [child’s] 20. You know, I just, I always had this worry that [child] was gonna end up in a coma and die.”

[Participant 3, Page 8]

III.

All of the participants talked about the anxiety they experience as a result of their child having T1D.

*“Sleepovers were pretty ehh nerve wracking when [child] was a wee [child] because [child] would get very excited about it, and [child’s] sugars would go all over the place, [...] and there was, *sighs*, loads of anxieties.”*

[Participant 2, Page 9]

Participants also described the anxiety about diabetes always being present. They talked about a lack of escape from diabetes.

“...and it’s just on your mind all the time. It never goes away,”

[Participant 1, Page 2]

“I don’t sleep very well cause I’m always listening out for [child],”

[Participant 3, Page 6]

IV.

Participants talked about the difficulty of seeing their own child in distress as a result of T1D.

“...[child] would get really upset about it. [...] but, to force [child] to inject [themselves] when [child] wasn’t doing it at home was really hard. [Child] would come out in a sweat, [child] would be all shaky umm and [child] would inject [themselves] into [child’s] leg, and [child] would often sit, [child] would sit with [child’s] hand, with the pen for ages and then go, I can’t do it I can’t do it, and then [child] would have to do it, so it’s a lot.”

[Participant 2, Page 6]

3. Other people’s understanding

Participants talked about two elements relating to other people’s understanding of their child’s diabetes.

I.

The first of these was the need to educate the network around the child so that they will care adequately for the child in the parents' absence.

"...you feel a bit stupid, turning up at somebody's house at midnight and the house is dark and they're all in their bed saying, d'you know, [child] didn't phone and I was really worried emm and stuff eh and, but we've only had to do that twice and then those parents have sort of realized, "oh actually maybe this is quite important", [...] So we've had to do a lot of education with other people's parents."

[Participant 2, Page 9]

II.

The second element was people's lack of understanding of the seriousness of Type 1 Diabetes.

"...they said "oh don't worry we've got a first aid certificate", and umm yeah ok that's made me even more worried now because you clearly don't understand,"

[Participant 1, Page 2]

4. Conflict

One of the super-ordinate themes that emerged was conflict. Four themes were identified within the super-ordinate theme of conflict.

I.

The main theme identified by all three participants was the role of being a nagging parent.

"I used to always say, show me the meter but I'm trying to not do that as a mum anymore and say well what was your sugar, was it alright, or, whatever and I don't, I try not to ask all the time and I try not to make it the first thing I say to [child] so [child] doesn't come in from school, and I say how was your sugar? And not, how

was your day? And then maybe an hour later, was your sugar alright today? Cause it's terrible that the first thing anybody every asks you is, what's your sugar, cause actually, well it's an important part of [child's] life but it's not, it's not necessarily the most important to [child]."

[Participant 2, Page 8]

II.

Parents also talked about feelings of frustration towards their child.

"...we're still going through phases where [child] does, weird stuff like umm even just last week, umm, [child] came home from school sat down, [...] playing on [child's] phone for half a hour and then [child] says "oh I need to change my set". Well, yeah, I'm like "how long have you known that you needed to change the set"? "Oh, since this morning". "So you've had no insulin all day"? "No", and the conversation carries on like well, "why did you think that was ok"? "Well I didn't have any at school". "Well I could've brought you some its only ten minutes down the road". "Ah, yeah but, I knew I'd be fine". "And are you fine"? "Yeah I'm fine", "what's your reading"? "It's 20". "So you're not fine". And it's those sorts of things where you think, you think you're getting there and you think, gee really? Why are you suddenly doing that?"

[Participant 1, Page 6]

III.

Participants said that their child would get angry with them during discussions about their diabetes.

"...when we nag [child], it gets [child] very frustrated and angry and with [child's] Dad he goes to work and he comes home, "what's your sugars been like?" "All you ever speak about is my sugars dad. Can you not speak about something else? All I hear

from you is diabetes this diabetes that". [Child] just gets really frustrated about it."

[Participant 3, Page 4]

IV.

Participants talked about the level of conflict with their child being one of the reasons they decided to back off and allow their child to take more responsibility for their diabetes.

"I think we've had to consciously do that, cause [child] used to come home from school and go "four point two"... before [child] would even do anything else, cause [child] knew that the first thing, that was always, it's terrible, you have to chase them. So that poor [child] was not getting quizzed on it so we've gradually changed that,"

[Participant 2, Page 9]

5. Control

The fifth super-ordinate theme that was identified was control.

I.

The participants talked about their need for control over their child's diabetes management. In relation to this they all said that their child was not ready to take on full responsibility for their diabetes, even as they were reaching transition to adult services.

"Yeah, and my husband even more so. He, he likes to be in control of everything [...] it kills him. He wants to sit down and fill in [child's] book, you know, and see everything and [child's] not letting him, and he hates it. [...] at night time I always have to know what [child's] reading is before I can go to sleep, even if [child's] awake, I still need to know, cause I can judge from that if [child's] gonna have a hypo or if [child] needs to have something to eat, [...] but it's always gonna be there, and, it, I'm always going

to think, I just wished I could be the one making those choices of how much insulin [child's] having, and, and making sure where [child's] having it and, you know, making sure [child's] in a good place, and [child's] rotating, and, I don't think that's ever going to stop,”

[Participant 3, Page 9]

“I guess because I’m not, I’m not seeing that [child’s] taking massive responsibility then I’m probably coping ok [...] I guess you always have it, you always can think of an excuse why [child] shouldn’t do that, take on that responsibility,”

[Participant 1, Page 11]

II.

The participants said that they had begun to think about how their child would cope when they leave home. Two of the participants had already begun thinking about how to provide support when their child left home and direct support from parents was no longer available.

“we’ve talked about using em technology a bit [...] there are lots of apps that you can get. So there’s a my sugar app and things like that that we’ve talked about well, [...] you know you could upload your sugar to that and then we could log in at home and see yeah you’ve done your sugar at 10 o’clock and yes it was ok. So we don’t have to phone you and say “what was your sugar, it’s your mum here”. Emm we could look at it remotely so nobody would know that we were checking up on [child] Cause that’s the big worry when [child] goes off to uni [...] Who would check that [child] was up in the morning? So I don’t know how we work that out, [...] I suspect that by the time we get to that point then we’ll be using technology to help us, supervise”

[Participant 2, Page 15]

Support

The final super-ordinate theme that was identified was support. This was broken down into four categories.

I.

The first of these was the support from the paediatric diabetes team. The positive that all of the participants talked about was how good the support had been. In particular they talked about the availability of the team.

“...they’re just there if you need them and you don’t feel that the question you’re asking’s silly, and you can, you know I can email them, or I can phone and leave a message and they’ll get straight back to me and check that, you know, check that I understand the answer.”

[Participant 1, Page 12]

Participants also talked about support in the form of information given at diagnosis.

“There’s a booklet that we got that was really useful, so that was the kind of, you know, simple guide to kind of, diabetes and things so we got that, and it had all the emergency numbers, and there’s flow charts in it. What to do if somebody develops keto-acidosis all those kind of things, and that was really helpful cause we refer to that a lot,”

[Participant 2, Page 4]

The only negative that participants talked about was the gap between diagnosis of T1D and the first clinic appointment.

“umm... and then it was like, “well we’ll see you in three months”. Ok, that’s quite a long time when you’ve got this pack of needles and all the guff that goes with it.”

[Participant 1, Page 2]

II.

Two of the participants mentioned a support group for families of a child with T1D in the Highlands. They had differing opinions about the support provided by this group.

“The mothers there had warned me of all the problems to expect as [child] got older. That was very supportive, listening to people, so I knew what to expect,”

[Participant 3, Page 7]

“I didn’t like going to it because, people just tell you about the problems they’ve had, and actually I was looking for solutions and good news stories and support [...] just told about all the near misses and all the difficult things, and people, need to unload that, but all that did was give me more worries, cause I was thinking god that’s never happened to us but that could happen to us.”

[Participant 2, Page 11]

III.

Participants said that emotional support is difficult to bring into the clinic appointments and suggested that more formal or routine emotional support might be of benefit.

“...it would’ve been nice to have had them, made, and had, umm, regular, maybe, a couple of times a year even, the families to get together to discuss with a, you know, a psychotherapist, how things are going, so that everybody could, cause when you’re sat there you do talk.”

[Participant 3, Page 10]

“...cause the thing is, the individual clinics are helpful and fine but I think you still need to come together sometimes in big groups, but it needs to be facilitated. That was the problem with the parent support group, it was unfacilitated, so people were just dumping and discussing their problems and you weren’t able to move on, [...] but, with the pump groups that we go to those are facilitated and there is a bit of an agenda but there is still time to chat so that really helps and makes a difference.”

[Participant 2, Page 22]

IV.

Finally, participants all mentioned anxieties about moving from the Paediatric Diabetes Team to Adult Services.

“...starting to talk about how [child] will come off the paediatric team, and that’s quite daunting because I know it’s not the same kind of care, same level of care probably.”

[Participant 1, Page 4]

Discussion

The parents interviewed were at different stages of their child's transition from childhood to adolescence and they had varied experiences of this transition, however, there were a number of similar themes that emerged from the parents descriptions of their experience.

It was evident from all of the interviews that there are a number of practical implications that occur as a result of a child's diagnosis of T1D. New equipment and management regimes require learning and parents experienced an increased need to be able to contact their child with T1D than previously or more than they would with the child's siblings who do not have T1D.

The participant's experience was that T1D has an emotional impact on the whole family and not just the child with the diagnosis. Parents' experiences of worry about their child fits with previous research carried out by Dashiff et al (11). Witnessing the child's distress in relation to injections was a common experience and an awareness of the possibility of death in relation to diabetes was evident across most of the interviews.

One of the issues that all participants mentioned was other people's understanding and having to take time to educate people who are around their child. This theme is of particular interest as it was not directly linked to any of the interview schedule questions and yet was present in all three interviews. This appears to add an extra layer of worry for the parents. It is not possible for them to be there all the time and therefore they need to know that people looking after their children have an understanding of diabetes and the implications if it is not well managed.

Participant's experiences of conflict were similar to that found in previous research. Parents experienced frustration towards their adolescent as found by Dashiff et al (11). This frustration can be contextualised in relation to Piaget's theory of cognitive development (21). The parents can think hypothetically and are therefore able to perceive the long-term consequences of poor diabetes management. The adolescent, who according to Sarni's theory of the development of emotional competence (22), is focussed on fitting in, and being like their peers in the present moment, which is unlikely to include keeping a close eye on what they eat and stopping activities to check blood sugar levels. They are currently going through what Piaget refers to as the formal operational stage of cognitive development during which abstract thinking is developed, however, they may not yet be fully able to connect present decision making to events that might happen to them in the future. Research by Holmbeck et al (15) found that adolescents experienced parents questioning about diabetes management as intrusive and controlling, and participants in this study felt as though they were nagging their child when asking about diabetes management tasks.

All participants talked about feeling that their adolescent was too young to have full responsibility for their diabetes. This fits with research by Dashiff et al (16), which found that parents who experience anxiety about separation from their child find it more difficult to encourage autonomy. Carter & McGoldrick's Family Life Cycle theory of development describes how parent-child relationships adjust during adolescence to allow adolescents more autonomy (23). It may be that, for these families, this normal developmental stage is disrupted by the presence of additional, critical responsibilities related to T1D. The parents appear to be finding this adjustment in the parent-child relationship particularly difficult in relation to the autonomy of diabetes management. All parents had already started to think about how their adolescent might cope with managing their own diabetes when they leave home, and two of the parents had begun thinking about solutions to their not being present to directly supervise diabetes care. These parents face a difficulty in feeling that their child is not ready to take on full responsibility for their diabetes while also knowing that the child will need to

take responsibility for their diabetes in the near future when they leave home. The parents appear to be coping with this by looking ahead to find ways to continue supervision once the child no longer lives at home.

Participants talked about how good the support from the diabetes healthcare team has been. Most of them experienced anxiety at the length of time before the first clinic appointment but all participants talked about the availability of the team whenever they needed their support. The difficulty with the length of time before the first clinic is possibly due to the parents not knowing the diabetes team very well at this point and therefore they may be unsure about how often is acceptable to phone the diabetes team. There was a suggestion that more emotional support would be helpful but that this should be facilitated and should be an automatic part of the service rather than something that can be requested. This is possibly due to the stigma that still surrounds psychological support so if it was an automatic part of the service, parents may not feel they were failing if they had to seek emotional support. All participants had fears about moving to the adult diabetes service as they felt that they would be excluded from their adolescents care once they moved away from the paediatric service. This links back to the parents need for control and the fear that without the parents input the child will not be able to look after their diabetes.

Study Limitations

The major limitation of this study is the sample size. The recommended sample size for doctorate level IPA studies is between four and ten (20). Eligible parents were given information about the study in four ways (newsletter, poster, letter and information given at clinic appointments). The study would have more relevance with more participants, however, qualitative research aims to explore individual experiences of life events and not to be generalisable to the whole population. Due to time limitations it was not possible to carry out a follow-up with participants to explore their opinions about the themes identified by the researcher.

Clinical Implications

There were three areas relating to clinical care that were discussed by the participants. As the study was qualitative and had a small number of participants it is not possible to draw generalisable conclusions from the data. The participants' experiences, however, could indicate possible areas for future research relating to clinical care. The participants spoke about it being difficult to be left for three months before the first clinic appointment after diagnosis. Although participants said that the availability of phone contact was helpful wider research could explore whether other parents find the gap before the first clinic appointment difficult. The participants experience was that clinic appointments were not an appropriate place to discuss the emotional impact of diabetes, and that peer support between parents is more contained when it is facilitated. Further research may identify an area for potential input from psychology services, however, it may be that there is a selection bias in the characteristics of participants who volunteered for the study towards a desire for more emotional support. All participants talked about beginning to take a step back from their child's diabetes management during their time in the paediatric diabetes service but mentioned concerns about moving to adult services. Future research could explore whether this experience was felt more widely within the Paediatric Diabetes population, and then look at how this transition process happens by exploring the experiences of parents of adolescents who are in the adult diabetes service.

Future Research

This study had a very small sample size and future research should consider recruitment from more than one NHS health board in order to meet the appropriate participant numbers for IPA studies. Future quantitative research could address the questions raised in the previous paragraph to explore whether some of the experiences encountered by participants in this study are echoed in the wider T1D parent population. Qualitative research could explore how parents cope with their child attending adult services between the ages of 16 and 18 when most adolescents will leave home.

Conclusion

This study set out to explore the experiences of parents of adolescents with T1D. The study found that these parents experienced worry particularly in relation to aspects of their child's diabetes of which they did not feel in control. The parents in this study felt that having a child with T1D had impacted on their whole family unit and they all talked about the practical adjustments that they had to get used to as a result of having a child with T1D. It is evident that the parents interviewed feel well supported by services but have concerns about whether that level of support will change as they move to adult services. Possible areas for future research were identified.

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APPENDICES

Appendix 1.1: Author Guidelines - Pediatric Diabetes

Pediatric Diabetes will consider for publication full-length papers, preliminary communications with important new information, clinical reports and reviews of major topics. Invited editorials and perspectives will be a regular feature. Full-length papers and reviews of major topics should generally not exceed a total of 5000 words (approximately 20 double-spaced typewritten pages) for the text, references, tables, figures, and figure legends, excluding running title page, title page, and abstract. Preliminary communications with important new information, clinical reports, invited editorials and perspectives should generally not exceed 2000 words.

MANUSCRIPTS

All manuscripts should be submitted in correct English suitable for publication, double-spaced (including references, figure legends, footnotes etc.). Each section of the manuscript should begin on a new page. The pages should be numbered consecutively and assembled in the following order: Running title page, Title page, Key words, Abstract, Abbreviations, Introduction, Methods, Results, Discussion, Acknowledgements, References, Tables, Figure Legends, Figures.

RUNNING TITLE PAGE

A short running title of not more than 40 letters and spaces should be provided. This page should also contain the complete address, telephone and fax numbers, and E-mail address of the author to whom correspondence about the manuscript, proofs and requests for offprints should be referred.

TITLE PAGE

This page should contain the following information in the order given: 1) a concise and informative title; 2) the author(s)' full names; 3) the author(s)' complete institutional/departmental affiliation (including city, state, country, zip/postal code) of each author; 4) a word count for the entire manuscript .

ABSTRACT AND KEY WORDS PAGE

The abstract should not exceed 250 words and should incorporate data on background, objective or hypothesis, subjects, methods or plan, results and conclusions. Please make sure that the data in the abstract accurately reflect the information provided in the body of the manuscript. Below the abstract, provide up to five key words, using terms from the standard Medical Subject Headings (MeSH) list from Index Medicus.

INTRODUCTION

The introduction should be succinct and should orient the reader to the state of knowledge in the specific area under investigation. The questions and hypotheses of the research should be clearly delineated here.

METHODS

Methods should be described and referenced with sufficient detail to allow other researchers to reproduce the results. It is often quite useful to subdivide methods into sections such as subjects, measurements, protocol, and data analysis. Describe selection of patients or experimental animals, including controls. Do not provide patients' names or any hospital ID numbers. Any complex data analysis should be reviewed by a statistician. Provide references and brief descriptions of methods that have been published. When using new methods, evaluate their advantages and limitations. Identify drugs, including generic name, dosage, and route(s) of administration. The manufacturer's name and location should be provided for chemicals, reagents, and special pieces of apparatus. Although not a Systeme International (SI) unit, Celsius should be used for body temperature or for laboratory measurement temperatures in the physiologic range. Please use conventional system measurements followed in parentheses by equivalent SI values. These can be found in Lundberg GD, Iverson C, Radulescu G. Now read this: The SI units are here. JAMA 1986; 255:2329-39. Young DS. Implementation of SI units for clinical laboratory data. Style specification and conversion tables. Ann Intern Med 1987; 106:114-129.

Submitted manuscripts are required to report HbA1c in both SI (IFCC) and NGSP/DCCT units.

Authors must indicate that the procedures were approved by the Ethics Committee of Human Experimentation in their institution/country and in accordance with the Declaration of Helsinki. All papers reporting experiments using animals must include a statement assuring that all animals received humane care.

RESULTS

The results should be presented in the most appropriate form, in logical sequence in tables and illustrations. In the text, explain, emphasize or summarize the most important observations.

DISCUSSION

Do not repeat in detail data given in the Results section. Emphasize the new and important aspects of the study. The findings should be related to other relevant studies. On the basis of your findings (and others') discuss possible implications/conclusions, revealing any limitations of the study. When stating a new hypothesis, clearly label it as such.

ACKNOWLEDGEMENTS

Acknowledge only persons who have made substantive contributions to the study, e.g., technical assistance, critical advice, or other assistance.

Authors are responsible for obtaining permission from everyone acknowledged by name because readers may infer their endorsement of the data and conclusions. All funding sources supporting the work should be acknowledged.

TABLES

Tables should be numbered consecutively with Arabic numerals. Type each table double-spaced on a separate page; each one should have a title. Each table should be intelligible without reference to the text. Redundant or repetitious entries in a table should be minimized.

ILLUSTRATIONS

All figures should clarify the text and their numbers kept to a minimum. Figures should be constructed in a clear and uncluttered manner and planned to fit the proportions of the printed page. They should be numbered according to the order in which they are cited in the text with Arabic numerals. Magnifications should be indicated in the legends rather than inserting scales on prints. Details must be large enough to retain their clarity after reduction in size.

Composite or long horizontal figures may, at times, occupy two columns. If the components (e.g., A, B, C, D) of a composite figure need to be referred to in the text or figure legend, the figure should contain the identifying letter. Titles should be provided in the legend rather than on the figure.

Photographs of patients' faces should be included only if scientifically relevant and if the identity of the patient is concealed by masking. Authors should obtain written consent for use of such photographs.

Halftones (e.g., photomicrographs or electron micrographs) should show only the most pertinent areas. A micron bar of appropriate scale marking is desirable on the figure.

LEGENDS

Legends should be typed double-spaced in consecutive order on a separate page and not on the figure. They should be numbered (1, 2, 3 etc.) and should include sufficient detail to make the figure intelligible without reference to the text.

ABBREVIATIONS, SYMBOLS AND NOMENCLATURE

They should be standardized and the full term for which an abbreviation stands should precede its first use in the text unless it is a standard unit of measurement. Consult the following sources: Scientific style and format: the CBE manual for authors, editors, and publishers. Style Manual

Committee, Council of Biology Editors, 1994; American Medical Association manual of style: a guide for authors and editors, 1998.

REFERENCES

Number references consecutively in the order in which they appear in the text and identify them by Arabic numerals (in parentheses). List all authors when six or less; when seven or more, list the first three and add et al. Include manuscripts accepted, but not published, and designate them as "In press". Manuscripts in preparation, manuscripts not yet accepted but submitted, unpublished observations, and personal communications should be cited as such in the text and not included in the reference list. References should be according to the style used in Index Medicus. For abbreviations of journals, consult the List of Journals Indexed printed annually in the January issue of Index Medicus.

Examples:

Journal articles. Zou L, Burmeister LA, Sperling MA. Isolation of a liver-specific promoter for human growth hormone receptor gene. *Endocrinology* 1997; 138:1771-1774.

Books and monographs. Sperling MA (ed). *Pediatric Endocrinology*, 2ND Ed. W.B. Saunders, Philadelphia, 2002.

Book Chapters. Menon RK, Trucco M. Molecular Endocrinology: Relevance to Clinical Management of Hormonal Disorders. In: Sperling MA (ed). *Pediatric Endocrinology*, 2nd Ed. W.B. Saunders, Philadelphia, 2002, pp 15-32.

For full details see:

[http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1399-5448/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1399-5448/homepage/ForAuthors.html)

Appendix 2.1: Quality rating scale for studies

Quality Rating Scale

<u>The impact of family conflict on adherence to diabetes medication in adolescents.</u>	
Authors	
Title of paper	
Journal title	
Date of publication	
Completed by	
Completed on	

1. Abstract		
1.1	Does the abstract give a structured summary of the study?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
2. Introduction		
2.1	Has a scientific background and explanation of rationale been provided?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
2.2	Are the aims/hypotheses clearly described?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
3. Methods		
3.1	Are the characteristics of the participants	2 Well covered

	clearly described?	1 Adequately covered 0 Poorly/Not covered
3.2	Is the method of recruitment clearly described?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
3.3	Is the level of drop-out described and were adequate attempts made to explore reasons for drop-out?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
3.4	Is there a clear rationale for the sample size e.g. power calculation?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
4. Assessment		
4.1	Are the main outcomes to be measured clearly defined?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
4.2	Is adherence to diabetes regimen assessed appropriately?	3 Observational and standardized self report measures 2 Observational or standardized self report measures – good validity 1 Standardized self report measures – poor/unknown validity 0 Non standardized measures
4.3	Is level of family conflict measured appropriately?	3 Observational and standardized self report measures

		2 Observational or standardized self report measures – good validity 1 Standardized self report measures – poor/unknown validity 0 Non standardized measures
5. Confounding variables		
5.1	Are the main confounding variables taken into account in the design and analysis?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
6. Statistical analysis		
6.1	Were the statistical analysis tests used to assess the main outcomes appropriate?	2 Appropriate 1 Adequate 0 Not appropriate
6.2	Were the main findings of the study clearly described?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
6.3	Are confidence intervals, effect sizes etc reported where appropriate?	2 Well covered 1 Adequately covered 0 Poorly/not covered
7. Discussion		
7.1	Are the limitations of the study described?	2 Well covered 1 Adequately covered 0 Poorly/Not covered
7.2	Is the generalisability of the study	2 Well covered

	described?	1 Adequately covered 0 Poorly/Not covered
7.3	Do the conclusions drawn directly link to the results?	2 Well linked 1 Adequately linked 0 Poorly/Not linked
Total Score (out of 36) =		
Percentage score (%) =		
Overall Quality Rating =		

Overall Quality Rating Key

80%+ = Good (A)

55-79% = Moderate (B)

0-54% = Poor (C)

Appendix 2.2: Individual item ratings

Study →	Gray et al.	Hilliard et al., 2013	Luyckx et al.	Moore et al.	Hilliard et al., 2011	Herzer et al.	Ingerski et al.	Anderson et al.
Rating scale item								
1.1	2	2	1	2	2	2	2	2
2.1	2	1	2	2	2	2	2	2
2.2	2	2	0	2	2	2	2	2
3.1	2	2	2	1	2	2	2	2
3.2	1	2	1	2	2	1	2	2
3.3	2	2	2	0	2	1	2	2
3.4	0	0	0	0	0	0	0	1
4.1	2	2	2	2	2	2	2	2
4.2	2	2	2	3	2	2	2	2
4.3	2	2	2	2	2	2	2	2
5.1	2	2	0	1	2	2	2	2
6.1	2	2	2	2	2	2	2	2
6.2	2	1	2	2	2	2	2	2
6.3	1	1	2	1	1	1	1	1
7.1	1	2	2	2	2	2	2	2
7.2	2	2	1	2	2	2	1	0
7.3	2	2	2	1	2	2	2	2
Overall Rating	Good	Good	Moderate	Moderate	Good	Good	Good	Good

Appendix 3.1: REC favourable opinion letter

15 March 2016

Miss Vairi A W James
 Trainee Clinical Psychologist
 NHS Highland
 Child and Adolescent Mental Health Services
 Phoenix Centre, Raigmore Hospital
 Old Perth Road, Inverness
 IV2 3UJ

Dear Miss James

Study title:	Parent's experiences of support from healthcare services during the transition from childhood to adolescence in Type 1 Diabetes Mellitus.
REC reference:	16/EE/0082
IRAS project ID:	196234

Thank you for your submission responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager Miss Georgia Copeland; nrescommittee.eastofengland-cambsandherts@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

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

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk 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 management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the 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).

Ethical review of research 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" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of advertisement materials for research participants [Flyer and Poster Changes Underlined]	2	03 March 2016
Copies of advertisement materials for research participants [Flyer and Poster Version 2]	2	03 March 2016
Covering letter on headed paper [Response Cover Letter]	1	08 March 2016
Interview schedules or topic guides for participants [Topic Guide]	2	10 February 2016
IRAS Checklist XML [Checklist_10022016]		10 February 2016
IRAS Checklist XML [Checklist_08032016]		08 March 2016
Letter from sponsor [Sponsor letter]	1	09 February 2016
Other [Academic supervisor review]	1	06 November 2015
Other [Opt-In Form Changes Underlined]	2	03 March 2016
Other [Opt-in Form Version 2]	2	03 March 2016
Participant consent form [Consent Form Changes Underlined]	3	03 March 2016
Participant consent form [Consent form]	3	03 March 2016
Participant information sheet (PIS) [Participant Information Sheet Changes Underlined]	3	03 March 2016
Participant information sheet (PIS) [Participant Information Sheet Version 3]	3	03 March 2016
REC Application Form [REC_Form_08032016]		08 March 2016
Research protocol or project proposal [Proposal]	3	29 January 2016
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	1	19 January 2016
Summary CV for supervisor (student research) [Academic Supervisor CV]	1	12 January 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees 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 HRA 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 HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

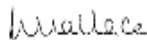
We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/EE/0082

Please quote this number on all correspondence

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

Yours sincerely


PP

Mr David Grayson
Chair

Email: nrescommittee.eastofengland-cambsandherts@nhs.net

Enclosures: *"After ethical review – guidance for researchers"*

Copy to: *Ms Frances Hines*

Appendix 3.2: REC favourable opinion letter for major amendment



East of England - Cambridgeshire and Hertfordshire Research Ethics Committee

Royal Standard Place
Nottingham
NG1 6FS

20 May 2016

Miss Vairi A W James
Trainee Clinical Psychologist
NHS Highland
Child and Adolescent Mental Health Services
Phoenix Centre, Raigmore Hospital
Old Perth Road, Inverness
IV2 3UJ

Dear Miss James

Study title:	Parent's experiences of support from healthcare services during the transition from childhood to adolescence in Type 1 Diabetes Mellitus.
REC reference:	16/EE/0082
Amendment number:	1
Amendment date:	27 April 2016
IRAS project ID:	196234

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Discussion

The Sub-Committee reviewed the amendment and asked why the reference to 'parents experiences of support from healthcare services' has been removed from both the title and body of the Participant Information Sheet.

The Sub-Committee agreed there are no objections to the change in title to make it clear that participants are expected to discuss parent/child relationships, but commented that the deletion of the specific reference to 'parents experience of support from healthcare services' is misleading to potential participants and is inconsistent with the stated aim in the protocol.

The applicant explained that in NHS Highland there is not a specific diabetes psychologist and anyone who requires support is referred to the paediatric health psychology service by the diabetes team. The applicant stated that there was a concern that, if the original wording was used, parents would come to the interview only thinking of the nurses and paediatricians, and the study would turn into an evaluation of the diabetes team rather than a more general account of the parent's experiences. The applicant added that the new wording would also encourage the parents to think more generally about the support they could have received rather than being constrained by their own perceptions of the limits of

support that the NHS is able to offer. It was explained that consideration was given to removing the word 'healthcare' and leaving the phrase 'support from services', although it was felt by the diabetes team that this would have the same connotation as 'healthcare services' for their patients parents since the flyers and information sheets would be coming directly from the team. The applicant pointed out that, as the study will rely on the diabetes team for recruitment, it was important to take into account the teams thoughts and knowledge of their patient population.

The applicant considered the concerns of the Committee regarding the Protocol and proposed a further updated version, containing a changed title and reworded aim.

The Sub-Committee considered the response and were content to accept the proposed amendments to the Participant Information Sheets and version 4 of the Protocol, to allow the study to be carried out in the form originally proposed, whilst also accounting for the suggestions of the Diabetes Team.

The Sub-Committee agreed that the removal of all references to 'support you have received from the healthcare services' from the further revised Protocol (version 5) radically alters the approved study, and requested that this update be disregarded.

The applicant confirmed the study will proceed with the use of Protocol version 4.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants [Flyer and poster]	3	22 April 2016
Notice of Substantial Amendment (non-CTIMP)	1	27 April 2016
Other [Opt in form]	3	22 April 2016
Participant information sheet (PIS)	4	22 April 2016
Research protocol or project proposal	4	03 May 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

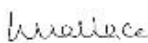
Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/EE/0082: Please quote this number on all correspondence

Yours sincerely



PP

Mr David Grayson
Chair

E-mail: nrescommittee.eastofengland-cambsandherts@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Frances Hines

Appendix 3.3: Participant invitation letter

Parents' experiences during the transition from childhood to adolescence in Type 1 Diabetes Mellitus. Parent-child relationships, and support received during this time.

Dear <name>

I am writing to let you know about some research that is being carried out by a final year Trainee Clinical Psychologist, called Vairi James, working within NHS Highland. Vairi is completing the research as part of her doctoral degree at the University of Glasgow.

Vairi is interested in learning about how your relationship with your child has changed as they transitioned from childhood to adolescence with Type 1 Diabetes Mellitus and what support you have had during this transition.

The enclosed participant information sheet (version 4, April 2016) describes the study. It also explains what will happen if you decide to participate. Please take your time reading the information, feel free to discuss it with friends and family, or the research team. Contact details are listed on the participant information sheet.

If you decide to take part in this project, please return the enclosed opt-in form to Vairi in the stamped addressed envelope provided, within two weeks of receiving this letter.

Please note that I am independent of the research team. Deciding not to take part in the project will have no impact on the service that you and your child receive from the Diabetes team.

Thank you for taking the time to read this letter.

Yours sincerely,

[Name]
Consultant Paediatrician

Parents' experiences during the transition from childhood to adolescence in Type 1 Diabetes Mellitus; parent-child relationships, and support received during this time.

Participant Information Sheet

1. Invitation paragraph

We would like to invite you to take part in our research study. Joining the study is entirely up to you. Before you decide, we would like you to understand why the research is being done and what it would involve for you. Please read the following information carefully and if you have any questions these can be answered by Vairi James (contact information provided on next page).

2. What is the purpose of the study?

This study aims to find out about the experiences of parents of teenagers with Type 1 Diabetes Mellitus. The aim is to find out about changes in your relationship with your child as they transitioned from childhood to being a teenager with diabetes, and about the support you received during this time. We know that this can be a difficult time for some families and we would like to examine how your experience through this time in your child's life has impacted on coping.

3. Why have I been invited?

You have been invited as you are a resident in the NHS Highland area who has a child aged between 13 and 17 who has Type 1 Diabetes. The study is aiming to recruit up to 10 participants.

4. Do I have to take part?

No, it is up to you to decide whether to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time 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 you receive.

5. What does it involve?

If you decide to take part you will be asked to take part in one interview with the researcher (Vairi James, Trainee Clinical Psychologist). The interview will last no longer than one hour. The interview will take place at Raigmore Hospital. The interview will be audio-recorded and then transcribed by the researcher. Transcribed interviews will have names of people and places anonymised. The interview will involve questions related to your relationship with your child, and your experience of support during their transition from childhood to adolescence.

6. Are there any disadvantages of taking part in the study?

There is the possibility that when discussing your experiences, you may recall experiences that make you feel upset. You would be free throughout the interview to stop and take a break or discontinue the interview at anytime. The researcher will do frequent 'check-ins' with you to check for fatigue or distress and ensure you are happy to continue.

7. What are the benefits of being involved?

There are no direct benefits to you by taking part in this study. However, it is hoped that the information gathered from this study will inform future practice in Diabetes.

8. Will my information be kept confidential?

Yes, all information gathered during the study will be kept strictly confidential. The audio-recording and transcription of your interview will be identified by an allocated participant number only. If any quotes from your interview are used in the final report, a pseudonym will be used. All references to people and places by name will be anonymised during transcription.

9. What will happen if I disclose an issue of poor practice or harmful behaviour by staff?

If you disclose an issue of poor practice or harmful behaviour by staff, the researcher will discuss with you the process of making a formal complaint against that member of staff. If you do not wish to proceed with a formal complaint, the researcher will have to pass on the information anonymously to the line manager of the member of staff concerned.

10. What will happen to the results of the study?

On completion of the research project the completed report will be submitted to the University of Glasgow in July 2016 as the Major Research Project of the researchers Doctorate in Clinical Psychology degree. It is hoped that the study would eventually be submitted for publication in a research journal. All participants will be invited to contact the researcher if they wish to be sent a summary of the results.

11. Further information and contact details

If you wish any further information or have any questions please feel free to contact a member of the research team below.

For general independent information on taking part in research please visit the INVOLVE website at: www.invo.org.uk/find-out-more/

Name	Role	Contact
Vairi James	Trainee Clinical Psychologist Chief investigator	Phoenix Centre, Raigmore Hospital, Inverness 01463 705597
Dr Sarah Wilson	Academic Supervisor	Mental Health and

		Wellbeing, University of Glasgow, Gartnavel Hospital, Glasgow 0141 2113935
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Study reviewed by East of England – Cambridgeshire and Hertfordshire
Research Ethics Committee.

Appendix 3.5: Opt-in form

Parents' experiences during the transition from childhood to adolescence in Type 1 Diabetes Mellitus; parent-child relationships, and support received during this time.

Opt-In Form

I am happy for Vairi James, Trainee Clinical Psychologist, to contact me on the following phone number(s) to discuss taking part in the above study.

If you would like to be sent a participant information sheet before being contacted by Vairi James, please provide an address in the box below.

<p>Name:.....</p> <p>Home</p> <p>Telephone Number:.....</p> <p>Mobile</p> <p>Telephone Number:.....</p> <p>Address for Participant Information Sheet to be sent to (optional)</p> <p>.....</p> <p>.....</p>
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Appendix 3.6: Flyer/Poster

Parents' experiences of support during the transition from childhood to adolescence in Type 1 Diabetes Mellitus; parent-child relationships, and support received during this time.

Are you the parent of a 13 to 17 year old?

Does your teenager have Type 1 Diabetes?

Were they diagnosed before the age of 13 and have been diagnosed for at least 2 years?

Would you like to share your experiences?

We are looking for people to take one hour of their time to tell us about the changes in their relationship with their child during the transition from childhood to adolescence with diabetes, and about the support they have received during this time. If you think you might be interested in taking part, please read the Participant Information Sheet provided where you will find more detailed information about the study. If you think you might want to take part after reading the Participant Information Sheet please complete an opt-in form with your contact details and the researcher (Vairi James, Trainee Clinical Psychologist) will contact you to arrange a meeting at a time that is convenient to you.

Alternatively you can contact Vairi James directly by emailing v.james.1@research.gla.ac.uk or by phoning 01463 705597.

Appendix 3.7: Interview Schedule

Topic Guide

Preamble

"As you know from the information sheet, this project aims to gather the experiences of parents of teenagers with Type 1 Diabetes. It aims to discover how your relationship with your child has changed, and how the support you have received has impacted on your coping with your child's transition towards more independent management of their diabetes.

Can I remind you that you are free to stop the interview at any point, or request a break. You are free to withdraw from the study at any point and do not need to provide a reason for your decision. When the report on this study is prepared, all participants will be given a pseudonym and any quotations used will be identified by pseudonym only. Names of people or places in the quotations will be anonymised. The interview should take no longer than one hour."

Get participant to sign consent form before proceeding.

Demographic information

To start I would like to ask you some basic information

- What age was your child when they were diagnosed with diabetes?
- What age are they now?

Start recorder

Topic guide (prompts indicated by bullet points)

Initial diagnosis experience

1. How did you find out that your child had Diabetes?
 - Was this a long process or did it happen very quickly?
 - What was good/bad about this experience?
 - How did the diagnosis affect you/r family?
 - What supports/information were you offered?

Initial diabetes management

2. How involved were you initially with your child's diabetes management regime?
 - How did you feel about your level of involvement?
 - Would you have liked to be more or less involved?
 - Why?
 - How supported did you feel by services/school at this point?
 - What form did that support take?

Encouragement to become autonomous

3. Has there been a change in your level of involvement as your child has become older?

- What is different now than from when your child was first diagnosed?
- Has this change been encouraged?
- How has this been done?
- How did you feel about this?
- Have you had any support during this change?
- In what way?

Confidence in child's ability

4. How confident are you that your child is able to manage their Diabetes without your help?

- How would you feel if they were at a friend's house?
- How would you feel if they went on holiday?
- How would you feel about them leaving home and looking after their Diabetes?
- How has any support you have received impacted on your confidence in your child's ability to manage their Diabetes?

Relationship with child

5. How has your relationship with your child changed as they have taken more responsibility for their Diabetes?

- Have you found it difficult to be less involved?
- Has your level of involvement caused any difficulties in your relationship?
- Have you received any support or advice about how to avoid conflict with your child about their Diabetes management?

Overall Coping

6. How have you coped with your child taking more responsibility for managing their Diabetes?

- Have you had any support?
- Where has this come from?
- Do you feel you could have been better supported?
- In what way?

Thank you. This is the end of the interview.

Stop the recorder

"Thank you very much for taking the time to complete this interview. It is hoped that the results from this study will help to inform services of how they can best support parents of young people with Type 1 Diabetes in the future. If you would like to be sent a summary of the results from the study, please contact me at the email address on your participant information sheet."

Appendix 3.8: Participant consent form

Patient Identification Number:

Parents' experiences during the transition from childhood to adolescence in Type 1 Diabetes Mellitus; parent-child relationships, and support received during this time.

Consent Form

Please read the following statements carefully and sign your initials in the boxes if you agree with each statement. Please sign and date the bottom of the form if you wish to participate in the study.

1. I confirm that I have read and understand the information sheet dated 22nd April 2016 (Version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason. ☐
3. I agree for the interview to be audio recorded. ☐
4. I agree that quotations from my interview may be included in the final written report, which may be submitted for publication in an academic journal. I am aware that the transcript of my interview will have been anonymised for references to people and places before any quotations are taken from it. ☐
5. I understand that data collected during the study, may be looked at by regulatory authorities or from the NHS Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
6. I agree to take part in the above study. ☐

.....
Participant Name

.....
Participant Signature

.....
Date

.....
Researcher Name

.....
Researcher Signature

.....
Date

Appendix 3.9: Example of identifying themes

Emergent themes	Original transcript	Exploratory comments
Others understanding of seriousness	[child] went away on the [activity] trip and they were so laxsidaysical about it and were just like you know what, [child]'s fine, [child] can sort [themselves] out, [child] can do it all, and they had, even when we spoke to them and told them about if [child] gets hypo, they had not a clue about the risks. You know, they didn't really seem to understand that [child] could die overnight if [child] was hypo. They were like, no [child]'s diabetic	Difficult to trust others to look after the child so vigilantly
Educating the network around the child	[child]'s been diabetic for ages [child]'ll be fine, and it's like, no actually, some people have diabetes go to bed and don't wake up in the morning. They were like, nah it won't happen, and people don't necessarily get that actually that could happen any night [child] goes to [child's] bed, ah, and until [child]'s able to function and deal with eh the hypos and know that [child] really has to get up it's a bit of a problem.	Need to make sure that others will know what to do if things go wrong and parent not there
Death	I: And I know it's a wee while off but how do you think you'll feel in terms of managing [child's] diabetes when it came to leaving home?	People don't realize child could die
Others understanding of seriousness	P: Well we've talked about that emm about what's gonna happen and how will we manage that, and we've talked about using em technology a bit cause at the moment [child]'s just got a very simple mobile phone and we've, there are lots of apps that you can get.	People think length of time changes seriousness of diabetes. Has survived until now so less risk.
Parents need for control		Parent needs others to understand child could die as this is their constant worry
Continued support when leaving home		Unable to care for self when hypo
		Need to manage when parent's not around
		Use of technology as substitute for parental care

Appendix 3.10: Example of shortened quotation

Quote as shown in report

“...cause the thing is, the individual clinics are helpful and fine but I think you still need to come together sometimes in big groups, but it needs to be facilitated. That was the problem with the parent support group, it was unfacilitated, so people were just dumping and discussing their problems and you weren’t able to move on, [...] but, with the pump groups that we go to those are facilitated and there is a bit of an agenda but there is still time to chat so that really helps and makes a difference.”

Excluded section as indicated by [...] symbol above

“and you just spent two hours of people telling you all the terrible things that had happened. Well, I don’t want to spend two hours of my Saturday hearing all the terrible things that have happened to other people’s children cause I have enough terrible things that happen to mine, so...”

Parent's experiences of support from healthcare services during the transition from childhood to adolescence in Type 1 Diabetes Mellitus.

Abstract

Background

Type 1 Diabetes Mellitus is a common chronic illness that requires close management of insulin levels in the blood. As children with diabetes move into adolescence the focus of healthcare services is to help them become more independent in managing their illness. At this stage the parents take a step back but still have overall responsibility for the wellbeing of their adolescent.

Aim

The aim of the study is to explore the perceptions of parents with children who have a diagnosis of Type 1 Diabetes. Specifically, the study will explore how supported by healthcare services parents feel, during the transition of their child into adolescence.

Method

The study will have a qualitative design. Parents of adolescents with Type 1 Diabetes will be recruited through a newsletter sent by the NHS healthcare team, posters in the waiting room during Diabetes clinics at Raigmore Hospital and flyers handed to parents of patients by the diabetes team. Data will be analysed using Interpretative Phenomenological Analysis.

Applications

The findings of this study will inform future practice in healthcare for providing support to parents of adolescents with Type 1 Diabetes. The findings will add to the literature about the emotional impact of being a parent to an adolescent with Type 1 Diabetes.

Brief Introduction

Type 1 Diabetes Mellitus is one of the most common chronic illnesses in childhood (Marks, Wilson & Crisp, 2013). If not managed effectively, it can cause serious short and long-term consequences (Silverstein *et al.*, 2005).

Type 1 Diabetes Mellitus is characterized by raised blood sugar levels (NICE Guideline 15, 2004) and can be detrimental to both life expectancy and quality of life (Konradsdottir & Svavarsdottir, 2011).

A diagnosis of Type 1 Diabetes Mellitus results in the need for a strict routine of managing diet, exercise, and insulin levels to avoid high blood sugar levels (Diabetes Control and Complications Trial Research Group, 1997). For young children, they must rely on their parents to manage these factors due to the complexity of the tasks involved. This can lead to difficulties when they enter school, as the parent will not be present during the school day (Marks, Wilson & Crisp, 2013). A systematic review examined the impact on parents of having a child with a diagnosis of Type 1 Diabetes, and found that anxiety and depression is common (Barnard *et al.*, 2010). A further study found that parents of children with Type 1 Diabetes experience increased stress in relation to parenting tasks in comparison to parents of healthy children (Moreira *et al.*, 2013).

As children with a diagnosis of Type 1 Diabetes Mellitus transition from childhood to adolescence they are faced with new challenges relating to their chronic illness. Adolescents go through major changes as they develop both physically and mentally, making the regulation of blood sugar levels more difficult (Konradsdottir & Svavarsdottir, 2011). At this time, responsibility of diabetes management begins to be passed from the parent to the adolescent as they learn to become more autonomous in controlling their blood sugar levels. Studies have found that control of diabetes during adolescence worsens (Pasquier-Fediavsky *et al.*, 2005), and there is a decline in self-care behaviours for disease management during this time (Urbach *et al.*, 2005).

As well as the consequences for the adolescent, the transition from childhood to adolescence also has repercussions for parents of children with Type 1 Diabetes. Studies have shown that parents handing diabetes management over to their teenagers find this stressful (Hardeman & Dashiff, 2006), and experience feelings of worry and frustration in relation to their teenager self-managing their diabetes (Dashiff *et al.*, 2011).

Evidence suggests that the most successful adolescent management of Type 1 Diabetes occurs when the right balance of adolescent autonomy and parental assistance and monitoring is established (Anderson *et al.*, 2009; Berg *et al.*, 2008). This is a difficult equilibrium to find, as many adolescents do not adhere to their treatment regime (Frey *et al.*, 2004) but well-intentioned efforts, by parents, to assist with diabetes management can be experienced by adolescents as controlling and intrusive (Holmbeck *et al.*, 2002).

Research by Dashiff *et al.*, (2008), of 131 families with an adolescent, aged 11-15, found that mothers will have more difficulty in encouraging autonomy in adolescents if they are anxious about separation from their child. A study by Luyckx *et al.*, (2013) found that more father-adolescent conflict resulted in higher treatment non-adherence in type 1 diabetes. In contrast, persuasive strategies used by mothers have been shown to lead to improvements in next-day blood glucose management (Berg *et al.*, 2013). Parents using an autonomy supportive approach will have an increased chance of their adolescent sharing their diabetes tasks with them (Hanna *et al.*, 2012).

Previous research has focused on the emotional impact of Type 1 Diabetes on parents and adolescents. There is also some research into interventions to reduce conflict between parent-adolescent dyads, but there is limited research into how supported parents feel by healthcare services during the transition of their child from childhood to adolescence. With the focus of the service being about promoting autonomy within the adolescent, do parents feel left behind? After consulting current literature to identify relevant questions, this study will explore parents' perceptions about the support they

receive from NHS Services as their child transitions into adolescence. This study will seek to discover how parents are affected by the shift from being primary caregiver with support and information from healthcare services, to an observer who is still expected to hold overall responsibility for their teenager's health. It will investigate how much information and support parents feel they receive in terms of assisting their adolescent towards autonomy while making sure disease management is continued, without creating conflict and confrontation?

Aims and Hypotheses

Aim

The aim of the study is to explore the perceptions of parents with children who have a diagnosis of Type 1 Diabetes Mellitus. Specifically, the study will explore how supported by healthcare services, parents feel during the transition of their child into adolescence.

Hypotheses

As the focus of healthcare professionals turns to encouraging autonomy in adolescent self-management of diabetes, parents will experience less support from the service in terms of advice on how to encourage adolescents' adherence to medication regimes.

Plan of Investigation

Participants

Participants will be parents of adolescents (aged 13-17) who have a diagnosis of Type 1 Diabetes Mellitus. Patients are encouraged to be carrying out most of their own treatment regime by secondary school so it is reasonable to expect that most adolescents will have some sort of autonomy by age 13. Patients leave the service at 16 or 17 so this is the top threshold for age. Participants will be recruited from the NHS Highland paediatric service. The project will recruit between 4 and 10 participants. There are currently 45 patients in the NHS Highland area aged 13-17 who have a diagnosis of Type1 Diabetes Mellitus. They are each seen by the team every 3 months so this is a feasible recruitment target for the study time frame.

Inclusion and Exclusion Criteria

Inclusion:

- Participants must be the parent of an adolescent (aged 13-17) with Type 1 Diabetes Mellitus.
- They must speak English fluently and have the capacity to consent to the study.

Exclusion:

- Participants will be excluded if they are deaf, as the project does not have sufficient funds for an interpreter.
- Participants will be excluded if their child has Type 1 Diabetes Mellitus but is aged 12 or under.
- Participants will be excluded if they are a parent to the same child as an individual who is already a participant in the study.

Recruitment Procedures

Participants will be recruited through an advert in a newsletter, produced by the Paediatric Diabetes healthcare team at Raigmore Hospital. There will also be posters and participant information sheets in the waiting room at Raigmore Hospital when Diabetes clinics are taking place. Participants will be given an email address and telephone number to contact the researcher or alternatively will be able to complete an opt-in form, giving permission for the researcher to contact them. This will be given to a member of the diabetes team and will be passed on to the researcher to follow-up. Interviews will be arranged for a time that is convenient for the participant. Consent forms will be completed before the participant begins the recorded interview with the researcher.

Measures

Participants in this study will take part in a semi-structured, one to one interview with the researcher. The researcher, along with supervisors, will develop an interview schedule containing between 6 and 10 questions. The interview schedule will also contain appropriate prompts that can be used during the interview. As Interpretative Phenomenological Analysis is used to gain an insight into a person's everyday lived experience of events there will be scope for interviews to venture away from the interview schedule if this will result in richer interview content.

Design

This will be a qualitative research project. Interpretative Phenomenological Analysis will be used to analyse the data. This involves carrying out one to one interviews with participants, transcribing those interviews and then exploring the content of the interviews to identify recurring themes. This method of qualitative analysis was chosen as it has an emphasis on examining how people make sense of their major life experiences. The transition from having a child with Type 1 Diabetes to having a more autonomous adolescent with the illness can be considered a major life experience. Part of this experience is the transition for the parent of being treated differently by the health service and therefore this method of analysis will appropriately address the research question.

Research Procedures

Participants will have the option of either leaving their name and telephone number for the researcher to contact them or to contact the researcher directly to show interest in taking part in the study. If, after any questions of the participant have been answered, they are happy to proceed with the study, a suitable date and time for interview will be arranged. Before the interview begins, the participant will read and sign the consent form. The interview will be recorded as it is conducted. After the interview is completed, it will be transcribed by the researcher who will anonymise references to places and persons during this process. The transcripts will be checked for completeness and accuracy by comparing with the source recording. Once all interviews have been transcribed and checked, data analysis will commence.

Data Analyses

Data will be analysed using Interpretative Phenomenological Analysis. This is a qualitative method of analysis, which focuses on the way in which people make sense of their significant life experiences (Smith, Flowers and Larkin, 2013). Analysis will follow 6 steps, as set out by Smith, Flowers and Larkin (2013). These steps are;

7. Reading and re-reading
8. Initial noting
9. Developing emergent themes

10. Searching for connections across emergent themes
11. Moving to the next case
12. Looking for patterns across cases

Justification of Sample Size

This project will aim to recruit between 4 and 10 participants and to interview each of them once. This is the number of interviews that Smith, Flowers and Larkin (2013, p52) recommend for a doctorate level research project. This should be achievable within the project timeframe as there are 45 adolescents aged 13-17 currently in the NHS Highland service.

Settings and Equipment

Recruitment will take place through an advert in a newsletter produced by the Paediatric Diabetes healthcare team and also through posters and participant information sheets put in the waiting room of the Diabetes Clinic at Raigmore Hospital. Posters, participant information sheets, and consent forms will be required. Participant interviews will be carried out in a clinic room in Raigmore Hospital. A digital voice recorder borrowed from the University of Glasgow will be used to record interviews.

Health and Safety Issues

Researcher Safety Issues

The researcher will carry out interviews with participants in clinic rooms within Raigmore Hospital in Inverness. The researcher will ensure that a colleague knows where and when interviews are occurring and will ask this colleague to investigate if the researcher does not contact them by a particular time.

Participant Safety Issues

Participants may find discussing their child's chronic illness distressing. It will be important that the researcher reminds the participant that they can take a break or stop the interview and remove consent to the study at any time up to the start of data analysis without needing to provide a reason. This will be written in the participant information sheet and a statement about this will require to be signed on the consent form. The researcher will also remind participants of this if they appear to become distressed at any point during the interview.

Ethical Issues

Information obtained during interviews may be sensitive and the recording device will need to be stored securely. It will be stored in a locked filing cabinet at Raigmore Hospital with only the researcher having access to the cabinet. Ethical approval for the study will be sought through the Integrated Research Application System. Approval from NHS Highland Research and Development will be required before the study can proceed.

Financial Issues

Funding will be required for printing 20 participant information sheets and 10 consent forms. Funding to print 2 posters to be placed in the clinic waiting room at Raigmore Hospital will also be required.

Timetable

Application for ethical approval will be submitted in October/November 2015. Ethical approval will be sought from NHS Highland Research and Development and from the Integrated Research Application System. Recruitment will take place between December 2015 and April 2016. Interviews will be carried out and transcribed during this time. Analysis will be completed during May 2016 and write up of the project will be completed during June and July 2016.

Practical Application

Information from this project will be used to inform future support provided by the NHS Highland paediatric service to parents of adolescents with Type 1 Diabetes. It may also be used to inform other health boards about the type of support that would be helpful for parents of adolescents with Type 1 Diabetes. Information from this project will add to the existing literature about the emotional impact on parents of having a child or adolescent with Type 1 Diabetes Mellitus.

References

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